

**Hearing Workgroup
December 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
Cori Hall, Service Coordinator, Special Instructor – Hanover County
Wanda Walker, System Manager, Southside
Debbie Pfeiffer, Specialist, Department of Education
Sandra Woodward, Program Director, CCC, Virginia Hearing Aid Loan Bank
Dana Yarbrough, Partnership for People with Disabilities

The minutes from the October 10 meeting were approved.

The new Virginia Department of Health Early Hearing Detection and Intervention program manager will start January 10.

Review of Advisory Committee Meeting

- The committee is reviewing the infrastructure and has decided to establish subcommittees. This workgroup will become one of the subcommittees. (Ellen asked that the name of this workgroup be changed. This will be addressed when the workgroup becomes a subcommittee). Subcommittee meetings do not require public notice. One of the subcommittees will focus on funding. Another will focus on follow-up. A family subcommittee was also discussed to facilitate family input for review of documents, communication with legislators, etc. The Advisory Committee will continue this discussion at the next Advisory Committee Meeting (February 8, 2008). Decisions will be made about which functions (including implementation of the Joint Commission on Infant Hearing recommendations) belong to which subcommittees.
- Membership of the Advisory committee is also being reviewed.
- Code of Virginia Regulations regarding hearing detection and intervention must be reviewed now (every four years) and revised as/if needed. Ruth and other VDH staff members are working to integrate recommendations from JCIH into the regulations. Ruth has identified a place in the regulations where the requirement for family-to-family support could be added or strengthened. (12 VAC 5 80-95) A teleconference has been scheduled by Susan Tlusty to work on the regulations. Sarah Peters will participate along with Ruth and others from VDH.

Guide By Your Side

Dana reported that the Guide By Your Side Program has just completed the first year, which has been considered a pilot. Evaluation of GBYS is not available due to low survey return rate. Those surveys that have been returned provide very positive feedback about the program. The surveys are now being given to families sooner in the process with the hope that there will be a

greater return. Results of the Giving the survey earlier to parents and will compile that to have available for legislators.

Jessee Georges stays in touch with guides. The guides also have conference calls. The importance of providing feedback (positive and negative) to the program managers was stressed.

Budget and Funding: GBYS and Hearing Aid Loan Bank

Virginia Department of Health funding (through grants) for the Guide By Your Side Program and the Hearing Aid Loan Bank will end August 31, 2008.

Dana discussed the budget for the GBYS. GBYS was originally funded for one fiscal year, but due to a late start with matching families (January 2007), the program had leftover funding for part of the current fiscal year. The projected budget for this year was less than the cost of the program. A budget addition requested through VDH was not funded. Visa cards have been purchased to simplify the reimbursement to the Family Guides.

About 65-75% of families Ruth talks with are interested in a family match. This requires an annual budget of approximately \$57,000.

Debbie Pfeiffer reported for Phyllis Mondak that the Department of Education could provide \$57,000 out of 619 (preschool) funds. Dana will talk with Phyllis about details. \$20,000 is needed to finish this fiscal year and \$57,000 is needed next year. Dana reminded the group that the Partnership is a temporary "home" for this program. They are willing to keep the program for a third year.

Potential funding sources for this program were discussed. Money may be available through the Deaf and Blind Project, though it would change the nature of the program since it would need to include children who are blind as well as deaf. At this point, Hands and Voices is not interested in sponsoring (funding) this project due to other priorities. VDH waiting for announcement about grants to see if there is the possibility of applying for grant funding through Health Resources and Service Administration (HRSA).

Regarding a "permanent home" for the GBYS program, there is still hope that at some point, the Department for the Deaf and Hard of Hearing may be able to sponsor this program. In most states, the home is another state agency, though there is a connection to Hands and Voices. Other options suggested for consideration include the Arc of Virginia, PEATC (Parent Educational Advocacy Training Center), the Family Involvement Project (through Arc of Virginia), and Northern Virginia Resource Center.

Sarah provided information about potential grant sources including:

- R.J. Reynolds Foundation.
- CBS Caremark Trust
- Dominion Foundation – grants up to \$15,000.
- Robins Foundation –
- Lawrence Foundation – challenge grants
- Carmax

There are different deadlines for the various grants. Dana said that Bill Tinsley at the Partnership for People with disabilities could look into the grants that have been identified and provide recommendations about what to pursue. Dana will report back at the next meeting. The Partnership may not be able to apply for some of the grants.

