

**Newborn Hearing Screening Committee Workgroup
May 11, 2005
Skipwith United Methodist Church
Draft Minutes**

Participants:

- **Beth Tolley**; Technical Assistance Consultant for Infant & Toddler Connection of Virginia, Virginia's Part C Early Intervention Part C System
- **Carol Wiegler**, Virginia School for the Deaf and Blind - Staunton (VSDB-S) Parent Infant Program
- **Jennifer Hutson**, Parent (Henrico)
- **Peg Suttentfield**, Parent (Richmond)
- **Fredia Helbert**, Audiologist, Wise Co.
- **Deana Buck**, System Manager, Infant & Toddler Connection of Richmond; Partnership for People with Disabilities
- **Linda Eggleston**, System Manager and Infant Program Manager, Infant & Toddler Program Connection of Virginia Beach
- **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**, System Manager and Program Manager for Infant & Toddler Connection of Blue Ridge
- **Pat Wiley**, Nurse Care Manager, Care Connection for Children
- **Pratibha Srinivasan**, Executive Director, Chattering Children (a nonprofit organization that teaches children with hearing loss to listen and speak)

Mission: 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."

Minutes of the April 8 meeting were reviewed and approved as written.

Announcements

Carol read a note from Frank Aiello supporting the work of the group and offering to serve in the role of consultant to the workgroup.

Fredia reported that she will be finishing up an intensive continuing education course that has included self study (reading, online chats) by attending a two-day workshop Thursday and Friday. This is a national training for Audiologists sponsored by NCHAM for which funding for Virginia audiologists were provided by VDH. Susan Shaw's cousin is one of the professors for the course.

Deana reported that the first Virginia teleconference on early hearing identification and intervention for physicians and other interested persons was held May 2. The teleconference was a replication of a national teleconference and CMEs were provided. The next teleconference is scheduled for May 20 from 12:00 noon to 1:00 PM.

Carol reported that Virginia has been notified that our grant proposal, submitted by Pat Dewey, Virginia Department of Health, for replication of North Carolina's Beginnings program has been accepted by the National Center for Hearing Assessment and Management (NCHAM) for funding at level three. Specific details are not available yet.

Dana shared information she had found on a parent funding toolkit. This can be found at http://www.handsandvoices.org/par/1_intro_par.htm.

Identification of Issues

The areas for improvement identified at the first meeting were reviewed. Items were clarified and additional items were identified. The information was then sorted into two major categories: Information/Education and Services and Supports.

Information/Education

Participants agreed that this category includes lack of, and/or biased and/or inconsistent information or information that is not provided soon enough to parents.

Specific issues identified include the following:

- Some families are receiving biased information
- Some families are entering the Part C system angry and distrustful
- Different philosophies of audiologists and PCPs, etc
- Families entering the Part C system with misinformation expecting the Part C system to pay for services and/or equipment already in place or on order
- Lack of consistent presentation of information
- May be a lack of education in medical community about which infants to refer and what is appropriate follow up
- Lack of knowledge and training of those providing services to infants and toddlers in areas of communication methodology options, resources, intervention, role of Part C, etc.

Services and Supports

- Some families aren't receiving information after screening at the hospital
- Some families aren't receiving information after hearing assessment
- Inconsistent presentation of information
- Lack of personal communication and connection for parents when they first learn of their child's hearing loss
- Lack of support for parents
- May be a lack of education in medical community about which infants to refer and what is appropriate follow up
- Lack of providers
- Lack of knowledge and training of those providing services to infants and toddlers in areas of communication methodology options, resources, intervention, role of Part C, etc.
- Insufficient training of providers
- Can take 2-4 months to get appointment with audiologist for new patient
- Access limited due to cost and limited reimbursement
- Delay in receiving hearing aids due to reimbursement considerations

Participants then identified what is currently in place to address these issues.

