

**The Nebraska Early Hearing Detection and Intervention Program
Advisory Committee Meeting
June 11, 2015
Minutes
1:00 pm - 3:13 pm**



Riverview Lodge, Eugene T. Mahoney State Park

Attending:

Members

Nina Baker
Kathy Beauchaine
Steve Boney
Linsay Darnall, Jr.
Rhonda Fleischer
Charlie Lewis
Kelly Rausch
Stacie Ray
Colleen Richart
Pete Seiler
Susan Stibal

Guests

Jeff Hoffman, ECHO
Brenda Hoover, BTNRH

Interpreters

Kelly Brakenhoff
Jamy Elker

Staff

Jim Beavers
MeLissa Butler
Kathy Northrop

Newborn Screening

Bloodspot Staff
Krystal Baumert
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Chair, Kathy Beauchaine, at 1:03 pm.

Open Meeting Act – Presented at the beginning of Advisory Committee Meeting by Kathy Beauchaine.

I. Welcome and Introductions

Kathy Beauchaine, Advisory Committee 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 March 19, 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 Nina Baker, and unanimously approved by the Committee members.

IV. Presentation – Early Childhood Period Hearing Screening Presentation

Jeff Hoffman, Research Scientist and Audiologist with Early Childhood Periodic Hearing Screening (ECHO) Initiative, National Center for Hearing Assessment and Management (NCHAM) at Utah State University, gave a presentation on Early Childhood Periodic Hearing Screening.

Jeff mentioned that one population that has been identified as a problem are children who are immigrants. Children who emigrate from other countries where a newborn hearing screening program has not been established often end up in Early Head Start programs when they come to the United States. Another population that often ends up in early head start programs are children who have not followed through on the newborn hearing screening follow-up protocols after they refer on the inpatient screening and are lost to follow-up.

Jeff stated that hearing loss can occur at any time in later childhood due to illness, trauma, or genetic factors. While on average two to three of every 1,000 children are born with hearing loss, by school age the incidence of childhood hearing loss doubles to about four to six of every 1,000 children having hearing loss. The ECHO Initiative challenges programs to find those children as soon as possible so early intervention services can be started.

Krystal Baumert asked if the Early Head Start program in Nebraska has high staff turnover. Jeff said yes, about one third of their staff turns over each year, which is why training is so important.

Nina Baker stated that she participated in a webinar with Jeff and had a question she would like to ask the Committee. Is anyone in the Early Head Start programs collecting information from families on whether or not the baby passed the newborn hearing screening at birth? Nina stated that if it is not being done, it should be. No one in attendance could answer this question.

V. **New Member Orientation Manual**

MeLissa Butler distributed the latest version of the *Nebraska Early Hearing Detection and Intervention Program Advisory Committee Member Orientation Packet* to each member present. She stated that anyone requesting changes or updates to the packet can send her an email at melissa.butler@nebraska.gov.

VI. **HearU/Hearing Aid Bank Update**

Stacie Ray provided the quarterly report for HearU Nebraska and reviewed the information detailed in the handout.

Stacie mentioned she was recently in Nicaragua doing outreach work. The country of Nicaragua is very poor and underserved with audiology services. She estimated that about 70% of the population is unemployed. Stacie stated that in the entire country of about six million people, there is one full-time and one part-time audiologist. Both audiologists were trained in the United States. Other than the services these two professionals are able to provide, audiology services do not exist.

Stacie stated that a child who is deaf or hard of hearing typically does not go to school in Nicaragua and parents of a child who is deaf do not learn sign language in order to communicate with their child. Children who are deaf or hard of hearing ultimately have few opportunities to learn. The only deaf school in the country is in an old woman's home.

One issue with providing hearing aids to children is that there is no air conditioning so the kids sweat a lot. Because of this, Stacie is looking into what kind of hearing aids to purchase that can withstand the moisture.

In May 2016 Stacie hopes to expand the services provided by HearU into Nicaragua and take audiology students back with her as volunteers.

Pete Seiler asked how the kids will obtain batteries for their hearing aids in Nicaragua. Stacie stated that batteries are available, but the cost is about \$1.50 each, which is not at all affordable for the families there. She hopes that HearU can find a way to get hearing aids for humanitarian efforts that offer something such as solar rechargeable batteries. She said she is looking into options.

VII. CMV Task Force Update

Kathy Beauchaine updated the Advisory Committee on the status of the CMV Task Force. Dr. Ann Anderson-Berry, a Neonatologist who serves on the CMV Task Force, is taking the lead in recruiting a Pediatric Resident to head up a research project in CMV education and prevention. In addition, Dr. Anderson-Berry is exploring the possibility of launching a pilot study which would include collecting a saliva swab inpatient to test for CMV on babies who do not pass the newborn hearing screening. The pilot study would then follow those infants to track their outcomes.

Julie Luedtke added that the CMV Task Force is looking into a two-part approach with their pilot study. One identified weakness is that they would only catch a small number of children with CMV if they only look at the subgroup of those children who do not pass their newborn hearing screening, so there is the possibility of expanding the pilot to catch more babies with CMV. Education through outreach to obstetricians and family practice physicians to disseminate information to all expectant families would be very beneficial.

