

Summary of Advisory Committee Meeting
Virginia Early Hearing Detection and Intervention Program
Virginia Department of Health
June 7, 2013
Draft

The following persons attended the meeting: Frank Aiello, Callie Beasley, Nancy Bond, Robert Boyle, Sean Dawson, Craig Derkay, Darlene Donnelly, Dr. Leslie Ellwood, Christine Eubanks, Ruth Frierson, Scott Gregg (CARTS), Ken Henry, Ann Hughes, Claire Jacobson, Paul Johnson, Rhorie Kerr, Valerie Luther, Daphne Miller, Janet Odishoo, Debbie Pfeiffer, Lisa Powley, Irene Schmaltz, Marie Antoinette Strayhorn, Sara Varner, Shuhui Wang, Susan Ward, Jill Young

Dr. Leslie Ellwood called the meeting to order.

Membership, Introductions and Travel Reimbursement were done.

DMAS

Brian Campbell did not attend the meeting so there was no DMAS update.

Hearing Workgroup

Christine Eubanks presented on behalf of the Hearing Workgroup. They have completed their assignments and are ready to begin new projects as assigned by the Advisory Committee Members.

Partnership for People with Disabilities

Deana Buck did not attend the meeting but forwarded an update. Christine Evans, Speech Language Pathologist and prior Committee Member, has agreed to work on the on-line modules for ENTs and Audiologists. Our e-learning specialist will format the first pediatric module.

In terms of accessing the first two hearing modules, here are the numbers:

The 1-3-6 Process: A Road Map for Newborn Hearing Screening and Follow-up — 86 graded (*102 attempts*)

Rules of the Road: A Foundation for Understanding Early Hearing Detection and Intervention — 131 graded (*151 attempts*)

DOE

Debbie Pfeiffer made the presentation. The department has been concerned about the effect of anticipated budget cuts on their commitments to various projects. DOE and the HI TA Center at the Partnership for People with Disabilities at VCU are collaborating to sponsor Opening Doors and Unlocking Potential 2013 which will be held Tuesday, August 6 and Wednesday, August 7, 2013 in Charlottesville. Registration deadline is July 24, 2013. This 7th Annual State-wide Professional Development Institute is being held for Teachers of the Deaf and Hard of Hearing, Related Service Providers and all who

work with students who are deaf or hard of hearing. The EHDI Program Manager, Ruth Frierson, will be present at the opening session on August 6 to provide an update on what the EHDI program and its stakeholders have accomplished and ask the question “Where do we go now?” Bradley Kessler, M.D., a cochlear surgeon, will be there to discuss the advances in technology. Claire Jacobson will also do a session. Presentations will emphasize language and communication access, the continuum of placement options and services, changing technology and transition needs. In addition to a Professional Development Certificate for attendance at this year’s institute, participants may obtain graduate credit through Radford University. DOE will also collaborate with the Deaf-Blind project at the Partnership to sponsor the 6-day INSITE training for Part C Providers and Early Childhood Special Educators of children with dual sensory impairment or one sensory impairment and additional disabilities. One 3-day session will be in Charlottesville and another in Williamsburg. VDOE will continue to provide funding for both of those programs at VCU, as well as the Hearing Aid Loan Bank and the Radford University Teacher of the Deaf Preparation Program in the coming year

VNOC

Ann Hughes made the presentation. VNOC (Virginia Network of Consultants for Professionals working with Deaf or Hard of Hearing Children) sponsored on May 17 and 18, 2013 a listening/language workshop which had an excellent response. Ann Hughes is working it into a Webinar which will be on the VNOC website. VNOC 2 handles individual consultations requested by a school. They have not received any requests this year but have done 24 consultations with children on that basis.

Early Intervention

Terri Strange Boston of Infant Toddler Connections did not attend but a presentation was done on her behalf.

The Infant & Toddler Connection of Virginia State Part C Office completed a survey “Part C and EHDI Program Collaboration Survey” recently sent from the National EHDI Program to each State’s Part C Coordinator. Ruth Frierson and Terri Strange-Boston collaborated on the responses and discussed how the survey is a good outline for the work to be done between the two systems. VEHDIP and Part C are working on procedures that when implemented will help with the CDC 1-3-6 Goals. The proposal includes allowing local Part C EI systems to gain access to VISITS for the purpose of receiving referrals for the Part C eligible infants and toddlers, along with the diagnostic audiological reports, the necessary release of information form to be signed by the parents and to report back as to whether a family has accessed or declined Part C services.

