

## Early Hearing Detection and Intervention (EHDI) Linkage Committee Hearing Workgroup Meeting Minutes

**September 12<sup>th</sup> 2011**

**11:00-1:30pm**

### **Members Present:**

Nancy Anderson	Ann Hughes	Debbie Pfeiffer	Nancy Smith
Deana Buck	Daphne Miller	Lisa Powley	Beth Tolley
Ruth Frierson	Sarah Peters	Sarah Shreckhise	

**Updates:** (All updates were provided by the appropriate parties prior to the meeting in an effort to save time and cover any changes since the last workgroup meeting on July 11, 2011.)

### **I. Hearing Aid Loan Bank (HALB): Submitted by Lisa Powley**

Hearing aid loan Bank will be funded next year by VDH/EHDI and DOE (Thanks to Joann, Ruth, and Debbie). Lisa reported that there were 140 aids and 25 FM Systems either on loan or available. 68 go out of warranties this year so they can be repaired but not replaced by Unos. Lynchburg area is now using HALB. Lisa reported that she was able to give away some of the old aids since the warranties have expired. August and September were very busy with August loaning 20 aids. Currently 141 children have hearing aids across Virginia from the HALB. Phonak was amazed at the numbers of children using the hearing aid loan bank in Virginia as opposed to Delaware where only 4 aids were out on loan. Debbie Phieffer reported that as of October 1, \$25,000 was available for HALB for the upcoming year. If there were not as many aids able to be purchased with this money, Lisa suggested that the loaner aids be recalled in 4 months instead of 6 months. There is presently not a wait list. Beth Tolly gave kudos to Lisa Powley for her hard work over the years.

### **II. Technical Assistance Center for Children who are Deaf and Hard of Hearing: submitted by Ann Hughes**

VNOC: For the 2011-12 year: 4 in-service requests have been received to date and Shirley Blake has been working with VDOE to encourage Wise Count and Rocky Mount to use services.

Ann reported on the continued development of HI in the coordinated state action plan through the following:

#### **Trainings:**

Project Support at Radford University Summer Institute 7/25-26 for Auditory Oral Training  
Visual Phonics was postponed due to Hurricane Irene

#### **Outside Professional Development:**

AG Bell Symposium (7/21-21)

**Upcoming Activity:**

Sept. 14-16 VNOC in SW Virginia Sites  
 Sept. 23 EDHI Advisory Committee –VHHA, Richmond  
 Sept. 26-27 VDOE ESS+ Work Session  
 Oct 3 Visual Phonics Part 1 – Lynchburg  
 Oct. 5 DHH National Summit Webcast  
 Oct. 6 VNOC- Fall members Meeting  
 Oct 10 Visual Phonics-Part 1 Henrico Co.  
 Oct 27-28 Visual Phonics-Prince William Co.  
 Nov 11 Visual Phonics Part 2-Lynchburg  
 TBA: Spring “ Listening and Spoken Language” symposium

**VNOC:** For the 2010-11 school year: 31 service requests were received and processed (includes 5 carryovers and 1 reopened consult from 09-10); 29 completed. There were 22 specific to student needs (12 of these are psycho-educational assessments; 5 CI specific; 4 multiple disabilities); and 9 for a regional training sponsored by a school division through VNOC. Nine consultations involved multiple visits; seven involved 2 or more consultants to complete request. One request was from EI agency for staff development.

Assist with the continued development and execution of VDOE coordinated state action plan.

Action Plan updated 4/28/11 with state team members attending the National Summit on Deaf Education (VA attended via distance conferencing).

**III. Part C: Submitted by Beth Tolley**

The Infant & Toddler Connection of Virginia staff communicates regularly with early intervention providers about training opportunities. Work is progressing towards an October 1, 2011 implementation of a new targeted case management program designed specifically for early intervention. Starting October 1, 2011, all children who have Medicaid or FAMIS coverage will be served under this Early Intervention Targeted Case Management program. We will continue to refer to the service in early intervention as “service coordination” in accordance with the Federal Part C terminology. Every child with Medicaid will have physician follow-up. Prematurity Workgroup helped add prematurity (28 weeks or less at birth or a NICU stay of 28 days) as eligible for Part C services. The number of children served in the early intervention system has increased about 18% over the past year. Issues raised are: (1) awareness by service coordinators and service providers that a child is now eligible under this criteria and (2) competency in dealing with very young infants who are premature. A subgroup of the Prematurity Workgroup is developing training modules. The Talks on Tuesday Webinar from early 2011 is archived and available at [www.eipd.vcu.edu](http://www.eipd.vcu.edu).

