

**Virginia EHDI Program Advisory Meeting**  
**Friday, June 2, 2017**  
**Meeting Minutes**

The following members and interested parties were in attendance: (Valerie Abbott, Colin Benusa, Nancy Bond, Wanda Council, Anne Dare, Cornelia Deagle, Julie Durando, Patricia Eitemiller, Christine Eubanks, Jeanne Fredrehner, Ashleigh Greenwood, Rhonda Harrell, Ann Hughes, Mona Iskander, Anita Jeyakumar, Adriana Lopez, Jennifer Macdonald, Daphne Miller, Stephanie Moody, Casey Morehouse, Susan Neighbors, Debbie Pfeiffer, Deepali Sanghani, Elyssa Sigurdson, Barry Strasnick, Teri Urban, Antoinette Vaughan, Kathleen Watts, Kenya Worsham, and Dana Yarbrough). The meeting was called to order by Dr. Ashleigh Greenwood. All members provided brief introductions and a review of the agenda was presented. All in attendance were reminded by VEHDIP Quality Improvement Coordinator Kathleen Watts to submit their forms for travel reimbursement if applicable. The Advisory Committee accepted and approved, March 3, 2017 minutes from the meeting.

**EHDI Updates**

Daphne Miller provided EHDI updates. The EHDI team has currently received 50% of the funding from the HRSA grant and waiting for a continued resolution regarding the funding. . Daphne Miller discussed some of the activities that will be implemented using the HRSA grant funding including creating a learning community, collaboration with LEND, and implementing tele-audiology. The EHDI team has recently applied for the CDC grant which will allow for some system changes and updates to VISITS. The EHDI team has revised and distributed a new brochure “Your Child’s Hearing Results.” The EHDI team attended the Virginia Otolaryngology Association conference in May 2017. The EHDI team plans to attend the Shining Stars conference in July 2017. The EHDI team will attend Deaf and Hard Hearing Day at Kings Dominion with the Virginia Chapter of Hands and Voices on June 3, 2017. The EHDI team received two ABR machines donated from by Henrico Doctors Hospital which were gifted to midwives in Lynchburg and Winchester Virginia.

**The VA Network of Consultants (VNOC)**

**Technical assistance and support:**

For FY17 (Mar17-May17): 77calls/email requests for technical assistance were received and addressed/processed; 8 were directly from parents. Total requests for FY 17 are 175; 20 of these were directly from parents of children who are d/hh. Several requests become direct consultations through the Virginia Network of Consultants (VNOC) described under VNOC. In addition, 31 announcements were disseminated during this quarter; 20 of these announcements were sent to parents. (There are currently 193 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 2016-17 academic year to date, VNOC has processed 26 consultation requests all from school divisions across the Commonwealth.

**Regional Trainings:**

*See-the-Sound Visual Phonics* (Decoding strategy for early reading skill development)

Since the March update, three full day STS-VP trainings were held. Two of these were led by trainers-in-training. (Ann Hughes is mentoring 4 trainers in Virginia.). VP training for pre-service students (TODHH and SLP) was held at Radford University (21 students). For the 2016-17 school year 157 people received VP training. Five trainings are scheduled in August for the beginning of the new school year. From 2006-present, more than 1,525 people have received training in STS Visual Phonics through TAC-DHH/VNOC sponsored trainings.

April 29, 2017: Opening Doors to Life Beyond High School – SW VA Regional, a collaborative event with DARS-D/HH Division was held in Abingdon (5 students, 6 parents, 2 teachers of the d/hh).

**Statewide Professional Development:**

***Opening Doors-Unlocking Potential 2017:*** Effectively Serving Students Who are D/HH PLUS and Opening Doors to Life Beyond High School are scheduled for June 28-30, 2017 at the Doubletree by Hilton Richmond-Midlothian, VA. [www.odup2017.shutterfly.com](http://www.odup2017.shutterfly.com) . Registration for these events is open until June 9.

**Program Support:**

Assistance to VA Hands & Voices, VA AG Bell, VCU Audiology and VSDB Outreach Services to disseminate specific d/hh related announcements.

