



Newborn Hearing Screening Advisory Committee Meeting Minutes

May 16, 2018

1:00 - 4:00 p.m.

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

Facilitator: Sara Oberg, Chair

Recorder: Darcia Dierking, Cara Weston

Attendees:

Ingrid Aasan, Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Laura Godfrey, Tina Huang, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Anna Paulson, Emilee Scheid, Sonny Wasilowski

Absent: Teresa Buck, Peggy Nelson, Lisa Schimmenti, Michael Severson, Kara Tempel, Jay Wyant

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements</p> <p>Sara Oberg, Chair</p>	<ul style="list-style-type: none"> • Sara talked about her recent personal experience with newborn hearing screening. • Meeting minutes from February 7, 2018 reviewed: Linda Murrans moved and 2nd by Anna Paulson to approve as written. Committee unanimously voted to approve those minutes. • Emilee Scheid gave report from the Newborn Screening Advisory Committee noting that Spinal Muscular Atrophy (SMA) was voted to be added to the MN Newborn Screening panel. She is now Vice-Chair of that committee. • Gloria Nathanson gave report about Deaf Awareness Day, over 2000 people in attendance and she thought it was a success.
<p>2. EHDI Story</p> <p>Joyce Dressler</p>	<ul style="list-style-type: none"> • She described her family, and her child's journey, which began in a different state. • Her child had a hearing screening and she needed follow-up with an audiologist at 3 weeks old, where they found to mild-moderate bilateral hearing loss. • She received a binder of information, and her child had an IFSP by age 2 months, and was working with a speech pathologist at age 3 months. • Her child started with a loaner hearing aid • She was connected a D/HH teacher, a parent support group and a Deaf Mentor providing home ASL instruction. • Moved to Minnesota and became connected with Minnesota Hands & Voices • She shared experience with genetic testing • She connected with a school, started DHH parent/child class, and got some experience with ASL and cueing

<p>EHDI Story</p>	<ul style="list-style-type: none"> • Things that worked for them: screening was fine, baby slept through it. Great experiences with early interventionists in both states. She felt supported choosing her path. She liked going to MNHV events, especially annual picnic and meeting adults who are DHH. Dad thought it was awesome that school district paid for busing • What didn't work for us: Being consistent with ASL was hard for them, and child told them at age 4 that child didn't want to use ASL. Now older and is wanting to use ASL more. Communication between healthcare providers and insurance companies for things like genetic testing and hearing aids was not working well when child was first born. • Challenges: Being consistent with hearing aid use. Also was hard when child was trying to say that hearing aid batteries were dead. Parents being on the same page when it comes to child's DHH identity, especially when thinking about language access. Using ASL when child was 2 was really helpful to them for understanding. Understanding IEP process and how to get what they wanted. Juggling appointments, knowing which appointments are most important, which therapies to ask for. They mainly just said yes to anything that was offered. Not knowing what to do was a challenge. • Wishes: Access to a DHH community in their neighborhood, so that child feels supported • Thank you: thanks for all you do for families • Questions: Does child have a para? Not at this time- has a DHH teacher that comes and cues with child and is being taught about self-advocacy to help social-emotional adjustments. Does child have an FM system? Yes. And I help caption the videos. What are child's summer plans? Child will be doing DHH soccer camp, and child likes acting, singing and dancing. Since you were so pro-active and seeking out support, do you also have suggestions for parents moving to MN or how we can help them know about the resources? Perhaps some sort of registry for kids to be identified by their doctor if child is not in school, maybe a booklet from the doctor.
<p>3. EHDI National Conference Highlights</p> <p>All</p>	<ul style="list-style-type: none"> • Laura: Talked about Theory of Mind, Resiliency for DHH children living in poverty • Joscelyn: focused on CMV, and also discussed the poster they presented, which won an award • Anna: saw many MN people there! There were plenary sessions on having crucial conversations, and also Betsy Moog Brooks and Thomas Horejes joint session on bringing people together to support families • Kathy: diversity of people coming to the conference, and EHDI binder poster; went to pre-session supporting fidelity in early intervention services • Nicole: we were fortunate to be able to support a parent (Joyce) in coming to the conference to help engage future parent leaders. Highlighted a presentation from Kentucky where they partnered with two universities for epidemiology support

