

## Newborn Hearing Screening Advisory Committee Meeting Minutes

February 8, 2017 1:00 - 4:00 p.m.

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

**Facilitator:** Sara Oberg, Chair

**Recorder:** Melanie Wege, Michelle Gin

**Attendees:**

Kathy Anderson, Nicole Brown, Teresa Buck, Mary Cashman-Bakken, Kirsten Coverstone, Candace Lindow-Davies, Joscelyn Martin, Abby Meyer, Linda Murrans, Gloria Nathanson, Sara Oberg, Emilee Scheid, Lisa Schimmenti, Michael Severson, Kara Tempel, Sonny Wasilowski, Jay Wyant

**Absent:** Joan Boddicker, Peggy Nelson, David Rosenthal, Tina Huang, Anna Paulson

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p><b>1. Welcome and Announcements</b></p> <p>Sara Oberg, Chair</p>	<ul style="list-style-type: none"> <li>• Review of 2018 meeting dates, all will continue to be held at the Wilder Foundation</li> <li>• Review of past meeting minutes – no corrections. Motion to approve minutes– Nicole Brown, second by Linda Murrans, vote – motion passed.</li> <li>• Announcement from Jay -Common Ground project will be having a workshop on Sunday of National EHDI conference – it is a working group of people and professionals representing schools for the deaf (sign language and deaf education) to develop an approach looking at children’s needs first, rather than focusing on the culture first (to ensure the child grows up with good communication skills)</li> <li>• Announcement from Nicole - MN Hands &amp; Voices contract is up June 30<sup>th</sup> of this year, so let Nicole know of any other organizations that provide DHH parent specific support so that the state can offer RFP for bid</li> <li>• Introductions of members</li> </ul>
<p><b>2. EHDI Story – Parent Perspective</b></p> <p>Grace Olakunle</p>	<ul style="list-style-type: none"> <li>• Came from Nigeria</li> <li>• Works at Regions in psychology dept.</li> <li>• Parent of 3 children, 2 who are Deaf/ Hard of Hearing – age 20 son at Gallaudet; second son age 17 is hearing; third child, daughter, age 11 was identified with hearing loss at birth</li> <li>• There was no newborn hearing screening in 1997 when her first child was born. She didn’t know difference between doctors, as a new immigrant, (specialists versus regular doctor) so she kept going to a family practice doctor who wasn’t concerned about her child’s hearing even though she expressed concerns that he was not making any sounds at age 1. After she moved, the new doctor WAS concerned and sent her son to Children’s Minneapolis for diagnosis. This new doctor also referred the family to early intervention and MN Hands &amp; Voices. The parent support group made a huge difference in her life!</li> </ul>

