

FAMILY CARE COUNCIL FLORIDA
BETTY KAY CLEMENTS, CHAIRPERSON
The Hilton Garden Inn Orlando Airport
Orlando, Florida
March 21st, 2009

MEMBERS PRESENT:

Betty Kay Clements, FCCF Chairperson
Patty Houghland, Past FCCF Chairperson
Lynn Carper, A1 Chair & FCCF Secretary
Frank Carroll, A3 Chair
Maria Quinones, A4 Co-Chair
Beverley DeStories, Suncoast West Region Rep.
Pauline Lipps, Suncoast East Region Chair
Donna Rauber, A7 Chair
Patricia Lurie, A10 Representative
Isabel S de Martinez, A13 Chair
Diane Ciccarelli, A15 Representative

STAFF & GUESTS

Dr. Dave Robinson, Deputy Director of
Operations - APD
Laurie LoRe-Gussak, Executive Director
and David Jones, President -
Florida Disabled Outdoors Assn. (FDOA)

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 to the meeting. She began by reviewing the FCCF information packet contents. Items include the following:

- FCCF March 21st Agenda
- A compact disc with a Letter of Intent template for anyone to use. Everyone should prepare a Letter of Intent for their loved one. If done on the computer it's easy to save and any changes/updates can be done at anytime. It can be shared with other families, as there was no copyright on the form.
- The Advocacy Center for Persons with Disabilities updated brochure and 2009 Public Policy Platform.
- Copy of Florida CHAIN 2009 Legislative Agenda
- Medicaid Advocate Coalition Call Notes – March 13th, 2009. Patty will forward any updates to Betty Kay who will forward on to the FCCF E-list.
- A document containing Informative Web Sites
- FCCF January Minutes
- AARP Public Policy Institute – Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update

Chair Clements asked for introductions and asked that everyone share the area council they represent, any area FCC news, and a little about their loved one who is responsible for their involvement in developmental disabilities.

II. BUSINESS

Governor Appointments Update - Chair Clements advised that the General Counsel is reviewing and comparing the FCC statute with the state constitution. There appears to be some conflict. They will address the issue and prepare a policy. Once Chair Clements receives the policy she will share with the council.

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

Treasurer's Report – Chair Clements called Phil, FCCF Treasurer for an update. He advised that FCCF has enough dollars to date to cover current expenses. No figures available at this time.

III. OLD BUSINESS

AHCA/Delmarva Reviews - Diane shared she learned recently that AHCA picked APD to audit. This is in addition to Delmarva audits. She questions why AHCA is paying to audit providers twice. She suggests when talking to legislators explain this to them and ask that they drop Delmarva reviews. She shared what Delmarva's role was supposed to have been as described in the initial lawsuit many years ago. Its purpose was personal outcome measures. They were to measure the quality of services by asking clients. How it has escalated into this huge contract that includes the monitoring of all providers is unknown. The people currently working on the ITN should be reminded of what the initial lawsuit stated needs to be done, not all that is currently included in the Delmarva contract. This would result in a substantial savings of dollars. Patty advised the Delmarva contract has been extended to December 2009. The ITN has not gone out for the new contract yet. FCCF has their name on the notification list to be notified once the ITN has been released for bid. She understands it will look considerably different.

Diane shared another issue of concern is since AHCA is now doing the monitoring this year the law (409.913) states that when your provider name is drawn for an audit, they lock your funding. If you bill for services you provided during that month, you don't get paid. They can hold the money due you up to 3 months during this audit. This results in a paperwork nightmare because there is no provider agency that has funds to pay employees for 3 months. This results in having to shuffle all those clients into another agency for that period of time so they can continue getting services during the audit. This is jeopardizing agency provider's livelihood by holding their money, plus creating a massive amount of paperwork and inconveniencing the families because services are being changed from one provider to another. Somebody needs to address the statute so money doesn't get held up unless there is a legitimate issue for doing so. It was suggested to contact Pam Kyllonen and ask her who FCCF could contact regarding this issue. Chair Clements asked for a copy of the statute 409.913.

