



# Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee November 20, 2024

Minutes prepared by: Sara Lammert

Location: Zoom

## Attendance

**Present:** Ingrid Aasan, Anne Barlow, Joan Boddicker, Kirsten Coverstone, Darcia Dierking, Kathleen Geraghty, Danelle Gournaris, Hannah Herd, Tina Huang, Calla Kevan, Joscelyn Martin, Abby Meyer, Jess Moen, Gloria Nathanson, Sara Oberg, Jessica Novak, Elizabeth Pai, Emily Smith-Lundberg, Cat Tamminga Flores, Katie Warne, Terry Wilding, Colleen Vitzthum

**Absent:** Mary Cashman-Bakken, Jay Wyant

## Agenda Item Minutes

### Welcome and Announcements

- Committee member attendance was confirmed by the participant list.
- Tina Huang moved to approve August minutes; Kirsten Coverstone seconded minutes approval. August minutes approved.
- Jay Wyant was nominated and accepted nomination for 2025 Vice Chair. Kirsten Coverstone moved to vote on Jay's nomination. Sarah Oberg and Danelle Gournaris seconded motion to vote on Jay's nomination. Vote was approved via thumbs up in Zoom chat.

### EHDI Family Story – Callie Holmes

- Mom presented her family's story as the parents of a daughter born with congenital cytomegalovirus (CMV) who is deaf and hard of hearing. She described the process of her daughter being identified and diagnosed with a profound hearing loss, fitting for hearing aids, follow-up testing, decision for cochlear implants and complications that followed. She discussed the support she received from her daughter's deaf and hard of hearing (DHH) teacher and school interpreter, the connections with Deaf Mentor Family Services and Minnesota Hands & Voices, as well as challenges with educational placement. She also discussed how she and her family learned to advocate for their daughter. The family decided to

relocate to live close to the Minnesota State Academy for the Deaf (MSAD). Her daughter is currently thriving at MSAD, and her mom described how wonderful it is to see her in this new environment!

### **Collaborative Experience Conference Highlights – Danelle Gournaris**

- The Minnesota Commission of the Deaf, Deafblind, and Hard of Hearing hosted the statewide Collaborative Experience Conference at Breezy Point, MN on November 1 – 3, 2024. Attendees of the Collaborative Experience Conference included professionals who work with deaf, deafblind, or hard of hearing individuals aged birth to 22 from across the state.
- The conference had three keynote speakers and approximately 26 breakout sessions and workshops that included topics such as education, mental health, congenital CMV, language acquisition, early intervention, curriculum, transition, and deafblind services. Keynote speakers discussed literacy, language acquisition, and educational equity for deaf, deafblind, and hard of hearing children.
- There were 298 attendees at the conference, including DHH teachers, early interventionists, parents, and state agency representatives, as well as sponsors and exhibitors. Danelle discussed the ongoing survey results from the conference.
- Danelle share that the next Collaborative Experience Conference will be in 2026.
- Attendees of the conference shared their experiences. They acknowledged the amount of work Danelle and the team at the Commission did to put on the conference. Highlights for participants were the parent panel, ability to host a peer-to-peer sharing session, the networking that was allowed during an in-person conference, keynote sessions, and seeing practitioners from across the state sharing their expertise and knowledge.

### **Congenital CMV Update from the Field – Jess Moen and educational professionals**

- Jess Moen led a panel discussion of two professionals, Ruth Schaefer (educational audiologist) and Carla Larson (birth to three coordinator at Metro Deaf School), working in Minnesota to discuss what educators in the field are seeing and hearing about congenital CMV.
- Question 1 –What are you seeing in the field regarding cCMV since newborn screening began in February 2023 (increase in students with cCMV, referrals, awareness levels...)?
- Panelists discussed their experiences so far in working with children diagnosed congenital CMV. Panelists discussed increasing outreach to ensure they are communicating correctly with families and how parents have differed acceptance levels of their child's hearing loss or delays.
- Question 2 – What questions are family asking about cCMV?
- Panelists answered questions on children's use of occupational therapy, physical therapy, speech language pathology, the projected course or outcomes over time for their child, and how the projected course may change.
- Question 3 – What conversations are being held around cCMV in early intervention settings?
- Conversations include the number of audiology appointments that are recommended for infants with CMV, what referral and support looks like for families of children who are asymptomatic, how to share resources around CMV with educational professionals on the early intervention team, and how to continue to forge collaboration and conversations with LPH.
- Question 4: What additional support could you see as helpful for cCMV in Minnesota?

- Panelists described documentation of congenital CMV in records, statewide virtual meetings for parents of those with congenital CMV as families in rural Minnesota may be isolated, continued messaging to clinical audiologists about the importance of a referral to Help Me Grow.
- Question 5: Anything else to share regarding cCMV?
- Panelists described the positive impact of a book study (using *Remedies for Sorrow*, by Megan Nix) and how they share the book with families and professionals and the importance of CMV education to families and providers.
- CMV Public Health and Policy Conference will be hosted in Minnesota September 7-9, 2025.

## **MNPQC Project Update – Darcia Dierking and Dr. Abby Meyer**

- Discussed phase one of the EHDI collaboration with Minnesota Perinatal Quality Collaborative (MNPQC). In fall of 2022, MDH and MNPQC entered into a grant agreement for an initiative to improve diagnosis by three months of age, and in spring of 2023, hospital and clinic teams were recruited to participate in a quality improvement (QI) project facilitated by MNPQC. The timeline of phase one, including process measures (data collected by the hospital systems) and state measures (collected by MDH), were discussed, as well as the results of phase one, recommendations and next steps.
- Next, phase two of the collaboration between MDH EHDI and the MNPQC was discussed. Phase 2 took place May through July 2024 as a Community of Learning (COL). The COL was established to identify and address critical gaps in timely identification and early intervention for infants who are DHH. Discussed hospitals teams that were included, content experts included on the COL team, project structure as well as changes from the hospital teams including education, streamlining of data collection processes, updates to the electronic health record (EHR), interdisciplinary collaboration, providing local options for referrals, addressing no show appointments, sharing education, and improving documentation of results in EHR. Results from phase 2, conclusions, and next steps were also discussed.

## **Closure / Adjournment**

- Call for Workgroup members to help update two guidelines: EHDI Guidelines for Otolaryngologists and Guidelines for Primary Care/Medical Care Providers.

## **Decisions Made**

- Jay Wyant was elected as the 2025 Vice Chair.

## **Action Items**

- No action items.

## Next Meeting

Date: February 19, 2025

Time: 1:00 – 3:00 PM

Location: Zoom

Agenda items: submit proposed agenda items to [ehdi@state.mn.us](mailto:ehdi@state.mn.us)

Early Hearing Detection & Intervention (EHDI) Program

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

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