

**Hearing Workgroup
October 10, 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 for Children
Melinda Smyth – Educator of the Deaf, Hanover
Ann Hughes – Consultant, Partnership for People with Disabilities
Ellen Rolader – Service Coordinator, Educator, Infant & Toddler Connection of Shenandoah
Sarah Peters, SLP, Infant & Toddler Connection of Henrico
Leslie Hutcheson Prince, Department for the Deaf and Hard of Hearing
Debra Holloway, Family Involvement Project

The minutes from the June 8 meeting were approved.

Statistics – Ruth Frierson

Ruth reported that the data system counts the number of children reported to the Virginia Department of Health who were born in the specified year. This means that if a child was born in 2006, but identified in 2007, that child would not be reported in the 2007 statistics. To date for 2007, 133 children were reported to VDH to be diagnosed with hearing loss; 51 of these children were born in 2007. At the next meeting, Ruth will report the total number of children birth through 2 who have been reported to VDH to have hearing loss.

It was suggested that it is likely that the statistics don't include 10-15% of children who are deaf or hard of hearing. There are a number of reasons for this:

- Not all audiologists report to VDH all children who are diagnosed with hearing loss. Some believe – ERRONEOUSLY – that they are only required to report children who are referred based on a failed hearing screening. This means that children with later onset hearing loss are not reported. This could include preemies whose initial screening didn't indicate a need to refer for evaluation.
- There is not a way to know how many children didn't pass, but instead no one sent in the information that the child failed.

Ruth reported that the Virginia EDHI program continues to work to educate audiologists about the requirements for reporting. Ruth also reported that when the VISITS system is in place, a number of the issues related to data would be resolved. The VISITS system is a tracking and referral database.

Ruth distributed a copy of the Virginia Early Hearing Detection and Intervention (EDHI) Program 2006 Annual report. The report is available online at:
<http://www.vahealth.org/hearing/documents/2007/PDF/2006AnnualReport.pdf>

Referrals to Early Intervention Systems

Ruth reported that after the discussion at the June meeting about referral practices, she has made referrals routinely to the early intervention systems rather than requesting permission from families prior to making the referral. She has encountered resistance from three people at the local level, who have requested that the referrals come from the family. The reasons for this request include the greater likelihood of complete, accurate information when the family makes

the call and the fact that some families aren't interested. In addition, there have been some situations where the initial diagnosis of hearing loss was later found to be incorrect. *

Beth stated that:

- Parental permission is not required to refer a child to Part C
- Local Part C Systems must accept referrals from any referral source
- All children with hearing loss ARE eligible for Part C

Beth will include this information in the Infant & Toddler Connection of Virginia Technical Assistance Update, which will be sent to all system managers in several weeks.

* Hearing loss is diagnosed by the evaluating audiologist. There are different standards of what is considered hearing loss, so it is possible for a child to be identified as having a hearing loss by one audiologist and found not to have a hearing loss by another audiologist. This is an issue that will be addressed at the Virginia Early Hearing Detection and Intervention Advisory Committee next month (November 9, 2007).

EDHI Goals and Communication Between VDH and Early Intervention Systems

One of the EDHI goals is that all children diagnosed with hearing loss receive early intervention services by age six months. In order to collect this data, there needs to be communication from the local early intervention system to Ruth (EDHI Follow Up Coordinator). Part C has recommended that Part C Service Coordinators routinely obtain permission to communicate with the EDHI Follow Up Coordinator from families whose children have hearing loss. Beth will put a reminder about this in the Infant & Toddler Connection of Virginia Technical Assistance Update

Pat Wiley reported that the Care Connection of Virginia referral form has a section at the bottom to be completed by the Care Connection of Virginia to provide outcome information (if and when the child was enrolled or if the family declined services). Form attached.

Center for Disease Control (CDC) Hearing Survey Findings

Ruth reported that the CDC Follow Up Survey Results from 2003 and 2006 are available. There are many recommendations for Virginia, including, but not limited to:

- Shortage of audiologists.
- No systematic way to inform physicians and audiologists of screening results
- Lack of standards for counseling and referring families and uneven follow up
- Lack of, or inadequate private health insurance coverage for children with hearing loss
- Cumbersome and lengthy process of referral and insurance authorization
- Some physicians downplay importance of screening results and say wait and see

VDH EDHI Staff

The EDHI Program Manager position has not yet been filled. Michelle Ballard is the new Surveillance and Evaluation Coordinator.

