



Newborn Hearing Screening Advisory Committee Meeting Minutes

February 7, 2018

1:00 - 4:00 p.m.

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

Facilitator: Lisa Schimmenti, Chair

Recorder: Melanie Wege

Attendees:

Kathy Anderson, Nicole Brown, Teresa Buck, ,
Kirsten Coverstone, Tina Huang, Joscelyn
Martin, Abby Meyer, Gloria Nathanson, Peggy
Nelson, , Emilee Scheid, Lisa Schimmenti,
Kara Tempel, Sonny Wasilowski, Jay Wyant,
Laura Godfrey, Colleen Ireland, Nathan
Meuser-Herr, Ingrid Aasan

Absent: Linda Murrans, Joan Boddicker, Mary Cashman-Bakken, Sara Oberg, Anna Paulson,
Michael Severson,

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements</p> <p>Lisa Schimmenti, Chair</p>	<ul style="list-style-type: none"> ❖ <i>Please record name of person when motions are made</i> ❖ <i>Note, slides are not included in posted minutes</i> • Gloria Nathanson moved and 2nd by Joscelyn Martin to approve minutes from November 15, 2017. Committee unanimously voted to approve those minutes. • Introductions of committee members
<p>2. EHDI Story</p> <p>Anna L. S. Krauss</p>	<ul style="list-style-type: none"> • Anna is post-baccalaureate research fellow at Mayo Clinic, Rochester, and will be getting a graduate degree in molecular biology and developmental biology at University of Texas at Austin. She hopes to help solve problems in medical science, and wants to be a mentor for other Deaf students who don't have a role model. • She grew up in Long Island, and was diagnosed with hearing loss in her left ear at age 3 due to Mondini defect. She grew up as a hearing child until age 9, when she suddenly lost hearing in other ear. She was essentially without communication (used a written notepad for 4 months) for a while as she was profoundly deaf. This was really difficult; her whole life was turned upside down. At age 12, she decided to learn sign language; at age 13 began using an interpreter. • She attended a summer camp in 2010 and realized she wanted to be part of a school that had a deaf population. She chose to attend Rochester Institute of Technology. She discovered that she loved science, and loved to teach sign language. She felt she was realizing her potential there through her research. • Came to Mayo Rochester for an undergraduate internship, and was happy to find a lab who would accommodate a deaf student. Came back to Rochester and received a Cochlear Implant. She shared some of the difficulties in being part of the hearing world, but acknowledge that it helps to be part of a welcoming scientific community. A good support system at home, work, school, and lab has been very helpful. They remind her not to give up in difficult times, and understand her struggles. • Many families of Deaf college friends do not know how to communicate with their child. This was really surprising to her!

<p>3. EHDI Workgroup</p> <p>Benchmarks</p> <p>Kirsten/Nicole</p> <p>Audiology Guidelines</p> <p>Melanie Wege</p>	<p>Benchmarks: Nicole/ Kirsten</p> <ul style="list-style-type: none"> • Strategic planning is underway for the next 5-10 years. Committee was asked to contribute ideas about what we want to be able to say or accomplish in the next 10 years. <ul style="list-style-type: none"> • Teresa – Providers have a better understanding of unilateral hearing loss and why is it important to follow-up • Laura – Success of our efforts toward early screening, diagnosis and connection to intervention is reflected in improved outcomes/ success rates of high school graduates. • Sonny seconds that – if community outcomes are better, then our work was worthwhile and successful • Gloria – that there are no obstacles to follow-up • Peggy – maintaining connections with Deaf mentors is important for next generation • Tina – greater awareness in the community of getting early amplification (now, families still want to wait until baby gets older) • Lisa – Earlier diagnosis of Usher’s Syndrome. Affected individuals with hearing loss need to have earlier awareness that they could lose their vision as well as hearing, to make lifelong decisions. Having access to genetic services for this, and having insurance that will cover it is important. • Kathy – Access to medical care, services, technology, educational communication options – no matter where you live in the state • Sonny – Access to support for deaf students at a younger age, so they don’t feel isolated • Emily – less barriers to services. “Educational significance” can sometimes be a barrier, when a child isn’t far enough behind to qualify for services. • Volunteers for a workgroup that will continue to discuss new benchmarks can contact Kirsten or Nicole <p>Audiology Guidelines Update: Melanie Wege</p> <ul style="list-style-type: none"> • Working on revision of pediatric audiology assessment guidelines • Gathering input from 12 audiology reviewers, nearly complete • Next steps are discussing this feedback in the workgroup, including stylistic and nitty-gritty technological comments
<p>4. D/HH Teacher Prep</p> <p>Deb Golos, Associate Professor of Deaf Education at University of MN</p>	<ul style="list-style-type: none"> • Work has been underway with the board of teaching to change processes in the Deaf Education Program. <ul style="list-style-type: none"> ○ The special education component has decreased. ○ Expanded coursework on how to better teach specific content areas (reading, science, etc.). ○ More funding to support teacher cohorts. ○ Program was approved last May ○ 6 students began last fall; new cohort is accepted each year ○ Pre-requisite for admission is an undergraduate degree, preferably in education ○ Marketing and recruiting of high school students is just beginning. • Current curriculum includes 3 parts: 1. State licensure requirements for MN licensure. 2. Three practicum experiences and then 1 full time 15 week internship. 3. Three special education courses. The rest of courses are specifically for deaf education. • No fully online courses; some hybrid, but they all require some on campus time. • All students need to know sign, and need to know how to change teaching strategies to meet the learning style and diversity of needs of their students. An understanding of the foundation for all communication options is expected. • Q- Does current programming take into consideration the current DHH teacher shortages? Currently the program can manage up to 12 students per cohort right now.

