

**FAMILY CARE COUNCIL FLORIDA**  
**BETTY KAY CLEMENTS, CHAIRPERSON**  
**Holiday Inn Select Orlando Airport**  
**Orlando, Florida**  
**November 21st, 2009**

**MEMBERS PRESENT:**

Betty Kay Clements, Chairperson  
Frank Carroll, Vice Chairperson, A3 Chair  
Patty Houghland, Past FCCF Chairperson  
Tracy Stewart, A2 Chair  
Pauline Lipps, Suncoast East Region Chair  
Beverley DeStories, Interim Chair Suncoast West Region  
Chris Dugan, A7 Co-Chair  
Jean Sherman, A10 Chair  
Phil Pearson, A12 Representative, FCCF Treasurer  
Isabel S. de Martinez, A13 Chair  
Pete Wesley, A14 Representative  
Nancy Moody, Area 15 Chair

**STAFF & GUESTS**

Dr. Dave Robinson, APD Central Office  
Stephanie Rogers, APD Central Office  
Ruth Wingate, A15 Vice Chair  
Christina DeCaso, A13 Guest

*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 asked for introductions to include area FCC news. Jean shared she believes a new ADRC (Aging Disability Resource Centers) is being set up in the Ft. Myers area with funding just released from the Administration on Aging and is being done in conjunction with APD. There are 11 AAA's (Area Agencies on Aging) in Florida. These are to be one stop resource centers for older people with a variety of disabilities to go to get services under the Older Americans & Community Care for the Elderly Acts but they are also able to offer them resources from the disability side. The AAA's had a very strong information and referral program since 1965. This was the first time Jean saw that an ADRC in Florida was to include individuals with developmental disabilities. This is very encouraging for the DD population, especially for aging families to be able to go to one place to obtain information on resources available.

Chair Clements shared that she, Phil and Patty have represented FCCFlorida in the iBudget 2 day meetings which have included many phone calls that have lasted several hours. Hilary and APD staff have been very open with including them (representing family members) in the input.

There have been additional meetings (most in Tallahassee) including rule workshops and DD Council forums, waitlist meetings and rule hearings that she, Phil and or Patty have attended which required travel and overnight accommodations. Chair Clements mentioned the importance of taking the time to read through the documents she forwards on to everyone. Any questions should be sent to her so whoever is attending these important meetings can ask and receive answers from the correct source. Discussion followed on how user friendly the iBudget PowerPoint presentations are and that FCCF members had been included on a regular basis in the creation of these tools. Beverley shared she received a copy of the QSI done on her daughter which took place at her ADT program. Beverley was not included and the QSI did not reflect Faith's needs or even Faith as a person. Chair Clements asked to hold off on that discussion until Dave Robinson is present. Beverley encourages everyone to request a copy of the QSI

report, as it must be requested. Chair Clements mentioned that FCCFlorida is currently being audited.

**Incontinent Supplies Update** – Chair Clements advised the first 2 areas that are working on the project have seen a slow down in progress for numerous reasons. As of the end of the week, there had been only 30 cases mailed in total. There should be a total of 100. The process has improved but it seems many people had not yet responded. As a result, they plan on putting a time frame on the process. They are holding off the next area assignment for a while. The next 2 areas will probably be area 1 and 15. Chair Clements shared that everyone in all the areas has been very cooperative.

