Newborn Hearing Screening Advisory Committee Meeting Minutes

November 12, 2014                 2:00-5:00 p.m.       Minnesota Department of Education
Conferece Center Room CC16
1500 Highway 36 West, Roseville

Facilitator: Emilee Scheid
Recorder: Melinda Marsolek, Nicole Brys, Cara Weston


Absent: Mary Hartnett, Tina Huang, Michael Severson, Rhonda Sivarajah, Emily Smith-Lundberg,

**AGENDA ITEM** | **DISCUSSION POINTS/DECISIONS/NEXT STEPS**
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1. Welcome and Announcements | • Linda Murrans motioned to accept September meeting’s minutes, John Gournaris seconded  
• Emilee mentioned that the Wilder Foundation is the new meeting location for 2015 and the time has changed to 1pm -4pm. Also, the May meeting date has been changed to May 27th.  
• Nicole Brown gave a brief summary of the web evaluation sent in August (members liked many different aspects of the new annual report format, several members requested a more stable meeting location)

2. Committee Workgroup Updates | Transient Hearing Loss Workgroup Update  
• Two priority areas were identified, get data on the final result and develop a strategy for encouraging families to return for follow-up  
• MDH has been collecting follow up data and found that secure email works better for obtaining results from audiologists, a large number of children continue to have fluid for 6-9 months after initial diagnosis, and PCP letter did not emphasize the importance of ongoing follow-up  
• Group decided that ‘transient’ is not a good term to use, caregivers should treat all hearing loss as permanent until proven otherwise.  
• A handout for audiologists to give to parents of children with this type of hearing loss was developed by MDH that we will try with some clinics. Card will be shared more widely after it has been tested and finalized.

NICU Guidelines Workgroup Update  
• Moving forward, but still a work in progress. Flowchart will be sent to the workgroup for review and vote before bringing to the full committee.
### 3. Partner Updates

**MN H&V – Loss & Found Video Pilot Project**
- Candace Lindow-Davies

**MN Collaborative – Teacher toolkit**
- Kristi Townshend

**Lifetrack – D/HH Adult Role Model/Mentor Needs Assessment**
- Beth Quist

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<tr>
<th>MN H&amp;V – Loss &amp; Found Video Pilot Project</th>
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<td>• National H&amp;V received a grant to distribute a video to hospitals and clinics to be used to encourage families to return for follow-up. Candace was involved in a pilot of this project.</td>
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<td>• Targeted to locations with higher lost to follow-up rates.</td>
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<td>• Sites could use the video however they wanted (broadcast throughout the baby center, broadcast to individual rooms, for staff training)</td>
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<td>• Participating sites were asked to complete a survey about their experience with the video.</td>
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<td>• 90 sites across the country were involved.</td>
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<td>• Results from the national survey were pretty generic so MDH/H&amp;V plans to do another state-specific survey after sites have had more time to use it (implementation is ongoing)</td>
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**MN Collaborative – Teacher Toolkit project**
- Omitted – speaker was not able to attend.

**Lifetrack – D/HH Adult Role Model/Mentor Needs Assessment**
- Beth Quist from Lifetrack outlined plans for a D/HH Adult Role Model/Mentor Needs Assessment through Wilder Research.
- Goal of the Needs Assessment is to develop recommendations for the enhancement of the Role Model/Mentor program
- Plan involves convening an advisory committee of 12 members (at least 6 will be D/HH); conducting a literature review; reviewing secondary data; and collecting data through key informant interviews, focus groups with parents of D/HH children and D/HH adults, and a web survey of parents of children who are D/HH.
- Assessment and a final report will be completed by June 2015.
- A formal communications plan will be developed to keep people updated throughout the project.
### 4. MDH Update

**Disparities**
- Melinda Marsolek & Zay Rezania

#### Disparities in timely newborn hearing screening
- Children whose mother is black or American Indian are less likely to be screened by one month of age than children of white mothers
- Children whose mother is Hispanic are significantly less likely to be screened by 1 month
- Children of younger mothers are also less likely to be screened by 1 month
- Mother’s education is positively associated with timely screening – mothers who are college graduates more likely to be screened by 1 month

#### Disparities in timely diagnosis
- Largest disparities are between races
- Children of Hispanic, black and American Indian less likely to be dx by 3 months
- Younger mothers were less likely to have children dx by 3 months
- Mother’s education is positively associated with timely diagnosis

#### Disparities in Enrollment and Timeliness of enrollment in Part C/Early Intervention
- Children whose mother is Asian are less likely to be enrolled in Part C/EI
- Children of Hispanic mothers are more likely to be enrolled
- Younger mothers are less likely to have enrolled children
- Children whose mother is black are less likely to be enrolled by 6 months of age, but no significant differences between groups in time from dx to enrollment
- A smaller percentage of infants whose mother is younger met recommended Part C enrollment timelines, but not significant difference
- Children of mothers with less education were less likely to be enrolled by 6 months of age, but no difference in time from diagnosis to enrollment

**Ideas to address**
- Adapt successful strategies used by other programs within MDH
- Identify clinics that see a higher percentage of the non-White population to use for trying out strategies
- Continue to work with Hands & Voices Cultural Guides to encourage families to connect with EI.

