

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

November 16, 2017

Meeting Minutes

12:00 pm – 3:28 pm

Autism Center of Nebraska

Attending:

Members

Laura Beshaler
Katie Brennan
Jenna Browning
Jenny Corum
Lindsay Darnall Jr.
Brenda Hoover
Kristin Jolkowski
Kim-Jae Kang
Rick Kang
Kelly Rausch
Stacie Ray
Colleen Richart
Karen Rolf
Pete Seiler
Pam Zegers

Guests

Kelly Malcom, UNL Student, HearU
Aaron Beard, Parent
Kaitlyn Keeling, Speech Path Grad Student
Madison Routier, Speech Path Grad Student

Liaisons

Julie Docter
Cole Johnson

Liaisons – via Zoom Teleconference

Rhonda Fleischer
Sara Peterson

Staff

Brenda Coufal
Jim Beavers
MeLissa Butler
Shelli Janning

Newborn Screening Staff

Krystal Baumert
Julie Luedtke

Interpreters

Kelly Brakenhoff
Frances Beurivage

Meeting start time – The meeting was called to order by Committee Chair, Lindsay Darnall Jr. at 12:00 pm.

Open Meeting Act – Presented at the beginning of Advisory Committee Meeting by Lindsay Darnall Jr.

I. **Welcome and Introductions**

Lindsay Darnall Jr., Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests. Lindsay introduced two new members: Pam Zegers, a pediatrician from Complete Children's Health in Lincoln, and Kirsten Jolkowski, an educational audiologist with Lincoln Public Schools.

II. **Review of Agenda, changes**

Brenda Coufal asked that Shelli Janning's presentation on *Hands & Voices Contract for EHDI Follow-Up & Family Support Events Update* be moved to the section during Brenda's presentation that addresses this activity. There were no objections from the committee.

III. **Review of April 13, 2017 Minutes – Action**

The Meeting Minutes from the April 13, 2017 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting. A motion to approve the minutes, as published, was made by Pete Seiler, seconded by Stacie Ray, and unanimously approved by the committee members.

IV. **2017 National EHDI Annual Meeting Overview & Project Presentation**

Aaron Beard, NE-EHDI Family Engagement and Leadership Development Scholarship recipient presented information on his experience at the EHDI Annual Meeting held February 26-28, 2017 in Atlanta, Georgia.

Aaron and his wife Angie have two boys; Hudson, age 5 and Fletcher, age 3. Fletcher was born profoundly deaf and received bilateral cochlear implants at the age of one. Aaron added that Dr. Rick Kang did the surgery, and he is very proud that his family is a part of the Boys Town family.

When Fletcher was identified, Aaron decided to pursue a career in Speech Pathology so he could support his son as he grew up. Aaron enrolled in the Speech and Language Pathology program at the University of Nebraska, Omaha, and is in his senior year of undergraduate school. He plans to pursue a Master's Degree in Speech and Language Pathology. Aaron added that he has a unique perspective, as he sees things from both the side of a therapist and a parent of a child receiving speech therapy.

Aaron was excited and anxious when he was accepted a scholarship to attend the 2017 EHDI Annual Meeting, which is a national meeting held to enhance the implementation of comprehensive state-based Early Hearing Detection and Intervention (EHDI) programs. During the meeting, Aaron served on the team that reviewed EHDI websites to select the top five. Aaron stated that his unbiased first choice for website of the year was the Nebraska EHDI website. During the review process he was encouraged to reflect on the status of his home state, their EHDI system, and determine what he would like to take from the sessions he attended. This review helped him to decide which sessions to attend. The highlight of his experience was the Parent Gathering. During this session, Aaron had the opportunity to meet parent reps from approximately 50 other states.

The one theme that stood out the most to Aaron was that no matter where a parent was from, they all shared a similar experience with the newborn hearing screening. While in the hospital with Fletcher, the nurses kept putting off giving Aaron and Angie the final results of their son's hearing screening. They made excuses for the results, saying things like "he was fussy during the test", "there was construction outside that interfered with the screening equipment", and "our equipment must not be working right". The hospital screened Fletcher 4 or 5 times while he was inpatient. Finally, before Fletcher was discharged, the nurse apologized that Fletcher had "failed" the newborn hearing screening, and referred them to Boys Town. Aaron stated that the news that his son had "failed" was the hardest part for him to process. By the time Fletcher was officially identified at Boys Town a few weeks later, Aaron and Angie had already experienced all of the anxiety and emotions many parents feel when they begin to understand what the identification means for their child.

Another aspect of the process that left Aaron frustrated was that his baby was taken for the hearing screening in the middle of the night while he and his wife slept, so they didn't even know that the screening was being done. He added that a person doesn't typically even let someone take their coat without a claim ticket, let alone their child. A survey of parent's experience of care with the newborn hearing screening revealed that many parents don't even know that the screening is being done before the nurse takes their baby, which adds more evidence that the parent's right to know is not a part of the process. The results of the survey, along with the experiences of many parent clicked with Aaron, and gave him the idea for his project.

After he returned for the meeting, Aaron's project focused on improving the way the whole newborn hearing screening process occurs in the hospital. He decided that he would produce a script for a training video that will enlighten hospital staff on the parent perspective, and develop index cards for hospitals to give to parents when their newborn is taken for the initial hearing screening.

