

Virginia EHDI Program Advisory Committee Meeting

Friday, January 11, 2019

Meeting Minutes

Attendees: Ashleigh Greenwood, Valerie Abbott, Marcus Allen, Judy Alonzi
Wanda Council, Julie Durando, Patricia Eitemiller, Christine Eubanks, Ann Hughes, Mona Iskander,
Debi Leekoff, Debbie Pfeiffer, Eric Raff, Irene Schmalz, Daniel Shearer, Teri Strange- Boston

Interested Parties: Elizabeth Allen, Taylor Arbogast, Lori Bobsin, Anne Dare, Avery Donald, Lee Hartman, Hilary Hodes, Mary Lynn Jones, Alison King, Kerri Lawlor, Valerie Luther, Ariana Morris, Leah Muhlenfeld, Rebecca Napier, Susanne Nelson, Kara Norcross, Bonnie Purtill, Emily Shane, Elyssa Sigurdson, Michele Van Meter

VDH EHDI Staff: Christen Crews, Cornelia Deagle, Jennifer Macdonald, Chyann Mealy, Daphne Miller, Rafael Randolph, Deepali Sanghani, Antoinette Vaughan, Kathleen Watts

The meeting was called to order by Ashleigh Greenwood at 10:09am. All members provided brief introductions and a review of the agenda was presented and approved. Minutes of the September 7, 2018 meeting was approved. All in attendance were reminded to submit their forms for travel reimbursement and to sign in.

Agency Updates:

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

Technical Assistance Center for Children who are DHH (TAC-DHH): From **August 21 to December 20, 2018:** More than 97 calls/email requests for technical assistance were received and addressed/processed; 5 were directly from parents. Several requests become direct consultations through the Virginia Network of Consultants (VNOC) described under VNOC. In addition, 61 announcements were disseminated during this quarter; 38 of these announcements went to parents. (There are currently 201 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 2018-19 school year (beginning August 1), 13 VNOC consultation requests have been received to date; 9 have been completed as of December 20, 2018.

Regional Trainings:

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

For the 2018-19 school year, 3 STS-VP trainings were completed. From 2006-present, more than 1,730 people have received training in STS Visual Phonics through TAC-DHH/VNOC sponsored trainings.

Additional Activity:

-October 1, 2018: Virginia Stakeholders Meeting - VA State Leads for the National Deaf Center's Engage for Change project second stakeholders meeting to address root causes identified as challenges that impact postsecondary attainment by persons who are d/hh. Two significant areas identified through these meetings were the need for appropriate Early Intervention services and use of Deaf mentors to connect with families of young children who are d/hh.

-VDOE *Guidelines for Working with Students Who are Deaf and Hard of Hearing in Virginia Public Schools*. (Update to be posted during the 2018-19 school term).

-Mentor Training for two additional *See the Sound Visual Phonics* trainers has been completed in NoVA and Tidewater; one trainer is in training in SW Virginia.

Program Support:

Assistance to VA Hands & Voices, the Parent-Child-Advocate Program, Hearing Journey and Families to Families to disseminate specific d/hh related event announcements.

Disseminate announcements on new Child Dev't module from Virginia Early Intervention eLearning Center to parents/Deaf adults (229), and professionals (700) [with Call for DHH-EI providers].

Upcoming:

TODHH Community of Practice – Literacy (online – January 21-March 30, 2019)

See-the-Sound Visual Phonics (Hampton City-January 28; Radford University –March 1, 2019)

Opening Doors-Unlocking Potential 2019: *Building Foundations for Literacy Success*
(Richmond/Midlothian, June 26-28, 2019)

Early Intervention:

No recent updates

Newborn Screening (Dried Blood-Spot and CCHD):

The lysosomal storage disorders, Pompe Disease and MPS-1, were added to Virginia's core newborn screening panel and screening was implemented on dried blood spot specimens received starting 1/1/2019. In addition, days of operation have expanded to 7 days a week, including holidays, for time sensitive critical results. For Critical Congenital Heart Disease (CCHD), a dedicated birth defects contractor is providing follow-up and referrals to the CCCs.

Virginia Hearing Aid Loan Bank:

As of January 1, 2019 1275 children have used the loan bank. I still have more of the Phonak Inspiro transmitters that were donated. If you know of anyone or a school system that may need some please have them contact Lisa Powley.

