

# MD EHDI Advisory Council Minutes

November 12, 2015

<b>MEMBERS PRESENT</b>	<b>MEMBERS ABSENT</b>	<b>GUESTS</b>
Jen Reesman, Ph.D., Chair, Mental Health Professional with expertise in deafness	Brian Reilly - Physician	Cheri Dowling, Parent
Stacy Fitzgerald - MSDE	Kisha Greenidge-Kader - Parent	Sue Griebler, Past president and past MSDE representative
Olga Polites - AG Bell	Lori Moers - MSD	Jennifer Mertes - MSD
Mary Ann Richmond - MDAD		David Alexander - MSD
Cheryl De Pinto, M.D., MPH - DHMH		
Kelby Brick Esq., CDI- ODHH		
<b>*On the Phone</b>		
*Claire Buxton, AuD., Audiologist		
*Judith Black (educator from Local Education Agency)		
<b>DHMH STAFF PRESENT</b>		
Tanya D. Green, MD EHDI Program Chief		
Debbie Badawi, M.D./Maryland AAP EHDI Chapter Champion		

**QUORUM PRESENT? Yes**

*(at least 4 board members constitutes a quorum)*

Meeting opened 12:40pm

**WELCOME and BRIEF STORY-SHARING**

Jen Reesman shared a story about a 10 year old client who received the newborn hearing screen but began to struggle in school and was found to have a progressive hearing loss. His mom has a history of progressive hearing loss. Jen spoke of missed opportunities which prevented the monitoring of his hearing. She stated that his parent was angry that others were not as angry as she was about missed opportunities to have learned about her son’s hearing at an earlier age.

**APPROVAL OF MINUTES:** Minutes from the July 16, 2015 meeting were reviewed and a few revisions were made. Kelby motioned to accept minutes with revisions, Stacy seconded, no

objections. July 16, 2015 minutes were approved with revisions.

### **BOARD MEMBER UPDATE**

Welcome to the new DHMH representative, Cheryl De Pinto. M.D. One of the two positions for a parent of a child with a hearing loss is vacant. We are still searching for this person. (Valerie Nelson was the last parent voted in but rescinded her application on June 15, 2015 prior to being appointed because she learned that she would be moving out of state.) The AG Bell representative is Olga Polites. The Maryland AG Bell chapter has been inactive; however this chapter has recently reformed. Their first meeting was October 22nd and the new president is Carrie Nicholson. Tanya has reached out to her to see if they would like to recommend Olga to continue serving or if they have someone else in mind to replace her. Olga will continue to serve until a new person is appointed.

### **MD EHDl Update**

**New Follow Up Coordinator-** MD EHDl has a new follow up coordinator, Theresa Ogide-Alaeze. She joins Theresa Thompson in conducting follow up for babies who missed or did not pass the newborn hearing screen.

**Physician Outreach** – The HRSA grant requires MD EHDl to reduce lost to follow up. MD EHDl was looking to hire an outreach coordinator to conduct outreach to physician offices in regions where loss to follow up was highest (Baltimore City, Baltimore County and Prince Georges County). After exhausting interview pools, it was decided that Angela Sittler (family resource coordinator within the Office for Genetics and People with Special Health Care Needs(OGPSHCN/DHMH) would spend some of her time fulfilling this role. Angela visits practices within the target areas that have 5 or more babies who are lost to follow up. Her first visit was on September 25<sup>th</sup>. Some babies have been located through her efforts. Physician relationships are being established and/or strengthened. Physicians are given the opportunity to register to use the MD EHDl database. Physicians who conduct follow up newborn hearing screenings in their office are required to report the results into the database. They are being updated on the new regulations. Because Angela also manages the family resources located she provides them with that information. Two additional staff from the OGPSHCN, Mary Jo Harris and Rebecca Furman, are visiting physician offices for various projects and have shared MD EHDl information to overlapping target practices. To date, 13 visits have been made.

### **OPEN DISCUSSION**

Kelby expressed concerns that many states seem to have a problem with intervention and asked if anyone follows up on early intervention (EI) in Maryland. Kelby expressed a desire to see data that would show that children are receiving language exposure, stating that otherwise

all we are doing is identifying and not following up on language, to ensure that every child has access to language.