Part of Aaron's project is to lead the *Hospital Training Learning Community* in partnership with the NE-EHDI team and other parent stakeholders. The learning community will implement a new protocol as best

practices for all birthing facilities in Nebraska. Aaron hopes the training video and cards will be used statewide. He also hopes that implementing these new tools will have an immediate effect on parent satisfaction and improve their experience. His goal is that when his grandchildren are born, he will see the cards in the hospital room when they get their hearing screened.

Aaron wrapped up his presentation by adding some advice for future scholarship recipients: be prepared to interact, meet new people, and share your contact information for future interactions.

Linsay Darnall Jr. thanked Aaron for his presentation, adding that the information shared was very valuable. Linsay appreciated that Aaron made it very clear what the Deaf Community is trying to accomplish with changing the way children who have hearing loss are labeled. Linsay offered his full support of Aaron's project and future endeavors. Linsay added that he feels Deaf individuals grow up being stuck with a "label" the audiologist or doctors give to the parents when their child is identified. Linsay has met many individuals who identify their child by their level of hearing. Linsay emphasized that a child is more than just a label. He often tries to tell people that the child should just be identified as "Deaf or hard of hearing", always making sure to put the "child" first. A child should be introduced as "my child who is deaf or hard of hearing", highlighting that a child is identified by their potential and what they can do, rather than what they can't do.

Pete Seiler also commended Aaron for his insights, adding that when his parents were told that he was deaf, they were also told that he may be deaf because they had sinned. His parents were weighed down with a lot of guilt as they navigated the journey of raising Pete. The reality was that they had no control over the genetic makeup that was passed to him. Differentiating the facts from the misconceptions was very challenging for his parents. They took him to many doctors who proposed surgical procedures as a "cure" for deafness, but none of the doctors could guarantee a very high success rate. Pete's parents felt that the low chances of success were not good enough, so they found a physician in Michigan, and made the trip from Chicago to see him. The doctor told Pete's parents that they were wasting their time trying to "cure" Pete, and what they really needed to do was focus on his language acquisition and development. This made a lot of sense to his parents. From this experience, Pete's parents always told him that he wasn't "not hearing" but he was a person who is deaf. Pete's parents worked hard to make sure that he identified himself in a positive way. Pete commended Aaron for working hard to do the same thing for his son.

Karen Rolf stated that the University of Nebraska – Omaha (UNO) has funding for undergraduate scholarly experiences, and Aaron's project seemed like something that would be testable. Aaron expressed interest in learning more about the scholarly experiences opportunity for graduate school.

v. Parent Perspective Presentation

Kelly Rausch, parent of deaf child, NE-EHDI Advisory Committee member, and stakeholder on the Hospital Training Learning Community shared her experiences with the newborn hearing screening process when her daughter Evie was born in April, 2013. Kelly stated that Evie's follow up protocol did not align with the JCIH 1-3-6 goals; it was more like 6-9-12. Her initial newborn hearing screening results were right pass, left refer. Evie is now identified with bilateral mild/moderate hearing loss. When Evie referred on the newborn hearing screening, Kelly was given a pamphlet at the hospital, and the nurses reassured Kelly that "this happens a lot, it's probably just fluid". Evie's general physician told Kelly to get Evie's hearing checked out "eventually", but no urgency was emphasized. When Evie was about six weeks of age, Kelly got a letter from DHHS/EHDI saying to follow up on the hearing screening. When Kelly got the letter, she wasn't concerned because the nurses told her that "it was just fluid", and Evie's doctor told Kelly that there was just fluid in her ears that would eventually drain out. Because of the lack of urgency relayed by the medical professionals involved in Evie's care, Kelly felt no need to be in a hurry to follow up on the hearing

screening. Kelly continued to receive more letters from DHHS/EHDI encouraging her to follow up on the hearing test, but she did not feel it was urgent.

Over time though, Kelly noticed that Evie was having a hard time sleeping, and she couldn't lay flat in her crib to sleep. Kelly suspected that Evie had a lot of fluid in her ears, so she took her to an ENT who confirmed those suspicions. Evie went on to have four sets of tubes placed and an adenoidectomy before her third birthday. After Evie's first set of tubes, Kelly asked her ENT about the hearing screening because she still needed to respond to the letters from DHHS/EHDI. Her ENT reassured her that Evie could hear, they just need to allow some time to let the tubes "do their thing."

Kelly shared that Evie had multiple hearing evaluations including tympanograms in the weeks after the tubes were placed to try and obtain hearing results that she could send back to DHHS/EHDI, but Evie continued to fail the many attempts to assess her hearing. By the time Evie was six months old, she was tired of being poked at, and Kelly was tired of taking her daughter back to so many appointments. Finally, Kelly asked the nurse at the ENT's office what she should do. The nurse said "if it was my child, I'd go to Boys Town and have an ABR. We have no other concerns for hearing loss, so just get the ABR done." So, Kelly scheduled an appointment at Boys Town just to get results that she could send back to DHHS/EHDI. In December when Evie was already nine months old, Kelly took her to Boys Town for an ABR. After the ABR was finished, the audiologist came in and informed Kelly that her daughter had bilateral mild-moderate hearing loss. Kelly was not prepared for these results, because at all of the medical encounters leading up to this appointment, she was continually reassured that Evie could hear. Kelly shared that she experienced a wide range of emotions in that moment. She was overwhelmed, terrified and she broke down. Now that Kelly is on this side of the experience, she understands that there is nothing "wrong" with her daughter and she's perfect just the way she is. However, at the time the news was a shock and it was difficult to process. The thing that scared her the most was that she knew nothing about raising a deaf child, and she was anxious about what the future held for Evie.

