Virginia Early Hearing Detection Intervention Advisory Committee Meeting Minutes

Monday, February 13, 2023, 1:00 PM-3:00 PM

In-Person Meeting

Richmond Marriott Short Pump

4240 Dominion Blvd, Glen Allen, VA 23060

Meeting called to order 1:09 PM

In attendance:

Advisory Members: Valerie Abbott, Judith Alonzi, Terese Urban, Wanda Council, Ira Padhye, Tracey Yurechko, Irene Schmalz, Ashleigh Greenwood, Terri Nelligan, Christine Eubanks, Sandra Woodward, Eric Raff, Marcus Allen

Interested Parties: Tommy Brown, Ashley Brown, Karl White, Karen Brennhofer, Karen Woolman, Melissa Forkner, Karen Spanbauer, Callie Strachan, Lisa Eickel, Rhonda Young-Rockingham, Rebecca Levorson, Sheena Cobb, Hunta Williams, Jill Young

VDH Staff: Daphne Miller, Deepali Sanghani, Noesha Ferrell, John Rogan, Antoinette Vaughan, Parker Brodsky, Brandy Cregger, Rafael Randolph, Brian Keith Revis, Abdelrahman Osman

ASL Interpretation provided by: Bernice McCormick, Heather Bovaird

Protactile interpretation provided by: April Jackson

Advisory Committee Business:

- Introductions/Roll Call
 - o Introductions of attendees and interested parties.
 - During introductions, participants were asked to provide a verbal and visual description of themselves.
- Review of Agenda
 - o The agenda was reviewed by Chair V. Abbott.
- Review of June, September, and December 2022 meeting minutes. Due to the presence of a physical quorum, the meeting minutes were accepted as submitted and no changes were made to the minutes.

• Travel reimbursement was discussed; advisory members requesting travel reimbursement will be sent travel forms via DocuSign after the meeting.

Agency Updates:

The Technical Assistance Center for the Deaf and Hard of Hearing (TAC-DHH)/Partnership for People w/ Disabilities:

Submitted by: Tracey Yurechko

Mission: The Technical Assistance Center for Children Who Are Deaf and Hard of Hearing is funded by the Virginia Department of Education (VDOE) to provide training and technical assistance in the area of deafness and hearing loss. Assistance is available to local public school systems as well as state-operated programs including early intervention through the Virginia Network of Consultants for Professionals Working with Children Who are Deaf and Hard of Hearing (VNOC) in areas such as identification, assessment (educational, psychological), communication of children across the spectrum of modalities (listening and spoken language, American Sign Language, Signed English, etc.), specific needs of children with amplification including cochlear implants, and instructional strategies.

Updates: Planning for **Opening Doors - Unlocking Potential 2023** (June 22-23, 2023) is in full swing. If you are interested in learning more information about ODUP (at the Richmond Marriott Short Pump Hotel) including presenting and exhibiting visit: https://sites.google.com/vcu.edu/odup-2023/home. Please check the website frequently as more information will be forthcoming.

- **Virginia Network of Consultants** continues to support school divisions across the Commonwealth.
 - There are currently five school divisions on waiting list and accepting more.
- If you would like to keep up with future events happening at the TAC-DHH, please complete the following form: https://airtable.com/shrgJBAmME9gYXjWz to receive our weekly newsletter.

DBHDS/Infant & Toddler Connection of Virginia:

Submitted By: Terri Nelligan

Updates: Update printed separately

- Launching new data system called TRAC IT
- New State Systemic Improvement Plan (SSIP) Workgroups forming this year
- Adopting pyramid model for promoting Social Emotional Competence in Infants and young Children
- Contract with Grafton Specialty Services
 - o Judy Alonzi overseeing special grants project (and is recruiting EI specialists).

Newborn Screening (Dried Blood-Spot and CCHD):

Submitted by: Claire Seckner

Mission: Provide timely reporting of critical screening results to healthcare providers and specialists across the state, as well as case management for timely follow-up and assistance through the diagnostic odyssey for infants identified through newborn bloodspot screening.

Updates:

- Two new employees are onboarding in February: Welcome!
 - One Senior Short-Term Follow-Up nurse / Nurse Educator Victoria Gohens on February 27th
 - One Program Support Technician / Admin Tahrin Wilson on February 10th
- The Next Recommended Uniform Screening Panel (RUSP) Meeting is on February 9th and 10th an update on Krabbe Disease will be discussed at this meeting
- Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) added Mucopolysacharidosis Type II (MPS-II) to the Recommended Uniform Screening Panel (RUSP) last year.
 - o NBS-DBS will be assembling a workgroup to review screening for MPS-II in order to determine if this will be added to Virginia's NBS-DBS panel
 - An MPS conference will be held in Minneapolis on April 10-12th (sponsored by APHL)
- Mary Lowe, Bloodspot Screening Follow-Up Supervisor is out on maternity leave and will be back in late March congratulations to Mary!!