Hearing Aid Loan Bank (HALB)

The Hearing Aid Loan Bank has served 151 clients. This project started with a budget of \$17,000, which DID NOT include the cost of purchasing the aids and warranties. Many of the warranties for the original hearing aids and FM systems have expired. There is a now a need to purchase new hearing aids and FM systems. There are 78 hearing aids and 37 FM systems in the Hearing Aid Loan Bank.

Care Connection for Children (CCC) is not a viable source for funding the Hearing Aid Loan Bank because the HALB does not meet CCC income criteria for recipients. \$52,000 is needed from September 2008 to August 2009. Debbie reported that Phyllis Mondak has indicated that DOE can fund this for one year. It may be possible to provide funding in the future, but it must be determined on a year-by-year basis. Sandra will communicate with Phyllis and Debbie to provide the scope and services and budget for this funding request.

A question was raised about donations of hearing aids. In order for donations to be usable, there must be a company that is willing to refurbish the hearing aid. This is not readily available. In addition, donated hearing aids are not always the type of aid that is needed. However, Barry Strasnick, member of the Early Hearing Detection and Intervention Advisory Committee is working with a foundation called the CHEAR foundation which is considering starting a program to refurbish hearing aids. Debbie will communicate with Barry about whether HALB could be a part of CHEAR.

It was reported that Delegate Hargrove has expressed interested in supporting legislation for funding hearing aids. The way to pursue this may be through a budget proposal through VDDHH. There is not time to pursue this for the 2008 General Assembly. However, this is something that should be looked into now for next year. Ann will talk with the Hands and Voices members to see if they are interested in pursuing this (since it needs to come from families). It was reported also, that Senator Blevins has a connection with the CHEER Foundation. There is the possibility that funding could be sought through the CHEER Foundation and/or that families could approach Delegate Hargrove and Senator Blevins to support legislation for funding for both Guide By Your Side and the Hearing Aid Loan Bank.

Support through Legislation

In order to have legislative support for funding, several things must occur:

- Legislators willing to support bills
 - Delegate Hargrove
 - Senator Blevins (possibly)
- Individuals/groups who can lobby for legislation (not state employees)
 - Hands and Voices. Ann will talk with members in the January meeting.
 - Speech and Hearing Association of Virginia. Sarah will talk with the Vice President for Legislative Affairs to see if SHAV would be willing to pursue funding for GBYS and HALB
- Budget to support (ex. inclusion of funding for projects in DDHH budget)

- Data – need; effectiveness reports, cost, etc.
 - JCIH recommendations
 - Possible Code revision to strengthen requirement for family to family support
 - Evaluation of Loss to Follow UP in State EDHI Programs: Findings from the Virginia EDHI Program

Hands and Voices

Ann reported that Hands and Voices meets every 2nd Saturday. Ann will talk with members at the January meeting about pursuing legislation for funding.

Development of Priorities and Workplan based on Review of CDC and JCIH Recommendations

Each of the JCIH recommendations was reviewed. Past, current and potential future workgroup activities were identified for each recommendation.

1. All families of infants with any degree of bilateral or unilateral permanent hearing loss should be considered eligible for early intervention services.

- Early Intervention for Infants and Toddlers with Hearing Loss and Their Families (fact sheet) was developed and disseminated to all local Part C systems, as well as posted on the Infant & Toddler Connection website. Periodic reminders are provided through the Infant & Toddler Connection Technical Assistance Update and through individualized technical assistance.
- There have not been recent instances of families reported to Ruth that they were told their child was not eligible. Ruth will add a question about this in her follow up calls with families.
- Ruth reported that some families don't understand how a very young child can be evaluated or what services could be provided to a very young child. The following response was suggested: *Evaluation includes not only assessment of the child's development, but also assessment of family needs. Hearing babies listen for the first year before they learn to process language and talk. Your baby may or may not be right on target developmentally. Early intervention supports and services can help you learn about all of your communication options, including amplification so that you learn how to communicate effectively with your baby and help him/her develop language, cognition (thinking skills) and communication. Early intervention can also provide you with information about resources to support your baby's development and to provide support to your family including connections with other families if you desire.*

2. There should be recognized central referral points of entry that ensure specialty services for infants with confirmed hearing loss.

- There are central points of entry (CPOE) for each of the 40 local systems. The CPOEs are overseen by local system managers who have been educated about infants and toddlers with hearing loss. Each local system is required to have personnel knowledgeable in assessment and intervention for infants and toddlers with hearing loss and their families. The statewide toll free number for the Infant & Toddler Connection of Virginia is another way for families to be routed to the local systems.
- The EDHI Follow Up Coordinator also serves as a link to the early intervention system

3. Early Intervention services for infants with confirmed hearing loss should be provided by professionals who have expertise in hearing loss, including educators of the deaf, speech-language pathologists, and audiologists.

