

VIRGINIA EARLY INTERVENTION AUTISM INITIATIVE
HENRICO MENTAL HEALTH CENTER
DRAFT MINUTES
07/01/04 MEETING

The Virginia Early Intervention Autism Initiative met Thursday, July 01, 2004 at the Henrico Mental Health Center. The following members were in attendance: Dr. Pat Accardo; Carol Burke; Karen Durst; Debra Holloway; Donna Rimmel; Bruce Schaffer; Carol Schall; Beth Tolley; and Charlene Wentland. Carol Schall served as the facilitator for the meeting and Karen Durst was the recorder.

The meeting began with a review of the development of the vision for the group. Carol reminded the members that the purpose of the vision was to define and guide the group and that it was not necessary for the ideas to be within the reach of the group. She stressed that the vision was a step in developing the action plan and the action plan would be what was positive and possible for the Autism Initiative to achieve within the next 12 months.

Carol identified and discussed the main vision points developed during the May 24, 2004 meeting. They included the following:

1. Understanding and Respect for Roles;
2. Part C Guidance;
3. Trust Issues;
4. Synergy;
5. Child First;
6. Training;
7. Funding;
8. Clarity About Resources;
9. Wider Community Understanding; and
10. Data.

Additional ideas were generated related to the vision of the Autism Initiative. They include the following:

- We know what autism is including knowledge of effective intervention and treatment.
- We have a clear direction and goal for the Early Intervention Autism Initiative.
- Individuals are teaming using a collaborative approach rather than divisive.
- At the team level, the physicians and the Individualized Family Services Plan (IFSP) team are working together and coordinating services.
- There is a cohesive system for supporting and educating people with autism, families and professionals from various disciplines.
- Respectful communication and professional debate toward supporting the family and providing comprehensive recommendations occurs.

- As the team functions together, the family is receiving complete information, is fully informed and receives team recommendations.
- The family's decision is honored.

The group then generated statements representing the present situation and what the Initiative is currently facing. The statements include:

- The Part C system is a truly under-funded system.
- The whole field of autism is a developing field that is nebulous with a diversity of views. It is not a simple field.
- There is no state system to coordinate the needs of individuals with autism.
- There are questions about what is included in the definition of Pervasive Developmental Disorder (PDD).
- The number of children being diagnosed with autism spectrum disorders is rapidly increasing. (The question arose as to whether the number of children with a diagnosis of developmental disabilities or mental retardation is decreasing.)
- There is no data about the number of children in the Part C system with a diagnosis of autism spectrum disorders.
- There is a pressure for a diagnosis and an increased demand for services.
- There are internet sites that make claims of cures and parents want the same treatments.
- There is a lack of data from the field of research to guide treatment.
- Part C does not have a convincing way to present results from their treatment experience.
- Many Part C localities do not have adequate training, staff, money and the comfort level to provide appropriated services to meet the demands.
- Many Part C providers are willing to learn and work hard to meet children's needs.
- There is not a systemic, coordinated approach to training.
- When some individuals say "you're wrong" people get defensive and parents get conflicting advice. The parents and the field get confused and this puts increased pressure on providers. There is no team. This happens everyday across the state!
- There is a zealouslyness to push for particular treatments within some existing support groups thus creating more guilt for families.
- Some parents drop out of parent support groups but continue to need support.
- There is a consistent lack of agreement as to diagnosis and treatment.

The members then worked toward the development of an action plan for the Early Intervention Autism Initiative. It was emphasized that this was a plan that was positive and possible to accomplish by July 01, 2005. The group identified four areas that included System, Data, Education/Training and Family Support. It was recognized that, based on topic, many of the individual statements could fall into more than one category. Specific plans that the Initiative will accomplish within the next twelve months include:

System

- The Autism Initiative coordinated with the Statewide Autism Planning Council through the sharing of minutes, training information, etc.
- We developed a proposed system of training and coordinated services.
- We developed a comprehensive list of competencies for staff and proposed training.
- We established a group identity and developed our decision-making system.

Data

- We collected information to document our current experience so we could present for and access funding.
- We added “autism” to our database in order to count the number of children with autism in the Part C system.
- We developed a report and presented it to key stakeholders to describe the state of autism in Part C.
- We formulated a plan to standardize data on outcomes that is workable and satisfies the autism community.

Education/Training

- We distributed the “Fact Sheets”.
- We worked with Janet Hill and offered Autism Awareness Training for Part C folks.
- We put a link on our “Autism” page to the web-based Autism Awareness Training.
- We contacted hospitals and offered speakers to do grand rounds on autism.

Family Support

- We sought federal funding to pilot a new parent support group.

Individuals were then identified who would take responsibility for addressing specific areas of the action plan. Those individuals are to serve as coaches in coordinating members toward reaching the goals of the plan. The following individuals agreed to serve as coaches:

System: Carol Burke, Karen Durst, Carol Schall and Beth Tolley

Data: Karen Durst, Bruce Schaffer and Beth Tolley

Education/Training: Bruce Schaffer and Charlene Wentland

Parent Support: Pat Accardo and Debra Holloway

The members discussed the progress that the group had made since it first began meeting in December 2002. It was recognized that the group has become more united and that

many challenges have been overcome. It was the agreement of the members that the Initiative is “moving forward”.

Plans for future meetings were then discussed. It was decided that following the August meeting, the Autism Initiative would meet the third Thursday of each month from 1:00-4:00.

Discussion also occurred regarding the membership of the Initiative. It was identified that some of the original members of the Initiative had not participated in some time. It was recognized that work schedules, changing job and family responsibilities, etc. might be preventing some individuals from participating. It was decided that an email would be sent to all members, along with the minutes, regarding the twelve-month action plan of the group and inviting all members to participate once again. Members would be asked to identify their desire to continue serving or their wish to discontinue membership. It was stressed that the contributions of all members have been greatly appreciated.

The group also identified specific areas where representation was needed related to membership on the Initiative. The following areas were addressed:

- Parents;
- Private Providers;
- Training Specialists;
- Universities-Early Childhood Education;
- Schools; and
- Autism Organizations.

Individuals were thanked for their participation and commitment to serving on the Early Intervention Autism Initiative and addressing the needs of children with autism and their families.

The next meeting of the Autism Initiative will be held Thursday, August 12, 2004 from 1:00-4:00 at the Henrico Mental Health Center in Conference Room C.