# Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee

## August 21, 2019

Minutes prepared by: Morgan Brown/Jenna Laine
Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

### Attendance

**Present:**

Ingrid Aasan, Renae Allen, Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Laura Godfrey, Colleen Ireland, Kathryn Lein, Joscelyn Martin, Abby Meyer, Gloria Nathanson, Jessica Novak, Sara Oberg, Anna Paulson, Sonny Wasilowski,

**Absent:**

Hannah Herd, Tina Huang, Emilee Scheid, Lisa Schimmenti, Jay Wyant

### Agenda Item Minutes

**Welcome & Announcements /** Kathy Anderson, Chair / 1pm

Previous Meeting Minutes: Gloria Nathanson approved, Anna Paulson second. Minutes accepted as written. Committee approves the minutes from the last meeting.

Danelle Gournaris – Deaf Mentor State Program Manager & Terry Wilding – Superintendent State Academics, Faribault are sitting with the committee. Terry and Danelle have submitted applications to be on the committee in the two new categories added in statute; a representative from the deaf mentor program; and a representative of the Minnesota State Academy for the Deaf from the Minnesota State Academies staff. Both applications are in process.

**Recognition /** Mary Hartnett / Senator Abeler

Senator Abeler Recognition: served in house of representatives and also served as senator, assisted with creation of advisory committee, and helped to lay the foundation for many deaf and hard of hearing programs, authored many bills that have assisted deaf/hard of hearing, and blind individuals

Mary Harnett: special recognition, flowers, and gift for her time, passion, and commitment towards shared goals.

**EHDI Story /** Jesi Novak, AuD

1-3-6 and Audiology

- Shared experience as a Pediatric Audiologist
- Reviews guidelines, testing with family, finds this helpful for family understanding, review audiogram
- Review Communication options*, binder from MN Department of Health with resources and information
- Use of the Beginnings Book – guides conversation with and is a great resource for families
- Review goals and process of referrals and continuing appointments
- Help Me Grow referrals are the hardest for families to understand when child is not school aged
- Patient A example:
    - Importance of working closely with the family and the families goals
    - Importance of timely appointments, timely referrals to EI with explanations of why services were important
    - All providers worked together as a team
    - Providers ability to adapt to changing goals.
    - What did we learn?
        - Timely follow up and referrals are key.
        - Clear messaging and expectations for families.
        - You may not be the best provider for a patient.
        - Goals can change and they need to be family driven.
        - Need for flexibility.
- Comments/recommendations about language from committee member:
    - *communication options should be communication opportunities
    - avoid using “failing”, but rather use “referred”

**MDH EHDI Data /** MDH Epidemiologists / Rachel Hannigan / Melinda Marsolek

Short-term follow-up data/Rachel

- Shared hearing screening pathway
- Percentage of newborns screened for hearing loss remains high and consistent: ~99% are being screened; ~97% of eligible patients are screened in a timely (within 30 days) manner
- Screening rates are high across racial groups.
- Babies with low birth weight are less likely to be screened within 30 days
- Majority of babies that were not screened were born at home or died prior to screening
- MN refer rate remains stable at 4.3%, approaches JCIH national guideline of 4%.
- Majority pass on re-screen
- A majority of babies who were not rescreened did not respond or refused screening
    - Question about why parents are refusing
- Over half of babies had normal hearing at diagnostic appointment
- Majority of babies received a diagnosis before 3 months of age
- Fewer babies born with low birth weight are diagnosed by 3 months of age

- Correlation between mother's education and timely diagnosis
- Lost to follow up rate of initial refers remains consistent
    - top 3 reasons: 1) no audiology appointment was made 2) Unable to contact family 3) Family was a no show to appointment
- Did not review socio-economic status differences with mothers (no access to that data)
- MDH contracts with Local Public Health to assist with patients lost to follow-up
- QI project with LPH; biggest barrier was found to be lack of knowledge and not feeling like it was important
- Lost to follow up rates differ by mother's race
- Lost to follow up rates differ by region

## Long term follow up data/Melinda

- Long-term follow-up works to:
    - Connect families with timely resources and support, early intervention
    - Collect and analyze relevant data (what factors are influencing development of children who are D/HH?) from partners inlcuding: local public health, audiologists, community groups, vital records, and birth defects program
    - Build MN EHDI system capacity
- Accept diagnosis of patient up to 10 years of age

