

Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee February 21, 2024

Minutes prepared by: Darcia Dierking

Location: Zoom

Attendance

Present: Ingrid Aasan, Anne Barlow, Joan Boddicker, Mary Cashman-Bakken, Kirsten Coverstone, Darcia Dierking, Kathleen Geraghty, Danelle Gournaris, Hannah Herd, Calla Kevan, Joscelyn Martin, Abby Meyer, Jess Moen, Gloria Nathanson, Jessica Novak, Sara Oberg, Elizabeth Pai, Emily Smith-Lundberg, Cat Tamminga Flores, Katie Warne, Jay Wyant

Absent: Tina Huang, Colleen Ireland, Terry Wilding

Agenda Item Minutes

Welcome and Announcements

- Jesi Novak called meeting to order, initiated roll call through meeting chat.
- Welcome of Kathleen Geraghty as new committee member.
- Katie Warne moved to approve minutes, Anne Barlow second, minutes approved.

EHDI Story – Valerie Abbott

- Presented her story as a mom of a child with late-onset hearing loss. She discussed her family's experience with initial developmental concerns in pre-school, Part C early intervention and hearing loss diagnosis, hearing technology, transition to Part B early childhood special education, and the steps they took towards kindergarten readiness and family acceptance.

Late Onset Hearing Loss – Valerie Abbott

- Presented data and information about late onset hearing loss awareness campaign, including risk factors, commonly overlooked signs and consequences of late identification, especially to communication skills, language, literacy. Most children in the US are not having their hearing truly screened between newborn and 4 years old or kindergarten. She described the awareness campaign to

help children be identified after the newborn period, and how states can leverage the awareness campaign close to home, to promote awareness and ongoing screening. Committee members invited to comment about Minnesota.

- Committee members described what is happening in MN: recommendations in MN to screen children in Part C and Part B, experience screening in the primary care, reporting hearing loss through age 10 to public health, Congenital CMV screening, how early intervention is structured in MN, EHDI regional teams, collaboration across agencies.
- Question: what would people want to change about MN?
 - Individual committee members said: primary care would have access to OAEs for in-office screening of 0-3 and would be routine at well child checks, racial and economic representation on EHDI committees.

Minnesota Commission of the Deaf, Deafblind & Hard of Hearing Collaborative Plan Workgroups & Legislative Agenda Update – Danelle Gournaris & Alicia Lane

- Danelle Gournaris from the Minnesota Commission of the Deaf, DeafBlind & Hard of Hearing (MNCDHH) described the Collaborative Plan and workgroups, and how it was developed with stakeholders, as well as strategic issues and strategies to improve outcomes for children. The MNCDHH facilitates several workgroups based on age of children, as well as workgroups for DeafBlind and language acquisition. MNCDHH hosts a statewide conference for professionals and parents, that will be held in November 2024. MNCDHH supports mental health and “whole child approach.” MNCDHH works to assess and address licensure and qualifications, including K-12 teachers of ASL.
- Alicia Lane, Government Relations from the MNCDHH, described past legislation, including MNCDHH efforts to pass the MN 2007 legislation that established NHSAC. Described laws about cCMV, Day treatment for mental health, birth-3 program funding for Metro Deaf School, hearing aid coverage for all ages for most insurance plans in MN, as a part of 17 laws benefitting people who are DHH in MN. In this session, working hearing aid bills, especially reimbursement rates, and on school age initiatives.

Congenital CMV Audiology Guideline: Updates from the Field – NHSAC Audiologists

- Clinic 1: Prior to statewide legislation, description of one program doing hearing-targeted CMV screening, beginning in 2018 – specimens collected (urine, and in some cases saliva) prior to hospital dismissal for children who referred on newborn hearing screening, children were referred on to primary care and infectious disease specialists. Now, after CMV legislation in 2023, this clinic hosts a cCMV positive follow-up multidisciplinary team – bloodwork, imaging, audiology, ophthalmology, pediatric infectious disease, families can go get this done all in one day. Of note, children often come for their initial ABR there but then have ongoing audiology monitoring more locally near where they live.
- Clinic 2: All of the babies who had cCMV passed their newborn hearing screen. $\frac{1}{2}$ of the babies had comorbidities including co-occurring prenatal infection, prematurity or extended NICU stay. $\frac{3}{4}$ of them had their diagnostic ABR by 1 month, the other $\frac{1}{4}$ had by 3 months. Most of the ABRs have been normal so far. A little more than $\frac{1}{2}$ of babies had their 4-month monitoring visit on time, $\frac{1}{4}$ by age 6 months. Babies have needed ENT follow-up for middle ear dysfunction. About $\frac{1}{2}$ of babies were scheduled for their 3rd monitoring visit at age 7 months. The three-month timeline is tight – babies won't sleep, middle

ear fluid, family illness. Suggests MDH guideline can be worded “monitored every several months” to allow for these things that are coming up. Family perspectives – some families report feeling blamed or like child will never be able to live a normal life. Seems to be a need for awareness and advocacy for ways to talk with families in a positive way. Discussed prevalence of unilateral hearing loss with cCMV, and some parents are making management choices (i.e. using ASL) because of concerns of losing hearing in a contralateral ear. There is still more we are learning about children with unilateral hearing loss and their risk of progression.

- Clinic 3: described difference between families who have met with infectious disease, versus primary care, how families can feel anxious and that not all healthcare providers are the same in the amount or quality of information they receive. A family has relayed they thought monitoring every 3 months is too strict, too often. She described several children who have experienced progressive hearing loss, which is why we are monitoring so closely.
- Clinic 4: described capturing a lot of middle ear dysfunction, which changes the timeline somewhat, along with some families that have relayed that they won't be coming to the recommended follow-up.
- Committee members: reminder that the guidelines are to help ensure children are identified earlier, and that the guidelines were written with flexibility knowing that there are family or clinical circumstances that can affect the timeline, and that the committee will look at guidelines again when there is more data on MN outcomes.

Closure/Adjournment

- Jesi Novak announced next meeting, Meeting adjourned.

Next Meeting

Date: May 15, 2024

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

Early Hearing Detection & Intervention (EHDI) Program

Minnesota Department of Health

651-201-3650

ehdi@state.mn.us

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

02/21/2024