**Early Intervention (EI)**

No update

**Newborn Screening****Dried Blood Spot/CCHD Program**

- Follow-up nurse have co-located to DCLS to improve communication, team build and efficiency of services
- The Virginia Genetics Advisory Committee sub-committees (VaGAC) are in the process of reviewing three new disorders added to the Recommended Uniform Screening Panel (RUSP) and making a recommendation to the larger VaGAC: Pompe Disease, MPS-1 and X-ALD.
- The next VaGAC meeting will be held on June 29<sup>th</sup> at DCLS
- There will be a comprehensive regulation review in 2017 to review dried blood spot regulations.
- QA/QI initiatives continue to focus on HL-7 messaging of results to hospitals and timeliness of receiving dried blood spot specimens into DCLS and reporting out of results by 7 days of life. Hospitals receive monthly report cards.
- The 2017 Newborn Screening & Genetic Testing Symposium will be held in New Orleans, LA, September 10-13. Virginia's dried blood spot & CCHD programs had 10 posters and 1 oral presentation accepted.

**Zika Pregnancy Registry and Birth Defects Surveillance**

- Program is fully staffed with a Pregnancy Registry Coordinator and a Birth Defects Coordinator

- Virginia Pregnancy Registry is fully operational
- The Virginia Zika Clinician Forum was held on May 24, 2017 where over 75 professionals attended in person and over 30 via webinar. Highlighted current state of Zika in Virginia, testing, DCLS activity, OB\_GYN perspective and care of the mom, pediatrician perspective and care of the infants and available resources to health care professionals and families.

### **VA Hearing Aid Loan Bank (VHALB)**

As of May 30, 2017 1134 children have used the loan back. Currently 3 soundfields are being used. The schools that are currently using the soundfields feel like all the children are benefiting from the system being used in the classroom. The budgets have been submitted for the operational expenses and the devices grant for next fiscal year.

### **Children & Youth with Special Healthcare Needs (CYSHCN)**

We are in negotiations with a possible vendor to create online medical home and transition (pediatric to adult care) modules for providers and families. This project is part of the Medical Neighborhood work that is going on in the Blue Ridge Region and has involved many different partners to include: Family 2 Family (Dana Yarbrough), DMAS, the AAP, Blue Ridge Care Connection for Children, several local physicians, and others. The CYSHCN team is preparing our part of the annual Maternal and Child Health (MCH) Block Grant report. The report is due in July and the entire MCH team will be traveling to Rockville, Maryland in August for the annual review with our funders.

### **Family to Family**

Adrianna Lopez is the new family educator in the tidewater region.

### **Partnership for People w/Disabilities**

Dana mentioned meeting with EHDI regarding a needs assessment for the creation of learning communities across Virginia. She shared with the group that a workgroup will meet during lunch to discuss the needs assessment for Virginia's EHDI learning communities. The Family to Family program with the 1-3-6 Educators are visiting audiologist and hospitals to share their family's story. Valerie a 1-3-6 Educator shared a few of her experiences with the group.

### **VA School for the Deaf & Blind (VSDB)**

The Audiologist for VSDB Casey Moorehouse announced her resignation as of June 2, 2017. The VSDB is currently in search of a new audiologist and the job posting was announced with the request to assist with recruitment.



Spring, 2017

Events Sponsored by Outreach Services, VSDB  
(for educators and family members from across Virginia)

### **Wednesday Webinars**

April 19, 2017 - Kendall Conversational Proficiency Scale, Martha French, Ph.D.

**May 10, 2017** – Visual Communication, Sign Language (VCSL) Assessment, Laurene E. Simms, Ph.D. and M. Diane Clark, Ph.D.

**May 17, 2017** – Following Assessment to Plan Communication/Literacy Instruction, Martha French, Ph.D.

### **Other Online Trainings**

**March 15, 2017** – Introduction to Cerebral/Cortical Visual Impairment, Dr. Julie Durando, Director, Project for Children and Young Adults with Deaf-Blindness, Partnership for People with Disabilities, Virginia Commonwealth University (open only to those attending live Sheline training)

**Developing Listening and Spoken Language Skills of Children Who are Deaf or Hard of Hearing**, short courses from Central Institute for the Deaf (CID)

Name of Short Course	Tentative Dates Offered:	Registration Fee:
Developing IEP Goals for Students with Hearing Loss: Speech, Language, and Auditory Development	Feb. 20 – Mar. 19, 2017	Paid to CID by Outreach Services, VSDB; participants will register with Outreach Services and receive an access code good for one month
Building Conversational Skills in Preschool Students	Mar. 20– April 19, 2017	
Building Conversational Skills in School-Aged Students	Mar. 20 – April 19, 2017	
Strategies for Improving Auditory Memory	April 20 – May 19, 2017	

### **Regional Activities for Students in all Virginia Schools and their Families**

**April 8, 2017** – Audible Easter Egg Hunt for children who are blind or visually impaired and their families.

Sponsored in collaboration with Virginia Department for the Blind and Vision Impaired; at VSDB, Staunton, VA.