Tanya explained that MSDE provides EI services. The MD EHDI Program ensures that babies who are identified through the Program are referred for EI services. Tanya stated that as of September 14, 2015 there were 35 babies documented with a confirmed hearing status that dictates they should be referred, 32 have been confirmed as having been referred to the MSDE Single Point of Entry/Infants and Toddlers Program for EI services. Language intervention would occur through MSDE. Kelby asked if someone from the Infants and Toddlers Program could attend an MD EHDI council meeting and provide data. Jen asked Stacy Fitzgerald (MSDE representative) if MSDE could provide the council with policies at the statewide level for children who are deaf and hard of hearing with what they expect from their local jurisdictions. Mary Ann Richmond was asked to contact Lori Moers to request information on what the Maryland School for the Deaf's policy is with regard to what steps are taken when a family is referred to them. Tanya was asked to provide MD EHDI policy and procedures information. The MD EHDI Program legislation regulations were mentioned. Kelby reminded everyone that EHDI really has no teeth and there is limited consequence. He stated that this is our constructive mission to move forward. We have no power to take away a license if someone does not enter information into the database and that we have little authority to find people who are not providing access to language. Dr. Badawi stated that accountability lies with the jurisdictions that are monitoring the child's progress through the IFSP and that if a child is not making progress, then changes would take place to ensure improvements. This is addressed on a local level.

Dr. De Pinto stated it boils down to the quality of services that are provided by the professionals. The organizations that are providing services should have a quality assurance procedures built into their practices.

Stacy asked if the hearing aid loan bank brochure could be included in the packet that is sent to families of babies diagnosed through MD EHDI. Tanya will discuss this request with the director of OGPSHCN.

### **MD EHDI Follow Up Stats**

**(Attached)**

### **2016 MD EHDI Stakeholders Meeting**

Jen - reminds everyone on the council to register and to mingle with the participants to be sure the word is being spread about the council. Jen asked if we can obtain video feedback from

participants about their thoughts on the meeting, so as the meeting is going forward they can give feedback.

Claire suggested that if time permits, time could be allowed for participants to give feedback.

MSD Audiologist asked if there could be computers or iPads available for participants to complete a survey monkey survey on the spot.

Kelby stated a QR Code could be created to connect to the survey.

### **Foster Care Update**

Kelby - One of the many issues that is being worked on through ODHH is starting a conversation with the foster care system to determine what are the policies and procedures in place with regard to deaf children that are wards of the state. How can we ensure they are being placed in a family that can communicate with them. Kelby says they are in the beginning stages of what he expects to be a very long process. There are a lot of kids in foster care that are being placed in homes with no language, they are not getting the appropriate resources. Kelby asks for anyone with information about the system please feel free to share with him.

Jen - In Baltimore City there is an issue with loss to follow up and there is a very large case load for foster care. The Department of Human Resources (DHR) is the agency that receives initial abuse and neglect complaints. The Department of Social Services at the local level is then responsible for placement and planning. The CHESSIE database is used when there is abuse. There is a box to check for a sensory disability. What's unclear is how much of that information is filled out, is available or is clarified. One of the challenging questions is how many children in Maryland are deaf and are in foster care. Placement personnel from Baltimore City have asked for a free ASL class. This could be part of a unification plan. Another important point is the importance of having interpreters present so communication needs are met between parents and children. This is something that is not always included. Any child who comes into the foster care system is required to obtain a medical report and this should include a hearing screen. Maybe we could find out who the doctors are that are providing this and to connect with them.

Dr. Badawi - Do we know how many foster families are available that do sign?

Kelby - We are asking for that data and have not received it yet. They recognize that they need more, and there are other obstacles that need to be addressed. We also need to build some connections between jurisdictions.

### **PROTOCOLS WORKGROUP**

The protocols are being worked on via a shared Google document. Mary Ann suggested a face to face meeting. Claire stated the consensus was that having a meeting would be challenging to people's schedules so it might be better to keep moving forward via email.

Jen - perhaps prior to our next meeting to have a "working document" distributed to the council. I realize that the document is not finalized at this time, but would be good to review in draft format. This would be helpful for the council.

Claire - I will be in touch with everyone on the protocols group to keep us moving forward.

### **PARENT CONNECTIONS UPDATE**

Cheri - *Parent Connections* was not funded for October, 2015. New funding started on November 1, 2015 and was slightly reduced and was not retroactive. An activity will be scheduled for December, 2015. *The Parents Place of Maryland* will hold a LEADers Training series which will be challenging but well worth it. There will be a maximum of 25 registrants with 21 already registered but the acceptance process for the 21 registrants has not been completed. The LEADers Program provides parents with the information they need to be informed and active in advocacy at the state and local levels around special education and health. (flyer attached)

### **NEW BUSINESS**

Jen - A brochure has been developed to help recruit new council members. The MD EHDI date will be updated so please do not distribute the copy received today.

### **ANNUAL NATIONAL EHDI MEETING**

DHMH will offer 1 stipend for a parent to attend EHDI this year that is funded by NCHAM. This scholarship waives the registration fee, and mail a check for \$425 which can be used toward travel expenses. Other expenses will come out of their pocket, the parent needs to fill out a W9, and then fill out an application. Registration open November 16th. Information will be emailed shortly. This will probably be a random selection. Must be a parent of a child who is deaf or hard of hearing.

