

**Hearing Workgroup
June 8, 2007
Henrico Mental Health West (Woodman Road)**

Attendance:

Beth Tolley – Technical Assistance Consultant, Infant & Toddler Connection of Virginia
Ruth Frierson – Early Hearing Detection and Intervention Follow Up Coordinator
Pat Wiley – Care Connection
Cory Hall – Service Coordinator, Educator, Infant & Toddler Connection of Hanover
Melinda Smyth – Educator of the Deaf, Hanover
Debbie Pfeiffer – DOE Technical Assistance
Ann Hughes – Consultant, Partnership for People with Disabilities
Fredia Helbert – Audiologist, Wise County
Claire Jacobson – Audiologist, James Madison University
Wanda Walker – System Manager, Southside
Dana Yarbrough – Director of state Parent to Parent, Manager of Guide by Your Side
Lisa Powley, Loaner Hearing Aid Bank
Sandra Woodward, Loaner Hearing Aid Bank
Judy Alonzi, VCU Extern working on ECSE degree
Jennifer Hutson, parent

Membership:

- New members were welcomed to the group.
- The group acknowledged with great sadness as well as best wishes that Pat Dewey will no longer be a part of the workgroup as she is retiring at the end of June. Great appreciation was expressed for her dedication, determination and hard work which has resulted in greatly improved identification, supports and services for children who are deaf or hard of hearing and their families in the state of Virginia.
- Potential additional members were discussed and it was determined that the optimum way to benefit from the experience and expertise from a wide range of additional professionals is through a “resource group” of interested persons who would receive the minutes from the meetings and who could be called on from time to time to participate when specific topics are addressed. The group indicated that it would be beneficial to add more family members. The group recommended that additional members be added through a letter to families inviting their participation. Include in letter the need to attend, the role of parents, and the fact that there are currently two slots available for new family members. ***Beth and Dana and Jennifer will draft an invitation. Information about participating as a member of the resource group (as an alternative to being a member of the workgroup) will be included in the letter.***

Minutes from the February meeting were approved.

Conferences and Trainings

- The next Speech and Hearing Association of Virginia (SHAV) will be held in Portsmouth from March 5-8. Opportunities for presentations by members of the workgroup were identified and include what happens after identification, Guide By Your Side and early intervention for infants and toddlers with hearing loss.
- Development of an Auditory Function/A-V Techniques (July 23-24) – Radford
- A-V Therapy – Development of Spoken Language Module (July 25-26) Radford
- Unlocking Opportunities, Unleashing Potential: Educating Students Who are Deaf and Hard of Hearing Through Communication, Literacy, Technology and Transition (August 8-9) – Staunton

- See the Sound: Visual Phonics (August 10) Staunton
Hearing Aid Loaner Bank

Sandra Woodward and Lisa Powley presented information and addressed questions regarding Care Connection and the Hearing Aid Loan Bank including the following:

- Care connection provides case management for children with special needs. Six centers cover the entire state. Care Connection is funded through the Virginia Department of Health through the Maternal Child Health grant. Nancy Bullock is supervisor.
- Hearing Aid Loan Bank:
 - 113 children have been provided with equipment since May 2005. 45 devices are currently out. The current inventory of available aids is low.
 - In May 2008, the warranties for the current aids will expire
 - A review of what additional assistive listening devices are needed is in process
 - Two bone conduction devices have been added (Headband BAHA)
 - Only order two items can be added to the inventory at a time through state procurement office
 - Funding has paid for other equipment such as batteries and strobe light.
 - There has been success with Medicaid coverage of FM devices. Brian has been very helpful with this process.
 - The application has a place to indicate if help is needed with obtaining the permanent hearing aid. If help is needed, assistance is provided through Care Connection for Children. Children in other regions are referred to the Care Connection that served the area where they live.
 - The majority of the aids are loaned to children birth to three. The average age of school age children who borrow the aids is 6 – 8. Many of the older children are immigrants who have not had early identification.
 - Two high volume regions are Northern Virginia and the Tidewater area.
 - The average length of time children borrow aids is 20 – 25 weeks.
 - Regarding the process for loaning:
 - Work is occurring to streamline the process.
 - Once a family has completed an application, the aids are usually sent out within 24 hours
 - Survey responses from families were mostly positive. Minor issues were identified, i.e. return shipping.
 - Ideas discussed for increasing awareness about the Hearing Aid Loan Bank
 - Information was provided at the Pediatricians Conference this spring. Referrals increased after that.
 - Participation as vendor at other conferences was discussed including Shining Stars, PEDS at the Beach, Annual Early Intervention Conference, etc.
 - Fredia will facilitate having them participate at SHAV conference
 - Dana and/or Jennifer will provide Sandra and Lisa information about Hands and Voices to provide to families who borrow aids.
 - Sandra and Lisa have direct contact with families and the referral sources. They assist families with funding issues, including helping them to obtain SSI. They provide information about Legal Aid/Just Children, which assists families to pursue funding when insurance companies deny coverage. Legal Aid: Just Children provides assistance with advocacy.

