

**Newborn Hearing Screening Committee Workgroup  
July 12, 2005  
Virginia Hospital and Healthcare Association**

**Participants:**

Beth Tolley, Carol Wiegler, Debbie Pfeiffer, Ruth Frierson, Susan Shaw, Linda Eggleston, Barbara Harding, Jackie Meeks, Pratibha Srinivasan

**Minutes** of the June 11 workgroup meeting were reviewed, revised and approved.

**Information was provided about the structure of the Part C system**, the intent of the Part C legislation and funding and the challenges facing the Part C system.

From a national perspective:

- Funding was never intended to cover the full cost of services for children, but was rather expected to serve as “glue money” to help support establishment of the infrastructure for coordination of existing services (and elimination of duplication and gaps in services).
- Part C must demonstrate specific positive outcomes for children and families served (Virginia’s outcome system for early intervention is process of development)
- More children are being identified, but federal funding has not increased.
- The Office of Special Education Programs is emphasizing compliance with regulations such as the 45-day timeline for the Individualized Family Service Plan Meeting from referral to Part C.

From a Virginia perspective:

- The number of eligible children has increased
- There are provider shortages in some areas of the state
- Virginia’s infrastructure has change. Each local system has a local lead agency and council coordinators are now local system managers.
- Documentation requirements have increased.
- Local systems (including public and private providers serving the infants and toddlers) are dealing with problems with third party payors including reduced reimbursement, services not covered, billing issues, etc.

**Follow Up from Prior Meeting:**

Debbie reported that the **trainings** (Meeting the Needs of Students Who are Deaf or Hard of Hearing) sponsored by the Department of Education went well. 70 people attended in Roanoke and 113 attended in Fredericksburg and included administrators, teachers, early intervention providers, speech language pathologists, audiologists and others.

**Books and Video/CD materials** have been purchased and will be kept at the Virginia Department for the Deaf and Hard of Hearing as planned. The Department will send to a local system manager upon request. The participants talked about identifying also a specific set of materials that would be provided to families as soon as the child was diagnosed with the hearing loss and possibly additional materials for additional points in time or stages in the child’s/family’s life. The group decided to defer that discussion until the meeting with Joni Alberg or her designee, to see what her recommendation might be. There was further discussion about the value of having the professional watching a video with the parent of a newly diagnosed child in order to be able to answer any questions he/she might have or to

provide support following the video. Participants also discussed that possibility of developing a frequently asked question document that could be left with the family after watching a video with the family.

Debbie reported that **guidelines for working with students** (public school system) with hearing loss are out for public comment until Friday, July 15. Following revision of the guidelines based on the public comment, the guidelines will be finalized and trainings will be held.

**Carol reported that she was able to communicate with Joni Alberg.** Joni had several questions for the group including: Who are the stakeholders? How do Infants and Toddlers currently get into the system? How do parents find out about the options?

The group generated the following responses to Joni's questions:

#### **Who are the stakeholders?**

- Parents
- VA Department of Health (VDH)
- Infant and Toddler Connection of VA (Part C)
- Private providers (speech language pathologists, audiologists, cochlear implant centers, speech and hearing centers/clinics)
- Care Connection for Children
- Family physician/pediatrician
- Community health workers
- Virginia Schools for the Deaf and Blind (VSDB) – There are two schools (Staunton and Hampton, neither of which have early intervention programs at this time)
- Public schools (Some school districts have EI services starting at birth)
- Private schools (River School, Speak UP)
- Hospitals (military, public and private)
- Insurance (public and private)
- Parent support and advocacy groups
- University clinics
- Government (state, local)
- National organizations (AG Bell, etc.)
- VA Department for Deaf and Hard of Hearing (VDDHH)
- Daycare centers (private and public)
- Child Development Clinics

#### **How do families get into the system?**

This is an area of major concern to our workgroup and one that we are diligently addressing and hope to receive assistance with from BEGINNINGS. At the current time, a family enters the system (which could be Part C and/or private therapy) through referral from:

- Diagnosing audiologist
- Early Hearing Diagnosis and Intervention (EHDI) Follow Up Coordinator (through VDH)
- Other parents

- Parents call service provider(s)
- Pediatrician or Primary Care Physician
- Implant Centers, Speech and Hearing Clinics or birthing hospitals
- Community Health Fairs
- Public school
- VSDB or VDDHH
- Organizations (AG Bell, others)
- Central Directory for Part C
- Private providers

Though the guidelines for physicians and audiologists posted on the EDHI website (on the Virginia Department of Health Website) direct physicians and diagnosing audiologists to refer infants and toddlers with hearing loss to the Part C system, there are also notes for referring infants and toddlers to other providers on the audiologists' forms. In addition, only a small percentage of the audiologists in the state are "approved" audiologists who receive the information and forms. Even when the infants have been diagnosed by the "approved" audiologists, the referrals to the Part C system are not routinely occurring.

