# Newborn Hearing Screening Advisory Committee Meeting Minutes

**May 14, 2014 2:00-5:00 p.m.**

**Minnesota Department of Education Conference Center**

**1500 Highway 36 West, Roseville, Room CC16**

**Facilitator:** Emilee Scheid

**Recorder:** Melinda Marsolook
Nicole Brys

**Approved:** August 6, 2014

**Attendees:**

- Kathy Anderson, Nicole Brown, Mary Cashman-Bakken, Dennis Ceminski, Kirsten Coverstone, John Gournaris, Mary Hartnett, Tina Huang, Candace Lindow-Davies, Joscelyn Martin, Linda Murrans, Gloria Nathanson, Peggy Nelson, Sara Oberg, Emilee Scheid, Lisa Schimmenti, Geoffrey Service, Michael Severson, Rhonda Sivarajah, Emily Smith-Lundberg, Kara Tempel

**Absent:**

- Karen Doenges, Karleen Maeurer

## AGENDA ITEM

### 1. Welcome and Announcements

*Emilee Scheid*

- Tina Huang moved to accept the minutes, Linda Murrans seconded.
- Proposal to change scheduled meeting time to 1:00-4:00.
- Introduction of new MDH staff: Cara Weston - Data Coordinator for long term follow-up & Maggie Dreon - genetic counselor with newborn screening program
- Gloria Nathanson shared that they will be holding a Deaf Awareness Day this Saturday (5/16) from 10-4 at White Bear Lake High School
- Candace Lindow-Davies shared that ASTRA training was held April 26th and there were 60+ attendees. It was filmed and will be made available in English on the H&V website and possible in other languages as well
- Dr. Severson and Dr. Schimmenti gave an update on the new NBS legislation to restore long term storage of NBS bloodspot specimens and data. It is no longer an opt-in system, but parents still have the option to opt-out at any point. Law will take effect on 8/1/2014.
- Linda Murrans asked if there was an easy way for families to check for CMV at birth. Dr. Schimmenti responded that this is not currently the standard of care. Should NHSC recommend that this become standard in MN for children who do not pass hearing screening? Candace shared that Utah has passed legislation to do this. Kirsten Coverstone shared that 2 other states are also doing this and there is a conference in Utah in September about this. Nicole Brown asks when we should discuss this next. Dr. Severson moves that we have a CMV agenda item at every meeting until question about CMV screening in MN is resolved. Motion was seconded.
| 2. EHDI Story |  
| --- | --- |
| Case Review – Conductive/Transient Hearing Loss | Melanie Wege |
| • Brief overview of MDH long term follow-up process for children with permanent hearing loss |  
| • Overview of process for follow-up of transient hearing loss identified through newborn hearing screening: a letter is mailed to the Primary Care Physician (PCP). In the past a fax was sent 6 months later to check back on the hearing status, but PCPs generally did not have that information. MDH also tried following up with diagnosing audiologist, but they usually did not have information either. Currently a letter is still mailed to the PCP, but no follow-up with PCP or audiologist. |  
| • Case example #1: premature, medically complicated infant who was diagnosed with unilateral conductive hearing loss. Hearing loss was still present at 5 months and after tubes at 7 months. Amplification was recommended at 9 months because of the continued hearing loss. Example of good follow-up. |  
| • Case example #2: multiple refer rescreens and a slightly late diagnosis of bilateral moderate conductive hearing loss. Recommendation for ENT and additional testing when ears were clear. 3rd set of tubes at 17 months and a dx at 18 months of mild high frequency sensory loss right and moderate to severe sloping high frequency sensory loss left. |  
| • Both cases where initial dx was transient, but child did eventually need intervention (Part C and amplification). Both cases where MDH did get follow-up data, but for most children MDH does not receive follow-up data and there is concern about what is happening with the ~100 cases per year that are in this category of initial transient loss. |  
| • MDH is considering what to do with these children moving forward. |  
| 3. MDH EHDI Update |  
| MDH Review of Conductive/Transient Hearing Loss | Abby Meyer |
| • Analyzed cases of children initially diagnosed with transient hearing loss born in 2010-2012. |  
| • Categorized into three groups: hearing loss resolved, hearing loss became permanent, hearing status is unknown |  
| • For 2010: 48 cases, 36 with unknown results, 4 false transients |  
| • For 2011: 74 cases, 54 with unknown results, 3 false transients |  
| • For 2012: 100 cases, 70 with unknown results, 9 false transients |  
| • About 40% of those with unknown status had seen ENT, about 40% had complex medical histories, and about 40% had unilateral loss (at initial diagnosis) |  
| • Since 45% had seen ENT at some point, could we encourage ENT to report results to MDH? |  
| • Since 40% have complex medical histories and are likely followed by pediatric specialists in one of the 4 main pediatric hospitals, could we work with audiologists at these sites? |  
| • For those with unilateral loss, is the proper bone conduction technique being used? Are they not being reported because the sense of urgency is reduced? |  
| • Recommendation to start small by working with a limited number of audiologists and/or sites. Perhaps working with LPH for children who have not been back to audiologist for care. |  
| • Tina Huang and Linda Murrans mention that they do not think it’s standard of care in the community to retest the hearing after tubes are placed. |  
| • Melanie Wege mentions that if parents notice an improvement in hearing after tubes, they may assume hearing is fine even though it may not be an improvement to full hearing. |
### 4. Screening after the Newborn Period

