Newborn Hearing Screening Advisory Committee Meeting Minutes
August 6, 2014  2:00-5:00 p.m.  Minnesota Department of Education Conference Center
1500 Highway 36 West, Roseville, Room CC16

Facilitator:  Emilee Scheid
Recorder:  Melanie Wege

Attendees:
Kathy Anderson, Mary Cashman-Bakken, Dennis Ceminski, Kirsten Coverstone, Karen Doenges, Mary Hartnett, Tina Huang, Candace Lindow-Davies, Karleen Mauerer, Linda Murrans, Gloria Nathanson, Sara Oberg, Emilee Scheid, Lisa Schimmenti, Kara Tempel

Absent:
Nicole Brown, John Gournaris, Peggy Nelson, Joscelyn Martin, Geoffrey Service, Michael Severson, Rhonda Sivarajah, Emily Smith-Lundberg

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<tr>
<th>AGENDA ITEM</th>
<th>DISCUSSION POINTS/DECISIONS/NEXT STEPS</th>
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<tr>
<td>1. Welcome and Announcements</td>
<td>• Correction in past minutes - Tina’s last name is mis-spelled</td>
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<td>Emilee Scheid</td>
<td>• Minutes were approved</td>
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<td>• Welcome to Margaret Ratai from Virginia, MN – joining as new advisory committee member representing LPH / EHDI team</td>
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<td>• Welcome new MDH staff in short term follow-up unit – Health Program Representative Nancy Silva and Nicole Frasier</td>
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<td>• Welcome new MDH staff in long term follow-up unit - Health Educator, Sierra Beckman</td>
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<td>• Introductions of all committee members</td>
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<td>• Next meeting will be voting for 2015 Vice-Chair so committee chair is accepting nominations. An email will also be sent out requesting nominations.</td>
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| 2. EHDI Story                       | • Harper born in Feb 2010, uneventful pregnancy, & planned C-section delivery. “The Dear parents REFER Hearing Screening letter was the beginning of the journey.” |
| Hearing Loss & CMV                  | • Began hearing follow-up testing 5 weeks later. Went to appt. feeling it was just one more thing to check of the list. Diagnostic ABR 1 week later and diagnosis was severe hearing loss in one ear and profound the other ear. |
| Kyle Christopherson                 | • In the midst of communication with health insurance and learning about many other concepts related to hearing loss, parents were connected to EI within 24 hours. Immediately questions were raised about communication mode…. “…maybe that could wait. Professionals need to help parents tease apart what needs an immediate decision and what can wait. There is a lot to take in a short amount of time.” |
|                                     | • At about 2 months they initiated CMV urinalysis and baby was shedding CMV. Due to timing of CMV testing they could not know for sure if it was congenital or acquired CMV. “Looking back, here are the opportunities where our life could have been different had I opted not to take the next step…these are key decision points.” |
|                                     | • PCP recommended meeting with Dr. Schleiss. At 3.5 months they started ganciclovir antiviral treatment. Husband quit job to deal with all appointments (weekly blood draws, etc.). Hearing loss in one ear progressed slightly, the other ear was stable. Hard to know if it would have been different. “The impact of NBHS and CMV screening are that they provide an opportunity – open doors.” |
|                                     | • Comment from Abbie Meyer, ENT – Clinically it is still helpful to have a negative test on an older child to rule out CMV. If it’s positive you don’t really know whether it was congenital or acquired. |
MDH EHDI Update

• New EHDI annual report available & in your packet of materials today. Thanks to Bridget Roby for the design & coordination of this report! Will send out a link for the online version after meeting.
• Review of MDH process of follow-up after diagnosis of permanent hearing loss
• Review of MDH EHDI data for confirmed hearing loss reported in 2013 (slides). Copy of numerical data in handout (see handout)
  o # reported hearing loss has increased over time – better reporting in general and better reporting of delayed onset and of slight/minimal loss
  o 62% were diagnosed by 3 months of age in 2013 (of reported cases)
  o Access to genetics – no difference in referrals between metro or not, different insurance, degree of HL – no real pattern
  o If referred to ophthalmology the child is also usually referred to genetics and vice versa
  o 10 biggest audio clinics in the state – Average time to amplification ranged from 31 to 86 days (goal is 1 month after diagnosis). Max ranged from 78 - 365 days. More severe losses are fit more quickly.
  o New data sharing with MDE so were able to match cases for ages under 5 years. 28% were not matched, many were more recent cases so maybe just not connected yet and some families had declined Part C so were not in MDE’s records. Many families who decline EI at diagnosis end up connecting with EI later on. 2010-2012 have the most complete reporting and we say that over 90% of children reported to MDH are eventually enrolled in Part C. Parents of children with unilateral or slight loss are twice as likely to decline at time of diagnosis.
  o Based on the most recent data available from MDH and MDE, the bottlenecks in the diagnosis to Part C process occur at diagnosis and referral (only 62% are diagnosed by 2 months of age and only 43% are referred to Part C within 7 days of diagnosis).
  o 45% were contacted by H&V within 1 month of diagnosis (double what it was in 2012); 73% w/in 1 month of notification by MDH; 85% total contacted by H&V
• Concern expressed about speed of referral to EI within 7 days as federally mandated (either from audiologist and / or from MDH directly rather than through LPH, if that adds delay). Discussion about current process and the benefit of involving LPH for referral to MDE is that LPH has access to most current info from the family.
• Concern expressed that with online referral to Help Me Grow the referring audiologist never gets confirmation that referral was received – “feel out of touch” – MDE cannot release due to FERPA w/o signed release from local district
• Limitation of our data matching may be that some children may be categorized as DD primary diagnosis / DHH secondary diagnosis and not always counted. Can’t see secondary diagnosis in MARSS system now – wonder if this is possible with an IT project and this will be explored by MDE

