Nebraska Early Hearing Detection and Intervention Program
Advisory Committee Meeting
June 11, 2014
Minutes
9:15-12:30

Nebraska Room, Eugene T. Mahoney State Park

Attending:

Members	Guests	Staff
Nina Baker	Kelly Brakenoff-Interpreter	Jim Beavers
Kathy Beauchaine	Jamy Elker-Interpreter	MeLissa Butler
Linsay Darnall, Jr.	Shelli Janning	Kathy Northrop
Kim Jae Kang	Richard E. Lutz	
Richard Kang, MD	Jessica Buckley	
Charlie Lewis	Barb Jackson	Newborn Screening
Colleen Richart	Michelle Kang	Blood Spot Staff
Susan Stibal		Krystal Baumert
Heather Witte		Julie Luedtke

Meeting start time – The meeting was called to order by Committee Chair Kathy Beauchaine at 9:15 am.

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. Per the Nebraska Open Meetings Act, the required quorum of at least 51% of the Committee was met as nine of the 16 Committee members were present.

II. Review of Agenda
There were no changes.

III. Review of Minutes
The minutes of the March 12, 2014 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting. A motion to approve the minutes as published was made by Richard Kang, seconded by Susan Stibal, and unanimously approved by the Committee members.

IV. Presentation on TIPS
Barb Jackson is the Director of the Department of Education and Child Development and the Director of the Interdisciplinary Center for Program Evaluation (ICPE) at the Munroe-Meyer Institute, where she serves as an Associate Professor. Barb presented information to the Advisory Committee on the Developmental Tracking Infant Progress Statewide (TIPS) program, which provides specialized follow-up for babies who have been in a Neonatal Intensive Care Unit (NICU). The goal of the program is to gather information about how these babies grow and develop. Barb has worked with the NE-EHDI Program to determine the number of children that were enrolled in the Early Development Network (EDN) who had failed their newborn hearing screen in 2011. For those children who were enrolled in the program, an analysis of the developmental outcomes was completed.

The purpose, description of study subjects, findings and conclusions of this study were detailed in the handout provided and presented in a PowerPoint presentation.

V. American College of Medical Genetics Guidelines for Genetic Evaluation of Hearing Loss & Cytomegalovirus (CMV) Screenings

Richard E. Lutz MD is Associate Professor of Pediatrics at the University of UNMC and works as a Clinical Geneticist and Pediatric Endocrinologist at Munroe-Meyer Institute. Dr. Lutz also serves on the Advisory Committee for the Nebraska Newborn Screening Bloodspot Program. Dr. Lutz spoke to the Committee about the importance of CMV testing in babies who do not pass the newborn hearing screening. CMV can cause hearing loss. Dr. Lutz explained that CMV is a virus that stems from the Herpes family of viruses. CMV is the most common infection in an unborn fetus and newborns are susceptible to the virus if the mother acquires it during pregnancy. Some babies who acquire CMV at birth will pass the newborn hearing screening, but acquire hearing loss later in life. Ideally, if all babies who do not pass the newborn hearing screening are screened for CMV prior to hospital discharge, the incidence of unidentified late onset hearing loss due to CMV could decrease if the child receives anti-viral therapy and the child's physician knows to follow-up with frequent hearing screenings.

Dr. Richard Kang shared that he attended a presentation at the Annual EHDI Meeting about CMV and efforts that ocurred in the state of Utah related to CMV awareness and screening. Utah passed a law regarding a public education and testing protocol for CMV. As a result of this law, the Utah Department of Health has created a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures. The law also directs medical practitioners to test infants, who fail two newborn hearing screening tests, for congenital CMV and inform the parents of those infants about the possible birth defects that CMV can cause and the available treatment methods.

Julie Luedtke stated that back in 2010, efforts were made to evaluate the evidence and the development of policies and recommendations regarding the use of residual dried blood spots (DBS) for CMV testing. Reviewing the research and findings of this project may be helpful if efforts are made to implement CMV screenings on infants who refer on the Newborn Hearing Screening. Kathy Beauchaine recommended that a task force be formed to review these documents and consider the possibility of implementing a process for screening infants for CMV in Nebraska. Jessica Jacobsen-Buckley stated that she has information on the Utah law and their website and will share the link with the Committee.

