

**Newborn Hearing Screening Committee Workgroup**  
**April 8, 2005**  
**Minutes**

The first meeting of the workgroup formed from the Newborn Hearing Screening Committee took place at the Virginia Department for Deaf and Hard of Hearing Offices in Richmond on Friday, April 8 from 10:00 until 2:00.

The following persons were present and introduced themselves:

Co-Chair: **Beth Tolley**; Technical Assistance Consultant for Infant & Toddler Connection of Virginia, Virginia's Part C Early Intervention Part C System; Co-Chair: **Carol Wiegler**, Virginia School for the Deaf and Blind - Staunton (VSDB-S) Parent Infant Program, **Jackie Meeks**, Parent and Alexander Graham Bell representative, **Fredia Helbert**, Audiologist, Wise Co., **Debbie Pfeiffer**, Partnership for People with Disabilities/Dept. of Education, **Dana Yarborough**, State Parent to Parent Program, **Ruth Frierson**, Follow Up Coordinator, Virginia Dept. of Health, **Susan Shaw**, Program/System Manager for Infant & Toddler Connection of Blue Ridge, **Leslie Hutcheson Prince**, Virginia Department for the Deaf the Hard of Hearing (VDDHH), **Pat Wiley**, Nurse Care Manager (attending for Barbara Harding) Care Connection for Children, **Sherill Nance**, Quota Club (and her friend, **Ola**).

The members of the group gave a brief explanation of their respective programs. **Alexander Graham Bell Association for the Deaf and Hard of Hearing:** This organization is a resource for parents and professionals. Jackie reported that it has a helpful website ([www.agbell.org](http://www.agbell.org)). The AGBell Association promotes spoken language, but informs parents of all choices. Jackie reported that the organization recently sponsored a one-day workshop preparing parents whose children would be entering the school system. She said the workshop was excellent, though not necessarily appropriate for parents of newly diagnosed children.

**The Care Connection** is a direct services component of the Children with Special Health Care Needs (CSHCN) Program of the Virginia Department of Health. It is the reorganization of what was formerly known as Children's Specialty Services (CSS). The Medical College of Virginia has the Central Virginia Contract for the Care Connection. Services are provided to children birth to 21 who have physically disabling conditions who require more than the normal amount of care and who have limitations in function. Services include: care coordination, advocacy, connection with resources and follow up, transportation, hearing aids (as payor of last resort if there is a confirmed hearing loss and if there is funding). Referrals should be made to Care Connection if it is believed that a child might be eligible. Care Connection staff will work with families to try to find other resources if the child is not eligible for Care Connection. A resource directory is online. (<http://www.vahealth.org/specialchildren/directory/health.asp>).

Beth Tolley reported that the **Infant & Toddler Connection of Virginia** serves infants and toddlers birth to age three who meet the diagnostic/developmental eligibility criteria. [Diagnosed physical or mental condition that has a high probability of resulting in a developmental delay even if a delay does not currently exist; and/or a 25 % delay in one or more of the following areas: cognitive, physical (fine or gross motor, vision, hearing), communication, adaptive, and social/emotional; and/or atypical development.] The Infant & Toddler Connection of Virginia is an interagency system of supports and services for infants, toddlers and their families. It is not a funding source for services or equipment ordered through other systems or agencies. Direct services and assistive equipment are provided for children who are deaf or hearing impaired based on the Individualized Family Service Plan (IFSP) outcomes which are determined by the IFSP team of which the family is a key member. Part C funds are used as payment of last resort after insurance, family fees, community resources, etc. Supports and services are provided through 40 local systems, which conform geographically to the Community Service Board (CSB) designations. There is a local lead agency for each local system; in 33 local systems, the CSB is the lead agency. A university, city, health department or other public agency is the local lead agency for the other 7 local systems. Beth provided public awareness handouts including the Infant & Toddler Magazine and the Developmental Checklist Brochure. She also provided a written overview of Virginia's Part C Early Intervention System (from the website: [www.infantva.org](http://www.infantva.org)), the hearing section of the "Policy Clarification and Technical Assistance on the Implementation of Requirements for Vision and Hearing Components of the Part C Evaluation and Assessments", and the executive summary and family information on individualized Part C early intervention supports and services in everyday routines, activities and places.