The Infant & Toddler Connection of Virginia office just completed six regional trainings entitled, “Weaving Early Intervention into a Child’s and Family’s Everyday Life based on Quality Practices for Improving Child and Family Outcomes”. States are required to report on the percentages of infants and toddlers with IFSP who demonstrate improved: 1) positive social-emotional skills; 2) acquisition and use of knowledge and skills; and 3)

use of appropriate behaviors to meet their needs. Therefore, a new IFSP and process has been introduced and will be in place by July 1, 2013.

The Infant & Toddler Connection of Virginia statewide system is also engaged in increasing providers skills at coaching, “to move to a different position alongside a parent as a coach rather than a lead player”. Dathan Rush and M’Lisa Shelden have completed 2 of 5 scheduled regional events.

Creating Connections to Shining Stars 2013

Registration is now open for the summer’s Creating Connections to Shining Stars. The conference is scheduled for July 22-24 in Virginia Beach. For detailed information and to register visit: http://www.eipd.vcu.edu/annual_conference.html

Newborn Screening

Kathleen Moline was not present for the meeting but sent a report saying the

- CCHD HRSA grant was approved for 2nd year
- NBS educational website development is on track

Virginia Hearing Aid Loan Bank

Lisa Powley attended the meeting by phone but due to technical difficulties she could not be heard. She sent a written report. As of May 31, 2013, the Virginia Hearing Aid Loan Bank has provided hearing devices for 737 children. 42 applications have been received since January 2013. She had a call last week from the father of a child that has been using a loaner FM system. He called to say that his daughter is now an A student, has many more friends and has gained a lot of self esteem. The school will now purchase one for her to use. Lisa said I love these wonderful stories!!!!

Children with Special Health Care Needs

Sidnee Dallas, Program Administrator, Children with Special Health Care Needs, made the presentation. She has taken the lead with the Title 5 Block Grant. Dr. Lauri Kalanges, MD MPH of the Virginia Department of Health is the state director. The VDH portion has been completed. The grant is due July 15, 2013. Sidnee and Dr. Kalanges will go to Washington to meet and speak regarding the funding. Receiving this grant is vital to the Children with Special Health Care Needs Program.

Guide by Your Side

Irene Schmalz gave the report for Guide By Your Side. From August 2012 through May 2013, there have been a total of 88 referrals to Guide By Your Side. Within the last three months, over fifty percent of the referrals were from the Tidewater area. Meet and Greet was held on March 9th and there were over 90 people that attended. We will be having another Meet and Greet on September 21 in the tidewater area and in October for the western part of state. At the Meet and Greet, we had several families videotaped and the link is <https://vimeo.com/channels/493137>. The Resource Guide has been published thanks to the help of many people especially Ruth Frierson, Daphne Miller, Dana Yarbrough, Ann Hughes, Christine Eubanks, Debbie Pfeiffer, and more! Anyone interested in obtaining a hardcopy can contact Irene Schmalz at

Irene2swim@yahoo.com or Dana Yarbrough at ptpofva@aol.com Upcoming Events: VICC; H&V Leadership Conference; Camp Loud and Clear; Shining Stars; Unlocking Potentials.

Hands and Voices

Bailey Vincent was not able to attend the Advisory Committee meeting on June 7, 2013 but she sent in a report and asked Paul Johnson to speak on behalf of the program.

Paul Johnson wanted to emphasize to the Committee that Virginia Hands & Voices has a strong Board of Directors, is making a lot of parent-to-parent connections, and is poised to grow aggressively.

Bailey Vincent's report is below

The Director was invited to the Governor's Mansion for a luncheon honoring non-profits that are making waves. Due to this conflict with the EHDI meeting on June 7th, Paul Johnson will be presenting in the Director's place

The Director was formally asked to join the EHDI Planning Committee for the national conference in Jacksonville, FL in 2014. This small group will be slotting speakers, plotting events and so forth- and will meet via teleconference monthly, and assigned differing duties. This is an exciting bit of publicity for our H & V chapter's involvement in large events, and a great way to delve deeper in to the hearing loss community of professionals

The Board

The VA Hands & Voices board met last week (Friday the 31'st), and determined the next 2 dates of their meetings: September 21st, after the Meet & Greet in the Tidewater area, and tentatively on January 25th at VSDB in Staunton for the Mason Dixon tournament fun. The board has reiterated that they will meet quarterly, but plan dates in advance so that they may be made public.

