

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

May 13, 2021

Meeting Minutes

12:00 pm – 3:00 pm

Zoom: Meeting ID: 928 1412 8785 Passcode: 726133

Attending:

Members

Jessica Anthony	Kristen Jolkowski
Laura Beshaler	Ashley Kaufman
Katie Brennan	Jessica Larrison
Carlena Conard	Sara Peterson
Brad Czaplewski	Kelly Rausch
Sue Czaplewski	Stacie Ray
Linsay Darnall Jr.	Colleen Richart
Heather Gomes	Karen Rolf
Jessica Hoss	Anne Thomas
Shelli Janning	Joanna Webster
Cole Johnson	Jana Wiblishouser

Staff

Brenda Coufal
MeLissa Butler
Jim Beavers
Mary Maraist

Newborn Screening Staff

Krystal Baumert
Jill Chance

Interpreters

Kelly Brakenhoff
Ben Sparks

Guests

Beth Anne Bryson
Amy Nejezchleb
Aaron Thompson

Meeting start time – The meeting was called to order by Committee Chair, Dr. Stacie Ray at 12:08 pm.

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

1. Welcome and Introductions

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

Brenda Coufal, Program Manager for the NE-EHDI program updated the committee on changes to the membership roster.

Retired Newborn Screening staff:

- Julie Luedtke - Newborn Screening & Genetics Program Manager

New Newborn Screening staff:

- Jillian Chance - Newborn Screening & Genetics Program Manager

Retired Advisory Committee Members:

- Nancy Hengelfelt – OB Director at York General Hospital
- Julie Docter – Part C Co-Coordinator with EDN

New Advisory Committee Members:

- Jessica Hoss, Parent
- Carlena Conard, OB Director at York General Hospital
- Joanna Webster, Audiologist with Children's Hospital
- Mark Andersen, Nebraska Association of the Deaf
- Brad Czaplewski, Deaf Educator with Educational Service Unit (ESU) #10
- Anne Thomas, Coordinator of UNL Deaf Education Program
- Jessica Anthony, Part C Co-Coordinator with EDN

Brenda also welcomed the new Graduate Audiology Student, Mary Maraist who replaced Bailey Heaton as AuD Intern/NE-EHDI Community Health Educator. Mary will be doing a one-year internship with the program.

2. Review of Agenda, changes

There were no changes to the meeting agenda.

3. Review of November 14, 2019 Minutes – Action

The Meeting Minutes from November 14, 2019, NE-EHDI Program Advisory Committee meeting were distributed via e-mail before the meeting. A motion to approve the minutes, as published, was made by Katie Brennan and Linsay Darnall Jr. seconded by Sara Peterson, and unanimously approved by the committee members.

4. NE-EHDI Program Update and Action Items

Per the handouts, Brenda Coufal updated the committee on the work that has been done and changes to the program since the last EHDI update that was posted on the NE-EHDI website in October 2020.

2022 Meeting Dates

The 2022 meeting dates were selected by majority vote on a poll sent to the committee ahead of time. The 2022 meeting dates are as follows:

- May 19, 2022
- October 13, 2022

Motion to Extend Chair and Vice-Chair Positions

Since advisory committee meetings were canceled in 2020 due to COVID, Brenda asked the committee for a motion to extend the Chair and Vice-Chair positions one more year. A motion was made by Linsay Darnall Jr and seconded by Carlena Conard. The current chair and vice-chair will hold their positions through 2022, and elections for new officers will be held at the October 13, 2022 meeting.

NE-EHDI Funding

Current NE-EHDI funding sources are detailed in the handout:

- HRSA
- CDC
- MCH Title V Block Grant
- NO State Funding

Training and Education for Parents

After presenting information about NE-EHDI's current efforts for training and educating parents, Brenda asked the committee for other ideas to educate families about the newborn hearing screening process.

Anne Thomas asked if there are video options for parents to review. Brenda stated that there is a video called [Loss and Found](#) that NE-EHDI provides to hospitals to share with parents, but we are not sure how often it is used.

