

The Nebraska Early Hearing Detection & Intervention Program
Advisory Committee Meeting
October 10th, 2024
Meeting Minutes
12:00p.m. - 3:00 p.m.

<u>Members</u>	<u>Guest</u>	<u>Staff</u>
Ashley Altman	Vickis Campbell	Angel Sumpter-McFarland
Jessica Anthony	Hannah Ditmars	Mujtaba Ebrahim
Laura Beshaler	Jessie Bogard	Clare Koneck-Wilcox
Vicki Campbell		Jackson Godwin
Carlena Conard		
Linsay Darnall Jr		
Cassie Garner		<u>Newborn Screening Staff</u>
Heather Gomes		Krizia Sanoy
Melissa Henry		Jillian Chance
Lindsey Hinzmann		
Jessica Hoss		<u>Interpreters</u>
Shelli Janning		Ben Sparks
Kristin Jolkowski		Rachel Smith
Joanna Webster		
Colleen Richart		
Anne Thomas		

1.Introductions:

Angel Sumpter McFarland, Manager for the Nebraska Early Hearing Detection & Intervention (NE-EHDI) welcomed everyone and introduced herself.

Meeting start time – EHDI Program Manager, Angel Sumpter-McFarland, called the meeting to order at **12:31 p.m.**

Angel Sumpter-McFarland presented the Open Meeting Act at the beginning of the Advisory Committee Meeting. The Open Meeting Act was placed on the door of the meeting room, as well as read aloud (with ASL Interpreters) and a copy of the meeting act was placed in each folder of the members attending.

Angel Sumpter-McFarland made note that NE-EHDI Advisory Committee strives to better lives of children in Nebraska who are Deaf or hard of Hearing by recommending policy that improves diversity, equality, awareness, and access. NE-EHDI is a unbiased program that informs families

of available resources and we respect they're right to determine what's best for they're family. Angel also stated that the committee has 2 advisory committee meeting per year due to budget limitations. She advised members and guest to refrain from using the words "hearing loss" or "hearing impaired" this may be difficult since some members may not view these words as negative terms. Although we do recognize these terms as negative for some members. If these terms are used in the duration of the meeting all members will recognize that it is not the intent to be negative or disrespectful. Thank you members for sharing your valuable perspectives.

2. Review of Agenda:

Mujtaba Ebrahim, gave the review of our agenda and descriptions for the meeting. Describing who and what they would be presenting.

3. Review of May 2024 Minutes

A Copy of the May 2024 Meeting Minutes was emailed to all Committee members. Mujtaba Ebrahim asked members if they would like to have any changes made to the meeting minutes and if they approve of them. Lindsay Darnall Jr motioned to approve the minutes from the May meeting, Anne Thomas 2nd the motion.

4. Review of program and Program Updates:

Angel Sumpter-McFarland directed committee members to review the handout that details our current NE-EHDI Funding and requirements from the three sources of funding for the NE-EHDI Program: (HRSA, CDC, and MCH Title V Block Grant). Angel also made note that NE-EHDI has no State Funding and is all Federal income. Angel also pointed out the family support agreements NE-EHDI regularly renews. Nebraska Hands & Voices, HearU Nebraska, Nebraska Association of the Deaf, and a new program being planned for 2025 through Boys Town, the "Roots and Wings Parent Weekend."

Program Manager Angel Sumpter-McFarland gave an update on the NE-EHDI Team. We've added Kylie Stewart as an intern to the EHDI team. She is an audiology student at UNL and gives the team vast knowledge and insight into the Hearing world. NE-EHDI is delighted to have her, We have also added Jackson Godwin who is part of the NE-EHDI team. Teaming up with the business analyst on our new "Natus" data system. Angel Sumpter-McFarland also noted that we broke down our HRSA program requirements into two phases.

The first phase was establishing and maintaining partnerships, as well as an assessment of how the NE-EHDI information system will collect data and track project performance. We evaluated our partnerships with stakeholders by holding meetings and through email, NE-EHDI also reached out to stakeholders for a baseline on what stakeholders could provide us as well as an outside perspective. This was able to help NE-EHDI find gaps for language acquisition and where we should be aiming for new partners.

New Partners NE-EHDI has established: Doulas, Head Start, Parents.