**IV. Guide By Your Side (GBYS): Submitted by Lisa Powley**

Since February GBYS has had 50 referrals. 45 of those were from EHDI and 5 were community referrals. All 50 families have been sent notebooks and referrals have been sent to Guides. 25

matches have been completed; some of those were marked completed/closed due to the family not responding to the Guide's numerous calls. After several emails and some phone calls to guides I do not know if the other matches have been made. I mailed reporting forms out to all guides that received referrals and I received most of those back on the 25 completed. I have ordered 450 family notebooks, 100 Spanish and 350 English. Priority mailing boxes and stamps were also ordered so notebooks can still going out in the interim between grants.

In June Ada Determan and Bailey Clark attended the National Hands and Voices Conference in Maine. Lisa continued to promote both programs at community events and meetings. Lisa expressed concerns about how to find a coordinator who could blend together GBYS and Hands and Voices as well as be the parent of a child that was deaf and /or had of hearing. Several suggestions were made to seek an individual with those qualifications as soon as possible since there were more families waiting. Discussion centered around where the existing list of GBYS participants and guides were adequate or whether communication could be done more electronically so that geographic area would be less important. Lisa to report at the next meeting.

#### **V. Hands and Voices: Submitted by Bailey Vincent Clark**

**Moving Along:** We have been actively recruiting new board members during the past couple of months, and hope to have at least 2 - 3 new, talented members on board soon. We are still in the process of firming up their applications, but will keep you posted!

**Virtual Chat:** The "virtual chat" I hosted at the end of July was a big success. We had upwards of 800 viewers (not all of whom were actual Virginia members or residents), but my guess is that at least a couple hundred were our "own" Virginia families and interested parents. The "show" featured two mothers of special needs children who spoke about their experience and advocacy as special guests, as well as 20 giveaways of Ear Gear! We hope to host another virtual event soon.

**Speaking Up:** I wrote an article for the Hands & Voices Communicator (their wide spread publication) on behalf of H & V Virginia and it will be publishing soon. Moving forward, we will continue to find new ways to spread the word and connect with families!

**Twitter Time:** We have a brand new Twitter account (which is admittedly going to take a little work to build and grow)- @vahandsnvoices. Please go and follow us to help build our page!

#### **VI. Virginia Department of Education (VDOE) submitted by Debbie Pfeiffer**

##### **Activities since last meeting, July 11:**

Facilitated panel on "Use of Telepractice for Professional Development and Provision of Therapy" at A.G. Bell Symposium, July 23, Washington D.C.

Facilitated meeting with state workgroup to develop graphic depicting placement options for students who are deaf/hh, July 29, Richmond.

Presented at INSITE Training (for families of infants and toddlers who are Deaf-Blind, or who have sensory impairment plus other disabilities) for early intervention providers and early childhood educators, August 3, Harrisonburg.

Met with special education administrators in Chesapeake Public Schools re: professional development plan for meeting the needs of oral deaf students, August 9, Chesapeake.

Led state meeting of coordinators/directors/fiscal agents of state grant for professional development for educational interpreters, August 10, Virginia Beach (Celebrations: 67% of our Educational interpreters now meet state required qualifications, up from 57% last year, and 9% in 1999!)

Met with administrators and teacher at ODU Oral Preschool Program to develop options for funding the program after 2011-2012 school year.

Participated in Dr. Emmet Jones' development of online sign classes/lessons for parents of young children who are deaf/hh and professionals working with them, and was videotaped on Aug. 18 providing lesson on language development.

Presented for Region II ed interpreters on "Interpreting for State Assessments", Aug. 30, Chesapeake.

(Many of my other activities focused on Blind/VI and Traumatic Brain Injuries, including developing and hosting my first state team training July 18 – 20.)

VDOE had to make sizeable budget cuts in special ed, and the grant to the HALB was reduced to \$25,000 this year.

