

Virginia EHDI Program Advisory Committee Meeting

Friday March 2, 2018

Meeting Minutes

Attendees: Ashleigh Greenwood, Christine Eubanks, Valerie Abbott, Marcus Allen, Nancy W. Bond, Wanda Council, Mona Iskander, Shannon Mueller, Debbie Pfeiffer, Irene Schmalz, Daniel Shearer, Terri Strang-Boston, Teri Urban

Interested Parties: Judy Alonzi, Lori Bobsin, Cynthia Clark, Cornelia Deagle, Valerie Luther, Jill Young

VDH EHDI Staff: Daphne Miller, Deepali Sanghani, Antoinette Vaughan, Chyann Mealy, Nadia Morgan, Rafael Randolph

The meeting was called to order by Ashleigh Greenwood. All members provided brief introductions and a review of the agenda was presented. All in attendance were reminded to submit their forms for travel reimbursement if applicable.

The VA Network of Consultants (VNOC)/ Partnership for People w/Disabilities:

Technical assistance and support:

From November 20 – February 23: More than 63 calls/email requests for technical assistance were received and addressed/processed; 4 were directly from parents. Several requests become direct consultations through the Virginia Network of Consultants (VNOC) described under VNOC. In addition, 39 announcements disseminated during this quarter; 28 of these announcements went to parents. (There are currently 194 parents on the TAC-DHH database.)

VA Network of Consultants for Professionals Who Work with Children Who are D/HH (VNOC):

VNOC service requests are reported following the school year calendar, August 1 to July 31. For the 2017-18 school year, there are 20 VNOC consultations processed.

Regional Trainings:

See-the-Sound Visual Phonics (Decoding strategy for early reading skill development) For the 2017-18 school year to date 7 STS-VP trainings were completed (6 one-day trainings and 1 refresher session). From 2006-present, more than 1,650 people have received training in STS Visual Phonics through TAC-DHH/VNOC sponsored trainings. A parent training in Virginia Beach is planned for March 17.

Statewide Professional Development: Upcoming

CASLLS The Basics and Beyond Training in collaboration with Radford University (March 23-24, 2018).

Opening Doors-Unlocking Potential 2018 scheduled for June 18-19, 2018. The 2018 theme is Language, Literacy and ~~the~~ School Home Connection.

Program Support:

Assistance to VA Hands & Voices, the Parent-Child-Advocate Program, Hearing Journey, Families to Families (Norfolk) and VSDB Outreach Services to disseminate specific d/hh related announcements

Early Intervention:

Early Intervention is currently exploring the concept of using tele-medicine to provide therapy. This concept is to ensure that those specialized care provides like for those who are D/HH can be available in all regions of the state.

Newborn Screening (Dried Blood-Spot and CCHD):

Newborn Screening has been focusing on two major initiatives:

Adding specific lysosomal storage disorders to the Virginia and expansion of screening hours.

Specific activities include:

- Following bills in the General Assembly:
 - HB1174 and SB449 which address the addition of Pompe Disease and MPS 1 to the Virginia panel. A report will be going to the Commissioner and BOH for approval to start regulation amendments
- Receiving a small grant from the Association of Public Health Laboratories to jump start implementation and education activities for these new disorders.
- HB1362 Expansion of dried blood spot screening to occur 7 days a week by January 2019. Hours have been expanded to a full 6 days a week starting this weekend and 7 days will occur by the end of the year.

Virginia Hearing Aid Loan Bank:

As of February 28, 2018 1195 children have used the loan bank. Currently all soundfields are being used. New aids will need to be ordered soon due to low inventory.

Children and Youth with Special Health Care Needs:

CYSHCN executed a contract with UVA to create two online training modules. They are for medical home and transition. The modules will be unique because they will include a training for providers and families. This project may take up to a year to complete, will be web based, and free to Virginia users.

Family to Family

For the period December 2, 2017 through February 28, 2018:

- Five 1-3-6 Family Educators conducted 14 site visits to survey hospitals and audiologists to learn more about their communication with families whose infant needs to have hearing rescreened.
- A 6 hour face to face training was held with four 1-3-6 Family Educators to revisit expectations and site visit and parent matching protocols and begin a parent leadership academy.
- 29 families of infants/toddlers were referred for parent to parent support.

- The Center for Family Involvement (home to the Family to Family and 1-3-6 Family Educator projects) and the EHDI staff were asked by Karl White/NCHAM to write an article for the EHDI Journal on the engagement of parents as leaders in EHDI system change. The article will appear in a fall journal edition.
- Two meetings were held with the Northern Virginia Learning Community. Plans are in place to start the second Learning Community in May in Central Virginia.
- A videotape project was started to capture best practices for supporting infants/toddlers who are deaf/hard of hearing receiving early intervention services. Completed video modules will be available April 2018 on the EHDI, Early Intervention Professional Development, and Center for Family Involvement websites.