After that appointment, Kelly made it her priority to find the best pediatric audiologist to care for her daughter. She received a Parent Resource Guide from DHHS/EHDI when Evie was identified, but she felt that it was huge and overwhelming, and she didn't know where to start. So, she called Evie's doctor for a referral, but they just referred Evie back to the same ENT. Kelly mentioned her situation to a coworker who told her to reach out to Stacie Ray at Barkley Memorial Center on UNL East campus. Kelly said she feels so lucky to have been connected with Stacie. Stacie has helped her and Evie through so much, and is now a dear friend. Stacie also connected Kelly with the EHDI Advisory Committee, which she feels has been a life changing experience and she loves being able to serve as a parent on the committee.

At Evie's nine month checkup, Kelly mentioned the hearing results and diagnosis to Evie's doctor. He told Kelly that of all the years he has practiced as a physician, Evie was the first one his patients to ever fail the newborn hearing screening. This emphasizes the fact that general physicians and even pediatricians will typically see only one or two children with childhood deafness in their career. Kelly added that she does not blame anyone for the misinformation she was given, but the lack of urgency conveyed by all of the professionals involved led to a significant delay in Evie getting the help she needed.

Kelly was selected as the NE-EHDI Family Engagement and Leadership Development Scholarship recipient for the 14th EHDI Annual Meeting in March of 2015. This was an eye opening experience for her. She sympathized with Aaron's feelings of being overwhelmed with the amount of information, adding that she tried to focus on attending sessions that would help her understand what she as a mother could do help Evie. She really enjoyed the panel presentations, especially those with high school and college aged kids. She was hoping to gain information about what difficulties deaf and hard of hearing kids will face, what

their challenges are, and what they need from their parents. One session in particular disturbed her as a parent. The session featured a panel of college students from Gallaudet University. Some of feelings expressed portrayed their parents as failures, because the students stated that they felt very distant from their parents. The college students emphasized that they don't blame their parents for the decisions they made, but the outcomes made them feel disconnected from the rest of their family. This experience made Kelly wonder if she was making the right choices for Evie, adding that she never wants her daughter to feel that she is not a part of their family. Kelly added that she did take other helpful pieces of information away from the conference. For example, one student shared that they had a difficult time going to the movies, so Kelly took note of that challenge for the future.

At the EHDI meeting in KY, Kelly began to fully understand the divide between the Deaf and hearing communities. In her experiences, many times the Deaf community has made her feel ashamed for the choices she made for her daughter, or they have chastised her for using what they perceive as "wrong" words or phrases. Kelly wanted to emphasize that as parents, whenever there is something going on in the lives of children who are important to you, you worry about them; that is a natural tendency and you would do anything to protect them. But, along with that you're also proud of them. Parents carry enough guilt as it is, especially parents who are just beginning to navigate the process of raising a child who is deaf or hard of hearing. People make mistakes; they use words and phrases they were provided by other people. The "hearing community" has no ill intentions of offending or speaking in a derogatory way about individuals who are deaf or hard of hearing. One of the most heartbreaking feelings she's experienced is that the Deaf community seems to imply that she thinks something is "wrong" with her daughter or that she is "impaired" because of the choices Kelly has made for Evie. Kelly does not feel her daughter is impaired, and raising a deaf child has enriched her life. Kelly begs the Deaf community to show patience and understanding to parents. This is a new experience for many families, and everyone needs to be sensitive to what these families are going through. Kelly emphasized that she feels all parents only want the best for their children. It can be terrifying to not know the answers. However, her goal is to be the best mother that she is able to be, and she feels that all parents share that same goal.

Shelli applauded Kelly for her frank and honest expressions about how she has been treated by some members of the Deaf community. Shelli added that there have been terms that she has used that were perceived as hurtful, even though she never intended for them to be taken that way.

Linsay stated that he hopes parents of children who are deaf or hard of hearing understand that they're not insulting members of the Deaf community. The Deaf community understands that parents are using words and phrases that are provided by the hearing community. The Deaf community is working hard to change the use of negative words so children have a positive experience growing up.

vi. HearU/Hearing Aid Bank Update

Kelly Malcom, UNL Graduate Student and HearU Graduate Assistant, presented the HearU statistics for January 1, 2017 to October 31, 2017, as detailed in the handout.

Kelly went over the current HearU application, adding that in 2018, changes are coming in the eligibility criteria. Currently, the criteria for hearing aids through HearU states that if a child is not eligible for hearing aids through Medicaid or Kids Connection, they can get their hearing aids at no charge through HearU. Stacie Ray added that 2018 marks the 10th year for HearU. Over the past 10 years, HearU has never had to turn away any child who needed hearing aids. However, with changes in funding and increased difficulty in finding grants or receiving donations, the criteria will become stricter. Currently there are no income guidelines. Stacie obtained information on poverty levels from Medicaid and Medically Handicapped

Children's Program. This criteria will help HearU determine where a family falls in relation to current poverty guidelines.

