

# MD EHDl Advisory Council Minutes

January 21, 2016

<b>MEMBERS PRESENT</b>	<b>MEMBERS ABSENT</b>	<b>GUESTS</b>
Jennifer Reesman, Ph.D., Chair - Mental Health Professional with expertise in deafness	Kisha Greenidge-Kader – Parent	Cheri Dowling - Parent
Claire Buxton, AuD., Vice Chair - Audiologist with expertise in childhood hearing loss		Charm Smith - MDAD
Stacy Fitzgerald - MSDE		Bridgetta Bourne-Firl - MDAD
Olga Polites - AG Bell		Kristin Crocfer – Intern KKI
Lori Moers - MSD		Adrienne Borschuck – Intern KKI
Mary Ann Richmond - MDAD		Sammasia King – Intern KKI
* Brian Reilly - Physician		Dawn Marsiglia – Audiologist, JHH
* Cheryl De Pinto, M.D., MPH - DHMH		Seth Marciniak – Regional Coordinator Pediatrics Medical Group
Kelby Brick Esq., CDI - ODHH		Jean Montgomery – Speech Language Pathologist, Hearing and Speech Agency
* Judith Black - Educator from Local Education Agency		
<b>*On the Phone</b>		
<b>DHMH STAFF PRESENT</b>		
Tanya D. Green - MD EHDl Program Chief		
Debbie Badawi, M.D. - Maryland AAP EHDl Chapter Champion		

**QUORUM PRESENT? Yes**

*(1/3 of board members constitutes a quorum)*

**Meeting Opened 12:45 PM**

**APPROVAL OF MINUTES**

The November 12, 2015 minutes will be approved at the next meeting.

## **WELCOME and BRIEF STORY-SHARING**

Claire – Claire is currently working with students at the University of Maryland, College Park. She also teaches pediatric audiology. The class wrote protocols for EHDI. Most were born in the late 90's, but do not have a lot of experience with the pre-screening era, so they have some interesting ideas. Claire stated that it was a good experience for the students and allowed them to become more invested in the process as they prepare to enter the work world.

## **BOARD MEMBER UPDATE**

MDAD is recommending a new representative and the new candidates paperwork will be submitted to DHMH shortly. Olga will continue to serve as the AG Bell of Maryland representative, serving her second term.

Responses were received from five parents for the vacant parent representative position. It was suggested that there be guidelines for the parent representative. It was stated that there have been parents to apply who have children who are adults. It was stated that we need to have parents that have young children and have recently gone through the EHDI process. The statute only indicates that the parent must have a child who is deaf or hard of hearing. There is a need to discuss the possibilities one parent being hearing and one deaf, and/or one ASL and one oral. It was stated that there needs to be a look at the make-up of the council considering there are very few men and no people of color.

## **MD EHDI UPDATE**

The newly hired second follow up coordinator is still learning protocols and is not yet fully trained. The physician outreach QI project to help reduce loss to follow up is in process. Interviews did not yield a viable candidate for the outreach coordinator position, so the Parent Resource Coordinator for the Office for Genetics and People with Special Health Care Needs within DHMH is fulfilling this role. She has experience (is a parent of children who have special needs) and expertise (currently works as a parent resource coordinator) that makes her a good fit for this need. Her first physician outreach visit was conducted on September 25<sup>th</sup>, 2015 and she has visited 14 offices and found 11 lost babies that would otherwise not be known to MD EHDI. The visits were made in the target areas of Baltimore City and Baltimore County. The next target area will be Prince George's County.

The National Annual EHDI Meeting will be in San Diego from March 13-15, 2016. Registration is currently open at [www.ehdimeeting.org](http://www.ehdimeeting.org). NCHAM (National Center on Hearing Assessment and Management; one of the organizers of the meeting) offers one stipend to every state each year. The stipend is to be used to partially fund a parent's attendance to the annual meeting. This opportunity was advertised through various channels. Only one parent responded. Ms.

Mariam George will be using the stipend awarded to Maryland. She is a Maryland resident and the parent of a child who is deaf. Claire asked if there is additional funding available. Cheri recommended Claire contact her county's SECAC (Special Education Citizen's Advisory Committee) and ask if they have any funding available.

