

Virginia EHDI Program Advisory Committee Meeting

Friday, December 3, 2021

Meeting Minutes

Attendees: Valerie Abbott, Judy Alonzi, Patricia Eitemiller, Christine Eubanks, Ashleigh Greenwood, Alison King, Debi Leekoff, Kara Norcross, Irene A. Schmalz, Barry Strasnick, Teri Urban

Interested Parties: Robin Bliven, Lois Boyle, Athena Crosby-Martin, Tom Dowling, Jacquie Johnson, Mary Lynn Jones, Rebecca Levenson, Valerie Luther, Christina Owens, Jenny Witteborg

VDH EHDI Staff in Attendance: Katherine Barrett, Parker Brodsky, Christen Crews, Markella Maschas, Daphne Miller, Dora Opoku, Rafael Randolph, John Rogan, Deepali Sanghani, Antoinette Vaughan

DCLS Staff: Leigh Emma Lion

Valerie Abbott called the meeting to order at 10:00 am. A review of the agenda was approved. Minutes of the September 10, 2021 meeting were approved.

Parent Story – L. Eickel

A mother shared her story about her son's diagnosis. She is a speech therapist that did not know much about cCMV before she gave birth to her son. Cytomegalovirus (CMV) is the most common infectious cause of birth defects in children and is the leading cause of non-genetic hearing loss in infants. 1 in every 200 babies is born with CMV each year. Her Igm levels were very high which meant she just had a CMV infection. Questions lead to the identification of CMV. She was not given much information. Hospital OBs told her all she needed to worry about was hearing loss. She was told his sample was sent to California. By his 9th day, they were still doing weight checks. He was diagnosed with CMV. He was immediately put on antiviral medicine. He had weekly blood draws until he was 7 months. Close family members were concerned he was having seizures. By 5 months, more diagnoses were added. Audio examinations were done but the results were not black and white. He finally received a pass/pass at the age of two (2). He participated in physical therapy. During this time, the mother struggled with guilt and depression, blaming herself. Additional tests revealed his brain struggled between transitioning between sleep and being awake. Covid hit when he was three (3) years old. She had another baby in 2020. The son she shared this story about is now 4 yrs old. He has gone through behavior therapy. He is thriving in schools with friends and teachers. This is her second year as a volunteer CMV advocate. She wants to help other families so they do not feel alone. They are now making plans for her son's kindergarten year. She wanted to share three (3) important things.

1. Her son's story is the exceptional not the norm
2. Your role as an educator is invaluable, what you do matters
3. CMV is avoidable

Standing Updates:

VNOC/Partnership for People w/Disabilities: T. Yurechko

TAC-DHH is partnering with Radford University and DARS' Pre-Employment Transition Services to offer Student Connection, an opportunity for students who are Deaf and Hard of Hearing to connect with other Deaf and Hard of Hearing students in Virginia via Zoom from 4:00-5:00 PM over 4 months (Jan 24, Feb 21, March 21, and April 18, 2022). Breakout rooms will be used to ensure age-appropriate activities for your child, including offering resources to students in grades 9-12 to help prepare them for moving from school to post-school life. Registration Information/Link

See the Sound Visual Phonics will be offered on Tuesdays: January 25, February 1, and February 8, 2022, from 4:00 PM – 7:15 PM over zoom. Please be on the lookout for registration coming out soon.

If you want to keep up with events happening at the TAC-DHH, email Kristen Stahr at khstahr@vcu.edu to join our weekly mailing list.

Early Intervention: T. Nelligan

The Infant & Toddler Connection of Virginia (ITCVA) action report series focuses on efforts underway to improve the long-term sustainability of Virginia's Part C early intervention system. The series began in 2019 when many local systems were facing fiscal challenges and provider shortages. While the COVID-19 pandemic has mitigated these challenges in the short term, we are continuing to work on your behalf every day to address these issues for the long term. These are challenges we have faced and successfully addressed before in the ITCVA, and we can do it again by working together and focusing on actionable strategies to make improvements.

Actions to address Medicaid managed care challenges:

- The EI-MCO Workgroup convened by the Virginia Association of Community Services Boards (VACSB) is meeting quarterly. The work group held a training on Part C for MCO care coordinators on July 19, 2021. During the October meeting, the group focused on challenges securing interpreters through the MCOs. MCO representatives committed to reviewing their interpreter procedures, with an eye toward making those processes more user-friendly and effective.

