

## Newborn Hearing Screening Advisory Committee Meeting Minutes

11/04/2015

1:00-4:00 p.m.

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

**Facilitator:** Tina Huang

**Recorders:** Cara Weston,  
Darcia Dierking, Melinda  
Marsolek

**Attendees:** Kathy Anderson, Joan Boddicker,  
Nicole Brown, Teresa Buck, Kirsten Coverstone,  
John Gournaris, Tina Huang, Candace Lindow-  
Davies, Joscelyn Martin, Linda Murrans, Sarah  
Oberg, Anna Paulson, Emilee Scheid, Lisa  
Schimmenti, Kara Tempel, Jay Wyant

**Absent:** Mary Cashman-Bakken, Dennis Ceminski, Gloria Nathanson, Peggy Nelson, Geoffrey Service, Michael Severson, Emily Smith-Lundberg

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p><b>1. Welcome and Announcements</b> August 2015 minutes approval 2016-end of term positions President-Elect Nomination Introductions &amp; VOTE Newborn Screening Advisory Committee Summary (Candace)</p>	<p>Teresa Buck motioned to approve minutes, Candace Lindow-Davies seconded; approved Tina Huang discussed term expirations and application process Tina's term is expiring. Next chair will be Joscelyn Martin. Vice chair position is open. Two candidates: Sarah Oberg and Lisa Schimmenti Candace shared the Newborn Screening Advisory Committee is looking for a representative since Candace is leaving that committee. She gave a synopsis of the work (meet 2x year), subcommittees, and will be available to discuss it with anyone interested. Agenda order changes: Workgroup updates first, then EHDI Story</p>
<p><b>2. Workgroup Update</b> Transient Hearing Loss Medical Guidelines Update Audiological Guidelines Update Nicole Brown</p>	<p><b>Transient Hearing Loss:</b> decided work is done as a committee. Created post cards, will be printed and using, maybe translating. At MDH, audiologists and Nicole have gotten together to review the standard operating procedure for these transient cases, continuing to make progress <b>Medical Guidelines:</b> first review done, revisions being done now. Not much controversial content, mainly just update. American Academy of Pediatrics documents have focused on reducing loss to follow-up, not as much on hearing loss. Need to add some things for medical providers to do post-diagnosis. <b>Audiological Guidelines:</b> Darcia working on this. Workgroup looked at old version of audiology assessment guideline and provided feedback regarding scope of document. The workgroup will decide on scope and then move forward.</p>

### 3. EHDI Story

Shamara Freeman

Shamara Freeman shared the story of her son who was identified with hearing loss. Received news he didn't pass hearing screen at birth. Wasn't concerned, thought it was probably fluid. Went to audiologist as instructed.

Did another test, still same issue. Referred for ABR, needed to sedate him. She did NOT want him to be sedated... he slept well through whole ABR, did not have to be sedated.

CAT scan revealed enlarged vestibular aqueduct (EVA).

Audiologist was very thorough, really loved her.

Lots of feelings: blindsided, confusion, lots added to her plate and to her son's plate, and her husband didn't always express his feelings but she kept him in the loop

ENT doctor was great. Husband is sports-oriented, thinks first about sports – my son has an issue where he can't play sports? ENT said he's a boy, don't put him in a bubble. He can't play football, but the things he can do are always going to be a risk. That gave them hope, shined light on the whole diagnosis.

That was a year ago. At this time, they are in a place where they're ok with the diagnosis. Trying to balance everything, work, doctor's appointments, being shunned at work for taking time away for doctor appointments, dealing with hearing molds, explaining everything to all caregivers in his life, falls are scary, taking out and putting in hearing aids.

Talked to the rest of their kids, grandparents, nobody really understands everything. Yes he can hear, it's the clarity of the hearing. Doing their best as working parents, to teach him ASL and also using spoken words. At the end of the day, all he needs is love. Don't need to control his life so he's looked upon as limited. He's a very intelligent kid. Well-rounded and well-loved.

One thing she asks of audiologists and ENTs is to understand that it's very hard to balance work and doctor's appointments, so many clinic appointments to reach end result. Keeping up is very challenging.

Question: [John Gournaris] Why can't he play football?

A: Doctors explained that any sport that with high chance of some sort of head injury would hurt the hearing he does have because of EVA.

Q: [John] What is EVA?