The NE-EHDI Team gave an update on the Intervention process or “EHDI System Pipeline” describing how the team works through cases. Describing the process of being referred to diagnosed to finally into early intervention processes. Clare Koneck-Wilcox explained how NE-EHDI receives files from hospitals, how she will manually file and upload the data making sure the data is accurate and there isn’t duplicates, in the system. Another way we get hearing screening data is through faxes. Audiology offices, Hospitals, and PCP’s will send NE-EHDI hearing screening data that the EHDI team will also upload into our data system (NX). Once the records are in the system Mujtaba Ebrahim along with Kylie Stewart will begin follow-up. This includes calling and mailing the families as well as PCP’s of the children referred for hearing screenings, this includes special cases, homebirths, and lost to follow-up children as well. Stressing to them the importance of follow-up testing. Once the children are diagnosed or referred into intervention services through the EDN referral process, Stacy Luther will call the parents to get a confirmatory verbal agreement, once done that is when she will make a referral to Hand & Voices, or the Deaf Mentorship program. Once Stacy gets the verbal confirmation NE-EHDI does not track them any further.

Question: Why doesn’t EHDI track after they have been referred to intervention services?

Angel: Once referred to intervention services, we expect the EDN network to do they’re part. And they are able to go through with the referral, as much as EHDI would love to be on top of the families, showing them resources, options. Too many people or groups in the process can make for a difficult process.

Angel also touched briefly on the phase two implementation of the HRSA agreement. Talking about how NE-EHDI is very eager to start the implementation of this phase. Including the Hospital champions campaign, the revision of our educational materials, and also increasing the screening, identification, and early intervention process for children up to **3** years of age. As well as the new data system (Natus) and making sure everything is culturally appropriate overall.

5. NE-EHDI Special Programs Updates

Mujtaba Ebrahim, Community Health Educator Sr. for Nebraska EHDI updated the committee on special programs that EHDI has updated for the HRSA agreement implementation phase 2. Including (cCMV awareness, Hospital Champions Campaign, Educational Materials, EHDI Newsletter)

cCMV Awareness:

Mujtaba talked about how NE-EHDI to date has sent out over **1000+** cCMV fact sheets, how the information was adapted from the CDC (Insuring accuracy), And on how NE-EHDI and Dry Blood Spot will be working together with parent advocates to get more education about Congenital Cytomegalovirus.

Education Materials:

NE-EHDI have worked on updating educational materials to changing the language, terms, and updating logos for our networks & groups. These brochures include the (FAQ Sheet, Hospital/Mailing Brochure, Deaf Gained) and coming soon the homebirth brochure.

Hospital Champions Campaign:

Mujtaba talked on emails being sent out to all hospitals OB units inviting them to the campaign. Hospitals have already emailed back requesting to join the program. Including CHI St. Elizabeth, CHI St. Mary's, and York General Hospital. The updated program includes setting up a in-hospital visit with NE-EHDI team and working alongside hospital staff, educating and understanding how they will be reporting results back to the State. As well as updating hearing screening policies. (if not done within last year of visit)

NE- EHDI Newsletter:

Mujtaba Will be starting a NE-EHDI Newsletter next month touching on topics including events in our community, training opportunities, meeting updates, and more. This is a way for all of us to connect and update ourselves on each other's programs.

6.NE-EHDI/BTNRH Collaboration:

The homebirth community is a growing community within the state of Nebraska. Homebirths account for **0.3%** of Nebraska births, but **45%** of Lost to Follow-Up. Currently the collaboration is developing a registry and homebirth specific materials. Our community advisory board will have input and give feedback on these. The next steps for the collaboration will be building a potential budget, and sending quarterly written & video updates to our community advisory board.

7. NE EHDI Data (Statistics & Data Projects)

Clare Koneck-Wilcox, Business Analyst for Nebraska EHDI presented state **1-3-6** hearing statistics vs the National average and updates on the Natus reporting system that will be rolled out for the NE-EHDI team, as detailed in the handouts.

Screening by 1 month 2023 Average: Nebraska:98.6% US:NA

Diagnosis by 3 months 2023 Average: Nebraska: 33.6% US:NA

Early Intervention services by 6 months Average: Nebraska:42.9% US: NA

Clare Koneck-Wilcox also noted that in May 2023 NE-EHDI reported **84.9%** of babies were being screened by **1** month of age for hearing. The same stat in October of 2023 saw **98.6%**, a **13.7%** increase in children being screened. At one point our caseload was at over nine thousand cases. NE-EHDI had a huge team effort to clean this que up, and was able to get us accurate data. Hence the large increase in screenings.

8. Nebraska Association Of the Deaf:

Colleen Richart, Nebraska Association of The Deaf (NeAD) Program Coordinator of the Deaf Mentorship Program shared updates on NeAD. Colleen talked about the referral process, and how NeAD handles a referral. Typically they will come from Stacy Luther and NeAD will reach out to the families. Colleen explained how NeAD uses phone, text, and mail to contact families. After 1 week of not hearing anything NeAD will send follow-up mailings. Colleen asked stakeholders to like the Nebraska Deaf Mentor Program on Facebook, as well as informing the committee that a Deaf Mentor Program website is under development.