Information and Education - Currently in Place

Training for Professionals

- Workshops for Audiologists provided and/or supported by the Partnership for People with Disabilities and the Virginia Department of Health (VDH)
- Trainings/workshops for Physicians provided and/or supported by the Partnership for People with Disabilities and the Virginia Department of Health (VDH)
- PREP (Providing Resource and Education to Providers) Training for individuals who work with children who are deaf or hard of hearing and their families- provided to 600 people - included an awareness level training and a three day training
- SKI-HI Training - 6-day training provided for 36 early intervention providers across the state who work with children who are deaf/hard of hearing and their families (Trainings sponsored through VDH with training provided by SKI-HI personnel)
- Trainings for Hospital personnel
- Parent Panel at MCV for 3rd year Med students
- "Meeting the Needs of Children with Cochlear Implants" (through the Department of Education - in Lynchburg and Williamsburg)
- Radford summer programs on auditory verbal therapy (part of a degree program and open to parents as well as providers)
- Sessions at Infant & Toddler Connection of Virginia Annual Conferences

Challenges or Barriers: Announcements about upcoming training events do not always get to the intended audience (I.e., from the front office or Director to the staff).

Information and Support for Parents

- Parent Brochure (in English and Spanish) to be provided to parents of all newborns at hospitals (provided by VDH)
- Hear and Now - Parent Group sponsored by VDH providing parent connection and support
- Parent Packet: *Information for Parents of Children With Hearing Loss*, which is to be provided to all parents at the time that their child's hearing loss is confirmed. This resource is also provided (prepared and supplied from VDH) to approved audiologists. Other audiologists can request them. The Department of Education and Parent Resource Centers and Directors of Special Education have them as do local Part C systems. The information in the parent packet is available online and is also available in video in American Sign Language. These packets will be updated.
- Follow up letters and phone calls from the Follow Up Coordinator at VDH
- Virginia Schools for the Deaf and the Blind (Staunton and Hampton) - classes and workshops for parents
- Parent to Parent

Challenge: Need to assure that parents who are supporting other parents re providing unbiased information.

Resources

- Virginia Department for the Deaf and Hard of Hearing Resource Library resources
- Training and Technical Assistance Center (T/TAC) resources
- Local Infant & Toddler Connection system resources
- Parent Resource Centers

Other

- Follow up calls to physicians

Supports and Services - Currently in Place

Hospital Screening Process

- Brochures for all parents
- Information for parents whose children do not pass the screening including a list of "approved audiologists"

Follow up Process

- Currently, 80% of the parents of infants who do not pass the newborn hearing screening at the hospital follow the recommendations for further evaluation.
- Parents can choose where, including whether to go to an approved site, to take their child for follow up. They can choose when to go for follow up and can opt not to go for follow up.
- Training is available for approved sites but is not required

- VDH Protocols specify referral to local Part C system for each child that has a confirmed hearing loss
- VDH Medical Management Protocol specifies in the flow sheet for *Management for Infant who Refers From Hospital Hearing Screen* that audiologists offer referral to local early intervention programs or other educational programs.
- VDH Early Hearing Detection and Intervention form (available on the web) is completed by audiologists and sent to VDH when hearing loss is confirmed
- When VDH receives report of child with confirmed hearing loss, Ruth calls the parent within 2 weeks. (She is finding that most have not been given the Resource Guide and have not been referred to Part C early intervention). Ruth refers the children to the local Part C system as well as giving them the name and number of the central point of entry for the local Part C system. Ruth also tells the families about Parent-to-Parent resources.

Challenges/Barriers: The children who do not go through the process as outlined or whose audiologists do not send in the EDHI report to VDH do not receive the follow up letter and call from the Follow Up Coordinator. These children and families are most at risk of receiving incomplete or biased information, little or no support or resources and no or late referral to Part C.

Supports and Services

- There are 40 local Part C systems (Infant & Toddler Connection of.....) These are organized in 6 geographical regions. Each child/family has a service coordinator. Supports and services are determined by the team (which includes the family) and are determined on the basis of what is necessary to meet the outcomes identified by the family. Persons providing special instruction (may be licensed in early childhood education , early childhood special education, teacher of the hearing impaired) or speech language therapists from 28 of the 40 local systems have participated in the SKI HI training. These providers and/or additional providers have participated in additional trainings including the Radford training programs, and other auditory-verbal workshops. Part C entitled services are provided within the local system or through a contractual arrangement by an individual with knowledge skills and experience working with infants, toddlers, and young children who are deaf or hard of hearing. In Part C, services must be provided in natural environments unless the outcomes cannot be met in natural environments. Some local systems contract with the school system to provide services.
- Virginia School for the Deaf and Blind at Staunton - Infant Outreach Program
- Virginia School for the Deaf and Blind and Multi-Disabled at Hampton (Outreach Program position not filled)
- A parent group recently had three deaf adults who used different modes of communication attend the group and talk about their choices and how they are able to function in a hearing world. (This was reported to have been a very valuable experience for the parents who attended and led to a discussion about providing this type of support

available to parents and also to perhaps developing a registry of young adults with cochlear implants who could meet with new parents.)

