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

Minutes January 17, 2019

Members Present

Jennifer Reesman, Ph.D., Chair Margaret Hargrove Patty Muldowney (Phone) Kelby Brick (Phone) Robyn Miller, Au.D. Tina Backe

Members Absent

Judith Black Bridgetta Bourne-Firl Brian Reilly, M.D. Jessica Thornton

Vacant

MSDE Parent Position

Maryland Department of Health (MDH)

Tanya D. Green Jed Miller, M.D., M.P.H.

Guests

Cheri Dowling Marny Helfrich (Phone) Olga Polites Richard Jeffries, Ph.D. (Phone) Dawn Marsiglia Jennifer Willis Mara Clement (Melinda) Nina DeSell

Call to Order

The meeting was called to order by Chairperson, Jennifer Reesman at 12:47 pm.

Welcome & Sharing of a Story

Chairperson Reesman welcomed everyone and Cheri Dowling shared a story about a child who was identified as hard of hearing through the newborn hearing screening process and is now three years old. The child now attends a pre-kindergarten program with no interpreter. The child speaks clearly and signs well. Cheri stated the child's mother wanted her child to have everything needed regarding language. Cheri stated it is important to let families know that it is okay to make decisions and for professionals to step back and think about those with whom we are working.

Approval of Previous Minutes

The minutes from the October 18, 2018 meeting were voted on and approved with no recommended corrections.

Old Business

Parent Connections Update

There are no events scheduled.

Cheri Dowling will no longer coordinate the Parent Connections program. Ashley Shindler of the Parents' Place of Maryland is the new coordinator.

Cheri's last day with the Parents' Place of Maryland will be February 1, 2019.

Newborn Hearing Screening Protocols/Best Practices Update

The draft of the protocols document has been submitted to MDH for review. The draft is currently under review and will be returned to the council or to the workgroup for a review of edits made by MDH. The MDH edits will likely frame the recommendations as best practices. It will also make a distinction COMAR and this document as a best practices resource.

MD EHDI Brochure

No update.

Membership Update

There are two vacant positions (MSDE representative and parent member) The filling of the MSDE representative position is currently in process. Marny Helfrich has been recommended for this position.

Applications are under review by the MDH appointments office for the parent position.

MD EHDI HRSA Grant Update

The three year HRSA grant is currently in year 2. Year 2 ends March 31, 2019. The current focus is on learning communities. Two physician practices have been recruited and are involved in a learning community which allows physicians and their staff to gain knowledge about the EHDI process. A survey was created and completed by the practices and yielded helpful information. One practice reported no newly identified babies who are deaf or hard of hearing during their reporting period but that they have approximately 15 children within their practice who are deaf or hard of hearing with 12 of the 15 having care coordination plans in place.

National EHDI Meeting

The National EHDI Meeting will be March 3-5, 2019 in Chicago, IL. The MD EHDI Program is able to use HRSA funds to send a parent of a deaf or hard of hearing child to the National EHDI Meeting. Council members are asked to contact Tanya Green if they know of a parent who may be interested. The parent will have to pay for their expenses up front and submit an invoice to be reimbursed for qualifying expenses upon return from the meeting.

MD EHDI Program Update

Program statistics were provided.

New Business

Connections Beyond Sight and Sound – the Maryland and DC Deaf-blind Project (CBSS)

https://marylanddb.org/

Jennifer Willis, Project Coordinator of Connections Beyond Sight and Sound – the Maryland and DC Deaf-blind Project, spoke to the Council about CBSS. CBSS serves families in Maryland and Washington, DC. The program has received funding for the next 5 years and provides assistance to any child from birth – 21 who has deaf or hard

of hearing and has vision challenges, including CVI (cortical vision impairment). CBSS provides infants and toddlers support by going into homes, supporting classroom instruction, supporting therapists, and post-secondary transition support is provided. CBSS staff are available to attend IEP, IFSP, and transition meetings. Marny added that MSDE recently provided CBSS with additional funding to hire a new staff person to support the school systems. One of the priorities is to encourage the families to follow up with doctor appointments.

The project maintains a database of deaf-blind children in Maryland and Washington, DC. The database currently shows 215 children identified in Maryland & Washington, DC and that number changes regularly. CBSS is a free service available to any school system around the state. Referrals are received from Infants and Toddlers programs, county programs, the Maryland School for the Blind and the Maryland School for the Deaf. Direct referrals may also be made. The referral form is posted on the website.

In addition to Jennifer Willis, CBSS staff includes project director, Donna Riccobono, IT specialist, Dr. Jennifer Stepanic, and Educational Specialist, Becky Calmer (also a mobility specialist with a strong vision background).

Medicaid changes impacting 1-3-6 timeline

Dr. Robyn Miller stated that new rules are impacting the 1-3-6 timeline and that the Maryland Hearing Aid Loan Bank is now out of hearing aids. Olga Polites added that the Hearing and Speech Agency has a list of 80 people waiting for hearing aids and that children make up 70% of the list. Dr. Reesman asked if we can invite Maryland Medicaid representatives to a council meeting to discuss this issue. Dr. Miller stated that he can help facilitate inviting Maryland Medicaid representatives to a council meeting.

Announcements

Next MD EHDI Advisory Council meeting – Thursday, July 18th, 2019, 12:30 PM – 2:30 PM, Hearing and Speech Agency; park in the rear lot.

MD EHDI Stakeholders Meeting – no update at this time.

New outpatient hearing screening clinic at Johns Hopkins Hospital

Nina DeSell MS, CRNP shared that she is starting a new clinic at Johns Hopkins Hospital for babies who receive a refer result on the newborn screening with the goal being to get ABRs (auditory brainstem response testing) done quickly. Johns Hopkins Hospital has about 150-200 children who receive a refer result. This new clinic will also be screening babies for CMV (cytomegalovirus).

Adjournment

The meeting was adjourned at 2:06 PM.