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Maine Newborn Hearing Program Advisory Board Meeting Minutes 06-25-2019

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

Members Absent: Cathy Lushman and Annette Bowman

Guest: Pam Dawson

Program Staff: Holly Richards and Anne Banger

Interpreters: Marisa Zastrow and Polly Lawson

CART: Marsha Swain (remote)

Meeting Chair: Nola Metcalf

Meeting Co-Chair: Duska Thurston

Scribe: Anne Banger

1. **Welcome and Introductions** – Nola Metcalf welcomed attendees, introductions were made. Holly Richards 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 March 26, 2019:** Unanimously accepted. Page 3, # 6 b, the date should be October 29, 2019 not October 25, 2019.
3. **Program Updates:** Holly Richards
 - a. Maine CDC has a new director – Dr. Shah
 - b. Hiring update -Anne Banger started at the Newborn Hearing Program Coordinator at the end of April 2019.
 - i. Pam Martin was hired as the CSHN Care Coordinator
 - ii. Angie Bellefleur was hired as a Maternal and Child Health Program Manager

- iii. Current vacancies – Newborn Screening Coordinator and Birth Defects Coordinator.
- c. Currently in the 3rd year of the EHDl grant.
- d. Anne and Holly are reviewing and updating the Rules.
- e. The data system contract was awarded to a new vendor – Nebulogic. Contract begins July 1, 2019. They have 3 months to implement, train all users and transfer data. Childlink’s contract will be extended through September 30, 2019.
- f. The contract with MECDDH for the follow-up coordinator, parent consultant and audiology consultant ends June 30, 2019. MECDDH will be using HRSA grant funds to pick up this work.
- g. EHDl 2017 Data Survey was submitted and a data brief was created to showcase the data.
- h. Anne presented at the Perinatal Leadership Coalition meeting on 3/29/19. It was well received, and a number of hospitals requested on-site training
- i. Anne is going to start site visits to birthing hospitals
- j. Holly is meeting with Laura Sweet to discuss a CMV grant. They will involve the CMV Work Group.
- k. Two ABR screeners purchased by CSHN – Nola asked for a status update. MNHP is looking at where in the State they should be placed, also considering where MECDDH’s ABR screeners will be located. State regulations do not allow the State to give equipment away to outside organizations. Holly worked with the Attorney General’s office to develop language for an agreement on another ABR screener being used by Northern Sun Family Health Care. She can use that language as a guide for these machines.

4. HRSA Grant Update: Karen Hopkins

- a. Parent consultant and Audiology consultant to work with MNHP:
 - i. They made some adjustments to the HRSA budget to include funding the Parent Consultant position. The position has been posted.
 - ii. The MECDDH Audiologist will do the work of the Audiology Consultant.
- b. Hands and Voices -ASTRA Training took place April 5th for parents and providers. Teaching the parent so they can advocate for themselves. The ASTRA Advocates are all parents. They will start working with families in the Fall.
- c. Darlene Freeman and Duska Thurston continue to work on an EHDl app specific to how things work in Maine. Duska reported that a lot of changes have been done, still work to do, they want it to be simple with links.
- d. Working on an updated video to encourage families to go for follow-up testing.
- e. ABR screeners – ongoing discussions, will start using in the coming year.
- f. Meeting with Linda Hazard on QI work and PDSA for the HRSA grant
- g. Began planning Camp Discover 2019
- h. Currently in the 3rd year of HRSA funding
- i. Looking at ways to fund the Deaf and Hard of Hearing Guide program and the Guide By Your Side program.

5. Advisory Board Meeting Revamp:

- a. Guidelines – Anne and Holly are reviewing and updating the Rules. It makes sense to wait to update the Guidelines until the Rules have been completed.

- b. Orientation Guide- Summary of discussion
 - i. Current hard copy of Orientation Guide needs to be updated.
 - ii. Looking at having an electronic updated version of the orientation guide on the MNHP website in a place that only board members can access. This will also help to get board members to access the MNHP website.
 - iii. Suggested that there also be a place for historical/archived documents on the website
 - iv. Members would have hard copies of the orientation guide that they could update as changes are made
 - v. Will have current hard copy of the guide at all board meetings for reference
 - vi. In the past in person orientation sessions were held on occasion, once or twice a year. Included short slide shows, discussion, very useful conversations. All board members present at the meeting though in person orientations would be a good idea. Would help new members understand how they can contribute.
- c. Other –
 - i. MNHP will update the Name Tags used at the meetings to include the individuals role on the board
 - ii. MNHP has used and will continue to use the powerpoint the Education Committee developed for Physician education.
 - iii. Website – some updates have been made, more to be done
 - iv. Board Vacancies-
 - 1. Parent of a hard of hearing or deaf child – Laura Sweet submitted application, in process
 - 2. Representative of hospitals – Vacant
 - 3. Representative of Health Insurance – Vacant – Karen Hopkins is going to check with their MaineCare Representative to see if they would be interested
 - 4. Representative of DHHS – Holly Richards is going to talk to the director of Public Health Nursing to see if someone would be interested
 - 5. Parent of hearing child – Lots of discussion on who could fill this – someone who is not connected to deafness at all, someone with a young child, maybe change the person holding this seat every few years, maybe a home birth parent, someone passionate about language and development, maybe late identified, a parent of a child with risk factors
 - 6. Other – could fill this seat with one of the types of parents that was discussed for parent of hearing child.
 - 7. Board has to have an odd number of seats
 - v. Risk Factors – something Maine needs work on, risk factors vary from state to state, not all providers diligent with risk factor follow-up
- a. Future meeting dates:
 - October 29, 2019 9:30am to 12:30pm

6. Adjourn:

Meeting was adjourned at 11:30 am.