- Virginia Network of Consultants (VNOOC) does not currently work with professionals serving the birth to three population.
- Private programs, including Chattering Children
 - There are 6 certified auditory verbal therapists in Virginia. Certification in AVT is not required to provide AVT. The location of the AVT certified therapists is: Two in Tidewater, one in Lynchburg, one in Charlottesville, 2 in Richmond, one in Staunton and one in McLean. (More than 6 listed because some serve multiple sites).

Challenges/Barriers: Inconsistent availability of services; Concerns that services for infants and toddlers who are deaf and hard of hearing are not comprehensive or of sufficient frequency; financial considerations limiting assistive equipment (aids, molds, fm systems) and diagnostic services

The group brainstormed long and short-term solutions to issues that were identified and also considered which issues would be affected by replication of the Beginnings program. Two major goals emerged.

- 1. Decrease time between diagnosis and provision of parent support, resources and services**
- 2. Appropriate intervention that is consistent across the Commonwealth**

A number of tasks were identified for each of these goals. Specific action steps identified at the meeting are italicized.

1. Decrease time between diagnosis and provision of parent support, resources and services

- Establish a Central Point of Entry for Children who are Deaf or Hard of Hearing*
- Establish regional specialists in the 6 Part C early intervention regions to serve as a resource to parents and to other providers. *
- Educate Pediatricians
- Educate Medical Students (consider Parent Panels as is done at MCV) at EVMS, MCV, UVA
- Educate Part C Providers, audiologists, ENT, nurse practitioners, hospital workers.
Plan: Ruth will bring information to the June 10 meeting about what has been budgeted for training.
- Family directed public awareness (consider a video for hospitals to use for mothers/fathers whose child does not pass the screening; consider a CD to mail to families whose child did not pass and who have not followed up)

- Revision of Protocol for follow up (follow up letter) *Plan: Ruth will send a copy of the current letter to Carol. Invite parents to the EDHI Advisory Committee Meeting on June 10th to help rewrite the Follow Up Letter to Parents.*
- Revise Audiology form and Medical Management Protocol to be clear that referral to Part C is required. *Plan: Ruth will take this recommendation to Pat Dewey at VDH.*

* This may be impacted by NCHAM grant to replicate Beginnings Program.

2. Appropriate intervention that is consistent across the Commonwealth

- Provide information about evidenced based practice for infants and toddlers with hearing loss to providers. *Plan: Fredia, Pratibha, Debbie and Carol will bring information to the next meeting. Fredia will send information via email to Beth.*
- Training for providers
- Mentoring
- Expand Part C networks (Each local system must provide the services the IFSP team determines are necessary to meet the child's outcomes. If the services are not available within the local system, the local system is responsible for making contractual arrangements to make them available.) *Plan: Part C Technical Assistance Consultants talk to local system managers about expanding networks and remind them of the requirement to make the necessary services available for each child.*
- Determine available resources - qualified personnel in the state - create a list. *Plan: Beth discuss with TA Consultants the best way to obtain this information.*
- Identify consistent list of video and print Parent Education resources each local Part C system should have. *Plan: Workgroup members are to bring suggestions to the June meeting.*
- Keep Registry of trainings providers have attended

One point made during the meeting was that some parents may not be ready to address their child's hearing loss when it is first identified. This led to a discussion of the need for ready access to resources that are available whenever parents need them. The NCHAM grant may provide the opportunity to offer information to families about the Part C early intervention system, referral to the Part C system, differences between government and private services, as well as specific information about communication options.

Next Meeting: June 10: 8:00 AM - 10:00 AM at Virginia Reciprocal, Richmond

July Meeting: July 12, 2005: 9:30 - 3:00 PM; Children's Hospital, Richmond