GBYS

The October Summary of Project Activities for the Virginia Guide By Your Side Program was reviewed. See attached Report.

- 60 families have been matched. Some families for whom GBYS was offered declined. It is not known how many have declined.
- The September Training for the new Family Guides and also for the current Family Guides was excellent!
- There currently are no bilingual guides, but there have been matches for Spanish speaking families. Two guides are themselves deaf (in Nova) and have matched and there have been matches with two families whose parents were deaf.
- The revised Choices in Deafness book was provided to all of the guides.
- A handout – 100 signs is being added to the Parent Toolkit.
- Approximately 10 evaluations from families who have been matched have been received. These have been very positive. Dana will be asked to provide a report on the evaluations from the families at the next meeting.

Administrative Changes

- Jennifer Hutson, the former Parent Coordinator has moved. Jessee Georges is the new Parent Coordinator. Jessee has a background in business, human resources, and has been through the GBYS program.
- Ann is no longer connected with the GBYS program; Tera Yoder will be the principal investigator.

Budget and Permanent “Home”

- The GBYS program is requiring more work hours than allotted in the budget, and the budget for the 2nd year is less than this year’s budget. Nancy Ford is working to increase the funding for the 2nd year. Unless there is an adequate budget, there will need to be prioritization about which families will be matched with Family Guides
- The Partnership for People with Disabilities is a temporary “Home” for the GBYS program. A permanent “home” must be determined.

Budget for Hearing Follow Up Supports and Services

Funding for the GBYS and for the Hearing Aid Loan Bank is provided through a HRSA Grant that ends August 31, 2008. There has not been an announcement from the federal government about a new grant. The database (VISITS) is funded through the EDHI grant from the CDC which ends June 30, 2008.

The person hired to fill Pat Dewey’s position will be responsible for grant writing. Sarah offered to assist with writing grant proposal if the new person is not going to be in place in time enough to put a proposal together once the information about new grants is available. Ann will see if Dana can assist if this is needed.

Approximately \$75,000 is needed annually for the Guide By Your Side Program. Attendees did not know the budget amount for the Hearing Aid Loan Bank. Nancy Bullock may include the hearing aid loan bank in the budget for the Care Connection for Children.

Funding possibilities include:

- New HRSA Grant funding (through VDH – EDHI program)

- Begin the process for a funding through the state (DDHH budget proposal to add to their budget). Challenges with this include the current political climate, the financial status of the state and the lack of a position at DDHH to administer the program. The original plan to have permanent home through one of the state agencies after 2 years was made when the economy was better.
- Private funding: Alexander Graham Bell, Cochlear, Kluge, Lions, Rotary, or other foundations. There was discussion that funding from AGB or Cochlear might be perceived to lead to bias even in the absence of bias, but this might not be an issue if funding was pooled from several sources.

Plans

1. Ruth will tell Nancy that members of this group will help write the grant. Sarah, Ruth, maybe Dana.
2. Explore private grant possibilities:
 - a. Leslie – internet research on funding resources and grant cycles next Tuesday
 - b. Leslie will send a report on what she finds with links and group will divide follow up exploration.

Ruth will send grant proposal to Leslie (both).

Online training

Ann reported that the committee explored the possibility of converting the PREP training to webshop. The estimate from Chris Colley for this work is \$1200 - \$2000.

Online options were discussed further. Ellen has taught an online class at Radford. T/TACOnline (<http://www.ttaonline.org/>) has resources and webshops/webinars. (A webshop provides 15-30 minutes content with a quiz. A webinar is a series of webshops). Beth reported about an option available through VCU to create audiovisual presentations that include verbal presentations paired with Powerpoint or other documents.

Only 2% of people at Hearing Conference for Teachers in summer indicated online training as a preferred mechanism for training.

The point was made that the content of the material in the PREP training is already available on the web in a variety of places. The issue is the amount of information available and the time and knowledge needed to sort through the websites to find the information. It would be helpful to have a structure or guide to where to look to learn about specific topics. The issue with any type of training, whether it is an online course or list of websites and resources, is the need to continually update the material.

The group discussed creating a document that lists topics with directions to “google” specific words or phrases to see what is available online and which could also include specific resources similar to the Early Intervention for Children with Hearing Loss and Their Families Fact Sheet. Such a document would need to be dated and would require periodic review and updating.

Topics could include (among others):

- Anatomy
- Kinds of Hearing Loss
- Communication Options

This document could be posted on T/TACOnline. Upcoming trainings might also be posted (and is already being done for at least some trainings).