Actions to address provider shortages:

- On August 27, 2021, the Department of Medical Assistance Services (DMAS) issued a notice that early intervention services are included in the telehealth supplement that was released on July 27, 2021. The supplement specifies policies for the permanent use of telehealth. These new policies offer an

exciting opportunity to maximize the accessibility of early intervention, and we are grateful to our partners at DMAS.

- The October statewide Zoom meeting for local system managers included discussion about how using Early Intervention Assistants can benefit local systems and families by increasing and diversifying the available early intervention workforce. Three local system managers shared their experiences using Early Intervention Assistants.
- The EI/Preservice Consortium, which includes James Madison University, George Mason University, Old Dominion University and Virginia Commonwealth University, has compiled focus group feedback from local system managers on hosting students in early intervention placements. During the November statewide Zoom meeting for local system managers, this feedback will be shared and use of students in early intervention will be discussed.

Actions to address broader fiscal picture:

- At the end of the August 2021 meeting, the Infrastructure Work Group decided to pause its work until we can better evaluate the need for and direction of additional infrastructure work based on:
 - Having the new statewide early intervention data system in place and understanding the ways in which it will streamline work and improve efficiencies; and
 - Trying some shared service models with local systems who are interested in actually implementing a shared service approach for some component(s) of early intervention.
- Virginia has received \$5.1 million in one-time American Rescue Plan Act (ARPA) funding for Part C. To ensure we can best meet both immediate and emerging needs over the period these funds are available, only a portion of the one-time ARPA funds will be allocated to local systems in state fiscal year (SFY) 2022. The funds have recently been released by the State, and this initial portion will be allocated to local systems soon. We will continue to examine data and solicit input from stakeholders in determining the most impactful use for the remaining ARPA funds.
- State staff, consulting with subject matter experts as needed, are meeting multiple times per week with the vendor for our new statewide early intervention data system. Among many other features and functions, the new data system will support improved fiscal data and billing. The initial work to identify any missing data elements in the vendor's off-the-shelf early intervention data system is nearing completion. Soon, stakeholders will have the opportunity to see demonstrations and provide input as sections of the system are customized for Virginia.

Newborn Screening: M. Lowe

The program now has a senior nurse and two (2) upcoming short term nurse positions

Virginia Hearing Aid Loan Bank: L. Powley

As of 11/18/21 1496 children have used devices through the loan bank. Due to covid, we extended the loan period from 6 months to one year. I think this has been very helpful to many families. Funding is secured, thanks Daphne and Wanda, for 2022.

Children & Youth with Special Health Care Needs: M. Allen

No new updates

Family-to-Family: I.Schmalz

Updates for the period September 10, 2021 to December 3, 2021

- Ten families were referred by the EHDI program to the 1-3-6 Family Educators.
 - 9 babies were under the age of one, and 1 child was a year old
 - 4 males and 6 females
 - 1 child had heart surgery and 1 has been identified with atresia
- Information/data collection from the 1-3-6 FE contacts with referred families was entered into VISITS Shared Plan of Care.
- 1-3-6 Family Educator meetings/trainings: (all virtual)
 - September 30, 2021 Meeting with EHDI
 - October 21, 2021 VNOC Meeting
 - October 22, 2021 Meeting about Fotonovela (Arabic)
 - October 26, 2021 COVID Needs Assessment
 - November 1, 2021 Meeting with EHDI
 - November 15, 2021 Statewide Learning Community Meeting
 - November 16, 2021 Meeting with EHDI
 - November 18, 2021 Meeting with EHDI and NCHAM – Mid Year Evaluation
 - Upcoming meeting with 1-3-6 FE will be held of December 8, 2021.

Other projects 1-36 Family Educators are working on include: COVID vaccine outreach to Spanish speaking community, tele-auditory health, and family resilience.