**MDH Commissioner Comments on Guidelines**

Nicole Brown

- MDH and MDE Commissioners reviewed and accepted the guidelines.
- MDH Commissioner had a few questions/suggestions during his review:
  - Hearing screening questionnaire section: Can we include risk factors in the appendix?
  - Developmental surveillance & screening: Are the screening tools culturally valid? (that this information is available from Child & Teen Checkups website)
  - Monitoring program quality: we need to make sure we are screening the people who need to be screened
  - Overall: It might be good to add a section about outreach. I’m sure there are some groups not being screened at the appropriate level. The technical screen is useless unless it screens the people who need to be screened. (NB asks what the NHSAC would like to do with this comment. Is there anything we’d like to add to the document related to outreach?).
- Peggy Nelson and Kirsten Coverstone share that they don’t think the document needs to be revised as it is already approved and being utilized, but we should continue to work on promoting and disseminating the guidelines and ensuring that we target the appropriate screeners to make sure everyone is being screened.
- Dr. Severson recommends surveying to determine whether screening is currently being done (i.e. by family practice/pediatricians)
- Kathy Anderson shares that they had done a survey like this with Part C providers.
- Actions: we will prepare a response to the commissioner and a dissemination plan for the guidelines. Also will consider surveying physicians.

### 5. National EHDI Conference

- Highlights from the National EHDI Conference. Committee members can access presentations at [http://ehdimeeting.org/archive/2014/Schedule/grid.cfm](http://ehdimeeting.org/archive/2014/Schedule/grid.cfm) (handouts typically uploaded and plenary sessions videotaped)
  - Kathy Anderson: Half-day session on ECHO provided good resources that we could use in working with Headstart Programs. Mary Pat Moeller had a wonderful presentation of her research on outcomes for children who are hard of hearing.
  - Candace Lindow-Davies: session on ‘keeping hearing aids on children’. Candace came away with some good talking points for parents related to this. Growing body of research around bilingual/bimodal. Popular session about web-based ASL classes.
  - Kou (Hmong cultural guide for H&V) – was searching out cultural sessions, but there weren’t many. He was impressed by the adolescent panels at the conference
  - Kirsten Coverstone: interested in the CMV screening in other states and how to implement in MN. Enjoyed Mary Pat’s presentation – 65% of kids with hearing loss have risk factors. Interested in figuring out how we can better reach these kids. QI tool from NICHQ to improve audiology practice.
  - Nicole Brown: Agrees that Mary Pat Moeller’s presentation was great – took away strategies for reaching kids with risk factors. NCHAM is doing survey for parents and audiologists about hearing aids that MDH is going to participate. Plan to partner with WI on teleaudiology. Took away ideas on how to improve the EHDI annual report.
  - Danielle Gourinaris: went to workshops on language intervention and took away information about early language acquisition and consequences of delay– thinking about how kids can be exposed earlier to language/ASL because most of the kids she works with are ages 2-4 years
  - Next year’s conference will be March 8-10 in Louisville, KY

