

## Summary

### **Early Intervention Autism Initiative Planning Session**

October 8, 2003

Henrico Community Services Board Building

**Present:** Pasquale Accardo, Rebecca Berlin, Karen Durst, Sharon Jones, Carol Schall, Sharon Sikes, Beth Tolley, Charlene Wentland, Noel Woolard, Judy Burtner (Facilitator), and Kathryn Burruss (Recorder).

#### **Objectives:**

1. Receive the CoCoA survey results and discuss next steps, if any
2. Review the “Welcome Book” outline and determine how it relates to the identified fact sheet topics
3. Clarify the purpose of the fact sheets, their intended audience(s) and how they will be distributed
4. Review the fact sheet review process; possibly modifying the process for efficiency
5. Review draft fact sheets and make a decision on next steps
6. Develop the process and organization necessary for short-term goal relative to resources
7. Set dates for future meetings

#### **Survey Results**

Carol Schall shared the results of the CoCoA survey, Results of Early Intervention Survey, relative to the skill level of the resources within each coordinating council. A summary of her remarks is not included here since a copy of her PowerPoint presentation was distributed to all present.

When members were asked what else they needed to know, it was suggested that information be collected from parents to determine their perspective on how well the Council’s resources are doing in meeting the needs of parents. The current survey indicates that providers are self-satisfied but there was concern expressed as to whether the recipients of services were satisfied.

In the discussion that followed, it was felt that the differences that often exists between the perceptions of the parents and the professionals as it relates to Part C is a result of differing expectations of the system by the two groups. It was thought that these conflicts needed to be addressed. The types of trainings needed as identified through the survey were surprising to some. There was no indication that there was a need for training on collaborating with parents relative to a child’s need. Diagnosis training also did not show up as a training need, yet it was felt this is a very difficult function to implement.

The survey indicated that there are 38 people willing to mentor others. Carol Schall has the list of names and will share it with Beth Tolley who, in turn, will research where these individuals are located and their level of training. She will report back her findings to the group in December.

Another area for follow-up was determining if local staffs have the skills to do in-depth training. It was thought it is important to know how much training individuals have had, what kind of training in what, and whether they are willing to assist in the training of new staff as they come on board. The level of training was a concern of members. Sharon Jones and Rebecca Berlin, working with Carol Schall, will research this issue and report their findings at the December meeting.

A similar survey to the one done with the CoCoA members will be conducted with parents. Carol Schall will head this effort working with Sharon Jones and Pat Accardo. Heather Elias will be asked to join them. Names of parents will be gathered from a variety of sources including the Family Involvement Project. This group will report their findings in February.

### **Virginia Statewide Early Intervention Conference**

The Virginia Statewide Early Intervention Conference will be held November 18 – 19, 2003. There will be an autism track. Beth Tolley can be contacted for more information.

### **Welcome Book Outline**

Karen Durst distributed an outline of the “Welcome Book” so the group could see the types of information that will be included in it. It was decided by the group that although the philosophy piece that was shared at the previous meeting will be a part of the Welcome Book, it should be written at a lower educational level and be made available to parents separately as well as in the Welcome Book.

### **Purpose of Fact Sheets**

Judy Burtner reported on researching past meeting summaries to determine the purpose of the fact sheets and reported the purpose of the fact sheets was never discussed. There was an assumption made they would be distributed to parents and professionals but this was never explicitly stated.

In discussion, the members agreed that the fact sheets had two purposes:

- To provide parents with needed information.
- To provide a vehicle that would start the process of getting members to agree relative to various aspects of autism (what it is, early signs, treatment, etc.).

The fact sheets will be distributed to parents by way of professionals and anyone else with an interest in the concept of autism. The fact sheets will be posted on the web and printed as needed by the various agencies that want to use them. Links will be added to relevant sites. It was agreed the reading level and flavor of the sheets needed to be appropriate for parents.

### **Fact Sheet Review Process**

At the previous meeting, Karen Durst and Judy Burtner agreed to bring to the meeting, a more efficient way of reviewing the fact sheets. After discussion and modifications of their proposed process, the following proposal was adopted:

- The review will be done by e-mail
- The review will occur in 3 rounds
- Karen Durst will send all proposed fact sheets as one packet to all members (first round). **Note:** Even though some of the fact sheets were reviewed at the previous meeting, all fact sheets will start over in first round.
- Members have 10 working days to respond to the author(s) with changes. Those suggesting changes should send their comments in writing (e-mail) with suggested language that they feel would be more acceptable.
- No response will imply consent/agreement with draft
- If there are suggested changes, the author(s) will rewrite and send the revised fact sheet to all members (second round) for another 10-day review period. Changes will not to be noted on the second draft. **Note:** It was felt that all members needed to reread the fact sheet in its entirety, not just the changes.
- If again there are suggested changes, they are made and resent to members (third round) for a 10-day review period. A statement will be added to the message stating: “this is the final change prior to the fact sheet going to the group for a vote. Can you accept this as it is?”
- If after 3 rounds, members are still making changes, the fact sheet will be brought to the group stating, “This is the point of concern to be considered by the group.”
- Group members will be told ahead of a meeting that a particular fact sheet will be discussed. Once a fact sheet is brought before the group for consideration, there needs to be 2/3’s agreement of those present (in person and on the phone) before the fact sheet is accepted. If there is no agreement, the fact sheet is dropped.

Charlene Wentland asked for help in identifying the content of the fact sheet on the definition of appropriate. She has put together a brief document. It was decided that this would be sent to the group members for their input as part of the initial packet Karen will distribute to members.

### **Format**

It was agreed that there needed to be a group to give oversight to the review process and determine the final format of the fact sheets so there would be consistency among them.

Beth Tolley, Noel Woolard, and Karen Durst agreed to perform this function. It was suggested that they use a format similar to the “Welcome Book”

The group also decided that there needed to be a writer outside the group to do the final writing/editing so they would be written at the appropriate educational level once there was agreement on content. Pat Accardo and Sharon Sikes agreed to explore this opportunity with a writer within their agency to see if she would be available for such an assignment. Beth Tolley and Karen Durst also agreed to check with a resource that they knew in case the writer from MCV was not available. Others will check their agency budgets to see if money can be found to cover the cost of having an outside writer review the documents for readability and possible editing and let Karen know within two weeks of the meeting their findings.

### **Next Meetings**

Due to the length of time required to address the above items, it was decided to hold the following agenda items for a future meeting:

- Short-term goal – Looking at Resources Statewide
- Long-Term Goal Possibilities:
  - Financing
  - Clinical best practices guidelines
  - Systematic approach to training for providers and families
  - Develop a comprehensive statewide developmental disabilities services system for clients/children, families

### **Dates**

Dates were set for future meetings:

December 4, 1:00 – 4:00 p.m.

- Update - fact sheets review process
- Survey findings - 38 people survey
- Survey findings - Training needs

January 28, 1:00 – 4:00 p.m.

- Parent survey findings
- Update – fact sheet review process

February 25

March 24

April 28

Prepared by Kathryn Burruss  
October 11, 2003