



Newborn Hearing Screening Advisory Committee Meeting Minutes

05/17/2017

1:00-4:00 p.m.

Amherst H. Wilder Foundation
451 Lexington Pkwy. N.
Saint Paul, MN 55104

Facilitator: Sara Oberg, Chair

Recorders: Darcia Dierking, Cara Weston

Attendees: Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Candace Lindow-Davies, Tina Huang, Peggy Nelson, Joscelyn Martin, Abby Meyer, Gloria Nathanson, Sara Oberg, Anna Paulson, David Rosenthal, Emilee Scheid, Lisa Schimmenti, Kara Tempel, Jay Wyant

Absent: Teresa Buck, Linda Murrans, Michael Severson, Sonny Wasilowski

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements Sara Oberg, Chair</p>	<ul style="list-style-type: none"> • Thank you David Rosenthal—this is his last meeting • Signed Oath of Office Form needs to be on file for each committee member • Correction to minutes: Gloria Nathanson: Deaf Awareness day on April 15, Deaf History conference was on March 15. • Minutes approved after correction by Committee vote.
<p>2. EHDI Story: Nicole Brown</p>	<ul style="list-style-type: none"> • A portion of a video from the Family Engagement Parent Panel at the EHDI National Meeting was played. Moderator was Janet DesGeorges. • In MN, we have a lot of engaged parents. • Candace Lindow-Davies has a new position with National Hands and Voices, MN has been very lucky to have her leadership. • Candace: Thank you. A lot of credit goes to our program staff. National MNHV has gotten a grant to provide technical assistance to states and also will work with Gallaudet on impacts on language and literacy and get info to parents. National MNHV also trying to raise awareness for Deaf Mentors.

<p>3. National EDHI Meeting</p>	<ul style="list-style-type: none"> • Lisa Schimmenti: attended Chapter Champions pre-meeting. Talked a lot about language usage for providers. • Abby Meyer: Dr. Nutt had a great personal story. From a medical side there was lots of interesting info on CMV for patient management. • Anna Paulsen: Georgia Pathways and Georgia early education alliance: they had reframed the work of making sure children are ready for kindergarten and ready to read. Language “nutrition” concept and agencies collaborating to help parents provide the 30,000 words (from studies) needed for children’s language input • Candace Lindow-Davies: Lots of great information we wanted to bring back and try here in MN. • Kathy Anderson: Georgia work interesting. What struck her was that it was a statewide multi-agency effort to raise the literacy for all the children in the state. Also went to some sessions on collaboration and reflective practices & to the Common Ground session. In Minnesota we have a lot of collaboration happening, how can we take it to a deeper level? Went to a Boys Town session on inter-professional collaboration that was good. • Melanie Wege: Had the opportunity to present some otolaryngology efforts with Abby Meyer. Ohio had an initiative on lost to follow-up. Designated parent advocate (available by iPad) to help parents understand/provide education, and then call and schedule follow-up. Neonatal opioid exposure and how that affects hearing screening: recommendations to try to do it 6 hours after birth or waiting a week until baby has gone through a lot of the withdrawal symptoms.
<p>4. EHDI Workgroups Audiology Guidelines Medical Guidelines Bylaws Darcia Dierking, Nicole Brown, Kirsten Coverstone</p>	<p>Audiology Guideline - 1st draft out to the workgroup and hoping to have comments back in a month.</p> <p>Medical guidelines – In the approval process with the Commissioner. Distribution plan discussion:</p> <ul style="list-style-type: none"> • MDH: post on website, mailing to PCP clinics and C&TC staff; • Advisory committee: forward link to organizations; • Other ideas: Lisa S.- Family physicians and nurse practitioners; Emilee: MN Family Practice, Physician assistants and Nurse practitioners- think about going to the conventions to present at CME conferences, and maybe a newsletter from organizations, but we need to brainstorm how to get details to providers that is not a quick email. Tina: We put out a poster at MN Academy of Otolaryngology. Emails can go out on distribution lists- providers may not click on it but it is free. Abby: Maybe at MN professional meetings the copy of medical guidelines could be tucked into the welcome packet. • Nicole: We may ask committee members to contact, work with, &/or present to their own affiliated organizations. <p>Bylaws –</p> <ul style="list-style-type: none"> • Section I - Statutory purpose: Changed to be word for word from our statute, (statutes updated in 2009, 2013); • Section II - Membership, Appointments, Responsibilities: We are using the statutory language, which references some agencies that have different names now » Peggy suggests you put asterisks that show the current correct names of agencies/organizations. Appointments: bylaws reflects that membership appointments can be extended. All members will have an orientation before they come to their first meeting. • Piece added about recognizing/valuing members and member expectations. • Piece added referring to guiding principles. • Information added about communication. No rules about communication at this time, may want to consider adding these in the future if needed. • Tina: Do we still have a rule about number of meetings attended? <ul style="list-style-type: none"> • A: Yes, Number 6 on page4 • Section III: Officers – Vice Chair would serve 1 year term, Chair would serve 1-y term, then 1-year as past chair.

