

Hearing Workgroup December 9, 2005

Attendance: Beth Tolley, Carol Wiegler, Joni Alberg, Leslie Hutcheson Prince, Susan Shaw, Frieda Helbert, Casey Morehouse, Barbara Harding, Debbie Pfeiffer, Pat Wiley, Debra Holloway, Phyllis Mondak, Ruth Frierson, Pat Dewey

Members and guests introduced themselves to each other including their role in early intervention and working with infants and young children with hearing loss and their families. Joni Alberg, Director of North Carolina's "Beginnings' Program was welcomed to Virginia and to the meeting.

Announcements

Congratulations to Frieda who received her doctorate in audiology last summer!
Good luck to Casey who is pursuing her doctorate through distance learning.

Minutes

Minutes of the October meeting were approved.

History and Summary of Work of the Workgroup

- The group was formed in Spring 2005 when it was determined that focused work was needed to address the intervention component of "early hearing identification and intervention".
- A group of stakeholders, including parents of children who are deaf or hard of hearing, providers of direct services and state and community agencies and organizations formed the workgroup.
- The group identified what was going well, what wasn't and strategies for addressing the gaps.
- Research was done on what was being done throughout the United States and beyond.
- A baseline collection of resource materials was identified and 7 sets were purchased and made available for long-term loans to local systems.
- Additional VCR/DVD resources (The Home Team and the Art and Science of Home Visits) will be purchased for local systems in December.
- A survey was developed to determine individual and system capacity in terms of personnel resources for providing supports and services to children who are deaf and hard of hearing and their families. (It will be administered in early 2006).
- Training opportunities have been publicized to local systems and have been made available through the Annual Early Intervention Conference
- PREP training can be requested and can be provided by Debbie Pfeiffer.

- A Loaner Hearing Aid (and auditory trainer) Bank was established (and is working well according to feedback today!
- Pat Abrams has approved the use of the Virginia Network of Consultants (VNOc) for early intervention as long as funding is available. VNOc provides consultation to providers serving individuals who are deaf or hard of hearing.
- Approximately 20 PREP training manuals are being distributed across the Virginia regions. Debbie is placing an information sheet about VNOc in each manual so that it will be clear how and who could be contacted to provide consultation and training.
- The group began looking into North Carolina's and Colorado's program's for children with hearing impairments. VDH requested to be included, and was accepted, in the NCHAM grant that offers technical assistance to replicate North Carolina's Beginnings program or establish a similar program.
- Discussions began in late summer about a system that would include someone trained/experience in all of the hearing options and able to provide complete and unbiased information to families about hearing options as well as provide support. The group is currently referring to the person who would be doing this function as the "family guide."
- Options have been discussed for who/what group of people might serve in this role including:
 - Infant specialist(s) from schools for the Deaf and Blind (position(s) are currently vacant those there have been meetings between DOE and DMHMRSAS
 - Care Connection for Children Staff
 - Part C Staff (Would depend of level of expertise and case loads)
 - School system audiologists (very few school system audiologists and school system personnel can not cross their jurisdictional boundaries)
 - Individuals hired to do this function (would require new funding)

Future Resources/Planning

For the past 5-6 years, the Department of Education, the Virginia Department of Health and the Department of Mental Health, Mental Retardation, and Substance Abuse Services have worked together to put together training and education efforts. Again this year, there is a contract with Debbie Pfeiffer managing it through the Partnership for People with Disabilities. It is a three-year contract, based on grant funding, and there is not a guarantee that it will be funded for all three years. Debbie and Pat are in the planning stages for offering reimbursement for taking online courses through IHHD.

Leslie informed the group that groundwork needs to be laid now if funding is to be requested when Governor Kaine makes his first budget proposal in 18 months. Proposals will be due in the summer of 2007. Data will be required along with a proposal. Debbie informed the group that an organization is forming that is bringing families together from

multiple groups and trying to speak as one voice. She reported that the group was started by Medical Home and Family Voices and that Dana is a part of this. She will get with Dana to put a presentation together for the next meeting. Joni suggested that the group find out who their representatives and delegates are, and begin now to determine where there is support from them.

Hearing Loss Identification Process

The diagnosis of hearing loss is made by the audiologist. The audiologist is expected to refer the child to early intervention as well as to inform the physician of the findings and send the required report form to the Virginia Department of Health (VDH).

Susan pointed out that Part C often sends children back to the audiologist (i.e., the flow sheet goes both ways!).

Family First Guide Discussion

Oversight of the "Family First Guide" system under the Part C system could be problematic due to the necessity to focus Part C funds on direct services. Oversight by Care Connection may give a connotation of a Hospital based or affiliated program. It might work well as a family support program under the Department for the Deaf and Hard of Hearing (DDHH).

Phyllis reported that the Part B system can provide service to Part C children depending on the local systems, but could not be part of a regional family guide system because of the issue of crossing LEA boundaries. Also, school system personnel can't talk about options before children's eligibility and needs are determined.

Discussion followed about the number of visits that would be made by the family guide. Frieda commented on the value for the family of someone that knows the child and family from diagnosis to 18 years who is available for the various transitions. Phyllis suggested that the group might want to present the concept to the Special Education Council.

Resource Materials

Leslie distributed 4 handouts including

- List of resource materials that were purchase with the grant funds (based on the recommendations from the group about what should be available for each local system)
- Detailed list (bibliography) of resource materials
- Request form for materials
- Draft guidelines for use of materials

Leslie reviewed the draft guidelines with the group. Initially, the materials will be loaned exclusively to local system managers. Parents and providers will access the materials through the local system managers. If early childhood specialist would like to borrow the materials that are only found in these resources (i.e., not available in VDDH's other library resources), they will need to contact the local system manager in their local system to borrow them (at least for the first 6 months).

