

**Hearing Workgroup
April 4, 2006
Department for the Deaf and Hard of Hearing**

Welcome and Introductions:

Alex Iwashyna, a 4th year medical student interning with the Infant & Toddler Connection of Virginia, was introduced to the group. Her role during her internship is to facilitate ways to increase physician involvement with early intervention.

Attendance: Pat Dewey, Debbie Pfeiffer, Ann Hughes, Debra Holloway, Beth Tolley, Ruth Frierson, Dana Yarbrough, Susan Shaw, Pat Wiley, Alex Iwashyna

Announcements

- 91 completed surveys have been returned to the Part C office and entered into a database by Sue Lau, Surveillance Manager for the Virginia Department of Health (VDH) Early Hearing Detection and Intervention Program. The information has been sorted by local systems with response averages provided for each major survey heading. Beth will follow up with Sue to request additional sorting to further assist with identification of areas of expertise, gaps in availability of providers with experience/expertise, and determination of local, regional and state training needs. Beth will also follow up with local systems for which there are no completed surveys.
- Virginia now has an AG Bell chapter.
- A Resource Fair will be held at Children's Museum April 22, 2006

Training Opportunities

- There will be a presentation on Genetics and Deafness at UVA on Tuesday, April 11 at 7:00PM.
- The follow up training for the individuals who attended the SKI-HI Training in 2004 and 2005 has been scheduled for June 26-27.
- The AG Bell conference will be held in Pittsburgh, Pennsylvania June 23-27.
- The Annual Early Intervention Conference, which includes a workshop on "Effective Early Intervention for Infants with Hearing Loss" by Debbie Pfeiffer and Leslie Hutcheson Prince will be held April 25 and 26.

Review of Minutes

The following corrections were made:

- Add "Programs" to Regional Care Connection for Children (first sentence of last paragraph on first page)
- Ann (not Debbie) reported about *Hands and Voices*
- Ann will contact Leanne Seaver (not Janet) to see if there is training material from *Hands and Voices* that Virginia can use

Minutes were approved as corrected.

Finalize Name for Program

The group discussed the use of the name suggested last meeting, "Virginia's Early Hearing Detection and Intervention (VEHDI) Family Guide Program" versus "Guide by Your Side" as recommended by Leanne Seaver. It is not known what would be required if Virginia decided to adopt that name. The decision on the name was thus pended until more information is received from *Hands and Voices*.

Report on Assignments/ Today's Discussion

Communication with *Hands and Voices* Organization

Ann reported that Leeanne Seaver reacted to Ann's inquiry that we should be adopting the Guide-By Your Side instead of re-inventing the wheel. According to Leeanne, replication of this established, well respected model of family –to- family support, including use of the name, Guide-By-Your-Side, is likely to have a positive impact regarding applications for Federal funding. Ann shared a handout about the program. This information is available on the *Hands and Voices* website (<http://www.handsandvoices.org/>). *Hands and Voices* is a non-profit organization dedicated to supporting families of children who are deaf or hard of hearing with information and resources so they can make the best choices for their child. They are a non-biased about communication modes or methodologies, and believe that given good information and support, families can make the choice that is right for their child. They also open their organization to professional who are interested in a family/child focused approach to service delivery. (From the *Hands and Voices* Newsletter).

Ann reported that training is available through *Hands and Voices* and that Leanne provides at least some of the training.

The group identified the following questions for Ann to ask Leanne:

- Who is the intended audience for the training provided by Hands and Voices: the people administering the program or for the parents who will serve as guides?
- Would Virginia be required to use their training and, if so, can the training be modified to meet Virginia's needs?
- What is the cost for adopting this program (use of name, cost of training, other associated costs)?
- How much adaptation of materials associated with the Guide-By-Your-Side Program is permitted for States who replicate the program and use the Guide-By-Your-Side name?
- How is supervision provided for the parents who are providing the service (parent visits; provision of information and support) and what is the mechanism for ongoing training?
- Is she aware of any available funds, such as grants for new programs?
- What about liability issue for parents going into other people's homes?
- Do they have a mechanism for accepting tax-deductible donations?
- Are there restrictions related to their child's age, degree of hearing loss, and other disabilities for parents who wish to serve as guides?
- What confidentiality agreements do they sign/need if multiple agencies are involved?
- How is oversight provided for the program?
- Do they have a flow sheet for the Guide-By-Your-Side process?
- How do they handle situations where families are not eligible? What do they tell families (for example, parents of older children requesting information and support)?

