

**Virginia Early Intervention Autism Initiative**  
**January 29, 2003**  
**Henrico Mental Health Center**  
**Draft Meeting Notes**

The second meeting of the Virginia Early Intervention Autism Initiative was held January 29, 2003 at the Henrico Mental Health Center. 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);
- Liz Fletcher, Council Coordinator, Parent Infant Program; Speech-Language Pathologist (Henrico);
- Brenda Crockett, Council Coordinator, Infant & Toddler Connection of Chesapeake (Chesapeake);
- Jill Donaldson, Speech-Language Pathologist, Infant & Toddler Connection of Rappahannock, (Fredricksburg);
- Sue Palko, Virginia Commonwealth University T/TAC;
- Donna Rimmel, Educator, Infant & Toddler Connection of Chesterfield (Chesterfield);
- John Clary, Mental Retardation Director, Colonial CSB, (Williamsburg);
- Sharon Sikes, Coordinator, Infant Program, Children's Hospital (Richmond);
- 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 the Autism Program of Virginia (TAP-VA) (Richmond);
- Heather Elias, Parent (Henrico);
- Beth Tolley, Technical Assistance Consultant, Infant & Toddler Connection of Virginia;
- Mary Ann Discenza, Acting State Coordinator, Infant & Toddler Connection of Virginia;
- Karen Durst, Technical Assistance Consultant, Infant & Toddler Connection of Virginia.

Connecting by phone were the following participants:

- Carol Burke, Council Coordinator/CSB Infant Program Manager (Rockbridge);
- Beverly Crouse, Technical Assistance Consultant, Infant & Toddler Connection of Virginia;
- Kerry Lambert, Old Dominion University T/TAC;
- Rebecca Berlin, (Charlottesville)

Notes from the December 18, 2002 meeting were approved as written. These will be posted on the [Infant & Toddler Connection website](#).

A decision was made to meet as a large group for the day's meeting rather than to break into smaller subgroups. The consensus was that the group needed to meet together as a whole in order to develop a more defined focus for the initiative. Mary Ann Discenza, Acting State Coordinator of the Infant & Toddler Connection of Virginia, facilitated the meeting.

The following issues and concerns related to autism and autism spectrum disorders were identified by the group as critical in Virginia:

- Early identification (diagnosis) is an issue in Virginia;
- Resources (funds and trained personnel) need to be available for children who need the level and type

of services recommended but who do not have the diagnosis of autism or autism spectrum disorder;

- o Reluctance of Physician to diagnose should not keep a child from receiving needed services;
- o In early intervention, individuals in the Part C system have worked very hard to move to a family-centered, asset-based, outcome-driven, parent teaching/training, family empowered system of intervention. Basing recommendations solely or even mostly on a diagnosis is counter to the philosophy of early intervention in Virginia;

- Whose responsibility is it to fund intensive services?
- What philosophy, intervention approach, specific services and resources are available for children when they turn 3 and leave early intervention;
- Providers have seen children improve (sometimes dramatically) using intervention approaches other than ABA (such as Floor time, etc). How do we move forward without discarding positive aspects of what is currently working?
- If research demonstrates good/great results for 33-50% of the children, is there a way to know whether a particular child will fall into that 33-50% category? Is it possible that children who do not respond to ABA could respond to other approaches? Is there a way to apply research methods used for testing ABA approach to other treatment approaches? (ABA lends itself to research, the other methods don't – Can ABA methodology be used as pre and post test for other treatment approaches?)

After extensive discussion it was determined that consensus among the group was necessary in order to move forward with the work of the initiative. The following points were identified as requiring a consensus:

- Population under consideration
- What is ABA? What is meant when someone talks about ABA?
- What does the research show and what is not shown by research? What research deals specifically with the 0-3 population? Does the existing research provide sufficient information to be absolutely definitive about guidelines? What is the appropriate interpretation of the research as a basis for development of information packets for families and providers and service guidelines?
- Interplay of evidence based practice and individualization of intervention. (Definition of evidence-based practice. Does evidence based practice refer to practice based on literature reports of research showing 33-50% of children with a particular treatment approach improved and/or does it refer to tailoring of intervention based on achievement of individualized outcomes?)
- At what point is a symptom something that needs to be treated versus an expression of the extreme range of normal behavior (which could or should be ignored)?

A decision was made that the Early Intervention Autism Initiative would begin its mission by focusing on service delivery guidelines for those children who have received a diagnosis of autism or autism spectrum disorder.

In order to assure that all of the participants in the autism initiative have a mutual basic understanding of autism and treatment approaches, it was determined that Jane Carlson would provide an information sharing session to the group at the next meeting. The following information would be included:

- Identification and diagnosis;
- Treatment approaches – including research support for the various approaches;
- ABA – What is it? What are the various connotations of “ABA”? What exactly is it that the research says is best practice?

Additionally, for the February meeting, it was determined that a small group consisting of Jane Carlson, Pat Accardo, and John Suozzi would develop a presentation and facilitate a discussion of best-practice recommendations for children with autism ages birth-three. The consensus was that this could be a starting place for the group to work on guidelines. A key component of the guidelines work would be a distinction between best practice guidelines and Part C service guidelines. The Part C service guidelines for children

with autism spectrum disorder must also be compatible with the state early intervention philosophy.

Further discussion surrounded the needs of families related to participation in meetings and on committees. It was identified that families need support in the areas of respite and daycare. It was reported that few individuals, or daycare facilities, have the training to care for children with autism. This concern was identified as a priority need in the area of training.

Financing the system was cited as a major concern related to autism and autism spectrum disorders. The following were identified as crucial steps that need to be taken:

- Explore potential funding streams;
- Explore grant potentials;
- Explore insurance reimbursement for some services. (It was reported that TRICARE is beginning to cover ABA in the Tidewater region.)

TAP-VA offered to post information on their web site that is sent to them related to continuing education/training courses. The Part C office will pursue linking the infantva.org website to TAP-Va's training page.

Due to technical difficulties with the phone conferencing, it was decided that the Part C office would explore the possibility of video linking for the February meeting. Additionally, the following activities will be completed in preparation for the next meeting:

1. Part C Office will disseminate the following information:

- a. Chapter from Educating Children with Autism (will be distributed to those participating by phone, individuals who participated in person received this information);
- b. Link to New York best practice guidelines for children birth – three with ASD;
- c. Link to Connecticut Early Intervention Guidelines for Children with Autism;
- d. Link to Georgia Early Intervention Guidelines for Children with Autism;
- e. Report to the legislature (Janet Hill will send to Part C office);
- f. “White paper” (Janet Hill will send to Part C office);
- g. DSM-IV criteria for diagnosis of autism (Jill Donaldson will send to Part C office);
- h. Finance Task force draft service guidelines (will be ready after February 6)
- i. Case-law information

2. Part C office will collect information from localities about how many children with autism spectrum disorders are currently being served by EI across the state – and the range of services these children are receiving.

**The next meeting of the Early Intervention Autism Initiative will be February 26, 2003, 9:00 AM-Noon, (please note the time change) at the Henrico Mental Health Center.**