<p>EHDI National Conference Highlights</p>	<ul style="list-style-type: none"> • Joyce: Brain architecture class, resiliency, and trauma-informed care (last day). Important that mental health of family and also professionals is taken care of. • Kirsten: Saw some CMV lectures. Some changes have been made to national curriculum for training hearing screeners. She is now on JCIH and the new document has been submitted for publication. • Darcia: Went to Horse as Interventionist training—what horses have to teach us about attachment and also leading/supporting families.
<p>4. Vestibular Screening</p> <p>Devin McCaslin, Ph.D., Mayo Clinic</p>	<ul style="list-style-type: none"> • Significant consequences of pediatric balance disorders • Seeing more pediatric centers beginning to build balance centers • There is no formal screening done for balance at birth • Lots of different things cause dizziness. Many different professionals could be entry point. Things are set up differently at different places. Audiology, physical therapy, ENT, and others. • Reasons why are kids dizzy? #1 is migraine. #2 is benign paroxysmal vertigo of childhood (migraine variant). #3 Ear infections. #4 viral infection. #5 Trauma. • Children with hearing loss can have vestibular impairments (GJB2, CMV, inner ear malformations (Mondini), Waardenburg, Pendred, Usher syndromes, ototoxicity, Enlarged vestibular aqueduct, superior canal dehiscence (SCD), vestibular neuritis, Persistent Postural Perceptual Dizziness (PPPD) • Symptoms of some of these come out after head traumas, especially with SCD • Meniere’s disease, earliest report is 9 years of age • Need epidemiology studies on prevalence on children. • Vestibular impairment is single most common associated feature of SNHL, studies have suggested up to 85% of children with SNHL have some degree of vestibular impairment • Vestibular rehabilitation is a sub-specialty of physical therapy, and work with children even more specialized. • Children don’t often tell physicians they are dizzy because they are born with it, and impairments could be overlooked and dismissed. • Why does this matter? Some studies suggest effects on gross motor development, effects on reading, effects on CI failure • Children with bilateral vestibular impairment were 8 times more likely to have CI failure, especially if explanted. Vestibular tests would be important

<p>Vestibular Screening</p>	<ul style="list-style-type: none"> • Some evidence that current from CI electrodes in cochlea can spread to vestibular nerve and that some kids use the current spread to activate vestibular system to help them with balance. So some evidence that CI actually good for balance. • How do we identify kids? There is a critical period for balance as well as hearing. Vestibular system is first sensory system to develop because there is stimuli in utero. Malformations in vestibular system will affect ongoing development. <ul style="list-style-type: none"> ○ Vanderbilt pediatric dizziness handicap inventory (DHI-PC), designed for kids, parents fill it out. ○ Questionnaire for Dizziness, Eye and Balance (Q-DEB) ○ Pediatric Vestibular Symptom Questionnaire • Discussed Predictive Factors for Vestibular Loss in Children with Hearing loss (Janky et al). Pure tone average of more than 60 dB of HL • Age for testing: If they can do conditioned play audiometry, they can do a balance test • Also made a children’s book for balance testing • Parents don’t always know that audiologists can help with dizziness • Most screenings are questionnaire based • Adapt adult tests for kids • Vestibular impairments will delay milestones to effects that are not yet well known. <p>Questions:</p> <ul style="list-style-type: none"> • Do kids’ vestibular systems improve? No, but they adapt, accommodate. Balance systems can re-wire and accommodate relying on vision and proprioception. Should we be looking at screening all kids with hearing loss for balance issues? Would like to see if they have a vestibulo-ocular reflex (VOR). Should pediatric audiologists add screening? Yes. • Questions about gaze stabilization and reading? Not sure yet—need more studies. • Abby: Screens for balance: Age at sitting, age at walking, standing on one foot. If they are not meeting milestones, then going to physical therapy. Physical therapy needs specialization in balance and children. Needs prospective epidemiological studies. There is much more to learn.
<p>5. BREAK</p>	
<p>6. MDH Update Melinda Marsolek</p>	<ul style="list-style-type: none"> • NCHAM Early Intervention SNAPSHOT Survey Data review – national survey that MN participated in. Shared Minnesota-specific results • Comprehensive report available – online, NCHAM website • Targeted parents/families with preschool-aged children, also survey to providers and audiologist • Tried to get a comprehensive look at early intervention system How MN participated: sent out surveys on behalf of NCHAM

