Department of Health and Human Services

Maine Newborn Hearing Advisory Board Meeting
October 27, 2020
Virtual Meeting Minutes

Members Present:	Donna Casavant, Susan Delaney, Katherine Duncan, Jennifer Gaulin, Harriet Gray, Karen Hopkins, Catherine Lushman, Nola Metcalf, Louise Packness, Eileen Peterson, Laura Sweet, Duska Thurston, Ariana Blethen Whiting
Members Absent:	Leigh Anne Gorecki, Nicole Dotson
Guests:	Pam Dawson, Rosie Hoffman, Tracy Miller
Program Staff:	Holly Richards, Anne Banger
Interpreters:	Marisa Zastow, Cid Pollard
CART:	Marsha Swain
Recorder:	Amy Fair

Welcome and Introductions	Communication Guidelines: 1. Mute your microphone unless you are the speaker. 2. After welcome and introductions please turn off your voice and mute your microphone unless you're an interpreter, or you are the speaker. 3. If you would like to speak turn on your video and raise your hand and wait to be called on. 4. State your name every time you speak 5. Speak clearly and at a moderate pace. 6. No side conversations unless it is to clarify what was said. 7. Listen without interrupting, no cross talk. 8. If sitting close to a microphone or speaker phone, do not rustle papers, etc. 9. Turn cell phones of 10. Reduce background noise whenever a phone conversation is taking place. 11. In addition to Zoom captions	Anne Banger Duska Thurston

	Direct link to streaming text: http://www.streamtext.net/player?event=mnhp Password: mnhp Individual introductions done.	
Review and Acceptance of the Minutes from June 23, 2020	Review and acceptance of meeting minutes from June 23, 2020. Susie Delaney moved to accept meeting minutes, second by Louise Packness.	Duska Thurston Susie Delaney Louise Packness
Program Updates COVID 19	Holy Richards – COVID is still a focus at our health department, our staff are still all deployed remotely. Our medical secretary, Amy Fair go into the office three days a week to do office tasks. We have been told this will continue through January 31st. Things may be changing where staff could start to be deployed to work on more COVID cases, we have had an influx where we were deployed to do consult calls, investigations and different COVID related tasks. Some of us have been taken off, we may be put back on. Some people may be deployed and pulled away from their job completely to do COVID, more to come on that.	Holly Richards
Program Updates MNHP-EHDI Grant	Holly Richards- July 1st we were awarded a new CDC EDHI grant, only 38 states were funded. The focus has changed a little but, it's really on further enhancing the capacity of active tracing and tracking and timely surveillance. Every year we have an annual survey of our data that's due, this year it's due November 13, 2020. It's not required, but highly recommended that we do this survey. Once we have this data finalized, we will be updating our infographics that we create every year with this new data. The annual Secretary of State report is due to the legislature December 31, 2020. We submit a similar report each year with updated data. The report includes the number of board meetings held during the year, membership list and hearing data.	Holly Richards
Program Updates MECDHH - HRSA Grant	Karen Hopkins – HRSA grant team has been very busy. Now that we are in the second cycle of this grant, we can do a lot more. One of the things we have done is to fund an audiology consultant position to support the Maine Newborn Hearing program. Katie Duncan is the audiology consultant. The other position that we are funding is a parent consultant. Dixie Herweh was hired to serve as the parent consultant. Dixie has	Karen Hopkins Katie Duncan