Stacie emphasized that if it were not for the annual funding that NE-EHDI provides, HearU wouldn't be able to say that they haven't had to turn a single child away over the past 10 years. So, as the eligibility criteria changes, she wants to involve the EHDI Advisory Committee in the discussions.

In 2017, it took about \$70,000 to run HearU. EHDI provides about \$30,000 of the funding each year. It is becoming increasingly difficult to obtain the rest of the money, and with changes at the federal level, the EHDI funding isn't even guaranteed. Stacie is looking into income tiers that would help to determine where the applicant fits into the guidelines. Tiers would include 100% coverage of all expenses, coverage for the cost of the hearing aids with the expectation that parents would cover the rest of the costs, or no assistance through HearU. Stacie passed around a handout showing the federal poverty guidelines. Currently, the guidelines for HearU are only that the child is not covered for hearing aids under a third party insurance plan. (Medicaid or private insurance.) Stacie discussed the poverty guidelines, and other options such as the Medically Handicapped Children's Program. She asked for the group to add their input regarding what they think the income guidelines should be for assistance from HearU.

Katie Brennan asked if Stacie is expecting that some of the families who seek assistance for hearing aids from HearU would be in the process of applying for Medicaid, and if there would be a time gap where a loaner would be appropriate. Stacie responded that the goal of HearU is to get kids fitted with their HA's as soon as possible, and they strive to have the HA's dispensed in the matter of a few days. Since this is the goal of HearU, they may have to be more strict about the "loaner" criteria, rather than just giving the child the HA's. However, Stacie added that it is tough for a child to get used to one type/brand/signal of HA, then have an audiologist fit them with something completely different a short time later.

Cole Johnson asked what percentage of patients they fit are under age three. Stacie stated the information was presented over a year ago at the Advisory Meeting, and she can't remember what the percentage is. Originally the focus of HearU was children ages 0-3, but they found that older children also needed HA's, and their parents could not afford them, so they started loaning out to older children as well.

Karen Rolf wondered if something could be put in the SPED law to require public schools to provide hearing aids to children. Kristen stated that, in her experiences with Lincoln Public Schools, it would cause a financial hardship, as the district already struggles to get kids FM's. The funding is just not there. Stacie added that if the public schools would pay for the hearing aids, they could not go home with the child, and if a child is going to receive amplification, they need it full time.

Karen asked about material hardship guidelines as they relate to poverty levels, adding that the expenses for parents raising a child with a disability often counts as two times the expense of raising a child who does not have a disability. Karen suggested that HearU take this factor into consideration, and look into material hardship as criteria. Stacie thanked Karen for the suggestion, and asked for her assistance in wording that on the application.

Stacie added that HearU will host a holiday fundraiser, and she is talking with one of HearU's largest funders about setting a funding goal, and having them match the amount raised.

Katie asked if Stacie has surveyed previous families whose data could be analyzed to help HearU get an idea of how this would have impacted families who have received HA's in the past. Stacie responded that they are looking into getting a retrospective study going with the assistance of a graduate student.

Stacie concluded by stating that HearU is implementing these guidelines as of January 1, 2018.

MeLissa asked if the additional out of pocket costs for things like ear molds could be covered by flexible spending account (FSA) dollars. Stacie stated that most often, FSA dollars will cover those costs.

Rhonda Fleisher asked how much money HearU would need in funding to not have to use income guidelines to determine eligibility. Stacie stated that currently, EHDI provides about \$30,000/year, and last year HearU needed to raise an additional \$40,000 to run the program.

Brenda Coufal added that EHDI is currently in year one of a three year funding cycle. EHDI has been guaranteed funding for year one, but funding could change in years two and three, so the amount of funding EHDI can provide to HearU is unknown at this time.

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

Jim Beavers presented information on the NE-EHDI Statistics and Lost to Follow-up information. He started with the *Jan-Oct 15, 2017 DOB NE-EHDI Status Report* which detailed the case status of the 823 infants tracked by the NE-EHDI program. Jim discussed the data related to the percentage of infants who were screened inpatient, who referred inpatient, and were identified as deaf or hard of hearing.

Rick asked for more information about 106 babies who are still “in process”, wondering at what point those babies tend to go lost. MeLissa added that the EHDI team will follow babies until we have no other leads to pursue. We use all available resources to find current contact information and current PCP information so we can constantly be contacting the parents and PCP to encourage follow up. The follow up team will also refer to EDN if the family appears to need additional resources. If medical neglect is suspected, a team will review the case to determine if referral to CPS should be made for further investigation.

Rick asked if EHDI stops follow up once a child is officially identified, adding that, at Boys Town they often see children who are a few years past the initial diagnoses, but the parents never did anything about the diagnosis. MeLissa responded that the focus of the HRSA grant in the past has been reducing lost to follow up, so once we got a diagnoses, EHDI’s scope of responsibility in the process ended. The coordination of care piece is then passed to the physician, the audiologist, the parents, and the early intervention providers.

Krystal Baumert added that the Newborn Screening Metabolic Program experiences similar issues when doing follow up on the Dried Blood Spot (DBS). Even though the DBS is mandatory, some parents are simply non-compliant. Both the DBS follow up coordinators and the physicians make great efforts to repeatedly call and educate the parents about following up, but actually following through is the responsibility of the parents.

Jim discussed the 2014 data which demonstrates how Nebraska is performing when compared to the US averages. Jim also illustrated the 2015 statistics for Nebraska, adding that the 2015 US average data is not yet available from CDC. Jim noted that for the first time in his 10+ years with EHDI, Nebraska is above the national average on all 1-3-6 goals.

