

**Early Hearing Detection and Intervention (EHDI) Linkage Committee
Hearing Workgroup Meeting Minutes
July 11, 2011, 10am-1230pm**

Members Present:

Deana Buck
Bailey Clark
Patty Eitemiller
Christine Eubanks
Ruth Frierson
MJ Goodrich
Ann Hughes
Daphne Miller
Casey Morehouse
Sarah Peters
Debbie Pfeiffer
Lisa Powley (by phone)
Nancy Smith
Melinda Smyth
Beth Tolley

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 May 2, 2011.)

I. Early Intervention (Part C): Submitted by Beth Tolley

Ruth Frierson and Daphne Miller joined the Part C Technical Assistance Consultants at their June Regional System Manager meetings to provide information and answer questions about VEHD. In two regions, Kathy Baker, Coordinator for CSBs for the Deaf and Hard of Hearing also participated. Great interest was generated during these meetings.

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.

Beth participated in the June Talks on Tuesday Webinar on Hearing.

*****Update during the meeting:** Beth reported that the audience for training and information provided relating to working with children diagnosed with hearing loss continues to be the people that already know [the

information being shared], but they're still missing the ones that don't know what they don't know. The training module that is being developed should help with some of this.

II. Hearing Aid Loan Bank (HALB): Submitted by Lisa Powley

As of 6/30/2011, 502 children have benefited from the HALB. 309 of those children are 5 years of age or younger. The Hampton Roads area continues to be the main area that uses the HALB with 210 children to date.

III. 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. I continue to promote both programs at community events and meetings.

IV. Technical Assistance Center For Children Who Are Deaf or Hard of Hearing: Submitted by Ann Hughes

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).

Exhibits:

H&V/HALB/EHDI/VNOC @ King's Dominion Deaf Awareness Day (6/4/11)

Trainings:

Visual Phonics: Loudoun County (6/6/11)

Coordinate statewide conference for school personnel re: d/hh

Opening Doors-Unlocking Potential 2011! Language-Literacy-Learning and Students who are D/HH. 6/28-29/11); Fifth annual conference, Charlottesville. (100 registered participants/88 completed evaluations)

Professional Development:

Conferences:

National VP Trainers Conference (6/22-24/11)

Webinars:

ICODA (5/21) All Senses on Deck: Reality Instruction

Upcoming Activity:

Jul 21-23	AG Bell LSL Symposium
Jul 25-26	RU Summer Institute (Fiscal and program support for two-day Auditory-Oral training)
Jul 29	State Action Plan Workday -Continuum of Placement
Aug 31	VP Part 1-Hanover County
Sept 23	EHDI Advisory Committee-VHHA, Richmond
Oct 3	VP Part 1 – Lynchburg
Oct 5	DHH Nat’l Summit Webcast
Oct 6	VNOC – Fall Members Meeting
Oct 10	VP Part 1-Henrico County
Oct 31	VP Part 1 – Rockingham County

V. Virginia Department of Education (VDOE): Submitted by Debbie Pfeiffer

ODU Oral Preschool Classroom:

VDOE is providing funding for 8 days of professional development in use of auditory verbal strategies for TODHH and SLP from Hampton Roads. Most of the todhh and slp have had students from their schools placed in the ODU preschool classroom, although some are from divisions who have provided services in their own school division. The training will coincide with the summer enhancement program, so participants will get hands-on time with the children, as well as training with Janet Knust, teacher and Cert. AV Ed, in the afternoons. Travel, lodging, and per diem, if needed, are being paid by VDOE, as well as tuition for graduate credits.

VDOE is also providing funding for salaries for the coming school year, as school divisions will not have stimulus funding to use for tuition after Sept. 30. We are working toward making ODU’s program eligible for status as a “regional program” in the future. A big part of our interest in this program is providing professional development with hands-on components to school division personnel.

