

Summary

Early Intervention Autism Initiative Planning Session

September 8, 2003

Richmond Times Dispatch Plant, Atlee, Virginia

Present: Staci Carr, Jill Donaldson, Karen Durst, Heather Elias, Liz Fletcher, Linda Hutton, Tracy Miller, Phyllis Mondak, Donna Rimell, Elizabeth Sarrett, Sharon Sikes, Beth Tolley, Charlene Wentland, Noel Woolard, Judy Burtner (facilitator) and Kathryn Burruss (recorder). Present by phone: Carol Burke and Beverly Crouse. Student observers: Beth Kunberger, Molly Purser, and Vicki Shen.

Objectives

1. Review the core values draft and bring closure to the discussion
 2. Receive the survey results – skill level of resources in each VICC
 3. Review the draft fact sheets
 4. Receive a status report – groups working with other draft fact sheet topics
 5. Develop the agenda – October 8 meeting
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Core Values

At the request of the last session's participants, Karen Durst took the initial work that had been done on values and drafted a list of core values for the participants' consideration. After a brief discussion, participants agreed to use the following values as they do their work:

1. We share a commitment to supporting families and professionals with continuous updated information obtained from research and from families' experiences, always respecting the families' choices.
2. We believe that intervention should be individualized and implemented to help support families in assisting the child reach his/her maximum potential.
3. We maintain respect for diversity and individualization of quality service delivery for children and families.
4. We maintain respect for families' abilities to make informed choices when given unbiased information.
5. We believe that intervention should be child and family centered and should be a collaborative partnership between families and professionals.

6. We support collaboration between professionals and families with the goal of improving services and outcomes for young children with autism and their families.
7. We encourage education and support for families that is ongoing and based on the individual needs of the child and family.

CoCoA Survey

The survey has taken longer than expected to implement. The survey is being given via the Internet and has been distributed to the VICCs with a mid-September deadline for returning the information. It is expected that the results will be available at the next meeting. The results are expected to be much broader than first anticipated.

Fact Sheet Review

As the fact sheets were being reviewed, it was determined there is a need for the following:

- A glossary of terms
- A panel to review all the fact sheets for consistency relative to reading level and use of language/terms once there is agreement on content
- A statement on each one that refers to other available fact sheets and a phone contact.
- A consistent format (once there is agreement on content)

It was also determined that the participants, at the next meeting, need to review the target audience for the fact sheets, how they are to be used (purpose), and their distribution.

During the review there was no attempt to wordsmith the content. However, there was an effort to gain agreement on the general content of each. The respective author(s) were to collect changes/modifications. Therefore, those changes/modifications are not included here other in a general sense. A summary of the review results were as follows:

- What is Autism? – After many suggestions, it was determined that the fact sheet needed to be reworked. Once modified, the fact sheet is to be sent to K. Durst so it can be distributed by e-mail to members.
- Parent's Definition – It was agreed that this information be included in “What is Autism?” Staci Carr indicated she would see that the two fact sheets would be merged.
- Part C Philosophy – It was felt this fact sheet, as written, was too long, the language may be difficult to understand. It was also suggested that all Part C fact sheets be retitled, “Infant & Toddler Connections”.
- What Part C Services Might Look Like – It was noted that this information is found in the “Welcome Book” that is being developed to give to all parents and

perhaps is not needed as a stand-alone fact sheet. Linda Hutton, Tracy Miller, Jill Donaldson, Beth Kunberger, and Karen Durst agreed to review this and make a recommendation to the participants at the next meeting.

- Screening for Autism – Review of this fact sheet was tabled since the author was unable to be present.
- What Experience or Credentials are Needed – It was agreed this information should be included in the Infant & Connection fact sheet and not stand alone as a separate fact sheet.
- What to Expect After the Autism Diagnosis – It was noted that this is part of the “Welcome Book” but families may still need something similar that tells them of the eligibility requirements for various programs and encourages them to start keeping records. It was agreed that work on this fact sheet should wait until after participants have had an opportunity to review the “Welcome Book”.
- Impact on Families – This fact sheet requires only minor changes and Heather Elias agreed to make them.
- Making a Referral – Who and How? – The Infant & Toddler Connection of Virginia developed a fact sheet on this topic. Copies were available and the participants decided to use it instead of developing another one.
- Treatment and Natural Environments and Outcomes in Autism fact sheets will be reviewed at a later meeting. Other fact sheets that were listed in the July 23 summary will be reviewed at the October 8 session.

Karen Durst was asked to bring an outline of the “Welcome Book” to the next meeting for review by this group to see if all of the fact sheets identified by the group at the July 23 meeting are needed or if they are already included in some way in the book.

It was also determined that the fact sheets developed by Heather Elias need to acknowledge that the content represents one parent’s perspective. It was noted that parents are very interested in knowing other parents’ perspectives.

The question arose as to what the group felt needed to be included in the resource fact sheet. It was acknowledged there is so much that could be included. It was agreed that suggested key words for searches would be helpful as well as how to determine which sources are appropriate/accurate. It was also agreed that a fact sheet on resources for families who have just received a diagnosis would be most helpful.

Because of the amount of time it took to review the fact sheets, it was determined that a better method should be identified. Suggestions included reviewing them by e-mail, mail, or fax, and using a set of questions that would assist with the review process. Karen

Durst and Judy Burtner will discuss the issue and bring a suggested solution to the October 8 meeting for participants' consideration.

Agenda for October 8, 2003 session

- CoCoA Survey Results
- Clarify purpose of the fact sheets, their intended audiences, and how distributed
- Review “Welcome Book” outline and determine the need for identified fact sheets if the information is in the “Book”
- Review the fact sheet review process; possibly modifying the process
- Develop the process and organization necessary for short-term goal relative to resources

Prepared by Kathryn Burruss
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