

FAMILY CARE COUNCIL FLORIDA
BETTY KAY CLEMENTS, CHAIRPERSON
Sheraton Suites Orlando Airport
Orlando, Florida
May 15th, 2010

MEMBERS PRESENT:

Betty Kay Clements, Chairperson
Patty Houghland, Past FCCF Chairperson
Lynn Carper, A1 Representative & FCCF Secretary
Frank Carroll, Vice Chairperson, A3 Chair
Pauline Lipps, Suncoast East Region Chair
Beverley DeStories, West Region Chair
Chris Dugan, A7 Co-Chair
Sharon Berry, A8 Chair
Paul Bell, A11 Representative
Isabel S. de Martinez, A13 Chair
Pete Wesley, A14 Representative
Lisa McGlone, Area 15 Chair

STAFF & GUESTS

Jim DeBeaugrine, APD Director
Pedro Moreno, APD Deputy Dir. Operations
Dixie Sansom, Arc of Florida
Christina DeCaso, A13 Guest
Ruth Wingate, A15 Guest
Brenda & Joey Carroll, A3 Guests

The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring quality services to individuals for dignity and choice.

I. CALL TO ORDER

Chair Clements called the meeting to order and welcomed everyone. She reviewed the contents of the information packet, which includes the following:

- FCCF Agenda
- FCCF March Minutes
- APD Crisis Status Criteria Rule 65G-1.047
- DCF/APD Rule 65G-11.001 – Wait List Prioritization
- Wait List Prioritization Checklist – Instructions
- FCC Schedule of Allotment Balances
- FCCF By-Laws (Rev. 3/10)
- Inspirational Sheet titled “Inspiration Line”

Chair Clements asked for introductions to include any area FCC news.

II. BUSINESS

Review of Minutes – Chair Clements asked if there were any corrections to the minutes. Patty makes a motion to accept the minutes as submitted. Chris seconds the motion. The minutes were approved by consensus.

By-Laws – Chair Clements mentioned a copy of the By-laws is in the information packet. The copy is the most recent with changes made by Jean and agreed upon at the last meeting. Pauline advised she did cross reference and the changes made are accurate. The By-laws were reviewed by everyone in attendance. Patty makes a motion to approve the By-laws as presented. Isabel seconds the motion. The By-laws were approved by consensus.

July Meeting – Chair Clements reminded everyone the next meeting is scheduled for July 30th & 31st. It's usually the third weekend of the month. This is a one time change as requested by hotel management.

III. APD UPDATES - APD Director Jim DeBeaugrine and Pedro Moreno, Deputy Director Chair Clements introduced Jim and Pedro to the audience. Hilary Brazzell will be calling in via conference call. Jim shared he wanted to talk about what took place during the legislative session and give an iBudget update.

Legislative Update – Jim advised APD legislative package passed almost in its entirety. He reviewed the items that would be of most interest to this group.

