

FAMILY CARE COUNCIL FLORIDA

FRANK CARROLL, CHAIRPERSON

Amerisuites Orlando Airport

Orlando, Florida

May 22nd, 2004

MEMBERS PRESENT:

Frank Carroll, D3 Chairperson
Patty Houghland, Past Chairperson
Joy Frazier, D1 Chair
Ann Millan, Suncoast Region 5 Chair
Rhonda Sloan, Suncoast Region 5 Chair
Donna Rauber, D7 Chair
Judy O'Halloran, D8 Chair
Joan Hinden, D10 Chair
Martha Sheldon, D11-A Chair
Ka Samar, D12 Chair
Pat Hawk, D13 Chair
Diane Ciccarelli, D15 Chair

STAFF & GUESTS

Wilma Lefler, DD Dept. - Guest
Eileen O'Brien, DD Dept. - Guest
Melinda Coulter, DD Dept. - Guest
Beverley DeStories, Suncoast Guest
Jadene Ransdell, Suncoast Guest
Robin Millan, Suncoast Guest
Margaret Watkins, Suncoast Guest

To unite the Family Care Councils in the State of Florida to represent/advocate for all persons with disabilities and their families.

I. WELCOME AND INTRODUCTIONS

Chair Frank Carroll called the Family Care Council Florida meeting to order. He welcomed everyone to the meeting. Ann announced the "Walk on the Moon" award goes to Beverley DeStories for doing such a great job of organizing lunch each meeting. Ann reminded everyone to fill out the meeting evaluation survey before leaving today. Chair Carroll asked for introductions and district updates.

Joy Frazier, District 1 shared in March they attended the exceptional Saturday forum held at one of the high schools where service providers share information with ESE students and family members. In April she attended the Self-Determination conference in Atlanta. They participated in the CDC+ training for support coordinators. A future training session is planned which will include CDC+ families with support coordinators. The council had an exhibit table at the Community Services Information fair at a local shopping mall. They are working on their service resource book.

Pat Hawk, District 13 shared they have used all district funding dollars this year. They have created their first newsletter which is currently at the printers. They have scheduled planning sessions such as guardianship around the counties. Many members have taken advantage of training sessions and conferences in the area. They are addressing membership issues as they have 10 members with several leaving soon. They have a committee whose purpose is visiting the area legislators.

Diane Ciccarelli, District 15, shared the county has now opened up 10 summers jobs for individuals with disabilities. They have filled one of the 3 full time positions. They have people meeting with other county representatives within the district asking them to hire individuals with disabilities. She has written the Governor regarding the issue of individuals with dual diagnosis in the state prison system. She received a phone call from Paul Waymons of the Governor's office. He asked her for a "wish list" which she sent to him. She shared the items she requested.

Judy O'Halloran, District 8 shared they had their first annual Treasure Trove of Services conference which was their initial effort at more widespread outreach to their district. They had a good turnout of about 200 people. They collaborated with the SW Comprehensive System of Personnel Development (CSPD), Families First of SW Florida, Florida Inclusion Network, Lee County School District and the district Developmental Disabilities program office. She provided

each chair with a presentation folder. Family input shared was the vast amount of information made available but disappointed they couldn't attend all break-out sessions.

Rhonda Sloan, Suncoast Region shared she created their first newsletter this year. Due to the council not being able to put labels on the newsletters, much of the information included was outdated by the time families it. However, she has received numerous requests for persons to be added to her E-list. The main drawback was families missed the CDC+ training session. She has created a separate CDC information E-list. Their council is very interested in advance directives that can protect our children. She shared how families taking adult children to the hospital for tests are being turned away because they don't have legal authority to make decisions. She shared Doctors evidently are not aware of Florida statute 765 which states a healthcare proxy can be appointed by a doctor. She and Melinda will be giving a presentation at Family CAFÉ titled "Protecting your Legal Rights, Options other than Guardianship". They continue to do a lot of outreach to Sarasota and Bradenton areas of the region.

Ka Samar, District 12 shared they had a good turnout at the CDC+ training session. He thanked Ann for helping him with providing some suggestions for using their funding dollars. He shared his concern regarding the plan of incorporating the DD districts into ACHA regions. What will happen to the Family Care Councils? It was shared that hopefully Shelly will have an answer. They continue to look for additional members.