Chair Clements reviewed the contents of the information packet which includes the following:

- FCCFlorida Meeting Agenda
- FCCFlorida September Minutes
- Family Care Councils Schedule of Allotment Balance – 11/10/09
- FCCFlorida Expense and Transfer Report
- FCCFlorida Quarterly Budget Report
- APD Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs – First Quarter, July through September, 2009
- FCCFlorida Legislative Platform 2009-2010
- FCCFlorida Action Plan Worksheet for 2009-2010
- APD CDC+ brochure
- Inspiration Line – Inspirational quotes
- Schedule of The Governor’s Commission on Disabilities December meetings
- Disability\*Gov Website information – Excellent informative website
- APD Cost Rebasing statute, timeline, Notice of Cost Plan Rebasing and procedures
- Action Alert: Support ABLE Act Which Allows Families to Save for Children with Disabilities – Patty urged everyone to read this. It is a federal act that would allow individuals with disabilities to create a disability savings account that would accrue interest tax-free. It makes it possible to save money for a person with a disability and not be penalized and would not interfere with any governmental benefits they have.
- A notice of a bill introduced by Senator Mikulski to strike terms “Mental Retardation” and “Mentally Retarded” from Federal Law books
- A document from Disability Coalition on Healthcare Reform – Access and Choice: National Health Care Reform for People with Disabilities

## **II. BUSINESS**

**Review of Minutes** – Chair Clements asked if there were any corrections to the minutes. There were none. Phil makes a motion to accept the minutes as submitted. Beverley seconds the motion. There was no discussion. The minutes were approved by consensus.

**Budget Report** - Phil presented three documents which included the area Schedule of Allotment Balances, the FCCFlorida Expenditure and Transfer Report and the FCCFlorida Quarterly Budget Report. FCCFlorida has only received \$500 transfers from 2 area councils bringing the FCCFlorida total to \$8500.00. Some councils have approved transfers which have not yet reached the APD accounting office; other councils have not taken a vote to approve transfers. The quarterly budget report shows total expenditures of \$5,349.00 at the end of December. He asked if the councils have not taken a vote as yet to approve additional dollars to FCCFlorida they need to do so now. Beverley, Jean, Pete & Chair Clements stated their councils had approved additional funding to FCCFlorida that aren’t appearing on the budget report. Stephanie advised she will check into this.

**By-Laws Committee Report** – Frank, chair of the By-Laws committee, stated the committee is working on the By-Laws. There is still time for chairs to send in any recommendations for changes, additions or deletions to current by-laws. The cut-off date will be January 15<sup>th</sup>, 2010. Frank said the by-laws can be found on the FCCFlorida website, click on FCCF Info. They are listed under Publications. Frank reminded everyone the by-laws pertain to FCCFlorida only, not the councils.

**FCC Documents Request** – Chair Clements asked Stephanie to review JR’s memo and timelines. Stephanie reviewed the memo sent by JR Harding to APD Area Administrators and FCC Liaisons requesting area councils to provide their FCC Bylaws, Support Plan, FCC Accomplishments, FCC Budget Projections and Expenditure Reports, any transfers to FCCFlorida and Governor Appointment update. The councils have been asked to supply this information to Central Office by December 18<sup>th</sup>. If a council needs an extension just notify her. Stephanie said she has been in contact with the Governor’s Appointment Office and if a council has included in their by-laws that any member who has three (3) unexcused absences will no longer be a member of the council, the by-laws can be sent to the appointment office and they will remove the member from the roster. Jean asked Chair Clements if she could E-mail out the FCCFlorida Accomplishments list as a guideline since all the councils are required to include this in their documents. Chair Clements will do so.

**HB81, Stopping Abusive Restraint and Seclusion Use in Schools** – Chair Clements mentioned that Sylvia Smith is asking for an FCCFlorida person to attend the upcoming press conference about the bill. She asked Patty to provide additional information. Patty shared that as this bill goes through the legislative process the wording can change through amendments. Things happen quickly and FCCF needs to know if the council can continue to support it or not. Some groups have indicated they will not support the bill if it allows prone restraints to happen, absolutely cannot do prone restraints. Issue 2, parents must be notified in a very timely manner of any restraints. Issue 3, aversive techniques only as a very last resort after trying everything else including positive behavioral supports. Issue 4, people who do hands on restraints, must be not only trained but certified in the process. If any of these pieces are missing, some organizations state they cannot support the bill. Patty is asking the council if some of these elements may change can the council still support it or if these elements are not in the bill does the council want to support it. Discussion followed. Frank makes a motion the council support HB 81 providing the four elements listed remain in the bill. Tracy seconds the motion. No further discussion. The motion was approved by consensus.