VI. 2014 EHDI Annual Meeting Highlights

Funding to attend the 2014 EHDI Annual Meeting in Jacksonville Florida was made available to the Guide By Your Side (GBYS) Program through the NE-EHDI Program. Colleen Richart, the Nebraska GBYS Coordinator presented a summary of the highlights that she, Shelli Janning, and Debb Niles took away from the meeting, as summarized in her handout. Colleen stated that she enjoyed the meeting, but found it difficult to get from one end of the building to the other in the allotted time between sessions and therefore missed the beginning of some of the sessions she attended. She also felt that the sessions were packed with more information than could effectively be presented in the allotted 30 minute time slots.

A parent stipend to attend the 2014 Annual EHDI Meeting in Jacksonville Florida was given to Jessica Jacobsen-Buckley. Jessica thanked the NE-EHDI Program for the opportunity to attend the meeting. She said that she was not sure what to expect when attending the conference, and wondered if she would be a lone parent in a sea of professionals. However, she was able to make a lot of good connections with many parents

of children who are deaf or hard of hearing, and especially parents from Nebraska. When sharing her highlights detailed in her handout, Jessica mentioned that CMV is a disease that has impacted her life a great deal, as she has a cousin who died from CMV, and her daughters hearing loss is likely related to a CMV infection.

Note: At 11:00 am, two Committee members had to leave. Due to the requirements outlined in the Nebraska Open Meetings Act, since the required quorum of members was no longer met, the meeting was adjourned. No voting or actions were decided after this point, and all agenda items going forward were a discussion and no longer a part of the official Advisory Committee Meeting.

Later, Kathy N. followed up with the legal staff at Health and Human Services and they agreed that the NE-EHDI Program Advisory Committee did not meet the definition of a "public body" under the Open Meetings Act.

VII. NE-EHDI Presentation at the 2014 EHDI Annual Meeting

At the 2014 EHDI Annual Meeting, Kathy Northrop and Dr. Stacie Ray did a presentation entitled *Connecting Families with Services in Nebraska.* Kathy shared the survey results from the presentation with the Committee as shown in the handout, and commented that they received good feedback from those who filled out the survey.

VIII. HearU

Kathy Northrop presented the statistics from the handout entitled *HearU 4th Quarter Report* for February 1, 2014 - April 30, 2014 as Stacie Ray was unable to attend the meeting.

IX. A Parents Guide to Hearing Loss Panel

Kathy Northrop noted that the link on the agenda is to a Nebraska Public Television Network on demand presentation entitled *A Parents Guide to Hearing Loss*. The purpose of the presentation is to educate viewers about the early identification and newborn screening process; prevention tips to protect children and teens from noise-induced hearing loss; and options to consider for education and parental support. There are many familiar faces in the presentation including Rhonda Fleischer, Stacie Ray, Jennifer Racine and Todd and Stacie Luther. The presentation was broadcast on four different dates in May in honor of *May is Better Speech and Hearing Month.*

X. Guide By Your Side (GBYS) Program Update

Colleen Richart stated the currently there are 10 families enrolled in the Nebraska GBYS program. The Nebraska GBYS website is under construction and she hopes to have it live soon. Coleen is also planning a series of workshops which will focus on helping families deal with issues they will face as their child, who is deaf or hard of hearing, grows up. For example, around the holidays many families will be bringing their child around extended family for the first time since identification. This can be stressful for everyone, as parents may be asked a lot of questions that they don't know how to answer and extended families may not fully understand the sensitivity of the issues many parents deal with when a child is identified. The workshop will focus on helping parents understand how they can best answer questions and manage the stress. Colleen also mentioned that she will be attending the Hands & Voices Conference in Savannah, Georgia September 19-21, 2014, and will be doing a booth at the Nebraska Speech-Language-Hearing Association (NSLHA) 2014 Fall Convention September 24-25, 2014 at the Cornhusker Marriott in Lincoln, NE.

XI. Update on EHDI Website

Kathy Northrop reported to the Committee that the NE-EHDI website is still under construction. The state staff member assigned to construction of the website has moved on to a different position and the job opening is still

in the process of being filled. Kathy will continue to update the Committee with progress reports once the project is resumed.