- **DOAH Hearings will be moved to DCF.** APD will be working with DCF. They will be getting new positions to handle the increased workload. APD offered to train the new hearing officers. Chair Clements wanted to give credit to Jim and Mike Palecki as they tried very hard to have the hearings remain with DOAH. Jim thanked Chair Clements for pointing that out. Jim shared that APD worked with Florida ARC, FCCFlorida, the Advocacy Center, and FARF to develop a compromise which they felt would not have been opposed. Jim was very pleased with the language developed by the stakeholders and staff. However, something happened at the legislative side that caused the entire APD package to be killed as a result of this one issue.
- **Developmental Disabilities Bill of Rights** – Jim advised the current document only gave a person the right to be free from sexual abuse in a residential facility. The law has been changed so a person has a right to be free of any kind of abuse in any kind of setting.
- **Tiers** – There were certain changes to the tiers that were passed. Primarily clarifying that age can be a person characteristic used in deciding tier assignments.
- **QSI Instrument** – There was a clarification in law that codifies APD’s QSI instrument. Jim mentioned the old ICG instrument is fast becoming obsolete. They are on a 3 year cycle which by now means most people will be assessed based on the QSI. APD will continue, as good practice with any kind of formal assessment instrument, a process of constant study and refinement.
- **iBudget Legislation** – In week six of a nine week session, the House of Representatives passed a law, and sent on to the Senate, requiring APD to implement individual’s budgets. A couple weeks after passing the House, APD saw for the first time a bill that would move the APD program into a commercial HMO environment. It would have been a good idea for proponents of such a bill to have recognized that 2 weeks earlier the House had passed something that was a 180 degree flat out contradiction. This newly submitted bill generated a huge outpouring of letters, e-mails, calls and good testimony from FCCFlorida representatives, especially from self advocate Jarl Jackson. Jim felt his statement was one of the most compelling he has ever heard. He mentioned the names of several Senators who were much more supportive of APD and indicated they were not in favor of managed care, at least not for the DD Home and Community Based Services.
- **Managed Care Legislation** - Jim shared some talking points to keep in mind with regards to any future managed care bill. The bill as originally filed called for a medical loss ratio of 15%. It represents the amount of money that HMO’s scrape of the top for profit and overhead. For APD, the managed care would have taken the private ICF’s and the HCBS waiver. That is a little over \$1 billion dollars. That would mean the managed care organization would have raked off the top about \$160 million dollars to cover administration costs, thus adding another layer of bureaucracy to the APD system that doesn’t exist today. Those are dollars that currently go to services. Jim shared in no way can he intellectually reconcile how that could possibly be a good idea given the challenges APD has to begin with in providing sufficient funding for services. They were able to make that point to a number of key people in the House and as a result the language was amended. For the DD programs only the medical loss ratio could not exceed 8%. That amounts to \$ 80 million. A ratio of 1% would be too much as it too takes away from services. Sharon asked what would the HMO

organizations be doing for this profit. Jim said that is the question. No where was it stated what the HMO's role would be to justify paying them the medical ratio percentage. The bill was never referred to an appropriations committee. He believes there is a need for educating policymakers that the nature of the services provided under the Home and Community Based Services Waiver should not take \$160 million dollars to manage that. They need to be educated that services provided to the DD population are not a medical model. Jim suggested that everyone visit their House Representative and Senator within the district where they live. It's important to educate them on the iBudget which is far more realistic and cost saving as compared to paying out \$160 million to an HMO.

iBudget Update – Hilary joined the council via conference call. Jim asked Hilary to give the audience a general overview of where the agency is going now in implementing the iBudget. Hilary shared they have been doing a lot of work in anticipation of iBudget becoming law. They are following Phase I which is doing a great deal of background work and research that will lay the ground work for stakeholders to come in and make real positive contributions. She mentioned it's amazing how much ground the stakeholders workgroup covered. They have been able to answer questions by going back through the documents to see what stakeholders said which allowed them the basis to move forward and begin laying this ground work. They have begun writing a new waiver to be submitted in July. Nearly everything they need to include in the waiver is in the iBudget plan. They will be having a call the latter part of May to discuss some outstanding issues. One piece they will be getting stakeholder input on is about their plan for implementation in terms of where APD will start geographically in the state and then how to proceed after that. The general plan they would propose for feedback includes beginning with one county in the fall. The main objective for selecting that county would be suitability for evaluation which would include ease of implementation. They want a good cross section of individuals and their service needs, CDC+, residential etc., so that they can have a good overview with little surprise when going to a larger area. They want a big enough number of people to evaluate but small enough to work effectively. Because they are moving quickly on this they need to make sure they can work closely with that area staff. Proximity to Tallahassee will be another factor. Once the county is selected they are looking to run that group for nine months to a year. Then review the evaluation data. After that, transition the county over the next 12 month period. All of these details must be included in the new waiver.

