

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

May 19, 2022

Meeting Minutes

12:00 pm – 4:00 pm

Nebraska Children’s Home Society

Attending:

<u>Members</u>		<u>Interpreters</u>
Jessica Anthony	Kristin Jolkowski	Pam Duncan
Jonathan Arteaga	Ashley Kaufman	Ben Sparks
Laura Beshaler	Sara Peterson	
Katie Brennan (Vice Chair)	Colleen Richart	<u>Staff</u>
Brad Czaplewski	Kim Texel	Amanda Adams
Sue Czaplewski	Anne Thomas	Brittney Biere
Linsay Darnall, Jr.	Joanna Webster	MeLissa Butler
Shelli Janning	Susan Whitaker	
		<u>Newborn Screening Staff</u>
		Jill Chance
		Krystal Baumert

1. Welcome and Introductions

Katie Brennan, Vice-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 Vice-Chair, Katie Brennan at 12:09 pm.

Vice-Chair Katie Brennan presented the Open Meetings Act & EHDI statement at the beginning of the Advisory Committee Meeting.

2. Review of Agenda, changes

Amanda Adams stated that Kelly Henry-Turner, 2022 EHDI Annual Meeting Experience from Scholarship Recipient would also present her experiences and takeaways from attending the 2022 EHDI Virtual Annual Meeting. The committee agreed to this change.

There were no other changes to the agenda.

3. Review of October 14, 2021, Minutes & Motion to Approve

The Meeting Minutes from October 14, 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 Sara Peterson, and unanimously approved by the committee members.

4. Program Update and Action Items

Amanda Adams, Program Manager for the NE-EHDI program updated the committee on changes to the membership roster, and welcomed new members & staff.

Amanda stated that there is still one opening on the roster. She stated that someone who could provide insight on diversity and inclusion would be a nice addition to the roster, and asked for suggestions on someone who could fill the spot. Susan Whitaker asked if there are limitations, regarding what kind of representation is needed for the open position. MeLissa Butler stated that all areas that need to be represented are outlined in the [New Member Orientation Packet](#) (Page 15), and our current roster fits all those requirements. Therefore, as Amanda had stated, finding someone who could bring insight on diversity and inclusion would be a beneficial viewpoint to bring to the committee.

Amanda 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. Amanda reviewed the current Family Support Agreements and updated the committee on the status of the Diversity and Inclusion Plan.

An update on expanding NE-EHDI's capacity to support hearing screening, diagnosis, and early intervention for infants who pass a newborn hearing screening but later develop hearing loss up to age three was also given per the information detailed in the handouts.

Krystal Baumert asked for clarification regarding whether EHDI works with Tracking Infant Progress Statewide (TIPS). MeLissa stated that NE-EHDI works with TIPS on the risk factor monitoring process. Sue Czaplewski asked who does the hearing screenings in Early Head Start (EHS) programs. Amanda stated that the EHS staff usually does them. Sara Peterson added that some places in western Nebraska already perform the hearing screenings, so she can share data with EHDI.

Amanda also updated the committee on the implementation of a statewide Deaf and Hard of Hearing (D/HH) Mentor/Role Model/Guide Program, and new legislation regarding CMV education. Ashley Kaufman asked for clarification on which physicians and hospitals will distribute the CMV educational materials. Amanda stated that any provider who will interact with pregnant women will be provided with educational materials to distribute.

Amanda updated the committee on the poll distributed after the October 2021 meeting regarding suggested presentation topics and/or for future meetings. These topics have been tabled, as there are other EHDI projects that need to be discussed during advisory meetings. The committee was also reminded that during the October 2022 meeting, elections for a new Chair & Vice Chair for the 2023-2026 term will be held.

5. Additional Specialty Programs Updates

MeLissa Butler, Community Health Educator Sr. for Nebraska EHDI updated the committee on the status of the additional projects, including the Newborn Hearing Screening Hospital Champion Campaign and JCIH FAQs per the handouts. Updates on revisions of the follow-up process were provided. Krystal Baumert asked for clarification regarding the process for when EHDI sends certified letters, stating that the blood spot program sends a duplicate copy of the certified letter via regular mail. Legal counsel to the blood spot program advised this as a best practice since people would often refuse certified letters since they are associated with other negative actions. MeLissa stated that in order to mark a case as "unresponsive" rather than "lost to follow-up" we need documentation that the parent/guardian received the letter so we prefer to get a certified receipt back for reporting purposes, but she will consider the recommendation.