XII. New Member Orientation Packet

Debie Seiler, Pete Seiler, Linsay Darnall Jr., and Matthew Thielker have worked on a new member orientation packet. Since Pete & Debie are not present at the meeting today, the new packet will be presented to the Committee at the next meeting in September, 2014.

XIII. Marshall Islands Family and Educational Services Unit (ESU) #13

MeLissa Butler shared with the Committee that there is a growing population of Marshallese families moving to the Chadron area. There is one family in particular that has six children, three of whom did not pass the newborn hearing screening and were lost to follow-up. Since three of the six children had not passed, there was some concern that there could be genetic hearing loss in the family. MeLissa reached out to Sara Peterson of ESU #13 in the Scottsbluff area. Sara was able to make contact with the family and screen all three of the children. All passed the hearing screening and are no longer lost to follow-up. MeLissa wanted to recognize Sara for her dedication and work ethic, as she really went above and beyond by actually going to their home and knocking on their door in order in order to speak with them face-to-face about the importance of hearing screenings.

XIV. HRSA Plan/Do/Study/Act (PDSA)

Kathy Northrop discussed the need for three task forces in order to satisfy the PDSA requirement in the HRSA grant. She reviewed the three PDSAs detailed in the handout. Kathy asked the Committee members to fill out the form if they are interested in serving on one of the task forces. She also asked that if anyone was interested in the assisting with an iniative to educate Nebraska medical professionals about CMV, or an initiative to educate nurses and screeners at hospitals about the most effective way to communicate results to parents, they could add that information at the bottom of the form provided. Kathy will also send information to the members who were not present at the meeting.

XV. NE-EHDI Statistics for Lost to Follow Up (***LFU/LTD***) Information

Jim Beavers discussed the two graphs in his handout entitled *NE 2011 DOB CDC LFU/LTD (lost to follow-up/lost to documentation) compared to other states* and *Nebraska "Lost" per ERS for DOB 2007 through 2012*. Jim stated that at the 2014 EHDI Annual Meeting, he, Kathy N. and MeLissa met with Dr. Karl White (Director, National Center for Hearing Assessment and Management [NCHAM]), Irene Foresman (Director, Universal Newborn Hearing Screening and Intervention Program/Maternal Child Health Bureau), Karen Muñoz (NCHAM) and Vicki Hunting (Quality and Operational Improvement Engineer, Center for Child Health Improvement & Innovation, University of Iowa) for a Quality Improvement Session. During the meeting, Jim explained to the group that he felt the way the CDC calculates their *LFU/LTD* number is an inaccurate representation of the data. He further explained that because the CDC only uses the total number of infants who have had at least one hearing screening (inpatient or outpatient), or who did not pass their most recent screening as the denominator, after an infant passes an outpatient screening they are *no longer represented in* the denominator, therefore the CDC denominator represents a much smaller percentage of the total number of infants who need follow-up. This method results in a higher total percentage of *LFU/LTD* for states (like Nebraska) where timely follow-up on hearing screenings is consistently taking place. Jim used the graphs in the handouts to demonstrate his theory, pointing out that despite Nebraska having a significantly lower total number of *LFU/LTD* cases when compared to other states, their percentage of *LFU/LTD* was one of the highest due to the way the denominator is calculated.

Julie emphasized the significance of this discussion taking place with Karl and Irene, as Jim was able to get the attention of the people who have the power to recommend whether funding for programs like EHDI continues. Showing someone like Karl White that data is misleading due to the method of calculation gives someone in Karl's position information to make strong arguments that EHDI programs are making an impact and merit continued funding.

Jim also discussed the *1st quarter 2014 NE-EHDI Status Report*, as detailed in the handout.

XVI. Other

Kathy Beauchaine stated that the Committee will reconsider the time and dates of future meetings due to some of the Committee members having other commitments on Wednesday mornings. Kathy Northrop said she would send a survey to all members to see if there is a better date and time for everyone.

XVII. Adjourn

Meeting was adjourned at 12:09 pm.

2014 Meeting Dates:

- *September 11, 2014 at Mahoney State Park, Riverview Lodge*
- *December 11, 2014 at Mahoney State Park, Red Oak Room in the Main Lodge*

Respectfully submitted by MeLissa Butler, Community Health Educator