

**Virginia EHDI Program Advisory Committee Meeting**  
**Friday, November 6, 2015**  
**Meeting Minutes**

The following persons attended the meeting: Nancy Bond, Christin Crews (for Marcus Allen), Cornelia Deagle, Julie Durando, Leslie Ellwood, Christine Eubanks, J. Gossimer (guest, Pediatrix Corporate), Ashleigh Greenwood, Catherine Hancock, Ann Hughes, Claire Jacobsen, Jennifer Macdonald, Casey Moorehouse, Mary Lib Morgan, Beth Musser, Ira Padhye (guest, Virginia Deaf Blind Project), Debbie Pfeiffer, Irene Schmalz, Terri Strange-Boston, Antoinette Vaughan, Kathleen Watts, Jill Young. Two doctoral candidates from JMU attending the meeting were: Lisa Powley joined by conference call.

Dr. Leslie Ellwood called the meeting to order at 9:15 a.m.

The May 8, 2015 meeting minutes were approved and adopted.

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.

### **Early Intervention**

Terri Strange-Boston spoke for EI. Current EI enrollment of infants who are deaf or hard of hearing is 249. A recent EI goal is to increase the number of EI teachers who work with deaf and hard of hearing children. There have been five new teachers across Virginia in the last five years. A letter which invites greater participation in certification for speech pathologists and teachers for the deaf and hard of hearing has been distributed across the Commonwealth. It targets educational specialists and various agencies serving the deaf and hard of hearing population. VISITS does not accurately reflect the number of infants and children in early intervention due to FERPA limitations. EHDI and EI are working together regarding referred and enrolled babies. EI requested a new report where they can see all children referred to EI from VISITS. A team comprised of representatives from EI, EHDI, and D/HH will meet quarterly to facilitate greater coordination of EI and EHDI service.

### **Newborn Screening**

Jen Macdonald spoke for Newborn Screening, which includes dry blood spot, Chronic Congenital Heart Disease, and EHDI. Severe Combined Immunodeficiency (SCID) was recently added as a newborn screening. An estimate of 3-4 births out of 100,000 are SCID births. A newborn screening training contract through UVA is now available for Virginia residents. There is a new midwife initiative for CCHD screening for the vulnerable. There was discussion related to hearing loss as it relates to sickle cell disease. Onset of hearing loss in adults with sickle cell is more prevalent than hearing loss in children due to sickle cell. The adult onset of loss would be addressed and care would be facilitated through the medical home.

### **Hearing Aid Loan Bank**

Lisa Powley spoke for HALB. She reported that 985 children have used devices from the loan bank since May 2005. For FY16Q1, 29 children have been served through the loan bank. 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 waiting list. Currently, 2 units are being used by preschoolers. Both parents are very pleased with their child's progress in school.

### **Children and Youth with Special Health Care Needs**

Christen Crews spoke for Marcus Allen, who was unable to attend. Care Connection for Children (CCC), Child Development Centers (CDC), Pediatric Comprehensive Sickle Cell Centers, and Virginia Bleeding Disorder Program provide services for children and youth with special health care needs. CDC and CCC are currently being evaluated; current program services and outreach efforts are being analyzed. A CCC study looking at DMAS reimbursement examines the impact of expansion of outreach. A VCU grant application is being completed. If awarded the grant, four regular pediatric sickle cell centers and adult sickle cell centers would partner, expanding service ages at the centers to 18 to 35 year olds. In conjunction with Virginia Blood Services, VDH would run a mobile van to provide services for underserved areas. The AMCHP medical neighborhood model would be followed; a provider toolkit would be created for additional reimbursement. Dr. Christine Eubanks commented about the incidence of hearing loss in adults with sickle cell. She recommended that CYSHCN consider adding this information to its sickle cell outreach services.