Donna Rauber, District 7 shared the council has been in a reorganization process the past few months. Her term as chair is over and no one wanted to take on the responsibility. They have divided the duties of the chairperson and distributed to other members of the council. The chairperson will be responsible for the business portion of the meeting. Other officers will continue to be Vice Chair, Secretary and Treasurer. There will be 2 persons whose contact information will appear on the webpage and an FCC spokesperson who will cover media calls, town meeting/conference presentations, etc. Donna will continue on as information coordinator and state district representative. The remainder of each meeting will be delegated to a member/associate member to coordinate a subject presentation. A schedule of meeting presentations has been confirmed through April, 2005.

Joan Hinden, District 10 shared their last meeting date was cancelled so everyone could attend the Personal Outcome Measures workshop. It was a very interesting workshop, a different approach of taking what services are available and translating them into business. She went to the Governor's Commission on Disabilities in New Mexico to visit one of their major providers. She shared the state's institutions have been closed for 5 years. They have no group homes with more than 3 or 4 persons. They no longer have ADT programs. They do have problems with employment but individuals unable to work spend their days involved in various community activities. She was advised of a Federal Waiver titled Personal Care Attendant. It's specifically designed for persons who need only personal care assistance. Their district held a workshop with the Social Security administration to determine ways of finding employment for persons with disabilities. One way is by establishing employment networks. According to SS under the new plan, Maximus can authorize any group, private or government, to become an employment network.

Frank Carroll, District 3 asked each council chair for the following information: How often do your councils meet? Are the meetings held on district site with district personnel or off site with or without district personnel? How long do the meetings last? The results were all have monthly meetings, most during the day for approximately 2 hours in length. It was 50/50 for on site versus off site and most have district personnel attending the meetings.

Frank shared his council is in the process of reorganization yet to be determined. They have 2 projects they are currently investigating, one being the feasibility of creating their own local website and the other to purchase a digital camera so they can create a District 3 presentation for outreach.

Ann Millan, Suncoast Region introduced members of her council in attendance. She shared she has a co-chair this year. She attended the self-determination conference in Atlanta. She also attended the

LAC (local advocacy council) meeting and asked that we all get involved in the LAC meetings in our districts. She attended the ADA meeting in Tampa and thought it very interesting. She shared how incredibly supportive her district has been with the celebrated employment project. She presented Wilma with a sea-shell wreath she made and would really like to see some ADT's get involved in becoming entrepreneurs by focusing on the tourism industry in Florida. She shared the Tampa area has a new DCF Inspector General's office. Their council meetings are directed towards mini forums and they hold separate planning meetings to coordinate the business portion of the council.

Martha Shelton, District 11 shared their council is working very hard with the network on disabilities. They are working on housing/personal care issues of many individuals with severe needs who are lacking supports.

II. BUSINESS SESSION

Review of March 20th, minutes:

Chair Carroll asked if there were any changes or recommendations to the minutes. **Rhonda makes a motion to approve the minutes.** Pat seconds the motion. The motion was approved by consensus.

Treasurer's Report:

Wilma provided each chair with a breakdown of funding dollars spent per district. It is possible if some expenses are not appearing in the total expended column, the district could have used a different organizational code and the monies are coming out of district dollars. Many questions were asked if the balance of dollars remaining could be spent before June 30th as the cut-off date has passed for submitting a purchase requisition. Central office is willing to help the districts spend down their dollars but we must act quickly.

III. DEPARTMENT UPDATES

Wilma Lefler:

Ann asked Wilma to share with the council the purchasing that has taken place with FCCF funding dollars and transfers of some district funding dollars. Ann thanks the council for being so supportive in this effort. Following is a list of items purchased: Authorware Software, Authorware Silver support software and Creative Suites software for the website, a laptop computer, 5,000 copies of the Celebrate Employment brochure for Family CAFÉ, 3 plaques for Celebrate Employment employers, and FCCF flyers which includes the contact information for each district chair. Ann thanks Wilma for all her assistance as our dept. liaison. It has been a pleasure working with her and knowing the items have been ordered and that she is taking care of our requests. Chair Carroll asked that word be taken back to Susan and Shelly that we appreciate them allowing Wilma to maintain her liaison status with the council. It was noted that Wilma's job description does include her as the dept. liaison to the FCCF.

