

MD EHDI Advisory Council Minutes

April 21, 2016

MEMBERS PRESENT	MEMBERS ABSENT	GUESTS
Jennifer Reesman, Ph.D., Chair - Mental Health Professional with expertise in deafness	Brian Reilly - Physician	Cheri Dowling - Parent
Claire Buxton, AuD., Vice Chair - Audiologist with expertise in childhood hearing loss	Cheryl De Pinto, M.D., MPH - DHMH	Ben Dubin – Past MD EHDI Advisory Council Chairperson
*Stacy Fitzgerald – MSDE (Maryland State Department of Education)		*Kunal Sanghavi, Genetics Counselor, JHU and works for NYMAC (New York Midatlantic Consortium for Genetics and Newborn Screening)
		Denise Purdue – Hearing and Speech Agency
Jessica Thornton – Parent		Amy Speers, ODHH
Lori Moers – MSD (Maryland School for the Deaf)		Sarah Groff – Montgomery County Public Schools
Bridgetta Bourne-Firl – MDAD (Maryland Association of the Deaf)		Dawn Marsiglia – Audiologist, JHH (Johns Hopkins Hospital)
		Jean Montgomery – Speech Language Pathologist, Hearing and Speech Agency
Kelby Brick Esq., CDI – ODHH (Governor’s Office for the Deaf and Hard of Hearing)		
Judith Black - Educator from Local Education Agency		
*On the Phone		
DHMH STAFF PRESENT		
Tanya D. Green - MD EHDI Program Chief		
Erin Filippone, Program Audiologist		

QUORUM PRESENT? Yes

(1/3 of board members constitutes a quorum)

Meeting Opened 12:35pm

APPROVAL OF MINUTES

Minutes will be emailed to everyone, comments can be made via email and the final vote can be conducted via email.

WELCOME and BRIEF STORY-SHARING

Lori Moers – Lori stated she was recently working with a family with an 8 week old baby. The baby received the ABR (Auditory Brainstem Response) hearing screen. The family contacted the county but the county had not contacted MSD (Maryland School for the Deaf). The hospital provided the information for the county and MSD for next steps. Lori (MSD representative to the MD EHDI Advisory Council) stated that MSD provided the family with information about their school and the services they provide. Lori stated the family contacted her to thank her.

BOARD MEMBER UPDATE

Welcome to new parent representative, Jessica Thornton (appointment effective as of April 12, 2016). Jessica has a son who is hard of hearing and attends MSD in the Pre-K program. Jessica states that he is an amazing child and this has been an amazing journey on which she has learned so much. Jessica is from southern West Virginia and moved to Frederick when she learned her son would be born because her family wanted to be closer to Washington, DC. At birth, she learned he has a unilateral hearing loss. Jessica stated she learned that the hard of hearing community is one that is difficult to be in and that her son identifies himself as a super hero, saying that he is “a little bit hearing and a little bit deaf.” Jessica is a clinical social worker.

The second parent representative (parent member 2 of 2) who received the majority vote is Sue Burnes. Her paperwork is in process and her appointment has not been finalized.

Bridgetta (Maryland Association of the Deaf/MDAD representative) expressed concerns about her term limit which ends June 30, 2016. Tanya explained that she is currently completing the remainder of someone else’s 3 year term which began on July 1, 2013. This term does not count as her own. If she wishes to continue serving she is eligible to serve two, consecutive 3 year terms beginning July 1, 2016.

The following board members have terms ending on June 30, 2016 and will soon be contacted by MD EHDI to initiate the application process should they wish to continue serving:

Bridgetta Bourne-Firl (MDAD) – completion of remainder of a term/to begin her 1st term

Stacy Fitzgerald (MSDE) – end of 1st term

Judith Black (Educator from Local Education Agency) – end of 1st term

Cheryl De Pinto (DHMH) – completion of remainder of a term/to begin her 1st term

DISCUSSION

Jen - One of the things we discussed previously was the logistics and process of what information is shared with families and what time and how is that information shared. Tanya shared this in detail with a flow chart. I will pass around the flow chart, and the letter sent to newly identified families, and the

handout from MSDE with all the contact information, this has all the single points of entry throughout the state, the “Communicating with Your Child” brochure, which was developed by NCHAM, and the Parent Connections brochure in both English and Spanish.