<p>MDH Update</p>	<ul style="list-style-type: none"> • Response rates: 17% parents, 15% EI providers, 6% audiologists <p><u>Family Survey</u></p> <p>Regarding information received for communication options, parents rated info received best for listening and spoken language and lowest for cued speech</p> <ul style="list-style-type: none"> ○ 88% didn't feel pressured to pick one communication option <ul style="list-style-type: none"> • Parents indicated a need to meet other parents • Frequency of EI services: most less than one per week, 18% 2 or more per week • Perceptions of EI: most agreed it was important, felt like part of the team, easy to get information, improved child's quality of life • Comments on experiences: most comments were positive; some negative themes = lack of services, lack of coordination, frustrated with level of advocating needed to get services • Around half said HL was a financial burden <p><u>EI provider survey:</u></p> <ul style="list-style-type: none"> • 24% had D/HH-specific training • How adequate was education in prepping for serving D/HH? Interventionists with D/HH-specific training indicated education was mostly adequate however less than half of interventionists without D/HH specific training indicated that their education prepared them well for serving D/HH students. • EI provider comments: would like more training • Providers felt mostly confident in ability to provide practical services • Lowest confidence in ability to connect families to services like child care, transportation, food stamps, etc • Q: Were results specific to language, or not? Child development, test scores? • A: We don't have that data. This survey didn't look at outcomes of intervention, more parent perceptions of EI system. • Kathy: We will have more data on language and learning outcomes in August, will share. • Nicole: Question that struck me – how many children are being served by EI teachers who are not trained in D/HH-specific services.
<p>MDH Update</p>	<ul style="list-style-type: none"> • Next study: Co-Occurrence of Hearing Loss and Mental Disorders among Privately Insured Children in the US • Full study is available online • Children age 3-17 • One in 6 children had a co-occurring mental, behavior or developmental disorder • MN results: pretty similar; ADHD most common but lower in MN, others equivalent

<p>7. Serving Diverse Communities Discussion</p> <p>Kathy Anderson</p>	<ul style="list-style-type: none"> • How are we serving Diverse Communities? • Focus is on Goal 5 in JCIH supplement– all children have access to culturally competent services – same quantity and quality of info available that is available to the majority culture. • Handout shows some of the revisions that have happened with current material the MN provides to newly identified children with hearing loss and their families • Committee was asked to provide ideas about barriers that diverse communities face: <ul style="list-style-type: none"> ○ Fewer support systems within minority communities; fewer that share the condition. ○ Rides to clinic, financial constraints. ○ Information getting lost through translation. ○ No interpreters for client that doesn't sign with ASL. ○ Translation sometimes not efficient; sometimes family doesn't understand it. ○ Cultural / religious beliefs impact how they families act on medical advice or not. ○ Finding supports within community more quickly. Availability of a support group within the community. ○ Being away from work to attend appointments. ○ Establishing first layer of trust. Allowing family time to understand and be ready to move forward. Having a consistent person to ask questions. Different interpreters sometimes impact their understanding as well. • Committee members should submit any additional resources they have to offer to Kathy Anderson
<p>8. EHDI Medical Guidelines</p> <p>Emily Scheid</p>	<ul style="list-style-type: none"> • Emily gave a 45-min presentation to peers to promote the medical guidelines • Will be on planning committee for pediatric conference in the fall, will be speaking at conference as well • Re: presentation: well-received; emphasized risk factors, CMV testing, • Looking for other places to give talks • Consider how to present other guidelines the NHSAC has developed to different audiences • Kathy: connect with HMG

<p>9. MDE EHDI Update</p> <p>Kathy Anderson</p>	<ul style="list-style-type: none"> • Cultural/linguistic diversity – comments typed up, considerations for all • Anything to add, let Kathy know • Subgroup – birth-5 looking at resources, services, how to do that for all of diverse communities, • Darcia and Anna and Kathy will meet w/Help Me Grow re: what has worked for outreach to different communities, will bring it back to the group • Do some collaborative work on supporting children/families that are parts of diverse communities • Outcomes – dual language learners, English not primary language at home, how do we measure? Urge continuing to measure this, ideas and questions • In August will be talking more about outcomes
<p>10. Topics / Partner Updates for Next Agenda</p>	<ul style="list-style-type: none"> • Mary: foundations for literacy, a new curriculum for D/HH children, will have some info on that in July; also biannual legislative report will be ready July 1st • Sonny: new identities for D/HH, should I look into it? Should I present about that? Changing the scope from intervention to identity, “Early Healthy Deaf Identity (EHDI)” • Email Kirsten/Nicole if you think of something • Sarah: American Speech Language Hearing Association, free phone app – CDC milestone tracker, 0mo-5y, tracking development, gives ideas for what to do if child is not meeting milestones • Time for annual committee survey, will be coming out in the next two weeks, please fill out to benefit the group. • Emilee: good feedback on H&V speaker Sherry Cook from Gallaudet, possible speaker for this group or other venues, school-age children would definitely benefit, teachers as well • Mary: Sherry visited MSAD, Rosemont school district, Mankato, Savage, visited many schools, students and parents • H&V Annual Picnic Thursday August 2nd, looking for volunteers
<p>11. Closure</p> <p>Sara Oberg, Chair</p>	<ul style="list-style-type: none"> • Next Advisory Committee Meeting: August 15, 2018 <i>LOCATION:</i> Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104 • Adjournment