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## Maine Newborn Hearing Program Advisory Board Meeting Minutes 03-26-2019

**Members Present:** Eileen Peterson, Duska Thurston, Louise Packness, Donna Casavant, Karen Hopkins, Cathy Lushman, Harriet Gray, Jennifer Gaulin, Melinda Corey and Susan Delaney.

**Members Absent:** Annette Bowman and Nola Metcalf

**Guest:** Anne Banger and Laura Sweet

**Program Staff:** Holly Richards and Maryann Harakall

**Interpreters:** Marisa Zastrow and Polly Lawson

**CART:** Marsha Swain

**Meeting Chair:** Holly Richards on behalf of Nola Metcalf

**Meeting Co-Chair:** Duska Thurston

**Scribe:** Maryann Harakall

1. **Welcome and Introductions** – Holly Richards welcomed attendees, introductions were made. Holly reminded the group of some effective communication guidelines for our meeting having interpreters and CART and Captioning at the meeting:
  - a. **Raise your hand and wait to be called on.**
  - b. **State your name every time you speak.**
  - c. **Speak clearly and at a moderate pace.**
  - d. **No side conversations unless it is to clarify what was said.**
  - e. **Listen without interrupting;** no cross talk
  - f. **If sitting close to a microphone or speaker phone, do not rustle papers, etc..**
  - g. **Turn cell phones off**
  - h. **Reduce background noise whenever a phone conversation is taking place.**
  
2. **Review and acceptance of the minutes from October 23, 2018:** Unanimously accepted. Page 2 # 6, the date was October 29, not October 25<sup>th</sup>.  
Asked for last names of people in minutes and add page numbers.
  
3. **Program Updates:** Holly Richards
  - a. The report to the Secretary of State was submitted.
  - b. Year 3 EHDI grant application was submitted.
  - c. EHDI 2017 Data Survey was submitted and a data brief will be created to showcase the data.

- d. Attended the EHDI Conference and presented
- e. Category A & B Facilities document was updated and will be posted to the website.
- f. Hiring update – Anne Banger was hired as the Newborn Hearing Coordinator
  - i. Interviewing for the Care Coordinator position
  - ii. The MCH Manager position is posted until April 5.
- g. ChildLINK data system is being competitively bid. It will be released on 3/27/19.
- h. Member update – we still have vacancies on the board.
  - i. Had a discussion about the new administration
- i. Anne will be presenting at the Perinatal Leadership Coalition meeting on 3/29/19.

**4. HRSA Grant Update:** Karen Hopkins

- a. Weekend with families just happened – this weekend focused directly on families being together
- b. Work on early intervention with HRSA grant and MeCDC, it's complicated, but a lot of work to find kids. They are working with CDS.
- c. Learning communities, one on interventions and one with audiologists
- d. Hand and Voices website has been revised.
- e. Developing a physician app to know what's next depending on where the family is at.
- f. Deaf Can Conference is November 8, 2019 – have a deaf developmental pediatrician presenting.
- g. Family shared plan of care- parent has a “living doc” to go with them to different providers – people don't want paper. Maybe use a database that exists already?
- h. Kindergarten readiness bill, waiting on dates for the public hearing.
- i. April 5<sup>th</sup>, Hands and Voices is hosting the Advocacy Support Training Program (AST) – how do you get your student what they need? Register on the Hands and Voices website or through Karen Hopkins directly.

**5. Public Comments:**

- a. Anne Banger introduced herself and gave some background. She is the parent of a deaf child and has been the contractor doing this work for the past 7 years.
- b. Laura Sweet gave a brief overview of the CMV workgroup and talked about questions/recommendations submitted with the report. We will restart the group now that the hearing coordinator is hired. There was discussion as to whether or not this could be added to the rules. Holly Richards said there is a section for CMV on the newborn hearing screening website and then the rulemaking process was discussed.

Duska Thurston shared that EMMC is working on a targeted CMV screening protocol. They are proposing that if the baby fails the screen or has SGA, microcephaly then a buckle swab is done and they work with pediatricians.

EMMC is also working on loss to follow-up protocols and the app development.

**6. Advisory Board Meeting Revamp:**

- a. Guidelines were last updated 9/12/12 and they need to be updated again. There was lots of discussion around the definition of “hearing loss”.

**Hearing loss** means a hearing level of greater than 15dB in one or both ears, which may be significant for access to language

**Person who is culturally deaf** means a person who is deaf or hard of hearing who identifies as a member of the deaf community and who uses ASL as the primary mode of communication.

**Person who is hard of hearing or person who is deaf** means a person who communicates using aural or oral skills for accessing language

Lots of discussion around what it is like to be a parent who goes through the screening process.

Question: can we change the guidelines to reflect the updates before changing statute?

Discussion on midwives and hearing screenings.

Decided to create a smaller workgroup to update the guidelines for the rest of the board to react to. Volunteers are: Donna Casavant, Jenn Gaulin, Laura Sweet and Eileen Peterson

b. Future meeting dates:

- June 25, 2019                      9:30am to 12:30pm
- October 25, 2019                9:30am to 12:30pm

## **7. Adjourn:**

Meeting was adjourned at 12:32 pm.