Kathy N. added that Jessica Buckley, a parent on the CMV Task Force, talked about the importance of using social media to raise awareness.

Kathy B. added that anyone can get the CMV Task Force meeting notes even if they can't attend the Task Force meetings.

The next CMV Task Force meeting will be scheduled for early August 2015.

VIII. Training Task Force Update

MeLissa Butler stated that the Hospital Training Task Force has been temporarily put on hold. Marietta Mathis, a University of Nebraska-Lincoln (UNL) Audiology student, who is doing her capstone project as part of the Hospital Training Task Force, is willing to fill the role of the audiologist. Marietta met with her capstone advisor on Monday June 8, 2015 to determine what she needs to do in order to fulfill her capstone requirements. Marietta will be responsible for the onsite trainings at the hospitals when the training plan is established. Once Marietta knows what she needs in order to fulfill the requirements for her capstone, the Task Force will know more about what our next steps are. MeLissa acknowledged that although this seems like a setback, having Marietta on the Task Force is a great asset.

IX. Nominations for Advisory Committee Chair and Vice-Chair

Kathy Northrop stated that the [2014 Newborn Screening Annual Report](#) has been distributed as a handout to each Advisory Committee member. In addition, an electronic version will be made available on the [NE-EHDI website](#).

Kathy N. also stated that the Advisory Committee needs to start preparing for the 2016 Chair and Vice-Chair elections. Nominations will be made in September and will be sent out via Survey Monkey. The announcements for the 2016 EHDI Advisory Committee Chair and Vice-Chair will be made at the December 2015 meeting with terms beginning in January 2016.

Kathy N. asked Susan Stibal to speak about the Lincoln Public Schools (LPS) project *Hear to Learn*, as recently the project has received some attention from the local media. Susan explained that the pilot project to add amplification with sound fields to four public elementary school classrooms in Lincoln was very successful. On June 10, 2015 LPS announced that the new budget will include \$2.5 million to be used to purchase amplification for all classrooms over next three years.

X. **The NE-EHDI Program Statistics and Lost to Follow-up Information – Jim Beavers**

Jim Beavers presented hearing statistics for Nebraska infants over the last few years. The 1-3-6 statistics for Nebraska included birth years 2011 through 2014 with “diagnosed within 3 months” showing a significant improvement in the last two years. Other statistics included “reasons for no inpatient screening” for 2013-2014 Nebraska births with expired newborns and homebirths accounting for over 65% of those without an inpatient screening. For 2014 births, 887 infants were tracked by the NE-EHDI Program staff (760 or 86% of this group of infants did not pass the inpatient screening).

Kathy Beauchaine asked Jim for an estimate of how many babies are screened with ABR inpatient, then screened with OAE outpatient each year in Nebraska. Jim estimated that approximately 100 babies per year are screened this way. Kathy B. stated that this screening method is a potential issue due to the possibility of missing auditory neuropathy. She went on to say that the NE-EHDI letters sent to physicians need to specify the protocols for using ABR on the outpatient screening if the child was screened with ABR inpatient. Melissa stated that physician letters need to be updated so this can be addressed when the letters are revised in the future.

Jeff Hoffman added that an ABR outpatient screening is mainly a concern for babies who have been in the NICU and referred on the inpatient screening. Melissa added that all NICU babies are rescreened with ABR, as this protocol is stressed to physicians through the NE-EHDI Program follow-up.

Susan Stibal questioned if NE-EHDI should track the 1-2-3 timeliness since that is becoming a trend on a national level. Jim stated that he will see if he can run those numbers to present at the September meeting.

Kathy B. stated that when it comes to the 1-3-6 goals, Nebraska performs consistently well on the “1”, however, we still need to improve on the “3” and the “6”. Another issue that needs to be addressed is the quality of the “6” - early intervention services and access to services. Even though a child is referred to early intervention by six months of age, if the services are not good quality then the outcome will not be ideal. The ultimate goal of 1-3-6 is to give each child the best chance at a successful outcome. Nina Baker stated that the data collected only says “enrolled” but it needs to be broken down further into subcategories of “referred” and “verified” so the data is clearly represented. In addition, Nina stressed that early intervention is a choice, so some families *do* refuse the service.

Jim Beavers hopes to present Nebraska data using a newer version of the CDC’s 1-3-6 calculation methods at the September meeting, adding that 2014 was Nebraska’s best year.

Steve Boney asked Jim to add whisker bars to the next set of handouts for variability as the averages are difficult to interpret without variability.

XI. **Other**

There were no other items.

XII. **Adjourn**

A motion to adjourn the meeting was made by Nina Baker and seconded by Steve Boney. The meeting was adjourned at 3:13 pm.

*Next Meeting: September, 10 2015 – **1:00 pm** at Mahoney State Park, Riverview Lodge*

2015 Meeting Dates:

- December 10, 2015

2016 Meeting Dates:

- March 10, 2016
- June 9, 2016
- September 8, 2016
- December 8, 2016

Respectfully submitted by Melissa Butler, Community Health Educator