Karen asked for details regarding how the US averages are figured. Jim encouraged Karen to go to the [CDC EHDI Data](#) website for details on the calculations.

Karen also asked if there is a treatment trajectory over time. Jim responded that, at this time we do not have that amount of detail. However, if she has a specific question she can email Jim.

Rhonda asked if there is additional information regarding why the number of children reaching the six goal in a timely manner decreased, as it appears that there are a large number of babies who are not enrolled in EI services. MeLissa pointed out that while these children weren’t enrolled *by 6 months*, that doesn’t mean they did not eventually enroll in EI services. Jim added that, if he were to analyze the number of babies who

were enrolled by 7-12 months of age, the number would increase significantly. MeLissa also added that the 1-3-6 goals do not allow us to compensate for premature and medically fragile babies, so sometimes the whole process is delayed because the baby just needs time to grow or get well.

Pete Seiler added that when a baby has multiple health concerns, parents may have to prioritize which treatments are more important at the time. So, sometimes the family may address the deafness at a later time. Julie added that it may be good to analyze reasons that families don't meet the six month criteria, and what percentage are enrolling at seven months, eight months, etc.

Lastly, Jim showed the 2007-2016 lost to follow up trends for Nebraska, noting the significant decrease of lost to follow up over the past ten years.

VIII. Program Update and Action Items

Brenda Coufal asked Dr. Rick Kang to provide the committee with an update on the Comprehensive Boys Town Hearing Clinic that opened in July, 2017.

Rick stated that part of what led up to the Comprehensive Boys Town Hearing Clinic was the start of the Neogenetics Clinic at Boys Town, where families could come and receive a wide variety of services in one stop. This has worked out well for families who need comprehensive care for their young child. In the past few years, Rick has found that some kids are being missed, and/or not coming in on time to receive the necessary services.

Another element that led to the opening of the Comprehensive Boys Town Hearing Clinic was results from national surveys conducted in 2005 and 2012. The survey results were presented at the 2014 EHD! Annual meeting. ([Meeting the Needs of Physicians in Support of EHD!](#)). The survey focused on physician's understanding, attitudes and confidence levels in regards to early detection of hearing loss in children. The survey cohort was pediatricians, family physicians, ENTs, neonatologists and OB/GYN's. The most significant finding of the survey was that while the physician's knowledge *decreased* between 2005 and 2012, their confidence levels *increased*. Reviewing this survey gave Rick the idea that something like a comprehensive clinic was needed so a family could get all of their care in one visit. The team includes pediatric otolaryngologists who have specialized training in hearing loss, geneticist counselors, speech language pathologists, audiologists, and ophthalmologists so at one visit they can see all of the necessary specialists and get all of the information in a very caring and sensitive way. The clinic started in July 2017, and is held twice a month on Fridays at Boys Town.

Laura Beshaler asked if Boys Town has reached out to local ENT's so they know the clinic is available to their patients. Rick stated that in the future, there will be more efforts to promote the clinic.

Pete commented on the use of responses to sounds or noisemakers as a screening method, adding that back in 1945 his doctor clanked two spoons together to see if Pete could hear the noise. Another physician told his parents that hearing aids would lead to other health problems. Common sense would tell you that hearing aids don't lead to health problems, but the doctor believed it to be true. As the survey showed, some physicians still don't feel trained enough to care for a child with hearing loss, which is scary, and something needs to change. Rick responded that it is difficult for physicians to stay up to date on every possible problem their patients may present. That's why we need these "centers of excellence" for physicians to refer their patients.

Brenda reviewed results of the Doodle poll that was sent to the committee after the April 2017 meeting. The committee agreed that the meetings should start at noon, and the length of the meeting should be limited to three hours. However, the meeting today is already running very short on time, so the committee may want to consider changing the length of the meeting back to four hours in the future.

Due to limited time and the amount of valuable discussions that took place, Brenda stated she will have to skip several slides she had planned to present, but she will make the entire PowerPoint available to the committee after the meeting.

Brenda C. presented follow up information on action items discussed at the April 2017 meeting. The committee discussed the possibility of providing educational outreach to audiologists to help educate them about timely appointments for diagnostic evaluations, timely reporting to EHDI and timely referrals to EDN. Brenda C. reviewed suggestions made at the April meeting, as detailed on the slides.

Brenda C. asked the committee if there are other organizations who publish newsletters where NE-EHDI could contribute articles to a newsletter, or present information or exhibit at conferences in order to get more information out to ENT's, family physicians and pediatricians.

Kelly Rausch suggested the Lincoln Public Schools Special Education program meeting. They have booths for many different special education programs, and many parents attend these meetings. Kelly stated it's twice a year, and she can provide the contact information for the meeting organizer.