<p>D/HH Teacher Prep continued</p>	<ul style="list-style-type: none"> • Q- What about increasing ASL fluency? Students need to take all 4 ASL courses, and need to be able to teach all different subject content areas with ASL. (comment that ASL courses are available at many different locations, not just in the cohort) • Q- Will your programming address needs for at home services? The hope is that the student can help educate families on the best options available to them for their child's situation.
<p>5. BREAK</p>	
<p>6. MDE Update</p> <p>Regional EHDI Teams MN Collaborative B-5 Subgroup activities Kathy Anderson</p>	<ul style="list-style-type: none"> • Regional Teams are multidisciplinary within education. Met in Nov for annual training. Dr. Cathy Carotta from Boys town led strategic planning. Also Dr. Lillian Duran (Univ. of Oregon) spoke, and shared her specialty in dual language learning from diverse cultures. • Metro area has about ½ of the DHH children that are served around the state. Goal in metro is to increase placement opportunities for 0-3 year old DHH children. Need to continue professional development within their communities for how to better support listening and spoken language with families (due to CI and use of HA's in the mainstream). • Birth to 5 group focusing on JCIH supplement – focus on ensuring every family has the basic educational information (in the binder). Reviewed, updated, added info. •
<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 requested 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. MDH EHDI Update</p> <p>MDH EHDI Strategic Planning</p> <p>Nicole & Kirsten</p>	<ul style="list-style-type: none"> • MDH 2 day session to identify priorities and plan goals, identified 4 target areas of focus. <ul style="list-style-type: none"> ○ Optimize collaborative resources, capacity and goals ○ Reformulate and launch process and plan ○ Pursue triple aim of health equity ○ Cultivate staff collaboration, engagement, and advancement

<p>MDH EHDI Update Continued</p> <p>CMV Study – Maggie Dreon</p>	<p>CMV study assesses sensitivity of dried blood spot to screen for cCMV in newborns, in comparison with saliva which is the current gold standard.</p> <p>Schleiss lab (U of M) and CDC labs are involved in study. Targeted enrollment is 30,000. Study now includes consented families from UMN, UMMC, Fairview Ridges, UMMC-NICU, Fairview Southdale, Fairview Ridges NICU, Allina, United, and Fairview Southdale NICU. Hoping to bring on two additional locations in the spring.</p> <p>As of 12-31-17, have 5153 infants enrolled. 52% enrollment rate when consenters are present. 60-85% of potential families are approached.</p> <ul style="list-style-type: none"> • 21 infants with actionable results (0.4%); 17 were confirmed with cCMV. 16 had consult with Dr. Schleiss. 5 of 17 symptomatic; 2 asymptomatic with isolated HL; 10 asymptomatic with normal (typical) hearing at time of initial evaluation. • 3 of 17 had atypical hearing at time of diagnosis • 1 of 17 has delayed onset hearing loss (rechecking every 3 months) • 13 of 17 with typical hearing at time of dx and remains stable • No insurance issues, except one that needed to be straightened out. • 4 false positive results (Positive saliva but negative blood spot) – appeared that saliva wasn't as sensitive as anticipated. Cut-offs on saliva test have been re-defined since then.
<p>9. Topics / Partner Updates for Next Agenda</p>	<p>Announcement: DEAF AWARENESS Day April 21st White Bear Lake High School.</p>
<p>10. Closure</p> <p>Lisa Schimmenti, Chair</p>	<ul style="list-style-type: none"> • Next Advisory Committee Meeting: May 16, 2018 <i>LOCATION:</i> Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104 • Adjournment