**April 10 and April 20, 2017** - Sounds of the James for students who are blind/visually impaired and their parents. Bald Eagle Tour featuring Capt. Mike Ostrander, with pre/post science education re: birds of the river and O & M training on land. This event is held in collaboration with Virginia Association of Parents of Visually Impaired (VAAPVI), through Virginia Wildlife e-Store grant funding from Virginia Department of Game and Inland Fisheries and the Wildlife Foundation of Virginia; Richmond, VA

**June 10, 2017** - Science Day with Jefferson Lab, for students grades 4 – 8 who are deaf or hard of hearing using any communication method; Instructor: Brita Hampton, Education Services, Jefferson Lab and Gary Talley, Virginia Department for the Blind and Vision Impaired displaying TAP equipment. This event will be held at the Thomas Jefferson National Accelerator Facility, Newport News, VA.

### **Live Trainings**

**Strategy to See: Working with Children with Cortical/Cerebral Visual Impairment**, with presenter Diane Sheline; for teachers of students who are blind or visually impaired, early childhood special educators, early intervention educators, and related service providers working with children with visual impairments. These two live trainings are exactly the same, offered in two locations in Virginia. Sponsored in collaboration with the Project for Children and Young Adults with Deaf-Blindness and Allied Instructional Services (AIS).

Thursday, March 23, 2017 9:00 am – 4:00 pm	Richmond, VA	The Richmond Police Training Academy 1202 W. Graham Rd. Richmond, VA 23220
Friday, March 24, 2017 9:00 am – 4:00 pm	Staunton, VA	The Virginia School for the Deaf and the Blind 104 VSDB Drive Staunton, VA 24401

**July 14-15, 2017** – Unified English Braille, Technical Materials, Wendy Buckley, Ed.S., Instructor, Vision Studies, University of Massachusetts Boston. This training is co-sponsored by the Virginia Department of Education, the

Department for the Blind and Vision Impaired, Outreach Services of the Virginia School for the Deaf and the Blind, and the Vision Consortium for Teacher Preparation in Vision Impairment.

**July 20, 2017** - Creating Connection to Shining Stars, Dr. Julie Durando, Lisa Auwarter, and Dr. Debbie Pfeiffer presenting on meeting the needs of infants and toddlers with deafness, blindness, or deaf-blindness.

**Online Training Series** (to be archived)

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.

**Dept. of Education (DOE)**

- Information is being reviewed for the FY '18 budget and grant funding.
- The *Opening Doors to Life Beyond High School* (ODLBHS) and *Opening Doors-Unlocking Potential 2017* (ODUP) events will be held on June 28-30, at the Double Tree Richmond-Midlothian. Educators, parents and students (grades 8-12) will attend sessions and participate in activities, which focus on students who are deaf and hard of hearing with additional disabilities.
- Wanda Council (VDOE), Mary Nunally (DARS) and Ann Hughes (TAC-DHH) will attend the National Deaf Center on Postsecondary Outcomes *Engage for Change* state event in Austin, TX on June 5-6. State team representatives will collaborate and engage in discussion and activities focusing on improving the postsecondary outcomes for students who are deaf and hard of hearing.
- The VDOE has developed a Statewide Inclusion Plan that includes programs for preschool-age children in general education and special education programs. Meetings are being held to discuss the barriers, concerns, and solutions for increasing inclusive program options for children with disabilities. Data is being gathered and reviewed with VDOE staff, early childhood special education administrators and special education directors. Technical assistance will be provided to support educators and administrators.
- *Creating Connections to Shining Stars* (CCSS) is a collaborative effort between many state agencies and early childhood programs in Virginia. The conference will focus on promoting and supporting the implementation of evidence-based practices in inclusive settings for young children, both with and without disabilities. The conference will be held at the historic Hotel Roanoke July 20-21, 2017. The keynote will be presented by Dr. Kate Gallagher.
- In the fall, leaders in early childhood will participate in a collaborative conference. Participants will include administrators from the Virginia Preschool Initiative (CPI) and VPI+, Head Start, and early childhood special education. The focus of the conference is to identify strategies to improve collaboration and provide a quality education for all children, including those with disabilities.