VA School for the Deaf & Blind (VSDB):



Spring, 2018

Events Sponsored by VSDB Outreach Services in areas of Deafness & D-B

(for educators and family members from across Virginia)

Wednesday Webinars

February 14, 2018 - Post-Secondary Realities for Students with Combined Vision and Hearing Loss: How to Prepare for Successful Transition, in collaboration with the VA Project for Children and Young Adults with Deaf-Blindness. Dr. Cynthia Ingraham, Helen Keller National Center for Deaf-Blind Youths and Adults, with Elizabeth Speirs and Caren Phipps, DBVI; and Dr. Julie Durando and Ira Padhye, VA Project for Children and Young Adults with Deaf-Blindness.

Online Trainings

VSDB Outreach Services has purchased rights for statewide viewing of short courses from **Central Institute for the Deaf:**

Name of Short Course:	Period for Registration:	Period for Completion:	CEUs:
Auditory Training for Vowel and Consonant Perception Skills	Jan. 10-Jan. 16, 2018	Jan. 17-Feb. 17, 2018	ASHA and LSLIS certification credits, as well as continuing ed units for licensure, are available for completion of these courses, paid for by Outreach Services.
Auditory Training for Connected Speech Skills	Feb. 12-Feb. 19, 2018	Feb. 20-Mar. 20, 2018	

SPICE Curriculum Kits have been purchased by Outreach Services and placed in TTAC Lending Libraries for borrowing, free of charge.

Regional Activities for Students in all Virginia Schools and their Families

March 10, 2018 –Matter Matters! Exploring Space and Matter, for students ages 8 through high school who are deaf or hard of hearing and their families; in collaboration with VA Hands & Voices and the Virginia Air and Space Center. Held at Virginia Air and Space Center, Hampton, VA

April 14, 2018 - Amazement Square for students who are deaf/hard of hearing or blind/visually impaired, sponsored in collaboration with the VA Department for the Blind and Vision Impaired. To be held at Amazement Square, Lynchburg, VA

Live Trainings

March 13, 2018, Developing Language and Literacy in Children Who are Deaf and use ASL, Dr. Melissa Herzig, VL2, Gallaudet, University. To be held at VSDB, Staunton, VA.

April 11, 2018– Virginia Headstart Conference. Presenting **Sensing the Needs of Infants and Toddlers with Vision &/or Hearing Loss**, in collaboration with the Project for Children and Young Adults with Deaf-Blindness and the Virginia Department for the Blind and Vision Impaired. Williamsburg, VA.

Online Training Series (these will be posted on the VSDB “Outreach Videos” webpages soon)

Family American Sign Language (ASL) – short lessons on vocabulary and phrases, presented with ideas for use in normal daily routines of infants and toddlers, and associated cultural/language building lessons.

Interveners: Providing Access for Students with Deaf-Blindness – brief video showing how interveners and teachers work together to provide students with deaf-blindness access in the classroom. Produced in collaboration with the Virginia Project for Children and Young Adults with Deaf-Blindness. (to be posted).

Wednesday Webinars, 2016 – present – 12 of the Wednesday Webinars were recorded and are being posted with transcripts/captions for free viewing. These are in the areas of deafness, blindness, and deaf-blindness.

Virginia School for the Deaf and the Blind - Current Enrollment is at 92 students (51 Deaf; 59 Residential). Deaf students continue to receive routine services (i.e. testing and equipment support) as well as IEP-directed support. VSDB has been continuing its TEMP program, which

provides an immersive one to two week residential experience for children to gain perspective of the technology and content available for their use. Older students have been piloting the school's new Independent Living Apartments, which have provided the opportunity for those students to hone their transition skills prior to graduation. The audiology department has updated and calibrated its diagnostic equipment and is currently suited for behavioral evaluations (6 months to 22 years) and DP/TEOAE screenings. An updated ABR unit is expected to arrive in March, 2018 and OAE equipment will be updated to allow for additional test protocols. Infant testing and ABR/ANSD studies will begin once ABR equipment is received. In mid-February, an introductory letter and flyer were approved and sent out to area school districts, pediatric practices, speech therapists, early interventionists, ENTs, birthing hospitals, and midwives. To-date, six (6) referrals have been received (Five (5) scheduled for testing; one (1) infant deferred to another provider due to current unavailability of ABR unit). The Outreach Program is considering a plan to provide classrooms and community groups with educational presentations based on the Dangerous Decibels curriculum. Through this program, hands-on activities and interactive tools may be used to inform children about the common presence of excessive noise, illustrate the effect of that noise, and influence listening behaviors to protect against noise-induced hearing loss.