#### **INSITE Training:**

Since there were three trainers who had experience in deaf-blindness and were sent to Utah to become trained as trainers of INSITE (working with birth to three year olds with deaf-blindness or a sensory impairment plus additional disabilities), Virginia offered two trainings in August and September with 23 people attending. Money was provided by VOE for training SLP's and special education personnel 0-5. Priority on this training will be given to those working with blind/vi.

#### **Budget cuts:**

VDOE has had to cut funding for Hearing Aid Loaner Bank to \$25,000.00 this year.

**VII. EDHI: submitted by Ruth Frierson (at meeting)**

They have gotten approval for a full time coordinator: Surveillance and Evaluation Coordinator is the official title. The position is currently posted and will close on Friday (7/15/11).

Participated in regional trainings for the EI RICC meetings. EI managers are very interested in collaborating. Biggest impact is obtaining the enrollment information. Date that the IFSP is signed is the date that will be used as the enrollment date. Daphne calls the family three months after the initial referral to find out the reasons as to why they are not enrolled in the EI system for whatever reason.

Last week we received notice that one of our grants that should have started July 1<sup>st</sup>, did receive funding (as of last week), but it was reduced by about \$20K. It should help enhance visits: VIIS (Virginia Immunization Information System). As the infant comes into the state systems, it will tell them what step they should take next. It will list which locality is the appropriate locality to refer to. Debbie asked a question about the VIIS system- do doctors pull this up every time the child comes in for a well baby visit? EHDl actually has newborn hearing results long before the pediatrician receives the information. They are receiving it in real time, but the pediatricians are still working to upload this information, but it will be uploaded into the VIIS. They will plan to continue with the letters and current follow up that they are doing. This will require a code change which will take some time. They are also working on having the audiologist report online and will be web based, but still working on how exactly that will be coordinated. They hope to link with various other systems of other programs throughout the state.

HRSA grant will begin in October.

Concluded Virginia Learning Collaborative activities. Has been very successful. Participated in the NICH-Q process until it concluded in May of last year. Have moved on to improvement activities to see where the gaps were to improve the processes in Virginia. Wise choice in our investment and our funds. Some things have required us to repeat ourselves over and over again. Really need to make an effort to communicate with the child's audiologist and then there is little follow up to ensure the links have been made and appointments have been kept, when the appointment was, and when the report was set. Christine, who participated in this process, reported that there was a large no show rate for various reasons. She found and will email a brochure that discusses "you may think your deaf baby can hear" and "that it's [hearing loss] not all inclusive." As part of the National Learning Collaborative- a group of parents developed a road map for babies and was tried and tested with 42 infant families; none of them remember the brochure or used it as a means to follow up. Wasn't because of the product itself, but the distribution. They were receiving it at the time of the newborn hearing screening at the hospital. Ann asked if the "Lost and Found" regarding follow up was used. Discussed the new generation of parents that are linked in different ways (i.e. web based, facebook, twitter, text messages, etc). They have found that a lot of the audiologists are trying "not worry" the parents when they first learn of their diagnosis. Parents don't understand

what “refer” means. Ruth emphasized that it is important that the child FAILING the screening is important to be communicate that to the parents, not to say what will make the families feel better.