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

CYSHCN recently finished the parent survey for the Care Connection for Children Program. The survey is done every 5 years. CYSHCN also partners with VCU to mail the survey to families and to analyze the responses collected. The survey is used to help measure parent satisfaction with the services that are provided. The results will be presented to the Care Connection for Children Center Directors in the coming months.

Center For Family Involvement (CFI) @ VCU-Family to Family

CFI had 8 referrals, 4 learning community (LC) meetings, finally finished resource guide for school aged children. CFI is currently planning a family retreat, preparing for the CARE project this upcoming spring, and working on a brochure for Spanish speaking families to educate them on hearing loss.

VA School for the Deaf & Blind (VSDB):



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

October 2018- January 2019

(for educators and family members from across Virginia)

Webinars:

October 10, 2018 - Sensing, Acting, Learning: Strategies for Learners with Visual and Multiple Impairments, presented by the VA Project for Children and Young Adults with Deaf-Blindness and facilitated by VSDB Outreach; this webinar is offered only to those individuals who attended the live training held July 17-18, 2018.

Online Trainings

Outreach Services, VSDB has short courses from Central Institute for the Deaf for state viewing as follows:

Name of Short Course:	Period for Registration:	Period for Completion:	(note about SPICE Curr)
The Art of the Structured Syntax Lesson: Assessing,	Sept. 27–Oct. 3, 2018	Oct. 4–Nov. 4, 2018 (62 completed)	ASHA and LSLS certification credits,

Planning and Prompting			as well as continuing ed units for licensure, are available for completion of these courses, paid for by Outreach Services. A SPICE Curriculum Kit was placed in TTAC Lending Libraries for borrowing free of charge.
Linking Language and Literacy: Strategies for Developing Reading and Writing Skills in Children Who Are Deaf and Hard of Hearing	Oct. 30-Nov. 6, 2018	Nov. 8-Dec. 12, 2018 (76 completed)	
Pediatric Audiology	(coming soon) Jan. 8-Jan. 15, 2019	Jan. 17-Feb. 17, 2019	
Developing IEP Goals for Students with Hearing Loss: Speech, Language, and Auditory Development	Feb. 12-Feb. 18, 2019	Feb. 20-Mar. 20, 2019	

Regional Activities for Students in all Virginia Schools and their Families:

October 27, 2018 – Science Museum of Virginia; for students ages 6 through high school who are deaf or hard of hearing, and/or blind or visually impaired and their families; in collaboration with the VA Dept. for the Blind and Vision Impaired. Richmond, VA (29 family members attended)

December 1, 2018 – Santa Clause is Coming To Town, Barter Theater. For students grades 1 – 12; interpreted for students who are deaf/hard of hearing and described for students with blindness/visual impairment; pre-session allowing students to “get to know” the set, props, and characters; and afternoon session with Project REAL educators! This event is done in collaboration with the VA Dept. for the Blind and Vision Impaired and VA Hands & Voices. Abingdon, VA (34 family members attended).

Live Trainings:

Oct 5 - 6, 2018 – Improving Academic Success in Writing and Mathematics of Students Who are Deaf and Hard of Hearing, Presenters: Theresa Johnson, Dawn Kidd, and Michelle Halvorsen, Texas School for the Deaf and trained trainers of the DeafTEC Project, National Technical Institute for the Deaf (NTID). VA Crossings Hotel and Conference Center, Glen Allen, VA. (32 attended)

Dec. 6, 2018 – Conducting Learning Media Assessments with students with blindness/visual impairment. Presenter: Tom Miller, formerly Teacher and Administrator, Perkins School for the Blind. At DBVI LRC, Richmond, VA. (64 attended)

VSDB Outreach Services Director (Debbie Pfeiffer) has attended meetings of the VEHI Learning Community in the SW and Roanoke.

Outreach:

VSDB Audiology saw its final outreach family of 2018 just before the school dismissed for the holiday break. In total, 62 children received diagnostic audiologic services through the school's outreach program last year. Referrals continue to be received from early interventionists, primary care providers, birthing facilities, community service boards, and other professionals.