Another key area being developed is the iBudget on-line tool. This tool will be beneficial to those people who are comfortable with using computers. It will allow people to manage their budget on-line and move funds around as needs change. They are also designing it to speed the administrative process. One of the upcoming calls will be dedicated to the IT issues. Jim added they plan on using the iBudget and IT support for iBudget as a good excuse to try to move their system to paperless. Hilary shared the challenges involved in creating the program from scratch. She mentioned they have been very, very busy and there is much more work ahead. They will be hiring another staff person who will be a counterpart to her in operations. That person will be working very closely with the chosen area and county. She shared they will continue to ask for stakeholder input as it has been so valuable throughout this process. Jim elaborated in terms of the content and the types of things APD should focus on. He really thinks they can get a lot of valuable advice from people like everyone in the audience who are experienced, have family members with disabilities and live this. Others may not be as engaged so how can they make sure that even the person that doesn't want to engage at least has fundamental knowledge to avoid mistakes with their budget. Jim advised they will have a certain threshold review but prior service authorization as it is known today will cease to exist. They will have certain flags built into the program to alert people if it appears they are headed towards a funding problem. Discussion followed with various questions relating to how and when accounts would be funded, etc. Jim and Hilary mentioned these are issues that are still being examined and not finalized yet.

Additional Updates – Jim mentioned that he and Pedro spent the past couple of days on the West Coast. He shared that Gulf Coast has 4 remaining residents that will be transitioned out by June 1st. He praised the current workforce for all they have done throughout this closing process. They have provided excellent care to the residents even knowing they were eventually phasing themselves out of a job. As of July 1st, APD will no longer own that facility or property. It will be given to Florida Gulf University. He shared a group of people from Federally Qualified Health Center in the Tampa Bay area had written a letter to their local Senator inquiring as to what APD was planning on doing with all the Gulf Coast medical and dental equipment. Jim suggested they could have the equipment if they in return would provide dental care to some of APD's waiting list and tier 4 people. They could do this and in time become comfortable with serving this population, then become a waiver provider. They have agreed to this and are very excited about it. APD hopes to develop a protocol where they can tell the General Revenue support coordinators that this is a resource available to wait list people. The Center is affiliated with clinics that operate all over the Tampa Bay area. Jim also shared they had attorneys go after fees in a legal case. He decided to offer them \$50,000, which is the state maximum, but in return ask the law firm to donate it back to the APD client welfare fund and earmark it for dental care in Southeast Florida. They agreed, and to their credit, were very receptive to the idea. APD is within 60 – 90 days from finalizing the proposal with a dental clinic in Southeast Florida. Jim has also talked with representatives from Nova Southeastern University who currently have a dental training program for people with disabilities. The Dean of the Dental College shared with Jim that they want it to be the premier training program in the world for dentists that work with special needs populations. APD is looking to buy a mobile dental clinic. Once purchased, they will need to work on finding the personnel to staff the clinic. Jim shared how he would like to get other resources involved in the dental issue. Several in the audience offered additional suggestions and referrals.

Crisis Rule – Chair Clements mentioned everyone has a copy in their information packet. Jim provided information pertaining to foster care children being part of the crisis criteria. By definition they are homeless, they have been removed from their home by the State of Florida because they have either been abandoned by their family or they have been the victims of abuse and neglect. Currently the foster care children are the second order of priority in the crisis rule. That doesn't change with the new law. One of the criteria for crisis is homelessness or risk of homelessness or being in danger of themselves or others. Technically all of the foster care kids are in crisis. Jim advised because there is a community based care organization that gets funded through the child welfare system to house and support foster care children generally, APD has not treated foster care children as automatically being in crisis. The child advocates came to APD and petitioned them to make foster care children in crisis. He shared as of last year, APD can enroll people off the waiting list to the extent that the savings from expanded enrollment in the CDC+ program will allow it without increasing the size of the deficit. Jim mentioned they could have said no to the child advocates but then would probably have been sued and end up doing it anyway because a judge made them. Therefore, Jim agreed to consider. The language used came from the child advocates attorneys. It will only apply to a small subset of the foster care population. It is Jim's goal to try to enroll all of the foster care children through the CDC+ savings. They want to move certain children out of priority 2 into priority 1 where they would be handled first. There will be public comment and Jim encourages everyone to make comments. Jim mentioned all of these children are developmentally disabled and eligible for APD. Patty questioned the current language. She asked Jim does this mean that a certain subset of these folks will receive a crisis slot and move them back home. That is not what the current language states. Jim said that is what this language is supposed to read. What the current language states is that each child in crisis will get a crisis slot. Patty has concerns about the elderly population who are still caring for their aged, adult child in the home who becomes in crisis as a result of death of the Mom and Dad has Dementia. Can the foster care child trump this family? Jim advised no, it just adds foster care children who have no possibility of

