

Maryland Early Hearing Detection and Intervention (MD EHDl) Advisory Council

Pending Approval – Minutes January 19, 2017

Members Present

Jennifer Reesman, PhD, Chair
Claire Buxton, AuD, Vice Chair
Judith Black
Bridgetta Bourne-Firl
Lori Moers
Sue Burnes
Stacy Fitzgerald
Kelby Brick
Brian Reilly, MD – by phone briefly
Olga Polites
Tina Backe

Members Absent

Jessica Thornton

Staff

Donna Gugel
Donna Harris
Russell Moy, MD
Stacey Little, PhD
Erin Filippone
Tanya Green (scribe)

Guests

Ben Dubin, Past Chair
Louise Colodzin, Past Vice Chair
Cheri Dowling, Past Parent Member
Debbie Badawi, MD, MD AAP Chapter Champion
Marny Helfrich
Allysa Dittmar
Dawn Marsiglia

Called to Order – 12:40PM

I. Welcome Introductions (Dr. Jennifer Reesman)

Members, Maryland Department of Health and Mental Hygiene (DHMH) staff, and guests introduced themselves.

Sharing of Story – Dr. Jennifer Reesman shared a story about a girl born in Maryland who was identified as deaf through the newborn hearing screening process, received a cochlear implant, and who later developed other medical issues including an autism diagnosis. The child is now 13 years old and her mother, who also has learning challenges, is no longer able to take care of her. The child's lack of language and communication is interfering with her parent's ability to keep her safe. This parent reported concern that she would hurt her child and is looking for help.

II. Previous Minutes

Board members received the minutes for review prior to today's meeting. Minutes of the July 21, 2016 meeting were approved as circulated.

III. Old Business

MD EHDl 2017 Stakeholders Meeting Update (Cheri Dowling)

The MD EHDl Conference will be held on May 4, 2017 at the Hearing and Speech Agency from 8:30am – 4pm. Flyers were distributed at today's council meeting and

the electronic copy will be distributed tomorrow. Register early. This conference has been filled to capacity for the past two years.

Kelby Brick offered to meet with Cheri to discuss the possibility of working with the Governor's Office of the Deaf and Hard of Hearing (ODHH) for next year's MD EHDI Conference to secure a larger space which will accommodate the increasing number of attendees. ODHH may also be able to help with finding additional funding for the event. Claire Buxton stated Gallaudet University may be able to provide simulcast support.

Parent Connections Update (Cheri Dowling)

The budget for the *Parent Connections* program has decreased over the past few years. Payments to the parent mentors has been cut. Mentors have continued in their roles even without pay. Mentors are hired based on their experience. The parent mentors include a dad who speaks Spanish and a mom who is deaf. One event was held which took place at the Cecil County Zoo. During this event as the parents talked to one another, two of the parents in attendance realized they lived near one another but had never met before. A lesson learned is that parents like to make their own matches naturally.

There was discussion about the possibility of DHMH providing parent information to the *Parent Connections* program. DHMH is unable to provide parent information as it would be a HIPAA/PHI violation, however, DHMH does provide *Parent Connections* information to parents.

Newborn Hearing Screening Protocols/Best Practices Workgroup Update (Dr. Claire Buxton)

A draft of the protocols document was distributed to council members today. The document will provide guidance to and serve as a reference for anyone working with a child who is navigating the EHDI process. Feedback from board members on the draft is requested within the next 2 weeks. Claire should be contacted if additional time is needed.

Membership Update

The council is currently full. The newest member is the DHMH representative, Tina Backe. Four members have terms that will expire June 30, 2017. All are eligible for a future term. Lori Moers (MSD representative), Kelby Brick (ODHH representative), and Jessica Thornton (parent representative), are completing the remainder of a term vacated by a previous board member. Dr. Reesman (mental health expert) has completed her first term and is eligible for a second term. They will all be contacted by DHMH to determine their intentions of applying for a future term.

MD EHDI Program Follow Up Statistics (Erin Filippone)

The MD EHDI Program follow-up statistics for calendar year 2015 show that there are 4 children in need of follow-up and there is 1 child with CMV still being monitored to determine if hearing concerns arise. 122 children were referred to the Maryland

Infants and Toddlers Program. 92 are documented as enrolled in early intervention services. For calendar year 2016, 73 children were referred to the Maryland Infants and Toddlers Program and 53 are documented as enrolled in early intervention services.

