

Meeting Minutes: EHDl Newborn Hearing Screening Advisory Committee

Date: 11/07/2018
Minutes prepared by: Darcia Dierking and Cara Weston
Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

Attendance

Present:

Ingrid Aasan, Kathy Anderson, Nicole Brown, Teresa Buck, Kirsten Coverstone, Laura Godfrey, Tina Huang, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Sara Oberg, Anna Paulson, Emilee Scheid, Lisa Schimmenti, Jay Wyant

Absent: Joan Boddicker, Mary Cashman-Bakken, Colleen Ireland, Nathaniel Meuser-Herr, Michael Severson, Sonny Wasilowski

Agenda Item Minutes

1:00 Welcome and Announcements

Meeting called to order by Lisa Schimmenti.

Nicole Brown discussed application and appointment process to be on the EHDl advisory committee. There have been some recent resignations.

Laura Godfrey gave remarks in support of her nomination for Committee Vice-Chair. She is a parent of a child with hearing loss and director of Minnesota Hands and Voices.

Abby Meyer gave remarks in support of her nomination for Committee Vice-Chair. She is an otolaryngologist and serves children with hearing loss.

Lisa: there is a quorum. Ballots were cast for Committee Vice-Chair.

Joscelyn Martin moved to approve the minutes from the last meeting. Linda Murrans and Jay Wyant seconded the motion.

1:15 Family Story (CMV video)

1:18- CMV– MDH Staff Maggie Dreon

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Discussed introductory information about the CMV virus, including characteristics of children born with the infection at birth (ranging from symptomatic to asymptomatic). She discussed the difference between children infected in utero and children exposed later.

National Conference Highlights: Growing interest from the NBS blood spot community. At the conference, there were presentations about current research and conversations on prevention and awareness. The group of advocates and parents continue to seek universal screening for CMV. There were conversations at the conference on the method of screening (saliva, bloodspot, urine, etc). Panel discussion moved toward consensus for universal screening in order to pick up symptomatic children that are not always identified at birth, and also better early management of hearing loss due to CMV. There is continued advocacy from parents in many states. Big takeaways for the Minnesota team were 1) need for coordinated system between several groups/programs 2) thoughtful implementation given volume and variable impacts. It is likely that universal screening is coming. There were some discussions about prevention, education for pregnant mothers (handling other toddlers while pregnant, using good hand washing, diapering, etc). Public education about CMV is an ongoing discussion, and was in previous proposed legislation.

MN Study Update: 6 hospitals, over 8000 subjects so far. Consented subjects skewed toward white and higher SES. Children identified with CMV classified as asymptomatic, asymptomatic with a hearing loss, and symptomatic (with and without hearing loss). Method detection rates for dried blood spot and saliva now not that different from each other. Methods have improved for testing dried blood spots over the last 10 years.

Questions needing to be answered in the future-

- Which approach is best? Education only, targeted approach (education with targeted screening, or universal approach (education and screening).
- If Universal approach, which method? Dried blood spot, saliva, or urine.
- Lots of concern for asymptomatic group: are we causing harm with screening when so many are unaffected?
- Does it meet criteria for newborn screening disorder? It is different than other disorders because there can be children classified as asymptomatic with normal hearing.

Discussion and questions (all):

- Surprised that hearing loss isn't considered a symptom. It is still a holdover from how things used to be categorized. It is not always clear- if we look at them closely they could be recategorized.
- CMV might have more of an impact on the asymptomatic population than we thought.
- There are lots of unanswered questions about what to recommend to pregnant mothers. What do you do with results if there aren't clear recommendations?
- Education is important, even if we don't have all the answers on what to do.

N H S A C M E E T I N G M I N U T E S

- Need to be careful with education because that implies these infections are preventable, and if a mom gets it even after good handwashing, she might feel guilt.
- Some people will appreciate having the education, in some it will cause fear.
- Education is important, even if there is not an action in place, it creates an environment for parents to come together.
- We could do more regular hearing screening of kids vs starting anti-viral therapy
- What is our role as a system to provide follow-up to these children, and this committee needs to think about what we should do.
- How beneficial is the anti viral therapy? There is consensus that symptomatic children should be offered the therapy.

2:15 Audiology Guidelines – MDH Staff

Kirsten Coverstone: We will start by voting on Audiology Guidelines: Assessment

- Motion to approve: Joscelyn Martin moved to approve, Linda Murrans seconded. All were in favor, approved. None opposed.

Darcia Dierking: Introduced proposed changes to Audiology Guidelines: Referrals. Walked through proposed changes in the document, differences between old and new proposed document

Discussion among committee:

- Should speech language pathologists be added to list of specialists audiologists would recommend to parents?
- Clarified EI eligibility in MN
- Wording about language access should apply to most sections, not just Deaf Mentor Program, should add this wording to introduction
- Deaf Mentor Family Program and DHH Role Model Services titles are being changed and programs are being reorganized
- On second page, there is link to MDH website for DHH as a condition, and there is confusion about eligibility considerations re: Part C services; the webpage needs updated wording so it's clear to help understand eligibility.

Plan: Revise document to include wording in the introduction regarding access to language, delete link to the MDH website of DHH condition description as wording in paragraph is enough, add "consider" speech-language pathologist evaluation under Medical Specialists section. Revised copy to be emailed to committee with vote happening before February meeting.

3:00 – Break

3:10- EHDI Educational Update- Kathy Anderson

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Discussed MN Foundations for Literacy Initiative Project, Developing an MDE summary document describing Part C Early intervention for DHH. Maryland has a similar document.

Discussed document from National Association of State Directors of Special Education, the third edition, which had several contributors from Minnesota.

Open position of MN Part C Coordinator (position vacated by Kara Tempel) has not yet been posted.

Collaborative discussions on clarifying wording on Part C eligibility for infants and toddlers with hearing loss (interagency).

Regional EHDI plan team updates- annual planning happened in September. Many activities including plans for dialogue with MNHV Parent Guides to help support culturally diverse families.

3:25 -D/HH Collaborative Summit: Anna Paulson

Highlights from Summit held October 25-26, 2018.

- Used to happen annually, now every other year
- Purpose: Celebration of 10 years of collaborating, Build strategic plan for next 5 years
- Summit participants: group of 50 stakeholders
- 2 facilitators
- Wilder did an environmental scan and SWOT analysis
- Shared one of many Impact Stories videos
- Asked group to come up with a vision statement, still a work in progress but a good start.
- Data “Placemat” – pulled together data from many sources, received data feedback from the summit participants
- Brainstormed solutions and ease/impact grid
- Participants split into 4 workgroups. Each group had strategic issues and action plans.
- Feedback from EHDI advisory committee members that attended the summit
- Need more rural representation and from diverse cultures

3:50 – MDH update

Lisa announced Laura Godfrey elected as Vice Chair for next year.

Nicole Brown: Introduced Audiology Learning Community to work on timely diagnosis, and engagement with MN EHDI.

Kirsten Coverstone: Discussed Audiologist Survey Results. Survey shows we have more education to do with audiologists about reporting, especially older children. Audiologists wanted more information about how our data is used.

3:55 – Topics/Partner Updates for Next Agenda

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Emilee Scheid: Doing a lecture on medical guidelines for newborn hearing screening for an upcoming conference.

Kathy Anderson: Survey of EHDI Advisory Committee suggested members would like to know how their individual participation makes a difference. In 2019, we will do an EHDI refresher, including where we have been, where we are now, and where we hope to go forward.

4:00: Closure/Adjournment

Next Meeting

Date: February 20, 2019

Time: 1:00-4:00 PM

Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

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