

SUMMARY OF ADVISORY COMMITTEE MEETING

Virginia Early Hearing Detection and Intervention Program

Virginia Department of Health

June 3, 2016

Draft

The following persons attended the meeting:

Leslie Ellwood, Marcus Allen, Nancy Bond, Deana Buck, Wanda Council, Julie Durando, Christine Eubanks, Ashleigh Greenwood, Fredia Helbert, Ken Henry, Susan Neighbors, Debbie Pfeiffer, Terri Strange-Boston, Dana Yarbrough, Hollie Monroe, Shannon Mueller, Ann Hughes (on phone), Cornelia Deagle, Jennifer Macdonald, Daphne Miller, Antoinette Vaughan, Kathleen Watts, Kristen Yates, Mona Iskander

Dr. Leslie Ellwood called the meeting to order.

The November 6, 2015 meeting minutes were approved and adopted.

Introductions were done around the table. The agenda for the meeting was reviewed with the attendees. There were no additions to the agenda. The committee membership list was reviewed for updates. The Committee was reminded to complete a travel reimbursement form if necessary.

Department of Medical Assistance Services (DMAS) No update

VNOC

Provided the following update via email prior to the meeting:

For FY2016 (Oct-May): 163 calls/email requests for technical assistance were received and addressed/processed; 14 were directly from parents. Several requests resulted in direct consultations through the Virginia Network of Consultants (VNOC) described under VNOC. VNOC service requests are reported following the school year calendar, August 1 to July 31. For the 2015-16 school year, VNOC addressed 29+ service requests. Consultation requests came from school divisions across the Commonwealth. Four regional trainings were held across Virginia during the 2015-16 school years. A total of 104 people participated in Visual Phonics training during this school year. A Parent training on Visual Phonics and the Virginia Communication Plan is scheduled at VCU Audiology's Camp TALK on June 22 in Bon Air. The 10th annual ODUP (Opening Doors-Unlocking Potential) Institute is scheduled for June 30-July 1, 2016 at the Four Points Sheraton in Richmond. (ODUP Pre-session offering: *Opening Doors to Life Beyond High School* on June 29.) Go to: <https://odup2016.shutterfly.com> for complete program information and registration link.

Pn2 collaborated with Virginia to provide a 14 week online Community of Practice with 30 VA teachers of the d/hh to explore in depth the pn2 online resource called *Map It: What Comes Next*. This resource is designed for students in middle/high school to better prepare them for choosing classes during high school which will support their career goals. EHDI Advisory Committee members should be aware of VDOE's *I'm Determined* resources which can be used with very young children and continue through their school career. *Map It* works well with *I'm Determined* resources. While *Map It* and other pn2 resources are designed for older students, parents of young children are often concerned about what may be available for their children as they grow up and may appreciate being made aware of such resources for later years.

The Virginia core team attended the National Summit of Deaf Education (February 8-10, 2016) in Atlanta and presented a morning session on the *Pepnet 2-Virginia Quick Class/Community of Practice*. VNOC provided technical and content support to Irene Schmalz on updates in process of the Family Resource Guide and the ASL brochure in development.

Early Intervention

Terri Strange Boston spoke for Early Intervention. The state office is busy, working on updating the referral database.

Newborn Screening

Jennifer Macdonald spoke for Newborn Screening. She is currently working on getting contracts out. The nurse supervisor recruit has closed and we hope to be filling this position soon. We are working with the lab on reporting. Three new birth defect screens have been added by the Secretary's Advisory Committee. A NBS Dried Blood Spot Conference will take place on October 21 (CMEs and CEUs will be offered). The CCHD HRSA grant funding has ended. We are also updating the electronic birth certificate. We are working on Zika Pregnancy Registry and will be applying for a CDC grant on Microcephaly.

Virginia Hearing Aid Loan Bank

Lisa Powley provided the update via email. To date 1034 children have used devices from the loan bank since May of 2005. Soundfield systems were recently purchased through a grant from DOE. The loan period is for 3 months with the option to extend if there is no one on the waiting list. Four units were used this year by school systems. Parents and teachers have positive comments about the systems, and one school system I know purchased a system for the child next year due to his progress in the classroom with the system.

