Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee

November 17, 2021

Minutes prepared by: Darcia Dierking, Venessa Heiland
Location: Virtual

Attendance

Committee Members Present:

Renae Allen, Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Danelle Gournaris, Hannah Herd, Tina Huang, Joscelyn Martin, Abby Meyer, Gloria Nathanson, Jesi Novak, Sara Oberg, Elizabeth Pai, Emilee Scheid, Katie Warne, Terry Wilding, Jay Wyant

Committee Members Absent: Ingrid Aasan, Colleen Ireland, Cat Tamminga

Parent Support and Deaf Mentor Program Staff Present: Emily Smith-Lundberg, Anne Barlow

Agenda Item Minutes

- Welcome and Announcements – Abby Meyer 1:05pm
- Logistics – meeting chat, CART, Zoom and Teams windows
- Roll call- committee members listed their names in meeting Chat
- Approval of Minutes
    - Renee Allen: I think there was maybe a typo on page 2 and on page 3. Minnesota on page 2 there's a typo. And then on page 3 I'm wondering about, it says one in two infants are born with congenital CMV and earlier in the document it said 1 in 200.
    - Minutes from previous meeting approved with correction/clarification stated above.
- Vice Chair Nominations – Kirsten Coverstone 1:11pm
    - Vice-chair is a three-year commitment (vice chair for one year, chair for one year and past chair for one year).
    - Katie Warne has accepted a nomination – introduced herself
    - Tina Huang and Joan Boddicker moved to accept her nomination.
    - Vote - None on committee opposed. Katie will be new Vice Chair
- Congenital Cytomegalovirus (cCMV) Update - Abby Meyer- Condition Readiness Work Group Report 1:13pm

- Presenting to Newborn Screen Advisory Committee in January
- Discussed NHSAC recommended considerations regarding CMV.
- Messaging to parents of asymptomatic infants regarding follow up testing -parent to parent support will be important
- Facts: cCMV is established condition eligible for Part C. cCMV affects >300 babies yearly. Approximately 20 infants symptomatic at birth. Approximately 20 more asymptomatic at birth will develop hearing loss later.
- Nicole Brown**:** Funding is also available for education and outreach as a part of the Vivian Act passed during the 2021 legislative session.
- Concern: the need to ensure that there are enough audiologists to see these children
- January date proposed for ad hoc meeting for Newborn Screening Advisory Committee (1/11/22) to discuss cCMV.

- Key Findings from DeafBlind Needs Assessment Report – Danelle Gournaris 1:25pm
  - This was a strategic plan process for Minnesota Commission of the Deaf, DeafBlind and Hard of Hearing (MNCDHH), facilitated Wilder Research who conducted 45 interviews
  - Deafblind census – approximately 379 children/youth in Minnesota with varying strengths and needs.
  - Key Findings:
    - MN lacks cohesive system to support deafblind children.
    - Parents are getting exhausted/burned out acting as service coordinators to their own children.
    - Improved communication and care coordination between service providers would help.
    - More training is needed for professionals who serve deafblind children and youth.
    - More professional support and guidance for deafblind children, youth, and their families is recommended.
  - Action Items based on Key Findings:
    - Coordinate services and shares information between service providers.
    - Help deafblind children, youth, and their families coordinate services.
    - Provide education to the parents of deafblind children and youth.
    - Offer social and emotional connections to other deafblind children and their families.
    - Prepare deafblind youth for transition into the community or community-based services at the age of 21.
    - Work with legislature focusing on policy and activities that would improve the lives of deafblind children and youth.
    - MNCDHH convening new deafblind work group consisting of professionals and parents of deafblind children.
  - MNCDHH convening meeting in December to discuss implementation of the six action items.
  - Questions and Answers:
    - *Is MNCDHH responsible for implementing the six action plans?* The new deafblind work group will track the progress and ensure that the action plans are implemented with the commission's support. There are 18 organizations that will work together and MNCDHH work group will oversee that plan.

        - *What roles of deafblind adults themselves do they have in reviewing the plan?* Two deafblind adults have been involved from the beginning and will continue with the project; they bring input from the MN Deafblind association.
        - *Were either deafblind adults or even older DeafBlind children or part of the needs assessment?* Yes, deafblind youth were involved.
        - *How accurate is the count of approximately 379 deaf/blind children? Do we want to check with MDE so see if the actual count is higher?* We did discuss that with Wilder and the DeafBlind study group. We said approximately because we're not sure the number is accurate because it really depends on the diagnosis. It does depend on what the family has chosen as the primary disability – medical diagnosis or deafblindness – and what was identified first. The number will fluctuate based on that variance.
        - *The six action items do not seem to include anything about co-navigators or SSP or anything similar. Other states are doing a lot in relation to legislative work and recognizing co-navigators. Would that be included as part of the plan? If not, is it part of a separate plan?* The SSP services are typically for deafblind adults. Our focus in this report was on children and youth. However, co-navigators and SSP could apply; it was suggested that the work group can address it in their meeting.
- D/HH Learning During Covid- D/HH Teacher Perspectives: Kathy Anderson and Doobie Kurus
    - Kathy Anderson: Discussions with Greater MN teachers – still have Covid challenges and acknowledge families still challenged and stressed. Virtual technology has resulted in less drive time for professionals in some cases. School districts are grappling with questions regarding covid safety, such as:
        - Are teachers allowed to go into family homes?
        - Are families coming into center instead?
        - Are face-to-face individual services an option?
        - What are the current levels of infection and transmission in our location and district?
        - What is the family's preference for receiving services?
    - Other challenges in Greater MN
        - Lack of available clinical audiological appointments is one of biggest! Note: Educational audiologists have stepped up to help where they can, for example getting ear molds made
        - Getting records from clinical audiology to schools Note: Ongoing project to address this has had great start
    - Doobie Kurus- Metro perspective -experiences from teacher of DHH
        - Issue: Varying Covid policies at each facility – some cause logistical problems; some are just extra things like temperature checks, paperwork, new masking, sign-ins in addition to regular service documentation.
            - Working collaboratively/creatively on how to be both timely with child's needs and respectful of building/program's Covid guidelines
        - Two deafblind children identified whose families spoke language other than English
            - Issue: Interpreters needed but limits on how many staff can visit the home at same time.