Eileen O'Brien:

Eileen shared how happy she is to be in her position as program administrator for the Family Partner's Unit. However, her phone doesn't ring enough. She wants to hear from us. If there is anything she can do or find out for us please contact her. She has an open door/open phone policy. She is working on becoming more E-mail friendly. Ann shared our council is very E-mail oriented. Eileen's E-mail address: Eileen_Obrien@dcf.state.fl.us.

Ann asked Eileen to send her (she will forward on to FCC E-list) any legislative or other information that would be of value to the council. Eileen expressed her concern regarding the surplus of FCC funding dollars across the districts that have yet to be used. She will sign any purchase order that is in line with the council's needs. She was asked if we needed to go through the district or can we go directly to Central Office. She replied we could go directly to Central Office and Wilma would be available to assist with the purchase requisitions. Eileen would like from each district FCC a breakdown of how the remaining dollars will be spent. It was stressed the need to meet with district FCC members and obtain majority approval for whatever expenditures the council is requesting prior

to presenting Central Office with purchase requisitions. Based on further discussion it was decided the proper procedure is (1) Obtain FCC majority member approval for spending remaining dollars, (2) Submit purchase requisition to district office, (3) If problem with district office approval, submit to Central Office. Remember all items must be shipped prior to June 30th. It was requested that Eileen contact District 14 to determine the status of their council and ask how they intend to use their funding dollars. It was requested the chairs share what types of items they have purchased or plan on purchasing. Chair Carroll asked that a list of items be prepared and sent to Ann for distribution to all the chairs. Ann asked for the balance remaining in the FCCF budget. Eileen shared the amount is \$3,024.77. Ann makes a recommendation that a laptop computer be purchased for the dept. liaison to be used when attending Blue Ribbon Task force meetings and conferences on behalf of the FCCF. Discussion followed with numerous suggestions for additional purchases. **Judy makes a motion that the executive committee be responsible for deciding how remaining FCCF budget dollars will be spent.** Pat seconds the motion. No further discussion. The motion was approved by consensus. Eileen advised that beginning with next fiscal year, a monthly analysis of district and FCCF funding dollars will be created and kept current by the dept. Ann asked the chairs to provide Eileen with yearly budgets so she will know how the councils intend to use their funding dollars. Ann asked Eileen if the councils have problems with district liaisons, will she communicate with them. Eileen's response was yes. Judy shared with Eileen the frustration councils have with having to follow the state guidelines for spending funding dollars. It's very difficult having to go through the district program office as compared to going to Office Depot and purchasing items needed then being reimbursed by the dept. She asked Eileen if she could come up with a more efficient way for the districts to access their funding dollars. Wilma shared changes could occur with the new agency. Eileen shared she will be establishing a file per FCC district and has received approval from Susan to start traveling the state to attend district FCC meetings.

Melinda Coulter:

Melinda is requesting Family Care Councils get more involved in presenting the Choice Counseling now known as the "Yellow Notebook" sessions in their district. She had sent an E-mail asking for at least one representative from each district to attend this year's session and be trained to give presentations next year. She didn't hear from the majority of the councils. The sessions will take place during the month of June preferably on Saturday and Sunday. She wants the sessions in conjunction with FCC meetings. The sessions will be 3 hours, 2 hours for yellow notebook and 1 hour for FCC meeting. A postcard will be mailed to all individuals receiving DD services advising them of sessions. On the postcard will be directions to check the DDP website for meeting date, time and location information. She handed out yellow notebooks to each chair and advised the updates are on the website. They are printing 3,000 additional notebooks and 22,000 updates. Notebooks are also available in Spanish. She will work with the councils anyway she can but the sessions have to be done by June 30th.