IV. APD UPDATE - Dr. Dave Robinson, Deputy Director of Operations - APD

Chair Clements introduced Dave to the Council. He shared some background information. He is a previous Area One Administrator. His primary goal as Deputy Director of Operations is to revamp and simplify the entire bureaucracy, which includes trying to make sense out of it. He shared that he does accept phone calls and gave the audience his cell phone number. He stressed he is big on accountability. A major management problem within the agency is many things are started but few are finished. He holds people accountable with numbers, data and deadlines.

New Provider Enrollment - Dave shared they have just about completed changes to New provider enrollment process. Data states that when providers fail, it is painful for everyone, especially to the consumers who don't understand the cause of the failure. It's usually a result of money, not following Medicaid procedures, or not ready to be business people. In an effort to try and avoid these type failures, Dave has put a couple of steps in place. One being that people will not be moved through the system until their background screening is complete. Training time and money are spent on prospective providers only to find they have not passed the background screening. They have expanded the training module to give the prospective provider more of an understanding of what they are to do, how they are to conduct themselves and how to

relate to people. They will learn more about continuity, security, well-being and the values of this community. A portion of the training module will also include communicating the difficulties involved with having a person with ability living in the home. They have expanded the curriculum and it will be increasingly difficult to become a licensed provider.

Supported Living Program – Dave advised he plans on a total reform of the supported living program. They don't plan on disrupting where anyone is living. They understand in some circumstances there are 6 or 7 people in a supported living arrangement working with one person. They are looking at simplifying that process.

Dental Services - A high priority right now is dental. They want to improve access and delivery of dental services. This will include a review of Medicaid codes. He shared the agency wants to look at outside community health centers who offer dental services as an option for consumers. They want to encourage people in Tier 4 to consider taking advantage of CDC+ expansion, which would give them access to dental services. Discussion followed with examples of what Medicaid and Med-Waiver are currently covering and not covering. Dave advised this is the whole process they want to straighten out.

Med-Waiver Services - Dave shared APD is looking at providing a flexible benefit program whereby services such as respite, personal care, in-home supports, supported living and supported coaching, if authorized, could be chosen when needed. This is a new and unique program. Once people choose this flexible benefit program they can manage these services without prior authorization. Dave indicated the target date for the program would be October 1st. He has already written proviso language to the legislature directing APD to do this. It would be an optional service.

Dave advised his goal is to put as many options to families that are flexible and personal as possible. He wants to get to a system of truly individualized budgets. Dave was asked if he envisions the retirement of the Tiers in the future. He advised yes, he envisions the Tiers to be replaced by individualized budgets. He shared there are approximately 7,000 appeals between the rebasing and the Tiers. He believes they have heard 50 administrative hearings to date.

Questions submitted prior to meeting –

CDC+ Update – Dave shared that CDC+ is an excellent program for the right family/situation. APD is looking at adding approximately 7,500 consumers to the program over the next 3 years. It is unknown how many people want the program. Dave explained that 42% of consumers are in Tier 4. The average expenditure in Tier 4 is \$8,500 less 8% discount is \$7,500 less administrative fee of 4% equals \$7,000. He stated the mathematical scheme of which the CDC program rests cannot bare putting people in the program who use only a couple of services. They are trying to look at various options. APD is developing a curriculum and a competency-based test for training families interested in the business based CDC program. They plan on drawing a random sample of people to invite to take part in the program next year. Those interested will take part in a training program with much more sophisticated materials than previously used. Dave shared he is currently working on language and in negotiation with JP Morgan, a provider for electronic benefit cards. The charge to use these cards is about \$2.00 per month. These reader cards can be used for billing/paying for services. An example, a parent takes her child to a daycare program where she has an electronic benefit transfer card and the provider has a reader. She places her card in the reader and upon return does the same. A bill will then be paid to the provider for the exact quarter hour time the child was in daycare. Another example is a Home Health Agency PCA/Nurse comes to the family home to provide consumer health care. The employee has a card, the family has the reader. When the employee arrives and leaves he inserts card into the reader and the agency gets paid. Dave believes the two ways possibility of this is tremendous. It's another generation of technology. His hope is that this process will take the place of the current, outdated ABC program. It would eliminate PSA.

Betty Kay asked if there was a powerpoint presentation or any other data regarding this that he could send to her. He advised yes, he would send her some data.