Electronic Reporting

• General program update first: As of 8-1-14 we can now indefinitely store bloodspots and data again.
• Electronic reporting explored (for hearing and CCHD) because of ~3000 missing hearing results, annually and inaccurate reporting of hearing results on bloodspot form.
• MDH signed contract with OZ systems in May 2014 to provide this capability
• Baby demographics from Electronic Health Record and screening data directly from screen equipment (for most, or manual for others who can’t send automatically) are pulled into MDH system automatically.
• Will provide an update on implementation status at the Nov. meeting
### 4. MN Collaborative Plan for Children who are Deaf/ Deaf-Blind/ Hard-of-Hearing

**Update and next steps**

Anna Paulson

- Anna is full time staff for the MN Collaborative. Goals include:
  - Working on how to collect outcomes data now that MDH and MDE have data sharing agreement
  - Ensure deaf mentor program is aligned with JCIH recommendations
  - Creating toolkit for Early Interventionists in the format that each population needs it (rural, metro, etc.) for birth to 3
  - See handout in packet for other goals

### 5. Break

### 6. Workgroup Updates

**Transient QI and NICU Guideline update**

Kirsten Coverstone

- Transient QI workgroup: Linda Murrans, Abby Meyer, Kirsten Coverstone, Emilie Scheid, Tina Meyer, Joselyn Martin, Nicole Brown
- NICU guideline revision workgroup: Linda Murrans, Joselyn Martin, Karleen Mauer, Kirsten Coverstone, & other MDH staff. Will be using Sharepoint in Aug/Sept to complete document updates with the plan to send out in October to vote on at Nov. meeting
- Question raised by Mary Cashman-Bakken wondering about updates to a guideline document from 1996 for hearing screening of school age kids. Mary wants to know background on update of that document and what the staff training plan is because that impacts Mary’s staff in the schools. It was noted that this document was revised by an MDH division associated with the Child & Teen Checkup Program, who was a partner along with MDE in the development of the EHDI Advisory Committee’s recommendations for Screening beyond the Newborn Period.

### 7. MDE Updates

**Part C Program Updates & Educational EHDI Team Activities**

Kara Tempel

Kathy Anderson

- **Part C Updates**
  - Phone line now dissected and seems to work better~ Option A: REFER a child / Option B: get info on ECE (Early Childhood Education)
  - Online referral system for EI updated; all referrals used to come to MDE. Now they will go directly to the district. If referral has not been picked up within 48 hours the district gets another notice; if not within 96 hours then it gets kicked back to MDE and they have to take action on it.
  - 0-3 is year round system; 3-5 is just active during the school year to intake referrals
  - Districts love new system and so does MDE
  - Referrals doubled from 2012 to 2013/14. Possibly due to region 11 IEIC pilot with National Help Me Grow (See # 8 for more discussion on National Help Me Grow)

**Educational EHDI Team Updates**

- Regional teams began in 1996 with Mary Cashman-Bakken (related to regional low incidence project); 16 teams met; priority then was universal screening as many hospitals were just beginning this
- Traditional team is educational audiologist, DHH teacher, ECSE teacher and ECSE coordinator. Will work to expand to include speech pathologist, local public health, and clinical audiologists.
- Starting over with a lot of new staff and new focus – NOW will focus on quality EI services for DHH infants and toddlers; expand use of ongoing progress monitoring
- Current EHDI team activities and primary responsibilities (see handout)
  - Standardize EHDI materials for families related to EI
  - EHDI outcomes data from MDE will be distributed to regional teams and partners
- Consider invite Lisa Backer to talk about Inspire Action
8. National Help Me Grow Update & Discussion
Kara Tempel

- **MN Help Me Grow** is an initiative for public awareness, not a program. Will replace **MN Parents Know** webpage (auto redirect)
  - Targeted outreach to targeted high risk families varies by region, focus on homeless and children served by welfare, materials translated in multiple languages available from 12 IEIC’s, community staff available to reach out to specific cultural groups
  - **MN Help Me Grow**- Part C referral is for very specific service and must meet eligibility criteria; it includes outreach to families; it has Part C funding to MDH from fed government. It is a funnel into early intervention.
- **MN Help Me Grow** and **National Help Me Grow** are two completely different systems
- **National Help Me Grow**- More like a colander into broader services that are already into place (including Part C). **National Help Me Grow** broadens the **MN Help Me Grow** system. It provides full array of child development and health resources beyond the specific identified special need in the MN system.
  - Universal access for at-risk.
  - Central access point with phone care coordination and facilitated handoff to the referral.
  - Outreach and education for health providers and the community.
  - Funding is interagency
  - States have to sign on as an affiliate. DHHS, MDE, MDH summit in Dec 2013 met to discuss whether to do this and decided to continue exploring to see if becoming an affiliate makes sense for MN.

MN has contract for 1 year of technical assistance to continue to explore. Will be identifying MN leadership team from the 3 agencies under the office of early learning. Will decide in 1 year whether to proceed or not.

9. Closure

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- Next Advisory Committee Meeting: November 12, 2014 2-5pm
- **LOCATION:** MDE Conference Center B, Room CC16 1500 Hwy 36 West, Roseville
- Notify Chair if there are any Partner Updates to put on the agenda
- Nominations for 2015 Vice-Chair can also be sent to Chair
- Adjournment