IV. OLD BUSINESS

Celebrate Employment:

Ann shared with the chairs the printed booklet. She shared how exciting it was to gather all the stories. The camaraderie between employee and employer has been wonderful to see. The three employers recognized by the Governor at Family CAFÉ are Publix, Dr. Steiman in Broward County and Morton Plant North Bay Hospital in New Port Richey. Shelly wants the project to continue. Discussion followed to distribute to transition specialists at the high schools and local and state chamber of commerce meetings. Ann indicated the need to create another booklet with pictures. She wants to know from the chairs if they are interested in moving forward with this as an FCCF project.

Joan makes a motion that the FCCF continue to work on the celebrate employment campaign for the next year. Diane seconds the motion. The motion was approved by consensus. The chairs thanked Ann for all her efforts throughout this very successful project.

CDC+:

Ann shared that in past months we have heard only the dept. side of problems within DD programs. It's important that the family side of problems be learned and acted upon. Therefore, this month she wants to focus on the CDC+ program. Martha has experienced many problems as a CDC representative. Rhonda has been on every CDC+ conference call. Many problems have occurred with the transfer from one fiscal intermediary to another. A few examples include serious problems affecting SSA benefits and families who have not had bills paid from December. The question has been asked in the past and ignored but the FCCF wants to know how many families statewide have not had bills paid. It was reported during a previous CDC+ teleconference call the audit has been completed. Fiscally the whole program is in the black, however, there are discrepancies between figures shown by the intermediary and what the program shows. Rhonda shared numerous problems with the new intermediary which included examples of inaccuracies within their accounting process. Jadene asked Rhonda to send Ann the E-mail with the details she received on the report and contact information so Ann can forward on to all the chairs. Rhonda was asked if a parent had ever been added to the CDC monthly workforce meetings. The answer was no. Martha shared how difficult it has been to understand what is going on with her budget. The question was asked if the dept. is bringing on any new consumers. The control group is coming on at 150 per month statewide. Much discussion followed expressing frustrations not only with the CDC+ program but with the program office in general. It was decided to go around the room asking chairs to share their frustrations. Following is a summary of those frustrations:

1. The dept. spend the past 2 years in a re-design effort trying to build a partnership and re-establish trust and collaboration with families and individuals served by the program. It's imperative to communicate with families, keep them informed. This isn't happening.
2. CDC+ training sessions – families allowed only if space available. If involved, only able to speak if they had something positive to say. The message coming out is families really aren't welcome.
3. Families continue to receive notice of meetings or teleconference calls the day before.
4. Important information not being passed on to families. Examples, 94 page legislative bill authorizing the creation of APD that was presented to the legislative committee the following day. No interest in family input. Also, the final 234 page document with the new legislation not sent to Ann for distribution.
5. Shelly not calling in when supposed to on several occasions. Also, she has not attended a single FCCF meeting this fiscal year.
6. Much frustration experienced is because the dept. doesn't listen to us.
7. The dept. knew they would be creating the CDC+ program yet they allowed no family input from successful families in the experimental group.
8. It was shared that the council feels that we're being ignored very strongly at this point in the council's development.
9. Shelly ignored FCC members at self-determination conference.

Overall, it appears the program office is ignoring the people that were legislatively created to support that program. A recommendation was made that FCCF write a letter to Shelly and the Governor saying enough is enough and the council is tired of being left out of which is happening in the program. Eileen offered to communicate our concerns directly to Shelly.

