

Virginia EHDI Program Advisory Committee Meeting
Friday, December 2, 2016
Meeting Minutes
Draft

The following persons attended the meeting: Valerie Abbott, Marcus Allen, Judy Alonzi, Nancy Bond, Wanda Council, Christin Crews, Shamaree Cromartie, Julie Durando, Leslie Ellwood, Christine Eubanks, Jackie Figgs, Ashleigh Greenwood, Catherine Hancock (representing Terri Strange-Boston), Beth Hopkins, Ann Hughes, Mona Iskander, Debi Leekoff, Valerie Luther, Jennifer Macdonald, Daphne Miller, Shannon Mueller, Beth Musser, Susan Neighbors, Debbie Pfeiffer, James Pickrul, Eric Raff, Deepali Sanghani, Irene Schmalz, Antoinette Vaughan, Kathleen Watts, Kristen Yates. Lisa Powley, Casey Morehouse, and Cornelia Deagle joined by conference call.

Dr. Ashleigh Greenwood called the meeting to order.

Participants introduced themselves. The meeting agenda was reviewed; no additional agenda items were added. The committee membership list was reviewed and circulated for updates. Committee members and interested parties were reminded to complete travel reimbursement forms if necessary.

The June 3, 2016 meeting minutes were approved and adopted.

EHDI Updates

Daphne Miller spoke on EHDI updates. The EHDI team applied for the HRSA grant to start in 2017, which concentrates on family involvement, care coordination, and early intervention. The newly updated Can Your Baby Hear Brochure was passed around. Two new follow up specialists were introduced: Deepali Sanghani and Kristen Yates. The VA EHDI team is currently recruiting a follow up coordinator. All 26 letters VEHDIP sends to parents and physicians were revised, and EHDI is hoping to enact a VISITS system change so that the letters are generated automatically. The team is moving towards a regional approach with a team member taking a region to aid in a personalized follow up with hospitals, audiologists, and EI in that region. VEHDIP is planning to update the policy and procedures for VISITS users. Daphne attended the New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC) conference with Jennifer Macdonald and Christen Crews. . Virginia is one of the few states with a procedure in place to collect genetic consult information. The National EHDI annual meeting is going to be held in Atlanta, GA on February 26-28, 2017, and the new grant includes a stipend for a parent to attend the conference. Additionally, VA EHDI submitted an abstract on risk factors to the National EHDI conference and it has been accepted.

Title V

Cornelia Deagle spoke for Title V. Title V is in year 2 of a 5 year cycle, and the team is planning regarding budget reductions. There is a meeting on 12/8/16 concerning the medical neighborhood pilot in Charlottesville. There was a perinatal council that was defunded in 2012, but a new model is being consider for working with hospitals, in which follow up in EHDI would play a part.

Department of Medical Assistance Services (DMAS): No update

VNOC

Anne Hughes provided the update via email prior to the meeting.

Technical assistance and support: For FY2016 (June-Sept)/FY17 (Oct-Nov): 77/46 calls/email requests for technical assistance were received and addressed/processed; 16/8 were directly from parents. Several requests resulted in direct consultations through the Virginia Network of Consultants (VNOC) described under VNOC. 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 2015-16 school year, VNOC addressed 27 service requests. For the 2016-17 academic year to date, VNOC has processed 14 consultation requests all from school divisions across the Commonwealth.

Regional Trainings: *See-the-Sound Visual Phonics* (Decoding strategy for early reading skill development) A Parent training on See-the-Sound Visual Phonics and the Virginia Communication Plan occurred at VCU Audiology's Camp TALK on June 22, 2016 in Bon Air/Richmond (27 parents/family members). Three regional SSTS-VP trainings have been held to date for the 2016-17 school year (99 participants). From 2006-present, more than 1,450 people have received training in STS Visual Phonics through TAC-DHH/VNOC sponsored trainings. VNOC provided an additional staff development for educational interpreters to one school division to date.