Funding

Ann said she was directed to Bill Tinsley about grant availability at the Partnership for payment of mileage for parents. The Partnership is not a 501 C3 organization that could receive tax-deductible donations that individuals or organizations could make.

Another possibility was suggested was partnering with Parent-to-Parent. Dana has been communicating with Care Connection for Children Programs and there may be some available funding through funds designated for parent support. Dana has contracts with the Care Connection for Children Programs in Roanoke, Tidewater, Richmond and she reported that some of that funding might be able to be used to support family advocacy and training.

The other three Care Connection of Virginia regions did not have funds available to support contracting with Dana for Parent Support.

There may be some available funding through VA-Info Grants. Medical Home Plus has agreed to support VA-Info after the three-year grant ends.

Funds are not available through the Arc of Virginia, though Debra reported that the Arc of Virginia may be able to provide phone cards for Family Guides and also may be able to help with printing materials.

Beth reported that Mary Ann Discenza indicated that some funding might be possible through Part C. More information about the program and specific funding request is necessary for a Part C commitment.

Debbie and Carol and Pat continue to check out available funding sources. Pat sent information to Jeanine Bedine to take to their state meeting. One of the northern Virginia clubs contacted Jeanine to let her know they wanted more information because they were looking for something to support.

The budget developed last meeting did not include money for oversight. Funding for this will need to be added to the budget bringing the estimated cost for one year to \$35,000. The budget also needs to include funds annually for training.

The group discussed the pay rate for Family Guides including consideration of regional differences and whether the rate should include consideration for child care costs versus separate stipends for child care costs. The group agreed to use \$15 as the rate for budgeting purposes with the understanding that it may need to be higher in some regions such as northern Virginia and less in others (where professional staff are paid less than \$15/hour). The group also agreed that an additional child care stipend would not be included. Dana agreed to prepare a draft budget for the next meeting.

Pat indicated that funding for the program could be written into the VDH grant application for the next two years. September 1 is the start of the grant year. (VDH received a three-year grant, though funding was not guaranteed for each year).

Potential “Family Guides”

Ann contacted two individuals in Henry County, Andrea Davis and Kim Myers, who are parents of children who are deaf as well as professionals. They are not available this summer but want to be kept in mind for the future.

Debbie contacted an individual (Lisa) who is not sure at this point whether she is qualified or interested. She requested additional information.

Beth asked Northern Virginia System Managers to contact parents of children who are deaf or hard of hearing who have been in the system for a year or more, to see if they might be interested and to provide contact information to Beth for follow up with those who are interested. Beth has not received any names yet.

- The group identified mechanisms to notify potential parents of opportunity to apply and decided to develop a consistent message that could be used on a flyer or sent via email with Ruth Frierson (ruth.frierson@vdh.gov) listed as the contact. The message for the

note/flyer needs to include a statement that the program is in the process of development and it may be a while before they are contacted by the Hearing Workgroup.

- Debbie will develop a draft flyer with the “consistent message” and circulate it to team members for review.
- Ruth, Debbie and Ann will use this information as they make contacts with individuals/groups with whom they are in contact or can contact. Debbie will plan to have flyers at the Annual Early Intervention Conference.
- The following list-serves/groups were identified as recipients for the flyer/email:
 - EI local systems
 - Virginia Network of Consultants (VNOC)
 - ArcFIP listserv
 - Project River listserv (Special Education listserv)

All potentially eligible candidates will be invited to apply. The group agreed that there need to be multiple “Family Guides” in each region to have the best possible availability when a referral is received. The group recommended the following:

- The program home will be responsible for interviewing and hiring
- The interview team will include members of the Hearing Workgroup.
- References will be required
- Consider including questions from Wisconsin’s interview guide as part of the application to have for review ahead of interview.
- Parents interested in applying would contact Ruth. Ruth would keep list of names/contact information.

Program Home

The program needs a home which includes a base from which the people function.

