

Virginia Early Intervention Autism Initiative
December 18, 2002
Richmond, Virginia
Meeting Notes

Karen Durst, Part C Technical Assistance Consultant for the Infant & Toddler Connection of Virginia welcomed participants to this first meeting of the Virginia Early Intervention Autism Initiative. The initiative was conceived as a mechanism to bring together the stakeholders across the state of Virginia to address challenges and opportunities concerning services for children diagnosed with Autism Spectrum Disorder. The purposes of the initiative include:

- Development of service guidelines for intervention for Part C eligible children with Autism Spectrum Disorder (ASD)
- Determination of availability of informational, support, intervention and funding resources related to ASD in the state of Virginia
- Identification of gaps in availability of resources
- Development of recommendations and plans to bridge the gap between what is needed and what is available so that children birth to three with ASD and their families receive consistent, appropriate information, support and services in Virginia.

Participants introduced themselves and provided their input about the greatest needs and the greatest opportunities facing Virginia concerning services for children with ASD. Participants included:

- Beth Sarrett, Instructional Specialist, Autism, Early Childhood Special Education, Severe Disabilities (Chesterfield County)
- Tracy Miller, Occupational Therapist, Program Manager, Rehabilitation Associates, P. C. (Tidewater)
- Carol Burke, Council Coordinator/CSB Infant Program Manager (Rockbridge)
- Liz Fletcher, Coordinator, Parent Infant Program; Speech-Language Pathologist (Henrico)
- John M. Suozzi, Ph.D., Clinical Psychologist, Children's Hospital (Richmond)
- Pasquale Accardo, M.D., Professor of Pediatrics, Developmental Pediatrician, Children's Hospital (Richmond)
- John Toscano, Executive Director, The Autism Program of Virginia (TAP-VA) (Richmond)
- Jane I. Carlson, Education Director, Autism Center of Virginia at VCU (Richmond)
- Janet Hill, Senior Research Associate, VCU Commonwealth Institute (Richmond)
- Noel Woolard, Program Director of Virginia (Richmond)
- Heather Elias, Parent (Henrico)
- Beth Tolley, Part C Technical Assistance Consultant, Infant & Toddler Connection of Virginia
- Mary Ann Discenza, Technical Assistance Consultant, Infant & Toddler Connection of Virginia

The following were identified as the greatest needs related to Autism Spectrum Disorder:

- Identifying children with ASD – early diagnosis
- IFSP team decisions related to frequency of services
- Informed choices for children by the family
- Helping families and providers in looking at appropriate and available approaches
- Technical assistance and support for families in making choices
- Availability of evidence-based intensive services for children
- Reluctance of primary care physicians to make early diagnosis due to lack of availability of services for children diagnosed with ASD
- Variety of views and families needing to sort it all out

- Gap in appropriate and available services
- Funding
- Balancing resources in order to serve all children
- Inconsistency of diagnosis
- Autism needs a “home” in Virginia – what agency is responsible?

The group identified the following as the greatest opportunities for the initiative:

- Pulling resource people together from across the state
- Development of guidelines for parents and providers
- Dissemination of research-based knowledge
- Autism is on everyone’s radar screen – the timing is good for garnering support for recommendations
- Bringing current knowledge to Virginia and making it widely available
- Autism is an NIH priority – there is intensive interest in ASD
- Diversity of people meeting today and expected to be a part of this initiative – committed to addressing issues association with ASD
- Working together from a statewide perspective
- To give each child a chance to have appropriate services so each child can thrive
- Training for Part C providers in ABA (Applied Behavior Analysis)
- Developing a packet for families including information about treatment, medical tests that should be done, support groups, contact list of local and national resources
- Paid training for parents
- Availability of research and guidelines from other states

The following comments were made concerning the current state of services for children with ASD:

- In Virginia, a mental illness/mental retardation model is employed. There are gaps in availability of services for children ages 3 – 21 who do not have an IQ under 70 or an Axis I diagnosis.
- Systems working together using a “wrap-around” model of services have resulted in parent satisfaction in Pennsylvania
- The guidelines developed in New York are helping people navigate the system
- Heather Elias said her family has 4 options concerning treatment for their daughter:
 - o Do what they are doing now (outpatient therapy sessions)
 - o Move to another state where services are available and affordable
 - o Give up everything (home, etc) in order to afford \$50,000+ annual cost of special school
 - o Sue

The group decided to proceed by creating three subcommittees:

1. Development of Service Guidelines
2. Systems Development – Maximizing Current Resources
3. Expansion of Financial Support

Concerning the development of guidelines, Dr. Accardo reported that the cost of developing the guidelines in New York was \$350,000 with an additional expense of \$200,000 to disseminate them. He reported that there was a big (positive) impact on the level of knowledge across the state as a result. The group discussed the fact that research has been done and guidelines have been developed in a number of states, so the time and cost for development of guidelines for Virginia should be reduced since the information from those states can be used as a baseline for development of Virginia’s guidelines. Concern was expressed about how recommended services/frequency of services could be funded and a suggestion was made that recommendations made need to be made initially in conjunction with available resources, then adjusted over time as resources are increased.