**Deaf Blind Project**

No update

**VA Dept. for the Deaf and Hard of Hearing (VDDHH) - Videophones in Public Libraries –**

As previously reported VDDHH, through the Statewide Interagency Team (SIT), has been working on an initiative to place videophones in public libraries across the Commonwealth. This project is in keeping with VDDHH's mission of reducing communication barriers, as it will greatly enhance communication access for users of sign language in areas where the required high speed internet access is often unavailable or unaffordable. SIT met with the two top providers of Video Relay Service (VRS) and both have agreed to take on this pilot project beginning in far Southwest VA, where the expressed need for this service originated. I am glad to report that the VDDHH Outreach Manager coordinated and oversaw the first two installations at the Abingdon and Pulaski libraries. We will keep you posted as more installations take place across the Commonwealth.

**Communications Access at the General Assembly (GA)** – In January, VDDHH received a call from Steve Gordon, Civil Rights Enforcement Coordinator for the Eastern Division of Virginia in the Civil Rights Division of the Department of Justice (DOJ) about concerns that have been raised regarding the provision of sign language interpreter services by members of the General Assembly. Based on that conversation, the VDDHH Interpreter Services Programs (ISP) Manager spoke with staff in the Senate and the House clerks' offices. Both offices have previously provided specific guidance to GA members about securing sign language interpreters for meetings and both offices have secured interpreters for committee meetings per request. It was soon recognized that not all requests for interpreter services for meetings with individual legislators have been handled in accordance with the guidance provided. Meanwhile, in March, Atty. Gordon requested a meeting that was attended by the ISP Manager and Deaf advocates, in an effort to address these communications access concerns at the General Assembly. The ISP Manager has agreed to work with the House and Senate clerks to develop clear procedures for future sessions, including floor sessions, committee and subcommittee meetings, and meetings with individual legislators. Atty. Gordon was very supportive of the concept of developing guidelines prior to the 2018 session to assist consumers in accessing the legislative process. A follow-up meeting is planned with staff from the clerks' offices.

**Staff** – The retitled "TAP Specialist Coordinator" position and its core responsibilities have been updated to support TAP and oversee the 'TAP Specialists.' The former incumbent was Sherry Ross who has since retired last January. VDDHH conducted recruitment and interviewed five candidates. Unfortunately, the top two candidates backed out and VDDHH will be doing another job bulletin. In addition, VDDHH is changing the name of a program, Outreach Services, to Community Services and adding a new position to support the "Community" Services Program Manager. Both positions will be advertised this May and conduct a national recruitment campaign and the goal is to fill both positions this summer.

**Open House-Save The Date** – In celebration of its 45<sup>th</sup> Anniversary and Deaf Awareness Week, VDDHH is planning to host an Open House on the afternoon of Friday, September 29<sup>th</sup> and the morning of Saturday, September 30<sup>th</sup>, 2017. We will send more details as the plans develop.

**Hands & Voices** - There has been a lot happening since our last meeting in March, but we are pleased that Virginia Hands & Voices has great momentum and we continue to grow our membership monthly.

We currently have almost 40 members, which is evenly split between parents and professionals. Our list of 'interested' parents and professionals' is just over 100 people. According to past records, I believe the most our chapter had in past years was about 15 members so I'm very pleased with these numbers so far.

Our focus since rebuilding our chapter has been on re-building our board, re-branding our name and promoting our mission of supporting families with children who are deaf and hard-of-hearing without bias around communication modes or methodology. We are steadily reaching families in all different regions – including areas like Abingdon, Staunton and Virginia Beach. In April, we were an exhibitor and guest presenter at the Opening Doors conference in Abingdon and met many great families there who are thirsty for more social opportunities for their children. We are hoping to get out to SW VA this fall, our only obstacle these days is funding.

In March, we were asked to help out at the Charlottesville Marathon serving White Claw Hard Seltzer to race goers and we raised \$600 in sales and donations for our chapter!

In May, we had an event at the Children's Museum of Richmond, piggybacking on their Special Night for Special Needs evening - which brought out a few families. We also had a meeting with the Parent Resource Center at Chesterfield Public Schools and shared our goals and brochures with them. We are also hoping to plan an event in Chesterfield this fall after school starts. Lastly, we hosted a 'parents and professionals night out' at Hattie's Mae's in Willow Lawn with almost 20 attendees. It was a great night, and it was amazing to see such a diverse group of people all come together.