- Extensive efforts have been made to increase the capacity of Virginia's providers to serve infants and toddlers who are deaf or hard of hearing and their families
 - Information about training opportunities is provided through email to all 40 systems and through the Infant & Toddler Connection Technical Assistance Update
 - Resource materials (print information, videotapes/DVDs, etc.) have been provided to all 40 local systems
 - 7 sets of resources were purchased and are kept at the DDHH library for loan to any local system
 - There is at least one session on early intervention for children who are deaf or hard of hearing at each Infant & Toddler Connection Annual Conference
 - More extensive trainings are offered periodically through the Department of Education, by private providers and through the Partnership for People with Disabilities (funded through VDH and DOE), including the SKI-HI training and the INSITE training. In addition online training courses have been made available to providers.
 - Consultants through the Virginia Network of Consultants (VNOC) are available for providers working with infants and toddlers who are deaf or hard of hearing and their families.
- We do not know how many providers there are to serve infants and toddlers who are deaf or hard of hearing through the Infant & Toddler Connection of Virginia, nor do we know the level of knowledge, skills and abilities (KSA) of those who are serving these children.
- Ideas to consider in addition to current strategies were brainstormed:
 - Develop a framework to help organize the training opportunities for individuals – utilize the ASHA/JCIH list of competencies and provide information/ resources/ references about how to attain the KSA for each competency. Look at the 2007 JCIH Position Statement and the 2007 ASHA report to see if there are changes to the competencies identified in 2000.
 - Consider a meeting of all individuals in Virginia who work with infants and toddlers who are deaf or hard of hearing and their families
 - Consider development of a list-serve for providers
 - Consider communities of practice for providers. (The group cautioned that there might not be the manpower resources to undertake this now).
 - Provide online access to resources. This might be possible through VNOC.
 - Provide displays at multiple conferences including the Infant & Toddler Connection of Virginia annual conference, physician conferences, Speech and Hearing Association conferences, etc.
 - Post the fact sheet on TTAC Online (www.ttaonline.org). (Ann)
 - Post conferences and resources on TTAC Online. Several workgroup members are able to post information. Private conferences cannot be posted, but information about organizations (such as the website Cochlear Americas HOPE Program) can be posted.

4. In response to a previous emphasis on “natural environments,” the JCIH recommends that both home-based and center-based intervention options be offered.

- Beth will follow up to learn the intent behind this recommendation.

Review of Recommendations from the Evaluation of Loss to Follow UP in State EDHI Programs: Findings from the Virginia EDHI Program

The recommendations on pages 5 and 6 of the executive summary were reviewed. The group discussed how each recommendation could/would be addressed and also brainstormed possible strategies for many of the recommendations. The Virginia Department of Health will play the lead role in responding to the recommendations. Many activities have been implemented since the report was written, so some of the recommendations may already be met. Activities planned or in process include:

- VDH is working to increase the number of audiologists trained, equipped and willing to be “approved” audiologists for the EDHI program. DMAS has revised reimbursement to make it more financially feasible for audiologists to participate.
- 90% of one VDH staff person’s time is devoted to identifying/working with medical home for infants and toddlers who are deaf or hard of hearing and their families.
- VDH has developed (but not yet printed) posters for physicians, midwives and OB offices
- Training for physicians is a VDH goal. Funding is needed
- VDH has a display table at the pediatric physician conferences
- Hospital brochure that was approved by the Advisory Committee has a place in it for the child’s ear specific hearing screening results to be recorded

The group agreed that one of the recommendations, “attention should be given to (the) comprehension and appeal” of educational materials is relevant to this group’s work and should be kept in mind as materials are developed and disseminated.

The recommendation that education and counseling activities would extend beyond the immediate family to significant others will be addressed by the Advisory Committee, but is also often addressed through the supports and services provided in the Infant & Toddler Connection. In addition, a fact sheet could be developed for dissemination by family guides through the GBYS program.

Activities/strategies brainstormed include:

- Members provide sessions at physician and other professional conferences
- Man a display table at all conferences that include professionals who need to be knowledgeable about detection and intervention for infants and toddlers who are deaf or hard of hearing.
 - Conferences identified today include “Birdsong” the third weekend in April and PEDS at the Beach in August. Members are to email Beth information about conferences including name of conference, location, dates and contact people. Beth will compile the list for the next meeting; strategies will be discussed at future meetings.
- Submit an article for the newsletter of the Virginia Chapter of the American Academy of Pediatrics (through Colleen Kraft).