A challenge in garnering support for increased resources is that the initial cost is high; the benefits are seen over time with reduction in cost of services for children who receive early appropriate intervention. A suggestion was made that medical insurance be considered as a possible funding source for treatment. Discussion about requesting funding through legislative action included concerns about the current Virginia budget.

Urgent issues which need to be addressed immediately include:

- Provision of information, training, resources for Part C Council Coordinators and providers
- Development of consistent information packets for families and providers

Plans:

1. The Autism Program of Virginia will develop informational packets and distribute these to each council
2. The Part C Office will work with the Department of Mental Health, Mental Retardation and Substance Abuse Services Office of Information Technology Services to create a page on the Infant & Toddler Connection of Virginia website for Autism. Notes from these meetings will be posted as soon as they are available (prior to "approval" and labeled as unreviewed)
3. Janet Hill will explore the possibility of seeking funding for training of providers in conjunction with the legislative request that is to be made through the Autism Council
4. A database will be created of people involved in this initiative
5. Additional members will be included in order to assure broad representation of key stakeholders across the state
6. The "Initiative" will meet each 4th Wednesday from 1 – 4 PM. The first part of each meeting will be devoted to subcommittee work. Subcommittee work will also be done via telecommunications and email.
7. The Guidelines subcommittee will have its first meeting January 15. There are two distinct goals for the guidelines subcommittee: development of recommendations concerning best practice for diagnosis and treatment of ASD in Virginia AND development of guidelines for Part C's responsibility in provision of services for children with ASD
8. Mary Ann Discenza will contact those who expressed interest in serving on the Systems Development subcommittee to set up the first teleconference. Focus of this group will include expanding the system, workforce development, capacity building.

The following persons volunteered to serve on the three subcommittees:

Guidelines:

Dr. Accardo, Noel Woolard, Jane Carlson, John Suozzi, Liz Fletcher, Beth Surratt, Heather Elias, Karen Durst, Beth Tolley, Tracy Miller. Additional members were suggested including Carol Schall, a representative of the Department of Education (DOE). Evelyn Shaw of the National Early Childhood Technical Assistance Center will be consulted also.

Systems Development (Maximizing Current Resources):

Mary Ann Discenza, Janet Hill, John Toscano, John Suozzi, Heather Elias (as time permits). Additional members suggested included Carol Schall, Bev Crouse, a representative of DOE, Karen Lawson of the Department of Medical Assistance Services (DMAS).

Expanding Funding

Janet Hill, Heather Elias. Additional members suggested included a representative of the Autism Society of

America, Sharon Siler, representatives of DMAS, DOE, Virginia Department of Health and private insurance (such as Anthem).

The meeting was adjourned at 4 PM.

Autism Spectrum Disorders Questions, Issues, Opportunities

What causes Autism Spectrum Disorder?

What are the medical treatments for children with ASD?

Is Autism Spectrum Disorder curable?

What treatments are effective?

What intensity of intervention is necessary/recommended/effective?

Are different treatment approaches and intensities effective for different children and if so, how do you know/predict what will be most effective for a specific child?

How are families being informed of options and how are they supported as they make decisions about treatment?

What information and training is needed by the individuals within the Infant & Toddler Connection who are serving children with ASD and their families?

Are there enough trained individuals to provide treatment (throughout Virginia)?

How can we increase the number of specifically trained providers available to provide services for children with ASD and their families?

What is the financial cost for services, including costs associated with recruiting and training interventionists as well as the cost of the intervention?

Who is responsible for paying for services?

Where will the money come from to pay for the services?

How can we assure that children throughout Virginia receive consistent, appropriate information, recommendations and intervention which is individualized on the basis of the child and family's needs and not dependent on the particular philosophy and/or availability of resources of the area where the child and family live?

What are all the resources that could be brought together to address the need for interventionists and funding and how can we pull this together?