

Newborn Hearing Screening Advisory Committee Meeting Minutes

November 9, 2016 1:00 - 4:00 p.m.

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

Facilitator: Kirsten Coverstone, Nicole Brown

Recorder: Darcia Dierking

Attendees:

Kathy Anderson, Joan Boddicker, Nicole Brown, Mary Cashman-Bakken, Kirsten Coverstone, Tina Huang, Candace Lindow-Davies, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Sara Oberg, Anna Paulson, Emilee Scheid, Lisa Schimmenti, Michael Severson, Kara Tempel, Jay Wyant

Absent:

Peggy Nelson, David Rosenthal, Teresa Buck

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p>1. Welcome and Announcements</p> <p>Joscelyn Martin</p> <p>a. August 2016 minutes approval</p> <p>b. Vice-Chair Nominees</p> <p>c. Voting for 2017 Vice-Chair</p>	<ul style="list-style-type: none"> • Vote to approve minutes from August Meeting: Jay Wyant motioned to approve, Tina Huang seconded, motion approved by vote. • Vote for Vice Chair for 2017: Candidates gave their remarks to be considered. <ul style="list-style-type: none"> ○ Joan Boddicker: parent of a child who is Deaf or hard of hearing--encouraged by work EHDI Advisory Committee is doing, and wants to also help children identified after screening ○ Lisa Schimmenti: has been involved in multiple EHDI initiatives in Minnesota and research on childhood hearing loss ○ Votes tallied: Lisa Schimmenti will be the Vice Chair (announced at the break).
<p>2. EHDI Story / Tele-Audiology Project</p> <p>A Day in the Life of an Educational Audiologist –</p> <p>Diana van Deusen</p>	<ul style="list-style-type: none"> • Every day is wildly different. First, I am assessing hearing, and ensuring kids are hearing as best they can. I encourage consultation with their MD, use of amplification (hearing aids, FM/DM systems and cochlear implants), and educating children, families and staff about hearing capabilities. Reminding that you can't see hearing loss, it is visible in behavior. • Have caseload of 120 kids age 3-21 in 7 schools, working with the students, teachers, parents, and staff. Works toward integrating education into the assessment—I want people to understand their hearing loss, and I make sure they have a qualifying hearing loss to receive service in the school. Minnesota's criteria is more generous than other states to qualify. • Described qualification criteria. Criteria for qualifying in early childhood is different than qualifying at school age. Described functional listening evaluation that helps describe how child hears in everyday life. Some children benefit from medical treatments, like PE tube or other surgeries.

EHDI Story / Tele-Audiology Project continued

A Day in the Life of an Educational Audiologist – Diana van Deusen

- Home visits with a good interpreter have been helpful, especially with families where English is not their first language, for helping families understand ear conditions and hearing loss. It's important for the interpreter to see the big picture and partner in order to get accurate understanding from families. There is a lot of variation in interpreters and their level of competence of being an interpreter, gave story of how an interpreter counseled family to leave hospital without doing surgery (which was not the advice of professional).
- Works often with physicians and clinical audiologists. Described kids who benefit most from amplification and those that have less benefit. St. Paul kids don't always wear amplification at the same rate as her suburban kids. Cultural diversity: 40% of kids on St. Paul caseload are Hmong. One thing found is that sometimes need to call families to tell them their appointment is tomorrow because they don't always use a calendar.
- I involve parents and teachers in as many assessments as possible so they better understand and believe results. Gave story of her family member diagnosed with unilateral hearing loss—the unседated ABR was difficult and subsequent ABRs were done. It was hard to believe results, test conditions, and disagreed with recommendations at first. Had 2 subsequent ABRs at a different audiologist and was diagnosed with mild-moderate unilateral hearing loss. Had CMV testing. Child is using a hearing aid and a pilot cap to retain hearing aid. Gave a second example of another child that is also getting genetic work-up.
- Question: Is it really ok to use a pilot cap?
- Linda Murrans: Pilot cap helps retain, and is acoustically transparent and kids don't have to wear it too long.
- Question: Do parents see the benefit with the hearing aid with the unilateral loss?
- Diana: It is difficult for the parents to see.
- Joscelyn Martin: It seems easier for parents to see when kids are older.
- Diana: Kids that are fit early seem to feel more comfortable with the devices

3. EHDI Workgroup

Medical & Audiology Guidelines

Nicole Brown & Darcia Dierking

- Darcia Dierking: Audiology guidelines update: Almost done with referral guidelines and researching the assessment and amplification guidelines.
- Nicole Brown: Propose a facilitated meeting immediately prior to the next meeting and come to consensus on the terminology we want to use. Whoever would like to participate, please plan to attend
- Jay Wyant: We should get parent perspective.
- Candace Lindow-Davies: That would be good to get parent perspectives.
- Kirsten Coverstone: It is very important to get the providers input as well since it will be their guideline. It will be coordinated, collaborative effort.

