

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

October 14, 2021,

Meeting Minutes

1:00 pm – 4:00 pm

Walt Branch Public Library

Attending:

<u>Members</u>	<u>Staff</u>
Jessica Anthony	Brenda Coufal
Laura Beshaler	MeLissa Butler
Katie Brennan	Jim Beavers
Carlena Conard	Mary Maraist
Brad Czaplewski	
Sue Czaplewski	<u>Newborn Screening Staff</u>
Linsay Darnall Jr.	Krystal Baumert
Heather Gomes	
Shelli Janning	<u>Interpreters</u>
Kristin Jolkowski	Jamy Elker
Ashley Kaufman	Sharon Sinkler
Stacie Ray	
Karen Rolf	
Anne Thomas	
Joanna Webster	
Pam Zegers	

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.

Meeting start time – The meeting was called to order by Committee Chair, Dr. Stacie Ray at 1:11 pm.

The Open Meeting Act was presented at the beginning of the Advisory Committee Meeting by Chair Stacie Ray.

The following reminder regarding the current mask mandate for Lincoln was read at the beginning of the meeting: “The City of Lincoln currently has a mask mandate in place. Everyone, regardless of vaccination status, must wear a mask in all indoor settings unless you are able to maintain at least 6 feet of distance from other individuals at all times. Please keep your mask on while inside our meeting space unless you are presenting or interpreting.”

2. Review of Agenda, changes

There were no changes to the meeting agenda.

3. Review of May 13, 2021, Minutes & Motion to Approve

The Meeting Minutes from May 13, 2021, 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 Anne Thomas, seconded by Katie Brennan, and unanimously approved by the committee members.

4. Program Update and Action Items

Brenda Coufal, Program Manager for the NE-EHDI program updated the committee on changes to the membership roster, and welcomed new members & staff who are attending in person for the first time:

- Jillian Chance, Newborn Screening & Genetics Program Manager – replaced Julie Luedtke who has retired (was not able to attend)
- Carlena Conard, OB Director at York General Hospital (Nancy Hengelfelt Retired)
- Joanna Webster, Audiologist with Children's Hospital
- 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 (Julie Docter Retired)
- Mike Tufte, PTI-NE Executive Director (Nina Baker Retired) (was not able to attend)
- Mary Maraist, NE-EHDI Community Health Educator (Graduate Audiology Student)
- Jonathan Arteaga, NeAD President - New Member, but not able to attend the meeting.

Brenda directed committee members to review the handout that details the current NE-EHDI Funding and requirements from the three sources of funding for the NE-EHDI Program: HRSA, CDC, & MCH Title V Block Grant.

She also shared information about current family support agreements with Nebraska Hands & Voices, HearU Nebraska, and Boys Town Roots & Wings Event, and updates on current NE-EHDI projects including expanding capacity to support hearing screening, diagnosis, and EI for those infants who pass a newborn hearing screening but later develop hearing loss up to age three. Brenda asked for other ideas of entities other than Early Head Start programs, pediatric audiologists, ESUs, PCPs, and licensed daycares who may conduct hearing screenings for early childhood age up to age three.

Pam Zegers stated that Lincoln Public Schools requires that all kindergarteners have a hearing screening before entering kindergarten, and all Complete Children's Health Clinics do a screening to determine if further testing is needed. Krystal Baumert added that several pediatric offices in Omaha screen prior to kindergarten as well. Brenda asked if any offices screen prior to age three, as that is the target population.. The group agreed that this is not required, so it is questionable whether or not pediatric offices screen prior to the required kindergarten screenings.

Karen Rolf asked if there is hospitalization data available about hearing loss that results from an illness. Brenda asked for clarification on how EHDI could identify those. Karen indicated that they might be able to pull it from a specific hospital data field. Heather Gomes responded that it is not a common thing to screen hearing in a hospital setting for the target population. Karen stated that the staff may pick up on a child not able to follow verbal directions and that may trigger a need to screen their hearing. Brenda stated that if a child older than a newborn is screened while in the hospital, often a pediatric audiologist would be the one to see the child, and they would report that information back to EHDI.

