

Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee November 15, 2023

Minutes prepared by: Samantha Colston

Location: Zoom

Attendance

Present: Ingrid Aasan, Anne Barlow, Joan Boddicker, Mary Cashman-Bakken, Kirsten Coverstone, Darcia Dierking, Danelle Gournaris, Hannah Herd, Tina Huang, Colleen Ireland, Calla Kevan, Abby Meyer, Jess Moen, Gloria Nathanson, Jessica Novak, Sara Oberg, Elizabeth Pai, Emily Smith-Lundberg, Terry Wilding, Jay Wyant, Katie Warne, Danielle Hayden (attending on behalf of Cat Tamminga Flores)

Absent: Cat Tamminga Flores, Joscelyn Martin

Agenda Item Minutes

Welcome and Announcements

- Logistics
- Roll call
- Approval of Minutes from August 2023 Meeting: *Minutes are approved.*
- Nominations for 2024 Vice Chair
 - Jessica Novak accepted nomination for Vice Chair
 - *Nomination approved by Committee.*
 - 2024 Chair: Colleen Ireland
- Members with terms expiring January 1, 2024
 - Applications due December 4, 2023

EHDI Story – Julie Olson Rand

- 7-year-old did not pass their newborn hearing screen
 - Further testing led to a congenital Cytomegalovirus (cCMV) diagnosis
 - Follow-up conversations consisted of special education and a lot of medical intervention
- Child received instruction in ASL at school and then later attended a mainstream school
 - She was able to build an identity, language, and relationships with peers

- At school she wears a soft banded Bone Anchored Hearing Aid (BAHA)
- She has made both hearing and deaf friends
- Questions
 - How did you choose the right pathway for your family?
 - Deaf Mentor Program
 - Julie is fluent in ASL and was signing to daughter at an early age, and she picked up 'baby-sign' naturally
 - Educational options available to them

Promoting CMV Awareness: Gina Liverseed & Bridget Walde

- MDH is developing a messaging campaign to increase awareness of cytomegalovirus (CMV) and congenital CMV among Minnesotans.
- Geography, prevalence, and demographics were taken into consideration when developing messaging
- Worked with a contractor with experience working with diverse communities for Phase 1
 - Goal: developing messaging to inform and educate expectant, planning, and current parents, family, friends, and fellow community members about CMV and cCMV
 - Primary audience: families who are pregnant or planning to become pregnant and their extended families and communities
- Communication findings: the most impactful way to expand knowledge of cCMV and encourage risk reduction practices is through comprehensible and information-based messaging that is straightforward, eye-catching, and does not use scare tactics
- Next steps: contracting with a communications vendor who will assist with visual design and getting focused messages to Minnesota communities (Phase 2)
 - Also evaluate effectiveness of the campaign
- Questions
 - Are people with disabilities a target population?
 - Not included in this campaign but can be considered for the next phases
 - Are there social media accounts to follow or share with others?
 - MDH Instagram, Facebook, LinkedIn
 - Campaign will include boosted communications via social media

MDH Update: Darcia Dierking & Kirsten Coverstone

- HRSA Supplemental Funding Awards
 - Support state/territory EHDl programs to access and build capacity to address language acquisition and other developmental milestones at age 3 for children identified as deaf or hard of hearing
 - Activities focus on building capacity in our data system between MDE, MDH, and ECLDS and offering a pilot of language assessments for children under the age of 3 who are not enrolled in early intervention
- Questions

- Committee member had questions about how Local Public Health would do language assessments
 - In proposed pilot, Local Public Health could provide standardized parent report tools for families to fill out and then assist families with obtaining answers
- Shared data on enrollment in Part C and parent-to-parent support by 6 months of age and over time in MN
- Provided an update on screening for congenital CMV in MN

Minnesota Education EHDI Update: Jess Moen

- Colorado Established Condition Database
 - cCMV and CMV have been included
 - A child with a database approved condition will qualify for services in early intervention
- “Remedies for Sorrow” is a book focusing on a family’s journey with a CMV diagnosis
 - Book study included a wide range of representatives who discussed specific questions from that reading that relate to education
 - Feedback: helpful for practitioners, enjoyable, provides steps for approaching families with a cCMV diagnosis
- Provided information about additional webinars and educational opportunities
 - MDH and the Minnesota Low Incidence Projects are sponsoring the two-part webinar series on congenital CMV for education childcare professionals.

Guidelines for the Organization and Administration of Universal Newborn Hearing Screening for Out of Hospital Births – Updates and Vote: Chandra Fischer

- Updates reflect current best practices.
- Language updated to align with the approved terminology updates in NICU and Well Baby Guidelines.
- Discussed workgroup updates to the Guideline.
- Vote: approved.

Next Meeting

Date: Wednesday, February 21, 2024

Time: 1:00-3:00 p.m.

Location: Zoom

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

Decisions Made

- Nomination of Jessica Novak as Vice Chair for 2024 approved.
- Updates to the *Guidelines for the Organization and Administration of Universal Newborn Hearing Screening for Out of Hospital Births* approved.

Action Items

- None.

Early Hearing Detection & Intervention (EHDI) Program
Minnesota Department of Health
651-201-3650
ehdi@state.mn.us
<https://www.health.state.mn.us/people/childreyouth/improveehdi>

11/17/2023