The Nebraska Early Hearing Detection and Intervention Program Advisory Committee Meeting May 9, 2019 Meeting Minutes 12:00 pm – 4:00 pm

Nebraska Children's Home Society

Attending:

Members Laura Beshaler Linsay Darnall Jr. Heather Gomes Jayden Jensen Kristin Jolkowski Ashley Kaufmann Johnna Lygrisse Sara Peterson Kelly Rausch Stacie Ray Pete Seiler Merry Spratford Pam Zegers

<u>Guests</u> Jana Lytle, Parent Kelly Malcolm, UNL Student, HearU

<u>Liaisons</u> Sue Czaplewski Cole Johnson

Interpreters Ben Sparks Pam Duncan <u>Staff</u> Brenda Coufal MeLissa Butler Shelli Janning Jen Lee Nicole Swanson

<u>Newborn Screening Staff</u> Krystal Baumert Julie Luedtke

Meeting start time - The meeting was called to order by Committee Chair, Stacie Ray at 12:05 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

There were no changes to the agenda.

3. Review of November 8, 2018 Minutes - Action

The Meeting Minutes from the November 8, 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 Laura Beshaler, seconded by Ashley Kaufmann, and unanimously approved by the committee members.

Introductions

4. NE-EHDI Program Update and Action Items

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

- Johnna Lygrisse, parent of a child who is hard of hearing is joining the committee for her first meeting today.
- Jessica Larrison from NCDHH is replacing Jenny Corum who moved out of state.
- Merry Spratford, audiologist from Boys Town is replacing Jenna Browning, who moved out of state.
- Jennifer Lee is the new UNL Intern and NE-EDHI Community Health Educator.
- Heather Gomes has replaced Rick Kang's as the new Chapter Champion since Rick is retiring.

Sustainability

Brenda continued the sustainability discussion that began at the November, 2018 meeting. Options for sustainability include utilizing MCH Title V Block Grant Funding and receiving a fee from the hospital Newborn Screening Program. Currently, NE-EHDI is not asking for a portion of the Nebraska Newborn Screening fee.

Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSPSHWA) informed EHDI programs that there are eight states who receive a portion of the newborn screening (NBS) fee to supplement their state EHDI program. The amount received ranges from \$3.00 - \$41.83. However, it's difficult to compare between states because there are so many variables to consider such as state legislation, number of births, conditions tested for the blood spot panel, the lab fees, etc. Nebraska newborn screening law only allows NBS funds to be used for the NBS program, so NE-EHDI will not be able to ask for a portion of that fee.

Colorado EHDI passed legislation in July 2018 to receive a \$4/baby fee for the hearing screening. The stakeholders on the CO committee began meeting in the summer of 2017 every other month and by e-mail. Once a bill was drafted and proposed, it was only revised one time. The bill was passed, and CO-EHDI now receives a \$4.00 fee that is separate from the newborn blood spot screening fee. CO bills hospitals, midwives, birthing centers based on the number of screens showing on the electronic birth certificate. The hospitals in CO did not react too much to the fee because it was a small amount.

At the November, 2018 meeting, a few questions were asked:

- Who pays the fee?
 - For the Nebraska Newborn Screening, which doesn't include hearing screening, the lab bills the hospital and the hospital bills the insurance carrier.
 - o Process is the same for in hospital or out of hospital births.
- Is the department of insurance 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?
 - State statute requires that all newborn screenings including hearing screenings are covered by insurance including Medicaid.

At the November, 2018 meeting, the NE-EHDI Advisory Committee voted to pursue approval to introduce a bill into legislation asking for NE-EHDI to receive a small fee for the newborn hearing screening. A NE-EHDI Legislation Proposal Summary was emailed to the committee on May 6, 2019, and included the following information:

- a. Purpose/Mission/Importance of the NE-EHDI Program
- b. Infant Hearing Act Requirements
- c. NE-EHDI 2017 Data (Most current finalized data)
- d. National 1-3-6 Guidelines for Hearing Screening, Diagnostic Evaluation & Early Intervention
- e. Partnerships for Family Support
- f. Improvement Initiatives
- g. Partners
- h. Program Challenges and Explanation of the Need
- i. Program Funding, Staffing and Costs
- j. Saving Money for the State and Nation
- k. Examples of Hearing Screening Fee Amounts and Use
- I. Process for Approval to Introduce a DHHS Bill into Legislation
- m. Colorado EHDI process for Hearing Screen Fee Legislation

Current NE-EHDI funding was summarized which included \$0 in state funding and program income, \$250,000 is received annually from HRSA, \$150,000 is received annually from CDC, which NE-EDHI can only utilize about \$120,000 of the funding due to restrictions of how funds can be spent, and ~ \$30,000 annually from the Title V MCH Block Grant. Over the years, federal funding has been reduced, and the way funds can be utilized has been restricted.

NE-EHDI currently staffs two FTE's, the Program Manager and Community Health Educator Sr. There are three staff members who work on a contract/sub-award including the Business Analyst, Community Health Educator Graduate Audiology Student, and the Community Outreach Coordinator contracted through Hands & Voices. Annual costs for the NE-EHDI Program are broken down as follows:

 Personnel with fringe benefits (34-37%) and indirect cost (32.6%) 	\$194,622
 Contracted staff (Business Analyst and SOS Graduate Audiology Student) 	\$112,918
Netsmart Maintenance cost for electronic data system	\$ 18,000
 EHDI Annual Meeting (Required by HRSA & CDC to attend) 	\$ 5,000
 Contract for Parent Rep scholarship for EHDI Annual Meeting 	\$ 2,000
2 Advisory Committee Meetings a year	\$ 3,500
Sub-awards for Family Support Organizations (includes Community Outreach Coordin	ator)\$ 62,500
Exhibits at Conferences	\$ 750
Health Professions Tracking Service Directory - Electronic (split with Newborn Screeni	ing) \$ 710
TOTAL	\$400,000

The cost savings benefits of the NE-EHDI program were emphasized. Special education for a child with unidentified hearing loss who does not receive EI will cost schools an additional \$420,000/child by the time that child graduates high school. On average, Nebraska identifies around 55 babies each year. This works out to a potential savings of \$23.1m/year.

