



**Maine Newborn Hearing Advisory Board Meeting
June 23, 2020
Virtual Meeting Minutes**

Members Present:	Melinda Corey, Susan Delaney, Katherine Duncan, Harriet Gray, Karen Hopkins, Nola Metcalf, Louise Packness, Eileen Peterson, Laura Sweet, Duska Thurston, Nicole Dotson
Members Absent:	Donna Casavant, Jennifer Gaulin, Cathy Lushman, Leigh Anne Gorecki
Guests:	Ariana Blethen, Jean Moreno, Pam Dawson
Program Staff:	Holly Richards, Anne Banger, Amy Fair
Interpreters:	Stacy Bsullak, Marisa Zastow
CART:	Marsha Swain
Recorder:	Amy Fair

Welcome and Introductions	<p>Anne - Went over communication and zoom guidelines to make things more accessible for everyone; choose gallery view which enables you to see all the participants, closed captioning is available to turn on as well as CART and interpreters, chat box which also has the link to streaming text and can be used to ask questions or add comments, turn off your video unless you are speaking, mute your microphone unless you intend to speak, turn your video on and raise your hand and wait to be called on if you have questions or comments, please state your name every time you speak, speak loudly, speak clearly, speak at a moderate pace, no side conversation unless it is to clarify what was said, listen without interrupting, no crosstalk, reduce background noise and turn cellphones off.</p> <p>Nola – Welcomed everyone introduced herself and invited everyone to take turns introducing themselves.</p>	<p>Anne Banger Nola Metcalf</p>
Review and Acceptance of the Minutes	Meeting minutes from October 29, 2019 were accepted by all members.	
Program Updates	<p>Anne – Holly sent out an update on March 23rd when we had to cancel the March 24th meeting, the Secretary of State report for the board was submitted at the end of December 2019. We continued to have monthly meetings with the program and MECDHH. This is the last year of the CDC grant and we reapplied for the new grant that starts July 1st. We received good news today, that we were awarded the grant. They only awarded 36 grants this year which is a decrease from the past.</p>	<p>Anne Banger Holly Richards</p>

	<p>We finalized the 2018 EHDI data and submitted it to the Federal CDC and prepared the annual data briefs that we started doing as of 2016 data. The three that we have done so far are 2016, 2017 and 2018 and those are posted on the Maine Newborn Hearing website. These data briefs have been a great way to show groups and hospitals a picture of what we are doing. The EHDI Annual Meeting was at the beginning of March, Anne traveled to this. It was a great conference.</p> <p>CMV workgroup started meeting again in November 2019, they were scheduled to meet April 6, 2020 but was canceled due to COVID. It has not restarted yet but is on the list to get back up and running.</p> <p>Recognized Katie Duncan as being the consulting audiologist for the program, this is funded through MECDHH as part of the HRSA grant. She has picked up the pediatric audiology workgroup. Katie along with members of the Pediatric Audiology Work Group drafted revisions to the MNHP risk factor guidelines to bring them in line with the JCIH 2019 Position Statement. A copy of the draft guidelines was emailed to the Advisory Board members for their review and comment. This workgroup has made a big difference with the interactions with the audiologists in the state, there seems to be a lot more cooperation. MECDHH and the HRSA grant is funding a parent consultant position again. Dixie Herweh is the new parent consultant. She is contacting families and PCP offices. She has been able to talk to families throughout the COVID shutdown and referred 5 or 6 families to the guide by your side program (GBYS).</p> <p>Anne continues to work with Nebulogic on the new newborn screening portal.</p> <p>Holly – We have been re-funded for CDC HDI Grant as Anne said. Our last competitive grant application was a 3-year grant from 2017-June 30, 2020 that funded 44 states. When this competitive application was released, we found out they were only going to fund 36 states, so it was more competitive. It was exciting to find out that we were 1 of the 36. We will have this funding for 4 years then we will have to re-apply.</p> <p>There are multiple statutes; newborn screening, newborn hearing, birth defects, CCHD. There is a new law that has passed for preventative care for infants which is erythromycin and vitamin K. Each statute or law requires a set of rules, so there are 5 sets of rules for hospitals, midwives etc. to keep track of what is required of them. We have started working on combining all 5 statutes into 1 rule, this is working its way through the process but has been delayed due to COVID and other things going on. It will get to the point where there are opportunities for public comments the board will be able to comment on the hearing section at that time.</p>	
<p>HRSA Grant Update</p>	<p>Karen – The HRSA grant has been really busy creating an expanded team for the next four-year cycle. They have Anne, Holly, Katie Duncan representing the role of audiology consultants and Darlene Freeman and they are looking to possibly add a couple other people to bring more perspectives to the team. They have</p>	<p>Karen Hopkins Katie Duncan</p>