A: [Tina Huang] Enlarged vestibular aqueduct. Connection between fluids of the brain and the inner ear. Head trauma can cause further hearing damage with rapid changes in the fluid. Head trauma is a risk of further hearing loss but the effects of trauma and EVA can be unpredictable.

Q [Jay Wyant]: With further impact, can kids get CI?

A: [Tina] Kids with EVA do very well with CI.

Q: [Teresa Buck] Is it your employer who is giving trouble, or co-workers?

A: I work in HR; have to take time off for molds or hearing tests every month and possibly difficult for co-workers to understand. I'm doing my best to limit it.

Q: [Linda Murrans] Did you make friends with other parents of children w/HL?

A: Yes, friends with a couple on facebook. Very encouraging. Found out about HL when slightly older.

Q [John]: Learning ASL. When did you find out about different communication options?

A: Second diagnosis meeting. Then received Parent Binder from MDH, read the whole thing, found out all the different language avenues. Got set up with Help Me Grow. Everybody had input. Was bombarded with knowledge, was good because of personality type. Other personality types would not have read the book, would not have responded well to so much info at once. How are those parents reacting? What if they have multiple kids? Can only imagine how hard it is. What if you don't have transportation? A lot of challenges.

	<p>Q [Jay]: Who do you suggest for that sort of parent?  A: Maybe a mentor, someone they can lean on to hold them accountable, check in. It's a challenge.</p> <p>Q [Kirsten]: Did you have discussions with your medical home about hearing loss?  A: You mean the pediatrician? They notice the diagnosis, ask if they're checking in with the audiologist, ENT. That's all.</p> <p>Q: [Sara]: What about speech language pathology?  A: Yes, though Help me Grow we have many providers. I do it every 2 weeks because that's when I can do it. I think that if I was a stay-at-home mom (in my mind) maybe he would be further along, but this is the best that I can do.</p> <p>Q: [Sara]: What about in the daycare?  A: I have a great day care, I'm concerned it would disrupt the flow there.</p> <p>Q [John]: What about Deaf Mentor Program?  A: Have had that mentioned, was at roller skating night at MN H&amp;V. During that time, so overwhelmed. Didn't know how to sign, people didn't know. Don't mind if someone come into the home, but would have to be evening time and the weekend.  John: Program would meet you when you needed.</p> <p>Q [Jay]: Speaking of coming into your home, I'm not familiar with Help Me Grow. Are they only available during daytime hours?  A: Usually do 7:30am or 3:45pm.</p>
<p><b>VICE CHAIR VOTE</b></p>	<p>Lisa Schimmenti: clinical geneticist, has been involved in EHDI for a really long time, since 1999. AAP EHDI Chapter Champion for Minnesota.</p> <p>Sarah Oberg: nominated for 3rd year in a row. Extremely passionate about this group, spread the word about NBHS and NBS in general. Grandparents lost hearing at 5 and 14 yrs old, been a part of Deaf Culture her entire life. Grandma signs. She works with children and adults with CI, can see how much they can dramatically change people's lives. How they can become more social. Started the adult CI social group, celebrating 5-year anniversary. Would be honored to have this position.</p> <p>Tina Huang: Results of vote: Sarah Oberg is new Vice Chair.</p>
<p><b>4. EHDI Performance Measure #2.3</b>  Focus on No Audiology Appointment  Kirsten Coverston  Melina Marsolek  Zay Rezanian</p>	<p>Melinda Marsolek: Introduced Results Based Accountability (RBA) framework. Been using RBA internally at MDH to improve EHDI program and now working with the advisory committee on an RBA for loss-to-follow-up. Focusing on EHDI benchmark/indicator 2.3 and 2.6</p> <p>Kirsten Coverstone: Story behind the curve: MDH works with local public health (LPH) in every county to help reduce loss-to-follow-up/documentation (LTFU/D); annual clinic specific data related to EHDI sent to PCP and audiology; MDH provides specific stakeholder education to promote EHDI best practices (i.e., pre-session to statewide audiology meeting). Several ENTs are willing to do presentations to their colleagues. MDH tries to get a better idea of why LTFU/D has occurred and try to find where improvements could be made. Provided pie chart regarding reasons for LTFU/D. Largest reason (33% in 2014) is "no audiology appointment made." This "no audiology appointment" was made into RBA. MDH has multiple contacts with PCP to try to get family scheduled with audiology appointment. Parents report reasons for not scheduling because they consider it low-urgency or they see their child responding to sound. In today's healthcare, if a test is important, the appointment gets scheduled right away. Studies have shown decreased LTFU when hearing follow-up is scheduled for the family before leaving the hospital, and this practice is recommended by state and national guidelines.</p> <p>Zay Rezanian: For 2014, Hennepin and Ramsey counties have higher numbers of LTFU due to no-audiology appointments. Children of African American or American Indian mothers are more likely to have "no audiology appointment" scheduled after a refer result on newborn screen. Birth facilities have different rates of LTFU due to no audiology appointment from 1-13%.</p>