The Board has determined that the officers still hold the right to call a closed session or private meeting per their discretion, especially as pertaining to the work of the Executive Director and discussion of potential future board members. They also hold the right to continue to send private board-related emails without involving additional committees [unless needed]

Even though officers had been established previously, position duties were assigned more specifically to keep the board on task

The Hands & Voices by-laws were finalized and concluded - including determining how long an officer holds their title, and how the cycle of new officers will be conducted periodically.

Cohesion

After much discussion, it was determined that in order to achieve better cohesion between Hands & Voices and its organization Guide By Your Side - the GBYS Steering Committee and H & V board meetings will be consolidated in a few specific areas.

- 1) In order to save funds, travel time and overall work time of many involved, we propose that both groups begin meeting on the same dates- H & V Board meeting followed by GBYS Steering.
- 2) The GBYS Steering Committee members would be invited to join the Hands & Voices board meetings officially as "Hands & Voices Advisors". They would be unable to vote on official board matters or hold an officer position- because this would throw off our parent-to-professional ratio. However, they would be able to share input during these meetings, and we would benefit from the professional-to-parent give and take.
- 3) The board may determine at a later date if or when to invite one of these professionals on to the board as an official voting member, to replace a professional or officer position (when a term is up) - if needed or desired.
- 4) Professional members would receive access to parents and ensuing dialogue, as well as insight to help their profession. Additionally they would have awareness of events and resources, free materials to provide to parents [please see "Materials" below], as well as a free Hands & Voices Communicator newspaper.
- 5) The Director of Hands & Voices and the Coordinator of GBYS will continue to work as a unit to plan the ensuing GBYS Steering Committee meeting and agendas, as well as aid one another in major events such as Meet & Greets.

501c3 Status

After our last submission on March 14th, we are currently awaiting the IRS regarding our 501c3 status (as of now, we've done all we can). However, a meeting on June 7th will be lined up with the Director, Treasurer (Paul Johnson) and Dana Yarbrough to gather all information possible on managing these many submissions. This includes but is not limited to items such as filing with the Department of Agriculture (or other specificities with which we were previously unaware).

Many fundraising efforts are being examined and discussed (including websites such as ShopFund) and we believe successful implementation can be achieved as soon as our non-profit status is reinstated

Events

H & V had a positive presence at King's Dominion on June 1st- Bailey (Director), Lisa Herbert (Professional) and Amber Tyree (Co-Chair) were present. Although the number of deaf in attendance was disappointing compared to years prior, the positive response from videos and photos posted on our Facebook page garnered new interest. Involvement in this event next year is to be determined.

The Parent-To-Parent online chats will happen the first Wednesday of every month at 8 PM/EST, with differing subjects to keep things interesting.

The Director and GBYS Coordinator will be attending the Hands & Voices national conference in Wisconsin the second-to-last weekend in June; and, hope to meet with Lisa Kovacks and other professionals to gain further advice on cohesion.

H & V is hopeful that the funding of a visit from Lisa Kovacks to help with group cohesion will not be needed, but regardless - the board hopes to plan a separate Planning Meeting to instate strategies and tactics for full cohesion. This is tentatively for the second week of July, although a majority of members will need to be present via telecommunication because of summer travel.

Materials

Materials were produced for distribution at conferences, events and professional H & V Advisor members. (Please let us know if you'd like to obtain any of these). This includes H & V magnets, as well as "post cards" that provide non-biased questions to ask professionals [if feeling overwhelmed in appointments] so families may know all their options.

Data

Data on Hands & Voices families, new members and online following will be provided by the Director quarterly to both Ruth Frierson and Dana Yarbrough, including numbers and graphs on how our newsletters, Facebook/Twitter/Pinterest, and emails are evolving.

EHDI Reports

Ruth reported that Kathrine Gangeri and the Workgroup have revised the *Can Your Baby Hear?* brochure. The committee reviewed the final Draft. It will be distributed to hospitals and birthing facilities this summer.

The final Draft of the VEHDI brochure for pre-natal populations was reviewed by the committee. It will be distributed to home visitors and OBGYN offices.