<p><b>Continued: EHDI Story – Parent Perspective</b></p> <p>Grace Olakunle</p>	<ul style="list-style-type: none"> <li>• Her oldest son had a cochlear implant at age 3. The implant did not work well for her oldest son – too much time had passed. He uses ASL and is doing great.</li> <li>• 2<sup>nd</sup> son born 3 years later. The hearing screening device was not working while they were in the hospital, but now she knew what to do! She made an appointment for the hearing screening and he passed.</li> <li>• 3<sup>rd</sup> child did not pass, and she was very upset, but knew what the resources were. Her daughter was fit with hearing aids at 5 months, started early intervention at 8 months, received a cochlear implant at 10 months old and went to Northern Voices School. She primarily used listening and spoken language. She speaks fluently and attends school at the Achieve Language Academy.</li> <li>• Immigrant families have difficulty accepting the diagnosis of a child’s hearing loss. They just need reassurance that their child will “be somebody” in life. In her country, nobody cares for deaf people. People believe that there is some kind of evil causing it. Deaf people are even cast out by their parents because they don’t believe their child can do anything.</li> <li>• When they moved to Maplewood, the school district told her they would help take care of everything for her younger daughter’s education (funding, transportation, IEP meetings, etc.). That really took a load off and if all school districts can learn that, that would be good.</li> <li>• Question - Did she know that a school for the deaf was an option? <ul style="list-style-type: none"> <li>○ Yes, she did. She did send her oldest son to one of them [school for the deaf] in Minneapolis. However, she was told that he wouldn’t be accepted in a school for the deaf because he already had a cochlear implant. Her oldest son has had a similar experience now at Gallaudet. He had a sense that he wouldn’t be accepted, so he just wanted to take the cochlear implant off.</li> </ul> </li> <li>• Question – sometimes in other cultures the grandparents don’t accept the diagnosis that their grandchild is Deaf / Hard of Hearing and sometimes that is a barrier to the child’s care and education. How can we better educate immigrant communities to improve this barrier? <ul style="list-style-type: none"> <li>○ Do some home visiting right away to give them resources so they know this diagnosis is not the end of life. They might think they are the only one out there, but they need to know that isn’t how it really is.</li> </ul> </li> <li>• Comment from Candace that funding for cultural guides has been key to help parents and families move forward.</li> </ul>
<p><b>3. EHDI Workgroup</b></p> <p>Audiology Guidelines Medical Guidelines Bylaws</p> <p>Darcia Dierking, Nicole Brown, Kirsten Coverstone</p>	<ul style="list-style-type: none"> <li>• <b>Audiology Guideline</b> revision will receive renewed focus after the Medical Guidelines are complete.</li> <li>• <b>Medical guidelines</b> – Today there was a pre-meeting workgroup discussion regarding wording to use to describe the hearing screening results. The recommendation of the workgroup was to use “PASS” and “ALERT: REFER Result (Further Testing Needed)” wording in the medical guideline. At the last meeting in November, the guideline was reviewed from beginning to end, so this was not being repeated today. <ul style="list-style-type: none"> <li>○ Summary of changes that happened since the last meeting included <ul style="list-style-type: none"> <li>▪ 1. Pass, alert/refer result wording,</li> <li>▪ 2. Addition of new link to NICU guideline,</li> <li>▪ 3. Recommended edits / formatting from Nov. discussion included removal of urinalysis from primary care evaluation,</li> <li>▪ 4. revision of Early Intervention section (broke out Part C and Special education section more) based on Kathy and Cara’s recommendation.</li> </ul> </li> <li>○ Jay motioned to accept the committee’s recommendation to use <b>PASS</b> and <b>ALERT: REFER Result (Further Testing Needed)</b> wording. Candace/ Nicole 2<sup>nd</sup>. No more discussion. Vote – motion passed.</li> </ul> </li> </ul>