	been doing a great job following up with parents, the numbers are increasing and parent to parent support is increasing, referrals for guide by your side are also increasing. She is doing a great job with these families. We applied for and received a second grant under the HRSA grant for funds to complete a need's assessment for the State of Maine. Katie Duncan was integral in writing the proposal for this. Katie Duncan– The audiologists have been really engaged in the last year in making changes to the process to support families, and to have a streamlined approach. They would like consistency across the state, so regardless of which audiology clinic a family goes to they would receive consistency in information and services. This is where the idea of our tip sheets grew, and this is our big project with the audiologists this year. Developing documents around how to prepare for an ABR evaluation, what the hearing aid evaluation and fitting process look like; different things that the audiologists can share, and our early intervention and early childhood providers can share with families to go back to the concept of consistency. One of the HRSA grant goal is to collaborate with local LEND programs. We are collaborating with both the University of New England and the University of Maine programs. I am working with their University of New England audiology LEND trainee, she is a 4th year extern at Northeast Hearing and Speech, her project will be supporting me in developing the tip sheets. Tracy Miller and Rosie Hoffman are from the University of Maine LEND program, Rosie has been working with us on the need's assessment, Tracy and I have been working together to develop a project in Early Intervention specific to children who are deaf and hard of hearing. The need's assessment will ask questions about training for midwifes, birthing facilities, and physicians focusing on their knowledge of enrolling families in early intervention. The needs assessment with also investigate training needs for each CDS site. There will be questions for parents about their Early Intervention experience and what support is needed to encourage successful EI enrollment. There will be questions to address the long term impacts of COVID. What impacts do parents and professionals think are going to happen due to COVID in the long term and what can we put into place to support that. We are working with a consulting	

	group for the need's assessment, we are meeting with them regularly and have developed a leadership group to try to pull from each of these different areas. We are also going to have stakeholder groups. Karen Hopkins – This consulting group is amazing; they are very professional and have a lot of experience. I think what is produced will give us, this board and the overall EHDI program a lot of information. We are developing a website; we have hired a web designer and PR communications person who has been working with us. We aren't ready to launch it, there is a lot more work to be done. The name of the grant has been changed to Earliest Interactions. We are putting all the resources into one and are hoping this will be a one stop for professionals and families. We are in the process of copywriting this. In addition to this, we are doing videos where families will have the opportunity to hear from each specialist such as a deaf ASL specialist. The goal is to have one process, from birth newborn hearing screening all the way through early intervention and bringing every provider in the state of Maine into this process. We are also working very closely with the Kindergarten readiness legislation team. It is going well and getting close to being final, that will be part of what happens as far as 6 months assessment on every baby and really looking at getting some data to see how we are doing. We have been busy and there is lots more to come.	
Public Comments	Duska Thurston asked for any public comments. Pam Dawson– Maine Medical Partners ENT offices are getting ready to move and expand their physical offices, as a result of that they are thinking of ways they can improve their pediatric services. As part of that effort Maine Health will be reaching out asking for feedback. Duska Thurston– Thanked Pam Dawson and asked for any other comments. None were brought forward.	Duska Thurston Pam Dawson
Advisory Board Discussion - Rules	Holly Richards- We have been updating our rules, in our program we have five statues and we chose about a year ago to take all those and put them into one rule. This is currently in review at the Attorney General's office.	Holly Richards
Advisory Board Discussion - Website	Anne Banger – I have done some relatively minor updates to the website; it is an ongoing process.	Anne Banger

Advisory Board Discussion - Publications and Brochures	Anne Banger – Audiology hearing loss booklet: shared screen and asked for comments. Karen Hopkins– One thing I would like us to consider is changing hearing loss to children who are deaf or hard of hearing. Laura Sweet– Is there a reason why the most common causes of hearing loss aren't included in these books? Why not mention important next steps and next tests? Anne Banger– Do you have a specific area in the books where you think these things could be added? Laura Sweet – The page that says childhood hearing loss that talks about early identification might be a good spot. Karen Hopkins– I agree with both especially the next step. The more different ways we can give information to families the better. I think the roadmap that was developed we could look at again. Adding in causes would also be great, it is a question that we hear a lot. Eileen Peterson– We started writing these back in 2004 and the goal at the time was so that audiologists would have brochures to choose from when they did the diagnostic evaluations to give to the families. At that point in time follow up is needed and they may not know the etiology of the loss at that point. The goal was to be simple yet have enough information to give someone to go home with knowing that immediately they would be meeting with their early intervention ECFS consultant who would go over it and meeting with their medical provider. Louise Packness– I agree with what Eileen was saying, the reason we didn't go in depth was to keep it simple, but I think the way Laura mentioned how important that issue is it certainly needs to be addressed. Not answered but mentioned. Donna Casavant – My thought is wondering whether in this early introduction page we can include a sentence or two that there could be many reasons for the identification of a child's referral for a hearing screening. That will be part of the journey moving forward to try to see if they could come up with answers, with the understanding that some parents find the answers, and some do not. Laura Sweet – Donna, I appreciate that. I recognize that some families don't necessarily want to or need to figure out why and I respect that but there are also families that do and sometimes there are other medical causes or complications that need to be addressed.	