### **ANNOUNCEMENTS**

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

May 5, 2016 - MD EHDI Stakeholders Meeting

**Meeting Schedule**

12:30-2:30 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

Motion to adjourn by Stacy, seconded by Kelby.

**Meeting Adjourned 2:37pm**

Infant Hearing Program Follow-Up Stats

as of 11-12-2015

**\*NOTE: Quarters are:      Jan-Mar      Apr-Jun      July-Sept      Oct-Dec**

<u>*QUARTERLY STATS:</u>	2014	2014	2014	2014
	Q1	Q2	Q3	Q4
<b>IN PROCESS AT L2</b>	2	2	5	20
<b>IN PROCESS AT L3</b> (further diagnostic testing needs to be completed)	0	0	4	4
	2015	2015	2015	2015
	Q1	Q2	Q3	Q4
<b>IN PROCESS AT L2</b>	74	149	294	-----
<b>IN PROCESS AT L3</b> (diagnostic testing needs to be initiated)	9	14	11	-----

**\*\*NOTE: "Year" = Calendar Year (Jan-Dec)**

<u>**YEARLY STATS:</u>			
	<b>CY 2014</b>		<b>CY 2015</b>
<b>TOTAL BIRTHS</b>	<b>70,999</b> (includes out of state births)		<b>52,855</b> (thru 09/30/15 includes out of state births)
<b>IN PROCESS AT L2</b>	<b>29</b>		<b>517</b> (thru 09/30/2015)
<b>IN PROCESS AT L3</b>	<b>8</b>		<b>34</b> (thru 09/30/15)

(diagnostic testing needs to be initiated)			
<b>CONFIRMED HL</b> (Sensorineural, Auditory Neuropathy, Mixed, Permanent Conductive)/eligible for referral to ITP)	<b>102</b> (including 8 late onset)		<b>58</b> (including 3 late onset)
<b>DOCUMENTED AS REFERRED TO ITP</b>	<b>100</b> (2 not ref'd due to clinical judgment)		<b>55</b> (1 not ref'd due to legal residence in Bahamas, 2 not ref'd due to clinical judgment)
<b>Not Yet Determined and Conductive Hearing Loss (Transient)/not eligible for ITP or further diagnostic testing needs to be completed</b>	<b>19/66</b>		<b>23/27</b>

**LEGEND:**

**L2 = follow-up of infants who missed or did not pass the birth screen and are in need of the initial screen**

**L3 = follow-up of infants who did not pass the birth screen in one or both ears and are in need of a diagnostic evaluation**

**Q = Quarter**

**CY = Calendar Year**

**HL = Hearing Loss**

**ITP = Infant and Toddler Program**



# LEADers Training

*"The PPMD class that I participated in was the most informative class that I have ever taken. The resources given to us have helped me tremendously and I often share them when I reach out to other parents who need help in the IEP process."*

*~ Bonnie, Baltimore County*

## TRAINING DETAILS

### • DATES

February 6, 2016  
February 27, 2016  
March 19, 2016  
April 16, 2016  
May 7, 2016  
May 21, 2016  
June 11, 2016 (snow date)

### • TIME

9:00AM - 4:00PM

### • LOCATION

MD School for the Deaf  
Columbia Campus  
8169 Old Montgomery Rd.  
Columbia, MD 21044

### • For questions contact

Kelly Meissner —  
kelly@ppmd.org

**The LEADers Program** provides parents with the information they need to be informed and active in advocacy at the state and local levels around special education and health. This program offers parents the tools they need to be an active voice for not only their own child, but also for other children with disabilities in their communities.

#### Participants will:

- Gain knowledge and understanding about special education law
- Increase understanding of where healthcare and education intersect
- Increase communication and advocacy skills in health & special education
- Enhance leadership skills
- Expand their network of colleagues with a similar focus

#### Topics covered during the training:

- Special education law and regulations
- Tests and measurements
- SMART standards-based IEPs
- 504 plans
- Dispute resolution
- Discipline under IDEA
- Health and the IEP
- Developing a leadership plan

### Who Should Apply

Applicants must be family members of children with disabilities who want to develop a better understanding of special education and health advocacy and make a difference in the lives of families of children with disabilities.

To apply, go to [www.surveymonkey.com/r/2016LEADersApplication](http://www.surveymonkey.com/r/2016LEADersApplication)

### Requirements

The program requires full participation in ALL sessions. Participants are required to provide feedback on their leadership activities after the training. You are committing to promote change using your newly learned skills after the completion of the project. Follow-up sessions will be offered after the program ends.