

**Hearing Workgroup
February 27, 2006
Department for the Deaf and Hard of Hearing**

Attendance: Linda Eggleston, Debra Holloway, Casey Morehouse, Pat Dewey, Ruth Frierson, Beth Tolley, Carol Weigle, Debbie Pfeiffer, Ann Hughes, Peg Suttentfield

Minutes from January 23, 2005

Typographical corrections were provided to the minutes; minutes were then approved.

Announcements and Celebrations

The date of the next meeting was changed from March 29 to Tuesday, April 4 from 9:30 to 3:00.

Ann Hughes was introduced to the group. Today is her first day in the position vacated by Debbie Pfeiffer at the Partnership for People with Disabilities. Her responsibilities include providing technical assistance for the Virginia Network of Consultants (VNOC), the Partnership training project which is grant funded through the Virginia Department of Health, and overseeing the Reading Priority Project Workgroup.

The Family Involvement Project just hired a Northern Virginia representative and they are in the process of hiring a representative for Tidewater.

90 completed surveys to determine capacity at the local and state level to meet the needs of children who are deaf and hard of hearing have been received. Discussion followed about who might be able to help with data entry and data analysis. Debbie, Ann and Pat will check about resources within their agency and will let Beth know.

Follow up from Last Meeting

Debbie contacted Jeffrey Bennett at the Sertoma club. Jeffrey was receptive to the idea, and he will take the idea to the club. He also informed Debbie that the national club has a matching fund program. Debbie provided written information gleaned from the minutes of past meetings.

Pat contact Jeaninne Beden, of the Quota club, providing the same written information that Debbie used. Pat has not heard back and plans to re-contact Jeanine. She will also ask for a state contact person.

Carol contacted Joni Alberg, but has not heard back. Carol reminded the group that North Carolina's Beginnings obtained their initial funding through the work of parents approaching organizations. Later, they were able to receive funding through the legislature.

The group discussed the need to firm up the model in order to be able to provide details about the program and in order to provide budget information in order to provide consistent information to potential funders.

Pat talked with Nancy Bullock, Director of the Program for Children with Special Health Care Needs. She manages the Regional Care Connection for Children Programs. Pat reported that Nancy believes that this project falls under the auspices of the Care Connection for Children. However, now this is not a good time to approach these centers. The newborn screening has

been increased to include 30 conditions, and Care Connection for Children case managers will be responsible for case management for the children who are identified through this screening. Nancy suggested that the concept would be introduced in the summer. Pat will go to a meeting of the managers in each region. (Managers meet once a month). They would need a flow chart of what is happening now and what we want to happen. Pat reported that Nancy understands there is no money and that the system we are building involves having people visit families in their homes. They would serve as supervisors and there also may be people within their system who are qualified to serve as family guides. Confidentiality issues would not be an issue if Care Connection were the link since this is a Health Department function.

Discussion followed about what this would mean about the system we have been discussing and whether we should start a system with volunteer professionals and paid or volunteer parents.

Carol had checked with Leslie Hutcheson-Prince about VDDHH taking this project on. Leslie indicated that this is within the scope of what they do, but they could not take this on without additional money due to their current workload. Leslie said that this couldn't be put into a budget until 2008.

Some of the concerns the group has raised about the program as discussed so far have included liability issues, including background checks for persons serving as family guides, liability for driving, etc. A possible downside of using Care Connection might be the perception that it is a medical model. A possible down side of using VDDHH is that they are viewed as a visual model and being a service mainly for adults.

Ann reported that *Hands and Voices* is taking over the training program for Wisconsin's Parent Guide by Your Side Program. So Wisconsin cannot share their training program because this is a national program. Janet DesGorges is a parent who is a leader with the Hands and Voices organization.

Casey reported that the Virginia School for the Deaf and Blind in Staunton could host the training after June. The charge for a dorm room is \$15. There is no air conditioning in most of the dorm rooms, though there is air conditioning in training rooms.

Pat indicated that they will be revising the materials on EHDl website. The group recommended that revision be made to clarify that ***all children under age three are to be referred to Part C.***

Ann will contact Leanne Seaver to see if there is anything in the Hands and Voices training that Virginia could borrow/use.

Debbie will adapt the contact report form from the one that is used for VNOC or from the Wisconsin program for next meeting.