### 6. BREAK
### 7. MDE EHDI Update

**Part C Outcome and D/HH Data Results**

Kara Tempel  
Lisa Backer  

Lisa Backer reviewed data on outcomes for kids identified early with hearing loss  

- Use theory of action – kids have good outcomes when they have high quality services and supports provided by good local, state, and federal policies and programs  
- 3 functional child outcomes are % of kids who: demonstrate positive social-emotional skills, acquire and use knowledge and skills, behavior to meet needs  
- Not a significant difference in positive social relationships between children who are D/HH, other MN children, and other children with disabilities  
- Children who are D/HH are pretty close to others in the outcome of acquiring and using knowledge and skills and the outcome of behavior to meet needs  
- Substantially more kids with HL are maintaining age expected skills compared to other children with disabilities  
- Of those children who entered the program below age expectations in the outcome area, the percent who substantially increased their rate of growth – kids who are DHH are significantly lower in this measure in all three outcomes compared to other kids with disabilities  
- % of kids functioning at age level by exit – kids who are DHH are doing significantly better than other kids with disabilities  
- Kids with a hearing loss but no cognitive delay are doing significantly better than kids with HL and cognitive delay on all 3 outcomes  
- Kids fitted with technology at age 0-6 months had better outcomes on all 3 measures than those kids who were fit later  
- Lisa Schimmenti asked about how age expectations were measured by practitioners – Lisa stated that practitioners had to use a defined set of measurement tools, but could choose which one  
- Emilee Scheid suggested breaking down data by district to see who is excelling and who is not – problem is that there are so few kids per district, even in large districts  
- Mary Cashman-Bakken: are looking at MCA data to see which districts are excelling and finding out why they are doing well  
- Lisa Schimmenti suggested looking at it based on kids that started EI before 6 months  
- Send any suggestions to Lisa.backer@state.mn.us or kara.tempel@state.mn.us

### 8. Quality Improvement Initiatives - EHDI Workgroup

Nicole Brown  

- Data sharing agreement has been signed allowing MDH and MDE to share a defined set of data.  
- Reviewed EHDI Advisory Committee’s Results Based Accountability measures: infants screened, diagnostic evaluation before 3 months, reduce LTFU, timely amplification, family support, enrollment in Part C  
- Need work of multiple partners to "turn the curve" to improve indicators (not just MDH)  
- Initiating 2 quality improvement teams. 1st is with local public health (LPH) – reducing LTFU, 2nd is with RBA measures  
- LPH – monthly meetings for 6-9 months, homework assignments, committed to working together to test, share and implement improvement strategies  
  - Focus of LPH group is resolution of cases lost to follow-up  
  - 6 PH nurses have agreed to participate  
  - Aim is to improve timeliness and # resolved  
  - First assignment is to map process  
  - Next month will begin to collect data (# phone calls, time it takes for certain steps)  
  - After that will try different tests to see if it improves process  
- The RBA QI teams with advisory and ad hoc membership – monthly calls/meetings for 6-9 months, small tests/homework assignments. Work together to share and test improvements  
  - In thinking about where to start, a smaller more focused project might make sense.  
  - Proposing that we start with how to better measure outcomes for kids with transient HL and come up with a good follow-up plan for MDH to follow-up with these kids  
  - Doing this work is a requirement for HRSA grant  
  - Will start with this first one, but hope to eventually have two teams going at once

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EHDI NHSAC MINUTES  
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<tr>
<th>9. Closure</th>
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<tbody>
<tr>
<td>Emilee Scheid</td>
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<td>• Next meeting: August 6th 2p-5p in Conference center A</td>
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<td>• Candace Lindow-Davies made a motion to dismiss and Rhonda Sivarajah</td>
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<td>seconded the motion</td>
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