Statewide Professional Development: *Opening Doors-Unlocking Potential 2016: Practical Assessments, Interventions and Resources*: The 10th annual ODUP Institute was held June 30-July 1, 2016 at the Four Points Sheraton in Richmond (105 participants). The ODUP Pre-session offering: *Opening Doors to Life Beyond High School* on June 29 was attended by 40 participants: 27 professionals, 9 parents and 4 students.

June 28-30, 2017: Save-the-Dates for ODUP2017: Effectively Serving Students Who are D/HH PLUS and OD2LBHS at the DoubleTree by Hilton Richmond-Midlothian, VA.

www.odup2017.shutterfly.com

Program Support: Technical and content support provided for revision of the Family Resource Guide and development of the ASL Resources brochure.

Ann Hughes also would like to express a call to action from an article titled: [EHDI Bill Likely to Die Unless It Moves Forward Now](#)

AG Bell members and friends. Please take a few moments to use [this tool](#) to write to your U.S. Senators TODAY! Early Hearing Detection and Intervention (EHDI) Programs have a pivotal role in making sure hearing loss is identified early in babies and funding is threatened. There has been great energy and effort by many in support of passing S 2424. However, this legislation is stalling and your help is needed NOW.

[Take Action](#)

Early Intervention

Terri Strange Boston provided the update via email prior to the meeting.

The vision for infants and toddlers who are diagnosed with hearing loss in Virginia is to have sufficient numbers of Part C early intervention providers available to work with families to reach all of their IFSP Family and Child Outcomes, especially as it relates to language development

(signed or spoken language). The following strategies would increase the number of providers available:

- Approval of tele-practice, so that providers can be available to families no matter where they live. DMAS will need to be involved in this decision;
- Increasing the numbers of EI certified providers who are fluent in ASL and perhaps certified as EI specialists, if they do not meet the EI Professional certification qualifications;
- Increasing the numbers of EI certified providers who are trained and experienced in listening spoken language development;
- Identifying an agency/local provider group that would be willing to contract with providers statewide, resulting in providers being available when a diagnoses and referral are made;
- An online database (license Look-Up for certified EI providers) that can be accessed by Part C local lead agencies when babies are diagnosed and referred to them.

As of today, 11/28/16, there are: 161 Infants/Toddlers diagnosed with hearing loss with active IFSPs and receiving Part C EI services in Virginia; and 26 Licensed Teachers of the Deaf & certified EI Professionals in Virginia.

Newborn Screening

Christen Crews provided the update via email prior to the meeting. Newborn screening employed a nurse supervisor, Christen Crews, in July to directly oversee Dried Blood Spot and Critical Congenital Heart Disease (CCHD) programs. Recent changes in the program include upgrading the Laboratory Information Management Systems (LIMS) for more timely reporting. This year marked the 50 year anniversary of newborn screening in Virginia and outreach activities highlighting this occasion included a booth at the Virginia State Fair and an inaugural statewide educational conference with attendees including nurses, metabolic specialists, genetic counselors, physicians, scientists, as well as individuals and families affected by newborn screening. Dried Blood Spot program will be reviewing the addition of 3 additional disorders to the panel in 2017. The CCHD program has recently expanded its reporting on the electronic birth certificate to include more detailed CCHD screening results and intervention for improved quality assurance.

Virginia Hearing Aid Loan Bank

Lisa Powley provided the update via email prior to the meeting. Almost 1100, (1094) children have used the loan bank since 2005. The average loan period is 36 weeks. There are three schools systems currently using the sound fields. Operational budget was approved from VDH and the devices budget was renewed by DOE, thanks Jennifer MacDonald, Daphne Miller and Wanda Council. Sandra Woodward and I met with Daphne, Deepali and Jennifer in November and are looking at a few ways that we may be able to save some money for the program. This may enable us to purchase additional devices or additional items. The total hearing aids loaned since 2005 is 1072, with a total of 77 hearing aids loaned from January to September 2016.