        - Issue: Technology helpful but also has downsides ie: glitchy, insufficient wi-fi signal, size of virtual interpreter on screen
- In-person meeting at daycare.
    - Issue: Different masking guidelines between schools/daycares. How to handle? Case by case but always respectful while keeping safety and student education as primary thought.
- Virtual conferences allow for speedier collaboration in some cases. A child was able to be placed in less restrictive environment, thanks to emails and video calls between service providers.
- Issue: Virtual meetings – sometimes too many people onscreen for families to track especially when using visual language. Experimenting with solution: Some providers call in only. When there is one big staff meeting with deaf/hard of hearing participants; in-person seems better.
- Issue: Length of virtual meetings with young people. Spring 2020 attempt was made to follow original IEP plans ie: 2.5 hours daily/5 days week. Children need mental and visual breaks from teaching-led activities. Children often don't have ability to verbalize need for breaks.
- Issue: Length of virtual service time for children located at home
    - Determined that 45 and 60 minute sessions weren't reasonable
    - Parents felt compelled to keep child in longer sessions.
    - Solution: 30 minutes with family online and 30 minutes of pulling together notes, resources, materials to share as appropriate.
- Issue: Clear masks, removing masks, visuals – best practices from field?
    - Best practice was to ask the student what they preferred within safety guidelines – personal microphone under cloth or plastic mask, clear mask or cloth mask alone, outside session – MN weather depending. Buy in from student led to less frustration.
- Questions and Answers:
    - *Is there a place where DHH teachers come together to share their creative ideas on how to handle their work, their Covid concerns, and potential solutions?* Receives emails every two weeks with Need to Know information, helpful links, etc.
    - What about access to technology?
        - Some districts provided devices to families.
- Doobie's Takeaways:
    - Goal is to do things and exist in the world we're living in today.
    - IEPs were written for the school environment. We need to adapt to the home environment while still being productive and knowing that eventually there will be a return to the school environment.
    - Bring valuable lessons from home environment into the school if applicable.
    - Please practice respect, consideration, understanding, compassion.

        - Let's be realistic, flexible, and open to change. Some past practices are still valuable to keep; others need to either change or be eliminated.
- MDH update: Kirsten Coverstone 2:20pm
    - MN babies eligible for screening who were screened, Rates consistent across the years, Slight decrease in screening within 30 days
        - Possible cause: early Covid staffing issues
        - Possible cause: providers not wanting to share equipment & holding off on screening
    - Slight increase in refer rates – refer result on hearing screen requiring additional follow-up – either at discharge or at >one month of age.
    - Total number of infants with a complete diagnostic assessment is lower than previous years, however, the percentage of these infants being diagnosed by three months of age has increased.
    - Post Covid some clinics changed from doing outpatient prescreening to direct diagnostic appointments.
    - Disparity of infants not getting timely and/or complete diagnosis by three months based on mother's race and ethnicity. Similar to previous data.
    - 2020 data: Preliminary, possible reporting delays. Potential for many delayed diagnoses. Increase in Lost to Follow Up/Documentation (LTF/D)
        - Contributors: Hospital and other clinician staffing issues, Covid ongoing; still possible that families delaying due to Covid, Still playing catch-up; staffing changes at MDH
    - Lost to Follow Up/Documentation Rates (LTF/D)
        - Largest factors - didn't receive a rescreen or diagnosis and parents either contacted but not responding or refusing screening
        - Many parents of older babies feel their baby responds so don't believe that there is an issue or that they don't need audiology follow up.
        - There has been some increase in miscommunications on the results or conflicting results between the birth hospital reporting and what we have in our system.
        - Higher Rates of LTF/D based on mother's race and ethnicity
            - Unable to Contact -Phone number not valid or unavailable
            - Unable to identify PCP
            - Sometimes local public health is able to reach. One nurse had success in getting some 16-18 month-old children in for follow-up screening.
    - Ongoing Initiatives:
        - Virtual education including screener tips and tricks to all birth providers
        - Consistent data reporting
        - Implementation of an on-demand data dashboard
        - Focused attention to proven QI strategies
        - Scheduling family follow-up – how to help hospitals implement
        - Teach back methodology to help family complete the cycle
        - Continue projects that improve documentation and reporting
        - Present EHDI as a Minnesota PQC initiative – Regina & Kirsten

        - MN PQC is a collaboration through MN perinatal quality collaborative and the Dept of Health, striving to bring together stakeholders from around the state to improve dissemination of information and improved perinatal health outcomes.
    - Kirsten's Takeaways:
        - EHDI as an MN PQC initiative could put us in line to have them support our work on improving outcomes & timeliness of follow-up.
        - Data drives change. Team is working to find meaningful data to promote change
- Closing: Abby Meyer- This is Abby's last meeting as chair. Joan will take over in the new year.

Next Meeting

Date: February 16, 2022 (**Canceled**)
Time: 1-2:30pm
Location: Virtual
Agenda items: submit proposed agenda items to ehdi@state.mn.us