Distance Oral Coaching for Todhh/SLP Pilot Project:

Professionals working in more rural areas with oral deaf students in 3 school divisions were given money to access coaching services from SLPs who are experienced in developing listening and spoken language skills. Coaches visited programs and met the target student(s), then provided consults on-going from November – present via telephone, Skype, email; videos of therapy were emailed and analyzed by the coach, and feedback was given; assistance was provided for writing IEPs, assessing skills, development of appropriate activities, etc. The program was considered a success by all involved, and may be expanded in the coming year if funding is available and there is a need.

I will facilitate a panel at the A.G. Bell Symposium in Washington, DC on July 23 on “Using Telepractice to Mentor Professionals and Provide Services to Families.” Todd Houston (NCHAM and Utah State University, but soon, University of Akron), Tracey Hopkins and Aleisha Davis of the Shepherd Centre, Sydney, Australia, and Amy Peters-Lalio, Wisc. Will be on the panel.

INSITE Training:

Money that Julie Durando (VA Project for Children and Young Adults with Deaf-Blindness) had left from the VDOE grant was used to send three people (Julie, Lisa Auwarter, and Morina Lamb) with experience in deaf-blindness 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). Money from my VI pot will be used for them to then return and present a 6 day INSITE training in August and September. Priority on this training will be given to those working with blind/vi.

Online Videos

Dr. Emmett Jones of the Deaf/Hard of Hearing Counseling, Discovery Challenge Program, is receiving a grant from VDOE to develop online videos for families of and professionals serving infants and toddlers who are deaf /hh. Some of the lessons will be sign language (provided as they would be if you were doing a home visit for Part C and related to daily routines of young child) and some will be lessons (eg. – effective discipline, increasing hearing aid wearing time, etc.)

Utah State University Coursework for Professionals working with students with Deaf-Blindness

VDOE is still funding this, and the VA Project for Children and Young Adults with Deaf-Blindness is recruiting, overseeing, providing TA to participants, and doing onsite visits after coursework is completed to ensure implementation of knowledge and skills. The 3rd cohort of 10 (5 paras and 5 todhh/tbvi/slp) is currently doing coursework.

Opening Doors Conference June 28 – 29, 2011 – Focus on Literacy for D/HH

Great turnout, terrific presenters, all went smoothly (once we were onsite!!) Ann did a wonderful job of planning this conference!!! She can talk more about this.

******The following are minutes of the information shared during the actual meeting.**

VI. Early Hearing Detection and Intervention (EDHI): (Ruth Frierson)

Official updates: Since our last meeting, the newborn hearing program participated in several activities:

Wonderful talk on “Talks on Tuesday” for the Early Intervention providers across the state in June.

They have been involved with site visits with hospitals (about 7-8, though seems like more). There are 63

hospitals. Don't have our summary completed yet, but it has been very eye opening. Some findings have been very positive. Gives us a great place to start so we know where to start with trainings. Some are basic things that for years we have assumed the hospitals are doing. Checking up with the JCIH recommendations to see what has been collected. Figuring out how they should be collected. Yearly we ask the hospitals to register. Never have asked how old the equipment is- one site the hospital reported the equipment is as old as the newborn screening is and taking about 30 minutes to do an initial screening. Some things are simple and easy to correct, and others are requiring more changes in their process. Some findings are related to how well the follow up is being completed in the areas that they serve.

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 1st, 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? EHDI 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.

Still waiting to hear from the other grant—HRSA grant.

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.

Hearing Aid Loan Bank is in the process of getting funding to continue to give loans to families. Some of the funding from the state is still going towards supporting this program.

Due to many changes within the Department Public Health...They were trying to determine for a long time if the workgroup could continue as a workgroup has to either be a committee or subcommittee and has to be announced publically. They have not announced as to what we need to provide. Need to plan for a public comment.

Unfortunately, their staff is being drastically reduced. They had a data management coordinator that has not been filled and will not be. Also, a quality improvement coordinator which is currently filled but will not continue after August. One of their follow up analysts (Katherine) will also be leaving as well at the end of August, though it might get filled if they get funding.