Children with Special Health Care Needs

Marcus Allen provided the update via email prior to the meeting. The CYSHCN program hired a new staff person. Her name is Shamaree Cromartie and she will be responsible for our blood

disorders program. This includes sickle cell and hemophilia. We are moving forward with our Medical Neighborhood initiative in the Blue Ridge area. The goal is for service providers in that region to work together on issues that impact CYSHCN and children in general (eventually). Our first project will be to create medical home and transition training modules for providers and families to access online.

Family to Family

Dana Yarbrough and Irene Schmalz provided the update via email prior to the meeting. Since June 2016

- Three 1-3-6 Family Educators (Fairfax, Charlottesville and Hampton areas) brought on in February conducted 14 site visits between June and November to survey hospitals (N=7) and audiologists (N=7) to learn more about their communication with families whose infant needs to have hearing rescreened.
- We are now sending surveys to the visited sites to gage their satisfaction with a visit from a 1-3-6 Family Educator. 4 have responded so far (28% response rate) and all indicated strong agreement that the purpose of the visit was clear, that the products provided were helpful; and that having a 1-3-6 Family Educator who is a parent of a child with hearing loss conduct a site visit helped them understand or see things from a different perspective.
- Three additional 1-3-6 Family Educators (Buchanan, Henrico, Prince George) were brought on in October bringing our total to 6 1-3-6 Family Educators.
- Two 5 hour face to face 1-3-6 Family Educator trainings were held (July and October) to review the role of 1-3-6 Family Educators and how to conduct site visits. The 1-3-6 Family Educator's also attended a Family to Family Network family navigator training in November to learn their role in providing 1:1 emotional, informational and systems navigational support.
- 49 families were referred to Irene Schmalz for parent to parent support: The trend is changing in terms of how parents would like to be contacted – there were more that would rather be connected by emails. Another interesting fact is the number of babies identified with auditory neuropathy – since June there were 5 babies.
- Presentation: We are pleased to announce that the proposal has been accepted at the national EHDI conference in February. The 55-minute workshop will be on our 'use' of parents as an intervention for loss to follow- up.

Partnership for People w/Disabilities

Dana Yarbrough provided the update via email prior to the meeting. - 6 parents are serving as 1-3-6 Family Educators under a VDH contract to VCU. We now cover far southwest, piedmont, central VA, northern VA, Richmond metro area, and tidewater. Several products have been developed for families, hospital, audiology clinics such as a poster for family to family support; postcard to list audiology follow up appt; ASL resources brochure; and the resource guide for families. A proposal to present for an hour on the 1-3-6 model was accepted for the EHDI conference in Atlanta. We are waiting to hear back from AMCHP on a similar conference proposal. The Partnership received a grant to start a diversity fellows program. A doctoral student will participate in a 9 month fellowship program each year conducting a capstone project on the intersection between disability and diversity (race, ethnicity, gender identity, etc). The first fellow will be on board in February and will conduct research on the Center for Family

Involvement's cultural broker model. Dana Yarbrough is working with VDH on a medical neighborhood initiative that will promote quality medical homes for families with children with disabilities and/or special health care needs

VSDB

Debbie Pfeiffer provided the update via email prior to the meeting.

Wednesday Webinars

September 28, 2016 – Working Memory of Children Who are Deaf/HH, Part II: Strategies for the Classroom and Home, Johnett Scogins, Curriculum Supervisor, Texas School for the Deaf

October 12, 2016 - Evidence-Based Strategies for Teaching Listening and Spoken Language Skills to Preschoolers, Janet Knust and Dr. Sharon Raver Lampman, ODU (will repeat Nov. 30, 2016, due to popular demand!)

Regional Activities for Students in all Virginia Schools and their Families

October 8, 2016 - Science Day with Jefferson Lab, 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 and Stafford County Public Schools. Instructor: Brita Hampton. This event will be held in Stafford County.

November 5, 2016 - Science Day with Jefferson Lab, 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 and Radford University. Instructor: Brita Hampton. This event will be held at Radford University.