Pam Zegers shared that from her experience, pediatricians don't get training during medical school or information in their residency about newborn hearing screening. Before Pam joined the EHDI Advisory Committee, she heard very little about the EHDI program, and today is the first time that she has learned about the 1-3-6 guidelines provided by the JCIH. So, as Rick mentioned, pediatricians need opportunity's to learn more information about newborn hearing screening, especially since pediatricians start the follow up process. Also, the nurses are usually the ones who schedule the follow up on a failed newborn hearing screening. Pam added that she works for Complete Children's Health, which is a large pediatric practice in Lincoln. They have 26 practitioners between the four clinics. There is also another large pediatric group in Lincoln, and a few smaller groups. EHDI could cover all the major pediatric practices in Lincoln pretty easily if they arranged a few presentations. As a group the pediatricians at Complete Children's Health in Lincoln hold monthly QI meetings, and each month, Children's hospital will send them a specialist to do a presentation. Sometimes there are even CME's that come with the presentations. Pam thinks it would be very beneficial for EHDI and Rick to do a presentation about Newborn Hearing Screening at one of these monthly meetings, adding that she could help EHDI partner with Children's to set up the presentation.

Brenda Coufal asked Pam if she thinks there's education opportunities at other pediatric clinics throughout the state. Pam stated that it is less likely that other clinics do the exact same thing that Complete Children's Health does to stay up to date continuing education, but Children's Hospital is doing outreach to help pediatricians tap into trainings throughout the state. Laura Beshaler added that Children's Physicians does have their own newsletter that goes out to all of their clinics once every couple of weeks, so that may be a good ice breaker with the clinics. Laura also shared that the pediatric audiology team at Children's recently met with the head of Children's Physicians to discuss working on some education pieces for the clinics, so there may be some opportunities to collaborate there as well.

Rick added that many pediatricians don't ever see even on child with hearing loss in their career, so there may not be much interest in learning about EHDI because it likely won't affect their caseload. Rick added that there is some fallacy on the part of pediatricians who think that if they refer their patient to an ENT, the ENT will know what to do with a child who has hearing loss. Often, that is not the case. Audiologists are really the ones who know what do to help a child who has hearing loss. Rick added that he doesn't think that outreach to ENT's will be productive because they will likely not be receptive to the information, and it will not change their practice patterns.

Brenda added, that, as part of our CDC grant requirements, in an effort to improve on timeliness of diagnostic evaluations, they are asking EHDI programs to survey ENT's and Audiologists, and then arrange

site visits to share information on the 1-3-6 goals. Rick reiterated that ENT's will likely say that they know what they're doing, and they're not interested in hearing what the EHDI program has to say.

Stacie added that she agrees with Rick. The audiologists are usually the ones who know what to do with a child who has hearing loss. Stacie added that she will go back and share the information on the Comprehensive Boys Town Hearing Clinic with the rest of the faculty, but likely the information will not go further. Often in facilities, especially large facilities, important information does not get shared with everyone. Stacie added that she would encourage Boys Town to reach out to all audiologists, and send them information on the Comprehensive Boys Town Hearing Clinic. Rick stated that they are planning to reach out to audiologists statewide to share the information.

Pete Seiler added that the medical professionals often tell him how he should live as a deaf person, and often take pity on him rather than approach his care with a positive attitude. He feels like families are often told what to do with their deaf child by the medical professionals, rather than being given the array of options available to them. Pete added that he feels like all medical professionals should approach the care of a deaf child holistically and view them as a whole person, rather than focusing on how to "fix their ears".

Kim-Jae Kang added that she is happy that this clinic has finally launched, because she feels like this is a good thing for Nebraska families. There was a similar clinic when she lived in Ohio, and many of the parents who took advantage of the multidisciplinary clinic really loved being able to access so many services in one appointment.

McLissa Butler commented on Rick's previous statement regarding ENT's. In her experience with follow up on the EHDI process, an assumption that fluid in the ears is the only reason a child continues to refer is often a roadblock to timely identification and intervention. The Primary Care Physicians rely heavily on the ENT's to coordinate and direct care for their patient. ENT's should be fully aware of all of timelines that need to be followed to ensure a good outcome for the child, and work closely with the audiologists who have a better understanding of what needs to be done to ensure hearing health. She has often read misinformation on reports from ENT's, which will say things like "since the child can hear in one ear, they will develop speech normally" or "there appears to be an anomaly with the hearing screening process." She feels like since the ENT's play such a large part in coordinating care for these children, the EHDI program needs to find a way to reach out to ENT's on a national level to help them understand more about the EHDI process and JCIH guidelines.

Kristen Jolkowski added that she feels like ENT's would be more receptive to information if it was shared by a peer, rather than the EHDI program. In her experience with working for an ENT, the audiologist's notes would disagree with the ENT's notes, but the ENT's notes were deemed the "accurate" ones. There is, unfortunately disagreement between the perspectives of ENT's and audiologists. So, unless the information is shared by a peer, it would likely not be well received.

Laura Beshaler added that, at Children's, they are trying to get some protocols outlined and in writing for the ENT's to follow. In her experience, some of the ENT's she works with are very thorough, and others are not and do not appreciate being questioned by the audiologists. Children's is hoping that they can find an ENT who would be willing to share the information with their peers, and maybe it would be better received that way. So, she recommended that the EHDI programs look for an ENT who could serve as a "Champion" for getting ENT's up to date with appropriate protocols.

Rick Kang, who is an ENT, the Director of the Ear, Nose & Throat Institute and the Cochlear Implant Center at Boys Town National Research Hospital, and the EHDI Chapter Champion added that he has reached out to his peers in Nebraska in the past, and it just doesn't work. Rick emphasized that when a child gets tubes placed, it doesn't mean that their hearing is fine once the fluid is resolved. He has found that frequently, the

parents are told that after the tubes are done, everything looks great and they are free to go, but they are not directed to get a hearing test completed. This all points back to the information gleaned from the physician's survey he discussed earlier. The confidence is high, but the competence is low when it comes to hearing. Rick encouraged EHDI and the audiologists to be the ones to educate the parents and let them know that after the tubes are placed, they still need to get a hearing evaluation completed.