VII. Partnership for People with Disabilities: (Deana Buck)

Participated in the "Talks on Tuesday" in June- worked so well as it happened at the same time as Ruth was doing the site visits with the hospitals. 75 people registered, 47 actually returned evaluations. Recording is being re-recorded today and will be posted on the website in the near future. All the "Talks on Tuesdays" are archived on the training website (www.eipd.vcu.edu).

Deana shared the information from the evaluation completed by the participants following the webinar. Overall the feedback regarding the content and presentation of the webinar was positive. The majority of participants also relayed that they felt the information was practical and useful and they learned of resources that they could use professionally. Participants also shared what further information they would like regarding hearing loss including: navigating resources; obtaining hearing aids; testing/testing results; information related to cochlear implants; therapy ideas/strategies to share with families; and transitioning for children with hearing loss were among the many responses. Deana shared that some of the things they [the participants] asked for could be developed into a smaller module or another type of training snippet that can be accessed on the website.

Deana sent out the hearing module to the group last Friday and asked for feedback from the group about any typos, or things that need to be changed. The second one that is being developed right now is focused on the 1-3-6 process for Early Intervention providers. Both should be ready by the end of July. They have come up with a site name: www.vaehdi.vcu.edu which will house both of the modules. The partnership has a Guide By Your Side spot on their website right now, but they are currently revising the website. They have built in a spot for GBYS and HALB on the site above if that is where we want them to be linked together. It will also be linked to the www.eipd.vcu.edu. They have landing pads that provide a place to find things on specific topics. The one about hearing loss (can be tracked as to how many people visit) – was one of the ones that has been most visited.

Beth asked if the eligibility considerations document has been posted. It is in the resource section, but not on the landing pad. It can be added to the landing pad.

VIII. General Discussion during the meeting

Bailey is trying an online chat for families. July 25th @ 7pm. She is trying to get someone from each methodology to present. There will be a chat box included where parents can ask questions and get answers right then and there. Beth requested that this be shared so that it could be on the latest Early Intervention Update which will go out later this week. Target audience will be parents in general.

Discussion: Status of the Guide By Your Side Program

History of VGBYS - Ruth – about 5 yrs ago, based on CDC's surveillance of VA EHDl program, at the time, there was no family to family support system. Considered starting from scratch and then they decided that was not a good use of funds. Why recreate the wheel when things are already working. Decided to go with the GBYS model. Put their own spin on it, with home visits, phone calls and parent support. Moved forward and implemented guide by your side guides would be trained. They should be experienced, do site visits, and provide parent notebooks.

Now to the present. Challenges as to how we should revise the GBYS program. Data will allow us to continue the program. Not been able to receive survey results, not compensated parent guides like we thought we would. Some have asked not to be compensated. For EHDl to continue to support, they will need to continue to collect some type of data to show the success of the program. They don't know how satisfied parents are with the program, they don't have an Hands and Voice chapter which is a requirement to have a GBYS program in the state.

From Lisa Powley (on the phone): Started receiving referrals and setting up matches at the end of February. Has received 52 since then. Closed five of those cases, phone calls to guides were not returned, bad numbers, addresses. Only 20 have been completed. Only seven sets of reporting forms have come back. Have some e-mails from the guides saying they have contacted, but not receiving the forms back. A few weeks ago she started emailing the guides regarding the status of the matches. She is getting a response from only a few, so she doesn't know what's been done. Started calling the families, of the few she talked to, some of them had not even heard from the guides. Notebooks were sent to the family after a guide had been linked. Several still wanted contact from the guides. They have 22 active guides- 12 chose not to be reimbursed. About six have been reimbursed since February. Most didn't want to do the paperwork. Once they were registered and an invoice was sent for them to return for reimbursement. Lisa looked at the stats from Regina from the last year and learned that Regina herself did 30 of the 37 contacts, rather than referring them out to guides.

Challenge: How to get the guides to respond?

