Newborn Hearing Screening Advisory Committee Meeting Minutes

August 9, 2017 1:00 - 4:00 p.m. Amherst H. Wilder Foundation
451 Lexington Pkwy. N
Saint Paul, MN 55104

Facilitator: Sara Oberg

Recorder: Jessica Cavazos
Melanie Wege

Attendees:
Kathy Anderson, Joan Boddicker, Teresa Buck, Mary Cashman-Bakken, Kirsten Coverstone, Joscelyn Martin, Abby Meyer, Gloria Nathanson, Peggy Nelson, Sara Oberg, Anna Paulson, Emilee Scheid, Lisa Schimmenti, Kara Tempel, Jay Wyant

Absent: Nicole Brown, Candace Lindow-Davies, Tina Huang, Linda Murrans, Michael Severson, Sonny Wasilowski,

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
1. Welcome and Announcements Sara Oberg, Chair	• Review of microphone operation • Reminder to turn name tags toward CART operator • Jay – correction to May minutes. #5 says have 2 representatives from each of the different types of schools which is not quite right. It is 2 representatives from all of the schools. • Jay motions to pass minutes with correction and Gloria 2nds to pass minutes. Motion passes.
2. **Minnesota State Academy for the Deaf** Terry Wilding	• Programs from birth to age 5. Early Intervention is the focus using ASL and English offering full access to language and develop the WHOLE child. Most of our students do sign. • Part C (birth to age 3) includes home service visits from DHH teacher and additional services from blind/visually impaired teacher, SLP, OT, PT as needed. • Part B (beginning at age 3) is all day programming tailored to meet needs of individual students. • Full assessment team is on staff to monitor ongoing development in all domains • MSA wants to become more connected with MN EHDI advisory committee to help common goal of meeting needs of DHH students. We want to see more collaboration between professionals to help students. o Q - where do most of students live? Response - Most transport in daily from 30-40 min within campus and do not live in dorm on campus. o Joan - What is VCSL? Response from Gloria – it is a checklist on age mode sign proficiency. It monitors progression in ASL skills up to about age 5 or 6.

Minnesota State Academy for the Deaf Terry Wilding	• Terry - How can MSA reach out to districts more (in addition to Help Me Grow) to provide support for parents? How can they support the Deaf Mentor Program? How can they reach out districts to provide support for assessments? Some districts don't have resources or can't find DHH staff. How do we work together to bridge that gap? o Kara comment– workforce issues are rampant among ALL disciplines in special ed, and there is a committee working on supporting the teachers we already have. o Kathy comment– thanks for your interest in wondering how MSA might fit into helping provide resources o Jay question – do you have budgetary authority that if we made a request, you have the ability to OK it moving forward? Response – Some. Some requests may need collaboration and innovative exploration to see how we can work together to develop a new initiative. • Terry - MSA is trying to reach out and collaborate more with MN Hands & Voices in the Faribault area in particular o Joan – wonders if MSA may have a role in helping make sure that DHH teachers have understanding of how other disabilities may or may not be impacting development (lack of development in other areas may not be due to being deaf). Response – assessment teams help assess underlying reasons for delays in all different areas. o Emily – concern about shortage of DHH teachers and sometimes case manager is not a DHH teacher. Those individuals may not realize that goals of services are not being met. Maybe consider give training and support to the case managers. Response – this is an issue throughout the state. MSA is working with U of M to restart the DHH program, and nationwide there are not enough programs. MSA went to superintendents' conference and talked about recruitment and retention of DHH teachers. MSA may be able to collaborate on project to train case managers and will consider exploring that. MSA has concerns about the recent changes in licensing for teachers in MN as it lowers the level of training of who can teach. This will negatively impact our DHH kids. • We collaborate with MDE to provide an information materials library to parents – they check out materials from MDE. We would like to expand that with more professionals. • We provide workshops for teachers, interpreters, paraprofessionals