V. GUEST PRESENTATION

Florida Association of Support Coordinators - Shani Stoutt

Shani introduced herself and Becky Morris. They are both on the board of FASC. It was noted that a newly established association exists titled Florida Independent Support Coordinators Association (FISCA). Shani shared they asked to attend our meeting on behalf of support coordinators who are currently going through a difficult time. She passed out copies and summarized the SC role and responsibilities taken from the waiver handbook. Many of the responsibilities SC's are supposed to be doing for the consumer and want to be doing are taking the back burner because of the tremendous amount of paper work and dept. assignments and directives. She shared how difficult it has become to find SC's and if successful what is involved in the training process. She shared they have their deadlines for support plans but with the new legislative bill every support plan will go to Maximus. She held up one PSA about 2 inches thick for an individual with significant disabilities. She and Becky shared how their documentation is going in conflicting directions between Maximus, Delmarva and the district program office. They are invariably having to resend documentation. Shani shared how much they enjoy their jobs and much of the dept. changes are positive but the current process they are experiencing has been very difficult. FASC is working very hard to insure quality among SC's. They have a training committee to create consistency across the state in best practices so that everyone is basically on the same quality level. Martha is requesting and possibly FCC's can help to contact the various state universities to establish a class for social workers in developmental disabilities so that when they desire to become a waiver support coordinator they have the background. Ka brought up a few excellent questions. 1. Why do parents have to recruit providers? Isn't that the job of the SC. Many are not doing their job. Shani & Becky stated that is the job of a SC. Their only answer was that if you're not satisfied with your SC then contact your district and request a new one. 2. Why do some SC's get paid \$150 a month for doing nothing? The answer is what they're doing is a lot of paper work. Becky shared that most individuals they serve that live with their families don't have expensive/time consuming cost plans. She can understand why Ka would think he is not getting his dollars worth. Becky advised that instead of one monthly fee across the board for all SC's FASC has asked the state to look at graduated budgeting. Becky passed out a Timeline of SC events for 2003/2004 as a brief illustration of how SC's are very similar to Delmarva and Maximus. Each SC has signed a contract with the dept. She pointed out to the council they calculated just for 2003 SC's saved the state \$5 million by not contracting out the extra activities listed on the first page. They would really like to work with FCC's and get feedback from the council.

Together We Can – Juntos Podemos:

Shani shared the final part of the above grant is to provide the Family Care Councils with the training materials in order for them to begin the train-the-trainer sessions. She passed out the manuals to the chairs who have not received one to date. She summarized what is included in the manual. Joan shared the original intent for this project was to teach parents how to ask for services.

VI. TELECONFERENCE CALL – SHELLY BRANTLEY

Questions:

1. What is your vision for the new agency? – Shelly replied that will depend on who is the new director. She shared the Governor's office will probably appoint a transition team. Therefore, it would be a number of people looking at the overall mission, etc. She is fairly certain the Governor will sign the bill at Family CAFÉ. She was asked if a representative could be included in the transition team. Shelly replied she didn't know how they would handle the transition.
2. Can Personal Outcome Measures be used for service authorizations to request services? Jadene tried to clarify by sharing that one of the problems she is hearing from lots of Support Coordinators is that when you use outcomes to identify services that people need and want in their lives, Maximus is throwing it out the window. Maximus must get on board with the use of outcomes. Shelly agreed and shared she has had discussions with Maximus specifically related to quality measures and outcomes.

Diane shared it's also the district office who are approving or denying services. The waiver support coordinator is stuck in the middle because this is the outcome of the consumer yet the district says no we aren't giving you funding for it and then Delmarva is saying to the WSC why aren't you assisting this individual to meet their goals. Shelly said she is open to suggestions and maybe this should be presented to the next quality review team. Now is the time to do it. Diane also suggested the need for the district support plan reviewers to be trained in personal outcome measures.

Ann shared that many were impressed with Kevin Edwards POM training as it was more consumer oriented instead of paper-work oriented. She asked if Delmarva's requirements would be changing any to that effect. Shelly advised that is exactly what the dept. is trying to do. Currently they have developed a new outcome based review for Support Coordinators. The ultimate goal is to move towards that with all of the providers. Judy shared Kevin Edwards suggestion that each district establish a steering committee to include consumers, family members and providers. The purpose of the steering committee would be to provide information, identify barriers, etc. to the district program administrator who in turn would filter up to Shelly. Judy asked if there was a way for a directive to come from her office requesting all districts to establish these steering committees. Shelly suggested it could be a top priority in the transition phase of the new agency.

3. What is the status of the RFP for Parent Support Activities (Parent to Parent/FND)? - Shelly advised they have an RFP but she thinks it's still being drafted as she has not reviewed it. She was asked if there was a deadline and if they were running out of time. Shelly replied no but they are behind on its completion. The concern is current contract is up on June 30th. If not renewed it's a loss of parent to parent support which the state has had since 1985. Florida would then be the only state in the country without a parent to parent support organization. Shelly apologized that she has been traveling the past week and currently not up to date on this issue. She will look into it. She doesn't for see a problem. Patty shared with Shelly that she has asked Wilma to follow through with her on this as there is some time-sensitive urgency involved.

