

FAMILY CARE COUNCIL FLORIDA
Teleconference Call with APD
Tuesday, December 6th, 2005, 7– 8:15 PM

Participants:

Area 1 – Patty Houghland
Suncoast Region 5 – Ann Millan, Beverley DeStories
Suncoast Region 6 – Rhonda Sloan
Area 7 – Donna Rauber
Area 10 – Bob Wessels
Area 11 – Margarita Montalvo, Lourdes Bravo
Area 13 – Betty Kay Clements
Area 14 – Pete Wesley

APD Participants:

Denise Arnold
Terri McGarrity
Eileen O'Brien

Purpose of the Call:

1. To review and discuss with APD additions to Chapter 393.502 – Family Care Councils
2. To review and discuss newly created addition to 393.507 – Citizens Support Organization

Chair Millan advised upon review of the Citizens Support Organization documentation it appeared the organizational structure was similar to Family CAFÉ. She has confirmed that is true. Previously it was discussed among Family Care Council chairs not to pursue putting FCCFlorida into legislation this year but as a result of the Citizens Support Organization being considered as an addition, several members felt this provides a good opportunity to add the FCCFlorida into legislation. One of the reasons being that family care councils could loose their status with the agency and end up reporting to the Citizens Support group. Concern was discussed for the survival of the family care councils.

Review of additions to Chapter 393.502 – Family Care Councils

(2) Membership:

- (a) – Addition: The agency will assist the local councils to find qualified individuals to serve.

A concern has been that councils and area PA's need to be partners in finding people for the councils.

- (b) – Addition: Grandparents should be allowed to become members.

Many grandparents are raising individuals with developmental disabilities.

(3) Terms; Vacancies:

- (c) – Addition: If the Governor does not act on the council's recommendation within 45 days after receiving them, the persons recommended shall be considered to be appointed.

Chair Millan indicated the council's request to re-instate this to the statute because the delay in appointment approval by the Governor's office is untimely making it very difficult for council's to find members and proceed with business.

The language in question was originally in the statute but removed at the time Chapter 393 was revised when the agency was created. No one knows who removed it or the reason for removal. It, however, has created many problems within area councils as applications for appointments are being delayed anywhere from 3 to 6 months. Also, a few self-advocates have applied and been turned down by the Governor's Appt. office. The concern is the Family Care councils will cease to exist because of the long, drawn out process for appointment approval. Each council is allowed up to 15 governor appointed members x 15 areas = 225 possible statewide members.

- (9) Collective Body – Family Care Council Florida – Addition includes (a) thru (f)

The language includes the hiring of a paid executive director.

- (10) Funding, Financial Review – Addition includes annual state funding dollars for both FCCFlorida and area councils to be placed with a sole source not for profit Florida corporation for disbursement.

Denise shared upon receiving the recommendations from Ann she met with Nita Calder, the attorney in their office who is working on the 393 changes. She advised that the addition of Citizen Support Organization was not intended in any way to circumvent FCC's, to limit powers, to effect in any way, it was strictly about CAFÉ's future beyond current governor. She did point out to Nita why people might come to this conclusion so she does understand that better.

Denise indicates that including the statewide council in the statute is not a problem at all. One of the issues is the 45 days because it used to be in statute, then taken out. Upon learning of the problems she mentioned including some language when the 45 days is not met because the councils can't operate. Denise thinks the issue is the automatic appointment. She asked for alternatives.

Bob mentioned he thinks the problem lies in the fact that most governor appointments are handled on a semi-annual, annual basis. The unusual structure of the FCC's requires monthly appointments and the governor's appointment office isn't set up to do this.

Possible Solutions:

1. FCC members be appointed on an annual basis but until that time a team of FCCFlorida representatives and the Agency Director would tentatively appoint them.

2. Upon recognition of the statewide Family Care Council, the members of that council could be Governor appointments and the local family care council members could follow a different process excluding the need for governor appointment. Bob suggested the problem with that is the current need is to keep the statewide council representatives open to whomever the local council so validates which could change from meeting to meeting if a current representative was unable to attend. Many agreed that action would weaken the purpose of the FCCFlorida. The concern also exists that active individuals with the councils who are waiting for appointments then get turned down by governor's office. The council will lose that person. Also, several self-advocates have been turned down by the governor's office which is very disturbing. Everyone was reminded it's a political appointment.

Discussion followed pertaining to whether local members should be governor appointed or not appointed. Bob indicated they should be appointed even with the large volume of possible members. Chair Millan doesn't object to keeping the language as is if the Governor's office makes a commitment to appoint every three months. Some council's have only 4 members with many applications waiting in limbo. Bob has suggested in the past that a representative from FCCFlorida and a representative from the agency meet face to face with supervisor in charge of Governor's Appointment office. Explain the situation, how can it be worked out?

3. It was suggested that language be included stating that the appointments to the Family Care Council's will happen four times a year (January, April, July and October). This would be used in place of the 45 day addition. Denise advised she could take this language back for negotiation. Denise indicated no matter what happens with the language, she thinks Bob's suggestion of a face to face meeting when the head of the Governor's Appointment Office should be arranged.

Next issue pertained to paying the executive director of the statewide council. Nita re-worked the language which Denise will forward to Chair Millan. It's the executive board that will determine who gets paid for what and what they get paid to do. All those type decisions are part of what the board does and should not be part of the statute. These are policies and procedures.