Carol reported that outreach services are available to infants and toddlers and their parents East to I95 and South to past Roanoke through the **Virginia School for the Deaf and Blind - Staunton**. Carol (a certified speech and language pathologist/teacher of the deaf) and an audiologist provide these services. Carol provided a handout listing the available services including communication therapy and developmental education (oral, auditory skill development, total communication, visual language systems; speech, slanguage and cognitive skill development); audiological services (ABR, OAEW, behavioral testing, support in selecting, obtaining and maintaining hearing aids and fm system, loaner hearing aids); parent education (communication methodology, understanding hearing loss, developmental information, choices in assistive technology, etc.); assessment (speech and language, developmental, audiological); coordination with Part C programs and other providers; transition assistance to Part B services, play groups, parent supports groups. There is no cost for the services provided through VSDB. Children may be referred by their doctors or other medical agency, audiologist, Infant & Toddler Connection of Virginia, parent or other.

Fredia Helbert serves as an **audiologist** on the **Early Hearing Detection and Intervention Advisory Committee**, provides follow up audiological testing to infants who do not pass their newborn screening test (in the Southwest part of the state) and provides a link with other audiologists in the state.

Debbie Pfeiffer is employed by the **Partnership for People with Disabilities**. She has been instrumental (along with a team of folks, including Pat Dewey from the Virginia Department of Health) in bringing the **SKI-HI training** to Virginia for the direct providers of services in the local Part C systems. Debbie reported that there are 334 interpreters in Virginia schools; only 30% satisfy the requirements. Debbie is in charge of the budget for training the interpreters.

Ruth Frierson reported that she contacts families when she receives the forms from the audiologists, which serve to notify the **Virginia Department of Health** that the child has been diagnosed with a hearing loss. As Follow-Up Coordinator, Ruth facilitates the communication and linkage with Part C early intervention system, provides resources to families and facilitates connections between families. A State Family Group was formed this year through Ruth's effort; the Infant & Toddler Connection of Virginia Family Involvement Project staff provided training to the parents in the group so that they could serve as parent matches for parents of newly diagnosed children. She reported that 8-10 matches have been made. Ruth informed the group that information about protocols, forms, and flowsheets are on the website. She provided a map showing the location of infants (at time of diagnosis in 2003). The website for these resource materials is: <http://www.vahealth.org/hearing/>. Ruth is also working to educate physicians about early identification and intervention.

Dana Yarborough provided information about the **State Parent to Parent** organization. Upon receipt of calls requesting a parent match with a parent of a child with a hearing loss, Dana connects the family either with the state Family Support Group (through Ruth Frierson) or the Infant & Toddler Parent to Parent Network. A number of parents of children who are deaf or who have hearing impairments have been through training by the State Family Involvement Project staff and are members of the state group as well and are also listed as resources on the early intervention parent match resource list.

Leslie reported that the **Department for the Deaf and Hard of Hearing** provides resources and services to individuals from birth through the lifespan. Services include assistive technology (oversight responsibility for Virginia TTY relay services), coordination of interpreters, testing of sign language interpreters, quality assurance screening for interpreters, library service for consumers and professionals and outreach specialists throughout Virginia. Leslie provided a list with contact information of the outreach specialists.

The **mission** of this Workgroup was discussed and as reported in the minutes from the last Newborn Hearing Screening Committee, "is to **address the needs of VA families with a newly diagnosed infant who is D/HH for timely, unbiased and complete information regarding communication options and available resources.**" The group further defined it's role: " to establish systematic methods to be used for infants with a confirmed hearing loss so that timely, unbiased, comprehensive and appropriate information can be given to their families in conjunction with timely referral for Part C services."