- Regional Learning Communities: Most learning communities are continuing to meet virtually.
- State Learning Community: Statewide Learning Community met on November 15th to begin prioritizing recommendations from results of the COVID-19 Survey conducted in early 2021. A survey will be sent to all Learning Community members across Virginia to finalize the prioritization and a plan will be shared with the EHDI program in early 2022.
- Family Materials:
 - Fotonovela 1 was piloted this summer at Fairfax Hospital and Fair Oaks hospital with spanish speaking mothers. Data is still being collected on its impact.
 - Fotnovela 2 was mailed to over 100 audiologists across Virginia Commonwealth University
 - Both fotonovelas were featured in the first Promising Practices developed by the American Academy of Pediatrics' EHDI Champions committee.

The fotonovelas and promising practice document can be found at <https://centerforfamilyinvolvementblog.org/family-to-family-network/programs/1-3-6-family-educator-program/>

Virginia School for the Deaf and the Blind: R. Bliven

The Outreach Clinic at VSDB is officially open and is a fully operational clinic again. Services offered: Newborn hearing screening and follow-up (including unsedated ABRs and OAEs) and comprehensive hearing tests. All services we offer are no cost to families. We are a diagnostic clinic. We do not dispense amplification devices or program any outreach patient's existing devices. For any hearing aid, cochlear implant, or assistive listening device assistance, we refer families to local practices that do offer these services. We serve children from birth-21 years. The children we see can live in any surrounding city or county. If traveling to VSDB is feasible for the family, then we are available to see them. Please know that our funding only allows us to serve families living in Virginia. Please keep this in mind when referring families to us. All scheduling needs and referrals are handled by Lindsey Richard, our educational audiologist. You can contact her at: lindsey.richard@vsdb.k12.va.us and (540) 332-9048.

Department of Education: W. Council

Dr. James Lane, Superintendent of Public Instruction, and the Virginia Board of Education (BOE) recognized November 2021 as Family Engagement in Education Month. School divisions across the Commonwealth engaged in activities to recognize the importance of families and schools working together for the benefit of all students. The impact of the COVID-19 pandemic on public and private schools has necessitated parents engaging more directly in students' education. Additional information and resources can be found at the following links:

- BOE Family Engagement in Education Month Resolution
- Family Engagement Month Resource Flyer

The VDOE Special Education and Student Services Department-Office of Facilities and Family Engagement recently launched a new Family Engagement Features forum for professionals and families to engage in discussions related to family engagement.

For additional information, contact Tracy Lee, Coordinator of Family Engagement, at Tracy.Lee@doe.virginia.gov or (804) 225-3492.

Deaf-Blind Project: I. Padhye

No new updates

Virginia Department of the Deaf and Hard of Hearing: E Raff

No new updates

VA Hands & Voices: T Urban

Virginia Hands & Voices has been busy, as always, behind the scenes, offering unbiased support to families and professionals that support deaf and hard of hearing children. We have been connecting with many families virtually this year to have discussions regarding the cochlear implant process and benefits of each manufacturer. Parents have been reaching out to us, overwhelmed with the decisions they must make about implanting their child and communication choices. Our Board of Directors has been meeting with families over Zoom offering parent mentoring sessions and it's been very well received from families.

We successfully held our first in-person events in October (since February 2020) which was very well attended. We welcomed about 70 folks at a park in Roanoke for an ice cream social, featuring author Valerie James Abbott reading her new story, *Padapillo*. For the first time, we held a regional event, Sundaes on Sunday, at parks in Chantilly, Fredericksburg and Henrico, which were also well attended. It was wonderful to see smiling faces of children, connect with

families in-person and gave us the much-needed energy to continue forward with the important work we do.

Our next few events will return to a virtual platform and include a Virtual Happy Hour for parents of newly diagnosed children along with a virtual ‘Meet the Deaf Community’ event in January featuring adults who use ASL, Cued Speech and Listening and Spoken Language.

Lastly, we continue to make progress with the Virginia Deaf Mentor Pilot Program. Volunteers include representatives from VDDHH, Virginia Association of the Deaf (VAD), Civic Access, Families to Families, parents of VA H&V and adults in the Deaf community. Our efforts remain focused on fundraising in order to train 15 deaf/hard of hearing adults under the national SKI HI curriculum. We have received a few large and generous donations so far. The SKI HI staff has been very supportive of offering us guidance throughout this process and we have their full support to see the program succeed in Virginia. Ideally, we will begin recruiting a Program Coordinator, interviewing mentors, completing background checks and ASLPI assessments and begin training in early 2022. There are currently 27 states with active Deaf Mentor programs, 11 of which use the SKI Curriculum.