Delmarva – Dave advised that he has written an Invitation to Negotiate that will be released about May 1, 2009. He shared it is much different from current Delmarva contract. Delmarva has been extended until they get a new provider. Dave was asked about the AHCA audits and providers not being paid during the audit process. Dave advised that is called a prepayment review which means that AHCA's computer system has recognized a provider is making more money faster than should be and they freeze funding and request an audit. Diane shared the problems with having to find new providers for the clients and all the excess paperwork involved while funds are frozen. She suggested the policy should be changed to if AHCA finds an issue, then they can freeze the funding. Dave said he would investigate how this is done and get more information. Diane asked why, if AHCA does audits, is APD paying another company (Delmarva) to do the same thing. Dave mentioned the Delmarva contract is paid 25% state and 75% federal dollars. He shared that he is working with Holly Benson, AHCA's director and the review process will be much more cost effective and family oriented. Chair Clements asked about IQC. Dave advised it is still there, just no financing at present time.

QSI - Dave shared APD is about 97% through with administering the QSI's. He believes they have completed about 30,000. There will probably be about 500 or so that won't be done as the consumers cannot be found.

Wait List – Dave advised the legislature wants the wait list to represent who should be served next. This, of course, will be upsetting to the person who has been on the list for 10 years. He advised that starting next week they will begin maintaining 2 wait lists; one by first come, first served, the other by service need. Beginning next week, all adults on the wait list will get a QSI because more than likely they are the most likely to be in a crisis situation. They will do a short form version similar to a telephone survey for them as well. Then APD will do the short form for children. They believe they can bring to the Legislature a more accurate number that represents the people most in need during the coming year. Chair Clements and Patty asked if FCCF could review the QSI survey instrument. Dave advised he would send it to Chair Clements.

Governor's holdback of 15% effect - Dave explained they immediately filed for a release for all the money associated with the waiver and with the institutional funding. They are OK with all of the General Revenue contracts and the waiver. Whatever occurs will be an APD administrative/management problem. This is related to the stimulus package issue. The current federal match is about 50% and increased to 67.4% effective 10/08. They will average that out across the year. This match will last for 9 quarters.

Planned Residential Communities – Dave mentioned the legislation that is currently before the house and senate that would, if passed, allow developers to create planned, gated communities for persons with developmental disabilities by eliminating the current 1000 ft. rule (group homes must be over 1000 ft. from one another). Discussion followed expressing pros and cons of the issue. Some consider this type community institutional for the DD population. Others consider it the same as over 55 or retirement communities. It was expressed, it is a choice that some consumers and families want. APD is neutral on this issue.

APD Organizational Chart - Chair Clements asked if Dave would send her the new APD organizational chart. There are many changes that will take effect on May 1st.

Family Member as Providers - Diane asked about family members not being allowed to be paid to provide PCA and Respite services. She asked Dave if it's a policy and not in the handbook, it needs to be removed. Its discrimination to not allow family members to be paid to provide services when they are the most qualified to provide the service. Dave shared it is a policy and the handbook is kept open for changes all the time. He asked Diane to write up the

issue and E-mail it to him. He was asked if he replies to E-mails. He advised yes and gave his E-mail address, Dave_Robinson@apd.state.fl.us.

Waiver Support Coordinators – Dave advised that Beginning May 1st Waiver Support Coordinators will start to input cost plans in the ABC system.

APD Paperwork Procedures – Dave shared he initiated a paperwork workgroup project that is working on developing a uniform and electronic paperwork system so every file will look the same. This will eliminate a lot of the current unnecessary, duplicated paperwork in existence now. They are also planning on making these files available for families to review. Dave reiterated his support of individualized budgets. He has written the proviso language and it has been presented to Senate Appropriations. Patti asked if he would send us the language. He advised yes.

Chair Clements thanked Dave for traveling to Orlando to meet with the council and providing us with excellent information. The audience agreed with their applause and sharing throughout the presentation their support for all he is trying to accomplish. Dave thanked everyone and shared his appreciation for all the council does and will be glad to come back another time.