Nebraska EHDI has never received a portion of the Newborn Screening charges, so this would be the first time that hospitals would see this type of fee.

Brenda provided an illustration of how much funding would be provided at various fee levels:

- \$3 x 26,500 births annually = \$79,550
- \$5 x 26,500 births annually = \$132,500
- \$7 x 26,500 births annually = \$185,500

Brenda stated that the stakeholder committee will have to decide how much to pursue for the fee. We don't want to ask for too much which they may reject right away without hearing the need. Brenda asked the committee how much they think the fee should be.

Pete asked for clarification on who funds EHDI programs. Brenda explained that currently, HRSA, CDC & Title V fund the program, but those grants cover the bare minimum costs for the program. The purpose of the fee is to help with sustainability if federal funding is reduced more. Pete asked for clarification on how the illustrations for {\$fee} x {annual births} were figured. Brenda stated that the number of births is the average of number of births over the past three years.

Julie Luedtke added that the blood spot fee started at \$3 in 1997. This was the results of parents working with a senator to get funding to support metabolic foods and formula. Over the years as the cost of formula and foods increased, they were able to increase the fee to \$10. When three additional diseases were recently added to the panel, increasing the number of disorders screened for to over 30 more diseases, the fee increased to \$20 due to

the need for more staff. So, they started with a small fee, but it increased over times as the needs and benefits were realized. Receiving a fee didn't start with staff pursing it, it started because there were parents who were strong advocates for moving the legislation forward.

Pam Zegers asked what the estimated shortfall would be if funding was cut, and what the funding received from the fees would be used for. Brenda explained that one example is with the current CDC funding cycle. Funding for the business analyst was cut from 100% funded salary down to 65%, and restricted funds to be utilized only for improving timely diagnostic and early intervention services. The HRSA **funding is already being utilized to it's fullest**. Since CDC no longer allows funding to be used to cover certain costs to run the program, Title V funds have been utilized to cover the bare minimum operating costs. If Title V funding was cut, EHDI would not be sustainable with HRSA and CDC funding only.

In Colorado, it only took one year for legislation to be passed, however, we don't know how long the process will take in Nebraska. It could be many years, so we want to make sure that we are pursuing this sooner rather than later, so the EHDI program can continue operating.

The fee could be utilized to supplement payroll for the Business Analyst and Community Health Educator positions, provide funding for birthing facilities to purchase updated ABR equipment, and assist in providing education and educational materials that NE-EHDI currently does not have funding to purchase, and providing scholarships to uninsured or underinsured families who need financial assistance to follow through with the screening and diagnostic process for their child.

Pete asked which fee level EHDI would need to fully sustain the program. Brenda stated that at the \$3 level, that would help *if* funding from HRSA and CDC continue at the same level. If CDC or HRSA funding is reduced or restricted further, the \$3 fee would not sustain the program.

MeLissa Butler asked for clarification from Pete, if he was asking what amount would be needed to fully fund NE-EHDI without any grants from HRSA or CDC. Pete clarified that he was asking because he understands that over time, the government does reduce funding in hopes that the state will take over and fully fund a program. Due to NE-EHDI receiving no state funding, the government may be suggesting that Nebraska consider funding their EHDI program. Pete recommended that NE-EHDI request the \$5 fee to start with, that way the funding will hopefully be sufficient for at list awhile.

Brenda added that the necessary costs to run the program are around \$400,000/year. That is the bare minimum the program can operate on, and that does not allow for extras such as assisting facilities with purchasing new equipment or additional educational outreach. Of the \$400,000, Title V provides \$30,000 as supplemental funding.

Brenda added that a stakeholder group will be needed in order to determine next steps for pursuing legislation. The number on the stakeholder group should be limited to 12 members in order for the work group to be productive. Members could be added in later phases as appropriate, depending on what next steps in the process are needed. Brenda reviewed a list of suggested stakeholders, and asked the Advisory Committee if there are any partner that should be added or removed, and how often the Stakeholder Committee should meet in order to be ready to introduce a legislative proposal to DHHS by July 1, 2020.

Stacie Ray commented that the members listed is a good core group to start with, and others can be added as needed. NCDHH would be a critical player as they have done a phenomenal job with pursuing current legislation. They have the experience and resources, and this aligns with their mission.

Brenda asked for volunteers from the advisory committee to participate in the stakeholders committee. The members agreed to think about it and get back to Brenda. Additionally, Sue Czaplewski had previously

that EHDI request letters of support from the Nebraska Regional Programs, so supporting this effort could come from other means as well.

Brenda added that the process to introduce the bill would need to go through four levels of approval at DHHS including the Unit Administrator, Deputy Director, Chief Operations Officer and CEO. If the bill is not approved, it would be up to the Stakeholder Committee to decide if they would like to pursue legislation without the assistance of NE-EHDI/DHHS staff.

Julie Luedtke clarified that DHHS does not introduce legislation, they work with a senator's office to do so. Additionally, in the past it has been helpful to have a senator or senator's aid attend advisory meetings so they can understand more about the program to become strong advocates. In the event that the bill is not approved, then that senator may be motivated to carry on the effort without DHHS. Brenda added that Senator Carol Blood has been instrumental in moving LB15 hearing aid legislation forward. Stacie stated that is why she thinks working with NCDHH would be beneficial, because they are already working closely with Senator Blood. Once the current bills are signed into law, the board would be open to moving forward with this effort. Brenda added that since hearing seems to be a hot topic right now within the Nebraska legislature, now would be the right time to move forward with this effort. Since we're not in dire need of funding yet, it's important to be proactive.

Kristin Jolkowski added that she believes NSLHA worked with NCDHH to move forward with LB15. It might be helpful to include NSHLA as well to tie together their connections with senators.

Pete agreed that the collaboration with NCDHH will be important. NCDHH represents children and individuals who are D/HOH so it's easier for the senators to grasp that idea, and reflect on the human side of these types of bills. EHDI programs also impacts the human side of hearing issues, and the funding is needed to continue to serve the families and children. The state senators were able to see the value of hearing aids for children, so the human side needs to be emphasized in how we approach the request for funding EHDI. Brenda agreed, adding the human side is key, and that's why we need to make sure parents are involved.