Q: Teresa Buck: Does having audiology integrated in the hospital system make a difference in LTFU for “no audiology appointment?”

A: Zay and Kirsten: yes—there is still variation.

Melinda: Does the advisory committee have insight on barriers or thoughts behind why children don't get scheduled for appointments? Does it matter where they are going for primary care? It sounds like it helps when the birth hospital has the schedule right there vs the parents expected to schedule the appointment themselves. What are other barriers?

Q: Jay Wyant: How do non-hospital births get in the program?

A: Kirsten Coverstone: MDH has helped midwives get a grant for equipment and training and they screen 97% of their babies, however not all midwives are choosing to utilize the program.

Q: Jay Wyant: Was the out-of-hospital births included in data?

A: Kirsten: Yes, screenings recorded from mid-wives included.

Q: Joscelyn Martin: How can we find ways to support families in getting to appointments in terms of transportation or time off of work?

Melinda: Or perhaps they don't make the appointment because they know it is unrealistic that they'll get to it. That could be one barrier.

Q: Tina Huang: What are the processes the hospitals use to get families appointments?

A: Kirsten Coverstone: It varies, some hospitals schedule the appointments and some say that the audiology clinic will call the families so that it is not on the families to call and schedule. How follow-up is discussed with the family also makes a huge impact. MDH offers trainings for hospital staff however there are lots of turnover in hospital staff and sometimes training quality within hospitals declines. Hospitals typically have a list of providers they refer to.

Q: Tina: If hospitals make appointments and that reduces the lost-to follow-up rate, is there a way to make it easier for hospitals that aren't currently doing that?

A: Kirsten: That is a good question. From what we have seen barriers have been “we just don't do that; we don't have time to do that; where they go depends on their provider so we can't do that; audiology isn't open to schedule on the weekends, & decreased capacity of audiology clinics to call to schedule families.”

We are getting ready to reach out to birth facilities regarding time to rescreen and the recommendation to schedule the follow-up appointment. We will be sharing information about difference between facilities that schedule the appointments vs. those that aren't. Maybe we could reach out to a few of them regarding barriers.

Q: Tina: Do hospitals have a list of places to refer families for appointments?

A: Kirsten: Typically yes, or perhaps they have an affiliated clinic.

Q: Linda Murrans: Were the babies connected with LPH nurse at time of discharge?

A: Kirsten: Hospital referral to LPH varies between level of training and risk indicators and other factors.

Linda Murrans: Perhaps referrals to LPH at hospital discharge would be helpful.

Teresa Buck: LPH nurses face barriers in connecting with families. Sometimes families don't answer calls from LPH nurses.

Linda: or family has moved.

Nicole Brown: We had a QI project in looking at LPH connections with families and their ability to get families to make appointments, sometimes the issue is education of the family—they may not understand the importance

Teresa Buck: If PCP is not on board it is difficult to get families to follow-up. When we do home visits we often do weigh checks and I wonder if we could do an ear check through home visiting.

Q: Melinda Marsolek: If more is done to get PCPs on board, would that be helpful?

Q: Kathy: Can we connect with families individually in a supportive way to find out what the barriers are to help them?

Nicole Brown: It is a unique population that the LPH nurses were able to track in the QI project. We tried tracking if barriers were insurance, transportation or language and some of the things we thought were barriers were actually not barriers. Again, it was a small test with a unique population.

Candace Lindow-Davies: Would love to dig deeper into specific clinics and specific families to find out the barriers and get a bigger, more public service announcement to reach families targeted to those populations.

Kathy – Yes, I agree. Also the print materials that go home targeted to groups of families in certain areas of the city? It may not be all the same kinds of materials. You were saying, everybody gets the same thing, but that might not mean anything to a certain group.