### **MD EHDI FOLLOW UP STATS**

According to MD EHDI Program records, as of January 14, 2016, for the calendar year 2015, 73 babies were identified having a confirmed hearing loss (includes sensorineural, auditory neuropathy, mixed permanent). This statistic includes 3 babies with late onset hearing loss. This statistic does not include transient conductive hearing loss. All babies identified have been referred to early intervention services except 1 baby who is a legal residence of the Bahamas, 2 babies who were not referred due to clinical judgment, and 1 baby who is still in the hospital.

The loss to follow up/documentation (LTF/D) goal is to be under 20%. In calendar year 2012, the rate has been as high as 34.2%. Since that time, the rate has been as low as 17%. As of last week the LTF/D rate was 25-26%. The fluctuation in this rate is related to extended periods of vacancy in the second follow up coordinator position.

### **2016 MD EHDI STAKEHOLDERS MEETING**

The date for the 2016 MD EHDI Meeting has been changed to May 12<sup>th</sup>. Bridgetta Bourne-Firl will present about the new resources at the Laurent Clerc Center (Gallaudet University). "Setting Language in Motion" is a new resource that was just released from the Clerc Center and can be found on their website.

### **PARENT CONNECTIONS UPDATE**

The *Parent Connections* parent to parent mentor program held a workshop with Dr. Rachel Plotkin on ADHD and the Brain. The workshop was successful and well-attended. An event is scheduled in April at a snowball stand in upper Baltimore County. There will be free snowballs and activities for families and children. *Parent Connections* is working with *Connections Beyond Sight and Sound* on another family learning weekend to be held in September, 2016. The topic will be post-secondary transition. Ms. Charm Smith and Mary Ann Richmond have asked if *Parent Connections* can work with Maryland Association of the Deaf /MDAD to develop a family fun day. Parent Connections response: they'd love to!

### **PROTOCOLS WORKGROUP**

The protocols draft is in process. Claire would like to include some citations at the end. Lori Moers and Bridgetta Bourne-Firl (once her appointment as MDAD representative is finalized) will join the protocols group.

## **MD AAP CHAPTER CHAMPION UPDATE**

### **MD AAP EHDI Website:**

Mary Ann, Claire and Dr. Badawi have a call scheduled to discuss the updates on the website. The protocols will be added to the MD AAP website once completed. Kelby suggests the MD AAP website consider using EHDI information from the national AAP website or linking to the national AAP website, which he feels has very strong EHDI information.

CRISP (Maryland's designated Health Information Exchange/HIE), provides IT services for hospitals in Maryland. CRISP is working with MD EHDI on a project that allows demographic information for patients to be pulled from the hospital's IT system into the MD EHDI OZ Systems eSP data system. CRISP receives data from hospitals and laboratories but not yet from private practices.

### **ADDITIONAL DISCUSSION**

Kelby stated that he is interested in information about what happens once a baby is identified with hearing loss and what happens after the baby is referred to early intervention services. He wants to know what parents are being told, what is happening in the hospitals and what is happening when the baby leaves the hospital. Kelby stated that we have the numbers but it is meaningless information without the information about what happens next. Tanya suggested that Kelby contact MSDE for this information, stating that babies who are identified with a hearing loss through MD EHDI are referred for early intervention services. At that point, the MSDE Infants and Toddlers Program provides follow up. Lori shared that each county is responsible for the follow up and MSDE states that the Maryland School for the Deaf (MSD) must be involved. However, Lori states, the counties are not following that. Lori further states that counties are controlling what is given to the families. She says there are times when counties are contacting MSD or parents are finding MSD on their own. Kelby says he is looking at the gaps in policy and where we can fill them in. Kelby said he would like to see on paper, the guidelines and documentation, the second after parents are informed that the baby has a hearing status.

Kelby would like to know what happens from the hospital to the IFSP. Tanya clarified that when MD EHDI receives information that a baby has a confirmed hearing loss, a diagnosis notification letter is sent to the family. Other resources are included in the envelope with the letter. If the baby is not referred to early intervention services within 2 weeks, MD EHDI makes contact with the audiologist and asks the audiologist to refer the baby to early intervention services. If the referral is not made by the audiologist, then MD EHDI contacts the MSDE Single Point of Entry and makes the referral. Kelby stated he would like to see written documentation of this procedure. Dawn Marsiglia (JHH audiologist) recommended that Kelby have a demo of the MD EHDI OZ data system and see the information that is documented when a baby leaves the hospital.

## **ANNOUNCEMENTS**

March 13-15, 2016 - EHDI Conference - San Diego, CA

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, April 21, 2016 Time: 12:30-2:30pm

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

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

**Meeting Adjourned 2:45 PM**