Brenda stated that she will send out invitations to various stakeholders and see who is interested in participating.

HRSA funding update

Brenda stated that the HRSA progress report was submitted in December of 2018. Additionally, the Learning Communities Survey was completed by members and submitted to HRSA on April 30, 2019.

Since the November, 2018 meeting, Brenda summarized the HRSA goals that have been accomplished, including events coordinated through the NE-EHDI/H&V-GBYS agreement. NE-EHDI has continued collaboration efforts with H&V to provide family support and leadership empowerment events, which Shelli will discuss later in the meeting.

Roots & Wings, which is hosted by Boys Town was cancelled this year due to lack of registrations. We are hoping that a 2020 event is in the works, and will receive enough registrations to hold the event.

NE-EHDI also continues to provide funding for HearU to help with the purchase of hearing aids for children, and assist with funding the graduate audiology student who runs the hearing aid bank.

In year three of the HRSA funding grant cycle, NE-EHDI will continue collaborations with H&V & HearU Nebraska. NE-EHDI is also working towards collaborations with the Deaf and Hard of Hearing (D/HH) Community, Nebraska Commission for the D/HH, and Nebraska Association for the Deaf, and will discuss collaboration ideas with the state Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. Brenda asked the committee if there are any other partners that NE-EHDI should consider collaborating with to better serve families.

Pete stated that Nebraska Association for the Deaf (NeAD) is partnering with the Nebraska Registry of Interpreters for the Deaf (neRID) to host a joint conference in June, 2019. They will have a guest speaker who is a young woman that hosts a YouTube show about Deaf issues in a talk show type format with interviews, etc. There will also be valuable information for parents to learn. NeAD is ready and willing to partner with various agency and collaborate on events such as this, so perhaps in two years at the next conference, EHDI could collaborate with NeAD.

Linsay Darnall Jr. added that the Nebraska Association for the Deaf conference is open, and EHDI can both attend and exhibit at a booth.

Brenda added that she also will reach out to the Leadership Education in Neurodevelopmental and Related Disorders (LEND) program to see if there are opportunities to collaborate with them, as required in the HRSA grant.

Sue Czaplewski asked for clarification regarding what the LEND program is. Julie stated that it has been around for a long time and is housed at UNMC. The program provides interdisciplinary leadership training for pre-service graduate students, postdoctoral interns, practicing professionals and disability and family advocates, as well as undergraduate students. There are opportunities for professionals to learn more about the program. Ashley Kaufman added that in North Carolina, there is a fellowship training program where graduate students go to work on multidisciplinary cooperation and how to work together to benefit the "whole person" especially in children and individual who have multiple concerns to ensure that they get all the care they need.

Brenda added that EHDI also wants to do lunch and learns, and plan to collaborate with Pam Zegers at Complete Children's Health in Lincoln to start with their clinic. From there, EHDI will work with Pam on how we can work together to educate pediatricians across the state. One ideas is to offer an online webinar and offer CME's to peak interest.

Terms for Advisory Committee Officers

The current NE-EHDI charter states that the terms of Chair and Vice Chair will last two years. The term begins at the first meeting of the calendar year. Nominations for the new Chair and Vice Chair are made at the last Advisory Committee Meeting of the term. Currently, voting for the new Chair and Vice Chair is scheduled for November, 2019. Beginning in 2017, the NE-EHDI Advisory Committee Meetings were reduced from quarterly to biannually. Since the meetings have decreased, Brenda asked the committee if they would be interested in revising the charter to extend the term of Chair and Vice Chair to four years rather than two, and if they would like that to start with the current term or the next term. If the committee agrees to this change, then a motion will be needed to revise the charter.

Linsay stated that as former chair, he was in the middle of the transition from four meetings a year down to two meetings a year. Things changed in the middle of his term, and his term was cut short. He stated that he would recommend extending the term from two years to four. This gives the chair time to guide the committee thoughtfully. Pam agreed, stating that when meetings are only held **twice a year, it's hard** to get things done. Pam Zegers made a motion to extend the terms with the current leadership. Kelly Rausch seconds as well at Pete Seiler. The committee unanimously agreed that the Charter will be revised. The next election for chair and vice chair will be at the Fall, 2021 meeting, with terms beginning at the Spring, 2022 meeting.

Upcoming Advisory Committee Meetings:

2019 Fall Meeting will be Nov 14, 2019
 Nebraska Educational Telecommunications - 1800 N. 33rd Street - Lincoln

Jr. NAD will present on Deaf Culture

2020 Spring Meeting will be May 14, 2020
Nebraska Children's Home Society - 4939 S. 118th Street - Omaha

2020 Fall Meeting will be Nov 10, 2020
Nebraska Educational Telecommunications - 1800 N. 33rd Street - Lincoln

5. NE-EHDI Learning Communities Update

MeLissa Butler, Community Health Educator Sr. for the NE-EHDI program updated the committee on the current Learning Communities.

Western Nebraska Teleaudiology Learning Community

For the Western Nebraska Teleaudiology efforts, ESU #13 is the pilot/spoke site and UNL Barkley is the hub location for the Teleaudiology initiative. After the November, 2018 meeting, the Nebraska Department of Education reached out to NE-EHDI and said they could provide a grant to purchase the medical equipment necessary for teleaudiology. MeLissa thanked NDE for providing the funding, as this was a huge step in making teleaudiology happen for western Nebraska.

UNL applied for the grant, and received funding on March 1, 2019. The equipment was purchased shortly thereafter. In early April, Sara Peterson from ESU#13 in Scottsbluff began training with UNL. By mid-April, Hanna Ditmars and Kelly Malcolm from UNL Barkley traveled to Scottsbluff to perform a diagnostic ABR onsite. Now that the the training process is completed, UNL & ESU#13 are live and ready to offer teleaudiology services to families in western NE.

Kelly Malcolm, third year UNL graduate student added that she assisted Hanna Ditmars in picking out the equipment needed for teleaudiology, and getting it all set up once the equipment arrived. When Sara came to Barkley for training, she observed how the equipment was set up so that she would be able to replicate the process when she sees patients at the spoke sites. Other steps include making sure Zoom was set up appropriately and is HIPPA compliant.