Virginia Hearing Aid Loan Bank (VA HALB):

Provided by: Sandra Woodward

Mission: The Virginia Hearing Loan Bank supports children and families who have a diagnosis of hearing loss with amplification devices.

Updates:

- VA HALB is currently reviewing the application to obtain hearing aids. There are endeavors in place to update the application process and the scope of services for the program.
- Lisa Powley, the previous representative for VA HALB on the VA EHDI AC, has retired after many years of dedicated service to the Commonwealth of Virginia. Sandra Woodward is the new representative in Lisa Powley's place.

VDH Children and Youth with Special Health Care Needs (CYSHCN):

Submitted by: Marcus Allen

Mission: To support children and youth with special health care needs (CYSHCN) include all children who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions <u>and</u> who also require health and related services of a type or amount beyond that required by children generally."

Updates: We continue to work with DOE, EHDI and UVA on the Hearing Aid Loan Bank. The team is reviewing policies and we have provided a small amount of funds to purchase hearing aids.

Center for Family Involvement @ VCU-Family to Family

Submitted By: Irene Schmalz

Updates:

A. **Family to Family Support**: five families were referred by the EHDI program to the 1-3-6 Family Educators and information collected from the 1-3-6 Family Educators matched with the families were entered into VISITS shared plan of care.

A. 1-3-6 Family Educator updates

- a. January 9, 2023: All three family educators completed training. A follow-up meeting will be held in March.
- b. January 26, 2023: Meeting (virtual) was held with all of the Family Educators present. Information was shared about the family-to-family support, product development (social medica, print, videos, Spanish ads).

- c. January 31, 2023, VA Families of Children with Hearing Loss Closed FB group held its first town hall event
- d. February 3, 2023 CFI was one of the 7 agencies represented at the Virginia Supplemental Early Language Resources for Deafness/Hard of Hearing Project Advisory Committee Meeting. The blue and orange Virginia Resource Guides for Families of Children with Hearing Loss was discussed as a possible resource which would include the updated language assessment information.

B. VA EHDI Conference – Feb. 13 – 15, 2023

- a. Family Educators will be presenting information on various topics.
- C. The next 1-3-6 Family Educator meeting will be held at end of March.

D. Family Materials:

• Postcard about "If your baby did not pass the hearing screening" has been completed. It has both QR codes and links for social media, connect, information, video library.

Questions: Please contact Irene Schmalz at ischmalz@vcu.edu

Virginia School for the Deaf and the Blind (VSDB):

No update

Virginia Department of Education

Submitted by: Wanda Council

Mission: The mission of the Virginia Department of Education is to advance equitable and innovative learning.

Updates: The Virginia Supplemental Early Language and Literacy Resources for Deafness/Hard of Hearing (VA SELLR-DHH) Project Advisory Committee met in-person on February 3, 2023, at 10 a.m.—3 p.m. The meeting was held at the Richmond Police Training Academy in Richmond. Pursuant to § 22.1-217.04, the Virginia Department of Education, in coordination with the Department for the Deaf and Hard-of-Hearing and the Department of Behavioral Health and Developmental Services, established an advisory committee for the purpose of soliciting input from members on the selection of language developmental milestones for inclusion in a resource for use by the parents of a child from birth to age five who is identified as deaf or hard of hearing. Subsequently, parents may utilize the information to assist with monitoring and tracking their child's expressive and receptive language acquisition and developmental stages toward English literacy.

Information pertaining to the advisory committee meetings can be found at the Virginia Regulatory Town Hall and the VDOE websites.

Virginia Project for Children and Youth with Deaf-Blindness:

Submitted by: Ira Padhye

Mission: The Virginia Deafblind Project (VDBP) is committed to supporting families, teachers, and service providers in their endeavors to improve outcomes for children and youth who experience both vision and hearing loss. Through providing technical assistance, training, and information, we aspire to improve the quality of life for people with deaf-blindness as they live in their homes, learn in their schools, and socialize in their communities and access the services they chose.

Updates:

- Changing name to VA Deaf Blind Project.
- The project created videos to support parents and children
- The National Charge syndrome conference will be held in Orlando, Florida. They have funding to support parents to attend the conference and encourage professionals to attend.