National Center for Hearing Assessment & Management (NCHAM) Project

Fredia reported on an NCHAM project, which involves provision of equipment and training for 5 early head start programs in Virginia. Fredia will be participating in this. The project will address gaps in screening and will provide equipment. The goal is to find children who were missed or lost to follow up, as well as children who have moved to Virginia and weren't screened at birth.

Guide By Your Side (GBYS)

Dana provided a written and verbal update on the GBYS program. She distributed brochures and provided a sample of the Family Notebook. The directory of resources has been translated into Spanish, but the family notebook has not. She reported that the GBYS website (www.vcu.edu/partnership/GBYS) should be functional next week.

Matches

There have been 33 requests for matches; 18 from Northern Virginia, 3 from Roanoke, 7 from Tidewater and 5 from Richmond. One person declined the match. One child died before a match could be made. Six families had languages other than English, including two Spanish, two Asian and two middle European. Only 5 matches have been completed/closed. The process is taking longer than anticipated due to cancellation of appointments and families stretching out the contacts over a longer period of time. The process is lasting 8-10 weeks.

Recruitment and Training Plans

More capacity is needed in Northern Virginia, Tidewater and the far southwest. Recruitment for applicants from across the state is in process. Five applications have been received to date. The next training will be held in Richmond on September 14 and 15, 2007.

Involvement of Professionals/Communication with Local Early Intervention Systems

Workgroup discussion included use of professionals and/or parents who are themselves deaf or hard of hearing as guides or as resources to the program. The National Hands and Voices organization involves professionals as resources, but not as guides. Discussions are occurring about to incorporate professionals in the process.

The group also discussed questions from Part C Local System Managers about the program. The expectations about the role of the Family Guides and the relationship/communication of the Guides to the Local Part C System have been a source of confusion. This is probably because initial discussions included the possibility of using a parent/professional model rather than a parent model for the program. Dana and Jennifer clarified that Family Guides are expected to provide only general information about Part C, and most importantly who to contact their local system. Jennifer keeps in contact with guides to make sure they are providing the essential information and in an unbiased manner. The sharing of information between Family Guides and the Part C System was discussed and it was decided that for confidentiality purposes, it is not appropriate to share information. However, Family Guides can recommend to the families that they let the Part C System know that they have been through the program and that they share with the Part C System the information and resources they have received. It was decided that it is not appropriate for the names of the family guides to be distributed. This is in keeping with other family matching programs where names are provided on an individual basis (when a match occurs). The

possibility of the guides meeting periodically for education, support and idea exchange was also suggested, including the possibility that a professional might be invited to address a specific topic.

In order to facilitate the Local System Managers' understanding of the GBYS program, the family notebook (which contains the information the Family Guides share with families) will be emailed to local systems. The information from the manual will also be posted on the GBYS website. System Managers must make sure that the local system staff understands the purpose and role of the Family Guides. Local systems may want to include an informational session about the GBYS program, including a Family Guide as a speaker. System Managers should contact Dana Yarbrough or Jennifer Hutson if they have questions or concerns about the Family Guides or the program.

Financial Information

It is anticipated that the budget for next year will be about \$30,000 less than this year's budget. Dana has approached Mary Ann Discenza about the possibility of some funding from Part C. The long-range goal is to determine a permanent home and permanent funding. The Virginia Department of Health and the Department for the Deaf and Hard of Hearing receive state funding; the GBYS program could be a good fit in either of these two agencies. Additional state funding would be needed to support the program. Frank Harlow, Delegate to VA General Assembly may be asked to sponsor a bill for funding this.