- Pat informed the group that the **Health Department** cannot serve this role.
- As discussed previously, the **Care Connection of Virginia Program** is a possibility, though not immediately due to the current demands of the increased newborn screening and their new role in this. Dana reported that that she has heard concerns from staff about discomfort with hiring and firing parents. Dana said this is why they have contracted with Dana (who is responsible for contracting with the families) for the parent support, parent advocacy and parent training.
- Debra talked with her supervisor at the Arc about having it under **Arc of Virginia**. Concern was expressed about the ability to monitor individuals across the state and about going into people’s homes. Liability insurance would be required. Debra reported that funds would be needed to cover the cost of managing the program if it were housed at the Arc of Virginia. Debra expressed willingness to put the idea before the Board. She also reported that the program could fit under the Family Involvement Project (which is a Part C funded project under contract with the Arc of Virginia).
- One possibility is for the program to be developed through the **Partnership for People with Disabilities** with oversight through the partnership as it is being developed. Some of the money from the Health Department Grant could be budgeted for this, according to Pat.
- While the program is a fit with the Virginia **Department for the Deaf and Hard of Hearing** (DDHH), this agency cannot serve as the “home” without additional funding.
- Medical Home Plus/VAInfo and Parent-to-Parent were also discussed as a potential home.
- ***It is possible that the program may need to start before the permanent home is determined. Possibilities for the permanent home include CCV, DDHH or one of the above.***

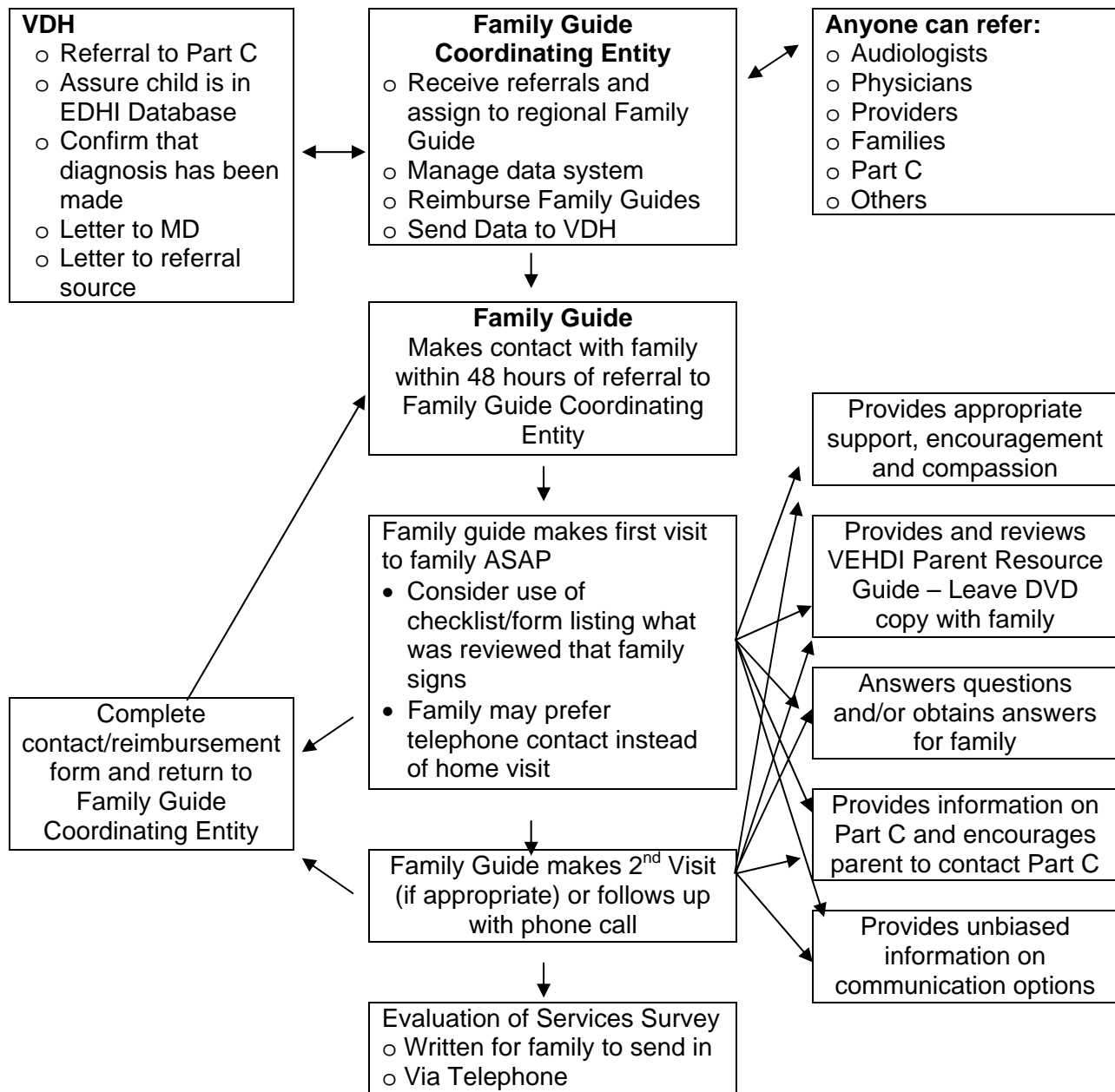
Development of the Program

Attendees agreed that finalization of documents (application, etc.) and establishing training dates are dependent on what is learned from Leeanne Seaver.

