

VIRGINIA EARLY INTERVENTION AUTISM INITIATIVE  
HENRICO MENTAL HEALTH CENTER  
DRAFT MINUTES  
08/12/04

The Virginia Early Intervention Autism Initiative met Thursday, August 12, 2004 at the Henrico Mental Health Center. The following members were in attendance: Dr. Pat Accardo; Carol Burke; Amy Compton; Karen Durst; Linda Hutton; Phyllis Mondak; Donna Rimmel; Bruce Schaffer; Carol Schall; Sharon Sikes; and Beth Tolley. Carol Schall facilitated the meeting and Karen Durst recorded the minutes.

Carol Schall began the meeting by reviewing the action plan that was developed during the July 01, 2004 meeting. The action plan included the four major categories of System, Data, Education/Training and Family Support. Specific goals were identified under each category. It was determined that the plan includes those things that are positive and possible for the Autism Initiative to complete within the next 12 months. They included:

**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.

Dr. Pat Accardo updated the members on his efforts to look into possibly funding an alternative parent support group for families with children with autism. It had previously been identified that some families have reported receiving pressure from some support groups regarding trying certain methodologies or alternative approaches to treating their children with autism. These families did not feel supported but felt additional pressure and stress.

Dr. Accardo reported that he had contacted Donald Oswald and that they had discussed that the effort to start an alternative parent support group may be too large as an initial step. He suggested surveying parents as to what is helpful within a support group and what is not.

Dr. Accardo suggested an alternative plan for conducting the survey. It was determined that the purpose of the survey should be to define the need for an alternative parent support group and to identify issues related to family support. Carol Schall reiterated by phrasing the purpose of the survey as identifying “the state of family support for families of children with autism in Virginia”. It was stated that the survey should be disseminated statewide. Carol Schall suggested possible working with the Autism Society in conducting the survey. The Family Support Committee will address the survey.

Beth Tolley then shared with the group that she had been attempting to contact Sharon Siler from the Department of Education regarding the School System’s Priority Project on Autism. Beth expressed exploring collaboration between the Priority Project and the Autism Initiative.

Carol Schall updated the members on the Priority Project. She reported the following related to the Priority Project on Autism:

- The Project began one year ago due to identified needs in Virginia for training of school personnel related to autism.
- Sharon Siler is currently filling the vacant position related to coordinating the project.
- The Project coordinates resources across the state with T/TAC assisting the schools under review.
- There are currently 13 Priority Projects in existence.
- The Project has developed brochures; brings in speakers; talks about how best to provide training; and provides mini grants in the amount of \$1,000 to identified school systems to help teachers in gaining skills in working with children with autism.

It was stated that the Priority Project is an initiative of T/TAC and the Department of Education and may not accept individuals for participation outside of T/TAC and the School System. It was decided that Phyllis Mondak would follow-up with Sharon Siler.

Beth Tolley also shared that she had spoken to David Mills at the Part C office about adding autism to the Part C database in order to obtain data on children with autism who are being served through Part C. It was reported that this could be done. Specifics must be identified such as defining autism spectrum disorder, what to record, and how to enter the information since many children are not diagnosed upon entering the Part C system. The Data Committee will further address this issue

Additionally, Beth shared information from her recent attendance at a conference in North Carolina. She reported that Robin McWilliam has conducted research with children under the age of three with autism spectrum disorders. Karen Durst will send this information to members, as it is available. Beth reported on information regarding intensity of treatment for children with autism. She reported that the National Early Childhood Technical Assistance Center (NECTAC) is referring to hours and intensity of engagement rather than hours of intervention.

In conclusion, Beth expressed the need for Virginia to have a systematic infrastructure of training between Part C and Part B for childcare. She stressed the need for developmentally appropriate practices for all children with extra help being provided for those with special needs.

The Initiative then planned to break into groups to look at the projected outcomes for each group and to develop a plan for reaching the outcomes within the next year. Individuals had previously been 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 names appearing in bold are individuals who agreed to serve as coaches. Additional members agreed to assist.)

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

Phyllis Mondak agreed to assist in the Systems/Data area.

**Data: Karen Durst, Bruce Schaffer and Beth Tolley**

It was decided to merge the System and Data groups into one group due to the duplication of members.

**Education/Training: Bruce Schaffer and Charlene Wentland**

**Donna Rimmel** offered to assist Bruce and Charlene in coordinating the area of Education/Training. Sharon Sikes also agreed to assist in the Education/Training area. Additionally, it was suggested that Cori Hill, the Part C Training Specialist, be added to this group as well. Upon previously being contacted regarding participating with the Autism Initiative, Cori had agreed and plans to begin participating in September.

**Family Support: Pat Accardo and Debra Holloway**

Linda Hutton and Amy Compton agreed to assist in the Family Support area.

Dr. Accardo raised the question as to whether there were enough people in the groups. It was decided that each group could identify if additional individuals needed to be brought into the Initiative to assist in addressing the goals. Carol Schall reminded the group that the plan is to develop the infrastructure the first year and that carrying out the services to children would occur later. Bruce Schaffer clarified that the purpose for the groups would be to identify what exists now and what is still needed.