Live Trainings: *Sensing the Needs of Children Birth through Pre-K: The Basics of Assessments & Strategies for Young Children with Vision &/or Hearing Loss*, for early childhood special educators, early intervention educators, and related service providers working with children birth to 5. Each participant attends two sessions and a webinar. Sponsored in collaboration with the Project for Children and Young Adults with Deaf-Blindness, Virginia Department for the Blind and Vision Impaired, and Part C.

Location:	Session 1	and	Session 2:
Abingdon	7/18/16		9/13/16
Staunton	7/19/16		9/14/16
Hampton	8/16/16		9/19/16
Fredericksburg	8/18/16		9/20/16

Department of Education

Wanda Council provided the update at the meeting. Due to state and federal budget cuts, special education grant funding was reduced for 2016-17. VDOE continues to provide grant funding to support centers/programs for children who are deaf/hard of hearing:

- Educational Interpreter Professional Development
- Technical Assistance Center for Children Who Are Deaf/Hard of Hearing
- 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
- VA School for the Deaf and the Blind Outreach Services

- § Beginning July 1, 2017, dyslexia awareness training will be required for all initial and renewed licensure through the VA Board of Education. An online awareness level training module is being developed. Kim Bausum-Brown is the new VDOE Dyslexia and Specialized Reading Specialist.
- § The VDOE *Guidelines for Working with Students Who Are Deaf or Hard of Hearing in Virginia Public Schools* document is being updated during the 2016-2017 school year.
- § The grant funding cycle for Pepnet 2 (Pn2) ended on September 30. The new federal grant was awarded to the University of Texas for the National Deaf Center on Postsecondary Outcomes, which will begin on January 1, 2017.

Deaf-Blind Project

Julie Durando spoke for DBP. DBP is getting ready for the child count census from birth to age 22. DBP is working on providing services and training to EI providers to get communication access from birth and to help parents communicate with children.

Virginia Hands & Voices

Valerie Abbott provided the update via email prior to the meeting. In September, Valerie Abbott (parent) attended the annual Hands & Voices Leadership Conference in Colorado. Her objective was to learn more about the organization and meet with chapters who had rebuilt themselves. She met and spoke with leaders from Michigan and Vermont as well as leaders from New Jersey, Connecticut, and several others. Since then, Valerie has met with Casey Morehouse and Ann Hughes to determine how best to rebuild the Virginia Chapter. In October, Valerie learned that the president of the Vermont Hands & Voices Chapter (Teri Urban) was relocating to Central Virginia with her family and that Teri was eager to serve our chapter as Chair in 2017. Two other former board members, Rachel Hockman and Amber Tyree, have also stepped up with offers to serve on the board. Casey, Valerie and Teri Urban have been exchanging emails and phone calls to refine the plans to rebuild the board in 2017. An email from Ann Hughes about Virginia Hands & Voices has resulted in 20 families across Virginia raising their hands to help rebuild the chapter and a preliminary meeting has been set for Wednesday, December 7 at 7:00pm via conference call. Hands & Voices Headquarters staff has been very supportive of the efforts made and will continue to help re-establish a presence in Virginia.

Virginia Department for the Deaf and Hard of Hearing

Eric Raff provided the update via email prior to the meeting.

Social Media – VDDHH is improving its' social media/internet presence. The VDDHH has overhauled its' website, active Facebook account, and a new YouTube account. VDDHH will be releasing a revised Virginia Relay website.

Advisory Board/Committee - VDDHH has two advisory boards, the Virginia Relay Advisory Committee (VDDHH-appointed) and the VDDHH Advisory Board (Governor-appointed). Both meetings are open to the public. VDDHH is always looking for deaf, hard of hearing, deaf-blind and speech disabled and hearing relay constituents as well as parents and professionals to serve on both boards. The 9-member Advisory Board is currently full.

Legislation – VDDHH is anticipating a legislative bill during the 2017 General Assembly addressing deaf children's language acquisition. A group of 3 deaf women has been advocating for a bill to test age 0-5 deaf children to monitor their language development and promote that

they have a language by kindergarten. The intent is to test in English and/or American Sign Language. (Copies of a handout from the group will be available).