Q: Tina Huang: If a hospital system has a built-in system for calling families after birth, could they assist in scheduling and roll some of this hearing education in for babies who referred.

Kirsten: like a home visit from the hospital

Tina: correct—it's home care.

Kirsten: Something to revisit with some of our larger hospitals.

Lisa Schimmenti: I want to stress the importance of primary care provider in the whole process. One of the families I worked with recently said they would not have followed up if their PCP had not really pushed them. They were told at the hospital not to worry about it so they weren't planning to followup until the PCP pushed them 3 times. Now the baby has hearing aids and parents are grateful. The communication at the 1st screen needs to be something clear because first impressions are really important and parents cling to those. Secondly it is important the PCP continues to stress the importance.

Emilee Scheid: I'm a PCP. I see a difference between providers that are salary based and have the resources (staff) to help. In a productivity based system, PCPs are working hard and may not always have the nursing staff to provide communication/education with the patient, and that may require an office visit to give the education to the families, which I see as a barrier. I try to educate my co-workers as well because I see a deficit in knowledge when the PCP sees mainly adults. PCPs who see mainly adults may not have hearing follow-up at the top of their mind unless the parents bring it up themselves. I do see there is a need to educate PCPs. If I didn't have my own child with hearing loss, I might also have not gone further than asking if they have done follow-up.

Q: Kirsten: Do you have any recommendations on what kind of education? We've offered presentations to clinics and colleague to colleague. Other states have offered CMUs—would that be a motivator?

Lisa Schimmenti: We are all slaves to our electronic health record. There are things we could do with AAP and work with EHR software companies to make hearing more of the checkbox on their office plan

Abby Meyer: we should target training programs (physicians, nurses, PAs, etc) to educate providers about follow-up for hearing screening

Teresa Buck: MDH High-risk pregnancy reports don't have hearing results on them but that might be an option.

Jay Wyant: I keep hearing about how the importance of follow-up is downplayed at the screening visit. Can we train people not to do that?

Kirsten Coverstone: MDH always provides training for screeners to be comfortable with talking about follow-up. Perhaps it is providing training in every hospital every

	<p>six months? We recommend annual refresher training over all screening</p> <p>Emilee Scheid: We should have a resource (PCP, audiologist) and talk to PCP conferences to talk about hearing. I haven't heard a pediatric hearing lecture</p> <p>Melinda Marsolek: Do I hear that you think educating PCPs might have different needs of educating pediatricians vs family practice?</p> <p>Emilee: It would have higher benefit by targeting family practice physicians because pediatricians are hitting most of the developmental milestones but family practice physicians might see mostly adults</p> <p>Melinda: so also more frequent opportunities for training screeners</p> <p>Abby Meyer: We would love to give training talks</p> <p>Q: Nancy Vanderburg: Is the softness of the language "refer" not enough to get families to follow-up? Maybe if the word was "fail" that would signal to the parent to follow-up?</p> <p>A: Kirsten Coverstone: Always a huge discussion. Families have said they don't want "fail" because that means their child did something wrong. "Refer" helps families know it is not their fault.</p> <p>Shamara Freeman: "refer" is just soft. It's like "we refer you, we suggest you" to go through this. Should be "did not pass" hearing screening. Maybe the word "abnormal?" But "refer" means suggestion to me. Coming from the African American community, if it is just a suggestion, then we don't think about follow-up</p> <p>Q: Candace: Have other states tested different words like "fail?"</p> <p>Nicole Brown: Nationally, we have gotten away from the word "fail."</p> <p>Q: Lisa Schimmenti: Is there a script available for the screener?</p> <p>A: Kirsten Coverstone: Yes, MDH has provided laminated copies to screeners with script and talking points</p> <p>Joscelyn Martin: I say to families "I want you to be just worried enough to come back to have a test." Our program doesn't use nursing staff- we used dedicated audiology assistants. At Mayo, we do target the residents and talk about newborn hearing screening and I give them the top 5 ways to get families to follow-up. Some providers go on to be good encouragers of families</p> <p>Q: Jessica Cavazos: Can we put educational materials in the email to parents or through patient portals?</p> <p>Q: Abby Meyer: Can MDH send emails or texts to families?</p> <p>Kirsten Coverstone: We are trying to get that information</p> <p>Jessica Cavazos: Texting for follow-up with phone numbers they have provided is being investigated</p> <p>Emilee: In order for the message to get to a parent, the parent has to sign up the child for mychart and they don't always sign up unless they need immunization records and that may happen when the child is a few months old.</p> <p>Melinda: This has been great, we'll take these ideas and think about next steps, possibly form a work group if that is an interest. Thank you.</p>
<p><b>BREAK</b></p>	<p>Candace: Linda Murrans is retiring after 40+ years in the field. Candace thanked her for her many contributions to audiology in MN and to Newborn Hearing Screening. Melanie Wege also thanked her and all stood for a standing ovation!</p>
<p><b>6. MDE EHDl Update</b> ECHO Project Kathy Anderson</p>	<p>Described composition of Regional EHDl teams (educational audiologists, DHH teachers, ECSE teachers, SLP, EI coordinators, IEIC member , Social worker)</p> <p>Regional EHDl teams had annual training in October 2015. Agenda included review of current EHDl system in MN, small and large group discussions of evidence-based practices, development of regional plans for 2015-2016, and review of resources added to Low Incidence Projects EHDl site.</p>