Krystal stated that the Monroe-Meyer Tracking Infant Progress Statewide (TIPS) program might be able to check hearing on patients they follow through TIPS. Brenda indicated that EHDI is already working with TIPS for NICU infants, and more information will be shared later in the meeting.

Ashley Kaufmann asked if EHDI has checked with the ESUs. Brenda stated that Amy Bunnell has provided a list of ESUs that may have the capacity to partner with EHDI.

Brenda shared an update on implementing a statewide Deaf and Hard of Hearing (D/HH) Mentor/Role Model/Guide Program. She asked if anyone on the committee had anything that they want to add or ask about the work done so far on the program.

Stacie Ray stated that EHDI is a small but mighty team, and has put so much effort into planning the Deaf and Hard of Hearing (D/HH) Mentor/Role Model/Guide Program, and they should be applauded for their efforts. It is unfortunate that HRSA is adding grant requirements to meet without adding funding to meet them. EHDI has put together an amazing team of individuals to support this effort regardless of lack of funding and lack of extra staff to support the added work. Stacie asked that suggestions made are for the greater good, and will not put unnecessary work on the EHDI staff.

Joanna Webster asked if the program will only cover certain areas of the state. Brenda stated that ideally, it will be a statewide program, although we may have to start small with a pilot and branch out later.

Karen Rolf asked about how the percentages and increase requirements will be measured, as the baseline date shows 0% and the goal is to increase by 10% by March 31, 2024. Brenda responded that the goal would be to have 10 families enrolled in the services through the program by that date. (Technically to improve by 10% since the baseline is 0, we would only need to have 1 family enrolled in the program by 3/31/2024.)

Brenda shared the suggestions that the members provided in the poll prior to the meeting for topics and presenters for future EHDI Advisory meetings. She asked if there were additional suggestions. No suggestions were made during the meeting. Brenda asked for members to email other ideas by 10/21/2021 and then she will e-mail a poll for members to prioritize.

Since CMV screening and CMV updates were suggested as topics for future advisory meetings, Brenda shared that a Lincoln Pediatric Hospitalist with Bryan Health is interested in getting CMV testing mandated for infants who don't pass the newborn hearing screening. Also, there are some Nebraska parents and families who are working on legislation to raise awareness and provide education about CMV. There have been discussions about restarting the CMV Task Force in 2022. In addition to awareness and education, there is discussion about adding CMV to the Newborn Screening Dried Bloodspot (DBS) panel, but there are many details that need to be worked out first.

Krystal Baumert from the Nebraska Newborn Screening program gave a brief overview of DBS screening mandates in Nebraska, and added information about what would be involved with adding CMV to the panel. Brenda added that approval to add CMV to the panel would need to pass Nebraska legislation, and to pass legislation, it would more than likely have to be added to the Recommended Uniform Screening Panel (RUSP) first. The RUSP is extremely conservative in what it recommends to the panel, so if it passed, it would be a very robust test. It was stated as a reminder that DHHS programs can't advocate for legislation and can't discuss legislation directly with state senators. DHHS programs can provide data and information if it is requested from a senator, however, the program will work with the DHHS Communications & Legislation office to provide a response.

5. Additional Specialty Programs Updates

MeLissa Butler, Community Health Educator Sr. for Nebraska EHDI updated the committee on the status of the Risk Factor Follow-up Procedure revision project and showed members an updated Risk Factor form and new infographic that was included in the handouts packet. Pam Zegers commented that all of the discharge summaries she sees coming from Bryan now include the recommendations to follow up based on the JCIH risk factors.

Linsay Darnall Jr. stated that the NICU information is available in English in Spanish, but asked about making it available in American Sign Language (ASL), as approximately 5% of Deaf couples who will have Deaf babies, and there may be a few families who need that information in ASL. MeLissa thanked Linsay for the suggestion, and said

EHDI will look into translating the information into ASL. Linsay volunteered to help with the translation efforts if needed.