4. D/HH Collaborative Project Update

Providing Resources and Information to families of children who are D/HH

Candace Lindow Davies
Anna Paulson

- Anna Paulson: We worked on one goal for getting families access to available resources and information that is accurate, well-balanced, comprehensive and conveyed in an unbiased manner
- Candace Lindow-Davies: Information gathering included parent surveys and agency partners and others. The goal was for information to be revised by July 2016.
- Anna: Took a deep dive into materials, it was more work than we thought it would be. We did materials review, we've removed, revised and tweaked. Next steps find materials in Spanish, Hmong, and Somali translations.
- Mary Cashman-Bakken: there is a language component missing—could we add another section on language development?
- Kathy Anderson: We are thinking resources on language development would be helpful, regardless of what communication mode they are using.
- Candace: The binder is a resource of information but also a receptacle for additional information that could be geared specifically for that child. Care plans for the specific child could be added later.
- Kathy: Right now parents are also getting the Beginnings books that does have some information about language development.
- Candace: Reminder that the goal is about all of the resources, not just the MDH binder.
- Anna: by January 1, 2017, the goal is to have resources reviewed and a plan for ongoing review of materials, how they are paid for, and a stakeholder group will meet annually in August. The 2nd goal is by March 1, 2017, there will be a plan on the mechanism of how the information is provided.
- Candace: Proposed an “extended road map” for who does what in the EHDI system and link to resources for each professional. Nicole has found a template and done an early draft. That is in progress and is not a finished product.
- Advisory Committee members asked to provide feedback or previous experience about information resources and how it is delivered.
- Emilee Scheid: It is good for resources to be able to grow with the children, because it may be hard for families to know what resources are appropriate as their children grow.
- Anna: It is important for parents to be able to self-advocate.
- Mary Cashman-Bakken: MDE has standards for all kids at the different ages. Expectations are the same as if the child is hearing.
- Candace: The collaborative does try to improve outcomes for children who are DHH and Emilee has a good point we should look into further
- Nicole Brown: Would be great to have a “welcome to kindergarten” information for families—we rely on our DHH teachers, but not all the kids have a DHH teacher.

<p>5. MDE Update</p> <p>Boys Town Modules update</p> <p>Kathy Anderson</p>	<ul style="list-style-type: none"> • Kathy: MN Regional EHDI teams—62 teachers of DHH, Educational audiologists, ECSE teachers, and SLPs. Also ECSE coordinators, IEIC reps, and part C service coordinators • Had annual EHDI team on Nov 3-4, 2016. Reviewing information provided to MN families, intro to parent-friendly JCIH 2013, provided MDE DHH and EC updates and created regional plans to work toward greater outcomes for children. • Boys Town online modules: Auditory Consultant Resource Network (ACRN). Assessment in early intervention for children is \$125. • Early Childhood hearing screens: documentation of hearing status of children referred to part C/B and IFSP/IEP planning. There is a national resource (Early Childhood hearing outreach- ECHO) that provides technical assistance and training. There was a training in 2014 and there will be a refresher training in Dec 2016. • Joan Boddicker: What is OAE? • Kathy: it is a hearing screen technology.(described). If there are concerns, family can have further follow-up. • Joscelyn Martin: further described OAE and ABR technologies and how they are used in screening and diagnostic applications.
<p>6. Break</p>	
<p>7. Vice-Chair Announcement</p> <p>Joscelyn Martin</p>	<ul style="list-style-type: none"> • Lisa Schimmenti will be the Vice Chair.
<p>8. MDH EHDI Update</p> <p>a. MNScreen</p> <p>b. CMV Conference</p> <p>c. EHDI HRSA Grant Application</p> <p>d. 2015 Annual Report</p> <p>Kirsten Coverstone</p> <p>Nicole Brown</p>	<ul style="list-style-type: none"> • MNScreen: More sites on board, nearly finished. • CMV Conference: Engagement of parents is similar to how it was for EHDI at the beginning. MDH was interviewed recently by MPR, and we can expect to be asked more about CMV. For the CMV project, the goal is to have over 30,000 infants enrolled across the sites. • Nicole: There is a need for awareness and prevention and how this fits with what we are currently doing and how it fits with EHDI. There was a consensus recommendation, Dr. Schliess from the U of M was in that group. There was great debate about whether it should be targeted, universal or no screening. Thinking more broadly about developmental implications of CMV, more than just how it fits with EHDI. • Joan Boddicker: Asked for clarification on how children get CMV and what method is used for screening. • Kirsten: there are urine, blood spot, and mouth swabs being studied. • Joan: What percentage of kids get CMV and what do they develop later on? • Kirsten: Without universal screening, we don't know the whole picture, but CMV is called the birth defect virus because it is more prevalent than other conditions. And there are children that are born with no signs but they could develop hearing loss. Also, only about 50% of kids with symptomatic CMV are being identified. • Sarah: What did people think about vancyclovir? • Kirsten: there was debate about that but the recommendation was to offer the treatment to kids with symptoms. Mark Schliess would be able to offer more details and information about that.

