

# Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee Wednesday, August 16, 2023

Minutes prepared by: Samantha Colston

Location: Freeman Building, room 144

## Attendance

**Present:** Ingrid Aasan, Anne Barlow, Joan Boddicker, Darcia Dierking Danelle Gournaris, Hannah Herd, Tina Huang, Colleen Ireland, Calla Kevan, Joscelyn Martin, Abby Meyer, Jess Moen, Gloria Nathanson, Jessica Novak, Sara Oberg, Cat Tamminga Flores, Katie Warne, Jay Wyant

**Absent:** Mary Cashman-Bakken, Kirsten Coverstone, Emily Smith-Lundberg, Elizabeth Pai, Terry Wilding

## Agenda Item Minutes

### Welcome and announcements

- Logistics
- Roll call
- Approval of minutes from May 2023 meeting: *minutes are approved.*

### Family story - Jodi Tervo-Roberts

- Discussing (in)equality in Deaf and Hard of Hearing (DHH) services in rural Minnesota for her son (aged 4.5 years).
  - Jodi and her family moved from their home in Grand Marais, MN to Duluth in order to have access to DHH services.
- Challenges
  - Obtaining intervention services.
    - Denied preschool entrance and left with no options.
    - Medical transitions were smooth.
  - Guidance by Kathy Anderson sparked the entrance into the school year with DHH services and the school district will cover the cost.
  - Travel time to appointments is significant.
  - There should be a more DHH qualified workforce.

## **ECLDS & EHDI – Jen Verbrugge, Dara Lammert, and Darcia Dierking**

- MDE ECLDS (Minnesota Department of Education, Early Childhood Longitudinal Data System).
  - Interactive, data based system through MDE, MDH, DHS, and OHE.
  - Was built to answer policy questions at state level with existing data.
  - Represents population or growth results of children’s growth and achievement in relation to their participation in a variety of education, health, and social public programs over time.
    - Birth to Pre-K reports
    - Kindergarten reports
    - Third grade reports
- EHDI / DHH data
  - EHDI category
    - 55% (99/180) of children are receiving services from EHDI + DHH.
    - 26% (47/180) of children are receiving services from EHDI + other category.
    - 19% (34/180) of children are receiving services from EHDI + no SPED.
  - DHH category
    - 63% (99/156) of children are receiving DHH + EHDI.
    - 37% (57/156) of children are receiving DHH services only.
  - One out of five kindergarteners identified by MDH EHDI were not enrolled in Special Education (2021/22 kindergarten cohort).
  - Data suggest that children identified by EHDI may share characteristics with other children in the overall population that are not in SPED, and perhaps are less likely to enroll in SPED.

## **MDE data update – Jess Moen, Cat Tamminga-Flores**

- Child Outcomes Summary (COS) and DHH Specific Questions.
  - 10 commitments to equity.
- What can the COS tell us?
  - Summarized information on child’s functioning.
  - Summative rating and collection of formative and discrete skills assessments, observations, and caregiver input.
  - Two questions asked and reported.
    - Percentage of children who substantially increased their rate of growth.
    - Percentage of children who were functioning within age expectations.
  - Three outcomes.
    - Positive social relationships.
    - Acquire and use knowledge and skills.
    - Take appropriate action to meet needs.

- Not domain-based, integrating skills across multiple domains, meaningful behaviors in a meaningful context.
- Timeline
  - 2007: MN EHDI formal legislation.
  - 2009-2012: Pilot reporting process was initiated with MN EHDI teams to collect demographic and outcome information.
  - 2012-2013: MDH agrees to adding outcomes data collection for young children with hearing loss to the MDE COS reporting process.
  - 2010-2018: Presentation on additional DHH questions.
  - 2018-current: MDE electronic system compiles and shares results of some of the outcomes with MMD for writing the DHH legislative report.

## **MDH data and CMV update – Sara Lammert, Darcia Dierking, Tori Kaye**

- EHDI data
  - The overall screening rate of babies in Minnesota has stayed consistent (2015-2022).
  - Overall increase in refer rate.
  - Percentage of newborns diagnosed within 90 days of birth remained the same for infants born in 2021.
  - Lost to follow-up rate of initial referrals continue to decrease in 2021.
  - More than 3500 children have been reported since EHDI began in 2007.
  - More than one third of children reported as DHH in 2022 were not infants identified through newborn hearing screening.
  - Sensorineural is the most common type of hearing loss.
    - 65% of infants have bilateral hearing loss.
    - Mild and moderate are the most common degrees.
- CMV data
  - New standardized surveillance case definition.
  - Awarded another year of CDC funding for cCMV surveillance.
  - 29,457 newborns screened for cCMV.
  - 88 newborns screened positive for cCMV.
  - 58 newborns with completed short-term follow-up data.
  - 15 (28%) have clinical criteria for cCMV disease.
  - Four newborns had permanent hearing loss
    - Four newborns have non-permanent hearing loss.
  - cCMV prevalence is approximately 1:350 newborns compared to 1:200, as previously believed.

## **Universal Hearing Screening Guideline Updates and Vote – Well-Baby and NICU Guidelines**

- Updated language throughout documents to align with terminology used by JCIH 2019 Position Statement.
  - Examples: hearing outside the typical range, elevated hearing levels, pass/fail.
  - Shortened background section.

- Clarified which hearing screening equipment is most appropriate to use for NICU and Well-baby populations.
- Updated stimulus parameters and passing criteria.
- “Single Screening Session” section updated.
- “Readmitted Infant” section updated.
- Updated references and links.
- Discussion and vote
  - Discussion – language.
    - Pass/fail
      - Stronger language.
      - Provider facing.
      - Motivates caregiver responses.
    - Pass/refer
      - Softer language.
      - Family facing.
      - Can be misleading in degree of urgency.
    - Elevated hearing levels.
      - “Elevated” can be confusing
  - Workgroup members felt it would be beneficial to postpone the vote by two weeks to thoroughly review both guidelines.
    - Motion to continue the discussion and finish the discussion virtually.
      - Motion seconded.
      - Passed.
    - Motion to delay the vote and vote electronically in two weeks.
      - Motion seconded.
      - Passed.

## Next Advisory Committee Meeting

Date: November 15, 2023

Time: 1-3pm

Location: Virtual

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

## Decisions Made

- Decision: continue the discussion and finish the discussion virtually.
- Decision: delay the vote and vote electronically in two weeks

## Action Items

- Schedule virtual discussion meeting.
- Schedule meeting for voting.

Early Hearing Detection & Intervention (EHDI) Program

Minnesota Department of Health

651-201-3650

[ehdi@state.mn.us](mailto:ehdi@state.mn.us)

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

08/17/2023