

Virginia Early Intervention Autism Initiative Meeting
October 21, 2004
Location: Henrico Mental Health and Mental Retardation

Attendance

Pat Accardo	Debra Holloway	Bruce Schaffer
Carol Burke	Cori Hill	Sharon Sikes
Karen Durst	Sharon Jones	Beth Tolley
Heather Elias	Sue Palko	

Minutes: The minutes of the September 16, 2004 meeting were approved. These will be posted on the Infant & Toddler Website.

Announcements

In follow up to the September discussion about alternative ways for people to participate who are interested but unable to attend meetings, an email list has been created. The committee membership list and the email membership list was distributed to attendees.

Heather Elias reported that John Toscano had a meeting with all of the Autism Society of America chapters in Virginia and they will be working toward developing a collaborative agreement. Heather will bring information about this to the next meeting.

Heather shared a newsletter from the Central Virginia Autism Society which included information about joining. Heather will be attending a training in Virginia Beach tomorrow on Verbal Behavior.

Carol Burke will be attending a training on assistive technology for children with autism by Linda Burkhart.

Several members plan to attend the Circle of Support sponsored by the Arc of Greater Prince William November 6.

Dr. Accardo is doing a presentation on Asperger Syndrome on November 10 at 7:00 PM at Children's Hospital.

Fact Sheets

As planned at the last meeting, the Intervention for Young Children with Autism fact sheet was drafted, then finalized via conference call. A question was raised about why ABA and Lovaas were listed separately. The committee agreed to list these together, separated by a /.

The following fact sheets were sent to Kristin Stenhagen and she has provided suggestions for editing the documents:

- What is Autism
- Diagnosing Autism in Young Children
- Autism Resources
- Interventions for Young Children with Autism

Next Steps:

- Completion of the Family Support Fact Sheet (Carol Schall is working on it now)
- Make the edits Kristin suggested to the four fact sheets she reviewed
- Post on the web (Infant & Toddler Connection of Virginia)
- Bring copies of the finalized fact sheets to the next meeting

Committee Reports (Work Done Between Meetings)

Systems and Data Committee:

Beth distributed the information that was received from other states in response to the questions about personnel preparation requirements related to Autism.

Beth reported that the Part C Office was concerned that the proposed additional atypical category might be used to reflect children who had those symptoms that were due to problems other than possible autism spectrum disorder (such as environmental deprivation). The group responded that there is an urgent need to collect the data about the numbers of children who have this cluster of symptoms and that this cluster of symptoms is distinct enough that people in the field will be clear about when it should be checked. The group felt this information was critical in order to know how many children with this cluster of symptoms are being served (in addition to those who have been diagnosed) in order to advocate for funding.

Committee Reports (Reports after Committee Work)

Education

- The subcommittee reviewed the draft competencies developed by the State Autism Council and added a column for early intervention providers. They put a check in the EI column by the competencies that they determined were appropriate for early intervention providers and they added additional early intervention competencies. Sue will take the work that was done today back to the State Autism Council to see if they want to make that part of their official document.
- Cori will check with Part C office to see what is needed to make this official from the Part C perspective.
- Sue will talk to State Autism Council to see if they are going to do the Autism awareness training again and if so, see if they can get part C folks to attend. If there are not plans for this to be presented again, Sue will talk to Phyllis Mondak to see if arrangements can be made to make it available for Part C providers. The target audience for this training includes teachers, parents, has also included mediators. The grant that supported this training has ended. The group talked about integrating more Part C information in the training.
- VCU has several online webshops. Cori will bring the Part C early intervention modules that have been developed and the subcommittee will talk about developing online training. The address to access VCU's Training and Technical Assistance online resources is: www.ttaonline.org.
- Sue also informed the group about Autism E-news which is accessible from www.vcu.edu/ttac. Click on "Whats New".
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Family Support

1. How [and to whom] to disseminate the questionnaire:

- * Past clients of EI
- * Parent groups (ASA chapters)/chapter newsletters
- * VCU autism registry (is this statewide or regional?)

(If the questionnaire were to be included in the ASA chapter newsletters, it would miss a segment of the intended sample.)

2. Who will administer the questionnaire? It was felt that administration by a professional involved with the family would inhibit responses; therefore the questionnaire must be self-administered (reading level then becomes important)

3. Questionnaires should be anonymous (with parent or child's last 4 SSN digits to restrict responses form families) if parents will reveal problems with service delivery, professionals and agencies/institutions.
4. Data analysis: will investigate whether we can (at what cost) utilize a scanner (through VCU).
5. To decide on how many questionnaires will need to be received in order for the responses to be representative we will need to learn how many cases of autism are identified in the state of Virginia. Heather Elias will canvas the ASA chapters as to the number of family subscribers. To encourage ASA participation, we may ask key persons to volunteer some additional questions.)
6. It was suggested that we could administer the questionnaire to two groups: 1) families with children with autism who are now between 2 and 5 years of age and 2) with children now between 12 and 15 years of age. This would yield data to compare changing trends over a decade in how parents perceive the responsiveness of the service delivery system. One could attempt to collect a larger number of responses from two narrower age bands.

ACTIONS:

1. Heather Elias will get some numbers from the ASA chapters
2. Heather Elias will contact John Toscano to invite him to be a resource person with regard to implementing the project
3. Pat Accardo will contact Don Oswald with regard to his input on the next draft of the questionnaire as well as possible recruitment of LEND graduate students to help in the data collection/analysis. (We might be willing to add a question or two to facilitate their cooperation.)
4. We will have (an almost final) draft of the questionnaire available for review at the next meeting in December.
5. Issues of funding (for mailing/return mail/Xeroxing/analysis) remain moot.

System and Data

- Karen will distribute minutes from the Statewide Autism Planning council to the EI Autism Initiative members
- Sue Palko will distribute minutes from the Autism Priority project to members.
- Karen will report on EI Autism Initiative (along with Sue Palko) to the State Autism Council at their meeting next week.

- Beth, Karen and Cori will take back to Part C staff the committee's recommendation that an additional atypical category be added and that these categories be listed on the ICDF form.
- Beth will check draft IDCF instructions to see if there are instructions for updating iTOTS when diagnoses is made after the child is already in the system (after the child's iTOTS has already been completed).

Next meeting:

December 16, 2004
Henrico Mental Health

NOTE: November Meeting Cancelled Due to Scheduling Conflict of Significant Number of Members.

Plan for next meeting:

Revisit the 12-Month Plans

- Do we remember/understand what they mean
- Are they still valid
- Are the items in the correct category
- Which items have been met

First Signs Autism video

Committee Work