

# The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

March 24, 2016

Meeting Minutes

1:01 pm – 4:12 pm

Eugene T. Mahoney State Park, Riverview Lodge

Attending:

## Members

Nina Baker  
Katie Brennan  
Linsay Darnall Jr.  
Rhonda Fleischer  
Brenda Hoover  
Shelli Janning  
Cindy Johnson  
Kim-Jae Kang  
Kelly Rausch  
Stacie Ray  
Colleen Richart  
Pete Seiler

## Guests

Nicole Kreikemeier, UNL Student, HearU  
Stephen Richart, Parent  
Jenna Browning, BTNRH  
Jennifer Sturgeon, EDN

## Liaisons

Amy Bunnell  
Cole Johnson  
Laurie Miller

## Interpreters

Pam Duncan  
Jamy Elker

## Staff

Jim Beavers  
MeLissa Butler  
Kathy Northrop

## Conference Call Attendees

Sarah Peterson, ESU #13  
Kiowa Rogers, ESU #13

## Newborn Screening Staff

Krystal Baumert  
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Chair, Linsay Darnall Jr, at 1:01 pm.

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

### I. Welcome and Introductions

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

### II. Review of Agenda

There were no changes.

### III. Review of Minutes

The Meeting Minutes from the December 10, 2015 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting and printed copies were available upon request. A motion to approve the Minutes, as published, was made by Pete Seiler, seconded by Kelly Rausch, and unanimously approved by the Committee members.

### IV. Presentation – Nebraska Relay

Pete Seiler, Nebraska Relay Outreach Specialist, presented information on Nebraska Relay. The Nebraska Relay offers free full telephone access to people who are deaf, deaf-blind, hard of hearing, or have a speech disability. This services allows them to connect with people who use standard telephones through a

TTY (Teletype Phone). The service is funded through a small fee assessed on all phone bills. Nebraska charges two cents per call, whereas other states may charge up to five cents per call. Every state has a 711 service accessible to those who need it. Nebraska Relay also has Spanish interpreters available for Spanish speaking individuals who use the service.

Pete demonstrated the TTY device, showing how to adjust the font size, font color, and background color. These types of adjustments can be made to personalize the device to meet the user's needs and preferences. Pete demonstrates these adjustments when he meets with the user to set up the device and teach them how to use it.

Stacie Ray stated that other TTY devices have Bluetooth capabilities where the audiogram results can be linked to the TTY device so it can work better for the user. She asked if Nebraska Relay uses this technology. Pete stated that he is not sure if that capability has been added to the updated TTY devices.

Nina Baker asked if Nebraska Relay could come to her office to demonstrate the device. Pete stated that he has a few devices at home that he can take to anyone's office for a demonstration.

Kelly Rausch stated that this service would benefit large corporations like the company she works for. Her employer currently uses Video Relay Services (VRS). She asked if larger corporations would be able to easily implement the TTY? Pete said he can demonstrate the TTY if they have access to the internet, however the larger companies would need have the IT department assist with set-up since the firewall has to be overridden.

Steve Richart added that he works for Northrop Grumman and they use CapTel VRS to support individuals who require VRS.

Rhonda asked if this service is only free to people who are deaf, deaf-blind, hard of hearing, or have a speech disability. Pete stated he will demonstrate the TTY device to any business who plans on hiring a person who needs the device. Nebraska Relay can make an agreement with the business, but the service is not free. The law doesn't permit people who are not deaf to use this service.

Linsay Darnall Jr. shared that growing up in Polk Nebraska, there were no VRS or TTY services. Since his whole family was deaf, if someone needed to get ahold of them they would call a neighbor. The neighbor would relay the message to the Darnall family and the family would pass a note back to respond. This made communication very difficult, so VRS gave them a lot of independence.

Pete added that if LB 938 passes in legislature, all carriers will be required to have 911 fully accessible via text messaging. This will help immensely in emergency situations.