permanent placement. Jim asked everyone to submit comments with their concerns at the rule workshops or in written form. They cannot do any revising of the rule unless it's in response to input received at the workshops.

Wait List Prioritization Procedures – Patty asked about the Social Services Block Grant funding appearing in both categories six and seven. Jim gave several reasons why this needs to be removed from the document. He mentioned they could replace that with “priority use of non-Medicaid funds would go to certain individuals on the wait list”.

APD Leadership Meetings – Jim advised an APD leadership meeting will be held May 17th and 18th in Tallahassee. These meetings in the past have included just Area Administrators. This time they want to include stakeholders on the second day. He said anyone is welcome to attend on day one which will be the area administrators turn to talk to him. Stakeholders turn to talk with him will be on day two. The meeting will begin at 8:30 and end at 1:00.

FCCFlorida – Jim mentioned how much he has enjoyed working with everyone in having these discussions and to be developing solutions to issues and problems together. He wants to congratulate everyone involved in Family Care Councils and particularly Chair Clements whose leadership has helped to make this possible. He praised the group as being key to developing the iBudget plan and will be key in developing the actual implementation as they move forward. He also praised the councils for being effective with legislators. It is because the councils have engaged the process intelligently. That function is not only based on the leadership of each council chair in all the areas but also Chair Clements at the statewide level. Jim congratulates Chair Clements for what can only be described as a tremendously successful term as chairperson under perhaps the most difficult trying circumstances. Jim presented Chair Clements with a certificate of appreciation from APD. He looks forward to continuing what has been a wonderful relationship. Everyone agreed with their applause. Chair Clements thanked Jim so much.

Dixie Sansom presented Chair Clements with a gift on behalf of the Arc of Florida in appreciation to her and all the Family Care Council members. She thanks Chair Clements for her support in bringing a new working relationship between the families, Arc and APD.

FCC Funding Dollars - Patty mentioned to Jim how frustrating it is when FCCFlorida still has no idea how much money they have in their accounts. An example, Area 1 did a budget request many months ago to transfer \$1,000 to FCCFlorida and it never came through. It came out of Area 1's budget but never made it to FCCFlorida. Patty asked Jim to please consider in this next fiscal year to use FICD as the fiscal agent. Jim advised, yes he will, it is not an issue for him. Patty mentioned she will come to his office to talk to him about it. Chair Clements added it's also a problem with each area council's budgets. No one knows how much they have left to spend or what they will lose if they don't spend it by a certain time.

Chair Clements thanked Jim so much for attending the meeting. It means so much to the council for his taking the time from his busy schedule to meet with the group. She also thanked Pedro for attending the meeting.

