

MD EHDI Advisory Council Minutes

July 16, 2015

Approved by Council on 11-12-2015

MEMBERS PRESENT	MEMBERS ABSENT	GUESTS
Jen Reesman, Ph.D., Chair, Mental Health Professional with expertise in deafness	Kisha Greenidge-Kader - Parent	Cheri Dowling, Parent
Olga Polites, AG Bell	Claire Buxton, Au.D., Audiologist with expertise in childhood hearing loss	Sue Griebler, Past Board Member
Judith Black, Educator from a Local Education Agency	Melissa Schober, DHMH	Stacy Fitzgerald, MSDE/Hearing Aid Loan Bank
Mary Ann Richmond, Maryland Association of the Deaf	VACANCY: PARENT MEMBER	Kelby Brick, ODHH
Lori Moers, MSD	Pending: MSDE Member	Jean Montgomery, HASA and AG Bell
*On the Phone	Pending: ODHH Member	
*Brian Reilly, M.D. - Physician	CHAPTER CHAMPION (Non-Board Member) Debbie Badawi, M.D. – Maryland AAP EHDI Chapter Champion	
DHMH STAFF PRESENT		
Tanya D. Green		

QUORUM PRESENT? Yes

(at least 4 board members constitutes a quorum)

The meeting opened at 12:50pm with a welcome, introductions and a shared story. Jen Reesman. Jen stated that Universal Newborn Hearing Screening (UNBHS) Programs began 15 years ago which means that they are now in their adolescence. We now serve transitional age individuals who are moving into adulthood. Some were born when there was no UNBHS. Their parents express multiple years of missed opportunities and misdiagnoses. Jen expressed that EHDI is ready to spread its wings and move to the next stage.

APPROVAL OF MINUTES

Meeting minutes from March 19, 2015 were approved as written.

BOARD MEMBER UPDATE

Kelby Brick, Esq., CDI is the newly appointed director of ODHH and is currently being processed as the ODHH representative to the MD EHD Advisory Council. Lisa Kornberg no longer works for ODHH. Stacy Fitzgerald, audiologist and manager of the Maryland Hearing Aid Loan Bank will be formally recommended by MSDE as their representative to the Council. One of the two possible parent member positions is vacant. Olga's term as the MD AG Bell representative has expired, however she continues to serve until a response is received from MD AG Bell or the national chapter indicating who the new Maryland chapter president is and/or who can provide a letter recommending a new board member. Jean Montgomery, speech-language-pathologist at the Hearing and Speech Agency and MD AG Bell member is interested in succeeding Olga.

An electronic vote was held for the vacant parent member position and Valerie Nelson was unanimously selected. However, Ms. Nelson had to decline the position because of unanticipated circumstances requiring her to move out of state. Jen will email an advertisement to board members soliciting interested persons for the parent member position. The email can be forwarded to any and all who may be interested in serving.

UPDATE ON 2015 MD EHD STAKEHOLDERS MEETING (May 14, 2015)

This year's stakeholders meeting had the largest attendance out of all the stakeholders meetings thus far (100 in attendance). 100 people registered and an additional 25 were on the waiting list. Some who registered did not attend, allowing all who showed up and or registered to be able to attend. No one was turned away. 82 evaluations were received and the responses were mostly excellent. Evaluation responses indicated most speakers and presentations were very well received. Some evaluations felt the last speaker/topic of the day (the Towson University survey results) was not engaging enough for the end of the day. This was the first stakeholders meeting where there were protesters (Audism Free America). The protest involved a gathering, displaying of signs, distribution of literature and interaction with meeting participants. It was stated that several parent meeting participants were upset by the protesters because of the things said to them by the protesters.

Funding availability for next year's stakeholders meeting has been reduced. DHMH/OGPSHCN provides funding to the *Parents Place of Maryland*. The *Parents Place of Maryland* provides funding for the *Parent Connections* parent mentor program and the annual MD EHD Stakeholders Meeting. The grant guidance requires the 2016 stakeholders meeting to focus on medical homes, transition and autism. The grant application is due mid-August. The desired but unconfirmed date for next year's meeting is May 19, 2016. The Hearing and Speech Agency is made available for the stakeholders meeting at no charge and offers free and easily

accessible parking. It is unlikely that moving the meeting to a larger venue or offering telecasting and/or a satellite location as discussed in previous council meetings to accommodate the growing number of participants is a possibility because of the cost and the reduced funding. Additionally, the executive director was not happy about the presence of protestors.

Kelby asked if there is total demographic information available on meeting participants to see what groups need to be targeted more. Kelby asked what is the target group for the 2016 annual meeting. There is not a specific group that is targeted. The meeting is open to everyone, to all stakeholders. There is no demographic information available except profession. Kelby stated that we are maintaining the status quo and in his opinion that is unacceptable. He stated that a generic conference is unacceptable. Cheri stated that each year the conference has a different focus. The 2015 focus was on students who are Deaf and Hard of Hearing. The 2016 focus will be on medical homes, transition and autism. Cheri stated that 120 people registered and 100 people showed up.

