

**Hearing Workgroup
May 3, 2006
Department for the Deaf and Hard of Hearing**

Welcome and Introductions: Lesley Kravitz, social worker for the Fairfax Bright Beginnings Program was welcomed to the group.

Attendance: Pat Dewey, Debbie Pfeiffer, Ann Hughes, Debra Holloway, Beth Tolley, Ruth Frierson, Dana Yarbrough, Pat Wiley, Linda Eggleston, Leslie Hutcheson-Prince; Lesley Kravitz

Review of Minutes

Several revisions were suggested; minutes were then approved as revised.

Announcements

Carol Wiegler has resigned from the group due to the time commitments of her new job.

Pat reported on information she received through AG Bell including:

- Information about the Hearing Aid Assistance Tax Credit Act bill (HR414), which would provide tax credits for hearing aids.
- A bill has been introduced to reauthorize early hearing detection and Intervention Programs (HR 5250).

See www.agbell.org for more information.

Determination of CoChair for Workgroup

It was suggested that a parent serve as co-chair. Debra will talk with Missy Colley, the Tidewater (Early Intervention) Parent Representative to determine her interest. If Missy is not interested, a collaborative process will be used for assisting with leadership of the group.

Training and Resources

Call to Action training will be held in Richmond on May 20, 2006 at the University of Richmond.

Celebrate Communication, a free conference geared for family and children, with information about technology and resources for hearing will be held at the Cultural Center at George Mason on May 13.

Lesley recommended that group members join the Northern VA Resource Center for Deaf and Hard of Hearing (NVRC) list serve which provides timely information relevant to persons with hearing loss. (nvrc.org) Lesley is on the Board for NVRC for Deaf and Hard of Hearing Persons.

Debbie brought two resources to share:

- Alexander Graham Bell Voices.
- Journal of Deaf Studies and Deaf Education

PREP manuals are being disseminated to the six early intervention regions.

Ann and Leslie and Debbie presented a program at the Annual Early Intervention Conference. 40 people attended. The presentation included practical information about resources (including information and training resources as well as the hearing aid bank and funding resources) and how to implement the Consensus recommendations using the available resources. Positive

feedback was received from participants. 14 individuals expressed interest in participating in the online training courses.

The hearing aid loan bank has traded half of the FM systems for hearing aids due to less demand for the FM systems. These loaners are available for children up to 18 years old.

Perspectives from Lesley:

Lesley reported that many of the children in the Bright Beginnings have multiple disabilities. About 20% have severe disabilities and hearing, though there is a loss, may actually be a strength. Many of these families are focused on dealing with the more critical issues. Also, multicultural issues present challenges.

Lesley commented that, at the time of diagnosis, the focus needs to be on language development, not on the choice of modality because there are so many variables that will affect the choice of modality. Debbie commented that we are advocating the philosophy that you use everything initially to help child develop language, with decision about modality being made later. One challenge now is that some of the diagnosing audiologists are recommending cochlear implants and the cochlear implant team is telling parents not to sign. Lesley responded that parents need to tell their story. Audiological issues need to be explained including the fact that hearing aids and cochlear implants don't make you a hearing person.

Lesley is involved in obtaining scholarships for children to go to a camp for children with hearing loss in Maryland. The camp is sponsored by the Lions Club.

Report on Assignments/Today's Discussion

Budget Information

Dana presented a copy of a draft budget for the Family Guide program. See attachment. It is not known how much is actually available for the in-kind donations.

The Medical Home Plus is new and is losing their leader (Fran Gallagher). Dr. Gewanter and Dr. Kraft are strong supporters of children with disabilities and their families, and are experienced in obtaining grants. The Medical Home Plus is a 503 C 3 agency.

VDH can simply write a contract with the Partnership. There are parents employed at the Partnership who could help with this. The Partnership does require funding for administration of the program. Other potential "homes" most likely require funding for administration of the program.

Parent guides should not be listed as "volunteers" since they are being paid. The group agreed that the program should aim to have a diverse parent population of parent guides because having parents whose culture is the same as the new parent makes a big difference in trust for the families. There are differences within cultures, which complicates the training and increases the challenge of having parent guides available who are able to meet families' needs. This will impact the budget as training costs need to factor in costs of (language) interpreters. The group discussed keeping the perspective of dealing realistically versus aiming for what is ideal, but not possible.

Dana will add the cost of interpreters into the budget. Consider Red Cross, schools, Police Departments, Social Services, Hospitals, and the language line, etc. as potential sources for interpreters. \$50 is the minimum cost which pays for a given number of hours and there is

additional cost for more hours. Dana will look up costs on www.languageline.com.

The budget that Dana developed didn't include costs of training. (Also, won't need the full budget amount because the program will not be up and running for a full year).