**How do parents learn about OPTIONS (communication, therapy, education, audiological, etc)?**

Again, this is another area of major concern to this workgroup. Families receive information through or from:

- Audiologist
- Other parents
- Cochlear Implant Team/hospital/Speech & Hearing Clinic
- Ear Nose and Throat Physicians
- Insurance providers (what they will provide)
- VA Dept of Health (follow up calls and letters and publications)
- Part C service coordinators
- Private and public service providers (speech language pathologists, auditory verbal therapist, special educator/deaf)
- (Virginia Schools for the Deaf and Blind (in the past))

**Potential Characteristics of Virginia's System for First Contact for Parents of Infants and Toddlers Who are Deaf or Hearing Impaired**

Participants discussed potential characteristics and criteria for system the group would like to see in Virginia for parents of infants and toddlers with newly diagnosed hearing loss. Criteria or characteristics of the "first contact" included:

- Consistent information provided about all of the hearing options for all parents (with sensitivity to parents' readiness to receive various information, the need to receive information in various formats and the potential need to receive the same information several or many times)
- Social and emotional support
- Networking information and opportunities

In order to achieve the above, standardized training would be necessary for the individuals who would be serving as the first contacts for families.

A possible scenario was discussed:

- As soon as the audiologist diagnoses the infant with a hearing loss, the audiologist notifies the first contact person in that region as well as the Part C point of entry for the city or county where the family lives. (This could be modified that the audiologist notifies only one and the one who is notified, contacts the other).
- The “first contact person (regional specialist) and the local service coordinator contact the family to schedule a home visit. (The regional specialist’s role is to provide the information listed above. The local service coordinator’s role is to provide information about local Part C supports and services). During this call, the regional specialist or the service coordinator can offer to have another parent call the parent. They can also provide information and answer questions over the phone. (Jackie (parent of a 12 year old with cochlear implants) said that a call from another parent made a huge difference for her.)

Potential issues to be aware of include the possibility of the parents looking toward the regional specialist for answers and support if they are perceived as the one who has helped them, thus overloading the regional specialists. There needs to be a way to use the expertise of these specialists and smoothly transitioning families to local providers. Perhaps involving the local service coordinators from the beginning will help with that.

The group discussed additional roles of regional specialists and the number of regional specialists that would likely be needed given the number of children currently identified with Hearing Loss in Virginia each year and where in Virginia these children are located. Five full time and a part time specialist were recommended with the following responsibilities:

- Serve as first contact (home visit + phone calls) for families of infants and toddlers newly diagnosed with hearing loss. Provide information about communication options and intervention, emotional support, networking, and with Part C service coordinator, provide information about local supports and services, parent groups and networks, etc.
- Serve as a resource for parents and the program
  - Continue to be available to parents (all parents, whether or not they are in Part C System) to answer questions, provide support
- Serve as a resource for the system
  - Contact audiologists in the region on a routine basis to ensure that that audiologists have current information about the system and that referrals are being made
  - Contact MDs and other referral sources
  - Communication with other stakeholders
  - Coordinate and provide trainings for region and local systems
  - Provide consultations locally as requested

Discussion followed about funding, location and supervision of regional specialists. Grant funding is the most likely funding source. Virginia Department of Health was recommended as the location for the regional specialists under the supervision of EHDI program manager. Discussion followed about the critical involvement of Part C in oversight of the “first contact/regional specialists” system. Management oversight options were discussed such as an advisory committee with state level Part C leadership playing a key role.

### **System Capacity Assessment**

In follow up to the June meeting, Debby provided the needs assessment that was developed from the ASHA/DEH competencies several years ago when the PREP curriculum was being prepared. The group reviewed and made suggestion for modifications to this assessment in order to be able to use it as a system capacity assessment regarding perceived competencies of providers for providing services for children who are deaf or hard of hearing and also to use as a tool for planning training. (The plan is for each individual who provides services to complete the form. Individuals will be asked to include their name on the form so a list of providers of services for children with hearing loss can be generated).

Next steps include:

1. Debbie will make the revisions discussed today
2. Beth will add the local system information and instructions
3. Beth will share the form and plan with the Part C staff for their review
4. Beth will send the form and instructions to Linda and Susan for their review
5. After review by Susan and Linda and any modifications, Beth will send the form to the 40 local systems

**Next Meetings: Friday, August 12: 9:30 – 2:00**

**Monday, September 12: 9:30- 3:00**