IV. LEGISLATIVE SESSION WRAP UP – Dixie Sansom, Arc of Florida

Chair Clements introduced Dixie to the audience. Dixie is the Lobbyist for Arc of Florida. She proceeded with a summary of the 2010 Legislative Session. She shared it was a very mixed session. It wasn't with the politics of the Governor, it was strictly in the internal one chamber within its own self. The House was within its self, the Senate within its self, and the two against each other. She shared (as did Jim) the best example of that was the Medicaid Managed Care proposal. One week the House and Senate passed the iBudget in 2 different bills and the very next week the House came out with the managed care package that included APD. The Senate did not support the package. It was supported by the next speaker of the House, Dean Cannon. He had the votes in the House and in the committee but it never went through any of the budget committees. The House was not successful in working with the Senate chamber. *Entering the room at this time was a special surprise visitor,*

Frank Carroll, his wife Brenda and son, Joey. Chair Clements said this is the best surprise the council could possibly have. Everyone agreed with their applause. Dixie continued saying APD did have some successes this year. She said the House was good to APD on funding, they made no cuts in their proposal. The Senate came out of its first subcommittee, the Health and Human Services Appropriations, with a 10% cut to APD budget. That was removed as it went through full appropriations on the full Senate floor and became the same as the House with no cuts, but with caveats contingent upon federal funds. When the Senate sat down in the Health and Human Service conference with the House and Senate on the APD budget, the Senate announced at that point they were starting out with the original budget that included the 10% cut. They weren't going to offer any of the federal funds to go back into APD and health areas for replacement. Dixie has never heard of anything like this happening before. In the last 2 weeks of session, they go into conference having to battle to get this changed. Dixie mentioned that J.D. Alexander is the chairman of the Senate Ways and Means Appropriations committee. J.D. needs to understand the APD world. The House ended up accepting a 2.5% cut to the APD budget with none of the FMAP going back into APD. She stated the Governor has just received the budget. He has 15 days to act on it. ARC is asking the Governor to veto 2 of the 5 paragraphs within the proviso language dedicated to the APD budget. Arc has prepared a letter which Dixie will E-mail to Chair Clements with the specific language included. She explained one paragraph is inconsistent with language to be put in a budget. The other relates to the 2.5% reductions to provider rates. She believes Arc is making, with this language, a good argument with the Governor's office that this is statutory language not budget language. Dixie is asking people to contact the Governor's office asking him to veto these 2 specific line item paragraphs. Use your own language but specify it's the proviso language associated with these line items within the APD appropriations budget. She asked that we copy Chair Clements so a compilation of requests can be determined and where they came from. Dixie mentioned this is the most important thing right now because it's a legislative item that is still in the action stage.

House Bill 399 - Dixie shared the Governor signed the bill yesterday. It will allow people to make a voluntary contribution to Arc of Florida when renewing your driver's license or any motor vehicle registration. She believes it will start in September. Arc will then use these dollars to help families with services. The money will be disbursed based upon the area of collection.

Senate Bill 1388 – Dixie shared that Senator Mike Haridopolos, from her area and is designated to be the next Senate President, introduced a bill that would delete the term mental retardation and substitute it with intellectual disability. The bill did not pass the Senate. It was a very technical bill and the staff kept finding additions to be added to it. There just wasn't enough time to get the bill restructured. It did not have a House companion bill.

House Bill 943 – Dixie shared Phil's lottery bill sponsored by Rep. Proctor and Senate Bill 2200 sponsored by Senator Altman didn't pass. The purpose of the bill was to get lottery funds into APD. The constitution is very clear the funds must go to education. They used the education vehicle of the Voc Rehab division. They didn't even push getting the bill out of committee this year because no one really understood it. She mentioned ARC did have some very productive meetings with the lottery agency. The big problem is with the Department of Education, Voc Rehab. What needs to happen is to get the involvement of the rehabilitation council. Arc will continue to pursue this issue. She mentioned Rep. Proctor has already said he wants to begin working on it this summer.