Sara Peterson asked if there is a short video to share at hospital orientation or birthing classes, Brenda stated that the [Did You Know?](#) video is available in English and Spanish, and would be good to share. Kristin Jolkowski stated that she supports the idea of sharing information at birth classes and possibly sending information to OB offices to have them distribute the information. Krystal Baumert stated that the Newborn Screening/Dried Blood Spot program does send brochures to OB offices that have agreed to distribute them, and there is a small section on Newborn Hearing Screening in their Parent Guide brochure.

Karen Rolf asked if there is data on access to care that would suggest that certain groups encounter barriers when seeking follow-up care. Brenda indicated that data has not been gathered at this time, but NE-EHDI will look into seeing if it can be compiled. Karen stated that Omaha Public Schools employs cultural ambassadors to reach refugee populations, and could potentially be a resource for NE-EHDI to connect with. Ashley Kaufman added that NE-EHDI could reach out to One World & Charles Drew to reach underserved populations.

Joanna Webster asked if the two EHDI brochures are given to pediatrician offices to distribute. Brenda stated that pediatricians do not give out the brochures, as parents are given the brochures at the hospital and additional brochures are mailed to parents with EHDI letters if the child does not pass the hearing screening.

Sue Czaplewski stated that it would be beneficial for deaf educators to get a supply of the EHDI brochures to share with families. If families get them from multiple people, it might help.

Jessica Hoss asked if EHDI educational information could be emailed to GBYS families. MeLissa Butler responded, saying that by the time a family is enrolled in the GBYS program, the EHDI brochures would no longer be applicable information for them, as their child would already be identified.

Stacie Ray stated that *Clinic with a Heart*, which is a clinic staffed by volunteer physicians and serves low-income, uninsured and underinsured families who live in Lincoln could also distribute brochures to expectant and new parents.

Training and Education for Professionals

After presenting information about NE-EHDI's current efforts for training and educating professionals, Brenda asked the committee for other ideas to educate families about the newborn hearing screening process.

Kristin Jolkowski suggested that EHDI work to educate EDN administrators about risk factors for late-onset and progressive hearing loss, and the importance of periodic hearing screening as part of that process. Carlana Conard stated that a video and educational handouts for professionals about next steps after birth would be good to have, along with doing presentations at periodic staff meetings. Ashley Kaufmann added that if presentations are done, it would be good to have them done by a physician. Brenda agreed, stating that when EHDI coordinates PCP and ENT presentations, we have tried to engage other medical professionals as presenters, because information is better received when it comes from a professional peer.

Due to time constraints, the discussion about training and education for professionals was tabled. Additional information about future EHDI project planning will be discussed either later in the meeting or at a future meeting.

5. Amy Nejezchleb, parent of an 8-year-old child who is deaf and wears bilateral cochlear implants received a scholarship to attend the 2021 Virtual EHDI Annual Meeting. Amy shared the highlights of the sessions she attended, stating that she chose topics focusing on social/emotional health and behavior, and Deaf Mentor/Role Model programs.

6. Additional Specialty Programs Updates

Tele-Audiology

Sara Peterson, Teacher of the Deaf at ESU #13 in Scottsbluff NE updated the committee on the status of Tele-Audiology in Nebraska. To date, 21 infants have been tested at three sites through teleaudiology. Additionally, one older student who could map has also been tested. Currently, six infants have been identified as deaf or hard-of-hearing since the program started.

Sue Czaplewski asked if there was any way to shorten the 1-2 week wait time for appointments. Sara stated that part of the struggle is the logistics of the UNL Barkley Center. Currently, Barkley can set aside one appointment slot per week for Tele-Audiology due to having only one audiologist trained to provide Tele-Audiology services. In the future, they hope to get a second audiologist and remote end technician trained so there are more options for serving families through Tele-Audiology.

Shelli Janning stated that she has received positive feedback from parents about the option to access care through Tele-Audiology. Families are happy to have options and not have to drive several hours to access care.