### **III. AUTOMATED CUSTOMER RECORDS – OUTCOMES** - Dr. Dave Robinson, APD Director of Special Projects

Chair Clements asked Dave to introduce himself. Dave shared currently he is the Director of Special Projects. His mission today is to update the council on the two projects he is currently working on. One is the implementation of a new Quality Assurance Program in the state and the automation of customer records.

**Quality Assurance Program** – The day before this meeting, APD posted an award for a quality assurance provider and it was awarded to Delmarva. It is for another QA contract presented in a different structure, for which they bid. Dave wrote the Invitation to Negotiate to restructure the entire quality assurance program, gave it to AHCA and a year later they finally had 3 bidders which were APS, Keypro, and Delmarva. Each bid was extensively evaluated, they spent a lot of time in negotiations with them and then posted the award to Delmarva. There will be a 10 day timeframe for the companies that lost to protest. That would result in an emergency extension of the current Delmarva contract. He will keep the FCCF posted on the outcome of the protest period.

**Automated Customer Records** - Dave explained that the developmental disability program has been a part of HRS, DCF and now APD. Each area/district had its own primary providers. The relationship between area program offices and these providers proved to be difficult at times. It was up to the agency to monitor the providers. Each of these agencies within the state of Florida developed their own documentation. Later when the agency initiated the Medicaid waiver, and added another 9,500 providers, each of them developed their own documentation.

The progress of each individual on the waiver is documented in numerous different ways, making difficult for families and WSC's understand because that documentation is all over the system. Another problem is Area Offices creating their own forms. An example of the problem is shown in quality assurance. Delmarva could only look at 2 to 4 records within a Support Coordinators Agency, resulting in only 5 – 10% of its records. The total cost of Delmarva's services over the years is \$20 million dollars, but resulted in only about 5% of the records being monitored. He shared some examples of how Support Coordinators could "beat the system" with no monitoring. The current system is not parent/guardian friendly. The Support Coordinators records are the legal records of the State of Florida, called the client "Central" records. However, the State of Florida cannot easily access those records. Dave said that one of the reasons he came to Tallahassee was to professionalize the client records. On January 15<sup>th</sup>, he will be starting an electronic central record in Area 2. He is also pleased to announce that parents/families/guardians will be able to log on from the internet and view their loved ones own record. Phil asked Dave what permissions would be needed to access the data. Dave explained APD will assign security level passwords that only allow access to one relevant record. Dave showed the electronic version to the council. The program is named "APD Connect". He showed the council how it works, how it will work for customers, parents/family members, guardians, providers, for the improvement of health/safety outcomes and how APD will be able to monitor it. Dave gave an overview, with examples, of each page within the system. The system is very user friendly for individuals and family/guardians to see all notes generated on the individual's record by providers and support coordinators. Tracy asked if Dave has any idea of how many APD customers have computer access. Dave explained he will have internet access available at each of the Area Offices. He also wants to have internet and E-mail access available to customers who in live group homes, as well as public internet sites. Dave explained the next generation of the system will include incident reports, how they will be documented and who will automatically receive them. There will also be E-mail alerts. For example a family can request they be notified of any incident via E-mail alert. Dave asked how everyone felt about adding a form where families can write notes (if they feel strongly about something) that could be included in the file. Everyone was positive in agreement. Dave reviewed all the reports that people would be able to view (which includes the ibudget, support plan, cost plan, service authorizations). It will also include a Parent report which can be filled out and submitted to APD. Discussion followed to determine who should receive the report. The attendees preferred it go to both area management and Tallahassee. Phil asked if a record could be included that notes the names of people he designates that can view the record. Dave said that can be done. Another suggestion is that families be able to receive information about the monitoring of the providers. Dave showed all the fields included in the support plan. This new system will allow Delmarva to do a quality assurance review on line of close to 100% of all support coordinator clients. This will allow Delmarva representatives to do paper work audits within their time frame and office location, thus allowing for a more person centered on premises audit. The new quality assurance program will include representatives talking with the customer, family or guardian and providers. Dave continued to review other reports which included an emergency information page, the annual report, personal plans (which include specific needs/goals) and a health page. Chair Clements asked if this data example could be made available for the council members to review. Dave advised yes. He also mentioned they are very committed to getting

