

The Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Meeting

June 9, 2016

Meeting Minutes

1:02 pm – 2:59 pm

Eugene T. Mahoney State Park, Riverview Lodge

Attending:

Members

Nina Baker
Katie Brennan
Steve Boney
Linsay Darnall Jr.
Rhonda Fleischer
Shelli Janning
Cindy Johnson
Kim-Jae Kang
Kelly Rausch
Stacie Ray

Guests

Nicole Pond UNL Student, HearU
Mary Pat Moeller, BTNRH
Karen Rolf, UNO
Jen Sturgeon, OPS

Liaisons

Laurie Miller
Cole Johnson

Interpreters

Kelly Brakenhoff
Frances Beurivage

Staff

Jim Beavers
MeLissa Butler
Marietta Mathis
Gabby Tachenko

Teleconference

Sara Peterson

Newborn Screening Staff

Krystal Baumert
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Chair, Linsay Darnall Jr, at 1:02 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 March 24, 2016 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 Kim-Jae Kang, seconded by Rhonda Fleischer, and unanimously approved by the Committee members.

IV. Presentation – Factors Affecting Early Services for Children who are Hard of Hearing

Mary Pat Moeller, Director of the Center for Childhood Deafness and Infant Language Development Laboratory at Boys Town National Research Hospital presented information on an ongoing study titled *Factors Affecting Early Services for Children who are Hard of Hearing*. This study is being conducted in cooperation with the University of Iowa and University of North Dakota, and has been ongoing for over

eight years. The study addresses two very broad questions: 1.) Is early identification making the expected difference? 2.) Are some children falling through the cracks? If so, why?

Mary Pat stated that 76% of the study participants were identified as hard of hearing by the newborn hearing screening, and the EHDI programs and the regional programs have been instrumental in recruiting study participants.

Prior to this study being conducted, the largest study to focus on hard of hearing children was conducted by Julia Davis at the University of Iowa back in the 1980's, and her study followed approximately 40 children. The current study being conducted has 317 children enrolled from 17 different states, so it has a much larger participant pool to collect outcome data from. Of the 317 children in the participant pool, only seven do not wear hearing aids due to very mild hearing loss. The groups of children with hearing loss and the groups of children with typical hearing who participated in the study were well matched on socio economic status, but Mary Pat cautioned that both groups had a higher than typical socio economic status, explaining that it was difficult to represent families with a lower socio economic status because the study required a lot of family participation. So, when the outcomes show that maternal education matters, the importance of maternal education is likely underestimated due to the participants being from families with a higher than typical maternal education level.

One question that the study hoped to answer related to the impact of early intervention services. Is early intervention producing the outcomes that are expected and hoped for? Several studies have looked at family satisfaction, however, one weakness of those studies is that families may be happy with the services they have been offered, but they also may not know what services they are lacking for their child. Many people mistakenly conclude that more services equal more progress, but that is confounded by many variables. So, this study is trying a new approach: a weighted score that measures the level of specialization of the provider. The score is weighted on a scale of 0-5, focusing on the type of degree and area of specialization. The weighted score is not designed to place a value judgment on the level of the education, but to measure how well the provider was able to produce a positive outcome for the hard of hearing child.

The study also collected data on four factors which helped to measure the outcomes of the study:

1. Where are services for children who are hard of hearing delivered in the birth-3 period?
 - a) The study found that families were receiving a number of services from multiple providers. Only 14% of the study participants were not receiving services in the home. A lot of those children had parents with lower education levels, which raises these questions: Is this a barrier for children in this situation? Are families with a lower level of parent education harder to engage, or are services more difficult for them to access outside of work hours?
2. What is the effect of setting on family participation?

- a) Providers were asked to rate how conducive outside-of-home settings were to providing adequate services. Settings outside of the home, like a daycare, were rated fair to poor by 33% of the providers surveyed. The poor rating was due to excess noise, visual distractions and frequent interruptions which prevented the child from concentrating. Parent support is also vital to producing a good outcome, which supports the need for home based services.