	<p>MN collaborated with Early Childhood Hearing Outreach (ECHO) to provide training to MN education and Head Start staff on OAE hearing screening for ongoing monitoring after the newborn period. 200 professionals have been trained across MN. Goal is to increase hearing screening in Early Head Start and increase documentation of hearing status for children who are referred to/receive EI and ECSE services.</p> <p>Participating districts have systems for follow-up and referral.</p> <p>5-6 Pilot sites with work with ECHO staff on data collection and recommendations</p> <p>Surveys of school districts on how they document hearing status will be done for 2015-2016.</p> <p>Jay: Please explain OAE, ABR</p> <p>Linda: Explained screening techniques.</p>
<p><b>7. MDH EHDI Update</b></p> <p>CDC EHDI Data &amp; MNScreen Update</p> <p>Kirsten Coverstone</p>	<p>The data that CDC reports is calculated differently than the data reported within MN (e.g. in our EHDI Annual Report).</p> <p>CDC uses last completed screen at any time/any age for screening status (including outpatient) whereas MDH program uses the screening status at hospital discharge.</p> <p>LTFU for CDC is # No Diagnosis/# Did not pass at any point</p> <p>LTFU for MDH is # No Diagnosis/#Did not pass at hospital discharge</p> <p>Some states consider anything done by an audiologist as 'diagnostic' (including rescreens) while others differentiate between audiology screening and audiology diagnosing.</p> <p>States define refusals differently which can have a big effect on the LTFU number.</p> <p>MNScreen Update: Hearing and CCHD screening results will be sent directly from equipment to MDH. This will eliminate information being misreported due to human error (e.g. refer result reported to MDH as pass/pass).</p> <p>For birth coverage: 63% of births are in hospitals that are actively implementing, 9% are already implemented, 29% are not active. We expect 70% of births to be covered by end of January 2016.</p> <p>Our implementation trajectory is similar to other states</p> <p>Challenges: implementing both hearing and CCHD at the same time. CCHD is new so involves big changes for facilities; getting facility staff onboard; Critical Access Hospitals which have low volume of patients and no internal IT support so they need to figure how to pay for external IT services; one technology issue due to a concern about security of the system; resistance at some hospitals to collecting information about risk factors – MDH is doing a survey of hospitals to get a better understanding of which risk factors can be collected at different sites;</p> <p>MDH staff time has been greater than expected</p> <p>Expect that ongoing QA with submitting hospitals will be needed</p> <p>Mis-entry of results into EMR is far more prevalent than we thought</p> <p>Serial screening is happening.</p> <p>MDH will declare EHDI and CCHD as a specialized registry which means that birth facilities will have an incentive to report electronically (meaningful use)</p> <p>CMV update: MDH/CDC/Schleis UofM Lab are collaborating on a grant to determine if universal screening for CMV is possible and which method is best for CMV screening of newborns. This is different than the way Utah is doing it (only screening babies for CMV if they do not pass their outpatient rescreen).</p> <p>Consent will be obtained in the hospital and children will be followed for 4 years.</p>

**8. Closure**  
Tina Huang

Next Advisory Committee Meeting: February 10th, 2016, 1-4pm

LOCATION:

Amherst H. Wilder Foundation

451 Lexington Pkwy. N

Saint Paul, MN 55104

As always, please notify chair to add any partner updates on the meeting agenda.

Joscelyn discussed next meeting and adjourned.