Karen Rolf asked what schools are doing through Part C of IDEA to develop IFSPs for children who are deaf or hard of hearing. Sara stated that as soon as a child is identified with a hearing loss that will have an educational impact, they qualify for EI services and are assigned a team of professionals including a Services Coordinator, Deaf Educator, and Early Childhood Coordinator. Services begin as soon as the paperwork is completed. Karen asked if families have difficulties receiving services. Sara responded that she has not seen any circumstances where families have a difficult time getting needed services. Shelli agreed, adding that most families she works with through Guide By Your Side receive services as soon as they are eligible if they are interested.

Ashley Kaufman asked how billing works with Tele-Audiology. Sara stated that recently insurance has become more flexible with billing for diagnostics, but billing tends to be more difficult for services like rehabilitation, hearing aids, and Cochlear Implant programming. For Tele-Audiology, Barkley bills for services the same way they would for in-person services, but adds modifier codes for Tele-Health. ESU #13 absorbs the costs for Sara's time. Sara and Hannah are still working through the logistics of adding services to determine how they can bill and obtain truly mobile equipment.

Joanna Webster asked if Tele-Audiology is a replacement for pediatric audiology services in Grand Island, Lincoln or Omaha. Sara stated that Tele-Audiology is not a replacement, but another option for families in central and western Nebraska.

Kristin Jolkowski asked if ESU#13 would be interested in working with other educational audiologists to support this expansion. Sara stated that they have discussed collaborating with the audiologist at ESU#16 once she gets her sound booth set up.

Hospital Champion Program

MeLissa Butler, Community Health Educator Sr. for Nebraska EHDI updated the committee on the status of the Hospital Champion Program and the Risk factor Follow-Up procedures project as detailed in the handouts.

7. Parent Scholarship Recipients Share National EHDI Experiences.

Beth Anne Bryson

Beth Anne Bryson, parent of a deaf child received a scholarship to attend the 2021 Virtual EHDI Annual Meeting, and shared her experiences. She thanked NE-EHDI for the scholarship and the opportunity to attend the conference.

Aaron Thompson

Aaron Thompson, parent of a deaf child shared his experience attending the 2021 Virtual EHDI Annual Meeting. This is Aaron's second year attending, as he attended the 2020 meeting in person. Aaron noted that the day after the 2020 meeting ended, the World Health Organization declared the COVID-19 pandemic. So, he felt lucky to attend in person in 2020, and felt the virtual conference was very good as well despite having to be held virtually.

Brenda stated that Angela Vapenik who is the parent of a deaf child also attended the 2021 Virtual EHDI Annual Meeting on a NE-EHDI scholarship, but was unable to attend today and present her highlights.

8. Hands & Voices Update

The Hands & Voices update was moved up in the agenda before the NE-EHDI Statistics presentation. There were no objections to this change.

Shelli Janning, Nebraska Guide By Your Side (GBYS) Program Coordinator and Community Outreach Coordinator for the NE-EHDI Program shared an update on EHDI follow-up and Nebraska Hands & Voices family support events as detailed in the handouts.

9. NE-EHDI Statistics

Jim Beavers, Business Analyst for the NE-EHDI presented information on 2019 EHDI statistics as detailed in the handouts.

Lindsay Darnall Jr. asked for clarification on the average number of children identified by age three for years 2016 – 2020. Did the number increase by 11 from 66 to 77, or were the initial 66 children identified, and later 77 more bringing the total average to 143? Jim clarified that the average increased by 11, bringing the number identified to 77 total.

Joanna Webster asked if hospitals will continue early discharges due to COVID. Jim stated that at this time, we are not anticipating more early discharges so the inpatient refer rate should be lower in 2021, and the numbers will be more like previous years when there was not a pandemic.

10. HearU/Hearing Aid Bank Update

Stacie Ray, UNL Professor and HearU President presented the current HearU statistics, as detailed in the meeting handout. Stacie also presented information on what is covered under each tier of HearU's new financial criteria.