away from prior service authorizations. APD is working towards a system where people can know when their accounts are correct and how to avoid fraud. APD will also be able to notify families of dollars that remain in their individual's budgets.

#### **IV. APD UPDATE -** Dave Robinson, APD Director of Special Projects

**Cost Rebasing** – Dave mentioned APD will be doing cost rebasing again this year. He did indicate that individuals who may have been hospitalized or out of state or unable to access services for a time within the year can be removed from the list. He was asked what kind of timeframe is being considered. Dave indicated it would be a person that did not access any services for a month, review the reason and make a determination based on that. Chair Clements asked about the rebasing appeal process. The direction coming from the area offices is you do the appeal and at the same time do reconsideration (same as the tier process). Dave said he would look into that. He indicated the agency is trying to reach out to people more to see if the issue can be informally resolved prior to having to get into the legal process. Pauline shared her son's reason for receiving a rebasing letter which proved to be inaccurate due to a billing error and wanted to know who to send the information to. Dave said to E-mail it to him and copy Denise Arnold. Beverly also shared a concern with her daughter's cost plan as dental services had been removed for the first time. She is on tier 1 and dental services are a medically necessary service for her. Dave said to E-mail him and he'll look into it. Pauline shared a letter she received from an APD customer and also an FCC member. He attended the last council meeting via spider phone. He uses a wheelchair and is non-verbal and had his provider read the letter. Pauline received a copy of the letter and the consumer approved her sharing it. As a result of rebasing his budget was cut by 1/3 and he had to give up his live in staff. Staff who are live ins have to pay half the bills. With what he could pay them plus having to pay half the bills nobody wanted the job. He decided to rent a room out to someone and get staff workers. This means after the staff worker puts him to bed, they go home and he is on his own all night. If there is a fire or somebody breaks in he is completely on his own. He says a lot of prayers and asks to be watched over. When he hears that APD is thinking about rebasing again he gets very upset. He ended the letter by stating that there is no way that he would ever consider moving into a group home. Dave asked for the letter. He did remind everyone that rebasing is legislatively required. Chair Clements asked Dave for clarification that there is no rebasing in the CDC+ program. Dave advised that is his understanding.

**iBudgets** - Dave explained meetings have been taking place to create an individualized budget system for APD customers. They are working on a report with recommendations to be delivered to the legislature in February, 2010. He is confident the legislators will approve and allow APD to get a new waiver. The ibudget is not mathematically complementary with the tiers. He gave an example. The hope is the individualized budgets will replace both the tiers and rebasing. Dave explained they will take a look back at the data prior to the tiers and look at circumstances such as how much on average they pay for an individual who lives in a group home, has CP, attends a day program and certain additional services. They will run a number which will become the beginning basis of the ibudget for that circumstance. He further explained this will lighten the load of the support coordinator. The ibudget is calculated, it becomes the prior service authorization. The dollar amount is determined, and then the customer/family work with the support coordinator to decide how to spend the money. The algorithm has not been determined yet. That should take place at the next ibudget meeting. The ultimate plan is that once the dollar amount is given the backside is totally flexible, using Medicaid providers, and services can be moved when needed but stay within the budgeted amount.