MeLissa discussed future revisions to the EHDI Parent Resource Guide (PRG). EHDI is trying to encourage all families to utilize the online guide as a way to reduce paper usage. Joanna Webster asked for clarification regarding how EHDI brochures are distributed since many hospitals are moving to more paperless ways of tracking records and distributing educational information. MeLissa stated that the *Can Your Baby Hear Brochure* and *Your Baby Needs Another Hearing Screening* brochure are still being routinely distributed as every birth hospital in Nebraska. Ideally we would move to just giving out the *Initial Screening* and *Refer Cards*, as they are much smaller and

require much less paper, but we need all Nebraska Birth Hospital to complete the Hospital Champion Program and implement the use of the cards before we can eliminate the brochures.

MeLissa also discussed adding a section called “Transitions” that would provide information about Deaf Culture, the importance of Deaf Mentors/Role Models, and preparing parents for educational advocacy. Ashley Kaufman asked Shelli Janning on her perspective regarding the “Transitions” section. This information would be necessary later on when a child is around three to four years of age. By that time, the family may have lost track of the PRG, so a small card with a QR code to take them back to the online PRG might be good to have for audiologists to hand out to families of a child who is identified when they reach the age of needing to consider educational advocacy. Shelli stated that parent guides do continue to go through the packet with families and will remove items when they are no longer age appropriate. A card referring them back to the educational advocacy information would be very helpful for later discussions with a parent guide.

Katie Brennan recommended having the PRG made into an app that will periodically send reminders via text may be helpful. MeLissa stated that currently, DHHS policy does not allow EHDI to send texts, but EHDI could collaborate with another agency to guide the development of a PRG app, and implement an “opt-in” option for families to receive the texts.

Jonathan Arteaga asked for clarification on the EHDI follow up process, and the various agencies involved with the family at each stage of the screening and diagnosis process. MeLissa provided a brief overview of the reporting and follow up process from inpatient refer to diagnosis.

Linsay Darnall Jr. commented that the information about Deaf Culture would include information about American Sign Language (ASL) and deaf identity, and that information may be more appropriately shared under section two “Language and Communication” as that would be a more ideal time to begin discussing ASL, and the conversation would naturally flow to Deaf Culture.

6. NE-EHDI Statistics

Jim Beavers, Business Analyst for the NE-EHDI was not able to attend in-person; however, he presented information on EHDI 1-3-6 statistics, 2020 and 2021 hearing screening statistics, and 2022 data projects via Zoom.

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.

8. HearU/Hearing Aid Bank Update

MeLissa Butler presented information on the current HearU statistics and financial criteria for receiving hearing aids, as detailed in the meeting handouts.

9. 2022 EHDI Annual Meeting Experience from Scholarship Recipient

Aaron Thompson was not able to attend in-person; however, he presented information on his experiences and takeaways from attending the 2022 EHDI Virtual Annual Meeting via Zoom. This was Aaron’s third time attending the EHDI meeting.

- Session 1: Aaron enjoyed was the opening plenary where Stephanie Olson talked about celebrating the little things with your deaf child, so he has implemented that when he takes his son to audiology appointments.
- Session 2: Another session discussed balance disorders, which is one issue his son has encountered since receiving a cochlear implant so the information and suggestions were very beneficial.

- Session 3: One session talked about having your child create their own book, whether it be with photos or illustrations, and having older siblings help with the book. Aaron's family took this suggestion seriously, and his son's older siblings enjoyed helping him make a book that he could show his friends and his grandparents.

Linsay Darnall Jr. commented that a variety of balance abilities are well known in the Deaf Community, and reassured Aaron that his son would learn to adapt and it would likely not hold him back in life.

Due to the meeting running ahead of schedule, Kelly Henry-Turner was not able to present her experiences.

10. Other

There were no other items to discuss.

11. Adjourn

A motion to adjourn the meeting was made by Anne Thomas, seconded by Linsay Darnall Jr., and unanimously approved by the committee members. The meeting was adjourned at 2:30 pm.

2022 Meeting Dates

- October 13, 2022

2023 Meeting Dates

- May 11, 2023
- October 5, 2023

Respectfully submitted by MeLissa Butler, Community Health Educator Senior