Sara Peterson added that she just can't believe what all has taken place since March 1^{st.} ESU #13 is set up to do repeat ABR screenings for babies who do not pass the newborn hearing screening inpatient. Babies ages 0-3 **months can be seen. Sara added that teleaudiology has been discussed for about 10 years, so it's great that the** service is finally available. This is a much easier avenue for families to be able to access care. Previously, a family would either have to travel to Denver, CO or Omaha, NE for follow up care, and that poses a challenge when you need to keep the baby awake so they will sleep through the ABR. ESU #13 has three offices throughout western NE, so no family is more than 1 ½ hours away from an office where they can have a hearing screening completed via teleaudiology. This lessens the travel burden on families greatly.

Laura Beshaler asked if they are doing screenings and diagnostic services. Kelly stated that they are able to do diagnostic ABR's along with tymps and otoscopy.

Kristin Jolkowski asked if information about teleaudiology is being incorporated into the physician and ENT trainings. Brenda stated that it will be included as part of the information shared during the trainings.

Stacie Ray wanted to recognize both Kelly Malcolm and Hanna Ditmars for their hard work on this project, adding that Hanna is so passionate and driven, and has led the way in the time and effort she put into setting up teleaudiology.

Sue Czaplewski added that it's important who you ask. As stated previously, this has been discussed for ten years, and many options were explored, but it wasn't until NDE stepped up to provide the funding that it finally happened. So, it's important to keep asking until you ask the right people.

Brenda added how important it is to continue to build relationship with our partners.

Johnna Lygrisse added that it would be important to include information about teleaudiology in our request for the fee to help sustain the EHDI program, as this shows that families all over the state are able to be served. MeLissa added that once the western Nebraska teleaudiology program is well established, we'd like to branch out to other underserved parts of the state, so funds from the hearing screening fee could possibly be utilized to help expand teleaudiology services through the central part of Nebraska too. Sara added that ESU #13 has been communicating with some of the other ESU's in Nebraska to see if the equipment could be used at their location to serve families, as the equipment is totally portable. So, the opportunity to serve other parts of Nebraska is already being explored.

Stacie also recognized Cole Johnson from the Nebraska Department of Education. He usually sits quietly and listens intently during the advisory meetings, but because of his attentiveness, this project was possible.

Hospital Training Learning Community-Parent Perspectives Video

MeLissa also updated the committee on the status of the Hospital Training Learning Community. This is a parent lead 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.

The cost to produce the first draft of the video was funded by Hands & Voices/Guide By Your Side. After reviewing the video that was filmed based on the original script, the Learning Community decided to go a different direction, and re-filming was necessary. Filming of the revised version was funded through NE-EHDI's agreement with NE-H&V/GBYS. The total cost to film and produce the video is \$8,629. This includes the original filming, original editing, re-filming, travel to film parent interviews, rental of studio to film parent interviews, rental of medical clinic to film the nurse's portion of the video, editing and producing time, payment to the professional actor who played the role of "nurse", and purchase of stock photography for the video.

Brenda added that the actor used in the video was a very small part of the expense. MeLissa added that the actor is a local actor, and he only charged a small fee, but did an excellent job pulling off the script.

The revised video and parent interviews were filmed in March, 2019. Editing is underway, and should be completed by the end of May, 2019. Currently the film is about 38 minutes long, with the plan to cut it down to around 30 minutes. MeLissa asked the committee if they felt a 30 minute educational training video was too long for the hospital nurses.

Kristen Jolkowski asked what is all involved in the training package. MeLissa outlined the timeline of the video for the committee. Kristen asked how the training will be executed in the hospital. MeLissa stated that once the video is ready to begin showing, NE-EHDI will begin work on the Hospital Champion program. This is modeled after the Nebraska Safe Babies recognition program. The reason for this twofold: 1) parents expressed a need to develop a system that keeps nurses and doctors accountable; and 2) we want to recognize and show our appreciation for the work the hospitals do with Nebraska families and NE-EHDI. Steps to the Hospital Champion Program Process include:

- 1. Birthing facility will take the NE-EHDI: Newborn Hearing Screening Pledge
- 2. Staff will view the Parent Perspective Hospital Training Video, review the initial screening and refer cards
 - Goal is that all birthing facilities across Nebraska provide consistent education to parents about the newborn hearing screening and utilize the information/scripts from the training when giving hearing screening results to parents.
- 3. Birthing facilities will revise their protocols to incorporate the training and utilize the information learned from the Parent Perspective Video
 - They will also continue to give the "Can Your Baby Hear? Brochure, initial screening card and refer card to parents as appropriate.

- 4. Once the birthing facility takes the pledge, completes and implements the education plan for the staff, they will become a Newborn Hearing Screen Champion Hospital.
 - > A certificate will be presented to them for display in the newborn nursery

MeLissa stated that she wasn't sure how long the training for the Nebraska Safe Babies programs have been. Pam Zegers stated that Complete Children's Health is in the process of getting certified now, as they are the pilot to offering the Champion program for outpatient clinics. The clinic has determined the need to space out the trainings, as a lot is asked of nursing staff in the way of trainings and continuing education. Based on her experience with the amount of training that is asked of nurses, Pam feels that a 30 minute video is too long, especially if there is other training that is supposed to go along with it. It would be ideal to reduce it to 20 minutes.

Kristin Jolkowski agreed, adding that it's important to remember that there are nurse shortages already, and the more training that is asked, the less meaningful the trainings become.

New EHDI Website

MeLissa also updated the committee about the new NE-EHDI website. This went live in early April, 2019. The new design gives all DHHS pages a fresh, modern look. It also helps users to have a more consistent experience across all pages, and it finally mobile friendly. The website also utilizes Google translate, and thus can be viewed in 32 different languages.

6. NE-EHDI Statistics

Brenda Coufal presented information on the NE-EHDI 2018 DOB Statistics, as detailed in the handouts.

Brenda commented that the improved diagnostic data is probably due to consistent staff, and the team efforts that make a difference.

Ashley Kaufman asked what happens to the follow-up if a baby moves out of state. MeLissa responded that a referral is made to the EHDI program in the state where the child is moving, in hopes that the EHDI program will follow up and help the family find resources in the new resident state.