### **Family to Family**

Irene Schmalz spoke for Family to Family. Irene reviewed the purpose of the HRSA grant around parent education through consultation with hearing specialists who also parent young children who are deaf or hard of hearing. She distributed a flyer announcing the need for hearing specialists in five regions across the state. Hearing specialists will be trained in the EHDI process and in mentoring parents without bias. They will assist parents in accessing resources and learning about the EI process in their regions. This could indirectly impact loss to follow up as parents who learn about EHDI and regional resources will be encouraged to share the same information with other parents with infants who are deaf or hard of hearing. It was asked if VA Cares and VISITS could be coordinated electronically so that parents of children with special needs could be targeted in Family to Family outreach efforts.

### **Hands and Voices**

Casey Morehouse spoke for Ms. Vincent-Clarke. She indicated that Hands and Voices is currently seeking a nonprofit status and that further developments will be shared in the future.

### **Virginia School for the Deaf and Blind**

Casey Morehouse and Debbie Pfeiffer spoke for VSDB. Budget cuts will reduce the level of audiological services in the summer. The parent-infant program will be reduced to part-time services. Services will be contracted out to Part C agencies. There are expanded outreach services funded through early childhood support from DOE. TTAC centers located at GMU, JMU, ODU, VA Tech, and VCU provide staff for consultation and training of educators, a

lending library for educators and families addressing the needs of the deaf, blind, and deaf/blind population. Online training series of Family American Sign Language brief lessons providing ideas for use in normal daily routines of infants and toddlers are being edited, voiced over in English and Spanish, and will be online soon. Language and Listening and Spoken Language Skills brief presentations explaining strategies for use in developing listening and spoken language skills. Embedded videos show parents and caretakers the application of the lessons. Dr. Lori Bobsin, a UVA cochlear implant specialist has developed 9 Listening/Spoken Language “just in time” minutes – brief videos to assist parents and caretakers in developing language skills. Wednesday Webinars feature evidence-based best practices for students who are deaf, hard of hearing, blind or deaf/blind. Live trainings from August through November feature the Fairview Reading Program, Haptics Awareness, technology, and science for students in grades 4 – 8. Deaf/blind, deaf, hard of hearing, and blind children in rural areas will be brought together with their families in a networking effort on November 14. This will reduce the level of isolation felt by these children and families when they are alone in their communities. Outreach information can be found on the VSDB webpage by visiting the home page, [www.vsdb.k12.va.us](http://www.vsdb.k12.va.us), and at the left side choosing “outreach”. Debbie thanked Ann Hughes for the opportunity to participate in Opening Doors/Unlocking Potential during the summer. This past year’s focus was on older adolescents.

### **Department of Education**

Wanda Council could not attend the meeting, but submitted this report:

Dr. Dawn Hendricks is the new VDOE Specialist for Early Childhood Special Education. Her email address is [dawn.hendricks@doe.virginia.gov](mailto:dawn.hendricks@doe.virginia.gov). State/Federal December 1 Child Count – indicators for preschool children are Early Childhood Settings (indicator 6), Preschool Skills Outcomes (indicator 7), Part C to Part B Transition (indicator 12). Grant funding supports programs serving students who are D/HH from PreK to 12 such as Educations Interpreter Professional Development Month, TTAC & VNOC, VDDHH, VHALB, VSDB, and VSDB Outreach Services. November is Family Involvement Month: Contact [Gloria.dalton@doe.virginia.gov](mailto:Gloria.dalton@doe.virginia.gov) for more information.

### **Deaf-Blind Project**

Julie Durando spoke for the Deaf-Blind Project. The focus is on early identification and referrals for children and young adults who are birth to 22 year olds. The project works with providers, facilitating online training modules, on-site coaching. One project goal is to increase awareness of the impact of dual sensory impairments across schools and communities. A tool being developed will increase the capacity to educate people in the community.

### **Partnership for People with Disabilities**

Julie Durando spoke for PFPD, which is celebrating its 30<sup>th</sup> anniversary. She indicated this organization serves individuals and the community by providing a variety of tools and resources to be used across the lifespan.