Children and Youth with Special Health Care Needs

Marcus Allen spoke for CYSHCN. The team is working on the Medical Neighborhood Project. The pilot area will be in Charlottesville. A meeting was held on May 6, 2016 in Charlottesville with community partners and stakeholders. This project was developed during an MCH Workforce training attended by the Title V state team.

Family to Family Support

Update provided via email. Family to Family Support participated in many events in May of 2016. Family to Family attended the VL2 Knowledge Festival at Gallaudet University on May 9, 2016 where they received materials about VL2 and toured VL2 lab (went with Ann Hughes). Family to Family participated in a webinar on May 18th on Described Captioned and Media Program (VSDB). Second Revisions for Virginia's Resource Guide for Families of Children with Hearing Loss were sent to the graphic designer on May 20, 2016. On May 21st, we attended the Better Resource Hearing Resource Day in Richmond, and on May 29th, we networked with 3 "Douglas" about newborn hearing screening tests in Christiansburg, VA. Additionally, we've been refining details for the ASL brochure and collecting 1-3-6 Family Educators Weekly Reporting Forms from Educators.

Upcoming events have been planned in the next few months. A home visit with a Spanish family was rescheduled for June 1st. Completed changes from the second draft for the Resource Guide and the ASL brochure are both due June 3rd, 2016. A Symposium in Pediatric Hearing Loss is being held at CHKD on June 3, 2016. Family to Family will be exhibiting at Opening Doors

Unlocking Potential 2016 on June 29th-July 1st. Finally, a follow up meeting is scheduled for the 1-3-6 Family Educators for July 20th.

VSDB

Update provided via email. VSBS Outreach Services sponsored a number of events in spring 2016 targeting educators and family members across Virginia.

Wednesday Webinars (Some of the webinars have been recorded and will also be archived for future viewing.)

- March 2, 2016 – “The ABCs of Literacy: Where to Start with Children who have Sensory Loss and Multiple Disabilities” Julie Durando, Ed.D., and Ira Padhye, M.Ed., Virginia Project for Children and Young Adults with Deaf-Blindness, Virginia Commonwealth University
- March 16, 2016 – “Working Memory: Chunks of Information”, Dr. Daniel S. Koo, Gallaudet University; focus is on children who are deaf/hard of hearing.
- April 20, 2016 – “Setting Language in Motion and Students with Cochlear Implants: Guidelines for Educational Program Planning” Terrell Clark, Ph.D., Boston Children’s Hospital, and Katie Prins McCarthy, MBA, Harvard University
- April 27, 2016 – “Unified English Braille (UEB): A Place to Start,” Donna Mayberry, M. Ed., NCUEB
- May 18, 2016 – “Described and Captioned Media Programs: More Accessible Media for 2016”, Jason Stark, Director, DCMP, Spartanburg, S.C.

Regional Activities for Students in all Virginia Schools and their Families

- April 2, 2016 and May 2, 2016 – 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. Virginia Association of Parents of Visually Impaired (VAAPVI) and the Virginia Department for the Blind and Vision Impaired, through Virginia Wildlife e-Store grant funding from Virginia Department of Game and Inland Fisheries and the Wildlife Foundation of Virginia; Richmond, VA
- April 9, 2016 - Audible Easter Egg Hunt, for children who are blind or visually impaired of all ages and their families, in collaboration with the Virginia Department for the Blind and Vision Impaired, VA AER, Hershey, and NIBCO; at VSDB campus, Staunton, VA.
- April 23, 2016 – A Paralympic Experience, open to the community, highlighting the prowess of athletes in adaptive sports and allowing able-bodied counterparts to experience Paralympic activities firsthand. Sponsored in collaboration with Sportable of Richmond, VA, Mary Baldwin College, and Wilson Workforce Rehabilitation Center.
- May 21, 2016 - Science with Jefferson Labs for students grades 4 – 8 who are deaf or hard of hearing using any communication method. In collaboration with Thomas Jefferson National Accelerator Facility Education Services. Instructor: Brita Hampton. Afternoon demonstration by VA Department for the Deaf and Hard of Hearing of their Technical Assistance Program (TAP) equipment for families; at VSDB campus, Staunton, VA.