3. What is the pre-professional and professional preparation of individuals providing services?

- a) The average caseload for providers ranged from one child to 60 children, with the mean being 20 children. Fifty three percent of providers reported caseloads composed almost entirely of children who are hard of hearing, and 27% of providers reported a caseload of less than 20% children who are hard of hearing. This measure indicated that the more experience with hard of hearing children the provider had, the greater comfort level and confidence they demonstrated with their case load. The years of experience of those providers surveyed ranged from less than one year to 37 years of experience, with the mean being around 12 years of experience.

This survey also assessed comfort levels on 18 skill areas. One remarkable finding was related to the providers comfort with helping parents develop sign language skills. This was rated the lowest comfort level, which is a problematic finding for families who want to sign with their child. One solution is to provide more training on sign language support. Another solution is to bring in additional professionals to provide sign support when the primary provider is not comfortable. Another remarkable finding was that this same group of providers rated themselves very confident in helping families choose communication options, again emphasizing the need to educate providers about sign support for families who choose sign language as a communication option.

There was also a lower comfort level when it came to helping families troubleshoot problems with hearing aids. This is another vital skill set to have among providers for hard of hearing children, so more training on hearing aids is also needed.

4. Do factors such as preparation, caseload composition, and/or experience relate to self-confidence in specific EI skills?

The conclusions of the study showed the following:

- Families have access to providers with considerable preparation.
- Providers with higher caseloads and higher specialization demonstrated higher comfort levels on most skill areas, with the exception of sign language skills.
- Years of experience was only weakly correlated with skills
- Specialization and teamwork are important

Kim-Jae asked if the study looked at parent support as a factor for producing a good outcome, since evidence shows that parent-to-parent support helps families be more informed about necessary services. Mary agreed that family support is crucial, but added that it was not included in this paper. However, other studies she has read show that there is a lack of parent-to-parent networking among study participants. This will be the topic of a different paper.

Karen Rolf commented that she was the Evaluation Coordinator at the Illinois State Board of Education for five years. She added that Illinois's data base is able to track the primary and secondary diagnosis on children, so she decided to review the administrative data collected over a period of ten years on children whose primary diagnosis was deaf/hard of hearing. Her findings showed that many children whose primary diagnoses was deaf/hard of hearing later went on to have their primary diagnoses changed to a "behavioral disorder". She expressed an interest in seeing if Nebraska's data would show similar findings.

Mary Pat responded there is a group currently reviewing IEP's and 504 plans, but their review is focused on observing the classroom environment by measuring noise levels and acoustics. Cole Johnson added that Nebraska's database can only identify a child as "developmentally disabled", but specifics about the diagnosis cannot be tracked at this time. An integrated database may be 2-3 years down the road.

Mary Pat added that Australia is conducting a similar study, and their data suggests that starting early does not matter. However, their growth trajectories tell a different story because there is a large group of children showing that delays were prevented due to early intervention services.

Lindsay Darnall Jr. observed that the study is focused only on hard of hearing children. He wonders if the study were to focus on deafness, would the outcomes be different? Could they find a group of early intervention providers who had higher confidence in their sign skills? Mary Pat responded that she is confident that if they had included deaf kids in the study, the confidence level of providers would increase because they would have a more focused skill set. Lindsay asked if the service providers surveyed in this study were the same group of providers who provided services to deaf kids. Mary Pat responded that it depends on the location. The Moog Center for Deaf Education provided a larger range of services, but not all schools were able to provide the same levels of services.

Karen Rolf commented that some professors have observed that students whose first language is ASL have a different writing style because the syntax of ASL is different from English. She feels there needs to be more sensitivity for ASL students because English is not really their first language, adding that more research on the subject would be helpful. Lindsay added that the quality of the child's education growing up greatly impacts their literacy skills, and not just for ASL kids but all kids. American schools require that students whose first language is English have to take classes on grammar, punctuation, spelling and writing English. Deaf kids should get the chance to take a class that is rich in ASL as well as English.

v. HearU Hearing Aid Bank Update

Nicole Pond, UNL Graduate Student and HearU Graduate Assistant, presented the HearU quarterly statistics for January 1, 2016-May 30, 2016.