Department of Education:

The Department of Education is currently working on revising the guidance document for D/HH children. The anticipated completion date is May 2018.

Deaf-Blind Project:

The Virginia Deaf- Blind Project in collaboration with Partnership for people with Disabilities and Virginia Commonwealth University are conducting their annual 2018 Census for Deaf-Blind children.

VA Dept. for the Deaf and Hard of Hearing (VDDHH):

Eric Raff was appointed as VDDHH Director

Release of Directory of Services publication is now available online on VDDHH website (hardcopy will be available to providers soon).

VA Hands & Voices:

In January 2018, Virginia Hands & Voices celebrated their first anniversary since being reinstated as a chapter. More than half of its members have already renewed their annual membership, and forms are coming in weekly from all over Virginia.

Also in January, VA Hands & Voices traveled to Matchbox Bistro in Fairfax for a Parents/Professionals Lunch Out. Twenty-two individuals joined, including one ASL interpreter. It was a relaxing afternoon spent and always inspiring to see many communication modes being used around the table.

Three parents at the lunch in Fairfax were interested in being regional contacts in Northern Virginia. Parents in Roanoke and Richmond and a parent/professional in Winchester were also interested in becoming a regional contact. Regional contacts will be responsible for coordinating and hosting two or

more Virginia Hands & Voices events each year and we will help them with marketing, money collection, and other logistics.

A virtual training in March will be held with hopes of launching events in each region as early as April! This is very exciting for us as we have been working very hard trying to reach more families across the state. As our list of events and activities grow, we are also actively looking to grow our board of directors so the timing couldn't be better. If you know of some parents who would enjoy spending time with families of deaf and hard of hearing children, I hope you will forward a brochure to them and encourage them to get involved.

The spring events calendar is filled quite nicely with a variety of events throughout the Commonwealth such as:

- March 3, presenting *Improving Communication with Our Deaf and Hard of Hearing Neighbors* at the 2018 Central Virginia EMS Education Expo at the Henrico Training Center
- March 10, Virginia Air and Space Center in Hampton, in collaboration with the VSDB and Outreach Services
- March 18-20, EHDI Annual Meeting, Denver CO
- April 21, *Outside the Lines* play by Arts on the Horizon in Alexandria
- May 20, Richmond Flying Squirrels baseball game at The Diamond, Richmond
- June 23, collaborate with Families to Families to host an outdoor event near Williamsburg/Hampton

Lastly, on February 24, we attended the Virginia Fire and Rescue Conference in Virginia Beach and were awarded the **2017 Governor's Virginia Fire Service Award** for Civilian Excellence in Virginia Fire Service Support. This award exceeded what we thought would be possible accomplishing in our first year of rebuilding our chapter. We have heard that other chapters of Hands & Voices across the country are already looking to implement this life-saving project in their states.

EHDI updates

- March EHDI Conference located in Colorado
- Letters have been redone in December- currently waiting to see if letters have reduced lost to follow up rate within the next 6 months
- Currently proposed updates and revisions to the VISITS system for users include:
 - working to make VISITS easier/ simpler to navigate
 - creating a pending list for audiology users
 - create guidelines on how to enter results in the system
 - Hearing screeners at hospitals will have collect the exact number of days babies stay in NICU
- Planning to collaborate with EHDI MD, EHDI DC, & Border States to give them VISITS access. There is a higher Lost to Follow-up rate in the DMV area due to children born in Virginia receiving follow-up services in other states. It is with hope that this collaboration will reduce the lost to follow up rate for VA EHDI.
- Recently completed home visiting training in NOVA (Alexandria and Arlington programs) through the Healthy Families program. Home Visitors will work with mothers

in 3rd trimester to educate them on newborn screening and conduct a pre-survey in the third trimester and post survey after delivery. Based on the preliminary surveys results, parents are not aware that their babies will be screened for hearing at the hospital.

- Hope to have texting program in place after April to help reduce lost to follow up rate as well

Amend bylaws

Committee member V. Abbott proposed to Amend *Membership and Leadership for Chair and Vice Chair* (Section III. C- 3) of the Advisory Committee Bylaws

The following revision to section III. C of the bylaws was requested:

3. Leadership positions may be held by any voting member of the committee including professionals, deaf and hard of hearing adults, and parents of deaf and hard of hearing children. It is the intention of this committee to increase family involvement in leadership whenever possible.

All support, none opposed

EHDI Family Stories

S. Mueller presented on her family's journey in the diagnosis of her son's hearing loss and the journey they chose for their family.

Ashleigh Greenwood adjourned the meeting at 3:00p.m.