A 3rd-year JMU audiology doctoral student, Julia Dawson, has begun her spring clinic rotation at VSDB and will continue through the end of the semester. This continued relationship with JMU audiology students will facilitate more reliable assessment of difficult-to-test children and may hopefully pique student interest in pediatric audiology within the commonwealth. Daniel Shearer will be attending the annual EHDI meeting in March as a representative of VSDB.

Department of Education:

The VDOE congratulated John Eisenberg, Assistant Superintendent for Special Education and Student Services, for being selected as the Executive Director for the National Association of State Directors of Special Education (NASDSE). John began his new role at NASDSE in December. Doug Cox was hired to serve in John's former position during the interim until a new Assistant Superintendent for Special Education and Student Services is hired.

Dawn Hendricks, Early Childhood Special Education Specialist, was reassigned to work directly with the VDOE Office of Early Childhood. Dawn continues to work collaboratively with the Office of Special Education Instructional Services for programs and services to support young children with disabilities.

A Community of Learning (COL) for early childhood leaders will begin in February. Ten school divisions will be selected to participate in the COL which focuses on improving inclusive practices for young children.

The Commonwealth received a \$9.9 million Federal Preschool Development Grant to Unify and Strengthen Early Childhood Education (birth-5) from the U.S. Department of Health and Human Services' Administration for Children and Families. The VDOE and its partners will collaborate to use the federal funding to support statewide initiatives that strengthen Virginia's early childhood system in 2019-2020.

Deaf-Blind Project:

Kicking off annual census in the next couple of weeks.

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

Executive Management:

VDDHH, Department of Aging and Rehabilitative Services (DARS), Department for the Blind and Vision Impaired (DBVI) and the Valley Community Service Board are the four agencies comprising of the Statewide Interagency Team (SIT) addressing issues as it relates to deaf, hard of hearing and deafblind constituents. On Saturday December 1, the SIT hosted a workshop and town hall meeting held at the Tidewater Community College as part of its ongoing effort to develop a needs assessment and identify new priorities.

VDDHH appointed Mrs. Rhonda Jeter as the new Business Manager who brings 13+ years of experience with the Department of Aging and Rehabilitative Services and additional experience with services to the deaf and hard of hearing.

VDDHH Advisory Board:

On Wednesday November 3, VDDHH hosted its' quarterly meeting of the 9-member advisory board. The agenda included board and agency reports. A guest speaker, Deputy Director with the Department of Professional and Occupational Regulation (DPOR), gave an overview of DPOR and the regulation process. The board motioned to petition the DPOR to conduct a formal study on whether to regulate sign language interpreters (see Interpreter Services Program). Another guest speaker, a Director with the Department of General Services gave a presentation about the accessibility of state owned/leased buildings pertinent to regulations, building codes, and hearing loss.

Virginia Relay:

The Virginia Relay Advisory Council (VRAC) hosted its semi-annual meeting on Thursday October 4th. The VRAC has four new representatives. Hamilton Relay and Devaney Associates (marketing) presented on its activities. There were several presentations with updates on the Internet Protocol Captioned Telephone Service and the Federal Communication Commission. In addition, Dorothy Spears-Dean, with Virginia Information Technology Agency (VITA), gave an update on Text to 911 deployment.

Telecommunication Assistance Program (TAP):

The Telecommunication Assistance Program (TAP) has been working with the contracted TAP specialists to coordinate the replacement of captioned telephones. The free exchange of old CapTel 800i with new 840i was initiated by the manufacturer, Weitbrecht (WCI), in response to the CapTel 800i not being able to meet the new FCC regulations for all Internet-Protocol Captioned Telephone Service (IP-CTS) phones.

A few highlights of outreach activities include participation at the annual statewide Veteran's conference in Richmond and participation with the distribution of emergency kits at the Richmond City fire department headquarters.

Interpreter Services Program (ISP):

The interpreter licensure workgroup had its final meeting in October and finalized the report addressing the Department of Occupation and Regulation criterion on why sign language interpreters should be regulated. The final report was submitted to the VDDHH advisory board with the recommendation that

the board motion petition the DPOR to conduct a formal study on whether to regulate sign language interpreters. The petition was submitted prior to the DPOR annual December 1 deadline.

Virginia Quality Assurance Screening (VQAS):

The Department of Education (DOE) hosted its' semi-annual meeting of educational interpreters grant coordinators at VDDHH. VDDHH will obtain the same amount of approximately \$80k for the new Federal Fiscal Year 2019. VDDHH proctors the VQAS and Educational Interpreter Performance Assessment (EIPA) for Virginia's educational interpreters on behalf of DOE.