	<ul style="list-style-type: none"> • Need to add information about serving on the Executive Committee – who makes up the committee, etc. • Section IV: Meetings & Reimbursement – Voting: in order for committee members to know what we’re voting on, must let committee know at least 2 weeks before for absentee voting. Added voting by email. Because this committee is advisory, it does not fall under open meeting law therefore members can vote by email. • Jay: Necessary to clarify that committee members can reply to email to vote by email in a timely fashion – set a deadline for voting. Agreed. Peggy: Should email vote be for follow-up to in-person discussion, new topics not discussed in person, or both? • Jay: Want to avoid chair rushing through vote. • Emilee: Could keep it vague. Could be useful in some situations. • Peggy: “When necessary” • Kirsten: “With approval from exec committee?” • Agreed. • Sections V and VI are the same. Amendments are the same. • Emily: Motion to approve bylaws with the noted changes. Joscelyn seconds. Motion passes. • Decision/Vote – Unanimous
<p>5. Common Ground Project A joint project of CEASD and OPTION Schools Jay Wyant</p>	<ul style="list-style-type: none"> • Group has been around for 5 years. It has 2 representatives each from Option Schools (schools for the deaf that tend to promote spoken language) and from CEASD (a coalition of schools that focus on sign language) • Goal is to find common ground between the two. • Common Ground recognizes that all stakeholders are not represented. • Over time the group has built trust and collaboration and are working toward a common agenda in order for children who are DHH and their parents can get the best outcomes that they want and have the choices to meet those outcomes. • The group developed a list of shared understandings • Had to learn how to use words very carefully, the cultural meaning and medical meanings. • Used the work of Otto Scharmer, described concept of negotiation and coming to a collective understanding. • This is important time for finding common ground: federal changes, EHDI reauthorization; proposed changes to Dept of Education, Grassroots movements, appropriate service levels in Special Education • Expanding interest: presented at national conferences • Current Activities: encouraging school pairings CEASD and OPTION; White paper on Lead-K; NASDSE Guidelines; Support for local collaborations; Working together: CEASD & OPTION Conferences in April 22-24, 2018
<p>6. Break</p>	

<p>7. Common Ground Project</p>	<p>Questions/Discussion:</p> <ul style="list-style-type: none"> • Joan: There was lack of mention of cued-speech. Jay: Trying to start with two organizations and get that to work before involving a larger group of organizations. Joan: wondering how Cued-speech gets their voice since then don't have a school. Jay: Common ground is getting conversations started and getting more stakeholders involved at the local level. Joan: If there is no one on common ground board that would reach out to cued speech on a local level, wouldn't that risk leaving them out. Jay: Common Ground is still coalescing and trying to create a model, and recognizing that they don't have all stakeholders represented yet but those stakeholders are still important • Mary: Concerns that not all voices are at the table, two diverse groups trying to make things happen Jay: Common Ground is trying to get stakeholders to talk at the local level but there is no legislative agenda. • Kathy: Common Ground is trying to develop a process for talking/collaborating, especially at a deeper level and work through challenges and come to common understandings. Really liked those levels of understandings to help work through those difficult conversations that respects different groups. Jay: that is great take-away • Mary Hartnett: Commission hosted a collaborative group of stakeholders in 2009 and it is important to have a common voice. MN has a structure of coming together with shared goals and shared purpose. It would be great to keep building our capacity and skills to respectfully work together • Kathy: One of our steps is to identify who are stakeholders are and get those people at the table. • Nicole: We do have the stakeholders at the table and we are ready to have deeper conversations. TheoryU is a great framework for doing that. Thank you to the Commission for getting all the stakeholders together. • Jay: We need to think about what is bringing people to the table. • Candace: Would love to see the deeper conversations come to MN, especially with rules of engagement. <p>Comments/questions on Jay's presentation:</p> <ul style="list-style-type: none"> • Q: What's next? <ul style="list-style-type: none"> • A: That's what we're trying to figure out. Now what? Other states want this kind of project too. Funding has included development of training modules that still need to be created. Will be meeting in July. • Nicole will email out color copy of handout. Also, can Jay give an update in August? <ul style="list-style-type: none"> • Yes.
<p>8. MDE Update Kathy Anderson</p>	<ul style="list-style-type: none"> • Regional EHDI teams continuing to work around the state. Many talking about options for families (especially in greater MN), teacher needs, professional needs, deaf mentor program with waiting list. Planning annual training in November. Working w/local school districts to do hearing screenings for all children referred to EI. Most districts understand the need to do this now. • Summer EI conference in June w/UMN and MDE, many topics. • Emily: First cohort has just taken MCAs, excited for update. • Mary: those results will be reported next year due to 1-year delay, could do a cheat and look at some data.