#### **VIII. Partnership for People with Disabilities: submitted by Deana Buck**

##### Activities since last meeting, July 11

1. Thanks to all for feedback and comments on “Rules of the Road: A Foundation for Understanding Early Hearing Detection and Intervention” (Hearing 101) and “The 1-3-6 Process: Road Map for Newborn Hearing Screening and Follow-Up.” Both modules are now posted on the [www.vaehdi.vcu.edu](http://www.vaehdi.vcu.edu) website, under training. A link to both modules is also on the Part C professional development website, [www.eipd.vcu.edu](http://www.eipd.vcu.edu).
2. The archived version of the “Everything you always wanted to know about hearing but were afraid to ask” webinar has been posted on the [www.eipd.vcu.edu](http://www.eipd.vcu.edu) website, under “Talks on Tuesday”. Forty nine individuals submitted evaluations. The summary of the evaluation data is attached.
3. In terms of developing the two modules for physicians, the content for both modules has been developed. The first module, “The 1-3-6 Process”, is ready to be formatted for on-line learning. At the beginning of the contract with VDH, the plan was to secure CME’s for these modules through the American Academy of Pediatrics. An application for CME’s was submitted, but the AAP committee asked for additional clarification, as a new module about EHDI has recently been developed and posted. Dr. Ellwood suggested that we consider securing CME’s through a medical school in Virginia. In discussing this plan with the VCU Health System CME officer, it seems like this is a better route to pursue. There is an application process and it is similar to the application required for AAP CME’s. Deana has drafted the application, and will meet with Dr. Boothby at VCU next week to discuss questions. One additional consideration is that, for VCU CME process, we will be responsible for formatting the module. If we pursued CME’s through the AAP, we would have been required to use the AAP’s content designers. We have a module developer ready to do the formatting for these two modules. Thanks to Dr. Ellwood for working on the contract for the final physician module, which is a series of four case studies.
4. The Virginia EHDI website for professional development, [www.vaehdi.vcu.edu](http://www.vaehdi.vcu.edu), is now live. Thanks to Bailey Clark and Ruth Frierson for their assistance with the content for the site, and to members of the workgroup for their assistance with links and resources to include. We will continue to add resources to the site so please send addition to Deana at [dmbuck@vcu.edu](mailto:dmbuck@vcu.edu).
5. On the EIPD website, a hearing landing pad has been posted. ([http://www.eipd.vcu.edu/pdf/dhh\\_landingpad\\_ra\\_linked.pdf](http://www.eipd.vcu.edu/pdf/dhh_landingpad_ra_linked.pdf)). Thanks to all for your help on this landing pad!.

## IX. General Discussion during the meeting

### Discussion: Status of the Guide By Your Side Program

From last notes: - Ruth –Guide by you Side continues to struggle with the smaller group of trained parents and the geographic locations (none in western Virginia and mor in metropolitan areas) discussed whether to keep smaller number of parents and how to best facilitate their communication with families (skype, phone, e-mail) rather than physical visits. Data continues to be collected.

Now to the present. Challenges were discussed as to how we should revise the GBYS program and find a Parent Coordinator. Names were suggested and housing of the program was discussed. Ideally someone like Sarah Shrenkhise was discussed as a coordinator. If the program was to be part of Hands and Voices, the description of a parent coordinator is already provided. If it is part of the \$57,000 HRSA Grant there will have to be a focus on multicultural families in the Guide by your Side program. As of today, no agency has taken this project on. Bids for a contract will come out later this month. Agency will need (a) steering committee (b) multicultural guides (c) need for support in detail. (d) consistent training schedule for families (e) build in compensation for parent guides. Consensus was that there were to be no more than 12 guides.

Other items in VDH Update: CDC Grant awarded with 13% budget cut in 2012. Money has to be used for systems improvement. These improvements include: (1) audiologists now report directly into the system (b) registration for audiologists will also be automated. (d) On-line training available. (c) Second year: Primary care physician will have access to the newborn hearing screen. (d) When a child is diagnosed with a hearing loss, the pediatrician will be notified so they can be followed. The Health Information Act will connect the VA results with other data banks. The HRSA Grant now has also been awarded and now has staff. Staff is trying to do follow-up with area ENTs and to provide training to them to get families back in. The loss to follow up in the 1-3-6 program is 90%. Presently the system records the referral but not the type of referral. Now Home Visiting Consortium is included to help with follow-up.

Teleaudiology Services : This was mentioned because there was an effort to get this underway south of Petersburg due to the lack of educational Audiologist. Johnny Sexton in NC has developed materials and resources and is willing to share his materials from the “care Project” for educational Audiologists.

ABR Testing of Premature Infants: A question was asked about ABR testing of premature infants. Ruth indicated that an additional ABR should be follow-up at three months. There are concerns that facilities may not have ability to fulfill this recommendation and Ruth replied that the regulations are still out for public comment on Town Hall. Discussion followed on concerns about why a protocol was needed and liability issues if not followed. Ruth replied that the protocol was recommended but not mandated. Due to the consistently reported lost to follow-up of the premature infants, a list of contacts in hospitals and with Part C will work to strengthen lines of

communication. Ruth said that the protocols are not to be reviewed until September 26<sup>th</sup> and that an open comment period should offer opportunities to provide feedback to the state.

Next Meeting: December 5<sup>th</sup> 10am- 12:30pm at Henrico CSB.

*Minutes Submitted by: Sarah Peters*