The group posed the question about whether Care Connection for Children would be able to implement this program (in whatever role is determined for that agency – mentor, supervisory, etc.) by January 1, 2007.

Training Opportunities

Debbie will follow up with Paula Pittman from SKI-HI to schedule a two day follow up training probably in June for the participants who have completed the SKI-HI training.

Online trainings (with tuition reimbursement) are available through IHHE. Information has been sent via email to local system managers and several have responded.

For information about the EHDI conference, go to <http://www.infanthearing.org/> and click on 2006 EHDI Meeting, in the middle of the page.

Ruth reported and the conference and said that several sessions focused on exactly what we are working on here. The majority of first contact groups were using parents and were paying the parents. They are having the same challenges our group is experiencing: funding and training.

Minnesota has a team approach, which includes an audiologist, teacher of the deaf, and special educator. Minnesota has 16 teams. Their approach also includes a family connection.

Development of Virginia's Family Guide Program

The group developed the job description and a list of skills and qualifications for parents and for providers serving in the family guide role

Job Description

The *Family Guide* will work with parents of newly diagnosed children, birth to age three with hearing loss. The *Family Guide* will:

1. Receive referral for the Virginia Department of Health, EHDI program
2. Contact parents and arrange for home visits within 48 of receiving the referral.
3. Provide "VEHDI Parent Resource Guide" and other support materials to the family
4. Review the Guide and support materials with the family (as scripted)
5. Answer or get answers to the family's questions
6. Provide contact information for other parents, professionals and resources
7. Provide appropriate support, encouragement and compassion
8. Provide information on Part C local Central Point of Entry programs and make contact with this agency (parent permission)
9. Provide unbiased information on communication options and the unique needs of children with hearing loss (according to scripted training document)
10. Provide timely follow-up to VDH within two weeks of initial referral
11. Complete contact report form for each referral within one week of initial visit
12. Attend initial and periodic Family Guide training program(s)

It was suggested that a form be left with families at the first visit including contact numbers etc, and including a place for the family to write questions they would like to ask at next visit or when they call the family guide.

The group discussed whether there should be one or two visits and felt that the decision should be up to the parent. Some parents may want or need two visits. Some may need or want a

phone call for follow up. Peg suggested that we monitor this and see how many families choose to have one visit and how many choose two for future planning. It was also suggested that we have families provide feedback about the helpfulness of the service.

Parent Skills and Qualifications

- Be a parent of a child with a hearing loss
- Be a good listener and communicator
- Be able to describe communication and educational options in a unbiased manner
- Willingness to learn a “scripted” intervention approach with families
- Demonstrate ability to offer appropriate care and understanding to families with newly diagnosed children with hearing loss
- Knowledge of or willingness to learn about local, regional and state resources
- Share information about self and other with ethical and confidential considerations

Provider Skills and Qualifications

- Knowledge and understanding of children with hearing loss
- Knowledge and understanding of child development
- Ability to describe communication and educational options in an unbiased manner
- Offers appropriate care and understanding to families with newly diagnosed children with hearing loss
- Ability to listen and communicate effectively, directly or through an interpreter
- Ability to work with others in a collaborative team approach
- Knowledge of local, regional and state resources
- Handles all information confidentially
- Ability to work independently and to maintain records and reports
- Willingness to attend periodic trainings

Discussion followed concerning coordination of parent involvement and fiscal management. The state family representative for the Infant & Toddler Connection of Virginia, Debra Holloway, could potentially manage the parent involvement and possibly serve as the fiscal agent. Parent-to-parent training, “Why Am I Here”, Collaboration and basic advocacy training can be provided through ArcFIP (the Family Involvement Project of the Infant & Toddler Connection of Virginia). Debra raised a concern about liability related to visiting in families’ homes.

Pat indicated that Virginia Department of Health could serve as the oversight body (management and quality control) through the EHDI program.

Preliminary Draft Budget:

The group generated a preliminary draft budget for the first year as follows:

Reimbursement for up to 6 hours of home visits for 100 children at \$15/hour.	\$9,000
(100 newborns identified/year x up to 2 visits x 3 hours)	
Mileage = .32.5/mile x 200 round trips x 80 miles average round trips:	\$5200
Training: Parents’ Time = \$15/ hour/ parent x 12 hours x 10	= \$1800
Meals = \$60/person x 15 (include trainers)	= \$1500
Mileage -	= \$ 500
	\$3800

Phone cards available through ArcFIP

The above estimates do not include the cost of materials for training, nor do they include lodging costs for parents or trainers or transportation costs for trainers. It is anticipated that the trainers lodging costs would be covered by their employers. When additional unanticipated costs are considered, as well as the cost of training additional parents in order to have multiple parents trained to respond in order to have the desired availability, the estimation of cost for implementation of this program for the first year is between **\$20,000 and \$25,000.**

\$7,000 is available through VDH through the Partnership for People with Disabilities would cover training costs, including developing the training, working on the script, materials, finalizing and providing the training.