Brenda Coufal added that she will be working closely with the committee in the future to see how we can get educational information disseminated so we can improve the EHDI process in Nebraska.

The next program update Brenda shared with the committee was how the required 25% of the budget allocated to family support activities is being used. Several activities have taken place since the April meeting, and Brenda discussed the partnership with Nebraska Hands & Voices/Guide By Your Side for Shelli Janning to conduct follow up activities with families who are just starting the EHDI process.

Pete Seiler commented on the Roots & Wings Parent weekend training listed in the family support activities on the slide. He stated that, if EHDI does provide funding for Roots & Wings, he hopes that EHDI will put a stipulation in the contract that states that Deaf people must be involved in the planning process from day one. Pete feels that the parties who plan Roots & Wings have consistently excluded Deaf individuals from being involved, and if EHDI is providing the funding, they should be able to put that stipulation in the contract. Pete asked Brenda to ensure that Deaf people are invited to share their opinions at Roots & Wings, adding that he does not want his tax money to be used to exclude Deaf individuals.

Brenda responded that she will talk about Roots & Wings later in the meeting.

Katie Brennan commented that, in her experience with Roots & Wings over the years, Deaf individuals have always been invited to participate, and there is strong support for families who choose to use American Sign Language (ASL) as a communication option. Often, the emphasis is stronger towards ASL than it is towards spoken language, and there is strong support for the Deaf community. So, the idea that Deaf individuals are excluded is a misconception about what is truly going on at this event.

Brenda added that, in 2017 no Roots & Wings events were held due to lack of funding. EHDI recently found out that Boys Town did receive funding for Roots & Wings in 2018, and for now that plan is to host an event in the spring. Since the planning for that event is in the early stages, Brenda doesn't know all the details. However, as more information is gathered, it will be shared with the committee.

Brenda resumed sharing information with the committee regarding the contract with Nebraska Hands & Voices/Guide By Your Side. Shelli conducts follow up activities with families who are just starting the EHDI process. Brenda added that Kiowa Rogers was conducting follow up with the Spanish speaking families, and had to resign due to constraints in her schedule. Gabby Meza has agreed to take over the Spanish follow up.

Brenda also mentioned that the contract with HearU Nebraska was finalized in May 2017. The contract with GBYS and HearU is planned to continue for the entire three year funding cycle, as long as the funding from HRSA continues as expected.

Kim-Jae stated that she loves the training topics for all of the family support events that EHDI and Hands & Voices has done so far, however, she suggested that a sibling workshop would be good to add. Shelli responded that, on the GBYS call, the parent guides suggested a sibling's session as well, so something like that will be coming in future events.

Shelli Janning presented information about the family support activities that she assists EHDI with. Shelli stated that half of her time is spent working for EHDI, and the other half for GBYS. Her EHDI duties include

calling families and PCP's about following up on a referred hearing screening. In her experience the parent to parent connection is so powerful when it comes to encouraging follow up. Since the other half of Shelli's time is spent doing work for GBYS, the transition from the EHDI process over to GBYS is much smoother now that she is involved from the start.

Shelli discussed some of the family support events that GBYS and EHDI have collaborated on recently. The first was a Deaf culture workshop where Linsay Darnall Jr presented information on Deaf culture and ASL. The presentation and the topics highlighted were wonderful, but it was hard to get good parent turnout for the events. In the future, Shelli stated that she will likely try to incorporate Deaf culture and ASL into other family support events rather than having a stand-alone Deaf culture event, and work hard to promote it at other events.

There was also two Grandparent and extended family workshops hosted, as suggested by Kim-Jae. Many parents that Shelli has met through GBYS have reported a wide variety of reactions from grandparents, everything from "I think the child can hear fine" to "this diagnosis is the end of the world" type of reactions. EHDI and GBYS collaborated with PTI-NE, Kendall Simms from Boys Town, and the Nebraska Regional Programs for Students Who are Deaf or Hard of Hearing. Events were held in Gretna and Scottsbluff. Shelli added that grandparents want information, so the event was very successful and she hopes that more grandparent and extended family workshops can be held in the future, and she has some ideas for modifications that can be made to include even more family members.

Kim-Jae added that a support group for families, including the grandparents may be another idea for family support. With a good facilitator, support groups can be very successful. Brenda added that during the grandparent workshop, she was observing the participants from the back of the room, and she was amazed at how the grandparents hung on to every word. They were as eager to learn as new parents. Shelli added that the feedback from the workshops was very positive. One participant commented that they felt like they won a prize because the information was so valuable, and another participant stated that they were eager to go back home and apply what they had learned in their interactions with their child and grandchild.

Shelli talked about the *Mom's Night Inn* event that was held in Scottsbluff, NE. Only two moms attended, but they both really benefited from the information they learned during the workshop. There will be another *Mom's Night Inn* event in Lincoln Feb 17-18, 2018. Shelli will send save the date flyers to anyone who is interested in handing them out to perspective attendees. Shelli added that they are expecting around 25 moms to attend, and they plan to host a panel for spouses and extended family to attend on Sunday of the event.