Bridgetta - Could you send us a list of everything that is included in that list?

Jen - This was sent out in February, but I will be sure to send it out to everyone again since we have new members.

Kelby - I would like to recognize and thank Tanya for sending that information out after our last meeting. As you all know I have been trying to get a better understanding of what is happening with early identification, we can now work to close the gaps. I'm not sure if you are familiar with the Walsh Bill. This is the informal name of the original federal law. This established the funding in all states for ELDI in 1999. I was heavily involved in the development of that bill, we actually had a meeting in my office with Audiologists, ENT, and a variety of different stakeholders and stakeholder groups, the day before and after Christmas to get that bill in before the deadline. We have a lot to be proud of, prior to the passing of that law there was a system of children being identified between 2-5 years old. We are addressing the issues of language delays and making sure that they have full access to language from day one. Without language, a child is already facing so many challenges in life, if they have access to language they can do anything they want. Language is a key piece. Since that time we have seen a fabulous job with children being identified early, we still have not been successful with the overall goal of the bill, the goal is to ensure every d/HH child has access to language, my office is constantly receiving calls, about children in ITP and they are concerned their children are not up to par, their language is not on level of their peers, they were identified early but regardless they are still falling through the cracks. Based on conversations I've had with experts, parents, all that boils down to the fact that we need to focus on language development, we need to focus on it, we have wonderful technology and tools and they provide support to connect, but it means nothing without that language piece. In Maryland that is a shame we have some of the best in the country. We have deaf and hard of hearing children doing some of the best in the country, and they are a product of the MD school system. However we still have a large number of students who are falling through the gaps, and they are not being informed that language is so important. We have the research that children need immediate exposure to language.

I would like to propose that as an advisory council we advise DHMH to draft or revise the current letter, instructing all professionals who are the first point of contact for parents that every deaf and hard of hearing child runs a risk of language deprivation and that the best way to ensure they are not deprived of language is that they are given access to a visual language. Research supports that children that are exposed to a visual language supersede other children that are not. I have written a proposal (Attached) and can pass that out, and again I would like us to take a vote to advise the Secretary of DHMH to draft a letter addressing language deprivation, in both English and Spanish and placed on the website. I am happy to send a copy to the people who are also on the phone.

Erin - I want to clarify that the State cannot tell audiologists they have to do this. The State cannot override the clinical judgment of the audiologist. I don't believe the state will allow us to tell anyone what they have to do.

Kelby - there is nothing in the proposal saying they must do x y or z. This is not something they must follow up on, no rule or regulation, just to have a letter available.

Lori - I would like to add something to the letter, all of us in Maryland have a single point of entry that is the county, at that level we need to make sure that MSD is included on that. Not all counties are sharing the same information. We see the screening reports versus the referral reports and we know which counties are referring and which are not. Some counties don't refer to MSD until a child is 3 years old or older and they are not being successful. I think families need to receive the message that ASL (American Sign Language) is important and that there are other options. I think that there isn't that now and encourages that language deprivation.

Bridgetta - I have questions with regards to how we are moving on. Is this a formal proposal? How does this work? Can we bring up proposals any time during the meeting? How long do we discuss this? How exactly does this process work?