### **VDH & EHDI Updates**

Cornelia Deagle spoke for VDH, announcing that Dr. Lillian Peake has been promoted to Deputy Commissioner for Population Health. Data Systems transition from the ICD9 to ICD 10 code has been completed, thanks to Chris Hill and Beth Musser. Steve Vecchione will present the EHDI

budget, reviewing the CDC and HRSA budgets at the next meeting. Dr. Deagle is the new manager for Title V programming. Mary Lib indicated that the EHDI program is near full staffing, reviewing current staff and positions and announcing that a new wage position was recently approved. Beth Musser presented rough data for January – December 2014 and indicated that geospatial data will be presented at the next meeting. The slide presentation is attached for review. There was a question about barriers to recruitment of pediatric audiologists to provide services in remote areas in Virginia. Suggested barriers included training and travel. Kathleen provided a QILT update, summarizing the first meeting where participants learned they would be focusing on the development of PDSAs that would range from easy to difficult, quick to implement to those which would require more effort. PDSAs will be internal to VDH as well as external, focusing on process improvements in the hospitals and audiologists' offices. One PDSA implemented recently was a new report form for audiologists, since there are several different forms which feature data entry information that is located in a variety of places on these forms. The new form is now available and will be posted online when the website updates are complete. Communicate with Your Child brochure is being sent out to audiologists. It includes a variety of Virginia resources. Other PDSAs include obtaining email addresses for parent contact in VISITS and developing EHDI PALS postcards. The second QILT meeting will convene today at 1:00. An update on social media by Mary Lib and Dr. Deagle summarized the VDH commitment to quality and consistency in messaging from new OFHS social media outreach policies. Several committee members and interested parties expressed concern regarding frequently used resources. They were assured that the EHDI webpage would be linked to in all EHDI-related Facebook postings and other social media posts.

### **Virginia Network of Consultants Professionals Working with Children who are Deaf or Hard of Hearing**

Ann Hughes spoke for VNOC. She summarized June 2015's Opening Doors, Unlocking Potential and connected gains in early intervention to greater academic, social, and career opportunity promises for adolescents and young adults. The 2016 pre-session of Opening Doors, Unlocking Potential will be held June 29. June 30 and July 1 will include many technical sessions. In FY15, 220 calls and emails were processed; resource and training information was disseminated 165 times. This includes 89 parent contacts through requests from TA-D/HH Project, DOE, and other agencies, 144 inquiries, 133 of which were parent inquiries. Total dissemination of information count: 74,078. 9,457 of these were to parents. VNOC addressed more than 32 service requests from schools across the Commonwealth. Participant count in See-the-Sound Visual Phonics during 2014-2015 school year: 122. Three trainings have been scheduled for the 2015-2016 school year. Virginia professional development is focusing on transition-age students.

### **Protocol Update Workgroups**

At the conclusion of the program updates and relevant discussion, EHDI staff introduced the need for updating audiology, hospital, and PCP protocols. A brief discussion followed and a list for each group was passed around the room for sign-up to chair or participate on the committees. Each work group included a member of EHDI staff for support. Work group chairs will call their next meeting by phone conference. EHDI staff will assist in coordinating the meeting by providing conference call numbers as requested and sending out the agenda. Each work group will have a draft protocol to present at the next Advisory Committee meeting.

Audiology Work Group: Chair – Christine Eubank; EHDI staff – Antoinette Vaughan  
Members: Claire Jacobsen; Casey Morehouse; Ann Hughes; Terri Strange-Boston; Ashleigh Greenwood; Jill Young

Hospital Work Group: Chair – Nancy Bond; EHDI staff – Daphne Miller  
Members: Ashleigh Greenwood

PCP Work Group: Chair – Dr. Ellwood; EHDI staff – Mary Lib Morgan  
Members: Julie Durando; Debbie Pfeiffer

Groups met briefly to discuss next steps.

The meeting was adjourned at 12:15 p.m.

Submitted by:

Mary Lib Morgan



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