June will be an exciting month! We will have an exhibit at Kings Dominion for their Deaf and Hard of Hearing Awareness Day on June 3. June 20 we will hold our first fundraiser by selling tickets online for the Richmond Flying Squirrels and we will receive a portion of those ticket sales. Our group will be sitting near the Nutzyville Kids Zone, so come join us! On June 24<sup>th</sup>, we are excited to partner up with Families to Families of Hampton Roads and the Coastal Virginia Resource Center for the Deaf where we will meet for lunch at Charly's Airport Restaurant in Williamsburg. This will also include a private tour of the Williamsburg Flight Center with the opportunity for the children to sit in a private airplane! We also will be giving a presentation at Camp TALK about our organization on June 20 and look forward to connecting with more families there.

We plan to take July and August off and don't have any events planned, since families always seem to be busy with traveling during the summer.

However, we already have big plans for this fall. We are spearheading a program in collaboration with the National Fire Protection Association and the Virginia State Fire Marshall's office to create a fire safety and awareness program aimed at helping people with hearing loss: adults and children alike. This Webinar and in-person program will be launched in November, and marketed in October – which is Fire Prevention Month. It's also right before the holidays, when many house fires occur. We are hopeful that this pilot project we are creating will be successful enough that it can be leveraged in other Hands & Voices chapters across the U.S.

We submitted a Call for Papers for the Annual Hands & Voices Leadership Conference this September in Illinois and our presentation was accepted. It is titled: "Picking Up the Pieces: Rebuilding Your Chapter One Brick at a Time". We will need to find a way to fund the transportation costs, with hopes that at least one board member from our chapter can attend the conference and present on this important topic – Virginia is a great example that rebuilding a chapter is possible. Our only obstacle to attending the conference is funding.

Lastly, we have established a wonderful relationship with Civic Access in Charlottesville. They are an organization dedicated to providing communication, education and advocacy access to the Deaf community and have graciously offered us some interpreters free of charge while we are still in the process of rebuilding ourselves. This has enabled us to have an ASL interpreter at all our recent events. We have also met with a grant writer and are fine-tuning a program that we are looking to start if grant money can be located. Also behind the scenes, we are working on creating a video to go along with a future direct fundraising campaign along and a t-shirt campaign.

At this time, we are actively seeking a fundraising chair or assistance from anyone with ideas on how to raise the money we need to do all that we need to do. While our board is comprised of people with outstanding knowledge and experience as parents or professionals, the one hole we need to fill is in the area of fundraising.

**Audiology Protocols Review** – EHDI Follow-Up Specialist Antoinette Vaughan met with audiologist via tele-conference on the following dates to discuss protocol revisions: 12/13/16, 11/21/16, and 8/17/16. The suggestions for changes were presented today to the board and will be discussed and possibly finalized during the next quarterly meeting.

**EHDI Family Stories** – Tidewater Family Educator Adrianna Lopez shared the story of her son's journey to a hearing loss diagnosis and details of the genetic risk factor.

### **Workgroups**

The Parent workgroup and the Learning Community workgroups met during lunch. The parent workgroup discussed revision of the current letters mailed by EHDI team to children in need of follow-up. The Learning Community workgroup lead by Family to Family (VCU) discussed creating a needs assessment around learning communities.

### **Public Comment**

No public comments

### **CMV (cytomegalovirus) Presentations**

Dr. Mona Iskander (pediatrician) and Dr. Stephanie Moody (ENT) both presented on this topic. According to Dr. Iskander, based upon the March 2017 International CMV consensus report, there is still not enough data to establish universal screening and that educating parents, providers, and legislation is essential.

Dr. Stephanie Moody's discussed on treatment of CMV. She noted that the virus is treatable and it is practical to do so. CMV is the most common cause of non-genetic hearing loss and is the 2<sup>nd</sup> most common cause after connexin 26. Delayed hearing loss may occur up to six years of age in 50% of CMV babies.

### **CDC Survey 2015**

Due to time constraints this information had to be postponed until the next quarterly meeting.

### **EHDI Next Steps**

Topics for the next meeting were discussed. These included a presentation on CDC Survey 2015, CMV discussion, a presentation by Bridie Abbott, review of EHDI protocols. The next meeting date was discussed as potentially September 15, 2017 or September 22, 2017 based on availability of meeting space.

Dr. Ashleigh Greenwood adjourned the meeting at 2:00p.m.