#### **v. EHDI Annual Meeting Reports**

Kathy Northrop informed the committee that in an effort to include stakeholders from western Nebraska, she is attempting to video conference Sara Peterson and Kiowa Rogers from ESU#13 via Zoom Room. Kiowa Rogers is also the parent of a child who is hard of hearing and she attended the 2016 EHDI Annual Meeting.

Kiowa presented her highlights from the 2016 EHDI Annual meeting via Zoom Room. She shared that she has a three-year-old son with unilateral hearing loss in the left ear. Her son was diagnosed at 22 months of age. She learned that most children are diagnosed by three months of age, so she feels like there is room for improvement in the diagnostic and support services available to families in western Nebraska.

Kiowa thanked the NE-EHDI program for the opportunity to attend the 2016 EHDI Annual Meeting. She described several of the sessions she attended, and added that the best piece of information she took from the conference was that being deaf is not a disability, and anything is possible for a deaf child.

Steve Richart stated that he was glad to have the opportunity to attend the 2016 EHDI Annual Meeting. Steve stated that he had three learning objectives in mind when deciding which sessions to attend. He wanted to: 1) learn how he could bring value and support back to the EHDI community, 2) understand how specific topics related to his family and, 3) network. He felt he successfully achieved all three objectives.

Steve also shared that in his professional life he works with meteorologists. There is a running joke that if there are four meteorologists in a room, there will be at least five different opinions. He stated that, from his experiences attending the meeting, he feels the same way about deaf and hard of hearing kids. Steve stated that attending the meeting helped him gain a better understanding of the challenges the NE-EHDI program faces due to the variety of opinions from all stakeholders.

Kathy asked Steve for his impressions of plenary speakers. Steve said he had mixed feelings. The opening plenary by Leah Katz-Hernandez was inspiring, if that was the intent. But he also felt that it was a disconnected story when compared to what most would experience and maybe not too realistic. He also did not see how it was applicable to the EHDI story. He enjoyed Rachel Coleman's plenary because he liked her message, her approach, and her journey.

Stacie Ray stated that the sessions that she attended were on CMV and were very well done. She also enjoyed the State Stakeholders Meeting and shared that she feels NE-EHDI excels on a state and national level. There is good collaboration, talents in many areas, and everyone works together towards the same goal of supporting families and children.

She also shared that after her presentation on HearU, people from five different states including Wyoming, Minnesota, Arizona, and New Jersey asked her very specific questions regarding how Nebraska handles various obstacles she talked about during her presentation. She felt that it shows that there are a number of states that need help figuring out how to pay for hearing aids for children. Kathy added that about 60 people attended Stacie's presentation.

Rhonda Fleischer shared that she learned a lot from the meeting about how to help parents advocate for their child during the IEP process. She also commented that Rachel Coleman was a dynamic speaker and wants to bring her to Nebraska for a parent workshop.

Shelli Janning reported that she attended many helpful sessions including one where she got information and ideas for the "Mom's Day In" event that the GBYS program hosts every February. She also attended an ASL workshop which helped her to understand how to prepare herself to answer questions her kids will ask. At another session she attended, only about 20% of the attendees were hearing, so it was good to see how it felt to be in the minority.

Kathy Northrop stated that she attended several CMV sessions and much of the information was the same she had heard last year at the CMV conference. She also stated that EHDI Pals has an exciting new app and she is looking forward to participating in the pilot project.

Jim Beavers reported that he was able to talk to other state EHDI programs about data and calculations, so that was helpful. One session that was interesting showed research conducted in the United States in 2005 which studied the two-step screening process. The results of the study showed that, of the infants who initially failed the OAE but passed an ABR, 23% ended up identified with hearing loss later in life, usually around nine months of age. This study was compared to an Israeli study conducted in 2015 where the same data was studied. The Israeli study results showed that 24% were identified at three months of age. The results of the data analysis showed the importance of having a repeat hearing screening conducted between the newborn hearing screening and the preschool screening.

