



Meeting Minutes: EHDI Newborn Hearing Screening Advisory Committee November 20, 2019

Minutes prepared by: Cara Weston

Location: Amherst H. Wilder Foundation, 451 Lexington Pkwy. N, St. Paul MN 55104

Attendance

Present: Nicole Brown, Kirsten Coverstone, Kathy Anderson, Jay Wyant, Jessica Novak, Sara Oberg, Renae Allen, Hannah Herd, Joscelyn Martin, Anna Paulson, Danelle Gournaris, Terry Wilding, Gloria Nathanson, Abby Meyer, Mary Cashman-Bakken, Ingrid Aasan

Absent: Joan Boddicker, Laura Godfrey, Tina Huang, Colleen Ireland, Kathryn Lein, Emilee Scheid, Sonny Wasilowski

Agenda Item Minutes

Opening:

- Previous meeting minutes: approved
- Open committee appointments: one half of Committee seats come open in January, email sent out to committee members with link to reapply for anyone planning to reapply. Committee member contact sheet also indicates term end date.
- Voting for vice chair: current vice chair Laura Godfrey will be taking over as chair next year, nominations were sent out for vice chair. Abby Meyer nominated and accepted. No other nominations, unanimous vote to approve Abby.

Family Story: Elena Miranda

- Supervisor for cultural DHH guides at MN H&V
- Liaison to Spanish-speaking community
- Has an adopted son - No language when adopted, came to US, began getting support from school district, speech, ENT, pediatrics, husband. Made decision to speak primarily Spanish in home
- Some families afraid of calls from unknown numbers, helps to say “we have nothing to do with immigration status, everything is confidential, and everything I’m going to share with you is free”

- Son uses: 1st ASL, 2nd Spanish, 3rd English; family reads to each other, oldest in ASL, middle in Spanish, youngest in English
- Q: Do you feel we need more resources in Spanish? A: We have a lot of resources, but we can do more.
- Q: Understanding culture is important, any tips to help the medical community/education community make sure we're understanding the culture? A: Yes, in general we are afraid about immigration. All of this is confidential, and free. Cultural thing is that nothing is free, may automatically say no to resources. Reassure people, it is free.

National Hands & Voices and FL3

- Candace Lindow-Davies (National H&V), Brenda Hommerding and Heidy Nazario (H&V of MN)
- FL3 = Family Leadership in Language and Learning, funded through HRSA
- Goals:
 - helping states/territories develop a relationship with a family-based org, MN is ahead of the game
 - increase by 30% the # of families that have an increased knowledge around becoming leaders
 - raise percentage of families receiving family-to-family support; MN really doing well
 - increase family understanding of impact of D/HH on child's language, literacy, and social/emotional development: access to first language leads to literacy, leads to domino effect of healthy social/emotional development
 - raise from baseline the number of families offered support by Deaf mentors; clarified with HRSA they mean the range from unilateral to profoundly deaf and everything in between, significance of having contact with an adult who is D/HH
- All this info can be found on the FL3 website: [The Hands and Voices Leadership in Language and Learning \(https://www.handsandvoices.org/fl3/index.html\)](https://www.handsandvoices.org/fl3/index.html).
- MN is ahead of the game; MN has provided a lot of info for national program guideline development
- D/HH guide program – sharing experiences, supporting families; different from what parent guides do but both offer support. How it works: parent guide connects w/family, ask if family is interested in having a D/HH role model, go from there. Guides trained by National, unbiased
- Often states will have parent guides, D/HH guides, and deaf mentors trained all at the same time
- Two advisory committees oversee/give guidance to FL3: D/HH Adult Advisory Committee and the Scientific Language Literacy and Social/Emotional Development Advisory Committee
- L2L – leadership to leadership: National program rolled out in Sept 2018, for anyone in the H&V family if they want to improve their leadership skills
- Lots of resources, tool kit – bank of ideas for family-based organizations
- Annual leadership conference: MN attends every year
- ASTra goal is to educate parents, not put them in an adversarial position at an IEP table
- H&V national facebook groups for D/HH
- Big interest in the FBO (family-based organization) in barriers to early intervention enrollment
- Working with AAP, training is coming out of that
- Have tip sheets on language, literacy, social/emotional development; working on tip sheet for milestones

- Working with D/HH adult role models, focusing on making sure Spanish-speaking community has access
- Developed a parent event guide
- Side project with Phonak – developed guide for hearing health care providers to be more inclusive and family-centered
- Q: Why are other states struggling while MN is a leader?
- A: This advisory committee, NHSAC, is one reason – convenes regularly, more often than some other states. Commission, too. Stakeholders stay in the room until reached consensus.