	Donna Casavant– I think that's exactly true and I think there are other families that focus on trying to find a reason, it gets frustrating and they end that road craving more information than they have. I think these documents could potentially honor both families and their journey's. Duska Thurston– This may be from the providers perspective and we could talk offline, for people who are looking for this information there really isn't a good structure on how to obtain this right now. I had a patient this summer that I needed to order a CMV on, I had to find Holly Richards to help me and it was a difficult process that probably took three weeks to do. Anne Banger– Bloodspot now has a procedure for doing this so I don't think it will be as complicated going forward. What we can do is look at the verbiage that is in there for possible causes and add information and tweak it so we can have something in there with some specificity but also says this is something to continue with your PCP. But let's definitely look at this, also some things are time sensitive and sometimes it's a long process. When we have time sensitive tests, we want to make sure that's addressed. Jennifer Gaulin– My kids are 10, 8 and 6 all with hearing loss. We're assuming it runs in our family, but I had the feeling for a long time that I wanted an answer but at some point, I had to put it to the side. We must keep in mind how much information is too much when this is first happening to you. Holly Richards– We haven't had that many CMV requests and our Massachusetts lab just processed them. The issue we have found is that we don't pay for it and the testing lab doesn't pay for it so our lab in Massachusetts was stuck paying for the testing. Because of the increase in people requesting CMV testing we had to look at a standard operating procedure, you can only send lab to lab so if our lab in Massachusetts sends a bloodspot to a lab in Michigan, Michigan is going to bill our Massachusetts lab so we had to incorporate a 3rd party. Massachusetts lab would send it to NorDX and NorDX would send it to the testing lab. The testing lab would bill NorDX and NorDX would bill the family because neither us or the Massachusetts lab has a billing mechanism and neither one of us has the funds to pay for the testing. It's a little more streamlined now.	

	Laura Sweet – On page 10 is the section on amplification choices, the section for cochlear implants I think is somewhat outdated now. It says cochlear implants aren't recommended for children younger than 12 months of age, in Boston they are doing them on children 10 months of age. Just updating that information to make sure it's correct. I also think it would be helpful if it was expanded a little bit, until I had my daughter, I had no idea what cochlear implants were. Explain how they work, an external sound processor and an internal device. I think if families are considering cochlear implants they need to understand when they need to start the process. Anne Banger– I think this section needs to be updated also, along the same lines this is just a small amount of information as far as digging into it and getting deeper, this would be done with their providers and early intervention. Donna Casavant– Are we only acknowledging that these documents need updates and we will work on different sections or are we deciding and taking them apart at this point? I would be willing to work as part of a group to do updates on these documents. Anne Banger– This is updating the documents, if you have tweaks, comments, thoughts you can mark up the document and scan it and send it to me. We don't have a deadline for updates at this point. If the board wants to set a deadline for feedback that would be fine. After revisions the board will see the document again. Karen Hopkins– Does it makes sense to make a workgroup from the board along with the audiologist's feedback? Katie Duncan– I think it's important to think about the brochure as the basic introduction then we can provide specific information to that family based on where they are. Louise Packness– I want to second what Karen Hopkins was saying, I think it's a great idea to make a workgroup. And maybe today set a deadline for comments and possibly create the workgroup. Duska Thurston– I like the idea of creating the workgroup and setting a deadline also. Anne Banger– Going back to fleshing out some of these sections and adding information. Something we could also do is say "see this tip sheet for additional information" where we could go into further detail. We have a lot of documents; it makes sense to	