Nicole also showed a picture of the new Phonak hearing aids HearU recently purchased. These hearing aids have an exciting new feature - a light indicator which shows if the battery is low or something is not working. Now, for the first time parents will be able to do a listening check with the light indicator.

Stacie Ray added that HearU International has now been launched. Stacie and four graduate students will be going to Nicaragua in August 2016, and will visit three different communities in Nicaragua. Travel has been funded through a SEED grant, and all other costs associated with providing hearing aids to children is being funded 100% by private donations made to the University of Nebraska Foundation. The cost of hearing aids in Nicaragua is much cheaper than in the United States. A care kit for a child is around \$250, which is a big savings in comparison to the cost of a care kit for children in the United States.

Karen Rolf asked if HearU group of volunteers are going with Anne Coin. Stacie confirmed that they will be going with Anne. Karen shared her excitement for Anne's involvement in the trip, stating that Anne is an amazing woman who has done a lot for the deaf community in Nicaragua.

vi. CMV Task Force Update

Kim-Jae stated that the proposal for the pilot project has been approved. The next step is trying to find grant funding to make educational materials for the OB/Gyn's. Kim-Jae asked that if anyone knows of grant funding opportunities the task force could apply for, please let her or Rick know.

vii. Hospital Training Task Force Update

McLissa Butler stated that the participant pool for the survey ended up being 13,418 surveys sent with a total of 491 surveys returned. This puts the response rate at 3.66%.

Marietta Mathis added that she is still in the early stages of analyzing the data, but during her first review of the responses, she has found an overall positive attitude towards newborn hearing screening. Most parents felt like they clearly understood the purpose of the screening and the results, which agrees with the data Marietta has read in the literature.

Some responses indicated that parents would like more information regarding how the hearing screening is performed, what is being measured, the opportunity to observe the hearing screening, and a written explanation of the results. So, Marietta feels it would be beneficial for the EHDI program to review the content of the brochures to ensure that sufficient information is being provided, and evaluate if all hospitals are routinely distributing the brochures. She also stated that it would be beneficial to survey hospital professionals to determine if the hearing screeners feel confident in their ability to perform the screening and explain the results.

Krystal Baumert stated that the parents are given a brochure with their birth information packet. Perhaps some parents are just not looking at it since they are overwhelmed with a lot of information in the hospital. Julie Luedtke stated that when the survey for hearing screening professionals is developed, it would be good to evaluate what the procedures are for parent education. Often times, just raising the question is a good reminder for hospitals to make sure they are distributing the education materials they are provided.

Kelly Rausch stated that she has a friends who works in the mother/baby ward at a Lincoln hospital. She has asked them what their procedures are, and what their comfort level is with delivering the hearing screening results. The feedback she has received is that nurses are definitely not comfortable delivering the results, which confirms what happened with Kelly's daughter in the hospital. Kelly shared that when she was told that her daughter did not pass the newborn hearing screening, there was no sense of urgency instilled in her to follow up as soon as possible. Marietta stated that the results of the parent survey agree with Kelly's findings. Kim-Jae stated that she feels there is a big gap in sensitivity training with hospital professionals.

Linsay Darnall Jr. agreed with Kim-Jae's comments, adding that he has heard from several families in other states that the results were downplayed when reported to the parents. He shared an experience he recently heard about from a family in California. The mother is the principal at the school for the Deaf in California, and while informing the mother that her baby did not pass, the hospital staff asked her what she planned to do about the failed screening. She informed the hospital staff that she would use ASL until the status of her baby's hearing was confirmed, and she intended to follow up on the failed newborn hearing screening. The hospital staff probed further, asking her what her plan was if the child was confirmed deaf. Their demeanor and questions suggested that they did not trust her judgment. After she once again told them the family planned to use ASL, the hospital staff suggested that they keep the baby until she figured things out. The hospital eventually reneged their recommendation to keep the baby and allowed the mother to take her baby home, but experiences like this make it difficult for deaf families to trust medical professionals.