MeLissa Butler shared that she felt the opening plenary sessions each day were very inspiring. However, after attending one session that talked about 'inspiration porn' she wasn't sure if she should be inspired by these types of sessions or not, as viewing Deaf individuals as "inspiring" can be offensive to the Deaf community, since they are ordinary people doing ordinary, everyday things that everyone else does.

Linsay stated how interesting it is to hear that the EHDI Annual Meeting is more balanced on presenting a variety of communication options. When he went to the EHDI Conference in Saint Louis in 2012, the sessions all seemed to be focused on auditory/oral communication, but there was not a lot about American Sign Language (ASL). Shelli stated that she also felt like the ASL was prominently featured as a mode of communication.

Kathy reported that Mike Hesser, from Gallaudet University, attended the State Stakeholders Meeting. Kathy emailed him and asked why he was coming, thinking it was an error that a Washington, DC resident signed up for the Nebraska Stakeholders Meeting. Mike responded that he is originally from Nebraska. Kathy said it was great to have him at the meeting. Rhonda stated that Mike is going to work as a counselor at Camp Anderson this coming summer. Mike gave positive feedback about the meeting, saying he felt that it was worth his time to attend.

#### **vi. EHDI Annual Meeting Award Nominations**

Kathy Northrop shared that Nebraska was well represented at the EHDI Annual Meeting. Kelly Rausch had nominated Stacie Ray for the Antonia Brancia Maxon Award for EHDI Excellence, and although she did not win it was an honor to be nominated.

The NE-EHDI Program was one of five websites nominated for Website of the Year. Iowa won the award. MeLissa stated that she is open to suggestions to improve the NE-EHDI website so Nebraska can win next year. Kathy added that any suggestions for resources to add to the Resources pages are welcome as well.

Courtney Smejdir's presented a poster titled *Exploring Nebraska Regional Differences and Factors for Lost Newborn Hearing Screenings*, which was included in the handout packet. The poster summarized data that was part of her capstone project.

## **vii. HearU Hearing Aid Bank Update**

Nicole Kreikemeier, UNL Graduate Student and HearU Graduate Assistant, presented the HearU quarterly statistics. Based on the most recent statistics, 2015 has been busiest year yet for HearU.

Nicole shared that she loves getting to know the families she works with through HearU, adding that she recently had the mother of an 8-year-old boy call HearU to thank them for everything they had done for her son and their family. The family has five children, including a few who have medical needs. When they found out their son needed hearing aids, they were already struggling financially. The hearing aids helped her son to improve his speech, which he was struggling with before he got the hearing aids.

Nicole also recognized the audiologists who are willing to work with HearU. HearU will reimburse \$562 for a unilateral hearing aid, which is the agreed upon amount for Medicaid. Audiologists who work with HearU do not make as much as they could working with other clients, but they are willing to do so in order to help families and children.

## **viii. CMV Task Force Update**

Cindy Johnson stated that Ann Anderson-Berry has the CMV pilot program protocol in place, so all babies born at Nebraska Medicine, in the well-baby nursery who do not pass their newborn hearing screening, will have a saliva swab. NICU babies will not be included in the study. The pilot program has enough funding to test all babies who meet the testing criteria for one year. The number of babies to be tested is estimated to be around 50-60. The swab will be sent to a lab for testing and the lab will compile the data which will be analyzed at the end of the study period to determine next steps.

The Task Force is also working on implementing a program to educate obstetricians. They will start with obstetricians in Omaha, and later branch out to obstetricians in other parts of the state. The outreach initiative will focus on educating expectant mothers about how to avoid contracting CMV. Prevention is all about raising awareness.

Kathy also stated that the Institutional Review Board (IRB) proposal has been approved, but a few things needed to be changed before final approval. However, they do not think the IRB process will hold up the pilot program. The Task Force also plans to model their educational materials after those produced by the Utah program and modify them for Nebraska. However, currently no funds have been secured to produce or distribute any materials. Kathy reported that Stacie Ray has joined the Task force.

