

Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee November 16, 2022

Minutes prepared by: Keeley Yang & Nicholas Vittum

Location: Virtual

Attendance

Present: Renae Allen, Anne Barlow, Joan Boddicker, Nicole Brown, Kirsten Coverstone, Danelle Gournaris, Hannah Herd, Tina Huang, Colleen Ireland, Abby Meyer, Gloria Nathanson, Jessica Novak, Joscelyn Martin, Sara Oberg, Elizabeth Pai, Emily Smith-Lundberg, Cat Tamminga, Katie Warne, Jay Wyant

Absent: Ingrid Aasan, Mary Cashman-Bakken, Emilee Scheid, Terry Wilding

Meeting Minutes

Welcome and Announcements

- Logistics
- Roll Call
- Approval of Minutes from August 2022 Meeting: *Minutes are approved*
- Vice Chair Nomination: Colleen Ireland has been nominated and accepted the nomination. No objections at meeting. Nomination approved.

EHDI Story, Cued Speech – Joan Boddicker

- Joan Boddicker shared about her daughter and the benefits of cued speech in her life. She was adopted from Columbia at 5 months old. Had an informal hearing test, which was not effective. 7 months later, hearing concerns arose. Screening done, and child was found to be Hard of Hearing. After some research, Joan discovered Cued Speech. Cochlear implants were placed but were not a perfect solution. Cued Speech turned out to be hugely beneficial, particularly in the family's efforts to teach her daughter to read. Joan attributes much of their success to Cued Speech.

Cued Speech and Deaf Children's Literacy Project - Kitri Kylo

- **Versatility and Benefits of Cued Language, all notes below are per Kitri's presentation**
 - Introduction to Cued Language (Cued American English or CAE)
 - Kitri Kylo shared her background in D/HH education. She is a part of the National Cued Speech Association and MN Cued Speech Association. She is retired but does volunteer work with different demographic communities.
 - Kitri shared that families need a range of communication choices to make informed decisions about their child's care. Cued Language is often not provided as an option to families.
 - Cued American English (CAE) is used to achieve English language, literacy, and listening/spoken language communication skills for deaf and hard of hearing learners.
 - Cued language is used more than people realize. Fluent language models in ASL and learners who have implants had benefited from spoken language strategies.
 - Discussed definitions and terminology surrounding Cued Speech and why these definitions are important.
- Provided resources for more information on CAE
- Question: What are the reasons behind Cued Language's marginalization in the D/HH community?
 - Answer: Several factors. Some reasons cited: Cued "Speech" has a potentially negative connotation, versus the term Cued Language; a lack of knowledge and understanding of the benefits offered by CAE; a general disinterest by school districts/educators in adopting CAE as part of their curriculum.
- Question: How are people getting connected to the Cued Speech Association? Where do native cueders come from?
 - Answer: More programs are available on the east coast and different pockets of America. There are in person and virtual cue camps where you can meet other families that are interested in learning. There are Adults who also use sign. Parents can get information from MN Hands and Choices. Also, you can refer parents to Kitri or connect with other parents who use cued speech.
- Question: Why is only 20% getting to use this language? Is it political or are there not enough resources?
 - Answer: There is resistance and not a lot of knowledge out there. Instead of being opened, people are not willing to take the time to understand what it means and not respectful to deaf community. There is a misunderstanding between speech versus language. Some teachers and training programs do not allow their students to be exposed to it. Some school districts confirm that they do not use cued speech here, but they are doing what may be convenient for them but not the child. Children deserve to have the opportunity to use and learn it.

Audiology Guidelines for Infants with cCMV Draft Review – Hannah Herd

- Hannah Herd from Lion's ENT Clinic shared that an audiology work group met in October 2022 and reviewed congenital cytomegalovirus (cCMV) monitoring protocols used nationally and in Minnesota and drafted a guideline for Minnesota audiologists. They met in November 2022 and discussed feedback

from colleagues. They finalized the protocol and sent it to the EHD Advisory Committee. Hannah provided an overview of the protocol.