Decisions:

- Post trainings/events on the T/TACOnline website. Beth and Ann will explore the possibility of Beth obtaining a login that would allow her to post training announcements. Beth will include information in the upcoming Part C Technical Assistance Update about using T/TACOnline to find resources and information about upcoming trainings
- Put this topic on the agenda for the next meeting to decide:
 - Whether to create an exhaustive list of resources
 - What topic to include
 - Whether subtopics can be included under the resource tab on T/TACOnline
 - Mechanism (who and when) for updating
- Consider creation of a webshop only if the strategies above are not effective.

Report on past trainings

- 104 teachers of deaf, speech language pathologists, interpreters, students, and (one) parent attended the conference this summer for teachers of the deaf. The conference was excellent. The plan for next summer is to have conference in conjunction with the dual sensory impairment conference.
- About 90 people attended the conference on dual sensory impairment. It was also an excellent conference.
- Insight training. Sarah reported that the training was good, but that information needed to be updated, particularly for cochlear implants. Sarah recommended that the SKI-HI training be repeated in Virginia. It has been an excellent training with up to date info and resources that can be given to parents.

Current and Future Training

- Professional Preparation in Cochlear Implants, a program for teachers, speech-language pathologists and educational audiologists working with children birth to 5 years old. <http://www.chop.edu/consumer/jsp/division/generic.jsp?id=73440> Ellen is attending the one of these online/onsite training courses in Atlanta.
- Auditory Brain Stimulation: The Key to Developing Spoken Language and Literacy in Infants and Children with Hearing Loss – November 8 and 9 at Children’s Hospital of the King’s Daughters
- The AVT training series in Harrisonburg had the first 2-day session last weekend. Lori Bobsin in the trainer. Approximately 25 people attended. Ellen reported that it was excellent.
- Three two-day sessions, Auditory-Verbal/Oral Intervention in an Academic Setting, also with Lori Bobsin, are planned with sessions in November, March 2008 and April 2008. Continuing education hours can be used toward certification offered through the AG Bell Academy for Listening and Spoken Language as well as AVT certification.
- Ann is going to a training in Massachusetts about mainstreaming children with hearing loss
- Ann is teaching a course on Visual phonics
- Ann is providing a visual phonics workshop for the Spotsylvania and Fredericksburg school systems

- Ellen will be doing a presentation about the importance of early intervention for hearing loss.

Shortage of Interpreters

In addition to shortages of Speech Language Pathologists, there is a shortage of Interpreters. Ann provided information about an exciting new technology, Teleportec, which might be available in the future (when cost comes down) for people offsite to provide interpreting services.

Revisit Goals for Hearing Workgroup

The group reviewed goals of the workgroup. The goals of developing/ implementing a Parent Support Program and of providing specific guidance to Early Intervention personnel working with children with hearing loss (Fact Sheet) have been met. Attendees agreed that there continues to be a need for the workgroup to:

- Monitor the system of supports, services and resources for families of children who are deaf and hard of hearing (including the Hearing Aid Loan Bank, the GBYS, and professional training needs and opportunities).
- Find a permanent home for GBYS
- Advocate for and assist with obtaining funding
- Follow up on the recommendations from the CDC survey, Virginia Parent Survey and the 2007 JCIH Position Statement. There is the possibility that the workgroup might be converted to a subcommittee of the Virginia Early Hearing Detection and Intervention Advisory Committee.

Assignments:

- Ruth will check to see if by becoming a subcommittee of VEHDI will it be a public meeting, which requires posting of meetings, open to public, etc.
- Ruth send grant application to Leslie and Beth
- Ruth will request a copy of the Hearing Aid Loan budget
- Ruth tell Nancy Ford that group members are available to help with grant writing
- Dana will send Beth and Leslie a copy of the Guide by Your Side budget
- Beth and Ann will follow up regarding posting courses on T/TAConline
- Beth will include information from this meeting in the ITCVA TA Update
- Sarah will send meeting minutes to System Managers
- Leslie will research grants
- Sarah will reserve a room for the next meeting

Next Meeting: December 10, 2007; 10:00 AM – 2:30 PM

Agenda for the next meeting

- Communities of Practice
- Review of EDHI meeting recommendations
- Development of priorities and Workplan based on review of CDC and JCIH recommendations, parent survey results and information from the November VEHDI meeting
- Report on GBYS Parent feedback survey