## **ix. Hospital Training Task Force Update**

MeLissa Butler stated that Marietta Mathis's capstone was approved by the University of Nebraska's Institutional Review Board (IRB) on February 3, 2016. Progress on the Hospital Training Task Force has started moving forward again. The survey invitation/consent forms were mailed out the week of February 22, 2016. A reminder card was sent the week of March 21, 2016 to encourage more participation in the survey. The survey will be open for participation from 03/01/2016-04/01/2016. Survey invitations were sent to 13,420 mothers over the age of 19 who have given birth to a child in Nebraska between 07/01/2015-12/31/2015. As of 03/23/2016 NE-EHDI has received 343 responses. The next step is to start analyzing the data after the survey closes.

**x. The NE-EHDI Program Statistics and Lost to Follow-up Information**

Jim Beavers reviewed the handouts entitled *January through December 2015 DOB the NE-EHDI Status Report* and *Nebraska 2014 Births-Hearing Status*.

**xi. Other**

Linsay Darnall Jr. stated that when ChildFind presented at the December meeting, he had asked how many children in that program were deaf or hard of hearing. Steve Miller followed up with Linsay and said that they are unable to track that information since they are not told the diagnosis or results of the evaluation are when they receive the referral. However, the majority of referrals they receive with speech concerns are due to hearing loss.

Pete Seiler stated that the Nebraska Association for the Deaf (NeAD) is hosting three activities in April:

- On April 3, 2016, in conjunction with Deaf History Month, they will be meeting at the Nebraska Deaf Heritage Museum and Cultural Center to share stories of famous Deaf and Hard of Hearing people in history. The stories will be of interest to children of all ages and parents.
- On April 9, 2016 there will be a Legislative Workshop that will help people learn how to make a positive impact on legislative bills such as LB 938 (the text to 911 bill). It will focus on how the political process works, developing a legislative agenda, and developing a commonly shared message. The speaker is Kim Bianco-Majeri.
- On April 16, 2016 a workshop on Public Safety, Access & Advocacy for People who are Deaf and Hard of Hearing will be held at CHI Health Lakeside Swanson Education & Conference Center. The purpose of the workshop is to provide the Deaf and Hard of Hearing community a better understanding on issues about public safety and to make them aware of resources that are available if they are a victim of crime. The workshop will also have information on how to advocate for yourself and how to make sure your communication needs are met.

Pete also stated that NeAD has become more proactive in helping parents understand that the world does not stop when a person becomes deaf or hard of hearing.

Rhonda shared that the Nebraska Regional Programs will be hosting a parent workshop in Scottsbluff on April 2, 2016 with Mark Keith presenting. The event will also have a panel of Deaf and Hard of Hearing young adults, and will be similar to what the Guide By Your Side Program did for their "Mom's Day In" event.

Roots and Wings will be hosted in Kearney the weekend of April 15-17, 2016. They currently have 20 families registered so they are full. Mark Keith will also be presenting at Roots and Wings.

The Nebraska Commission for the Deaf and Hard of Hearing will be hosting a workshop on Saturday April 16, 2016 for Deaf and Hard of Hearing teens. The workshop will focus on how to avoid problems with domestic violence, avoid becoming a victim and avoiding bullying. A police officer will present, as well as Mary Guthries who is a counselor in Kansas.

**xii. Adjourn**

A motion to adjourn the meeting was made by Pete Seiler and seconded by Rhonda Fleischer. The meeting was adjourned at 4:12 pm.

Next Meeting: June 9, 2016 – 1:00 pm at Mahoney State Park, Riverview Lodge

2016 Meeting Dates:

- September 8, 2016
- December 8, 2016

Respectfully submitted by MeLissa Butler, Community Health Educator