MJ brought up the idea of developing a contract for the guides. Lisa reports that the guides are volunteers for their services. Back ground checks are done. Ann reported that they are not really volunteers, they went through an extensive process so that they could become guides. The payment for hours was cumbersome so it was decided that they would be reimbursed, so they are more like "semi-contract" but there is not a specific time commitment. The communication system with the guides is almost non-existent.

Ann reported that the Hands and Voices chapter has had a very rough start, but is a very small group that is still working to get a administrative board. Bailey attended the National H & V conference and got a clearer picture of what needs to be done. Some of the more successful GBYS programs have a very small group of guides, that are under contract and considered part time employees. Need to wean down to the guides that are good and really want to provide this service. Need a clear outline for the guides – if we made it smaller and it would get bigger and better. Most of the meetings have been done on the phone. In the VA Beach area there is only one guide but this is where most of the referrals are coming from. Also having a dedicated regional coordinator and a few devoted guides that makes the success even higher. Might need to make some exceptions to what Hands and Voices requires. They need to do more events but this requires funding. Someone needs to be in contact with the guides. Wondering if some of the guides are no longer interested in being a guide. Needs to be a feedback loop when the guide gets the referral, acknowledging that its been received.

Most parents don't want to be reimbursed. If its housed at state agency, there will be paperwork. If we are going to continue it, there has to be a better way to communicate with each other. If something is sent there needs to be a deadline as to respond by. Bailey suggested that we need much more training of the guides, maybe a quarterly training on the phone and/or a yearly training. Ruth will send out the email to all the parent guides and give them a date to respond by. If they don't respond, they will become inactive. Evaluate what regions are covered. Then have less parent guides. Determine the number of parent guides by area and need. If parents really sincerely do not want to be reimbursed- could they donate their reimbursement to Hand and Voices. They need to really work on developing a chapter, because if we don't end up with a chapter, we will have to let go of GBYS program all together.

Challenge: Who houses the Guide By Your Side program?

Where it is housed will be placed out for bid to various agencies/programs. Then they will develop the criteria of what it will be. Maybe there will be a steering committee for the program. GBYS brochures have no phone because we don't know what that will be. They talked about having the parent guides names listed on the website. Other state GBYS has a listing and a little bio next to each guide. It was brought up if this is contradictory to the guides having an unbiased opinion. Having an e-mail listed to monitor. Ideas of online and/or face to face. Christine pointed that we may have more people interested if they would be the email parent. Parent coordinator needs to be a Hands and Voices board member. Does the coordinator have to live where the program is being housed. A lot of the calls need to be done in the evening/weekends to reach the families.

Hands and Voices Chapter NEEDS to be established. Discussion ensued on what the requirements are for board members. Parent members need to have a child with hearing loss, though the parent themselves does not need to have hearing loss. Former acting executive director, Tiffany Johnson still wants to be counted. They currently have four people.

Contract with Guide By Your Side with Care Connection has ended. Lisa has agreed to continue on the side for the meantime. Do we want to do interviews for the parent coordinator? If Hands and Voices wants to be the sole source, then who writes the grant. The money is not dependent on who the source is. Several schools for the deaf that are the home for the Guide by Your Side- Casey learned this at a recent conference at Gallaudet. How are you going to recruit for the coordinator? The same way that it was done the first time.

Game plan: Letter to all Guides- are you in or out?

Letter for bid will go out.

Parent Coordinator posting will go out next week for distribution.

Ruth will need volunteers for the panel for interviews.

*All of this will be determined August 1st.

How do we want to proceed with the matches from now until September? (asked by Lisa). Ask the guides if they are willing to do voluntary matches until September 1st. Daphne will hold off on doing more referrals for the time being. Notebooks will still be sent, though concerns were raised that they notebook is a bit intense and includes a lot of information.

Next Meeting: September 12th at 11am- 130pm at Henrico CSB.

Minutes Submitted by: Patricia Eitemiller