The following needs were identified:

- Education (awareness and specific KSA) of audiologists
- Education (awareness and specific KSA) of midwives
- Education (awareness and specific KSA) of childbirth educators (prenatal class instructors)
- Education of obstetricians

- Education of hospital personnel – screeners and the individuals who provide the information to the families
- Mechanism to facilitate screening for infants born at home. There are billing and liability issues for hospitals when screenings are done for infants who are not inpatients. One option is to establish approved sites for screening.
- Funding is not adequate to support follow up with all families whose infant failed the hospital screening.

Strategies for increasing awareness include:

- Placards on buses
- Posters in Physicians offices and anywhere pregnant women congregate
- TV – public awareness announcements
- Stickers for babies' bassinets that say "I had my hearing tested today"

Workgroup Priorities

1. Assure the Infant & Toddler Connection local systems' Central Points of Entry provide appropriate information to families whose children are deaf or hard of hearing are referred to early intervention (what training is needed)
2. Provide information to local systems periodically to remind them that all children are eligible. Monitor through discussions at regional meetings and through the VEHD Follow Up Coordinator's communications with families. State EI conference
3. Increase capacity of the Infant & Toddler Connection of Virginia system to provide effective, appropriate supports and services for children who are deaf and hard of hearing and their families regardless of the families' communication choices or where the families live.
 - Provide information about expectations/standards
 - Provide resources about hearing loss and intervention.
 - Provide information about resources for continued education and training – Develop a framework or guide to assist providers in determining their training needs and developing personal plans for increasing their knowledge. Use JCIH guide as framework for self-assessment and where to find the help
4. Play advisory role for the GBYS
5. Continue to advocate for and educate people about the Hearing Aid Loan Bank

2008 Infant & Toddler Connection of Virginia Annual Conference

Melinda, Sarah and Ellen will submit a proposal to present a session (possible 2) at the Infant & Toddler Connection of Virginia Annual Conference April 30/May1, 2008. The session may include information about the new JCIH recommendations and discussion about mechanisms to work together across the state to increase knowledge and skills including development of a system for mentoring.

Sandra and Dana will take responsibility for a display table at the conference to include in big letters the statement about eligibility for early intervention. The display will include information about GBYS, the Hearing Aid Loan Bank, Virginia Network of Consultants, and the Resources available through VDDHH (including having one of the bins with all of the resources available for people to see). Sandra and Dana will solicit volunteers (knowledgeable about the information at the table) to help man the table.

Training Opportunities/Announcements

Making myself Heard – January 5 – Register by Dec. 20, 2007. This training is for consumers, students, and other interested people. It is provided by a parent who is a lawyer and who has a daughter who is deaf.

Next Meeting: February 12, 2008 from 10:00 AM – 2:30 PM – Henrico Mental Health - West

Agenda for Next Meeting:

- Intro new program manager
- Priorities and Goals
- Report from Advisory Committee
- Update from GBYS
- Funding updates
- Various conferences – opportunities to present info
- Update on plans for EI conference
- Update on regulations
- Guide for providers – self assessment and training

Assignments:

- Post Fact Sheet on TTAC Online (Ann)
- Send name, dates, location and contact person for conferences (where group members could present or have display table) to Beth – Everyone
- Communicate with Phyllis Mondak about specifics for HALB funding – Sandra (Debbie to assist)
- Communicate with Phyllis Mondak to clarify amount of funding and time frame for GBYS (Dana)
- Ask Bill Tinsley to review potential grant opportunities and make recommendations (Dana)
- Compare 2007 JCIH and ASHA document to the 2000 ASHA/JCIH documents to see if there are changes to the list of competencies for professionals working with infants and toddlers who are deaf or hard of hearing and their families. Begin developing a framework of resources/references/information sources linked to the competencies (Beth, Ann, Debbie)
- Talk to Barry Strasnick about possible support from Senator Blevins for a bill for funding for HALB (Debbie)
- Talk to VP for Legislative Affairs (SHAV) to see if the possibility of SHAV support can be addressed at the spring SHAV meeting (Sarah)
- Submit proposal for presentation at the EI conference (Sarah, Melinda, Ellen)
- Submit request for display table (when info about how to do this is disseminated to the field) – Sandra and Dana
- Participate in teleconference about review/revision of regulations (Sarah, Ruth)
- Follow up regarding JCIH's fourth early intervention recommendation (Beth)