- Coming June 18, 2016 – Where the Wild Things Are, for regional students who are deaf/hard of hearing and/or blind/visually impaired and their families, featuring the Wildlife Center of Virginia educators and rescued animals; on VSDB campus.

Live Trainings

- March 9 – 10, 2016 - Kay Ferrell, Ph.D., Professor Emerita, University of Northern Colorado; provided the keynote address and a concurrent session at the VA AER conference; sponsored in collaboration with the Virginia Project for Children and Young Adults with Deaf-Blindness.
- March 14, 2016 – Looking Beyond Vision: Early Development, Assessment, and Interventions for Young Children with Visual Impairment, presented by renowned author, Kay Ferrell, Ph.D., Professor Emerita, University of Northern Colorado for Early Intervention (Part C) providers; sponsored in collaboration with the Virginia Project for Children and Young Adults with Deaf-Blindness; and Part C; at VSDB campus, Staunton.
- April 5, 2016 – A Sensory Experience: Partnering with Families with Deafness and Blindness, Virginia Headstart Association (VAHSA) Annual State Conference, Julie Durando, Ed.D., and Debbie Pfeiffer, Ed.D.

Online Training/Videos (to be archived; in final stages of editing/captioning/voice overs)

- “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.
- “LSLS Minutes” – brief presentations explaining strategies for use in developing listening and spoken language skills, with embedded videos that demonstrate application. Dr. Lori Bobsin, University of Virginia (coming soon to www.ttaonline.org)
- “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.

Department of Education

Update provided by Wanda Council.

- December 2015 State/Federal Special Education Child Count
 - Hearing Impairment Total 2,255
 - Hearing Impairment Primary (2-21) 1,511
 - Hearing Impairment Primary (2-5) 163
 - Deaf-Blindness Total 32

The reauthorized Elementary & Secondary Education Act-Every Student Succeeds Act (ESSA) was enacted to replace “No Child Left Behind”. Revisions to the current IDEA regulations are forthcoming. The U.S. Department of Education recognizes VDOE for leadership in improving outcomes for students with disabilities. VDOE earned the USED’s highest rating for results, compliance, dispute resolution and fiscal management. In 2015-16, the VDOE Office of Special Education Program Improvement conducted on site Results Driven Accountability (RDA) monitoring reviews focused on compliance and performance outcomes for students with

disabilities. VDOE continues its collaboration with state partners and provides grant funding to support specific programs serving students who are deaf or hard of hearing (PreK-12). These collaborations and programs include: Educational Interpreter Professional Development, Technical Assistance Center for Deaf and Hard of Hearing /Virginia Network of Consultants, VA Deaf-Blind Project, VA Department for the Deaf and Hard of Hearing, VA Hearing Aid Loan Bank, VA School for the Deaf and the Blind, and VA School for the Deaf and the Blind Outreach Services.

Deaf Blind Project

Julie Durando spoke for DBP. The annual census has been completed. Have identified children however would like to identify children earlier.

Partnership for People w/ Disabilities

Dana Yarbrough provided the update. Meeting was also attended by two of the 1-3-6 Family Educators. The family educators are working to decrease the loss to follow-up.

For February through May, 2016:

We provided 1:1 enhanced emotional, informational, and systems navigational support to 147 families and 17 professionals. 13 of these families were referrals for young children with hearing loss. Of the total families:

- 57% Caucasian 26% black 8% Hispanic 3% Asian 6% Other/Unknown
- 59% autism 17% ADHD 6% Deaf/Hard of Hearing 6% Blind/Visually Impaired 3% Intellectual Disabilities 3% Developmental Delay 3% Mental Health 3% Multiple Disabilities

Another 2,208 parents and professionals participated in one of 36 events (our trainings or vendor table at a community resource fair). We distributed 9,135 products (see sample family audiologist visit postcard). Three parents were contracted with (NOVA, Blue Ridge, and Tidewater) to conduct visits with birthing hospital newborn hearing screening coordinators/teams. Results from 5 hospitals are being reviewed. Audiologist visits are being scheduled. We provided training on cultural agility to 45 health care, education and human service personnel. We participated on the VDH Medical Neighborhood initiative (including two meetings with Va AAP PreSip2 project staff). We attended a Family to Family Health Information Center meeting at MCHB; the AMCHP conference in Washington DC; EHDI conference in San Diego; and NYMAC genetics advisory council meeting in Baltimore.