	<p>renamed the HRSA grant to Earliest Interactions. They are also creating a new website that will be a means of communication about the HRSA Grant, where this is a four year grant, they wanted to make sure information was out there and accessible. The website is looking good and should be out soon with lots of added resources. In addition, they are working on a video series, looking to start at the screening and go all the way into early intervention and beyond. Two videos are done and will be put on the website. One is the newborn screening video and the second is parent to parent support. The third one that will be started soon is the communication opportunities process which will involve the specialists and parents that come from different perspectives. This will go hand in hand with a new visual that is being created that is also funded by the HRSA Grant for families to get and be walked through by their early interventionists to make sure we are doing everything possible that we can to make sure families are getting complete information in a way that is acceptable to them. Just this week we secured Maine Hands and Voices to be the HRSA Grant family-based organization again this year. They submitted a fabulous proposal and have some nice things planned for these next four years. We will continue with their parent to parent support and their deaf hard of hearing guide support programming as well as other things that you will see come out of their proposal. Katie - We have written a proposal that will be submitted soon to allow us to do a needs assessment in the state to look at from professional's perspective and parents' perspectives to assess what the needs are and what gaps may have been created in the EHDI process due to COVID-19. The pediatric audiology group this year has done a variety of different things. There has been a smaller group developing the new risk factor draft. We also went through the brochures that get passed out by audiologists; mild hearing loss, unilateral hearing loss and general hearing loss to be able to suggest updates. They also just finished reviewing the states pediatric audiology guidelines and made suggestions that will be going to Anne soon. They have started integrating some different CU opportunities for the audiologists and have been doing the American Academy of Audiology Journal Club. Dr. Kris English an audiologist whose area of expertise is counseling joined them for a two-hour workshop, she presented on child centeredness and audiological care.</p>	
<p>COVID-19</p>	<p>Holly - Many CDC staff members have been reassigned to COVID related items. This has been challenging, but they are looking to hire people to take these calls to free up staff. Anne - All the audiology practices are closed. Some hospitals continued to do outpatient rescreens during the shutdown and some hospitals stopped doing outpatient rescreens during the shutdown. We had really good communication between birth hospitals, audiologists and the program that lead to some diagnostic testing being done during the shutdown. This led to at least two babies being diagnosed with hearing loss in March and April. Once things opened back up the cooperation including</p>	<p>Holly Richards Anne Banger Karen Hopkins Melinda Corey</p>