	me if we work through the list and prioritize. If we start with the four documents: 3 hearing loss brochures and hearing in infants and young children I think this would be a great starting point. If the workgroup gets through those to a point where they think it makes sense to come back to the board before the next meeting, we can go down through the list and pick more documents. Katie Duncan – I really enjoy the idea of a workgroup and I would be happy to spearhead that if the board is in favor. Duska Thurston– Asked and majority were in favor of a workgroup, members interested in being part of the workgroup were: Katie Duncan, Louise Packness, Donna Casavant, Laura Sweet, Eileen Peterson and Nola Metcalf. Laura Sweet– What is the thought process of having the three: unilateral, mild and general? Karen Hopkins– The workgroup can certainly change this but, way back we were getting a lot of feedback from families that they were overwhelmed by all the information they read. In the lines of deaf children and most of the children we serve are mild and unilateral. While we needed to speak to deaf children, we also didn't want families with a 30db unilateral hearing loss leaving the office feeling like their child needed cochlear implants. Louise Packness - That was our thinking to keep it simple, as you raise this now one of the things, I want to say is there has been so much more organized information made available in recent years. We should talk about how that impacts individual families in the moment of finding out that their child has a hearing loss. It was very clear that people expressed they were overwhelmed, and we didn't want them to feel like that. Donna Casavant– When I look at these three documents, I must remind myself that our role in this board is thinking about families that are entering this journey after the newborn screening process so that's an important thing for us to remember. In my role as a Teacher of the Deaf I think about the families that start this journey when their children are 4, 5, 6 or older and I think for this project I need to push this out of the way and remember these booklets were identified for newborn screening. These are the families that we are trying to communicate with for these documents. With that in mind I think having that general hearing issue and the unilateral ones,	

	those are two that are going to come from our subsequent testing. The mild one I get stuck on because in the screening process we often identify those children in that mild up to moderate certainly severe range. But some of those mild kids are getting lost so if we think about that third booklet for those children who are not deaf but in that other end of the spectrum. Whether that might be a helpful way to look at these three booklets. Eileen Peterson– I think that everybody has explained why we did these two extra books. These are not handed out after a screening these are handed out after a diagnosis. So, audiologists are seeing the child and making a diagnosis, they are saying your child's hearing loss is profound in one ear or whatever the diagnosis is at that point in time. We were having parents especially with the binder who were overwhelmed. I would be supportive of audiologists not having one booklet but to divide out the mild. I think we need to be sensitive to all of it, so let's just keep that in mind when we review these as a working group. If questions are submitted to Katie Duncan, we can make sure we touch on all of these and that would be great. Karen Hopkins– In addition to Laura Sweet it might be helpful to have a few different parents, a parent of a child with unilateral and a parent of a child with mild. I wonder if we could find a few more parents to have a few different perspectives. Donna Casavant– I am aware that these booklets are post diagnosis, I was referring to those families who start the process in screening then follow up with diagnosis and are now on the other side of that diagnosis and knowing where to go. I did not mean to imply that the mild booklet doesn't have a place because I think it does. I think the focus of these three books focus on three big clusters of families that are going to be starting this process. I was just thinking about those three clusters as we look at these three booklets to make sure that we meet the needs of those three very distinct situations. Eileen Peterson– I do remember the discussions and I still feel it in my heart. We used the word mild for this hearing loss, mild to so many people make it not important but it's an important hearing loss. There is a wide range of ramifications for that hearing loss.	
Advisory Board Discussion -	Anne Banger– In the packet that was sent to the board was a final updated risk factors for hearing loss and testing	Anne Banger