Julie asked about those who identified late after passing the hearing screening. Does NE-EHDI do an analysis of why that happens? As with any screening, there can be false negatives, so she wondered if research has been done to identify if it is truly due to later onset due to risk factors, or if it was a hospital error. Brenda said those QA measures are not in place at this time, but NE-EHDI would look into whether that would be appropriate.

Brenda also clarified that EHDI and CDC determine what is considered "Lost to follow-up" differently. CDC groups lost to follow up and unresponsive in the same category, whereas when NE-EHD reports to the advisory committee, lost to follow up and unresponsive are separated out.

7. EHDI Follow-up & 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 worked with 741 families during the contract year 4/1/18 3/31/19 (Data from NE-EHDI).
- Shelli worked with 332 families from 10/24/2018 4/15/19
- There are currently 14 trained Parent Guides who provide support throughout Nebraska.
- As of 4/15/2019 GBYS are serving 138 families and 83 families were referred by NE-EHDI (60%).

Shelli shared feedback from families regarding how GBYS has made a difference for them:

"The GBYS program was a welcoming surprise at a very confusing time with our new baby. The support I received in my first conversation with our Guide made me definitely feel I was not alone in our hearing challenges".

"I love this program and feel like I'd be lost without having your support".

"It is nice to talk with someone who understands and can help understand my own feelings".

Shelli talked about the family support events that have taken place since the November meeting, including:

- <u>Hands & Voices and NE-EHDI collaborations for Family Support Events since 11/8/2018 (last Advisory</u> <u>Meeting):</u>
 - On-going Monthly activity "Rising Stars" Deaf & Hard of Hearing Youth Leadership Award This is an opportunity to recognize a youth (up to age 21) once a month who is deaf or hard of hearing. It is empowering as well as helps promote our youth to become positive role models in the D/HH community. The selected youth receive an award certificate, a \$10 gift certificate to a location of their choice (Amazon, Starbuck or Target), and is recognized on Nebraska Hands & Voices Facebook. Please spread the word about nominating a D/HH youth so they can be recognized for their great leadership skills and/or serving as a role model for their peers. Monthly Rising Stars is doing great. We are needing more referrals, the Regional Programs have been very helpful but we would like to get referrals from various sources.
- Couples Night Out Event for parents of D/HH children 12/8/19 (Omaha) 24 people attended and received very positive feedback.
- Parent Night Out Event for parents of D/HH children 1/19/19 (Hastings) 10 people attended and received good feedback. There was more interest from parents who had to travel to attend.
- Hands & Voices Social Emotional Workshop 1/20/19 (Hastings) and 2/2/19 (Omaha)
 - o Hastings- 8 people attended
 - o Omaha 22 people attended/ 2 zoomed
 - o Received great feedback from both events
- Hands & Voices Fall Family Bash 8/14/18 (Omaha) <u>Postponed due to winter storm</u>. Replaced with <u>Winter Family Bash 2/24/19 (Omaha – Saddlecreek Community Center)</u> – 60 people attended & fun was had by all.
- Moms Night Inn Feb 16-17, 2019 (Lincoln) An opportunity for moms to share experiences and provide support to each other. Topics included – Self Advocacy, Empowerment, Literacy, Socialization, Communication & more.

 ${\rm o}\,{\rm 21}$ mothers attended- feedback showed it was the best one yet.

UPCOMING Events:

Due to the changing needs of families, the next grant year will focus on providing trainings and informational sessions via Zoom.

- Zoom Events:
 - Aug 2019 Getting Ready for Back to School weekly Zoom meetings during the month
 Nov 10 & 17 2019 Surviving the holidays
 - o Feb 2, 2020 Dads Panel
 - o May 3, 2020 Summer Events and Activities
- Spanish Only Extended Family Event (South Omaha) Sept 14, 2019
- Collaborating with NCDHH and fire departments to provide community education and resources to families with children who are D/HH (Tentatively late summer into the fall) Planning events throughout the state at fire departments to educate them on the needs of people who are D/HH or Deaf blind. We are

collaborating with Jessica Larrison with the NCDHH to educate the emergency professionals about the D/HH needs and we want to hear from them what we can do to help stay safe in an emergency. Jessica will also present about funding options for families to get fire alarms etc. to help ensure the safety of our kids. We plan to host an event in Omaha, Lincoln, Norfolk, McCook, Kearney and South Omaha/Bellevue.

- Moms Night Inn Nov 2-3, 2019 (Norfolk) An opportunity for moms to share experiences and provide support to each other. Topics included – Self Advocacy, Empowerment, Literacy, Socialization, Communication & more.
- ASTra Training pending approval and funding weekend of Jan 18, 2020
- Moms Night Inn Feb 8-9, 2020 (Lincoln) An opportunity for moms to share experiences and provide support to each other. Topics included – Self Advocacy, Empowerment, Literacy, Socialization, Communication & more.

Shelli added that H&V/GBYS also plans to host additional Dad's events in the Spring and Fall on an annual basis. They are also looking for a strong parent advocate with a deaf plus child to hire as a guide, so she asked if anyone on the committee knows of someone, please refer them to her.

Pete Seiler thanked Shelli for her work with parents. The work that she's doing is truly a godsend for many families.

8. EHDI Annual Meeting – A Parent's Experience

Jana Lytle, recipient of the 2019 Parent Scholarship to attend the EHDI Annual Meeting in Chicago, IL shared her experience from a parent's perspective.

Jana and her husband have three boys. Their older boys have normal hearing, and their youngest boy who is two is profoundly deaf. After he was born, he was in the NICU for a week. The night before he was discharged, he had his hearing screening. The nurse informed them that their machine was "broken" so they weren't able to complete his hearing screening, and they were referred to Boys Town for follow up. Before they went home, the nurses reassured her and her husband that the baby could obviously hear, he just needed to get his hearing rechecked. So, about three weeks later they went to Boys Town where he was identified as profoundly deaf and would be a candidate for a cochlear implant (CI). It was a shock to her and her husband. The day after identification, she went through the EHDI parent resource guide, and it calmed her fears and helped her establish what direction to go. At about three months of age, her son got hearing aids. In March of 2018 he was implanted with Cl's. Shortly after he was implanted, both her and her husband wondered if they had made the right choice in getting him implanted. They were told that around 2-4 weeks post-surgery, he should start responding to his name. However, he did not begin responding. Even two months after the surgery, he still was not responding. Their concern continued to grow, until one day while their family was at the zoo in a very crowded area. There happened to be another little boy there with the same name, and his mom was calling him from all the way across the room. Every time she would call for her son, their son would whip his head around and look at her. At that point, both her and her husband realized that he did know his name and he could hear them, his "selective" hearing was just much more of a problem than his actual deafness.