House Bill 1111 - Dixie shared this is the prepaid services bill sponsored by Clay Ford and Senate Bill 2192 sponsored by Senator Peadon. She mentioned that this year Senator Peadon has been an extraordinary friend. The major complainer of the bill came from the folks who have the prepaid college tuition fund. They believe they have proprietary rights to the word "prepaid". There was not enough time to get everything resolved in order to get legislation amended. The final version of Senator Peadon's bill 2192 created a task force and renamed it the Services with Developmental Disabilities Task Force. The word prepaid was removed. The task force is created to make recommendations and develop a plan for the creation of and enrollment in the developmental

disabilities savings plan. Chair Clements asked Dixie to send this information to her so she can forward on to everyone. The task force will complete its task before or no later than April 2nd, 2012 whichever occurs first. The task force shall continue until enrollment in the Developmental Disabilities Savings Program has commenced at which time the task force is abolished or June 30, 2013 whichever occurs first. This was included in the APD conforming bill. The conforming bill 5303 is the same legislation that has the iBudget in it. Also included is the reduction in tiers. The Governor has until May 28th to act on it.

Key Legislators - Dixie shared the key legislators on the Senate side are Joe Negron, Don Gaetz, Mike Haridopolos, J.D. Alexander, Mike Bennett, Mike Fasano, Nan Rich, and Dennis Jones. On the House side, Dean Cannon, Bill Proctor, Matt Gaetz, Clay Ford, Denise Grimsley, Scott Plakon, Trudi Williams, Michelle Vasilinda, Will Weatherford, Chris Dorworth, Debbie Mayfield, Eric Eisnaugle, Steve Precourt, Gary Aubuchon, Alan Hayes, and Marti Coley. Dixie mentioned that Arc will be spending the summer visiting with legislators and she encourages everyone to do the same. Chair Clements thanked Dixie for attending the meeting and how appreciative FCCF is that Arc has kept the council informed throughout the session. She believes the support from Deborah and Dixie has helped the council accomplish so much more this year. Everyone agreed with their applause.

V. BUSINESS (Continued)

Budget Report – Pauline is filling in for Phil who is on vacation. Pauline advised the total expenses to date are \$13, 804.73. This results in a negative \$1,304.73 to date. The projected YTD balance after all bills are submitted is a negative \$2,084.00. Area 14 has requested a transfer of \$500 and Suncoast Region East a transfer of \$1,500 which is still considered in progress. Chair Clements mentioned this was different from what Stephanie had sent to her. It also doesn't include May expenditures. There are other area councils who have requested transfers that are not showing on the expenditure report.

FICD – Patty, President of FICD (Florida Institute on Community and Disabilities) shared they are proposing to FCCFlorida that FICD become the Financial Entity that receives the total \$150,000 FCC dollars. FICD would interact with the councils, rather than APD. FCCFlorida approval must be done by the end of June. The FICD Treasurer is Bob Wessels. He or whoever takes on the responsibility will require a % of the \$150,000 for the work involved. Every council would have its individual account and the ability to know on a daily basis the balance in the account. It will require the agreement of all the councils to approve this. Discussion followed with numerous reasons why having FICD as the FCCFlorida fiscal agent is a good idea and definitely worth pursuing. FCCFlorida gives Patty its OK to explore the issue with Director DeBeaugrine.

VI. ELECTIONS OF OFFICERS – Nominating Committee

Lynn advised during the March meeting the nominating committee presented a slate of officers. The slate stands as the motion. Frank volunteered to go through the slate individually and take requests for nominations from the floor. The slate of officers is:

Chairperson – Frank Carroll – Frank asks if there are any nominations from the floor. There were none. The motion was approved by consensus.

Vice Chairperson – Phil Pearson - Frank asks if there are any nominations from the floor. There were none. The motion was approved by consensus.

Secretary – Patty Houghland - Frank asks if there are any nominations from the floor. There were none. The motion was approved by consensus.

Treasurer – Pauline Lipps – Frank asks if there are any nominations from the floor. There were none. The motion was approved by consensus.

All officers have been approved. The audience approved with their applause.

VII. ADJOURNMENT

Chair Clements asked if there was any further business to come before the council. There was none. Meeting adjourned at 3:25.

The next meeting will be held on July 31st at The Sheraton Suites.

RESPECTFULLY SUBMITTED,

Donna Rauber, Florida Institute on Community and Disability (FICD)