Jen - As a council one of our jobs is advising and overseeing, and other responsibilities. DHMH often brings us questions, etc. One of the council's roles is also to represent and bring together diverse stakeholders. Because we are so diverse our council takes a thoughtful approach, we will discuss and request additional information and act accordingly, in terms of action on items. In order to propose a change to something or an advice, that can be done through a motion, second and a vote. We are also an open meeting so we do seek input and solicit feedback, this is also why we have a stakeholders meeting in May. The Stakeholders meeting is no longer a requirement of the grant. Business of the council can be done as discussion, voting and acting on items. Looking at the rest of the agenda for today, I will say that even though our council can have some excellent discussions, it can become long-winded. I would say we ensure we come to an idea of whether we would like to take action, etc. in the next 15-20 minutes.

Judy - To respond to Lori because this is a critical topic to provide information to parents, but I'm remembering something Tanya showed me at the beginning of my term that had MSD and all the public schools listed, don't we have an official document that we share with parents when they have a child identified as deaf or hard of hearing? I want to clarify that we do provide that but parents are taking in so much information in such a short period of time, that we can encourage others to share that information. I believe there are gaps even through we do provide it, and we know parents can only take in so much.

Tanya - That is what was emailed in February. We share the MSD brochure and the MSDE brochure.

Lori - it's not really our position to determine if a parent is overwhelmed. It's our responsibility to give them all the information they need. The message I get from families is that some counties say this and

that, they go through all options, some counties give limited number and they don't share all the information. Those counties are relying on their county information only. We want to make a point that they are required to explain all options available to them. We can't determine if they are overwhelmed or not.

Judy - I'm trying to say that we, as a council, do provide the information. They are receiving MSD brochures and I'm agreeing with you that we need to do a better job of reminding counties to continue to share. But as a teacher in Maryland, on every IEP that we provide to parents, there is a section that says "Have parents been informed about MSD?" and I'm going to take a big leap that this is happening.

Kelby - Because of time constraints, I would like to focus only on council members and not guests, we can save guests comments until after the meeting if there is time.

Jessica - I wanted to share the parent side of things. I would love to see a little more clarification. In my own personal journey, my son was hard of hearing and MSD was discouraged because of that. Information that is available and skewed viewpoints that many have, many times I go to a doctor and people ask why am I signing with my son. A lot of information is given, and it's how it's given and approached. Many people said he would be able to talk, and discouraged MSD because he could hear and would be able to speak. I'm interested in a conversation about the letter, but I feel the letter is very scary for new people who are coming into this blindsided. I'm appreciative of the information as well.

Kelby - Thank you Jessica for sharing your experience, I think this is something that needs to be included in the letter. I want to respond to Lori's idea in terms of the referring system. I would like to ask that there be a separate item and separate issue. Again, we are asking for a letter. I think we could have a separate discussion about what the state can do to enforce referring and what can be done. It's a separate conversation as to what this letter does and addresses. I would like to focus on one particular thing.

Bridgetta - With social media and everything happening in the community there are a lot more deaf adults coming out and sharing their frustrations, anger and resentment about why they were deprived of language when they were young. My mother is an example. My mother had no language until she was 6 years old. There are many children out there that are not able to develop any language of any kind. In the spirit of Kelby's proposed letter, obviously that will lead to a better life for these babies. They won't be babies forever. As the MDAD representative I feel the spirit of the letter should be presented. I feel we need to review the letter you submitted. We could address various hearing levels. My personal view point is I support deaf and hard of hearing children having access to language. There are no ASL failures, but there are many examples of oral failures. Again I support the spirit of the proposal but would like to see some tweaking of the language of the proposal. I have also been in touch with many parents as well as being one myself. Everything in the letter is positive, however the use of the word "hearing loss" in the letter is antiquated.

Claire - My understanding is that this is a motion to create a letter. I agree, we should wrap up this

conversation in the next 5 minutes.

Jean - I think it's important to provide timely and appropriate information. There is linguistic and cultural diversity within the deaf and hard of hearing community and I feel that addressing this in the body of the letter would be important.

Jen - To clarify - that diversity within the community must be included in the language of the letter.

Jean - I believe it should be both: linguistic and cultural diversity language should be in the letter.