Shelli also talked about the *ASTra* training which will take place January 12 & 13, 2018. The focus of *ASTra* is to empower parents so they can feel like they are a part of their child's educational team, and give them tools and strategies to help them advocate and plan for their child's success in school. Flyers for this event are available for distribution.

Shelli concluded by saying that if any of the members think it would be beneficial for her to present information from the perspective of a parent, an EHDI professional, or a Hands & Voices family support mentor, she is available to come speak.

Brenda stated that she wants to get feedback from the committee on three areas, however, the time to adjourn the meeting has arrived. The committee agreed to continue the meeting past 3:00 in order to discuss the necessary agenda items.

Brenda first asked for feedback from the committee about planning family support events for year two of the grant.

- Pete Seiler suggested adding adults who grew up deaf or hard of hearing to the existing family support events that Shelli is organizing through GBYS. They can share their perspective on what their parents did that was helpful. You could include those who used ASL and those who did not use ASL so families have the opportunity to evaluate different viewpoints, but it's important to add a variety of different experiences to the panel of individuals parents are exposed to. Karen added that it would also be helpful to include hearing parents who raised a deaf or hard of hearing child to this panel of individuals. Kim-Jae stated that it would be valuable to include minority families, because they also offer a different perspective on their cultural considerations, and the different issues they face.
- Karen Rolf suggested that, after the various workshops surveys are done to see what other information people want. Shelli and Brenda discussed the evaluations from the previous workshops, adding that people often don't answer that question. Karen suggested sending a survey out maybe six months after the workshop to see if, once they've taken information and tried to apply it, if new topics or questions have come up. Brenda and Shelli agreed that this is good idea, and they will explore the possibility of sending something along the lines of a post workshop outcomes survey.
- Kristin Jolkowski added that minority and lower socioeconomic status families are often the ones who need the most help with resources, but there needs to be a better way to reach these populations and encourage them to take advantage of these types of workshops. They need support, but in a different way than families who are middle class and higher need support.
 - Karen Rolf stated that, through her work with UNO and the Nebraska Children's Home Society, she has some options and ideas that could help the committee. Brenda Coufal stated that she would like to follow up with Karen after the meeting.
 - Julie Luedtke added that minority and lower socioeconomic families are getting healthcare through federally funded health clinics, so we could possibly partner with some of those clinics to see if they know how we could reach out and help those families.
 - Pete Seiler stated that, through the Nebraska Association for the Deaf (NAD), the often collaborate with the Omaha Inclusive Communities, which is mostly for minority groups, and they come together in that forum. They have invited NAD to come talk about Deaf Culture, so that may be another opportunity to learn how to reach other populations.

Brenda also added that there is room for two more advisory committee members. She feels like we need another parent, and another individual who is hard of hearing or deaf.

Stacie stated that she has ideas for both a parent, and a hard of hearing individual, but she would like to speak with them first before she recommends them to the committee. Brenda stated that would be fine, and she will follow up with Stacie about her ideas after the meeting.

Katie Brennan stated that it would good to include a deaf educator.

MeLissa Butler added that, once Steve Boney retires, he will be stepping down so that will create a third opening on the committee.

Krystal Baumert suggested that the committee recruit a family practice physician.

Rhonda Fleisher asked for clarification regarding the requirements to serve on the committee. Brenda stated that, according to the open meetings act, in order to serve on the committee you have to be able to attend the meetings in person at least half of the year, so that would be one meeting a year. Rhonda stated that the open meeting act eliminates a lot of people from being able to serve on the committee, with the central and western parts of Nebraska mostly being excluded from serving. Brenda agreed, adding that even though Sara can only attend via Zoom, so she cannot be a voting member, she is still a very valuable part of the committee and her input is appreciated.

IX. Election of Officers

Brenda Coufal informed the committee that it is time to elect a new Chair and Vice Chair for the 2018-2020 term. She reminded the committee that only voting members can be elected. She reviewed the responsibilities of both the chair and vice chair, as outlined in the charter.

Brenda asked the committee to make their nominations at the meeting today, and she will send out a poll after the meeting to get the final vote.

Nominations for Chair:

- Pete Seiler nominated Linsay Darnall Jr for Chair. Linsay accepted the nomination.
- Rick Kang nominated Stacie Ray for Chair. Stacie accepted the nomination.
- Pete Seiler moved that nominations for Chair be closed. Kim-Jae Kang seconded.

Nominations for Vice Chair:

- Karen Rolf nominated Kim-Jae Kang. Kim-Jae declined the nomination.
- Pete Seiler nominated Rick Kang. Rick declined the nomination.
- Stacie Ray nominated Katie Brennan. Katie accepted the nomination.
- Pete Seiler recommended that the committee accepts Katie Brennan as the Vice Chair by acclamation. There were no objections from the committee. Katie Brennan will serve as Vice Chair for the 2018-2020 term.

X. Other

The next meeting date was discussed. The committee agreed upon May 3, 2018 for the spring meeting. The committee also agreed that the meeting length needs to change back to four hours.

XI. Adjourn

A motion to adjourn the meeting was made by Rick Kang and seconded by Pam Zegers. The meeting was adjourned at 3:28 pm.

Next Meeting:

- May 3, 2018

Respectfully submitted by MeLissa Butler, Community Health Educator Senior