There is money in the current HRSA/MCH grant to provide training this year (through end of September). Money that is not spent from MOA is sent to VDH and the money can plug into next year's grant. Money has to be spent (not just encumbered) by end of contract year (which will be end of September) for this year.

Expect to know in July if grant for next year is approved.

The group recommended using this year's fund to purchase curriculum and to contract with H & V if there is a cost of having the program.

Potential Funding Sources:

Pat contacted Joni Alberg from the Beginnings program in North Carolina regarding the conference in September. Joni indicated that the grant will not cover the cost of training or training materials. Joni indicated that she is available for helping with training, specifically on the topic of unbiased information. She is not available to train family guides. Joni also indicated that they are trying to obtain funds to cover transportation for more parents to attend the conference, which will be in Salt Lake City.

Jeannine Beden of the Quota Club has reported that two clubs have indicated that they will be able to contribute funds to the program. The amount is not known yet. Jeannine also indicated that additional clubs may also decide to provide funding.

If VDH receives next year's Health Resources and Services Administration (HRSA) grant, there will be \$30,000 available for this project. There are already funds available through the Partnership (from current grant) for training. The VDH grant from HRSA is in the first year of the 3 year grant. This program will be included in year two (06-07) and this program can also be put in the HRSA grant budget for (07-08). The grant year begins in September.

If Virginia develops a Hands and Voices chapter, it could serve as a 501C agency for this agency.

Debbie was unable to reach Jeff Bennett from Sertoma. She will obtain new contact information for him and contact him.

The Lions Club is invested in serving the deaf and hard of hearing. They have a hearing aid bank.

The Rotary Club sponsors children giving speeches and are invested in hearing and hearing loss and may be a potential source for funding.

Long term funding will be sought through legislative action to include this program in the state budget. Leslie reported that in August, state agencies will prepare their budgets for FY 07-09. The best chance to get something accepted in the budget is the first year. This August, agencies will begin preparing budgets that will start in FY 07-08 (July 07). Leslie advised that more information is needed, possibly piloting, before presenting to the legislature for requested funding. Leslie recommended being prepared to put this in the budget (through VDDHH) for FY

09-10 (working on this in August 08). If this process is used, there will be a gap in funding between August 30, 2008 and July 1, 2009. Leslie will talk with the VDDHH Management team about possibility of providing financial support during the gap. The transition of the program could be achieved through a memorandum of agreement.

Information from Hands & Voices

Ann reported on conference all with Leeanne Seaver, Executive Director of Hands & Voices, about the questions the group generated concerning Guide by your side representative. See handout. While there is flexibility in implementing the Guide-By-Your Side program, you cannot use the name unless you are following the basic guidelines of the program. One of the requirements is that a parent be the leader. Lesley commented that with the programs that are parent run in Fairfax, parents do all of the work, but she and the principal attend meetings and provide critical information and guidance that is essential for success of these programs.

Ann and Debbie will see Leeanne in Mid May at a conference to ask additional questions..

- If you purchase the curriculum, do you have to adopt the program?
- Is there a contract associated with the program? If yes, can we see a copy.
- What does it cost to buy this packet? Is there a yearly cost? What are the strings attached to the program?
- Can you purchase one Training packet and make copies?
- Is the parent leader required to be a parent of a child who is deaf or hard of hearing?

Recruiting Parents

Debbie contacted several parents - Billy and Kelly Reynolds are interested. Lisa and Steve Kearns are interested. Pat and Karen Rhatigan (Nova) and Jackie Flagler and Heather Harwood have been approached about their interest. All except the Rhatigans are from Tidewater. Irene Schmalz from Northern Virginia is also interested. Debra reported that Missy Colley, the Tidewater Early Intervention Family Representative who is also the parent of two children with hearing impairments could possibly serve as a family guide. The group suggested that Missy be invited to join the workgroup. Debra will invite Missy to be a part of this workgroup.

Debbie is aware of a parent who is a potential candidate for coordinating the program.

A flyer was developed and was given out at the Early Intervention Conference. Debbie will send members the flyer. Before disseminating further, more decisions need to be made. Will update the flyer with application process.

Debbie is developing a group of teachers of the deaf. She will create a listserv. This can be used to solicit assistance with contacting parents who may be interested in applying to be a parent guide.

Dana will send Beth info from National Parent to Parent program about recruiting parents and Beth will send copy to members.

Planning for Training

The group identified the need to think about alternative mechanisms for training because new people will come on board after start of the program. Alternatives include webcast, one on one, etc. In order to be considered for the program, potential candidates must have a commitment to come to training.

Safety issues in program implementation need to be considered as plans are developed for training. The Police department is a resource for safety issues. Liability is handled through home agency. Training needs to include confidentiality information and expectations for guides. Parents would have to give permission for their name to be sent to the Parent Guide program.

Ann Hughes will plan to attend the Hands and Voices Conference July 20 and 21 which includes train the trainer content for Guide by Your Side. Consideration will be given to having another person, perhaps a parent, also attend.