DHMH receives information about the child's early intervention enrollment status only. DHMH has no impact on what happens once a child has been referred to the Infants and Toddlers Program. Some children may be receiving private EI services that MD EHDI does not have documentation to support. According to MSDE, all children with hearing loss should be eligible for services. Marny Helfrich, MSDE Low-Incidence Resource Specialist, stated that she will look into possible reasons why some children who were referred to the Infants and Toddlers Program in follow up to the MD EHDI process, may have been found to be ineligible for services.

MD EHDI Program Update (Tanya Green)

The MD EHDI Program is fully staffed with a program chief, program audiologist, and two follow-up coordinators.

Council members were reminded of the requirement to attend fifty percent of the meetings. Meetings are quarterly. Currently, there are no issues with member attendance. It was asked if the Council has fulfilled the requirement of holding at least 4 meetings per year, since the October, 2016 meeting was cancelled. An exception is made when the meeting is cancelled by DHMH.

It is recommended that all members take the Maryland Open Meetings Act training. The requirement is for a designated member to receive the training for each council. Tanya Green and a number of council members have taken the training and emailed their certificate of completion to Tanya. Council members should contact Tanya if they need the website link for the training.

HRSA Grant Application

The MD EHDI Program has submitted a new HRSA grant application. A decision is pending. This is a 3 year award from April 1, 2017 to March 31, 2020 for up to \$250,000 per year. Award letters typically arrive mid-late March. The main objectives of the grant are to:

1. Increase by 30% the number of infants who receive a diagnosis by 3 months of age after a failed hearing screen.
2. Increase by 20% the number of infants identified as deaf or hard of hearing who are enrolled in early intervention by 6 months.
3. Increase by 25 % the number of infants who received a timely referral to early intervention after identification as deaf or hard of hearing.

Objectives are to be accomplished through collaborating with various partners, including the Parents' Place of Maryland, University of Maryland School Medicine, and the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program, and by forming an ad-hoc advisory council.

The National EHDI Meeting will be held February 26-28 in Atlanta, GA. The meeting's website address is: www.ehdimeeting.org. NCHAM (National Center for Hearing Assessment and Management) offered a family engagement leadership scholarship to a parent from each state which covers much of the costs to attend this meeting. Acceptance of the opportunity comes with a commitment to become actively involved in the state's EHDI program during the upcoming year. A parent who learned about this opportunity contacted the MD EHDI Program to express interest and accepted the scholarship offer and the committed to working with the EHDI program as required.

A second opportunity is being provided for a parent to attend the National EHDI Meeting. Through HRSA funds, the State is offering reimbursement of expenses to attend the Meeting. The flyer advertising this opportunity will be distributed by email. Board members are asked to please encourage parents to apply.

IV. New Business

Revised MD EHDI Program Diagnostic Letter (Donna Gugel, DHMH)

After much stakeholder input, the revised MD EHDI diagnostic letter has been approved by the Secretary of DHMH. The Department has committed to having this letter available on the MD EHDI Program website. It will be translated into Spanish and also into ASL. Many agree that the letter has a much warmer and more compassionate approach to parents. The NCHAM *Communicate With Your Child* brochure will no longer be sent with the diagnostic letter. The revised letter is final, however, the Department will accept and respond to comments and questions. The Department has been involved in discussions with Kelby and Marny Helfrich, MSDE Low-Incidence Resource Specialist for the revised letter to include a website link to a Maryland-specific resource document, possibly on the Maryland Learning Links website. The resource has not yet been determined. Kelby added that while the website link is a good idea but new mothers may benefit more from a handout. It was clarified that the Council will be included in the selection of website link resources before a decision is made.

MD AAP Website Demo (Debbie Badawi, M.D., AAP EHDI Chapter Champion)

The EHDI section of the MD AAP website was updated 2 years ago, but is currently not linked to the MD AAP website. The EHDI section link will be added to the right side of the home page. The MD AAP website home page is www.mdaap.org. This website is mostly for pediatricians' to use. The website will be updated to make it more family friendly. A link to the page will be distributed to Council members so they may provide feedback and suggestions on what pediatricians need to know when they have a child as a patient who is deaf or hard of hearing. It was recommended that the website be 508 compliant.

V. Announcements

It was suggested that someone from MSDE attend the next meeting to educate the Council on what is happening at the local and county levels within the Infants and Toddlers Program.

The Hearing and Speech Agency has hired Erin Stauder from Loyola University as the new Executive Director. She will begin in February. Susan Glasgow retired in December.

VI. Adjournment

The Chair adjourned the meeting at 2:37PM.