Claire- I am motioning to table the discussion to our next meeting. Maybe we could form a sub-committee to look at the letter and bring back suggestions and feedback to the group... feedback on things to change.

Tanya - In tabling the discussion, I would like to ask you to consider the MSDE role in terms of the language aspects. The EHDI program is focused on identification and ensuring all babies are referred to EI (early intervention) services. MSDE and EI programs pick up at that point. That's where the language development interventions will occur. Please keep that in mind as the conversation continues.

Kelby - I recognize this is still a health issue. This results in other problems growing up, education comes into the picture but DHMH has a role in this. This is a public health problem. This is a proposal only, not a draft of the letter itself. This is asking for the Secretary to develop a letter to address language deprivation. I think it's important to take a stance and we ask the Department to develop a letter. I suggest we vote on this now.

Judy - I thought Claire was making a motion to table. The Council needs to take more time to discuss the diversity of other approaches. This requires so much more discussion and depth that we would be doing a disservice as a council to vote today.

Lori - I totally agree that this is a health issue and I have no problem voting with that. MSD is in a position to vote. I agree and support endorsing that this needs to be included.

Claire - So the motion is suggesting a separate letter, not a revision of the current letter?

Kelby - I would leave it to the Department on whether or not they want to incorporate this into the existing letter or draft a new letter.

Bridgetta – I have a procedure questions. How many votes are required to pass it now or to table it? How does this process work? EHDI, the I in EHDI is intervention so I'm not really comfortable leaving this to MSDE. When babies are born you may have a 6 week old identified and they can learn sign language. I believe this is part of our responsibility here. How do we move forward and how many do we need?

Jen - First we need a quorum in attendance, which we do have today. And of that we need a majority vote. I'm hearing from the council there is agreement on the importance of language and agreement on the importance of closing gaps and providing timely information to ensure that kids that are identified are getting information. In summary as a council, I would suggest Kelby, if you were to motion to end that in the paragraph one sentence earlier. I know part of this is the rationale. What I'm hearing from all council members is the importance of doing that and communicating that. I don't know if you would like to move on a substitute proposal.

Kelby - I think we take the chair suggestion and vote on the first, third and fourth paragraph only.

Judy - I think this is another example of why we need time to discuss. I don't feel the council has had time to read this, discuss, and come to an agreement. We all need time to share all of our concerns and views.

Kelby - I want to be sensitive to what you have to say, the role of the council is to advise to the State. I have not seen any objection to the heart of the proposal, if there is subtext we can discuss that. I don't know why we can't vote.

Bridgetta - I suggest that we bring it to vote. If it does not have the majority vote at this time, we continue the discussion at a later time.

Judy - I have no objections per say. I feel as the public education representative it's important to be concerned about speaking only ASL. It doesn't mean that I support one or the other more, but we have members of this council who are diverse. Montgomery County Public Schools offer three options: cued speech, oral and ASL. I feel we need more time to discuss what is the role of our group and are we comfortable sending any kind of policy, statement without including all diversity and language, and if everyone feels it's ASL and English. I feel we have not given the time and discussion needed.

Lori – I want to clarify - it says English, that's been taken care of in speech. ASL that is another language. Cued speech is not a language so we can't really include that. I feel like we need to set clarification in the body of this letter and it's already there.

Bridgetta – Again, referring to the infants that are 6 weeks old, we are looking at babies who are not in the school system yet. We are looking at that age, not school age.

Kelby - I would like to vote.

Bridgetta – Second.

Kelby - I am asking for a vote on the proposal, focusing on the first, third and fourth paragraph of the paper the council members have in front of them.

In favor – 5

Abstained – 3

(Absent – 3; 1 Vacancy)

Motion passed.

Judy - I'm not comfortable with taking this vote in such a short time.

Dawn - From what I understand this is to revise this letter. I feel it's the council's job to support and assist, to understand that critical language starts when the babies are born not later, so it's not so much which language they decide on, but that they become educated and make this a priority. I would emphasize this more than the avenue they choose.