Title V Updates

Dr. Cornelia Deagle provided the update. Currently working on the annual report for 2015 and writing for 2017 funding, due July 15 (level funding is expected). The state team will meet with the reviewers in August. We are partnering with AAP chapter and PreSIP2 on the Medical Neighborhood.

EHDI By-laws

The By-laws were reviewed by the Committee. Vote on By-laws with revisions passed.

Election of Committee Chair

Ashleigh Greenwood was elected Chair of the EHDI Advisory Committee. Christine Eubanks was elected Co-chair of the EHDI Advisory Committee

Dr. Leslie Ellwood was presented with a plaque for his years of service as the Committee Chair

Public Comment

There was no public comment

EHDI Updates

Daphne Miller provided an update on the 2014 data. Kristen Yates joined the EHDI team on March 22 as a follow-up specialist. EHDI currently has a new wage follow-up position in recruit with a closing date of June 15. The CDC grant was submitted on May 27, 2016. The team is currently working on the logic for VISITS and rewriting letters for follow-up. The team is currently providing one on one VISITS training to hospital users to improve reporting and to help decrease the technical assistance calls.

The EHDI team is working on developing a regional approach to the program. Initially, each region will have one contact person who all hospitals, audiologists and other stakeholders will call with questions or concerns. That person will also provide the education and training for that region. This involves a lot of training among the staff, so that everyone is familiar enough with all the 1-3-6 and VISITS protocols to be of assistance to their region.

QILT

There are several exciting PDSAs. The PDSA on making letters more family friendly showed that changing the color of paper used for the letters did not lead to an improvement in follow-up. The next change in the PDSA cycle is to have a different logo on the envelope, which is not as official. The logo has been designed and the envelopes were recently ordered. These will initially be used for parent letters when a rescreen is needed.

VEHDI has been working with CDC and EHDI-PALS on two projects. The first involves providing a flyer (attached) to parents whose babies need follow-up. The flyer is being tested at Henrico Doctors' Hospital, where the hearing screening staff was unfamiliar with EHDI-PALS until a recent site visit. They have copies of the flyer and will add it to the information provided whenever a baby does not pass the hearing screen. UVA will also be asked to use the flyer, because they have many babies who are born there who are not from the immediate area. They believe their loss to follow-up is those babies who live too far to return for rescreens or diagnostics at their facility. Information about EHDI-PALS would provide a way for parents to find a convenient audiology facility for the needed follow-up.

The other project being undertaken in collaboration between VEHDI and EHDI-PALS is the EHDI-PALS App. This computer application was designed to assist parents whose children need follow-up from the time the baby does not pass the hearing screening in the hospital until follow-up is completed. The nurse in the hospital will provide information to the family on how to download the app. Once the app is on the family's Android or iPhone, it will remind parents of upcoming appointments and ask them about outcomes of testing until the child either passes or is enrolled in early intervention. VEHDI will be a pilot state for the app when it is completed, which is expected to be sometime later this month.

EHDI Workgroup Updates (PCP) Protocols:

Documents were provided for Committee review. Any comments should be made directly to Dr. Ellwood or Kathleen Watts.

Annual EHDI Meeting Update

At the National Meeting Daphne Miller attended a session on using texting in EHDI follow-up. Since the meeting, VEHDI and several other EHDI programs have had a conference call with Iowa, where they have been using texting for a few months. The Iowa program provided several tips, including talking with the health department attorney at the beginning of the project to ensure that all regulations are being met and all messages meet HIPAA and health department standards. Texting will be done in one region of the state with comparisons to follow-up in other regions and to that region prior to texting.

Irene attended the session “Understanding the Response of Parents to Newborn Hearing Screening” by Dr. Robert Nutt. He emphasized that speech and language are most influential during the first three years. According to Dr. Nutt, "Over reassurance" is why we have loss to follow-up today.

Dr. Ellwood adjourned the meeting.

Next Meeting Sept 9th