### 5. BREAK
- Announcement of Vice-Chair election results – Joscelyn Martin

### 6. Electronic reporting for newborn screening
- Amy Gaviglio

**Meeting Membership**
- Nicole Brown

#### Electronic reporting for newborn screening
- Contract with Oz Systems signed in May. Minnesota’s name for MN’s Oz Systems is MNScreen
- MDH have reached out to several hospital to begin implementation
- 3 hospitals are currently reporting via MNScreen (Oz System)
- MDH is working with 40 additional hospitals. Hospitals using Epic and members of CHIC have been excluded for now. Because of special circumstances will work with these groups individually.
- Margaret Ratai, LPH Nurse has resigned as member due to change in position
- Jocelyn Martin was elected as Vice Chair
CMV disproportionately affects African American children
Utah has implemented CMV testing for all infants who do not pass their newborn hearing screening. As a secondary result there has been an improvement in their 1-3-6 goals
Dr. Schleiss described various studies regarding CMV. Study 1: examine newborn blood spot who had failed newborn hearing screening for presence of CMV DNA (anonymized bloodspots):
- Important to test for CMV in infancy because it is common for infants to acquire through breastmilk or through contact with other infants/children.
- 2.7% of babies who did not pass their newborn hearing screening tested positive for CMV compared to 0.4% who passed their newborn hearing screening
- Unknown if amount of CMV DNA in blood spot correlates with amount of disability
- Linking CMV testing to Newborn Hearing screening could be useful
Study 2: Contribution of CMV infection in the setting of established hearing loss in MN children:
- Majority of children who have CMV-related hearing loss do not have a hearing loss at birth
- Examined archived newborn blood spots for the presence of CMV DNA in children with hearing loss
- CMV DNA found in 19 of the 68 blood spots tested
- 7/19 had passed newborn hearing screening
- 15/19 had bilateral hearing loss
- Cochlear implantation was performed in 10/19 of the children
- The diagnosis of congenital CMV had not been suspected in any of these subjects
Is universal newborn screening for congenital CMV good public health practice?
- Utah CMV Public health initiative
  - Requires department of health to offer information to a variety of groups including child care workers and pregnant women
  - Directs medical practitioners to test infants who do not pass their newborn hearing screening
  - Notify medical practitioners of requirement to test
- Several other states have similar bills in process
- Most babies with congenital CMV are destined to have typical development
- Unclear whether there is a demonstrated benefit of early detection, intervention, and efficacious treatment of CMV for asymptomatic infants
- Utah screening law was criticized by AAP because the state is telling the physician how to practice medicine and the language in the bill that specifically mentions off-label treatment with valganciclovir (concern with liability risks if not prescribed)
- No clear economic benefit of early ganciclovir prescription
- Genetic privacy concerns in MN may make CMV blood spot testing more difficult
More information needed about cost-benefit of early intervention and specifically antiviral therapy (symptomatic vs. asymptomatic)
Proponents of universal CMV screening point to infants who have congenital CMV but pass their newborn hearing screening – they could be monitored to see if hearing loss develops if family knows they have CMV and are at risk for developing a hearing loss
Would it cause unwarranted amount of worry in parents? Focus groups have shown that parents overwhelmingly would prefer to know that their child has CMV and could develop hearing loss.

A major paper on the improved neurodevelopmental outcomes associated with ganciclovir therapy in symptomatic infants with congenital CMV will be published soon.

8. MDE Update

**Report – Students who are D/HH**

Mary Cashman Bakken

- Legislative Report 2014 – MN Students who are Deaf/Hard of Hearing (D/HH)
- Visited 5 schools last year that exceeded MCA standards (D/HH students did better than hearing peers) – did observations and interviews
  - Highly qualified teachers
  - Strong parent involvement
  - High expectations
  - Great use of technology
  - Strong community support
- Survey
  - Asked school districts several questions and determined that this was an area we needed to focus our attention on to provide leadership and consistency
  - D/HH graduation is 69%, which is higher than all special education at 57.9%. General education is 83%
  - Dropout rate for D/HH is 1.5% compared to 2.5% in general education

9. Closure

**Item Description**

Emilee Scheid

- Next Advisory Committee Meeting: Feb. 11th, 2015
- Time change for 2015 meetings – 1-4pm
- LOCATION change for all 2015 meetings:
  
  Amherst H. Wilder Foundation
  451 Lexington Pkwy. N
  Saint Paul, MN 55104

- Notify Chair if there are any Partner Updates to put on the agenda
- Adjournment – Candace moved to adjourn, Linda Murrans seconded