

**Hearing Workgroup
Richmond, Virginia
October 21, 2005**

Present:

Beth Tolley
Deana Buck
Pat Dewey

Leslie Hutcheson Prince
Casey Morehouse
Barbara Harding

Ruth Frierson
Pratibha Srinivasan
Debbie Pfeiffer

Review of Minutes

Minor corrections were suggested to the minutes of the September 13, 2005 Hearing Workgroup meeting and the minutes were approved as revised. Revised minutes will be emailed to members.

New Member

The group welcomed Casey Morehouse, Audiologist for the School for the Deaf and the Blind as a new member representing the School.

“Family First Contact”/“Family Guide”

The group reviewed the draft document sent by Pat Dewey. Discussion included the following:

- Referral to the Part C system needs to occur immediately when the diagnosis of hearing loss is made. (One of the first functions of the “Family First Contact” would be to assure that the child had been referred to the local Part C system).
- A flow chart is needed to understand how the process works or should work
- Local early intervention systems have great variability in how they operate; the “Family First Contact” would need to understand each local system with which he or she worked to be an effective partner. The “Family First Contact” would need to build relationships with the local point of entry with each local system in their region and with the Care Connection contact.
- It is important that the child’s physician remain in the picture. As other professionals are brought into the child and family’s life, the physician’s responsibilities should not be usurped.
- Potential names for the project and for the people serving in the role of the “Family First Contact” were discussed. A number of suggestions were made. The group decided to use the term “Family Guide” as the name for now for the person serving in the role that is being developed.

Wisconsin Guide By Your Side

Ruth reported on Wisconsin’s Guide By Your Side Program, which involves trained parents of children with hearing loss serving in the role of providing information and support to parents of newly diagnosed infants with hearing loss. Ruth reported that Wisconsin had tried a program like we are attempting to set up with professionals and did not find it to be successful. They are finding this program with parents to be successful. Handouts were provided including the “Job Description of the Regional Parent Guide” and the flyer for the program. The website is

www.wesp-dhh.wi.gov. The group discussed pros and cons of families serving in the role of providing information and support, including the concern about their ability to be unbiased about choice of amplification. On the other hand, parents often accept support more readily from other parents, and professionals, also, are not always unbiased. Discussion included the possibility of pairing parents and professionals. Funding is another issue, since funding is required to support a program like Wisconsin's.

The group felt that it would be beneficial to invite Judy Hudgins, Phyllis Mondak and Debra Holloway to participate in the next meeting.

Regarding bias, Debbie reminded the group that we have worked to counter bias through development of manuals and training. Pratibha reported that she requires families to meet other families who have chosen each of the various hearing options prior to making a final choice.

Referrals – Long term Good News

Pat reminded the group that there is still a plan for an automatic database transfer of information from VISITS to ITOTS. This process has been designed and piloted successfully at Children's Hospital of the King's Daughters. The process is on hold, however, since the VISITS database has been brought in-house to the Virginia Department of Health and new linkages must be created. Once this is in place, efficient automatic referrals can occur. This is at least a year out.

System Capacity Survey

The survey is ready to be sent to local systems. Local system managers have indicated that due to the high workloads related to unexpected requests for data subsequent to Office of Special Education Program requirements, the survey is likely to be set aside if it is sent now. In order to get a better response rate, it will probably be best to send this out in early 2006.

Plans

Pratibha will develop a flow sheet of the proposed process for family guides (including assuring that the Part C referral has been made and linking to Care Connection). She and Beth will work on this together and route to members by email prior to the next meeting.

Beth will invite Judy Hudgins, Phyllis Mondak and Debra Holloway to participate in the next meeting.

Joni Alberg plans to attend at least part of the December meeting. The meeting is scheduled for **December 8 from 9:30 to 3:00**. The location is yet to be determined. An agenda will be sent to members in advance.