- Question: How do you propose these guidelines get pushed to audiologists? Is this a recommendation or taught how to follow up?
 - Answer: Hannah: Guidelines are available through MDH. Like any other best clinical practices shared to the audiology community, we hope they adhere.
- Question: Are the guidelines something they must search for?
 - Answer: Kirsten: We send a mass email to all known audiologists to MDH EHD. We also ask the MN Academy of Audiology to share information in their formats such as newsletters. Additionally, we ask individual audiologists to share and promote. The guidelines are on the MDH website as well.
- Question: Any concern about visits being covered by insurance?
 - Answer: Yes, there are concerns and it will vary family by family. We will make this suggestion for monitoring regardless of insurance guidelines.
 - Abby: If it is one of the diagnostic codes used for the visit then it will be covered. This is evidence-based protocol.
- Question: Can M Health or Children's look for cases where there were any insurance concerns?
 - Answer: Hannah: Will look into this and see if there is data of what is covered or not. Currently, they are hospital-based billing, so they need different orders for what is being done.
- Question: What is MDH tracking with these patients? What data will be followed? What are the outcomes?
 - Answer: Kirsten: This is still being reviewed keeping in mind the balance of public health surveillance and what is needed for follow-up. We wanted to start off with this suggested protocol and get it shared with the implementation. This is being fine tuned at this time as they prepare for implementation. We will be looking at trends and monitoring overtime and can adjust this as needed.
 - Answer: Gina Liverseed is a nurse on the CMV LTFU team. We plan to follow kids longitudinally through childhood and are working with MDH for the data elements in collaboration with STFU & Kirsten. Hearing related elements are indicators as to how kids are doing long term.
- Question: Why monitoring only through 10 years old? Any concerns that they could develop hearing loss after 10?
 - Answer: Hannah: At 10 years old they can report hearing changes reliably. They are able to report to their school or PCP. School or PCP can continue outside the recommended protocol if or when hearing changes occur.
 - Kirsten: With majority of cases the progression would have started by that age. There are cases where it does not start until they are older. Study in Houston through *** team follow protocols out there that recommend this age.
- Question: Did you mention about adding making a connection through Help Me Grow or local programs at appropriate points on the protocol in writing?
 - Answer: Hannah: Not yet indicated in the cCMV guidelines. If hearing loss is detected, this is a follow through with that detection.

- Kirsten: Related to this guideline, you tend to follow if there is a confirmed loss- there will be a referral
- Cat: It would be helpful to have to listed somewhere because cCMV is an audio qualifier. If a referral is not made- it would make an automatic connection. They may be eligible for Help Me Grow but may not move forward with services- depends on if they want to. Helpful to have it somewhere but because cCMV is an audio qualifier it might be nice to have.
- Kirsten: Requested Cat propose the acknowledgement of this for the guideline.
- Question: Does primary care make that referral to Help Me Grow?
 - Answer: Cat: Yes, it depends. Often the PCP makes the referral, but it depends on when cCMV is first discovered. Audiologists are also responsible in making a referral and follow up
- Question: What is “connection”?
 - Answer: Cat: Connection is referral. Referral isn’t always a positive word for families. It can create an initial barrier for families for needing support. Resource or connection is a more comfortable term. Connection to early intervention, school services, and other services.
- Question: Is there a way to know if they had had a referral to Early Intervention or Help Me Grow?
 - Answer: Cat: Trying to find an easier way to see if referral was made. Currently, you need a ROI if family is not aware. If family is given a submission/referral number, you can use this to check. Also, can check provider notes. Duplicate referral is better than no referral.
 - Jess Moen: Once a child has a diagnosis of a hearing loss, our MN Low Incidence Projects website has an EHDI Information Packet for Clinical Audiologists that specifically mentions the referral process to not only Help Me Grow but also programs like MN Hands and Voices and such. The link to that packet is: https://mnlowincidenceprojects.org/Projects/ehdi/EHDI_InfoPacketClinicalAudiologists.html
- **Plan** – Take feedback, finalize protocol, and hold an electronic vote for final approval

MDE Update – Cat Tamminga

- Cat Tamminga is a Part C Coordinator at the MN Department of Education. Her role consists of supporting children, providers, and families to navigate through the educational system. At this time, there are no major updates for MDE. She plans to complete a more detailed update at the next meeting in February 2023. No questions were asked.

MDH Update

- Kirsten: Planning to collaborate with MNPQC on EHDI specific quality improvement project. MNPQC’s purpose is to improve maternal and infant health outcomes and decreasing racial and ethnic health disparities.
- Next new quality improvement initiative: Improving Timely Diagnosis after Newborn Hearing Screening
- The idea/project was presented with data they shared to the committee before and will begin to put it into action.
- Currently recruiting hospital personnel, clinic personnel, and providers.

- First meeting planned for February 2023 and will wrap up in September 2023.

Partner/Stakeholder Updates

- No additional updates.

Closure / Adjournment

- No additional comments.

Next Meeting

Date: February 15, 2023

Time: 1:00 – 3:00 pm

Location: Virtual

Agenda items: submit proposed agenda items to ehdi@state.mn.us

Decisions Made

- Colleen Ireland elected as Vice Chair for the EHD Advisory Committee

Action Items

- Audiologist Workgroup:
 - Seek information regarding insurance companies and the recommended guidelines for cCMV screening (esp. those requiring long-term follow-up).
 - Finalize recommendations and complete vote for final approval of the cCMV Audiology Guidelines.
 - Cat Tamminga requested to add and create a statement to the screening guidelines with connecting to Help Me Grow and Early Intervention.

Early Hearing Detection & Intervention Program

Minnesota Department of Health

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ehdi@state.mn.us

<https://www.health.state.mn.us/people/childreneyouth/improveehdi>

11/16/2022