- 2500 children have been reported to MDH as D/HH (245 through 2018)
- 2/3 are identified through newborn screening; 21% late onset; some patient move into state and were not tested previously
- Reporting of children with late onset hearing loss has increased
- Sensorineural hearing loss is the most common type (2/3)
- ~70% of children have bilateral hearing loss. Mild and moderate are the most common degrees (least affected ear)
- 56% of bilateral CHL were fit with amplification within 2 months of diagnosis (less timely than previous years) *discussion here about using the word "worse", but rather use "less timely"; clarification that this is only for families that chose to pursue amplification
- Over 40% of children have a known comorbidity *clarified to around the time of birth/diagnosis; not getting a lot of information for kids who are older.
- 90% do enroll in EI services for children ages 0-3
- Early Childhood Special Education: ½ are enrolled by 6 months of age
- Over 100 children who are D/HH exit part C each year. About 85% of them use hearing technology.
- Hearing aids are the most commonly used technology; this has been consistent
- Over 100 children exit part B ECSE for kindergarten
- Over 80% of children entering kindergarten, who are D/HH, have no known cognitive delay and have early literacy and numeracy skills within age expectations
- EHDI data added to the early childhood longitudinal data system in 2016
- 57% are served under Special Education DHH label
- Proficiency on standardized tests discussed
- Students who are D/HH have lower attendance

**Break**

## CMV Study / Maggie Dreon

MN study update

- Every 6 months, review enrollment and data, now through end of June 2019
- Funded through CDC's EIP Cooperative Agreement
- Partners with Fairview and Allina Health. St. Cloud to join
- Focus of study: How sensitive are newborn dried blood spots for detecting cCMV compared to saliva?
- Goal to enroll 30,000 babies
- Enrollment through 6/30/19: 12,475 infants
    - 66 abnormal results, and follow-up occurred,
    - 9 were false abnormal (did not have CMV).
    - 56 were confirmed to have CMV infection.
    - 10 infants classified as symptomatic (more than expected)
- Questions about what symptomatic looks like – Dr. Schleiss makes this determination; idea for talk in the future
- Enrolling 5000 infants a year, 70% of time families say yes to study
- Detection rates comparison between DBS and saliva. Findings so far:
    - blood vs. saliva-99.8% agreement either both are positive or negative,
    - 47 out of 48 times blood spot was correct;
    - 52 out of 60 times saliva was correct
    - 85.7% blood spot accuracy (finding higher sensitivity in blood than expected)
    - 92.9% saliva detection accuracy
- Discussion of sensitivity vs. detection rate
- Positive predictive value comparison between DBS and saliva
- Of 56 confirmed positive cCMV:
    - 51 passed newborn hearing screen;
    - 5 infants with hearing loss confirmed to date.
- Discussion about targeted screening (only test when NBHS is referred) vs universal cCMV screening.
    - Targeted screening does not catch all kids that have infection
- Project management leadership change – Sondra Rosendahl, MDH Genetic Counselor, will be taking over for Maggie
- Interim analysis of results is underway
- In the process of developing a parental assessment survey
    - What is the emotional impact on the family when a child's CMV status is known?
    - What questions do you think we should ask parents to understand this?
    - Comment: The blind community is very involved in CMV – they may have questions that would be good for parents. Mary has a contact for this.
- Who refers to genetic testing? When? Why? How often?
- Best practices talk with the PCP which includes genetic testing

- What else should the state be doing for CMV?
- What does the EHDI advisory committee see as their role around CMV?
- A picture/pamphlet/educational handout for parents to understand the need for CMV testing.
- ACHDNC (federal advisory committee) makes recommendations on what should be screened for. CMV was submitted to them in April.

## Educational EHDI Update /Kathy Anderson / Mary Cashman-Bakken

New MDE guidance for Part C early learning services / Kathy

- Clarifying one of the avenues for part C eligibility/definitions for state
- Making it more uniformly defined so when looking at how kids are found eligible, it is clear.
- don't have to have a certain kind of hearing loss to be eligible, any confirmation of hearing loss qualifies (all community and state groups now have this clarification related to updated definitions and eligibility)
- Part B is separate, still looking at those requirements differently

NASDSE – Optimizing outcomes for students who are deaf or hard of hearing: educational service guidelines / Mary

- Kathy and Mary are traveling and providing overview presentations of these guidelines
- To support a statewide process of district and regional self-review
- Having regional meetings
- Directors of special education are asked to:
    - Disseminate
    - Raise awareness
    - Self-review
    - Create implementation plans for improvement
- Asking directors to put together an implementation team and start to discuss these chapters of this book
- Study guides created for each chapter will be provided to each region/community of practice
- Work to identify gaps in education
- 80% of learning is incidental; DHH individuals need specific, directed learning

## Topics / Partner Updates

- Anna Paulson – Collaborative Experience Conference-funding for parents of under-represented communities, registration open on Monday 8/26

- Ingrid – working in collaboration with MDE to bring the information to directors across the state.

- Terry – we are also a resource if you need support, outreach, training. Family emersion weekend coming up. The second weekend of October. Look on our website for more information. Monthly literacy family events will be starting again shortly. This will be live-streamed as well.
- Sonny – Nicole to send out flyers regarding the family emersion weekend. The 3rd weekend in October the Minnesota association for deaf citizens is hosting a conference in conjunction with MRID. MRID.org for more info.

## Next Meeting

Date: November 20, 2019
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

## Decisions Made

- N/A

## Action Items

- N/A

Early Hearing Detection & Intervention
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