4. Does the FCC own the Macromedia Authorware software just purchased? Yes
Shelly apologized but she has to end the call. If there are any further questions, give to Wilma and she'll make sure that answers are provided as soon as possible.

Eileen shared that the final draft of the RFP mentioned will be on Susan's desk before she leaves for Family CAFÉ. Jadene shared the process of review which could take at least another 6 weeks before it's even advertised. If the RFP ends on June 30th without a new approved RFP, there is no money to continue funding FND's participation in the parent to parent program.

VII. NEW BUSINESS

Self Determination Conference:

Ann shared that she, Patty, Joy and Wilma attended the Self-Determination conference in Atlanta. Included in the information packet is a summary of issues presented at the conference. A homework assignment during the conference was to develop a plan. She is presenting the plan to the council and asking for support during this next year. Patty presented the FCC plan. The FCC goal is to assist families to believe in the Self-Determination concept – birth to death. They are targeting the very young children and their families. They want to partner with school districts, SMI, FDDC, individual support groups, etc. The plan is to sponsor events in various areas of the state and have a facilitator to facilitate discussion of what self-determination really is. A brief description of the FCC plan appears in the summary of issues paper. Discussion followed suggesting the plan follows exactly the mission of the SMI. The plan would be done in conjunction with SMI & other organizations. Patty advised she would contact SMI.

Emergency Funds:

The executive board met and they hope to have a draft budget for presentation at the July meeting. They are requesting the councils to consider increasing the amount of dollars allocated to the FCCF budget. The following areas provide justification for increased allocation: 1. Increased cost of the website to maintain on a regular basis; 2. Additional travel expenses to attend meetings and conferences representing the FCCF; and 3. Consulting fees for grant writing, etc. The current budget of \$500 per district can't support these additional items. Ann will prepare an E-mail to send to chairs requesting they ask their councils for an additional \$500 bringing the total allocation to \$1,000 per district. District chairs be prepared to have approval/disapproval by July meeting. Wilma shared that Susan is requesting each district to prepare a budget for 2004/2005 funding year.

By-Laws:

Chair Carroll advised of an amendment that needs to be added to the by-laws. The current by-laws list an officer of Secretary/Treasurer. An amendment needs to be made to separate the two. **Judy makes a motion that the by-laws be amended to separate the Secretary/Treasurer position into two officer positions.** Ann seconds the motion. Motion approved by consensus.

Nominating Report:

Judy, chair of the nominating committee puts before the council the slate of officers which are:

- Chairperson – Ann Millan
- Vice Chairperson – Patty Houghland
- Secretary – Joy Frazier
- Treasurer – Rhonda Sloan
- Past Chairperson – Frank Carroll

Chair Carroll asks for further nominations from the floor for each of the above officer positions. There were no additional nominations. All officer positions were approved by consensus. Patty proceeded to present Chair Carroll with a plaque which read “Presented to Frank Carroll, Chairperson in recognition and sincere appreciation of your leadership and vision, however, YOUR NOT DONE YET”. This was followed by a round of applause.

Public Comment:

Chair Carroll appointed Patty as the council's representative to arrange for an in-person appointment with Shelly to express the councils concerns regarding the issues expressed earlier.

Chairperson's Comments:

Chair Carroll thanked the council for the opportunity to serve as chairperson. He believes the council has improved considerably. There is more to accomplish but the meetings he has chaired have been good with a business-like atmosphere. He believes the council can still be something special as long as it continues to maintain organization, mission and focus. A round of applause followed.

Newly elected Chairperson Comments:

Ann shared she has three goals for this coming year. 1. Wilma supplied each chair with a copy of the operating procedure titled “Community Resources/Volunteer Management”. Ann wants each of the chairs to become certified volunteers with the dept. so that we will have authority to affix mailing labels to FCC mailings. This topic will be discussed at the July meeting. 2. Councils do what the law tells us to do. 3. Attend other organizations meetings and become more involved in networking.

VIII. ADJOURNMENT

With no further business to come before the council, Chair Carroll officially adjourned the meeting at 4:00.

RESPECTFULLY SUBMITTED,

DONNA RAUBER