Virginia Department for the Deaf and Hard of Hearing (VDDHH):

Submitted by: Eric Raff

Mission: The Virginia Department for the Deaf and Hard of Hearing (VDDHH) promotes accessible communication so that persons who are Deaf and Hard of Hearing may fully participate in programs, services, and opportunities throughout the Commonwealth.

Updates:

VDDHH is continuing to recruit for open positions.

- Open roles were filled:
 - D/HH Regional Specialist, Deaf Mentor Coordinator.
- The Statewide Interagency Team (SIT) has been meeting but unable to finalize needs assessment report due to unforeseeable circumstances.
- The Virginia Higher Education Accessibility Partners (VHEAP) was awarded multiple captioning contracts.
- VDOE AC: first meeting was 12/2022 and next meeting was 2/3/2023.
- Currently VDDHH has four vacant VA Relay Advisory Council seats.
- Currently improving the technology assistance program.

- Support Service Provider (SSP) Pilot Project
 - Lynn Odom spear heading the project.
 - o Lyn met with Reynolds Community College to develop a training curriculum.
- Deaf Mentor Program Supervisor positions has been filled.
- SKI-HI training was scheduled for February 10-12, 2023.

Virginia Hands & Voices:

Submitted by: Teri Urban

Mission: Virginia Hands & Voices is a non-profit, 501(c)(3), parent-driven organization. We are dedicated to supporting families with children who are deaf and hard-of-hearing without bias around communication modes or methodology. Virginia Hands & Voices provides parents with the resources, networks, and information they need to improve communication access and educational outcomes for their children. This is the 6th year of the program.

Updates: Virginia Hands & Voices, in collaboration with the Technical Assistance Center for Children who are Deaf and Hard of Hearing (TAC-DHH), the Virginia Department for Aging and Rehabilitative Services (DARS), the Virginia Department of Education (VDOE), and the Virginia School for the Deaf and Blind (VSDB) Outreach Programs is excited to launch a student-led virtual Pals Program. We have almost 50 children from across Virginia registered who will meet monthly between February and May for one hour via Zoom. Elementary-age students will be matched with Middle and High school students to lead structured activities during the sessions. All modes of communication will be represented, and adult supervision will be provided. Activities will vary monthly and supplies for each activity will be mailed to the students in advance. We are eager to create a space where deaf and hard of hearing children in Virginia can connect with each other virtually and provide mentor/mentee opportunities, all while having fun! First meeting at the end of February 2023.

We are hosting an event at Solace Brewery in Sterling on February 4 and have almost 150 people registered representing families who speak, sign and/or cue! This is our first time partnering with Little Hands Pediatric Therapy in Ashburn and it's sure to be a great event. Attendees will be treated to free drinks, pizza, crafts, and arcade games all while socializing with other deaf and hard of hearing families, professionals and adults.

Looking ahead, we will be exhibiting and presenting at the Virginia EHDI Conference in Richmond in February. Teri Urban will be attending the National EHDI Conference in Cincinnati, OH in March as a parent representative for Virginia. A few of our board members have joined the Opening Doors Unlocking Potential 2023 Conference planning committee and enjoy participating and giving feedback when able. Future Spring events we are working on

include a virtual roundtable discussion with deaf and hard of hearing adults, a social event in Roanoke and possibly Winchester, participating in the Flying Squirrels 2nd Annual Disability Inclusion Day at The Diamond in Richmond in May, and partnering with DARS to offer a virtual presentation focusing on Transition.

Public Comment

Each attendee is allotted two (2) minutes to provide a public comment.

Public Comment 1: the first public comment was provided by Hunta Williams- Hunta stated that he represents the National Association for the Deaf (NAD). He stated there is a discrepancy between the deaf children, and deaf and blind children, and hearing children and how they acquire language. He stated there needs to be consistency on language acquisition for children across all areas.

Public Comment 2: the second public comment was provided by Tommy Brown-Tommy asked a question on the difference with ENT and Audiologist. He noticed that there are issues with communication with the ENT and audiologist that they used for their child.

Public comment 3: the third public comment was provided by Karen Woolman- Karen described the difference between ENT and audiology. She mentioned at CNMC there are different offices. She said the best is when there are audio and ENT in the same office for easier communication. She also asked, "what is the status of the VAHALB program?"

Review of AC Bylaws

Reviewed section on the advisory chairs.

Proposed changes:

Section:

"Advisory Chairs":

- Motion to change wording:
 - "...residents of the Commonwealth of Virginia elected annually by the Advisory Committee[.]"
 - o Remove "...and shall not be employed...state government."

"Procedure for AC Member to Request Virtual Assistance":

- Add captioning requirement verbiage.
 - O Questions on whether to add to bylaws and how to add to bylaws.