9. Legislative Update MCDHH

Update provided by Mary Hartnett

- We have a strong foundation and lots to be proud of in this state, further to go.
- Committee needs representation from many areas, parents, committees, communication modalities
- Focus: education, employment, access to pub services, age-related HL. Commission puts together strategic plan every 5 years.
- Goal is to promote civic engagement and voter outreach
- Bills: waiting for decisions to be made, most bills have been vetoed. Good news: if things go well, things are looking good for bills put forth this year. Increased funds for deaf mentors rolled into D/HH Services bill. Bills proposed for age-related HL & school acoustics. Good acoustics = optimal learning environment. Bill passed to include accommodations for all new construction for any gathering space that state pays for. New law passed for assisted living facilities to provide age-related hearing loss training & communication strategies. Bills related to employment and vocational rehab services and state services for blind proposed. Exec order passed to increase % of state employees with disabilities to 7%. Continued centralized fund so employers aren't afraid to hire.
- Emilee: Anything related to CMV?
 - Maggie Dreon: CMV related bills are HF2653, SF2383. Education-focused bill, requires commissioner create a program to develop evidence-based info to health care providers, parents, at-risk communities so people are more informed. Info on recommendations upon individual not passing hearing screening, but not a targeted screening bill. The bill is called the Vivian Act. MDH is supportive of bill as it is currently written.
- Q: Who writes legislation?
 - A: Committee members write, review. Researchers in house provide help.
- Q: If wanted to make sure there was language about cued speech in bills, who do I talk to?
 - A: None of legislation is specific about communication modality.
- Q: Like legislation that says funding for ASL teachers, how do I make sure cued speech is mentioned there?
 - A: We follow JCIH on what is included, translate a lot of legislation into making sure those evidence-based measures are supported. We can talk later about those options.

10. MDH EHDI Update

- EHDI Reauthorization Act has been introduced in congress. MDH gets EHDI federal funding both from the CDC and HRSA.
- CDC will be coming to MN in June for a site visit
- Nicole: HRSA funding – federal budget had not been passed when received notice of grant award. We are now working with ~50% of budget; waiting for new notice of grant award now that budget has been passed.
- NCHAM website – project with Rachel Coleman on developing curriculum for families of children who are D/HH, 7 different modules. Available for free now. Working w/deaf mentor and D/HH role model program to get the word out. Will be putting info in parent organizer too. Previews are online.
- Gloria: you could request access if your child is older, costs money but you can have access.
- Candace: Deaf individuals do the signing in the videos.
- Through the collaborative, MDH is working to get parent resource organizer into an accessible online format. Thank you to Anna for spearheading coordination.

<p>11. Topics/Partner Updates for Next Agenda</p>	<p>Discussion: 10 year anniversary of EHDl legislation, ideas to celebrate?</p> <ul style="list-style-type: none"> • Mary Hartnett: 10 year anniversary includes a lot of important legislation around children who are D/HH. We are ahead of a lot of other states. Opportunity to celebrate, commission would love to be a part of it. Recommend pulling together a planning committee. • Emilee: Any conferences, state meetings that we could add a celebration to before or after? <ul style="list-style-type: none"> • Kirsten: Maybe during part of November advisory committee meeting, invite people to come? • Nicole: Good idea. Collaborative experience? <ul style="list-style-type: none"> • Anna: Two celebrations, up north and metro area. • Collaborative – conference for all professionals who serve children who are d/ hh and parents. Around 350 ppl, Breezy Point, Nov 2-4. • Jocelyn will make chocolate ears.. • Nov NHSAC Meeting is a good time. 3:30-4:30? • Fun to have families, children here. • Mary Hartnett: every bill we put forth that year passed. We have pictures of the celebration at that time, so many families. Maybe even extend it, have a reception. • Lisa: Move that we form a committee, divide tasks. • Volunteers? <ul style="list-style-type: none"> • Nicole, Kirsten, Mary H, Darcia, Kathy, Abby, Emilee, Candace, Lisa • Hand in oaths of office. <p>Motion to end meeting – David, seconded by Jay. Meeting ended.</p>
<p>12. Closure Sara Oberg, Chair</p>	<p>Next Advisory Committee Meeting: Aug. 9th, 2017 1-4pm LOCATION: Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</p> <p>Notify Chair if there are any Partner Updates to put on the agenda Adjournment – Candace moved to adjourn, Linda Murrans seconded</p>