Leslie will monitor the use of the materials. If the use is high, VDDH can supplement the materials. If they are not actively used, materials can be transferred to the general collection for everyone's use.

Leslie will add ordering information to the bibliography and will send an announcement and updated circulation guidelines and bibliography to the group.

Information from Joni Alberg, Director of Beginnings Program, North Carolina

Joni explained that NCHAM has a grant with Health Resources Services Administration (HRSA) to help other states get screening and resources off the ground. This is currently in the 2nd grant cycle and is focusing on diagnosis to intervention and how to reduce "lost to follow-up." The first focus is on the parents. They also work with providers who work with kids who are deaf and hard of hearing including linking them with other resources.

The Beginnings Program doesn't following families closely, but families can call the program anytime.

In September 2006, there will be a workshop in Washington DC which will focus on teams developing action plans. (Joni commented that we were beyond that.)

Level two involvement per the grant includes technical assistance and level three involves replicating Beginnings, getting the program off the ground. Joni reported that they are working also with DC, Florida and Arkansas. She and the resources from the grant will be available to us for 5 years.

Beginnings was started in the 80s by parents who got together and approached the legislature. They were successful in receiving a \$30,000 grant to develop materials. The focus at that time was making sure parent were informed about what their options were. Parents were involved in the development of materials. Beginnings is an independent, nonprofit agency. Funding is received from the Office of Educational Services as a line item in the budget. Initially, the state absorbed funding for Beginnings for one year. Philosophy changed to reflect the philosophy of the School for the Deaf the budget increased. The following year, the agency became independent and nonprofit.

There was resistance initially as the organization moved away from services provided solely within residential schools for the deaf and the preschools to early intervention and changes brought about by Beginnings. Stakeholders were brought together as changes occurred.

In North Carolina, when a child is diagnosed with hearing loss, they are to be referred to Beginnings. If they haven't been referred to Part C, Beginnings makes that referral. Beginnings contacts the referring audiologist for information. A home visit is scheduled within 2-5 days when possible. A notebook with information tailored for that child and family is taken on the home visit and left with the family. (The Beginnings notebook is being updated. There is a core set of information within the Beginnings Notebook that the Parent Educator goes through with every family.)

The child is put on a biweekly log to assure follow up. The parent educator makes sure that the family understands hearing loss and how it impacts language development, how children develop language. The parent educators explain that the way to help the child is through early intervention and assists the family with the application.

The parent educator finds out what the parent needs first - what are the most important concerns, then links the family to the people or resources or helps them formulate the questions they need to ask their audiologist or physician, etc. The parent educator may assist with connecting the family with another parent of a child with a hearing loss.

One parent group, HITCH-UP, is a parent initiated parent support group. Parents bring their children. The children who attend use a variety of communication options. Beginnings supports this group. AG Bell also has a support group for parents.

Beginnings doesn't fall under HIPPA. Updated child information is shared via email or secured fax. Child find information is communicated via email. Within 48 hours of receiving a referral, that information goes to early intervention.

Research currently underway includes looking at the language skills of children exiting the early intervention system.

Joni reported that she has seen a change in choices families/children are making regarding spoken language from less than half choosing spoken language to now, more than half of parents choosing spoken language. It is important to inform families that they can change their mind!

Education for parents who are deaf is another component of services provided by Beginnings.

In *Beginnings*, the Parent Educators include people with the following backgrounds:

- Teachers of the deaf
- A person who became deaf, who is now implanted
- Recreational therapy
- Maternal and child health
- Business and finance
- Early intervention

Criteria for Parent Educators in the *Beginnings* Program include:

- Must have worked with families in family support role for three years
- Good listening skills
- Ability to be an unbiased presenter
- Compassionate
- Ability to learn the information about hearing loss
- Ability to learn the information about the system

The Early Hearing Diagnosis and Intervention program has 6 Child Health Audiologists and 8 Speech Language Pathologists. There are 20-30 families per educator. The Child Health Audiologists work well with the primary private audiologists. They have approximately 100 FTE teachers of the deaf for infants.

The *Beginnings* Program sends information to parents when the child turns 2 years 6 months to assist them with transition.

Family First Guide

The group discussed the possibility of Part C service coordinators serving as Family First Guides. Several concerns were raised including turnover rate and service coordinators being trained, but not using their training because there are no children with hearing loss in their system. The group also expressed the importance of families supporting families, and reiterated the importance of including both the professional perspective as well as the parent perspective.

As Virginia develops its system and roles, North Carolina, through this grant, can assist us with developing roles and job descriptions and tailoring the system to meet family needs in Virginia.

Ruth suggested that one organization to consider for family first guides is the Community Health Outreach Organizations that provide prenatal and assessment services. They do home visiting already, but do not work with all of the early intervention families.

Assignments:

Beth - Send System Capacity Survey to Part C System Managers

Leslie - Revise Library Forms (Email to group or bring to next meeting)

Leslie - Develop Draft plan to begin legislative funding proposals for 2007

Phyllis and Debbie - VNOC update - How can this resource be used?

Debra - Contact Dana to prepare presentation about new group

Next Meeting:

January 23, 2006 Department for the Deaf and Hard of Hearing (DDHH)

9:30 - 3:00

Richmond