Communication Disorders Foundation is an organization that could receive donations and also disperse the funds. It is a 501C organization.

Workgroup Decisions/Recommendations

The group decided to develop this program with parents as the Family Guide and to train as many parents as are interested and qualified in order to have a sufficient pool statewide to meet the needs of new families. The group suggested calling the program the Early Hearing Detection and Intervention Family Guide Program (EHDI Family Guide Program).

Work that is Necessary to Implement the Family Guide Program

- Confirm approval of name – VEHDI Family Guide Name
- Provide information to Part C and other systems and agencies who might be impacted
- Develop application and application process
- Develop Interview questions and interview process (including interview team – oversight body)
- Develop training (4 hours PREP training is appropriate and ready, Beth can do Part C, Debra can do parent training,
- Identify potential applicants, obtain their contact information, develop consistent information to provide to them to explain what we are asking them to apply for and invite them to participate
- Accept applications, interview and select “guides”
- Develop Training
- Implement Training
- Start Program
- Ongoing – QA/parent input, tie in with Part C

Potential Parent Applicants

A list of names was generated of parents who might be interested in applying to serve as Family Guides. This list included 6 parents from Richmond, one from Northern Virginia, one from Staunton, two from Tidewater and two for whom the region was not specified. Peg Suttentfield who is a member of this workgroup is interested in serving as a Family Guide!

Agenda for Next Meeting

1. Finalize name for program
2. Report on assignments
3. Develop protocol for program
4. Set training date
5. Finalized documents (application, etc.)
6. Determine next steps

Assignments:

Development of the Program

- o Carol Weigle will draft a flow chart of the process for the next meeting.
- o Debbie will adapt the contact report form from the one that is used for VNOC or from the Wisconsin program for next meeting.
- o Beth and Sue and Ruth and Pat will determine which local systems fall into the 7 regions that were identified in the September meeting based on location of the children with identified hearing loss.
- o Pat will approach Care Connection for Children in the summer to see if this is something they are willing and able to take on. Pat will be able to provide written information and a flow sheet of the model, and tell them about the training that will have been done by the time she presents this opportunity to Care Connection for Children personnel. Pat will meet with regional managers of Care Connection for Children in the summer
- o Carol will draft revisions to the forms from Wisconsin's Guide by your Side program to reflect Virginia's Program

Funding:

- o Debra will ask the Arc of Virginia if money can be donated for specific project.
- o Debra will also check with INFO-VA to see what role this organization might be able to play.
- o Ann will check with the Partnership about grant opportunities to support this project and whether the partnership can receive donations to support this and disperse funds.
- o Beth will ask about whether there is money from the Part C office to support this.
- o Debbie and Carol and Pat will continue to check out available funding sources

Training:

- o Ann will contact Janet to see if there is anything in the Hands and Voices training that Virginia could borrow/use.
- o Carol and Casey will check about the availability and specific details (how many rooms are air conditioned, for example) for lodging as well as for the training room at the VSDB at Staunton. The group suggested a Friday and Saturday in June, July or early August.

Potential Family Guide Applicants:

- o Carol will contact parents that she knows and the parents that are running parent groups and the Virginia chapter of Alexander Graham Bell group.
- o Carol will contact Fredia and Ellen Austin to see if they know of other parents might be interested in serving as Family First Guides.
- o Beth will ask Northern Virginia System Managers to contact parents of children who are deaf or hard of hearing who have been in the system for a year or more
- o Carol, Debbie, Ruth and Ann, Debra and Beth will contact parents about their interest.

Other:

- Pat, Ann, Debbie – check on data entry and analysis capabilities for Hearing Intervention Capacity Survey

Next Meeting:

Date: **Tuesday, April 4, 2006**

Time: **9:30AM – 3:00 PM**

Location: **Department for the Deaf and Hard of Hearing**