The following people were identified as trainers for Virginia's program: Lesley, Ann, Debbie, Debra, Dana and Beth.

Informing Early Intervention Programs

Beth reported that information will be included in the Virginia Infant & Toddler Connection Technical Assistance Update about communication with the EHDI coordinator.

Flow Chart

The revised flow chart was discussed and further revisions were made. See attachment.

Decisions

The group agreed that there is not enough information yet to make the decision about the program being affiliated with Hands and Voices. Ruth contact Idaho and Minnesota to see how they implemented the Guide-By-Your Side program and their assessment of their experience. Ruth indicated that some of this information may not be available because the program is new for Hands and Voices as they have just purchased it from Wisconsin in the last several months.

Additional information is also needed from Hands and Voices. Debbie and Ann will talk with Leanne and Janet at the National Deaf Ed Summit in mid-May. After the above information is obtained, the group will do a cost analysis comparison of going with Guide By Your Side and developing Virginia's own program.

Clarification was provided that inclusion in the Beginnings grant does not obligate Virginia to following the Beginnings approach. The grant supported consultation from Joni Alberg to Virginia.

Discussion followed about what it would take for Virginia to develop the program if the decision is made not to proceed with Guide by Your Side. The Train the Trainer training in July at Hands and Voices will provide information. Content for training has already been identified by the workgroup. The cost for the training would include time to develop curriculum, including scripts, and cost of printing for handouts. The cost of people's time needs to be calculated even if they are not charging for the time in order to do an accurate cost-benefit analysis.

Advantages of going with the GBYS program include being included in research and it also may be easier to obtain federal grants.

Lesley emphasized the fact that Fairfax's experience is that the needs of the program are

constantly shifting (economic issues, mix of children and parents - more complicated kids, cultural mix, etc.) Being with a national program may help the program be aware more quickly of shifts from the national perspective. The program must be very flexible in order to adapt to changes in needs from the national and local perspective. Planning also needs to consider the ability of parent guide to meet needs of parent of child with multiple disabilities. Connecting immediately with Infant & Toddler Connection would be very important. If program is connected to Care Connection for Children, the case manager could make a joint visit with the parent guide.

The workgroup decided that a pilot would be useful to evaluate what has been developed and work out the kinks. Recommended plans include identification of potential candidates, targeting 4 from one region (If more parents, including those from additional regions, are identified and interested, they would also be included in the pilot). The timeframe for announcing the program and obtaining responses from parents would be June and July. A set amount of time would be determined for implementation and evaluation of the program before expanding it statewide. Money donated by the various organizations that have been approached (such as the Quota Club, etc, could possibly be used to support the pilots).

The workgroup discussed possibilities for the "home" for the program. The following possibilities were identified:

Short Term

Partnership for People with Disabilities
Parent to Parent
Virginia ARC
Medical Home Plus

Long term

VDDHH
Medical Home Plus
Care Coordination for Children

It is expected that VDH will receive the HRSA EHDI grant and if so, management of the program will be possible through the grant. Pat indicated that it would work well to incorporate this program through the Memorandum of Agreement with the Partnership for People with Disabilities. The Partnership could subcontract out part or all of the program.

The program home would be responsible for identifying and hiring the coordinator for the program. Eventually, if not immediately, a parent of a child with hearing loss needs to be involved with the program.

If we have another year for grant funding, the same management approach could be used.

The workgroup identified the need, prior to the 2nd year, to present budget amendment to fund the program permanently. VDDHH may have some bridge money, or whoever is going to be the permanent home (VDDHH or Care Connection of Virginia (VDH) may be able to bridge the gap between grant funding and inclusion of the program in the state budget.

Plan/Homework

Everyone will circulate information they receive between now and the next meeting. Beth will send contact list for everyone to be able to share information with entire workgroup.

Ruth contact Idaho and Minnesota to see how they implemented the Guide-By-Your Side program and their assessment of their experience.

Dana will provide sample application and screening tools. Ann will ask if we can see Hands and Voices application and screening form. Anne and Dana will integrate this into a draft application and email it to members.

Lesley will email a form that Bright Beginnings uses or will bring it to the next meeting.

Dana has a reference form from the Virginia Board for Disabilities. She will send this to members. Ann and Dana will tweak and distribute.

Debbie will draft a letter to go with the application for the June meeting.

Debbie and Ann will talk with Leanne and Janet at the National Deaf Ed Summit in mid-May.

Dates and Location for next meetings

June 7 – Skipwith United Methodist Church

July 12 - VDDHH

August 16 - VDDHH

Agenda for June Meeting

Flow chart

Decisions

Finalize application process (forms and process)

Start plans for training

Review revised budget

Identify pilot expectations and evaluation criteria for pilot

Review who has expressed interest

Finalize letter to go with application -

Family Guide Flow Chart from Point of referral to the Program