Jana added that her son is just like any other child. He's a wonderful little boy who has had a big impact on their family. It's amazing to see how her extended family has tried to learn sign language so they can communicate with her son. Her parents even attended the SEE workshop. Jana expressed appreciation for the way her son's circumstances have given them the opportunity to connect with many families and professionals who have supported them along the way. Additionally, they were able to adopt a deaf puppy back in October, 2018 which has been beneficial to everyone. The new puppy responds to signs, which helps her son to be more consistent about using sign language and helps the family to use their signs more often as well. Additionally, their other dog has learned and began responding to signed commands. This whole experience has opened her eyes and given her the opportunity to be a part of a community that she never would have had the chance to be involved with otherwise.

Jana shared that she was so excited to be chosen to attend EHDI meeting in Chicago, IL. The best session she attended was a four hour session that focused on advocacy and learning. She felt like she learned so much during

the session, and there was still so much more for her to learn. She added that she is excited to attend the upcoming ASTRA training which will be hosted by NE H&V/GBYS.

Other sessions she enjoyed included one about Dinner Table Syndrome, one that demonstrated a new EHDI app that makes information more accessible to families, and a dad's panel that helped her to understand more clearly the dad's perspective.

Jana also enjoyed networking with professionals and other parents, adding that it was amazing to build relationships and realize how much she had in common with the people she met. One person she got to know better was Shelli Janning who talked to her about H&V/GBYS. The conference was a great environment to learn more about H&V because there were so many representatives there from different chapters around the nation.

The only two disappointments Jana experienced were that she couldn't make all sessions she wanted, and she wished more parents could come. She feels like she benefited immensely, and other parents would benefit as well. The experience also encouraged her to get more involved, and has increased her desire to give back so she is working towards becoming a Parent Guide with NE-H&V/GBYS. She added that she is excited for next EHDI annual meeting, and plans to attend.

9. Deaf History & Culture

Linsay Darnall Jr. presented information about Deaf history and culture. As a historian, Linsay is excited to share information on something he recently found out. Over the weekend while he was in Washington DC, Gallaudet students gathered for **an "open stage"** ASL poetry night. The sign **"poetry" in ASL**, emphasizes that poetry comes from the heart, and **there's** a lot of emotion. The **students'** performing that night were pushing the boundaries of poetry. It was amazing, and he thought it would be great if others could see that for themselves.

During his visit to Gallaudet, he stopped by the archives. A friend of his who works there shared a newspaper called "The Deaf American" printed in 1907. It was published in Omaha, NE. So that was very exciting to find something like this that was produced in Nebraska. The printer was Russell Smith, who graduated from the New York School for the Deaf in the 1880s, and later came to Omaha with his wife. He was a member of the Populist Party, and round the turn of the century, there was a big populist movement.

Linsay then decided to do some research in the Omaha Herald. In 1896, Russell Smith gave a presentation to a deaf audience on behalf of William Jennings Bryan. In 1902 Russell Smith was the first chair of the NeAD, and William Jennings Bryan attended a NeAD meeting and presented to its members. Linsay stated that he knew Smith was a Deaf centric publisher. At the time, all Deaf institutes had their own little newspapers that the Deaf community would subscribe to so they could keep up with Deaf news nationwide. However, "The Deaf American" was the first independent, nationwide Deaf newspaper. It is noteworthy that issues talked about in the paper seem to be the same issues that Deaf individuals discuss currently, namely that Deaf schools should hire more Deaf teachers so Deaf children can have Deaf role models.

In 2019, here in Nebraska the Deaf community is celebrating 150 years of deaf culture. That can be traced back to the origin point of 1869 when William French came to Omaha and found that there was no school for the Deaf. He began a movement to establish the Nebraska School for the Deaf (NSD). On April 1, 1869 a little girl named Kate Callahan became the first student at the NSD. Within two months, the number of students grew to 11. The following fall, 30 students were enrolled, and it grew from there. The population for NSD peaked at 200 students.

Rather than share Deaf history with dates, Linsay stated they wanted to share a story more focused on the human side of the Deaf population. For years, deaf people have always strived to tell the world they are just like the hearing population. All they need is respect, recognition, and an invitation to sit at the table with everyone else and be part of the discussion and decision making process. When NSD was founded, it opened the door for many Deaf students to become successful as adults, many becoming instructors and teachers at schools all over the nation. Currently there are two Deaf schools nationwide. The one in Illinois named their gymnasium after a Nebraska Alum, and it is known as The Marshall Gym. There is another Deaf school in Washington whose High School is named after a Nebraskan, Louis Devine.

When Louis Devine graduated from the NSD in the 1890s, he went on to Gallaudet. A female student had founded a newspaper called *The Buff and the Blue*, and was the first editor of the paper. The second editor of that newspaper was Louis Devine. When he graduated Gallaudet, he came back to Nebraska to teach for a while, then moved on to Arkansas School for the Deaf. From there, he moved around quite a bit, until he moved to Washington, which is how the school came to be named after him.

Linsay invited all members of the committee to come and tour the Nebraska Deaf Heritage Museum and Cultural **Center. Tours can be arranged through Linsay, and are by appointment. In 1931 the NSD youth boys' basketball** team, won a state championship, and the trophy from that championship is on display at the museum.

Kyle Miers was a classmate of Linsay's, and they grew up together. Kyle is currently CEO of Deaf Australia, which is a sister agency to NAD. Last year he visited America, and he was recognized in the hall of fame.

The point of all of this is that the Deaf community and Deaf people, those who communicate through ASL and are visual learners make up about 1% of d/hh people in the United States. Pete and Linsay represent that small sliver of their society on this committee. Linsay stated that his presentation just scratches the surface of Deaf culture, but he wanted to give us a taste of what Deaf culture is like.