Discussion was held prior to groups dividing as to whether or not the competency goals under Systems should be moved to Training/Education. The members agreed that this change should be made related to the following goal:

- We developed a comprehensive list of competencies for staff and proposed training.

It was decided that due to some members serving on multiple groups that Systems and Data would be joined into one group. It also was identified that the systems piece would need to be in place prior to Education/Training being able to address all of their goals. The members then divided into groups. Following discussion and planning time, members reconvened and reports were given from each group. The reports from the groups are attached. It was decided that groups may chose to work outside of the regular meeting times and could communicate by email or through phone calls.

Discussion about the completion and distribution of the fact sheets occurred. The following fact sheets were identified as needing to be finalized:

- Resource List-Final Revision;
- What is Autism;
- Interventions; and
- Family Information-Final Revision.

It was stated that Christine Stemhagan from Children's Hospital was to edit and format the final fact sheets. Sharon Sikes reported that Christine might currently be off from work on leave and not available. Sharon will check further.

The Initiative decided that the fact sheets would be made available on the Infant & Toddler Connection website as well as provided to local councils. The local councils would then determine the best locations for distribution.

The next meeting of the Virginia Early Intervention Autism Initiative will be Thursday, September 16, 2004, from 1:00-4:00 at the Henrico Mental Health Center. All members are encouraged to attend.

**Please see reports below.**

### Family Support Committee Report:

The Family Support subgroup included Amy Compton, Pat Accardo, and Linda Hutton. We discussed the domains of information that will be included on a questionnaire to assess the status of family support resources for parents of autistic children in Virginia. Some individual questionnaire items were rough drafted. Amy Compton agreed to type up a rough draft of the questionnaire, and all the subgroup members agreed to work via email to revise and edit the document. Our goal is to have a draft to present to the entire group at the next meeting, at which time the subgroup will continue its work on issues of sampling, survey administration, data collection & dissemination."

### System/Data Committee Report:

- The Autism Initiative coordinated with the Statewide Autism Planning Council and DOE Autism Priority Project through the sharing of minutes, training information, etc.
  1. Cross membership (Karen, Phyllis and Carol Shall are members of the Autism Council as well as the EI Autism Initiative; Phyllis can communicate/collaborate with Sharon Siler about the DOE Autism Priority Project
  2. Sharing goals and plans with members of the three groups
  3. Sharing minutes across groups
- We developed a proposed system of training and coordinated services.
  1. Phyllis will check with Sharon Jones about the status of the follow up work she had spearheaded to the Jan 03 provider training survey.
  2. Beth will research how other states provide system wide personnel training on autism spectrum disorders (possibly through the NECTAC Part C List-serv).
  3. Beth will talk to Cori Hill about the group's suggestion to explore the possibility of establishing a training system similar to the service coordinator training
  4. Phyllis will check with Sharon Siler about what the DOE Autism Priority Project is working on and how we might collaborate
  5. Plan to build into the training system a mechanism for providing awareness training for child care workers that is coordinated through DSS. Make awareness training available for all EI providers and for parents.
  6. Develop technical assistance and support system related to autism for early intervention providers.
  7. Phyllis will check with DOE/T-TAC about the possibility of setting up an online list serve and/or online community of practice.
  8. Carol Burke will explore options/gather information about communities of practice.
- 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.
  1. Carol Burke asked David Mills to request that Autism Spectrum Disorder be added to the IDCF and iTOTS database.
  2. Carol Burke and Carol Shall will develop a definition for inclusion in the iTOTS TA document.
  3. Carol Burke/Beth Tolley will request that the following cluster: Communication, social and behavior, be added under “Atypical” on 5b of the ICDF as well as in the iTOTS database.
- 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.
  - Research what outcomes have been measured by other organizations
  - Determine what can be built into the General Supervision Enhancement Grant (contingent upon our being awarded the grant)

Education/Training Subcommittee                      8-12-04

## Fact Sheets:

- Decided to ask the larger group how the fact sheets would be distributed

## Awareness training:

- Bruce will contact Janet Hill regarding disseminating “Autism awareness” training to Part C
- All Part c providers should at least have received awareness level training
- Adapt existing information to fit the Part C model-Donna

## Existing training packages:

- All committee members to identify current training packages for autism practitioners in Virginia
- This training is mostly geared for school-aged children-needs to be re-worked for younger kids
- Carol-will identify early intervention training and early indicators
- Implementation of training staff: pair a trainer from the autism field with a Part C trainer

Contacting hospitals:

- Fact sheets will be disseminated to doctors
- Contact hospitals by region to offer speakers to do grand rounds on autism

Competencies:

- Committee felt it was important to identify competencies for providers and councils in order to effectively address the autism population
- Carol-will bring competencies that were developed by the Autism Planning Council
- Donna-will revise these competencies to meet the needs of part C