[Break]

Representative Heather Edelson – Award presentation from David Dively of the MN Commission of the Deaf, Deafblind, and Hard of Hearing: Champion of Newborn Infant Hearing Screening

Amplification Guidelines – Darcia Dierking

- The 3rd and final section of comprehensive audiology guidelines
- Previously approved sections of the comprehensive audiology guidelines: overview, referral guidelines
- First amplification guideline approved in May 2008; revision for third section began about a year ago
- This guideline is for audiologists working with families that have already chosen amplification
- Background of workgroup timeline for this section of guidelines:
 - Nov 2018 – literature review, new content additions and revisions
 - Summer 2019 – external clinical audiologist reviewers submitted comments
 - Fall 2019 – workgroup reviewed external comments and wrote final draft
- Introduction and background: reviewed – no comments or additional discussion
- Insurance and Medicaid coverage and loaner program information
 - Comment: need to fix notation numbers, confusing
- Candidacy criteria – more guidance on unilateral and auditory neuropathy spectrum sections
- Q: Is this document for parents or audiologists? A: Audiologists, very technical
- Orientation and counseling and partnering with parents to shape outcomes
 - Suggestion: pg 8, paragraph 3 – add “spoken language”
- Validation of aided auditory process
 - includes some questionnaires and direct measurements
 - Q: Asking the audiologist where to find the questionnaires referenced.
 - A: Those are clinical tools, available in pediatric clinics.
 - Q: Can we include a link to pediatric minimum speech test battery? A: Yes
 - Suggestion: include explanations for the tests for audiologists who may not have as much experience using them for different age groups
 - Group can do a quick email review of the speech test battery
- Documentation and reporting – explanation of why MDH needs reporting by audiologists
- Quality assurance and quality improvement
 - Q: We’ve been talking about revising our benchmarks; in goal 3 indicator, leave it a little bit more generic? A: sure

Discussion:

- Terry: We hear stories about audiologists who tell parents that signing is bad for speech and that it will contraindicate their acquisition of spoken language. Any place in this document where that is addressed?
 - Darcia: Not sure we're telling audiologists what not to say, rather what to say. In previous two sections, talks about sharing results and recommendations in an unbiased manner, recognize unique situations and backgrounds, etc.
- Terry: Does it include links for visual language research?
 - Darcia: In guidelines for audiology assessment and referral, yes. These are just amplification guidelines. Trying to have them stay open to all communication modes, not really going into the details of each individually.
- Terry: It becomes biased, if these things aren't mentioned.
 - Joscelyn: We could include a small sentence that says it is always appropriate to consider sign language, or something like that?
 - Add on page 2 "Birth to age 2 years is a critical period for brain development in the infant/young child, and all language input is essential. Multiple spoken and visual languages and their combinations are opportunities to be considered for each child and family."
- Joscelyn moves to accept with edits, Jay seconds

Partner Updates

- Kirsten: new JCIH statement came out, available electronically
- Nicole: HRSA grant application, screening through the age of 3, need to pull together a work group to think about recommendations; one measure is how many families are connected to D/HH adults, so that's new
- Anna: the Commission has a new executive director, Darlene Zangara will be introduced in Feb; Collaborative Conference up at Breezy Point, 327 people attended, keynote presentations will be up on Commission website soon; 50 parents attended
- Terry: monthly literacy night, join online, people signing stories; archived on our youtube channel, follow us on facebook
- Kathy: regional EHDI teams – met along with statewide DHH community of practice, in process of doing some updated annual goals
- Kathy: Help Me Grow, 11 metro area teams got together earlier in 2019 w/goal of increasing communication w/clinical audiology and educational audiology and the referral process as well; meeting with the Help Me Grow IEIC (interagency early intervention committee) in early December

Next Meeting

Date: Feb 19, 2020

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