<p>MDH EHDl Update continued</p> <ul style="list-style-type: none"> a. MNScreen b. CMV Conference c. EHDl HRSA Grant Application d. 2015 Annual Report <p>Kirsten Coverstone Nicole Brown</p>	<ul style="list-style-type: none"> • EHDl HRSA Grant: March 31, 2017 is the end of a 3-year HRSA grant cycle (about \$250,000) per year, and the new application has more goals than the traditional 1-3-6. They required applicants to use 25% of the funding for family support. For a lot of other states, that will really impact how they currently run their program. One great thing is that there will be more partnerships with parent-support across the country. Discussed requirements of new HRSA grant application. Some of the requirements were easy for us in MN because we had them in place already. They also wanted us to reach out to the LEND program in Minnesota, which is at the U of M. They also wanted us to have learning collaborative and engage health providers and provide education. They want to embed QI activities in the EHDl program and implement health information technology. We will be looking at ongoing needs of families through partnerships with local public health agencies. ECLDS update: Will look at experiences and educational results for children who are DHH across the programs. Has not been approved yet but we are well on the way. • Mary Cashman-Bakken: How do they do the match without giving the names? • Nicole: Matching happens behind the scenes and then de-identified. There is strict security on how the data warehouse is used. Hopefully in February EHDl stakeholders can test it. • 2015 EHDl Annual Report: this is the 3rd EHDl annual report: Committee given annual report. This report focuses on families, partnerships and data/evaluation initiatives. Our reporting is getting better and better, which affects the rates. Plan is to focus on the timely diagnosis. We will be asking for input from this group on what should or could be in this report in the future. • Dr. Severson: Great report format! What about distribution? What about hospitals/nurses at the front lines? Maybe a booklet for the breakrooms at the hospitals with a cover letter. • Kirsten: yes- it is distributed in print form and electronic form to several audiences and online and it would be great to share back with nurses doing screenings. • Linda Murrans: Great idea to share information back. • Kirsten: It is great to have EHDl advisory members send notes and share this report, electronically, preferably, but will be available in the form you need.
<p>9. EHDl Workgroup Priorities</p>	<ul style="list-style-type: none"> • Nicole: Discussed current EHDl advisory committee workgroups and their importance, and gave some topic ideas. • Group discussion • Anna Paulson: Children from recent immigrant communities could benefit from hearing screening so they are placed appropriately in school, could there be overlap with ECHO initiative • Mary Cashman-Bakken: add benchmark on language development—this can't be done in school—it needs to be done earlier because it is a serious gap. • Kathy Anderson: Benchmark on enrollment to EI • Gloria Nathanson: There is a need for funding for Deaf mentors • Voting on workgroup topics categorized by before identification, after identification, and other. • Committee leadership will look at results of voting.

10. Closure

- a. Topics / partner updates to put on the agenda
- b. Next Advisory Committee Meeting: February 8, 2017

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Adjournment

Joscelyn Martin

- Lisa Schimmenti: next year (2017) is 10 year anniversary of EHDI legislation in Minnesota, can we do something to commemorate.
- Joan Boddicker: Would like a presentation of what happens after diagnosis and connection to teachers, etc.
- Lisa: perhaps maybe an EHDI 101, like at national conference
- Jay: Would like demonstration of how and when audiology tests are done. Joscelyn/Linda: perhaps by video.
- Candace: Cultural experience presentation from a parent with a child identified later after newborn screening.
- Abby Meyer: There are considerations now for children with single sided deafness to get cochlear implants, but right now it is all off-label because there are not FDA guidelines.
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- Notify Chair if there are any Partner Updates to put on the agenda
- Adjournment