Debbie shared the record keeping form that she developed (as an assignment from last meeting) based on what is used for VNOC. The job description and family guide qualifications were adapted at the last meeting. Further development or finalization of forms is deferred until the group determines whether it will replicate the Guide-by-Your-Side program and learn if Virginia can adapt the materials if a decision is made to replicate the program.

The flow chart prepared by Carol Wiegler was reviewed and adapted. As the process was discussed, the following recommendations were made:

- Anyone can refer to Family Guide, not just the VDH, though the Follow Up Coordinator for the EDHI program will be the primary source for referral
- Referrals must be made via a referral form to the Family Guide Coordinator/supervisor/oversight person.
- Need to develop a protocol for referrals of families not eligible (child over three, hearing loss not confirmed) and include information about the protocol as part of the training.
- Referrals would be directed to a Family Guide Coordinator/supervisor/oversight person who then contacts the appropriate regional Family Guide to contact the family. This individual would also inform the Follow Up Coordinator for the EDHI program of referrals from sources other than EDHI.
- Confidentiality must be addressed.
- Only families who want to be contacted will be contacted.
- The Family Guide is not expected to be the expert. The family guide is expected to provide information and support.
- May need to inform parents who decide to participate that they may receive calls after the visit. Consider including information as part of the training about how to handle these situations including options for other parent contacts if the assigned Family Guide doesn't want to continue to be contacted.
- The Family Guide program would be also for children of late onset hearing loss. Hearing loss would have to be confirmed to be included in the program.
- There has to be a two-way communication between VDH and the agency coordinating the family guide system.
- Also build into the system a report back to primary care provider. VDH could do this. It was suggested that information about Family Guide program be included in the letter.
- Consider developing a database to manage the information/data associated with the program. VDH has a web-based database. It might be possible to add this to that existing database. There is software available from Family Voices. This software has been available to Medical Home Plus and Parent-to-Parent and VAInfo.
- Send information to physicians when the program is up and running.



Revision of Resource Materials

Pat reported that Virginia’s manual for families of children with hearing loss (*Information for Parents of Children with Hearing Loss*) needs to be revised. There are plans for revising the resource section this year. The long-term plan is to revamp this resource to make it Web-based with the capability for downloading/printing individual sections/pages according to user need/preference.

Additional Members for the EHDI Workgroup

Debbie will contact Fairfax’s Bright Beginnings (school system program for infants and children with hearing loss) to invite a representative to join this group.

Next Meeting

May 3, 2006

9:30 – 3:00

Skipwith United Methodist Church

Agenda

Review assignments

Make Decisions

Fine-tune application and other forms

Assignments:

- Dana – develop draft budget
- Ann – Contact Leeanne to obtain answers to the questions generated today
- Debbie – develop flyer with a consistent message to let parents know about opportunity to apply to participate in family guide program and send to everyone for feedback. (Debra and Dana may send Debbie a copy of their job descriptions to assist her with development of the document). Debbie will circulate the draft to Hearing Workgroup members for review.
- Ruth will translate the flyer into Spanish
- Debbie will contact Bright Beginnings to invite a representative to join this group.
- Debbie will obtain the VDH *Information for Parents of Children with Hearing Loss* video and see if copies can be made into DVD by DOE. IF that is not possible, Ann will check to see if this can be done at/by the Partnership for People with Disabilities
- Debbie will re-contact the Sertoma club
- Pat will follow up with Jeanine
- Pat ask Joni Alberg about funding for training through Guide-By-Your-Side and if there are scholarships for the fall conference
- Pat will put this project in the grant application and also include initial SKI-HI training, and will consider funding for INSITE also.
- Beth update flow chart through minutes.
- Beth will follow up with Ruth about the issue Ruth raised concerning lack of feedback from local early intervention systems to EHDI