As of September 1st,2024:

- 18 Referred for NeAD
- 2 Enrolled into NeAD

Colleen Richart, talked about upcoming opportunities NeAD was going to be hosting/attending including an Autumn Blaze October 12th, Parents With Deaf & Hard of Hearing Children panel workshop November 3rd 2024, and the Nebraska Association of the deaf biennial Business meeting November 2nd,2024.

9.Nebraska Hands & Voices Update:

Shelli Janning, Nebraska Hands & Voices Program Coordinator shared updates on Nebraska Family support programs through the group. There are **14** parents guides throughout State, **150** Families being served through Nebraska Hands & Voices.

- Started ASTRA brochure **1 ½** years ago (Advocacy Support & Training) not government funded (based on memberships)
- Guide By Your Side (GBYS) work as “Guides” directly with families who have just learned of their child’s hearing condition.
- “Moms Night In” Events in Scottsbluff and Lincoln
 - Scottsbluff 11/09/2024-11/10/2024
 - Lincoln 02/01/2024-02/02/2024
 - Try to duplicate events but the needs of mothers in western and eastern NE are very different.

Shelli made note that they have started a quarterly zoom series named “You Are Not Alone” for children being diagnosed later or not followed up on, in English and Spanish. They have collaborated with our neighboring states. Bringing mothers and fathers together sharing experiences and similar situations in the journey of raising a Child who is Deaf or Hard of Hearing.

Shelli also shared how **3** parents guides and Stacy Luther visited the Hands & Voices leadership conference in Spokane, Washington. This was an opportunity for Nebraska Hands & voices to collaborate with other states, share ideas, and information with other Hands & Voices chapters.

Nebraska Hands & Voices Referrals:

- **16** referrals to Guide By Your Side since May' 2024
 - **7** From NE-EHDI
 - **9** non EHDI (From audiologist, deaf educator, etc.)

Shelli Janning noted that Nebraska Hands & Voices have continued working along with planning region teams and services coordinators. Trying to get older children, children that moved into the State later, as well as children with late diagnosis. They hope to continue the great work done so far. One collaboration Shelli felt would be a good benefit to this initiative is pulling from the NE-EHDI database. The babies about **2 ½** years old who are referred and if we can reach back out. See if they would like any support through GBYS or the ASTRA program. Parents of children at that age are typically getting them ready for preschool and are generally more worried.

10. HearU/Hearing Aid Bank Update:

Dr. Hannah Ditmars, With the University of Nebraska HearU presented information on the HearU Financial criteria for receiving hearing aids, and the current HearU Statistics, as detailed in meeting handouts.

HearU Nebraska Annual Statistics (past 5 years)

- **45** Hearing Aids were fit on **28** Children in **2020**
- **54** Hearing Aids were fit on **29** Children in **2021**
- **27** Hearing Aids were fit on **17** Children in **2022**
- **43** Hearing Aids were fit on **24** Children in **2023**
- **41** Hearing Aids were fit on **25** Children so far this Year.
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- **2008-Current: 1,009** Hearing Aids fit on **601** Children
- Over **210** Communities Served

Dr.Hannah Ditmars noted that Nebraska HearU accepted the annual sub-award from EHDI. This award provides HearU with critical support allowing to serve families across Nebraska. Since **January 1st, 2024** HearU has served **25** families and has **7** pending applications. Dr.Ditmars also explained the stock of hearing aids, with **70** new hearing aids and **19** chargers currently in stock. Dr.Ditmars also noted that the HearU Advisory Board currently visits focusing on community outreach, and long-term sustainability.

11. Other Items:

Angel Sumpter-McFarland talked about the 2025 EHDI Conference Parent scholarship. How NE-EHDI would like to bring two new parents along to the conference. Since it is such a good experience for new parents of deaf gained children. Angel touched on the Advisory committee charter asking the stakeholders to review the charter and if they would like to amend or keep the same charter mission.

12. Advisory Board Elections:

- Linsay Darnall Jr. is the new Chair for the Advisory Committee
- Hannah Ditmars the newest member of EHDI Advisory Board

10. Presentations:

Nebraska Association of the Deaf – Presented by Colleen Richart

Hands & Voices Updates – Presented by Shelli Janning

Nebraska HearU/Hearing Aid Bank- Presented by Dr. Hannah Ditmars

11. Adjourn:

A motion to adjourn the meeting was made by Angel Sumpter-McFarland at 15:03 p.m.

Review/Approval of Minutes from October 2023 meeting:

The May 9, 2024 minutes were approved by Linsay Darnall Jr.

Dates and Locations for Next Meetings: **Virtually**, Thursday May 08th 2025 / **In-Person**, Thursday October 02nd 2025

Meeting Adjourned 15:03 p.m.

Respectfully Submitted:

Angel Sumpter-McFarland

Mujtaba Ebrahim

Clare Koneck-Wilcox