<p><b>Continued - EHDl Workgroup</b></p> <p>Audiology Guidelines Medical Guidelines Bylaws</p> <p>Darcia Dierking, Nicole Brown, Kirsten Coverstone</p>	<ul style="list-style-type: none"> <li>○ Linda motioned to accept and approve all overall changes to the document. Joscelyn / Jay 2<sup>nd</sup> the motion. No further discussion. Vote – motion passed.</li> <li>● <b>Bylaws</b> (Kirsten and Nicole) – Suggested edits to this document were e-mailed to members 2 weeks ago. The goal with edits was to update, clean up, and align with current processes and statutes. The committee can't vote on changes today...need 60 day review. Suggested edits were reviewed and the floor was opened for any additional comments on the document. A tentative plan is to complete a vote on this document by e-mail. <ul style="list-style-type: none"> <li>○ Question – Is this committee required to follow the open meeting law? *"YES", was the response. Second question was whether the committee could then complete a vote by e-mail. MDH will look into that to be sure.</li> </ul> </li> </ul> <p><i>*Clarification: this committee is NOT subject to the Open Meeting law. The committee meetings are open to the public.</i></p>
<p><b>4. D/HH Mentor &amp; Role Model Update</b></p> <p>Danelle Gournaris Chelsea Paulson</p>	<ul style="list-style-type: none"> <li>● <b>Deaf Mentor Family Program</b> is focused on teaching ASL to families who have chosen ASL from birth to age 6. Story of a child with cochlear implants struggling with language at age 2 and then the family decided to try ASL. Prior to ASL the child had many tantrums. With ASL, she was able to understand what "no" meant. Then the parents felt better about discipline. <ul style="list-style-type: none"> <li>○ Program is currently serving 37 families</li> <li>○ Funding comes from MDH and DHH services. This only covers serving 30 families. The program is still growing, and they now have 29 families on a waiting list.</li> <li>○ Needs assessment survey was completed for participants in the Family Mentor Program last year to determine next steps for program expansion. Link for the full survey report is here: <a href="http://www.lifetrack-mn.org/news/blog/2015-09-14/mentoring-needs-minnesota-families-children-who-are-deaf-and-hard-hearing">www.lifetrack-mn.org/news/blog/2015-09-14/mentoring-needs-minnesota-families-children-who-are-deaf-and-hard-hearing</a></li> <li>○ Main needs determined from the survey were 1. Focus on mentoring and support, 2. Program structure, 3. Characteristics of mentors (flexibility in providing services, patience, and unbiased are 3 key desirable characteristics of mentors)</li> <li>○ ASL classes are being offered at Lifetrack or via livestreaming for greater MN families; expanding to serve school age children (7-21); also now partnering with DHH Role Model Program at MN Hands &amp; Voices events.</li> </ul> </li> <li>● <b>Deaf and Hard of Hearing Role Models Program</b> - role models are available for Listening Spoken Language, Cued Speech, and ASL – need flexibility to understand and discuss whatever the family wants. Need to "put hope within reach" – motto of Lifetrack. <ul style="list-style-type: none"> <li>○ They set up 1-3 sessions with a baby newly identified as DHHH</li> <li>○ All MNH&amp;V events have all role models available to answer questions</li> <li>○ Role model guidelines have been developed (2013)</li> <li>○ Need for role models in NW and NE Minnesota</li> </ul> </li> <li>● Question – what is "LSL"? – Listening &amp; Spoken Language <ul style="list-style-type: none"> <li>○ Danelle noted the need to present unbiased information to families and represent all different modalities– need to support families and what families need, not trying to convince family of a certain system. Need to provide information and let the families decide.</li> </ul> </li> </ul>

<p><b>Continued - D/HH Mentor &amp; Role Model Update</b></p> <p>Danelle Gournaris Chelsea Paulson</p>	<ul style="list-style-type: none"> <li>• Question about LEAD-K and what it is – LEAD K is an educational movement – <u>L</u>anguage <u>E</u>quity <u>A</u>cquisition for <u>D</u>eaf through <u>K</u>indergarten. <ul style="list-style-type: none"> <li>○ Sonny - All children must achieve by grade level by kindergarten. Children who are DHH fall through the cracks and if still not at grade level then must find a modality that is at grade level.</li> <li>○ Candace – goal of Lifetrack is to respect ability of parents provided with well-rounded information to be making best decision for a language option for their child. Lead K can positively lay this out, that the goal is for child to have adequate language by Kindergarten.</li> </ul> </li> <li>• Question – Could the Deaf Mentor Program share a mentor for multiple families at once, to accommodate the shortage of role models? <ul style="list-style-type: none"> <li>○ For the Deaf Family Mentor Program they assign a mentor closest to the family’s location. But costs/ resources are stretched. They try to do groups with multiple families. They try to take advantage of MN &amp;V events to provide access to multiple mentors.</li> </ul> </li> <li>• To clarify – the Role Model Program is for ages 0-21. Family Mentor Program is for ages 0-6, but wanting to expand to older ages (limited funding)</li> <li>• Question - How do you measure success? <ul style="list-style-type: none"> <li>○ Danelle – Good question! Focus is on communication, so they measure language development. They use VCSL checklist to evaluate skills and where children are at. For Chelsea’s program, they support the family – social, exposure, education, etc. They have a checklist and that shows that parents who are more involved have children who develop more self-esteem. Determining success based on graduation rate, post grad employment – that is the scope of the schools.</li> </ul> </li> <li>• Question – Are there ASL guidelines for working with children from 0-6? <ul style="list-style-type: none"> <li>○ Yes they have a deaf mentor curriculum for ASL instruction for age 0-6 – and it is evidence based.</li> </ul> </li> <li>• MN is the first state to provide a role model for all communication modalities!</li> </ul>
<p><b>5. Break</b></p>	
<p><b>6. MDE Update</b></p> <p>National Help Me Grow</p> <p>Kara Tempel</p>	<ul style="list-style-type: none"> <li>• <b>Current initiative:</b> child and public awareness and outreach for children birth – 5 years old.</li> <li>• <b>Expansion</b> is based on national model based out of Connecticut Children’s Hospital to link children and families to services other than early childhood education and special needs child and toddler intervention.</li> <li>• <b>Referrals</b> <ul style="list-style-type: none"> <li>○ The rate of referral by parents, family, friends, and professionals grew from ~5,000 in 2014 to ~15,000 in 2015. Now in 2016, can see ~1,500 in one month.</li> <li>○ Have an online referral form on <a href="http://helpmegrowmn.org">helpmegrowmn.org</a></li> <li>○ When one calls in referral, the person on the other end of the line is filling out the online form.</li> <li>○ If a professional is making a referral, option to add child’s primary care physician and additional notes that would be relevant for the referral.</li> <li>○ Physicians have requested a release be allowed to be uploaded at the same time so they can notified of updates</li> </ul> </li> </ul>