**Waiver Tier Emergency Rule** - Dave began by reminding everyone the original waiver consisted of the Home and Community Based Waiver and the Florida Supported Living Waiver. The FSL waiver included 6,000 people capped at \$14,000. The original design of that waiver

was to give people in supported living greater freedom with just a few services so people could migrate out of the system or not as involved. Those 2 waivers were then divided into 4 tiers which became 4 waivers. The 6,000 in FSL were moved to Tier 4. Additional people were moved out of the HCBS waiver into Tier 4 and services were cut in some cases dramatically. Next came the most recent court decision. Everybody on all the waivers has a QSI. APD adopted an emergency rule which will probably be challenged on Monday. They are currently reviewing everybody that was placed in Tier 4. They have agreed to drop the age restriction which they had put in place because it is discriminatory. All of the people that appealed will have to be reassessed. Between the people currently in Tier 4 that require being reassessed and those who appealed the total reassessments will be about 11,500 people. He was asked about the term reassessed. Dave acknowledged it is not a reassessment of the tool but a review of the assessment. Patty asked how the 11,500 assessments are going to be re-evaluated. Dave said the APD has stopped their examiners from doing QSI's on the wait list people. They will now do these assessments. They will come up with a strategy to do a prioritization. Patty asked what happens to the people who appealed and lost. Dave will have to research that. Frank asked if there was a timeframe for completing this whole process. Dave stated it is a priority and they have put a lot of resources into it. He is estimating March or April.

**The Waiver Handbook** - Dave advised the waiver handbook will be coming up for a rule hearing in the next few days. The rule workshop dates will be submitted by AHCA and posted in the Administrative Weekly. He mentioned the only changes are reduction of paperwork. There will be another handbook (the 4 tiers) with significant changes scheduled for rule hearing shortly thereafter. He will keep the council updated on dates. The CDC+ handbook will be coming in February. Meetings are currently being held pertaining to PCA's for children.

**IFS Dollars** – Chair Clements asked Dave in regards to the Family Care Council charge. It is written in statute (Chapter 393-503 – Respite and Family Care Subsidy Expenditures; Funding) “the family care council shall review the expenditures and make recommendations to the agency with respect to any new funds that are made available for family care.” She stated she is sure he is aware that FCC's are never asked for any recommendations. She asked Dave what would be his recommendations on how the council's can follow through with their charge. He suggested that Jim could help with developing any changes to the statute the council would like to make. She mentioned again it is a matter that the council's are never asked by APD for their recommendations on how IFS dollars could be spent when it's stated in statute they should have the opportunity to review the expenditures. Chair Clements suggested perhaps Jim could come to a future meeting to address the statute with the council.

**CDC+ Update** - Dave was asked if he could give an update on CDC+. Dave advised APD is currently involved in preparing training sessions for people who applied. The trainings will be during the month of December. They hope to have people using the program in January. He is hoping people currently on CDC+ will help with the trainings by sharing experiences. He was asked how many applications were received. Dave replied about 1750. He has asked Jim to include in the legislative budget request an additional 2500 slots. He would like for people to have a choice between CDC+ and the waiver, receive trainings then decide which works best for his/her needs and supports. His vision is they have enough surplus slots to make it an option. Patty asked Dave to make sure the CDC+ trainings are performed by good quality people who know and understand the system. Dave mentioned what he would like to see happen is the monies allocated for the PSA (prior service authorization process), a company that is eligible for Medicaid match, go forward by changing the PSA to a professional training organization and have them do the CDC+ training. He also mentioned the new quality assurance program will include the monitoring of CDC+ customers.

Dave mentioned he would like to come back and share the completed automated customer record program with the council. Beverley asked if FCCF could have paper copies of the screens.

Dave replied yes. He mentioned he could E-mail the support plan to Betty Kay. Any comments could be submitted between now and January.

Chair Clements thanked Dave for attending the meeting and shared how much everyone appreciated his time and information. Everyone agreed with their applause.