EHDI Protocols Review

The EHDI Protocol for Primary Healthcare Providers was reviewed. Documents were provided for Committee review. Any comments should be made directly to Dr. Ellwood or Kathleen Watts.

EHDI Family Stories

Valerie Abbot gave a presentation: Beyond Our Imagination. This presentation was a discussion into the hearing journey of the diagnosis of hearing loss in her youngest daughter.

Deepali Sanghani followed by showing a video presentation, “Nobody Suspected”.

(<http://www.infanthearing.org/videos/ehdi/nichq-nobody-suspected.php>)

The journey a parent of a child with hearing loss goes through is not always black and white. Sometimes a hearing loss diagnosis is very easy to spot when a parent notices cues that their child does not respond to their voice or surrounding sounds. However, often there are cases when the children will respond to visual cues or vibrations of sounds. These children are often difficult to diagnose. This video is an example of a parent who never suspected her children of having a hearing loss diagnosis because they responded to vibrations in sounds and visual cues.

Ultimately, the key with hearing loss is to have timely diagnosis to allow the child to have the ability to have excellent literacy abilities and language acquisition skills.

QILT

The Quality Improvement Leadership Team met during lunch. Current PDSAs were discussed, and ideas generated for further quality improvement activities.

Public Comment

There was no public comment.

Follow Up with Pass with Risk

Dr. K. Dodson gave a presentation on follow up for children with pass with risk results. With the goal to improve follow up rates for children with risk factors, data was analyzed concerning babies born between the years 2010-2012. 21,000 out of 50,000 babies requiring follow up had a pass with risk result. Syndromes and craniofacial anomalies were the risk factors most likely associated with hearing loss. Her team wants to work with EHDI to aid in follow up, possibly through letters sent, mandates, or other legislation.

Risk Factor Analysis

Beth Musser gave a presentation on risk factors from data analyzed between 2009-2015. Over this timeframe, 32,695 babies passed with risk with 257 diagnosed with hearing loss. Children pass with risk account for 24.4% of all children diagnosed with hearing loss. Out of 257ss children diagnosed with hearing l, 144 children had a neonatal indicator. Based on in depth analysis, follow up could be based on a tier system, as being developed by Boston’s Children Hospital, where there is an individualized protocol for each tier in terms of follow up time and procedure. Problems that Virginia faces in adding additional follow up procedures include needing more pediatric audiologists, equipment, and staffing.

CMV Update

Antoinette Vaughan presented on what she had learned at the CMV conference in September. CMV is the leading non genetic cause of sensorineural hearing loss. Babies can be tested for CMV via urine or saliva in the first 21 days, and a question to contemplate is if babies should be universally screened. Currently, only six states have CMV legislation in newborn screening.

Zika Update

Jennifer Macdonald presented a Zika update. Zika is spread via mosquitos. One in five people infected get sick. There are 91 total cases in Virginia. There is no treatment but they are trying to develop a vaccine. Prevention is the main course of action to fight infection. There is causal evidence of Zika causing birth defects like microcephaly. There is testing available for pregnant women traveling to infected areas within 12 weeks of travel. A CDC “Assessment of infant hearing for infants testing positive for Zika virus infection” was handed out, with recommendations on follow up for infant hearing.

VISITS Surveys

Colin Berusa and Kristen Yates gave a presentation on the audiology and hospital VISITS user trainings held in September concerning reporting, updates, and enhancements. Pre and post surveys were given and analyzed for change in knowledge and confidence in using the VISITS enhancements as required by the CDC grant. Most hospital users showed an increase in confidence levels and learned about new features. The audiology surveys are still being gathered and analyzed.

EHDI Next Steps

Topics for next meeting were discussed. These include the presentation of hospital protocol revisions, General Assembly updates, EHDI updates, Zika update, HRSA grant and the learning community development, and an EHDI conference update. The next advisory committee meetings are tentatively March 3, 2017; June 2, 2017; September 1, 2017; and December 1, 2017.

Dr. Ashleigh Greenwood adjourned the meeting at 3:00pm.