Ben - For those of you who don't know me, I have an adult daughter who is profoundly deaf and what we have done here today has really taken the back door approach to the "Deaf Child's Bill of Rights" and stating that all deaf children should use ASL. I feel you have taken away parents' choice as to what language a child should use. This council should be neutral and should not take any position with regard to language choice. We need to remember what ELDI stands for, and we need to provide a path for intervention and it's up to parents to decide which they would like to use. We don't want to take that choice away from parents. I think you have done a disservice to the ELDI program.

Sarah - I'm wondering if the council, instead of focusing on what the parents' language choices are, maybe work with a better way to work effectively within the system. The other county I worked in would put hearing aids or cochlear implants on kids. I think the breakdown is occurring in the IEP and IFSP process and as educators we are responsible for giving parents the correct access to guide them neutrally and we aren't doing that in Maryland or throughout the country. There needs to be a better relationship between county schools and MSD.

Judy - Could you clarify exactly what we have done with regard to that letter?

Jen - It concerns me that there is confusion on what we voted on in the council. The motion voted on today was a motion for the council to advise DHMH to develop a letter that explains the list of difficulties of language deprivation this included paragraphs 1, 3 and 4 that Kelby distributed to the council after the discussion.

Tanya - What is the next step? Will this be sent to the department?

Kelby - I'm assuming that you will be responding back to the Department that the council is advising them to draft a letter. You can incorporate this or develop a new one. It's up to you.

Jen - Also that the council devotes time, action and diversity to these efforts if that is wanted.

Tanya - I guess this is the small segment I'm missing. Will someone from the council provide me with a revised document?

Kelby - I'm willing to send you an electronic copy with the second paragraph removed.

Tanya - It's the council that is advising the Department. So if that is the advisement to the Department, it must come from the council.

Jen - We will get that to you.

Erin - Did you vote that you want to write a letter or that you are sending that letter?

Jen - We are advising DHMH and the EHDI program to develop a letter.

Kelby - We are not writing a letter. We want the staff to write the letter.

Erin - So the council is going to write a letter and send it to someone at the Department?

Kelby - The letter is going to be from the Department to the parents. We are advising them to write a letter. I would suggest the chair work with them to determine what will be sent out.

Bridgetta - If I'm understanding correctly, the motion is based on this handout that Kelby sent out removing the second paragraph. So with the removal of the second paragraph, the remaining #1, #3, #4 will now comprise our formal motion. It was a motion based on majority vote. We are in agreement.

Claire - Who do we contact?

Tanya - It can come to me and I can forward it to my superior. I recommend it come to me and I forward it to my superior and it can go up the chain. They will come to us and we should deal with it in the Office for Genetics and People with Special Health Care Needs and Donna Harris (Office Director) will take it to the Administration. Because some things will change.

Jen - We will need to follow up procedurally on that. I will draft the letter that will accompany that.

Erin - if you are going to do that, I suggest you draft the letter you want to send. Otherwise we will not be clear on what you want us to say.

MD EHDI UPDATE

The second follow up coordinator who began in August, 2015, resigned in February, 2016. Three 6-month emergency, temporary employees were hired during March to assist with follow up. There are now 4 follow up coordinators (1 permanent, and 3 temporary).

Face to face physician outreach to reduce loss to follow up/documentation in target areas has yielded has continued. Twenty visits have been made and 17 pediatricians were identified allowing the babies' files to be updated with corrected information. Hearing test information was obtained for 17 and documented in the MD EHDI data system. Additionally, through this outreach effort, it was learned that one previously "lost" baby has an appointment scheduled. The loss to follow up goal is to remain under 20%. During a time when the program was fully staffed, the rate had been as low as 17%. As of March 16th, the loss to follow up rate is 21% (down from a baseline of 31.34%) and this was achieved during a period of extended vacancies within the program.