Community Services:

On Saturday November 3, VDDHH hosted an all-day legislative training workshop for the deaf, hard of hearing and deafblind communities. The Virginia Board for People with Disabilities (VBPD) had approved the small grant that partially funded the workshop including an out-of state guest speaker nationally renowned for her legislative training. The morning session focused on the legislative process and how to work with legislators. The afternoon session was about brainstorming numerous issues and narrowing it down to the top two issues: 1) establishment of regional centers for the deaf and hard of hearing 2) improving education access for deaf and hard of hearing children. The audience identified a leader to take the lead for each issue. Afterwards, VDDHH received numerous compliments for hosting the workshop with an excellent presenter.

A few highlights of education and training activities include trainings at two (2) Criminal Justice Academies (9-1-1 dispatchers and new police officers), Americans with Disabilities Act (ADA) training for the Department of Corrections and the State Police Trooper Academy.

Virginia Quality Assurance Screening (VQAS):

The new VQAS testing materials continues to be a success with positive feedback from candidates. Three groups of raters: Expressive Raters, Interactive Raters and Receptive Raters have completed their training on the new testing materials. The Interactive Raters did give feedback on the new segment of Interactive Interpreting and VDDHH is now revising that segment. A new VQAS database was developed and VDDHH is in the process of evaluating it. There are significant improvements over the old database. After providing input and correcting a few items, the database will be ready to launch.

Community Services:

Community Services performed ongoing education and training activities to 37 EMTs (state convention), 28 police officers, 12 9-1-1 dispatchers, 27 counselors (involved with sexual assault/domestic violence) Provided technical assistance to the Richmond Metro Communications in creating an accessible video (captioning and sign language) to inform the deaf and hard of hearing community about the benefits – and limitations of Text to 9-1-1. Also provided technical assistance to Mass Care Task Force about communication access in in disaster evacuation / sheltering situations. The outdated VDDHH brochure, which was drafted on MS Word and printed via in-house copier, was replaced with a new, professionally printed version now available on the VDDHH website.

VA Hands & Voices:

2018 List of Accomplishments & Activities

January

- Hosted a Parents and Professionals Lunch Out at Matchbox Bistro, Fairfax

February

- Awarded the Governor's 2017 Virginia Fire Service Award for Civilian Excellence in Virginia Fire Service Support at the Virginia Fire and Rescue Conference, Virginia Beach

March

- Presented at the 2018 Central Virginia EMS Education Expo on the topic "Building a Bridge: Improving Communication with our Deaf and Hard of Hearing Neighbors", Henrico
- Co-hosted event with Virginia School for the Deaf and Blind and Outreach Services at the Virginia Air & Space Museum, Hampton

April

- Gathered at The Lab at Convergence to see the play, Outside the Lines, Alexandria

May

- Family event at The Diamond, Richmond Flying Squirrels, Richmond

June

- Exhibitor at Kings Dominion for Deaf/Hard of Hearing Awareness Day
- Hosted an Ice Cream Social at Starkey Park in Roanoke
- Gathered at Cartwheels & Coffee for Coffee Chat, Richmond
- Exhibitor at Opening Doors Unlocking Potential conference in Midlothian
- Co-hosted Pizza in the Park event with Families to Families at Veteran's Park in Williamsburg

July

No events

August

- Partnered with the VDOE and hosted a virtual learning opportunity with focus on the IEP process and parental rights

September

- Hosted a gathering at Skate Nation for family fun including laser tag and ice skating, Richmond
- Sent a board member to the H&V Annual Leadership Conference, Cheyenne WY
- Hosted a gathering at Launching Pad Trampoline Park, Salem

October

- Hosted a gathering at Whitehall Farms for fall family fun, Clifton

November

No events

December

- Co-hosted event with Virginia School for the Deaf and Blind and Outreach Services at the Barter Theater, Abingdon
- Partnered with the VDOE and hosted a virtual learning opportunity with focus on IEP Accommodations for Students who are D/HH
- Ended 2018 with 48 members: 28 parents, 13 Professionals, 2 Deaf adults and 5 organizational members

Partnering:

We are always eager to partner with other organizations who wish to collaborate on social or educational opportunities for families and professionals. If you wish to brainstorm ways on how we can collaborate with your organization, please contact us at vahandsandvoices@gmail.com.