Risk factor Guidelines	recommendations document that we use, the board has seen it but we have done some tweaks to it since it was last seen by the board. I didn't receive any comments back, so as of this meeting that document is considered final and we will post it on our website and distribute it.	
Advisory Board Discussion - CMV Workgroup	Anne Banger- The CMV workgroup, the last meeting was canceled due to COVID, we are looking at getting that up and running again next spring. In the meantime, we have three or four national CMV flyer handouts that we are going to put the Maine CDC logo and contact information on so we can at least get some handouts and documents that we can use. Laura Sweet and I are going to talk to the perinatal leadership meeting on December 11, 2020. Laura Sweet– I wanted to mention the potential possibility of including CMV screening information in the pediatric audiology tip sheets, Katie Duncan I would love to chat with you about that. Laura Sweet– Karen Hopkins, I am excited to see that website, I think it looks fantastic it is very exciting from a parent's perspective. I see great opportunities for including CMV information in that website I hope as well. I saw briefly on the side it said parent roadmap and I'm not sure if eventually you will be sharing that with us but including CMV screening in that follow-up and roadmaps seems like an opportunity that I would love to talk more to you about before things are finalized.	Anne Banger Laura Sweet
Advisory Board Discussion - Membership	Anne Banger – Melinda Corey who had been serving in the representative CDS seat since 2018 has stepped down. Ariana Whiting was signed off by the Governor to represent that seat for Child Development Services. We still need a parent of hearing child and a representative of insurance carriers; all the other seats are full. This is the last meeting for 2020 so we need to set dates for the 2021 board meetings. The board decided three meetings a year, in the past the meetings have been in March, June and October so the dates that run on the same cycle as what we have done in the past would be Tuesday, March 23, 2021, Tuesday, June 22, 2021 and Tuesday, October 26, 20201. Louise Packness– Moved to accept these dates for our 2021 meetings. Laura Sweet– Seconded the vote meeting dates in 2021.	Anne Banger Louise Packness Laura Sweet

Advisory Board Discussion – Board Co-Chair	Anne Banger– In the last board meeting we appointed Duska Thurston as the chair, but typically we also appoint a co-chair for situations where Duska Thurston can't attend the meeting. What we have done in the past is if you serve as the co-chair, the understanding is you would take on the chair position. Typically, it is a 1-year appointment. I don't recall, in the past how have we handled the co-chair. Has it been a volunteer from the board? Duska Thurston – I think by nomination. Karen Hopkins– I think there are lots of people who can do this job very well, but I would like to nominate Katie Duncan. Louise Packness and Cathy Lushman both second the nomination. Duska Thurston– Called for a vote. Unanimous vote for Katie Duncan as co-chair.	Anne Banger Duska Thurston Karen Hopkins Louise Packness Cathy Lushman
Other	Holly Richards- Nebulogic is the company that does our data surveillance/management system which was formerly Childlink. They are working on meeting our needs but still have not finalized all the pieces of hearing data and the functionalities that we want for hearing. Laura Sweet– I wanted to share some information from the CMV Canada virtual series. They have reframed the CMV discussion instead of should we screen for congenital CMV infections it's should we enhance screening for early permanent hearing loss risk? In Ontario they include CMV and the most common genetic causes for hearing loss. They decided to frame it this way to bring together and improve their newborn hearing screening and newborn bloodspot screening program. I thought this reframing was interesting and would like to discuss it when we have time. Anne Banger– This is certainly something we want to consider when looking at the guides, how and where to include these. Everybody should have received copies of the three audiology booklets; one on hearing loss, mild hearing loss and unilateral hearing loss as well as the Hearing in Infants and Young Children brochure.	Holly Richards Laura Sweet Eileen Peterson Anne Banger Karen Hopkins Jennifer Gaulin Katherine Duncan Louise Packness Duska Thurston
Break	No break was taken	
Adjourn	Duska – Adjourned meeting with no additional questions.	
Next meeting dates	Tuesday March 23, 2021 Tuesday June 22, 2021 Tuesday October 26 20201.	