3. EHDI Early Childhood Education Data Kathy Anderson	• 2016 (July 1, 2015 – June 30, 2016) educational DHH data provided by teachers o Copy of data was distributed to advisory committee members – please reference handout • EHDI activities overview – goal is to continually improve communication and learning outcomes for DHH kiddos and their families o Regional EHDI teams focus on resources for DHH families, and service providers ▪ Next EHDI training meeting Nov 1-2 o Hearing screening – OAE training activities using ECHO (NCHAM now does online webinar training so teams now support this) o Learning outcomes survey is completed through reporting to MDE using the COSF (Child Outcome Summary Form). Looks at how DHH children are functioning relative to typically developing children their age. Additional questions are reported for DHH children when they exit Part C and when they exit ECSE (entering kindergarten). Districts do much more monitoring than this, but this is the date that is reported. ▪ Assist teams in planning
4. EHDI Workgroup Updates Darcia Dierking Kirsten Coverstone	• Audiology Guidelines o Committee decided a year ago to merge all of the guidelines that audiologists reference. This will eventually include the diagnostic guideline, referrals guideline, and amplification guidelines in one document. The Referral portion is complete and needs to have committee vote eventually when the rest is complete. Currently working on diagnostic portion. This has already been vetted with committee work group members. Will be vetting with audiologists in the state to make sure they all agree it represents best practices. • Medical Guidelines - Accepted by the MDH Commissioner of Health • 10 Year Anniversary of EHDI Legislation o Celebration will be on November 15th. Planning committee is led by Cara Weston. Each NBHSAC committee member needs to gather and submit e-mail addresses for people within their organizations who should receive an invitation. Those e-mail addresses can be sent to Cara, or to Kirsten/ Nicole. o The anniversary planning committee will be developing a presentation • Need suggestions for an amateur photographer, and 1-2 volunteers to serve cake.
5. BREAK	•

6. MDH EHDI Update Melinda Marsolek	Long Term Follow-Up Data for Children Reported to the MDH Early Hearing Detection and Intervention (EHDI) Program in 2016 • 226 children reported at D/HH permanent, 83 conductive (likely non-permanent) • 57% ID'd through NBHS, 18% passed NBHS but later ID'd as D/HH (through age 10), 17% out of state birth (all ages, includes non-recent dx), 6% other MN births (did not pass, but dx after one year old OR unknown screen result) • Laterality and Degree: 2/3 of children have bilateral hearing loss. Mild and moderate are the most common. • 60% of children have SNHL, 18% conductive, 7% mixed • Amplification: most children are fit with amplification and the status of children with unilateral hearing loss looks more like children with bilateral loss than in previous years. 28% of children were fit with amplification within 1 month of dx (includes children with bilateral HL who did not decline) 69% of children were fit within 2 months of dx (includes children with bilateral HL who did not decline) • Part C: Close to 90% of children born in 2009-2013 and ID'd as D/HH before age 3 were enrolled in Part C. 60% of children are enrolled in Part C within 3 months of dx, 8% are enrolled more than a year after dx • MNH&V continues to contact nearly 90% of families, close to half are contacted within 1 month of dx • Late onset (pass NBHS but ID'd as D/HH later): 39 children in 2016. Children ID'd as D/HH after passing NBHS are Id'd at all ages • Early Childhood Longitudinal Data Set (ECLDS) eclds.mn.gov: 148 children who are reported to MDH as D/HH are matched to a public kindergarten education record. 60% of the 148 were in D/HH primary disability category, Other primary disability category 20%, no IEP 20% • 45% of 2015/1026 kindergarteners receiving Special Education services under the primary disability category of D/HH were not reported to the MDH EHDI Program

7. CMV Study Mark Schleiss Maggie Dreon	• Most common congenital viral infection in the US • Found in approx. 1% of all births • Clinical obvious disease is evident in only 10% of all babies born with infection • All infants with cCMV are nevertheless at risk for neurological and neurodevelopmental sequelae • In MN: 70,000 born per year, about 1% congenital infection rate = approx. 700 cCMV babies affected • cCMV can't be accurately dx in a newborn beyond 14-21 days of age • Screening identifies infants at risk for neurological sequelae and/or hearing loss. cCMV may be treated with antiviral therapy • There is a need to increase knowledge and awareness among clinicians and women of child-bearing age • Study is to determine if we can use dried blood spots to screen for cCMV (compared to saliva) • Previous studies found that dried blood spots had a sensitivity of 30%, but newer technology could increase sensitivity • Of 3106 enrolled, 10 participants have either positive or inconclusive results • Parent and provider worksheets created by MDH are provided • cCMV legislation in the US include laws enacted in OR, ID, UT, TX, IA, IL, TN, CT, HI • cCmv related laws proposed in MN, MI, PA, NY, ME and drafted in OH • Stakeholder interest in legislation: CA, AZ, AK, CO, WY, MS, FL, SC, NC • cCMV legislation in MN: It has been proposed in both the house and senate. It is an education only bill, no screening or testing requirements as part of it. It seeks to establish an educational program.
8. Topics/Partner Updates for Next Agenda	• Contact Kirsten or Nicole with updates/topics
9. Closure Sara Oberg, Chair	• Next Advisory Committee Meeting: November 15, 2017 *LOCATION*: Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104 • Adjournment