Reimbursement of Family Guides through the state financial system has been challenging. Visa cards will be purchased/used to simplify the process. A suggestion was made to purchase Visa cards with any leftover funding that must be spent this year.

Family Guide Feedback and Survey

Only one feedback form has been received from the Family Guides. It was very positive. A survey of the Guides is being considered to obtain their perception of current and future training needs.

Hands and Voices

Jennifer is working to establish a Virginia Chapter of Hands and Voices. A Board will be developed. There must be 51% representation of parents on the Board. There will be an initial planning meeting for all interested families and professionals on July 10 from 6-8 at the DDHH. Topics will include steps needed to form the chapter and goals for the chapter, etc.

Follow Up Process through the Virginia Department of Health

If an infant fails the newborn hearing screening:

- VDH sends a letter to the family
- VDH sends a second letter reminding them to have follow up testing
- VDH sends another letter if the child is found to have a hearing impairment
- The Follow Up Coordinator calls the family and asks if they would like a referral to early intervention, GBYS and Care Connection. (Referral means a call to those organizations to provide child/family info). Referrals to Part C can be made directly by the Follow Up Coordinator to the local Part C system. GBYS should be offered to all families regardless of their language. There is some funding in the GBYS budget for translators.

In addition, Ruth may be able to provide translation services for families who speak Spanish.

Referrals to Part C

Clarification was provided to the group that infants are not referred to Part C when they fail the newborn hearing screening because not all of these children are diagnosed with hearing loss when the full audiological assessment is completed. Discussion followed about when and how children are referred to Part C. The following should refer children with hearing loss to Part C:

- Audiologist who makes the diagnosis
- Child's pediatrician
- VDH through the Follow Up Coordinator – upon receipt of paperwork from the audiologist who made the diagnosis

These individuals can make the referral directly to the Part C system. Part C regulations do not require parent consent for referral. (Individual agencies may require parent consent to meet HIPAA requirements).

- Family Guides are expected to provide families with the contact information for their local Part C system.

Ruth reported that some local systems do not accept referrals from her, but tell her to have the families call. Beth will follow up on this. Local systems must accept referrals from all referral sources, not just from families.

The group discussed the importance of early referral to Part C and also commented that radio and TV public service announcements would be beneficial.

Resources

Debbie Pfeiffer has a list of Teachers of the Deaf/Hard of Hearing in Virginia's public school system. Local System Managers can contact Debbie to request that she send information/requests for contracting or consulting to school based Teachers of the Deaf/Hard of Hearing in their area. Debbie can be contacted at debbie.pfeiffer@doe.virginia.gov or (804) 371-4059.

The Virginia Network of Consultants is available for early intervention systems also. This is accessed through contacting Ann Hughes.

Fact Sheet

The group reviewed and revised the fact sheet and the links. It was acknowledged that some of the linked websites would be biased; the key is to provide a balance of resources. Wording was tweaked and several links were added. The group agreed to include a list of the resources at the Department for the Deaf and Hard of Hearing.

Curriculum/Training

The Curriculum/Training subgroup presented information and recommendations. The group discussed options. Discussion included:

- Adapt the existing "PREP" training to online training modules. This involves much more than posting materials to the web. Segments should be between 15 and 20 minutes, link

the segments and include interactive portions. The modules need to be engaging and interactive, not just something in writing put online.

- Locate the training modules on "TTAC online". This website already has a tab (section) for hearing
- Clare Talbert, Nancy and Ann have discussed this project. Clare can assist with the process and Nancy will help with the content. Together they can provide oversight for the project.
- The group explored options about who could convert the training content to web-based training, including Deaf Education students, technology students, other individuals known by workgroup members who have the necessary knowledge, skills and abilities.
- Cost/funding was discussed. At this point, not enough information is available to estimate time needed and therefore cost

Between now and the next meeting:

- Claire will check about graduate student possibilities.
- Ann will contact an individual who does this work and who is a parent of two children with hearing loss.
- Workgroup members will consider if there are other people they can identify who may be able to help with this project.
- Ann will send workgroup members information on how to create webshops
- Budgets will be reviewed to determine what funding could be available for this

Next Meeting: Sept 13, 2007 9:30 AM – 2:00 PM