EHDI Updates

C. Mealy presented updates on travel, educational materials, and future events on behalf of the VA EHDI Program. A bitable video was shown to the committee on the VA EHDI program. V. Abbott then followed up with Learning Community updates. Northen, Central, Southwest, and Roanoke learning communities are consistently meeting in their respective region. V. Abbott also showed a video that will be presented at the EHDI Annual Meeting for the Parent to Parent presentation. Blue Ridge and Hampton Roads are scheduled to begin their learning communities this year. K. Watts also provided updates on the Shared Plan of Care (SPoC). The SPoC will serve as a guide to assist families with care management and follow up after their child is newly diagnosed with a hearing loss. The SPoC will be piloted soon among parents to see if the SPoC was helpful as well as to provide feedback.

Cued Speech

A. Laptewicz and R. McAnallen presented on cued speech (CS). CS involves lips, shapes, and sounds. Cued speech, the system, is a communication mode but not a language. Cued American English (CAE) is a language. In fact, CS is currently in 70 different languages.

Benefits of cued speech include literacy, phonemic awareness, and comprehension. CAE can be paired with American Sign Language (ASL) to provide visual access to two different languages.

Some disadvantages to CS include lack of awareness, lack of CL translators (CLTs), and CLTS/Cuers are isolated from each other.

Conversation on CMV

J. Macdonald discussed the bill for mandated testing for congenital Cytomegalovirus (cCMV) at hospitals. The VA EHDI Advisory Committee (AC) was then tasked with creating a work group to legislate CMV testing. There are states with mandated education by health providers and mandated testing- universal or targeted. She also discussed who should be involved in the CMV workgroup, future impact, and costs.

If you are interested in becoming a stakeholder for the CMV workgroup, please contact the AC Chair and Co- Chair. A vote will need to held by the advisory committee to determine whether a CMV workgroup should be formed to reiew this virus and work on advocacy.

Public Comment

A greenwood motioned to create a formal workgroup to review CMV and work on advocacy. All advisory committee members voted in favor and no members opposed.

Genetics

T. Causey is a Genetics counselor at VCU. She discussed the genetics of hearing loss. She also discussed the effects of CMV on hearing loss and as well as other causes of non- genetic hearing loss. She also discussed syndromic causes of hearing loss such as Usher, Pendred, BOR and Stickler syndromes. There has been an increase in non- syndromic hearing loss. Non- syndromic Hearing loss is associated with a gene called GJB2- associated hearing loss. Genetic testing is important because gene mutations can provide information on the range of hearing loss in a patient as well as improving medical management. Parents also want to know their family history or risks for development issues. Private insurance is more likely to cover genetic testing than Medicaid.

EHDI Data Driven Improvements

D. Sanghani provided a summary of the EHDI program and the 1-3-6 process as recommended by the CDC. She also discussed the incorporation of “9” into the EHDI follow up process. Colin discussed outcomes and referrals data. He also discussed a current CDC grant deliverable on creating an interactive Virginia map that displays hearing, Part C, and referrals information.

Workgroup meetings

Audiology workgroup

Audiologists discussed testing logic for VISITS. The purpose of this logic is to determine when an AABR/ ABR is not needed for diagnostic testing.

EHDI National Meeting

The EHDI Conference presentation workgroup made final edits to the presentations that will be shared by EHDI and collaborators at the 2019 EHDI annual meeting in Chicago.

Shared Plan of Care (SPoC)

The SPoC workgroup discussed possible names for the document for parents. Some ideas were: “A Guide to Care for Children with Hearing Loss”, “A Guide for the Journey with your Child with Hearing Loss”, and “A Roadmap for the Child with Hearing Loss.” The idea of connecting the SPoC to the CDC Milestone Tracker was considered. However because CDC is a national entity, it would probably not allow a state plan to be included. Getting an app for the document may be possible in the future.

The group also discussed the Shared Plan of Care for Primary Care Providers and how to best get the information to physicians. One idea was to provide a laminated copy of what they need to do. It was decided that it would be best to ask a group of physicians from different practices and different settings if possible.

Meeting adjourned at 3:03pm.