The other issue that has not been resolved yet is the state funds being transferred to the non-profit. She has not received any decision on this yet. Bob mentioned if FCCFlorida can be created as an entity within the statute then why couldn't all the FCC council funds be deposited to FCCF do the disbursements. Denise advised that late that afternoon she received a message from Barney Ray who has concerns about this. Therefore this can't be resolved at this time. Terri and Denise were asked how does CAFÉ receives their funding from the agency? They must get their monies up front. How is what FCC's are asking to accomplish any different from what CAFÉ does? Terri & Denise could not answer. Denise added that the people who have an issue with it are not trying to be

uncooperative; they're trying to make sure the agency rules are followed. Now that they have their own agency, everything is very carefully scrutinized. Discussion followed with regards to what CAFÉ can do and also reference to the language in 393.507 – Citizens Support Organization. Patty added that the language allows CAFÉ to do anything, everything and FCC's object to that. Denise asked for the council to send her what we suggest it be clarified so she has something more concrete to present.

Citizens Support Organization – Chair Millan expressed concern as to how the creation of this organization (CAFÉ) got in the statute revision to begin with? Denise advised it was to make sure that the CAFÉ event lives on. Chair Millan shared she would have liked to be involved in some of the brainstorming. Bob asked since when do you try to statute an event. Why couldn't it have been done under the Statewide Family Care Council? Denise advised good questions but she doesn't know the answer. She indicated again that she will do whatever to help us whether it be to present the councils change in language or ask for a meeting with whatever audience we're looking for. She will carry the torch for the councils. Bob shared how much the council appreciates her assistance. Denise advised it really needs the councils official comments to the agency, not her words as a go between. Patty really believes this whole piece doesn't need to be put in statute. It's her opinion that CAFÉ, the event has a time and place, it does not serve the vast majority of people with developmental disabilities anymore. Where does the council go with their concerns? Denise suggested writing to Shelley. Another option would be to set up a conference call with Shelley.

Lourdes shared she was on the original re-design where the language was created for the Family Care Councils. She was in contact with a legislator who knew of statute 393 and mentioned family care councils but there was no reference to it in 393. He talked about putting money in for the FCC's as a way of getting the support needed to move forward. Discussion pursued between the legislator and a group of advocates to determine a dollar amount to be able to provide education for families, etc. Originally the amount arrived at was \$30,000 per council. When they went through the redirection, half of that money got allocated to the Family CAFÉ. What she has learned within the legislation pertaining to this Citizens Support Organization will do in the Family Care Councils. Everything in that created organization is the role of the family care councils minus the grassroots effort. Based on the Citizens legislation and being a former DD council member she sees very little difference between the two. Her opinion is that if Citizens Support Organization legislation is approved, that organization will come to FCC's, ask each chair to participate on their board which eventually will end the grassroots effort. The FCC appointment problems by the Governor's office are meant to discourage and dissuade the FCC grassroots kind of organization. Having been through the governor's appointment process she says it's not that difficult. Normally the appointments are based on who the council refers. The councils are the ones who know best the people that are committed within the group. Her suggestion is that all council members call their legislators and advise them that FCC's don't want the Citizens Support Organization amendment in 393 and ask them to vote against it. Chair Millan asked others on the call to comment. All indicated their disapproval. Lourdes suggested that someone find out who introduced the legislation and find out why. Chair Millan requested committee volunteers to prepare a letter to Shelly of the FCCF position on this issue. Denise advised she would be glad to meet with Kerry and Nita tomorrow and share with them the concerns expressed during this call. The committee members are Chair Millan, Bob Wessels, Patty Houghland and Beverley DeStories. Chair Millan asked Denise to find out how Lori Fahey has received money from the agency in the past. Chair Millan advised Denise that she is still not receiving documents from the agency which include the final copy of IFS policy to PA's, the latest employment figures from J.B. and the enrollment numbers.

Denise mentioned that some people have the expression that the only reason FCC's want the dollars

going into a non-profit is so council members can get travel reimbursements quicker. She indicated that is a reason but it's not the only reason, right. Chair Millan advised absolutely not. She shared that FCCFlorida can't even get an expense report from the agency to show what has been spent in order to know what is available to spend which makes it impossible to plan a forum or initiative. Denise and Terri both advised that reports are being processed that will provide budget and expense information on a monthly basis.

Chair Millan mentioned an issue with regards to the IFS policy and procedures. Kerry had indicated at the FCCFlorida meeting that providers didn't have to be Medicaid waiver providers. An example used was families could hire a neighbor to provide respite. Denise said that was not correct, any individual who would be hired to provide a direct care service needs to go through background screening. It's the law. Families need to be aware of this as this process can take up to 3 months. They could lose their dollars waiting for this process to be approved. The guidelines need to specifically state that background screenings are necessary and can take several months. Chair Millan asked what was required, a criminal background check or can the person go to the local police dept? Denise wasn't sure. She would find out and make sure guidelines are included in the document.

It was learned during the PA call today that the original number of families designated to receive the one-time non-recurring fee has been reduced to 750 statewide because the legislative committee that was to meet on December 8th has rescheduled for sometime in January. Denise shared they don't know what the total number will be until the committee meets. They have put the procedures in place in hopes that the legislative committee will approve the plan but nothing can move forward until it's approved.

Chair Millan asked if any other questions or concerns. No reply therefore she thanked everyone and adjourned the call.

Respectfully Submitted,

Donna Rauber