MeLissa also showed members two new OAE & ABR infographics, one for parents and one for professionals. This project was recommended at a previous EHDI Advisory Committee meeting. The committee asked for pdfs of the infographics so they can share them with patients and families. MeLissa stated that pdfs would be emailed out after the meeting.

MeLissa updated the committee on the current status of the Hospital Champion Program as detailed in the handouts.

6. NE-EHDI Statistics

Jim Beavers, Business Analyst for the NE-EHDI presented information on 2018-2020 EHDI 1-3-6 statistics, 2020 hearing screening statistics, new EHDI data projects planned in 2021 that include the iEHDI data file that will be the new format to submit data to CDC and Audiology Data Evaluation Work Group, and a new EDN report as detailed in the handouts.

7. Hands & Voices Update

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.

Shelli added that she had called the Omaha Fire Department (OFD) to see if they could bring a fire truck to the Fall Bash. She was put into contact with Mike Davenport, who is Fire Apparatus Engineer and Public Education Specialist for OFD. He told Shelli about a grant OFD received back in 2016 to provide smoke detectors equipped with strobe lights in the homes of individuals who are deaf or hard of hearing. He stated that they have around 120 left, and that he would like to get them into people's homes. Shelli agreed to spread the word among the families served by GBYS, and she encouraged the committee to share the information as well. Families who live within 1 ½ hours of Omaha can have the OFD come to their home and install the equipment. Families outside of that area can still request the equipment, but it will be mailed and they will have to install it themselves. The West Omaha Service Club pays postage on the systems that have to be shipped outside of Omaha.

Kirstin Jolkowski stated that she believes Lincoln Fire and Rescue (LFR) has a similar grant for fire alarms. Stacie Ray confirmed LFR has a similar program, adding that she was one of the individuals who worked on the first grant for Lincoln.

8. HearU/Hearing Aid Bank Update

Stacie Ray, UNL Professor and HearU President presented information on the HearU financial criteria for receiving hearing aids, and the current HearU statistics, as detailed in the meeting handout.

9. Olmstead Act/Plan

Sherri Jones, Dean of the College of Education and Human Sciences with the University of Nebraska-Lincoln was unable to attend the meeting in person. Sherri provided a pre-recorded presentation that was captioned about the Nebraska Olmstead Plan that was played in her absence. Committee members were directed to email questions to Brenda Coufal, and she will compile them and forward them to Sherri to answer.

10. Other

Brenda Coufal shared some additional information about updates relevant to Nebraska and the EHDI program.

Sarah Peterson was unable to attend the meeting in person today, but wanted to share with the committee that there is a new audiologist serving western Nebraska. Her name is Caitlin Nichols, and she works at the Morrill County Hospital in Bridgeport, NE.

Brenda also announced the 2023 EHDI Advisory Meeting dates that were selected in the poll that was sent prior to the meeting. The dates are:

- May 11, 2023
- October 5, 2023

Brenda stated that the 2022 EHDI Annual Meeting/Conference will be held in Cincinnati, Ohio March 13-15, 2022. EHDI hopes to offer three parent scholarships to attend the meeting. More information will be sent out in the near future, but she wanted to encourage the committee to start thinking of parents who may want to attend and share the information with families.

Brenda shared that one of the goals in the HRSA grant is to collaborate with the Leadership Education in Neurodevelopmental and Related Disorders (LEND) program. A LEND trainee expressed interest in working on a project with NE-EHDI. She will be working on the diversity and inclusion plan, and also helping NE-EHDI to develop educational materials about genetic counseling. She will start with EHDI in the near future, and plans to work on the project through April, 2022.

Brenda thanked everyone on the committee for their hard work and contributions to the program, adding that she appreciates the expertise of our members and the time they put into improving the EHDI process.

There were no other items to discuss.

11. Adjourn

A motion to adjourn the meeting was made by Kirstin Jolkowski and seconded by Anne Thomas, and unanimously approved by the committee members. The meeting was adjourned at 3:41 pm.

2022 Meeting Dates

- May 19, 2022
- October 13, 2022

2023 Meeting Dates

- May 11, 2023
- October 5, 2023

Respectfully submitted by MeLissa Butler, Community Health Educator Senior