

SUNCOAST REGION QUALITY
STEERING COMMITTEE

Meeting Minutes
May 24, 2007

Attendance: David Hawthorne (Provider), Betty Beauchaine (FCC), Carl Littlefield (APD), Rebecca Vasey (Consumer of Service), Debra Morgan, (Provider/Support for Ms. Vasey), Stepanie Engley (Medicaid), Joanna H. Rydzewski (Parent), Patricia Hayston (Family member), Tom Nurse (Parent), Dierdra Walker (Provider), Cliff Capron,(Consumer of Services), and Don Mailler, (Provider/Support for Mr. Capron), Patty Rendon (WSC), Marcia DiGrazia (AQL).

Guest: Jennifer Stone (Provider), Janis Alberti (Provider), Ann Graybeal (Parent), Barbara Hawkins (Delmarva representative, Terry Geiba (FND for Richard LaBell), Eileen O'Brien (Statewide Advocacy Coordinator).

Not in Attendance: Karlton Ballard (Transition), Deborah Davis (Transition), Marcus Hall (Provider), David Brown (Consumer of Services), Beth Kelzer (WSC),

Meeting began @ 9:00 AM at the Tampa program office.

The minutes from the **April's** meeting were approved.

- The meeting began with a discussion about the Synergy conference. David Hawthorne thanked members for their attendance and assistance at the table. It was well attended. In the future we should not schedule provider meeting at the same time as breakout sessions. Steering members talked with many people. Four (4) cards addressing concerns were disseminated to appropriate supervisors. Rebecca's speech was great. Two other gentlemen spoke on Advocacy. Anne Millan has their contact information. Having them speak at various events would be helpful in getting the word out about APD changes. Tom Nurse observed that the families and individual were the speakers, the voices of the people and is needed to present information as they understand it. It was noted that overall people had a lack of understanding of what is happening in the state. We may need to look at having another similar event at various locations. Carl indicated that the question at the opening focused the group being able to agree on something and the second question was, "what did you do during the legislation session". We need to find champions at a high level. The members asked how this committee is going to address this. Tom noted that adopting legislatures and having a concerted effort to address the legislature would be a start. Getting the information out was a concern of all members. APD is at a disadvantage to being listened to. Eileen O'Brien stated that advocacy is the answer. Tom noted that mentoring system is needed for consumers to understand the problem and how to go about addressing issues. Joanne noted that persistence is important and we need to show collaborative effort.

Patty Rendon noted that all we hear is negative but never what is working. We need a method to show the positive.

➤ **A motion was made to form an Advocacy subcommittee. It was seconded.**

Discussion: Tom noted that the group should be looking at how to inform consumers and families of legislator. The members discussed whether it is our job? The final answer was, "If we don't who will?" Assemble those groups. Carl suggested we create a list of those groups to contact all senators and Congresspersons. The subcommittee should discuss, what the best form to approach issues regarding APD. Eileen suggested we build relationship with legislator's staff, make a video of self advocate to give to legislators.

The discussion was tabled to provide an opportunity to participate in a conference call with Lucy Mohs - legislative liaison @ APD Tallahassee office discussed the approved changes in the Agency for Persons with Disabilities' budget. Detail can be found on the APD web site. She stated that the overall picture is not as bad as it could have been. Ms. Mohs explained the creation of the 4 tiers in Big Waiver in terms of service delivery. She noted that there are concerns about the implementation and impact on consumers and families. The Central office has already sent out proposals for changes for next fiscal year 2008-09 issues.

Bill takes effect July 1, but APD is not able to implement right away. There was discussion from several Senators and Representatives regarding the length of time it will take to implement this bill.

Tom asked: How are current updates being disseminated?

1. posting updates on APD home page
2. Every Tuesday, Jane Johnson has meetings with area administrators via conference calls.

Lucy Mohs closed with offer for anyone to call her anytime 851-414-0488.

Betty B. would like to invite legislators to come see her son S in his own apartment. He does so well and is so proud.

Tom suggested identifying people who are willing to open their homes to visits from legislators.

Eileen: Facilities ARE NOT the wave of the future.

MOTION: Restated by Patty Rendon: to set up sub-committee to educate the Region's consumers, families and providers on what will be happening July 1.

Discussion about how to obtain up-to-date info It will not all happen on July 1. It will be happening through the year. CMS approval has to be obtained. A lot of families, consumers & WSC's do not know what is going on.

There are over 1400 providers in SunCoast. The SunCoast Region APD is charged with dissemination of information. Carl stated that we are lacking a comprehensive email list and it is difficult to keep it current; many don't have email.

Carl stated that in a nutshell, it's a MOTION to educate.

What can we do to improve communication?

We need to find champions at a high level.

****The MOTION was revised and seconded by Tom. All members voted in favor of the steering committee becoming/creating the sub-committee on/for communication.**

How many legislators were at Synergy? 40-45 were invited, 10 said they'd attend, but didn't.

Carl: we've gone beyond the think tank and have to put boots to the ground.

Joanne stated that with her experience working on veteran affairs she suggested "writing from the heart" to legislators.

WSC's could suggest helping families to tell their stories.

Delmarva representative, Barbara Hawkins stated that we need to find a way to transfer the power of the family to the individual consumers and bring it all together to unify this effort.

Discussion of committee participants' experience with communicating with legislators and communication options:

It was suggested that a helpful resource would be to have a booklet that identifies all legislators; also can search by zip code on the internet.

Tom noted that he communicates with them while they are at home, when they are in Tallahassee a power cloud lowers and they are hard to access.

How to disseminate good info?

Tom noted that part of the problem in contacting consumers & families is confidentiality. Patty noted that having a support coordinator is something every consumer has in common.

Tom: (back to Synergy participation) 1200 invitations went out; 250 consumers attended; 150 providers attended. The support coordinators need to buy into the need to communicate.

Need to ask "do you want updates?" AND "How do you want to get updates?"

Avenues to access are WSC's, providers, and Family Care Council.

Cost of mailing Synergy notice to all SunCoast consumers was \$6k; it's cost (manpower/money) prohibitive to do a mailing for every update

Additional suggestions were discussed:

- A memo on people's payment remittance slips
- Reverse 911 (is this available throughout Region? Could APD access a similar system?)

- Interested stakeholders, including providers
- Telephone tree-Carl continues to research.
- Does the FCC have a toll-free phone number that an info message could be entered?
 - Who would record? What gets recorded?
 - Who at FCC can leave a message on their number? Ann Milan? Joanne? Betty? Patty?

Sun Coast is unique because of its large size – six counties. One of every five consumers is in SunCoast Region.

Discussion encompassed exchange about emergency planning and response, Verizon, Honeycutt funding, Hillsborough County having 3 med shelters, personal responsibility for emergency preparedness, group home and supported living annual planning requirements.

Barbara, WSC and Carl: How can we address individuals and families on a local basis? If we need to say something, how will we do it?

General agreement that the provider community, including WSC's, have to "step up" Suggestion arose to find out how other APD regions are addressing communication issues.

Suggestion to draw up info sheet of important phone numbers and websites with resources such as

APD

FASC – FI Assoc. of Support Coordinators

FCC - Family Care Council

DDC - DD Council

Participants recommended and agreed upon holding a meeting Wed 5/30 or Thurs 5/31 to focus on (1) education (What do we communicate) and (2) communication (how to we communicate)

The meeting adjourned at 12:30 pm. The next full meeting will be June 28, 2007 at the DD Center, 1201 102nd Ave. N., St. Petersburg, from 9 AM to 12 Noon.