#### **Research and reports on topics were presented:**

- Debbie reported on current comprehensive programs in NC and CO (her summary has been sent to workgroup members through email) and the workgroup discussed other states that appear to have programs established as a result of the UNHS including MA, RI, TX, NM, ML, WI, UT. These programs all have early intervention specific for D/HH babies funded through state Medicaid, Dept. of Health, State schools for Deaf and Part C. Some started through state or other grants.
- Beth provided information (handouts) on services in North Carolina (Beginnings), Oregon, Florida, and Massachusetts.
- Information on the National Center for Hearing Assessment and Management (NCHAM) was disseminated. It was reported that NCHAM is considering removing the risk component of the hearing screening/follow up recommendations. The website for NCHAM is <http://www.infanthearing.org/index.html>.
- Ruth explained the current tracking and referral system used at the Dept of Health and ongoing efforts to get more timely return of reports from audiologists.
- Fredia reported on two responses that she received from other audiologists about timely reporting, including a mechanism for electronic submission of reports, use of stickers to flag charts that have reports that need to be sent to the Health Department, personal contacts from the early intervention program, fax number on follow up page from Health department. Ruth responded that many changes had recently been made to the forms and have incorporated some of these suggestions about the forms. At the suggestion of audiologists, 4-page forms were condensed into 2-page forms. There is a page of instructions and one page with HIPAA information and the fax number is on the form. (The forms can be found on the EDHI website). She noted that HIPAA concerns have been a barrier to electronic entry of children's data. Ruth also reported that special envelopes have been developed and supplied to audiologists.

- There are three lists of audiologists/audiology offices: a list of "approved" audiologists (those who have all of the diagnostic equipment), "screening audiologists" (those who applied to be on the approved list, but who do not have diagnostic [ABR] equipment) and the remaining audiologists who are licensed in the state of Virginia. There are approximately 22 audiologists on the approved list and 400 total audiologists in the state. Ruth reported that there are times when it is appropriate to refer families to audiologists who are not on the approved list for follow up (for example when there are language barriers, insurance issues, transportation considerations, etc.).
- Carol presented Virginia's Early Hearing Detection and Intervention timeline for newborns: screened at birth, confirmation of hearing by one month, diagnosis confirmed by 3 months, and appropriate services (to include amplification) by 6 months.

First contact with families, resources, audiological and medical reports, Part C services and the parents' role were also discussed relative to identification. The point was made that in 1999, the average age at diagnosis was 15.5 months. In 2003, the average age was 4.8 months!

The workgroup generated a list of "**strength areas**" which included the services of the agencies present at this meeting and acknowledgement of Pat Dewey and the Virginia Department of Health for the work they have done to coordinate the Newborn Hearing Screening. There are many good resources available including existing protocols and follow-up coordination from VDH, parent support groups, new loaner hearing aid bank, PREP and SKI\*HI training, library and other resources at VDDHH.

#### **Discussion of Areas for Improvement:**

- Some families aren't receiving information after screening or the information is biased.
- May be a lack of education in the medical community about which infants to refer and what is appropriate follow-up.
- Lack of personal communication and connection for parents when they first learn of their child's hearing loss.
- Lack of knowledge and training of those providing services to babies/toddlers in the areas of communication methodology, options, resources, intervention, role of Part C, etc.
- Lack of consistent presentation of information

- Families arriving at Part C with misinformation or expecting Part C to pay for services or equipment already in place.
- Lack of comprehensive services across the state; areas where little or no service is available specific to D/HH.
- Timely acquisition of hearing aids
- Different philosophies of audiologists and PCP, etc.
- Parents entering the Part C system angry and distrustful.

The workgroup started discussing the immediate need for trained professionals to be the "first responder" after the baby's hearing loss is confirmed. Fredia and others suggested the possibility of separating the state into geographic areas (6?) that could be managed by Part C Early Interventionists who are specifically trained to meet families and provide the timely and unbiased information needed immediately, including resources, parent groups and Part C services. Carol and Fredia will develop suggested training components and concepts and Beth and Susan will look into regionalization concepts and will report at the next meeting.

Next meeting will be on **Wednesday, May 11, 9:30 to 3:00** at a location to be announced later (in Richmond area).