Shelli Janning commented that when her daughter was identified and needed a hearing aid, she and her husband could not afford it, and as a mother she felt terrible. So, she commended Stacie and all the work she does through HearU, because the assistance HearU provides parents helps them out in a time that is otherwise very stressful. Shelli added that she has recently heard from families whose child needed cochlear implants (CI), and that also has been a huge financial burden because either their insurance doesn't cover it, or it's written out of their insurance plan. Shelli asked if HearU has plans in the future to assist with other devices like CIs. Stacy stated that she encourages people who are pursuing CIs for their child to reach out to HearU, because they may be able to provide some financial assistance like \$1,000 - \$1,500 toward their deductibles. They would still need to apply and meet the financial criteria, and it does depend on where HearU is with funding, but that could be an option for families pursuing other types of devices.

Joanna Webster asked if HearU offers rechargeable hearing aids. Stacie stated that they do offer both rechargeable and non-rechargeable options. They also have receiver and canal options for older children, and maybe would not be able to utilize that type of model, but most of the HA's they offer are behind the ear hearing aids.

Karen Rolf stated that under Rule 51, assistive technology is supposed to be covered for families. She asked if there are issues with schools providing assistive technology under special education. Stacie responded that the schools will provide the accessories that go along with hearing aids. In the past, some school districts have paid for hearing aids, but the HA's cannot go home with the child as their personal devices, so the child does not have access to them on weekends, school breaks, or over the summer which is problematic because the child needs to be able to hear outside of school as well.

Ashley Kaufman echoed Stacie's comment, adding that when she was a school audiologist she had seen similar issues occur.

The committee also discussed [Ally's Act, H.R. 477 and S. 41](#). These bills were re-introduced on January 25th, 2021, and the purpose is to ensure that private insurance companies provide coverage for osseointegrated hearing devices (OIDs), including Bone Anchored Hearing Aids (BAHA) and Cochlear Implants (CI), for children and adults birth to age 64, including services, upgrades, surgery and associated costs that come along with these devices. If Ally's Act becomes the law, this bill would help hundreds of thousands of children and adults have access to life-changing treatment, allowing them to live the lives they dream of, participate in the workplace and community and enjoy a high quality of life. Jessica added that if this bill is passed, it doesn't mean that the family doesn't have to pay the deductible, coinsurance, co-pays, etc. so it could still end up being quite expensive even if insurance coverage is mandated. Jessica Hoss stated she is working with NCDHH to make needed changes to legislation, particularly for CIs, adding that her family had to finance \$21,000 for her child to receive upgraded devices. The cost of hearing devices hurts a lot of families financially, and it's not right. Stacie agreed that the legislation needs to be improved, and suggested that people reach out to Josh Severe at UNL Barkley, as he worked with NCDHH to mandate coverage for hearing aids. Karen Rolf added that a good education advocate could help work on this initiative as well. Ashley Kaufman shared that some insurance companies have claimed they have exemptions from providing coverage, and HearU has been helpful in those situations.

11. Other

Brenda shared that NE-EHDI is working on implementing a Deaf and Hard-of-hearing Mentor/Role Model program. A workgroup consisting of parents, D/HH individuals, deaf educators, an EDN Services Coordinator, Early Intervention professionals, and an audiologist has been formed to provide feedback and work on various pieces of the project. The workgroup met for the first time on April 21, 2021, and will continue to meet through March 2022 to help identify what organization will house and operate this program once it is implemented. Anyone who has questions about the program or who would like more information can reach out her. She also thanked the committee members for their participation, as the wealth of information they bring to the meetings is critical to the success of the NE-EHDI program.

12. Adjourn

A motion to adjourn the meeting was made by Anne Thomas and seconded by Laura Beshaler and Carlena Conard. The meeting was adjourned at 3:02 pm.

2022 Meeting Dates

- May 19, 2022
- October 13, 2022

Respectfully submitted by MeLissa Butler, Community Health Educator Senior