Learn the Signs. Act Early: D Buck

No new updates

Late Onset Hearing Loss: V. Abbott

Valerie was invited to EHDI Utah to give a presentation. Karl White stopped the meeting to say this should be a priority. Valerie met with Karl White’s team in August. Karl White offered to formally endorse Late Onset Hearing Loss Awareness Campaign.

VA EHDI Update:

- Virginia Statewide Learning Community Meeting was held on Monday, November 15, 2021.
- Covid Needs Assessment was held May 15, 2021 in conjunction with the Center for Family Involvement.
- Your Role in Workplace Diversity, Equity & Inclusion webinar for VA EHDI Stakeholders will be held between January and May 2022. Please register by January 11, 2022.
- 21st Annual Early Hearing Detection and Intervention Conference will be held March 13-15, 2022 in Cincinnati, Ohio.
- The VA EHDI website has been updated.
- Seven (7) New EHDI text messaging videos
 - Introduction to EDHI
 - Introduction to cCMV
 - Failed
 - Failed with Risk

- Pass with Risk
- Missed hearing screen
- Hearing loss
- cCMV Yearly Progress Report and Sample Collection Checklist added to the website.
- 100 ipads will be distributed to families until Jan 31, 2022 or until supplies last.
- ASL Connect Family Feedback
 - 6 out of 13 families gave feedback
 - Survey included 8 questions about Level 2
 - 4 families reported very valuable and 2 families reported somewhat valuable
- Parents that are interested in attending the EHDI Annual Conference should send an email to va_ehdi@vdh.virginia.gov

VA EHDI DATA 2020:

- Total occerrent births:94,482
- Total documented as screened: 92,440 (97.8%)
- Total pass: 88,649
- Total did not pass initial: 3,791
- Total Without Initial Screening: 2,042
- Total with no Documented Screening: 731
 - Missed child before discharge: 269
 - Parents Refused: 164
 - Parents Refused, Religious Exemption: 3
 - Transferred to In-State Hospital: 107
 - Transferred to Out of State Hospital: 188
- Total diagnosed with permanent hearing loss: 133
- Total enrolled to Early Intervention :132
- Total enrolled in early intervention:46 (34.8%)
- Total referred to ENT: 132
- Total enrolled in ENT: 40
- Total referred to genetics in 2020: 52
- Total enrolled in genetics in 2020: 7
- Total referred to ophthalmology in 2020: 58
- Total enrolled in ophthalmology in 2020: 8
- Areas of Future Focus
 - Loss to follow up after screening stage
 - Regional trends in loss to follow up
 - Location of audiology facilities
 - Timing of screenings, diagnosis, and enrollment in intervention

Public Comment: J. Witteborg

A public comment was made regarding an upcoming legislative bill regarding language acquisition for children who are deaf or hard of hearing.

Workgroups Overview:

- Late Onset Hearing Loss
- ENT Workgroup

VA Center for Inclusive Communities: J Johnson

VCIC started in 1935 at Lynchburg College. A thousand people showed up to the discussion and after the 1935 gathering these conversations continued. VCIC's mission is to achieve success through inclusion. Diversity is the presence of difference. Inclusion is the accepting, respecting, and valuing of diversity. The Virginia Center for Inclusive Communities is increasingly called upon to help schools, businesses, and communities across Virginia achieve success through inclusion.

The Virginia EHDI Program is sponsoring a training *“Your Role in Workplace Diversity, Equity & Inclusion”*,

Cohort 1 will meet on Tuesdays from 10:00am - 11:30am – January 18, February 8, March 1, March 22, April 12, May 3 REGISTER: <https://forms.gle/1KeycTGnSchsLWxu9>

Cohort 2 will meet on Thursdays from 1:00pm - 2:30pm – February 3, February 24, March 24, April 14, May 5, May 26 REGISTER: <https://forms.gle/1KeycTGnSchsLWxu9>

Next Advisory Committee meeting is March 3rd, 2022

Meeting adjourned at 1:30 pm.