## **V. WORKING GROUP UPDATE**

**FDCC Consortium** - Phil shared he attended the meeting where they discussed legislative platforms among various organizations. It was attended by representatives from the Dept. of Education, Florida ARC, DD Council, FARF and others. He took the FCCF legislative platform that is currently listed on the website. It is included in the information packet. He spoke to the consortium about FCCF's support of Senate Bill 1660 (Provision to re-prioritize the Wait List) and mentioned to the group that FCCF was in support of removing Category 5. It refers to clients who are expected to graduate within the next 12 months from secondary school. It didn't seem fair they should have priority over clients who have already graduated. Discussion followed. Phil makes a motion for FCCF to eliminate their support for Category 5. Pete seconds the motion. No further discussion. The motion was approved by consensus. Phil advised a letter from FCCF should be sent to the Senate Health and Human Services Committee. Phil volunteered to write the letter, Chair Clements will sign and send. Phil mentioned that other organizations within the consortium agreed with and supported the elimination of Category 5 and would write their letter to the committee. Phil presented to the consortium a document based on the question "So where do we go from here?" He felt comfortable in stating that "FCCF supports empowering families to make maximum use of supports currently available to them". He developed a "family life cycle" based on age broken down as follows: (In information packet).

- 0-3 years: Finding out that something is wrong or different;
- 4-22 years: In School;
- 23-45 years: Prime working years;
- 46-65 years: Parents or Caregivers are getting older;
- 65+ years: Getting older;
- All Ages – We need to come together as a group to identify categories of care level that tear families apart and destroy them.

Phil added that this needs to be expanded by developing where the supports are and how to support parents. Beverley suggested this be part of the FCCF action plan for next year. Tracy mentioned there are numerous agencies, groups and organizations out there that could be of assistance. Maybe through JR, FCC's could be of assistance in helping to develop a central repository where all this information could be compiled where people can obtain assistance within the community. Tracy also mentioned APD is good about documenting where the dollars are being spent. The school districts and insurance companies are not. There are numerous situations where Medicaid Waiver dollars are being spent on services that are supposed to be picked up by the school districts and insurance companies. Medicaid dollars are to be the payer of last resort. She is requesting that FCCF start making this an issue. Everyone agreed the document is good.

Phil shared the FCCF legislative platform with the Consortium. The first item, End the Wait List which includes "We recommend the creation of a strategic plan that will reduce and eliminate the waiting list for services for Floridians with development disabilities" was very well received by Debra Dowds. She shared she would love to work with the Family Care Council to create a strategic plan. Chair Clements indicated that Debra wants FCCF to take the lead and FCCF needs to know the implications there, since they need to remember FCCF is a volunteer group with limited resources. Once she talks to Debra and learns more of her thoughts and understands

FCCF's role it would be time to sit down with her and any other agencies/organizations. Chair Clements complimented and thanked Phil for his efforts.

**FCCF Action Plan Worksheet** – Chair Clements asked everyone to look at the action plan worksheet. She reviewed the worksheet with changes and deletions that were determined by the workgroup the day before. Chair Clements reminded everyone that some area FCC web pages are not up to date. She asked that they be updated. Phil makes a motion to support the FCCF action plan as corrected. Pauline seconds the motion. No further discussion. The motion was approved by consensus.

**Annual Report** - Chair Clements reminded everyone to get their area FCC documents together as the deadline is December 18<sup>th</sup>. Discussion followed, with examples, of the benefits of documenting what your council accomplishes throughout the year.

Chair Clements recognized all of Stephanie's hard work and wonderful support she provides to the FCCF.

## **VI. ADJOURNMENT**

Chair Clements asked if there was any further business to come before the council. Frank makes a motion to adjourn the meeting. Phil seconds the motion. The motion was approved by consensus. Meeting adjourned at 3:15.

The next meeting will be held on January 23, 2010 at The Sheraton Suites.

**RESPECTFULLY SUBMITTED,**

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