- o Will add tentatively.
- The member requesting "the...must include reason for request...and make a request for ADA accommodations and notify[.]"
- Eric Raff made a statement about this discussion. Informed us his policies are "captions available upon request."

Will need to find guidance to figure out if the implementation of closed captioning should be given automatically or should be based upon a request for the service.

The AC discussed the various platforms and options for captioning or live CART.

EHDI can use RCC (Virginia) Relay/remote conference caption, it is free.

Discussion on adding RCC Relay to bylaws as captioning option in bylaws on page 6, section 3.

On page 3, Advisory Meeting section, make amendment to the following part:

• "the notice will include...agenda, and a contact to make reasonable ADA accommodations."

Conversation will be discussed at next AC Meeting.

EHDI Updates provided by Daphne Miller and Deepali Sanghani

Virginia EHDI Conference Update:

Welcomed the AC members and Interested parties to pre-conference day. The pre-conference will include the Advisory Committee and the Statewide Learning Community meetings. The first EHDI conference will be held on Feb 14, 2023.

The EHDI team thanked the Advisory Committee members, planning team, speakers and past and present EHDI staff that helped pave the way to Virginia EHDI having its first conference.

- 143 registrants for the Virginia EHDI Conference and a waitlist
- Various speakers and topics each day of the conference

National EHDI Conference Updates:

- The 2023 National EHDI Conference being held in Cincinnati, Ohio from March 5-7.
- Daphne Miller, Deepali Sanghani, Parker Brodsky, Dr. Levorson and Teri Urban will be attending
- Two presentations and one poster presentation have been accepted at the National Conference

- 1. Adjusting EHDI systems of Care to Provide Timely and Automated Follow-up
- 2. Tracking and Analyzing Hearing Outcomes among Infants Born with Risk Factors
- 3. Virginia's Hearing Targeted cCMV Program

HRSA and CDC grant Updates:

- Distributed OAE equipment to Birth Centers
- Supported families by providing iPad's to support communication and language development.
- Completed VISITS enhancements which include a phone tree system, call recordings and enhanced texting platform. (EHDI program was able to text over 800 families to notify them of the Virginia EHDI conference)
- Provided DEI Lunch and Learn series for EHDI stakeholders

EHDI Team Updates:

- Keith Revis is the new Follow-Up Specialist with VA EHDI.
- Currently the VA EHDI team has three interns from Virginia Commonwealth University-Nikki Van, Brandy Cregger, Abdelrahman Osman.
- There are two vacant positions with the VA EHDI Team: a full time Grants Specialist and a Technical Assistance Specialist.
- After 11 years of dedicated service to the Commonwealth of Virginia, Antoinette Vaughan our Follow-up Specialist will be leaving.

Prenatal Collaboration:

VA EHDI has collaborated the Newborn Screening program to create materials to
provide education for women of prenatal age to know what to expect after the birth of
their child. There have been several materials developed including a poster, a brochure,
decal and short videos for distribution.

Newborn Hearing Screening Updates:

- In order to address lost to follow up with children born at home, VA EHDI has provided OAE loaner equipment to out of hospital birthing facilities. In 2021, 13 OAE equipment were loaned and in 2022, 12 OAE equipment were loaned.
- VA EHDI has identified that children over 36 months are not being diagnosed or referred in a timely manner. Thus, VA EHDI has expanded the follow-up plan to include thorough follow up for children up till the age of 36 months.
- Since the onset of the COVID-19 pandemic, VA EHDI has shifted to virtual site visits with hospitals. In 2022, VA EHDI conducted twelve (12) virtual site visits with hospitals. Additionally, four (4) hospitals received a 3-month check in visits. VA EHDI noted significant improvements in all of these facilities after the site visit.

- In order to provide timely notification to Primary Care Providers (PCPs), VA EHDI has opened access to the EHDI Information System, the Virginia Infant Screening Infant Tracking System (VISITS) for PCP facilities. Currently approximately 100 PCPs have been provided access. VA EHDI interns will be assisting with one-on-one outreach to increase the number of PCP facilities who gain access.
- VA EHDI continues to incorporate automated follow up into VISITS. Some upcoming enhancements include outgoing parent calls initiated through VISITS, enhancements to existing texting platform such as appointment reminders and abilities to text families back on demand, and an interactive dashboard to allow timely follow up.

Family Perspective

Ashley Brown and Tommy Brown shared their family's journey with their child's diagnosis.

Next Steps

Next meeting is scheduled for June 2, 2023.

Adjournment

Meeting adjourned at 2:59 PM