MD EHDI UPDATE

Current MD EHDI follow up stats were provided and explained and it was pointed out that the Program is down by 1 follow up coordinator. The 2nd follow up coordinator position has been vacant since September, 2014. There is an interested applicant being processed for the position however a change to the hiring process was changed last week and MD EHDI is awaiting direction on how to proceed with hopes that the applicant will not lose interest before being hired. Some council members spread the word and encouraged others to apply for vacant positions. It is important to also communicate that all applicants must meet the minimum requirements indicated for the position to be considered. Two pools of applicants and interviews were exhausted in the search to fill this vacancy. Many applicants did not meet the minimum qualifications indicated on the job announcement.

Two pools of applicants and interviews were also exhausted in the search to hire a community outreach coordinator to advance the efforts of the HRSA grant by providing face to face outreach to physicians and their staff in the areas of the state with the highest lost to follow up rates (Baltimore City, Baltimore County, Prince Georges County). Because the community outreach coordinator position was to be temporary, ending March 31, 2015, the plan now is to not hire an outreach coordinator, and to instead utilize DHMH/OGPSHCN staff to conduct the outreach. It was suggested to use *Parent Connections* mentors to conduct the outreach.

A draft of an informational MD EHDl post card was circulated and will be sent out electronically to board members for feedback and an approval vote before distribution to families and providers.

It was asked if the council minutes can be posted on the MD EHDl website. Council minutes are posted on the MD EHDl website but need to be updated with more recent minutes. Dr. Debbie Badawi has moved to a new position within DHMH but continues to serve as the MD AAP EHDl Chapter Champion. Please email Tanya Green if you are available, willing and able to commit to being a part of a stakeholder team to assist with the Quality Improvement efforts of the Program.

Feedback from the group was solicited about the administration of ototoxic medications as a risk factor for later onset hearing loss. The current JCIH Position Statement does not specify a threshold of amount or time length of administration of ototoxic medications, only that the baby received it. The recent, effective MD EHDl regulations indicate that MD EHDl follows the current JCIH guidelines for risk factors. Some research indicates that the administration of ototoxic medications is not a significant risk for later onset hearing loss unless the baby received the medication for more than 5 days. Some research indicates that if a certain genetic factor exists in conjunction with the administration of ototoxic medications of any amount for any duration, then that puts the baby at risk for later onset hearing loss. It was expressed to MD EHDl that it may be a burden on pediatricians and audiologists for babies whose only risk factor is the administration of ototoxic medications which was less than 5 days to be required a hearing evaluation by 12 months of age. The question to the voting board members is, should MD EHDl consider "administration of ototoxic medications for more than 5 days" as a risk factor instead of keeping consistent with the current JCIH Position Statement and the current MD EHDl Regulations "administration of ototoxic medications"? It was added that it is unclear if it can be justified (by the DHMH attorney general) to not be consistent with the language that is in the regulations. 5 out of 5 board members present at the time of this vote, voted in favor of being consistent with the regulations and the current JCIH Position Statement.

MD EHDl REGULATIONS REVISION UPDATE

The revised regulations (COMAR 10.11.02) became effective June 22, 2015.

COUNCIL BY-LAWS WORKGROUP

No Report

PROTOCOLS WORKGROUP

A Google document is being used for workgroup members to enter revisions to the document. Jen stated that the protocols should work on the document and have a draft available for review by board members at the next council meeting.

COMMUNICATIONS WORKGROUP

No Report

PARENT CONNECTIONS UPDATE

Parent Connections will conduct 6 events this year, including a Family Learning Weekend for 25 parents to be held in September, 2015 at the Sheraton, Columbia. This year's Family Learning Weekend will include all children who have special health care needs, not just Deaf and Hard of Hearing children. *Parent Connections* will work with *Connections Beyond Sight and Sound* and *Talking Hands* to conduct this weekend event. Jen Reesman will donate books from the Kennedy Krieger Institute's *First Books Program* for the event.

ANNOUNCEMENTS

Former dedicated board member and ENT, Dr. Stephen Epstein recently passed away. He will be greatly missed.

Jen Reesman has 4 incoming trainees who arrived July 1st and are working with her at Kennedy Krieger Institute for 1 year (then 4 new trainees will begin). They will train at Kennedy Krieger Institute and then return to serve underserved populations. None of the trainees are Deaf or Hard of Hearing, however one is fluent in cued speech. One trainee is from Guam and one is from Louisiana. Jen wants to provide as much exposure for them as possible. Contact Jen if you are willing to give them a tour of your work environment, allow them to do a ride along, etc. Cheri said they can attend the Family Learning Weekend which is planned for September, 2015, though their hotel stay cannot be covered. Jen said they can volunteer at the event.

Jen suggested board members take the Open Meetings training if they have not already done so.

MEETING SCHEDULE

All meetings time and location: 12:30-2:30 at the Hearing and Speech Agency

(Park in the rear lot)

October 15, 2015

January 21, 2016

Meeting Adjourned 2:40pm