VEHDI and the Newborn Screening program collaborated on a development of posters that will be distributed to primary care provider offices.

The revised Virginia's Resource Guide for Families of Children with Hearing Loss can be found on <http://centerforfamilyinvolvement.vcu.edu> .

Shuhui Wang presented data on loss to follow-up and hearing loss for 2011 births. This data was broken down by health district. Loss to follow-up data was reviewed by race, ethnicity, maternal age, and maternal education. Proven strategies to improve follow-up, presented at the 2013 EHDI Conference, were collaboration with Women Infants and Children (WIC) and immunization programs.

Daphne Miller reported that since January 2013, there have been 85 children diagnosed with hearing loss with 51 diagnosed before 6 months of age, 17 between 6-12 months and 17 after 12 months of age. 85 children were referred to Part-C Early Intervention. 48 were before 6 months of age, 20 between 6-12 months and 16 after 12 months of age. 40 families were referred to GBYS since January 2013. Review of the VAHALB report helped identify 4 additional children with hearing loss that were not previously reported to the VDH.

VEHDI PSA campaign will be aired July 1 – 7 on Pandora and local radio stations. A detailed plan of times and stations will be sent to the AC.

Antoinette Miller reported that audiology site visits continue to be conducted throughout the state. The next one will be in Roanoke. The list of approved audiologists is now maintained by registering on Early Hearing Detection and Intervention Pediatric Audiology Links to Services (EHDIPALS) Annual certificates will be issued to approved audiologists registered with EHDIPALS. We continue efforts to encourage audiologists to use the VISITS Module as the primary reporting method.

Ruth Frierson shared that Kathrine Gangeri and herself attended the 2013 EHDI Conference. The sessions indicate that there is much Virginia can share with other states re; proven strategies and recent successes. She encouraged stakeholders to attend the 2014 EHDI Conference which will be held in Jacksonville, Florida.

EHDI will provide training sessions during the Creating Connections to Shining Stars Conference July 21-24, 2013.

The Virginia Hearing Aid Loan Bank will be funded for one more year, starting July 1, 2013. We continue to work on linking with the immunization database. The Hearing Screener Training Curriculum developed by the National Center for Hearing Assessment and Management (NCHAM) will be distributed to hospitals during the summer of 2013. A competency certificate is issued after the completion of this training.

The findings of the survey to gauge providers knowledge on EHDI was analyzed, and the findings shared by NCHAM, with participating states. Virginia mailed the survey to 800 pediatricians and otolaryngologists. The results showed a lack of knowledge, among providers, pertaining to EHDI and its goals. A copy of the survey and results were shared with the AC and will be kept in the EHDI Program Office.

Leslie Ellwood distributed a copy of an article in the Pediatrics Official Journal of the American Academy of Pediatrics which would be a supplement to the JCIH Position Statement for 2007: Principles and Guidelines for Early Intervention after confirmation that a child is deaf or hard of hearing. The article discussed guidelines for rescreening in the medical home following a “Do Not Pass” hearing screening. The purpose, equipment, screening techniques and communication of results to families were outlined

Craig Derkay questioned what follow up had been done on a prior meeting discussing contractor charges. Ruth explained we have followed up with policy and legislation staff

but Susan Tlusty, who led on our behalf, is no longer with the Virginia Department of Health. We are awaiting her replacement. He believes we need to enforce safety and quality standards. If the training DVD for hospital hearing screeners is comprehensive and complete we should require this as the training for standard of care. The regulations need to be revised to state this as a requirement. Ken Henry stated he and his staff have been doing competency exams for years to cover themselves legally and professionally. Craig Derkay asked how do we get to the point we can require this. Susan Ward of the Virginia Hospital and Health Care Association, felt the VHHA should work with EHDI on communications pertaining to this effort because of their work with the hospitals and the health department. Craig Derkay felt phrasing regarding this subject should be tactful and presented as though it is to keep everybody up to date and competent.

Ken Henry recommended a standard follow-up document should be given to families that is detailed on what to do next, when, and with who.

Craig Derkay recommended the program focus on collaborating with the immunization program as a priority, followed by collaboration with WIC. Immunization would have more information on the child's medical home.

The Committee broke into workgroups to discuss the following topics; Health Disparity in EHDI, Follow-up recommendations for infants in the NICU and with risk indicators, the audiology and otolaryngology role, and provider education.

Adjourned 3:08