Everyone in the room has ears, mouths, and sound. As Deaf individuals, they have eyes, hands, and light. These three elements are not in competition. Gallaudet published a research study that showed the brains of deaf children are the same as hearing children. The Deaf community already knew that, but it is nice to have a study like that to back up what they already knew, and this helps to lend a foundation to the deaf **population's** existence.

Not all Deaf experiences are golden. Culturally, Deaf people have always experienced oppression. In 1988, after 124 years of deaf presidency, the board at Gallaudet decided they did not want another deaf president, so they hired a hearing individual. The students rebelled, held a revolt, and for the first time the world got to see the Deaf perspective. The board brought in a Deaf president, and now Gallaudet is on its 4th Deaf president since that revolt.

Another example of resistance lead by Deaf individuals is the name labeling. Deaf individuals in Nebraska are **working to remove the term "Hearing Impaired" from the books entirely. Deaf individuals are constantly striving to** reframe themselves in a positive light so society will understand, respect and recognize Deaf individuals as human, and not something that needs to be fixed. In line with that, the Deaf community believes EHDI goals should be centered on *Early Healthy Deaf Identity* rather than focusing on the medical aspects so deaf children can thrive just like they want them to do.

Pete Seiler added that his wife is hearing, and when they first walked into a Deaf club, she was surprised to find that it was a noisy place. The TV was on, but there was no sound. She asked if the TV was broken, and he stated **that the volume was down because they didn't need it. It was a culture shock to her, but she began to ponder how** Deaf individuals live without sound.

When Pete was the principal at NSD, there was a program in Scottsbluff. He drove out there, and his other passengers observed that the radio wasn't on. They asked how he could drive so long without the radio. He explained that he didn't need one, because he couldn't hear it. They asked how he could stay awake and focus on the road without a radio. He didn't know how to respond.

Another time, someone asked him what he did for a living. When he explained that he was the principal at NSD, they chuckled and responded "No really, what do you do?" At that point, Pete realized this person could not accept that he could be in school administration. He responded, "I'm the janitor." His son, who was 11 at the time said "Dad, that's not right." His son proceeded to state how he had a doctorate degree, and the man was surprised to hear that, and couldn't understand how a deaf person could achieve that level of education and success. Pete was able to achieve this because he was given the proper tools. This experience taught him that what deaf children need should be reframed so they have access to all aspects of learning.

10. HearU/Hearing Aid Bank Update

Kelly Malcolm, UNL Graduate Student and HearU Graduate Assistant, presented the HearU statistics for November 1, 2018 to May 1, 2019, as detailed in the handout, noting that the number of hearing aids dispensed has dropped.

Stacie added that they've been looking at the data, figuring out if their numbers are dropping because they're not receiving referrals from audiologists, or if parents don't want to fill out applications that share financial information. So far, they don't know if it's one reason or the other, or a combination of both. There has been a lot of hard work done on LB15 which would require insurance companies to cover hearing aids for children. However, there will still be a need for HearU when the legislation passes. Continued collaborations will be important to ensure all kids' needs are met. In the future, there will be a three pronged approach to hearing aid coverage for Children: 1) Hearing aid coverage through medical insurance, 2) HearU for uninsured and underinsured, and 3) Coverage through Medicaid or Medically Handicapped Children's Program. Involving insurance companies will complicate things, but it is exciting because there are more options. HearU will continue to counsel parents about what other options there are, so they can chose the options that is best for them. Stacie's hope is that with all components, there should be no reason that any child doesn't have access to hearing aids.

Laura Beshaler asked if they have considered helping with BAHAs or other nontraditional forms of amplification. Stacie stated that HearU is currently able to offer alternative forms of amplification. They **aren't** able to cover them at 100%, but can cover some of the costs, up to 75% in some cases. Johnna asked for more information about the **patients that didn't qualify** for assistance through HearU. Kelly clarified that they were well over income, **and didn't** qualify. Johnna asked what happened with the family **from there. Kelly clarified that it's an out of pocket cost for the** families if they **don't have insurance coverage.** Pete asked why those families **weren't referred to the hearing aid** bank. Kelly explained that HearU is the hearing aid bank in Nebraska, adding that HearU serves ages 0-18, Lions serves ages 19-64, and Sertoma serves ages 65 and over.

Brenda asked for clarification on what procedures within the three pronged approach are in place to ensure that no child will go without hearing aids. Stacie stated that the goal is for HearU to be family and patient centered, but they need to meet with audiologists and figure out the best approach to ensure there are not gaps in hearing aid coverage.

Pete asked for clarification regarding how insurance will cover hearing aids through LB15. Will it be covered under the regular health coverage, or will parents need to purchase a separate insurance plan like with vision and dental. Stacie clarified that LB15 mandates hearing aids to be covered through regular health insurance coverage. Premiums will increase by pennies because the numbers needing hearing aids will be very small.

Ashley Kaufmann asked if the insurance companies will have to go through buying groups. Stacie did not know the answer, or if that information was covered in the way the legislation was written.

Kristin thanked HearU for their services. She has utilized them as a resource to determine how to help families qualify for Medicaid or Medically Handicapped Children's Program. It is much easier to work through HearU than it is to try and figure it out for herself on the DHHS website.

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

Merry Spratford, Research Audiologist at Boys Town National Research Hospital presented information of the Question Prompt List (QPL.) Her hope is that will be incorporated into the EHDI PRG and H&V will use it to help parents guide conversations, and promote family centered practice. 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 discussed the need to balancing information and support counseling. Karen Munoz's group at NCHAM is finding that "missed opportunities were observed, including not validating patients' emotional concerns, providing technical responses to emotional concerns, providing information without determining patient desire for the information, and not engaging the patient in a shared planning process." The lack of validation could have been due

to several reasons, including the audiologist did not hear the concern, the audiologist may be concerned about running out of time, or the audiologist may have insufficient knowledge of how to address emotional concerns.

Once factor could be that a family may not be committed to consistent use of amplification. If the family is not fully committed to the **child's** use of consistent amplification, the child could also become uncommitted to optimal hearing as he/she grows up.