Nina Baker shared that she also dealt with professionals who are not comfortable with giving bad news, adding that it was almost comical when her pediatrician informed her that her daughter had Down syndrome, because he was obviously uncomfortable and could not wait to get out of the room. She agreed with the finding that professionals need to learn how to be okay with giving bad news, and not fearing the likelihood of an emotional reaction from parents.

Kim-Jae stated that the next step should be to look at the hospital protocols and procedures to see if they provide sensitivity training to the staff.

Linsay added that he wonders what is included in sensitivity training for medical professionals. Marietta responded that the Audiology students at UNL take a counseling class as part of their required curriculum, but very few doctoral degree programs require counseling coursework.

Kelly added that Boystown was amazing with her and her daughter and explained everything very thoroughly, so once she got to the right place she was very happy with the services she was provided.

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

Jim Beavers reviewed the handouts entitled *January through March 2016 DOB the NE-EHDI Status Report*.

Linsay Darnall Jr asked how many babies on average are identified each year in Nebraska. Jim stated that it can range from 50 to 80 children per year. Jim added that he just reported the statistics for 2014 births to the CDC, and there were 78 total identified in 2014; 72 identified through newborn hearing screening, and an additional six later identified with progressive or late onset hearing loss.

ix. NE-EHDI Program Manager Retirement and Succession Plan

Julie Luedtke stated that Kathy Northrop, former Program Manager for the NE-EHDI Program retired effective Friday June 3, 2016. Julie advised the committee that Kathy completed all pending grant reports before she left the program. The next report that will need to be submitted will be a year 5 report due in September, 2016. The Annual Report is completed and will be distributed electronically once it is approved by the upper level staff at DHHS. Hard copies will be distributed at the September Advisory Committee meeting.

Julie also advised the committee that she received approval to fill the Program Manager position on Friday June 3, 2016 and the hiring process will begin shortly. She will share the posting with the committee if they want to forward it on to other agencies who may have eligible candidates

Stacie Ray asked what the hiring criteria for the Program Manager position is. Julie stated that a Bachelor's Degree is required, and Master's Degree is preferred.

Stacie also asked if any recognition of Kathy's years of service with the NE-EHDI Program was done. MeLissa stated that she filled out an application requesting a retirement gift from the State of Nebraska funds, but it was denied due to a freeze on state spending. Kim-Jae suggested the NE-EHDI Advisory Committee pool funds as a gift to recognize Kathy's contributions to the NE-EHDI Program. A total of \$30 was collected at the meeting.

Linsay suggested that the committee make a resolution to recognize Kathy's contributions to the NE-EHDI Program. A motion was made by Rhonda Fleischer, seconded by Kim-Jae Kang, and unanimously approved by the committee. A gift card and a certificate of appreciation will be sent to Kathy.

xi. Other

Kim-Jae stated that MeLissa Butler, Community Health Educator for the NE-EHDI program has proved to be a valuable member of the team in the five years she has been with the program, and hopes that MeLissa applies for the Program Manager position. Kim-Jae asked where letters of recommendation for MeLissa could be sent. Julie Luedtke stated that letters can be sent directly to MeLissa, and she can submit them with her application.

Linsay thanked Sarah Peterson for attending the meeting via Zoom Room. Sara stated that she hopes to attend a meeting in person someday soon.

xii. Adjourn

A motion to adjourn the meeting was made by Rhonda Fleischer and seconded by Nina Baker. The meeting was adjourned at 2:59 pm.

Next Meeting: September 8, 2016 – 1:00 pm at Mahoney State Park, Riverview Lodge

2016 Meeting Dates:

- December 8, 2016

2017 Meeting Dates:

- March 9, 2017
- June 8, 2017
- September 7, 2017

- December 7, 2017

Respectfully submitted by MeLissa Butler, Community Health Educator