<p><b>Continued - MDE Update</b></p> <p>National Help Me Grow</p> <p>Kara Tempel</p>	<ul style="list-style-type: none"> <li>• <b>Other changes to the website</b> (Kara Tempel is the one who manages it): <ul style="list-style-type: none"> <li>○ Resources for Professionals – the ‘Request a Presentation’ or ‘Request Materials’ will show a map of the state to select county in which you live in which then shows one the region they live in so relevant materials may be downloaded.</li> <li>○ Definition of Deaf or Hard of Hearing links to MDH’s webpage</li> <li>○ Good resource: Milestone handouts are now printer friendly</li> </ul> </li> </ul> <p>About the <b>EXPANSION</b></p> <ul style="list-style-type: none"> <li>• Moving forward with support from all three state agencies: Education, Health, &amp; Human Services</li> <li>• State Leadership Team continues to meet</li> <li>• Help Me Grow Implementation Coordinator began in January 2017, Shya Tran is leading this which includes many stakeholders beyond state agencies</li> <li>• Continues to be a Legislative funding request -request for 3 million over two years</li> <li>• The Help Me Grow National Forum will be held in Minnesota April 24-26, 2017 <ul style="list-style-type: none"> <li>○ 30 states are involved with this model</li> </ul> </li> <li>• Question <ul style="list-style-type: none"> <li>○ Sonny: Does Shya have a disability? <ul style="list-style-type: none"> <li>▪ A) Not that Kara is aware of.</li> </ul> </li> <li>○ Sonny: is it too late for the State Academies to join and add their resources? <ul style="list-style-type: none"> <li>▪ A) No, not too late. Need to look at National Help Me Grow to make sure goals align.</li> </ul> </li> </ul> </li> </ul>
<p><b>7. MDH EHDI Update</b></p> <p>MNScreen Learning Collaborative ECLDS</p> <p>Kirsten Coverstone Nicole Brown</p>	<ul style="list-style-type: none"> <li>• <b>MNScreen:</b> Looking at Hearing Screening Process from before, involved manual data entry. All the manual steps are areas of where we can get inaccurate data. Currently with new system in place, it is a shorter process and only one of ten steps is manual data entry.</li> <li>• Review OZ Systems Platform to implement MNScreen</li> <li>• Observations: <ul style="list-style-type: none"> <li>○ electronic work flow isn’t perfect</li> <li>○ From May 2014 to January 2017, have 87/90 (99.8%) using MNScreen</li> </ul> </li> <li>• Next phases: <ul style="list-style-type: none"> <li>○ complete implementation</li> <li>○ interoperability with blood spot results</li> <li>○ refining follow-up workflows</li> <li>○ addressing submitter/system challenges</li> <li>○ renew focus on midwifery practices</li> <li>○ send EHDI/CCHD results back to EMR</li> <li>○ updating system reporting platform for diagnostic data</li> <li>○ obtaining risk factors from EHR</li> </ul> </li> <li>• 2016 data will be challenging to review because we are in two systems</li> <li>• Question <ul style="list-style-type: none"> <li>○ Teresa: Will this ever be available on the MDH birth record for high risk? <ul style="list-style-type: none"> <li>A) we are still exploring how to collaborate with other MDH programs like WIC. I know you have brought up this before Teresa and it is definitely worth us exploring too.</li> </ul> </li> </ul> </li> <li>• Question <ul style="list-style-type: none"> <li>○ Jay: Looking at the new workflow process, is the data following data standard? <ul style="list-style-type: none"> <li>A) Yes, follows national data standards regulations.</li> </ul> </li> </ul> </li> </ul>