	<p>parent consultants and audiologist, there was a high rate of response for scheduling follow-ups. There is an expected impact in the loss to follow up because some families may not return for testing, possibly more than usual. There were some children that were not screened due to refusal for COVID test by parents or due to babies being born to COVID positive or suspected COVID positive parents. These babies were scheduled to come back for an outpatient screen but at least one or two were known to not return for the rescheduled visits. Lots of appointments have been canceled due to the COVID 19 shutdown and we are unsure where we stand on exact numbers. Most audiology facilities are re-opened at this point. There is still 1 that we are aware of that has not reopened. Offices have been working well together throughout the shutdown, utilizing offices that were open and referring patients there if possible.</p> <p>Karen – Referrals are very low right now for early intervention, so either there haven't been many babies, or they are lost in the system which we are working on.</p> <p>Melinda – Confirmed that their referrals overall are down because people for example are not going to their well child visits, so we aren't getting the referrals from there. Our captive referrals from DHHS are even down and we know that's because children were not in school so families were not being reported to the state at the same rate that they typically would be during normal times. We have encountered families with infants and toddlers that are identified with a hearing loss who have expressed frustration because they have failed a newborn hearing screen and they haven't been able to get the follow up test or they were scheduled to get aided and they have not been able to get the babies hearing aids. This is sad and hard and hopefully some of those services are starting back up now that some medical practices are starting to reopen, but I do think there's some really significant challenges for people accessing at all levels of support; medical and educational.</p> <p>Karen – One positive thing in Maine is, early intervention didn't stop, there was a lot of virtual support available to families. We had a lot of families participating in continuing service.</p> <p>Anne – The guide by your side referrals that were made by the parent consultant, a number of those referrals were for families that the child didn't pass the hearing screen but couldn't get the testing yet because the facilities weren't open. So those options were bring offered to the families even though they were at the very beginning of the process and a number of those families did take advantage of it. We are reaching out to the families that audiologists are having a hard time reaching to connect and get the appointments scheduled. Also reaching out to families that audiologists have tried to schedule with, and the families haven't wanted to go quite yet. We are working with families and PCP's on that, parent consultant has been very helpful with these families.</p>	
Board Chair	Anne – It is time to elect a new board chair. Melinda Corey nominated Duska Thurston, Louise Packness seconded the	Anne Banger Melinda Corey

	nomination for Duska Thurston to serve as the next board chair. Nola called for a vote, unanimous vote in favor of Duska Thurston to serve as Board Chair.	Nola Metcalf Louise Packness
Public Comments	Nola – There were no public comments..	Nola Metcalf
Break	Vote, unanimously in favor of skipping break	
Report Out	<p>Laura – Attended a portion of the Massachusetts CMV Meeting on June 10th via Zoom. She called in to share about Maine’s CMV workgroup and what has been happening over the past few years. A doctor from New York shared that they have created a testing protocol that they have put into place and it will be published soon, this will be a hospital protocol that others can use as a reference. Dr. Laura Gibson, the chair of the Massachusetts CMV group said they are striving for in Massachusetts is adding CMV to their list of reportable conditions and didn’t know what this would entail in Maine or when we would get to that in Maine.</p> <p>Karen to provide an update on the status of the use of ABR screenings in the community for babies that are born at home.</p> <p>Katie – We are stopped at this point because of COVID and the restrictions in terms of any real face to face work that we can do given our place under DOE and their restrictions at this time. We aren’t in a place where we can go out and do the screenings and follow up with the equipment that we have. This is a goal for us, we are working towards having some sort of teleaudiology program that would allow us to expand our services and reach parts of Maine that don’t have the best access to screening and diagnostics. But it is still in the planning stages given everything that has been happening.</p> <p>Karen – If COVID hadn’t happened we would have been well on our way but given that we can’t go into homes right now that’s challenging.</p> <p>Nola – Asked Anne if the two other screeners went out to the community.</p> <p>Anne – No, the program does have the two screener machines as well but at this time are not being used in the community because of the same reasons Katie mentioned.</p> <p>Louise – Are there any home visits taking place through CDS or MECDHH directly into the homes?</p> <p>Melinda - CDS is not providing in home services right now, we are offering families telehealth so many families are accessing services including through MECDHH providers via teletherapy but no one is going out into homes and we don’t have a timeline on when this will happen yet.</p> <p>Karen – Agreed with Melinda’s answer.</p> <p>Louise – Wishes that this summer we could do some sort of outdoor arena assessment where everyone could be outside at a distance because it seems important.</p> <p>Melinda – Concerns for CDS developmental evaluations would be that they need to be able to hand a child an object as part of the evaluation. They are doing the evaluations via zoom where parents offer the child objects and are directed by the evaluators on what to do, it’s not ideal but it is helping kids become eligible</p>	Laura Sweet Karen Hopkins Katie Duncan Nola Metcalf Anne Banger Louise Packness Melinda Corey

	who otherwise wouldn't because they wouldn't have had a developmental evaluation otherwise. If a child comes to them already diagnosed with a hearing loss, they don't need to go through the whole assessment process. We are still able to make children eligible on those established conditions as well.	
Adjourn	Anne – Thanked everyone for their participation and hard work.	Anne Banger
Next meeting dates	October 27, 2020 9:30AM-12:30PM	