MD EHDI WEBSITE

Bridgetta stated that the MD EHDI website and the MD EHDI section on the NCHAM website (National Center on Hearing Assessment and Management/ www.infantheating.org) needs to be updated. Bridgetta suggests sharing the link to the Laurent Clerc Center (Gallaudet University) Learning Opportunities resources on the MD EHDI website. Resources include how to manage hearing aid use. Tanya asked Bridgetta to email the requests to her. Bridgetta also stated that it is old fashioned to request babies to be sedated for a hearing test. Jen stated these concerns will be addressed at the next council meeting in July.

MSDE UPDATE

The Hearing Aid Loan Bank bill was passed last week. The bill extends the age limit from 3 to 18. Kelby stated that many other states are inquiring how they can model legislation after Maryland. Kelby states that we have many wonderful things in place but we still have gaps. Kelby stated that this is a great step to ensure access to communication and is a great tool for parents to ensure children have language access; the ODHH office is very excited to have this signed into law.

Stacy stated that the Hearing Aid Loan Bank has a nice supply of top of the line hearing aids, along with some BAHA's (bone-anchored hearing aids) as well. They are looking to purchase more hearing aids. Some older technology hearing aids which are in good condition are still available. All hearing aids can connect with FM systems. There is no concern for meeting demand. Claire stated that the University of Maryland received several of the old hearing aids from the loan bank and many of those hearing aids have been donated to organizations around the state. Judy stated that Montgomery County Public Schools also received some of the old hearing aids and asked how long the students can have the hearing aids on loan. Stacy answered that the loan period is for 6 months. An extension can be requested for 3 additional months by completing the extension form. After a 3 month extension expires, another 3 month extension can be requested. The Hearing Aid Loan Bank has the discretion to request the return of the hearing aid but they try to allow hearing aids to be loaned for as long as needed.

Kelby stated that ODHH also has boxes and boxes of hearing aid cases. If anyone wants them, they can contact him.

PROTOCOLS WORKGROUP

A draft of the protocols will be presented at the July meeting.

AGENDA ITEMS FOR NEXT MEETING

Demo of MD EHDI Data System (OZ esP™)

Review draft of protocols

Discuss MD EHDI website update suggestions expressed by Bridgetta

ANNOUNCEMENTS

May 12, 2016 - MD EHDI Stakeholders Meeting – Hearing and Speech Agency, Baltimore, MD

MEETING SCHEDULE

12:30-2:30pm at the Hearing and Speech Agency (Park in the rear lot)

(Quarterly on the 3rd Thursday of each month, beginning in January)

Thursday, July 21, 2016 Time: 12:30-2:30pm

Thursday, October 20, 2016 Time: 12:30-2:30pm

Motion to adjourn by Bridgetta, seconded by Judy.

Meeting Adjourned 2:50pm

EHDI Advisory Council Motion

We move that the EHDI Advisory Council advises the Department of Health and Mental Hygiene to issue a letter immediately to every parent of a child identified as Deaf or hard of hearing explaining that their child runs a severe risk of language deprivation and that the best way to prevent such deprivation is to ensure that their child is exposed at the earliest possible age to visual language in addition to English. In Maryland, this typically means English and American Sign Language (ASL).

Research over time has consistently shown that Deaf and hard of hearing children who are provided early exposure to American Sign Language (ASL), acquire strong English speech skills and better vocabulary and reading skills, compared to their hearing peers exposed to only spoken English. Exposure to ASL provides critical language access in order for young Deaf and hard of hearing children to achieve language-related milestones on the same timeline as their hearing peers. Language deprivation is preventable and a serious public health concern. Parents need to be informed of the steps that they can take to ensure that their Deaf and hard of hearing children are exposed to ASL as early as possible in order to achieve strong health related outcomes.

Copies of the letters should be distributed through every EHDI channel along with instructions that professionals of first contact with families of newly identified Deaf and hard of hearing children pass on this letter to the families.

A copy of this letter should also be posted on EHDI's website as well and also translated into Spanish and ASL.