<p><b>Continued - MDH EHDI Update</b></p> <p>MNScreen Learning Collaborative ECLDS</p> <p>Kirsten Coverstone Nicole Brown</p>	<ul style="list-style-type: none"> <li>● <b>Learning Collaborative:</b> We want to look at communication systems between hospitals, clinics, and audiology clinics. We know there are significant disparities of diagnosis among diverse families compared to white families. <ul style="list-style-type: none"> <li>○ We are in the middle of a 10-month quality improvement project including North Memorial Hospital, Broadway Family Medicine Clinic, NorthPoint Health and Wellness Clinic, HCMC Audiology and Children’s Audiology.</li> <li>○ North Memorial realized that MDH materials that they give out lacked information on brain development. They also want to work on helping families make follow-up appointments before leaving the hospital</li> <li>○ NorthPoint, struggling to figure out which kids needed a rescreen because couldn’t easily find it in the EHR.</li> <li>○ Audiology, noticed notification of PCPs was inconsistent among audiologists. Are going to focus on families who are missing their first rescreen appointment.</li> <li>○ Focusing on Teach Back tool. Practiced role playing among participants.</li> <li>○ All providers are working on making appointments before a family leaves</li> </ul> </li> <li>● Question <ul style="list-style-type: none"> <li>○ Sonny: Do schools report a child who has failed a screen? A) No.</li> </ul> </li> <li>● <b>Minnesota’s Early Childhood Longitudinal Data System (ECLDS)</b> <ul style="list-style-type: none"> <li>○ It’s live!</li> <li>○ It is all de-identified, and numbers under 10 are considered counts too small to show.</li> <li>○ EHDI data is now included into the Longitudinal Data System! <a href="http://eclds.mn.gov/">http://eclds.mn.gov/</a></li> <li>○ additional filters and charts will be made to review on child and family demographics, participation in childhood programs, 3<sup>rd</sup> grad proficiency scores, etc.</li> <li>○ will be 3-year cohort for older kids.</li> <li>○ over time, there will be more info added. Goal is to connect with the SLEDS data. <a href="http://sleds.mn.gov/">http://sleds.mn.gov/</a></li> <li>-</li> <li>○ Question <ul style="list-style-type: none"> <li>■ Sonny: Does this give us more data for enforcement? A) This is more for guidance of policy and to review in committee</li> </ul> </li> </ul> </li> </ul>
<p><b>8. Topic Requests and/or Partner Updates for Next Agenda</b></p>	<ul style="list-style-type: none"> <li>● Gloria: Announcement US Deaf history Conference on March 15<sup>th</sup> &amp; Deaf Awareness Day on April 15<sup>th</sup> in White Bear Lake. There will be interpreters</li> </ul>
<p><b>9. Closure</b></p> <p>Sara Oberg, Chair</p>	<ul style="list-style-type: none"> <li>● Next Advisory Committee Meeting: May 17, 2017 <i>LOCATION:</i> Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</li> <li>● Adjournment</li> </ul>