Overall, the consensus is that there is a shared, almost universal concern. Families tend to get stuck in a conventional counseling toolbox which is insufficient. To help facilitate breakthrough and forward movement, families need encouragement, hearing loss simulations, hearing aid demonstrations, support from other parents, connections with D/HOH adults, and referrals to a social worker or family therapist.

The challenge is to intervene before a non-committed approach becomes entrenched. In order to determine how best to accomplish this, interviews were conducted with 13 colleagues from nine different professions including social work, pediatric medicine, pediatric psychology and psychiatry, professional clinical counseling, marriage and family therapy, early intervention providers, and speech language pathologists. The interview format asked two questions: 1) does this situation present itself in your profession? and 2) how does your profession work with it/your advice? Overall, all interviewees agreed that this is a common situation, and their advice was to actively intervene by engaging the family. This is done by talking to them, drawing them out, exploring issues, and developing strength based approaches to change. The issue is, audiologists are not professional counselors. Therefore, we need to find an approach that is compatible with our scope of practice, professional boundaries.

The Question Prompt List (QPL) is a communication aid. It resembles an FAQ page, but there are only questions, no answers. It serves as an invitation to choose question(s) patients or parents want to discuss, in any order, and can be revisited as desired at each appointment. Often times, a patient will forget to ask their questions, or may get the impression that only some questions are welcome. The QPL is the epitome of patient/family-centeredness.

Questions developed by clinicians often tend to be patronizing and paternalistic, whereas patient generated questions are helpful in identifying unexpected questions clinicians would not have thought to address.

When the QPL was being developed the initial approach was to develop a set of 13 "jump-start" questions that clinicians had drawn from their clinical experiences with families. Input from 21 parents in the US & UK resulted in the set of questions expanding to 49, which were organized into categories. This second version was reviewed and revised by an additional 16 parents in the US & UK, resulting in the number of questions being reduced to 47. The questions were voted on item by item with the idea of either keeping the question as is, revising the question, or omitting it all together. In the end, the QPL was reviewed by ~200 international families.

The final 32 questions on the QPL are broken down into four categories: 1) Our Child's Diagnosis, 2) Family Concerns, 3) Management of Devices, and 4) Support Systems Now & in Future.

Based on the question on the QPL, audiologists have expressed a need for more support. In an effort to help audiologist use existing tools to increase their knowledge and confidence, an online document is in the works to help with the guidelines. Additionally, there are many options such as Phonak tutorials, HeartoLearn tutorials, and IDA institute Time and Talk workshop examples.

Overall, the purpose of the QPL is to address three main areas: 1) Alert pediatric audiologists to potential "noncommitment" before it becomes established family routine, 2) Help audiologists develop confidence with difficult conversations, and 3) provide a parent/family-centered platform to support these conversations.

Merry concluded by comparing the Phonak QPL to the CDC questions document and stating that while this is not the first QPL, it is perhaps the most family centered and focuses on more positive language.

Kristin asked if they have received audiology feedback on barriers to implementation. Merry stated that the UK has implemented it and received some feedback, including concerns that 32 questions is an overwhelming number for families. Overall, the families that have used it have given positive feedback. Many Audiologists feel that **they don't**

have time to ask and provide responses to 32 questions, however, the goal is that families will choose 2-3 questions each visit based on their priorities.

Pete stated that in the opening of the meeting, Stacie Ray mentioned that **the term** "hearing loss" might inadvertently be used. He feels like Merry should talk to Phonak about not using that **term** "hearing loss" in their materials, especially when many of the infants who were born deaf **have not** "lost" anything. Additionally, teachers of the deaf should be the ones to help determine what the right choices are for the child, because they have specialized training in assisting children who are deaf or hard of hearing. Merry stated that she will talk to Phonak about that, as she agrees that it helps for the approach to be more positive. Merry also agreed that teachers of the deaf are more competent in the skills necessary to working with children who are deaf or hard of hearing. There is a difference in the quality of care, and teachers are more cognizant of appropriate milestones.

Jana stated that usually, you have to wait until the end of your appointment to ask questions, which leaves the audiologist very little time to discuss the answers. Jana asked if the **QPL model could have parent's questions** addressed at the beginning of the appointment. Merry agreed that in a family centered model, using the QPL questions helps the professional and parents to create an agenda together.

Laura added that a pediatrician usually has you fill out a questionnaire before the appointment. Similarly, the QPL could be used for audiologists to have parents fill out their questions ahead of time. Merry stated that a QPL is being developed so parents can pull it up on their mobile device at the appointment.

Linsay Darnall Jr stated that a few months ago, ASHA sent out a questionnaire. The first question **was "Is ASL an** actual language?" **The NAD responded** to ASHA, informing them that with that question, they had raised the level of concern in the Deaf community. The NAD challenged ASHA to collaborate with the professionals in the Deaf community who have training in language assessment. Linsay is bringing this up as an FYI to professionals. Deaf professionals need to be the ones who assess the language development of Deaf youth, and Deaf youth need to be assessed in their native language.

12. Thank you and Goodbye to Pete Seiler and Kim-Jae Kang

Brenda Coufal thanked Pete Seiler for over six years of service to the NE-EHDI advisory committee. Brenda also acknowledged Kim-Jae Kang for over six years of service, adding that she appreciates the contributions that both members have made to the committee.

Pete stated he has enjoyed serving on the committee, and remembers when Brenda first became the program manager, there were a lot of questions but he was happy to answer them. He added that since he's moving to California, they will enjoy wearing shorts and short sleeved shirts most of the time. He will continue to volunteer, and plans to do so at the school for the deaf in Riverdale where he is moving. Since he's an English major, child literacy will continue to be something he is interested in promoting. Pete closed by expressing his appreciation for each person on the committee he has had an opportunity to work with over the years.

13. Other

No other items were discussed.

14. Adjourn

A motion to adjourn the meeting was made by Pete Seiler and seconded by Kristin Jolkowski. The meeting was adjourned at 3:57 pm.

Future Meetings:

- November 14, 2019 NET Nebraska, Lincoln NE
- May 14, 2020 Nebraska Children's Home Society, Omaha NE
- Nov 10, 2020 Nebraska Educational Telecommunications, Lincoln NE

Respectfully submitted by MeLissa Butler, Community Health Educator Senior