V. FLORIDA DISABLED OUTDOORS ASSOCIATION - David Jones, President and Laurie LoRe-Gussak, Executive Director

Chair Clements introduced David and Laurie to the audience. Laurie asked David to share his history and how he started FDOA. Included is a powerpoint presentation. David began by sharing how the association came about as a result of a severe accident he sustained which left him with a severe brain injury, many months in a rehab hospital, another year of outpatient therapy progressing from complete paralysis on one side, loss of speech and vision, confused state of mind, no mobility, and no use of his left arm (which he still has none). He came from a state of being very healthy, young and active to no physical ability and limited mental ability. Through his rehabilitation process he was fortunate in learning about people with disabilities. He learned through being around and working with people with disabilities for the last 20 years that people with disabilities are just people. A lot of people don't understand that. He learned through his years of therapy in the hospital about therapeutic recreation (TR). He found it to be very enjoyable and looked forward to it everyday. He shared about the numerous projects he became involved in during therapeutic recreation and how much he enjoyed interacting with other people with disabilities. He shared more of the barriers of life he had to learn through his years of rehabilitation. His outdoors experiences were so meaningful that it gave him a reason to live. All of this led him to going back to school to get his business/marketing degree. He learned that marketing is really identifying a need of people, finding a solution for that need and matching up the two. This led him to create the vision of an organization that became known as Florida Disabled Outdoors Association (FDOA), a non-profit organization. He shared some background information about FDOA and how it has now grown into an organization that began emphasizing the outdoors but now includes all types of recreation and leisure activities. They took the therapeutic recreation process, self evaluation in a controlled setting by the individual, determining interests, recognizing disability, inability and ability, and build plans to get involved in recreation. Their mission is: **FDOA enriches lives through accessible inclusive recreation and active leisure for all.** Therapeutic Recreation uses treatment, education and recreation services to help people with illnesses, disabilities and other conditions to develop and use their leisure in ways that enhance their health, functional abilities, independence and quality of life. David took the healthcare clinical type setting scenario programs and moved it into a community based setting. They are doing the same things therapists do in hospitals only now in the communities to people of all abilities. Rehabilitation is a lifelong experience. He shared some statistics on Disabilities. Laurie shared that one of the handouts is a brochure titled Recreation Inclusion, a Consumer's Guide. It provides information on your rights and what to expect.

David and Laurie reviewed the benefits of Therapeutic Recreation as part of the powerpoint presentation. Also, any type of active leisure helps people with disabilities. David shared that many, many health conditions can be avoided just by being active. The Therapeutic Recreation process goes through the evaluation of a person's interests, abilities, disabilities and choosing areas of activities the person may be interested in. As presented in their powerpoint presentation, there are numerous possible recreation activities as listed under physical, outdoor, indoor, creative, and social activities. Chair Clements asked David how he got involved in the Miracle League. He shared by attending one in St. Petersburg, he was so impressed he was determined to bring a Miracle League to Tallahassee. He and Laurie shared how members of the community, the city, the Kiwanis Club, and contractors got involved to make his dream a reality. David shared how his involvement with disabled people interested in various different recreation activities led to the creation of an event in 1990 titled Sportsability Expo. They shared a video. Over the years the Sportsability Expo has grown into a popular event attended by many children and adults with disabilities and supported by many organizations/providers within the area. It's a free two day event with one day being indoor sports/activities and the other day being outdoor sports. The upcoming Sportsability Expo 2009 will be in Tallahassee on April 16th through 19th. He invited everyone in the audience to attend and asked them to share the event with other FCC members. They are planning another expo in Ocala on October 2nd and 3rd. Laurie invited anyone interested in being added to their mailing list to give her their contact information. Laurie shared information about some of the different programs they are involved in. She shared they are currently working on developing an accessible recreation database. It will include resources, products, programs, events and destinations in Florida. They brought a variety of products/equipment and explained how they work. They brought with them an all terrain electronic Beachscoot vehicle for people with disabilities, which can be used on the beach, trails, fishing and hunting. Laurie asked if anyone knows of recreation type programs in their area to E-mail her with the information and they will add to their database. Everyone in the audience received a copy of their powerpoint presentation.

Chair Clements thanked David and Laurie for coming to the meeting and providing a very interesting, fun presentation. The audience agreed with their applause.

VI. WORKING GROUP MEETING

Stakeholder Meetings - Patty shared they discussed the strategic plan the stakeholders are working on. The stakeholders developed a concept, which states – People with Developmental Disabilities live self-directed lives in the community. Everything else is driven by this concept. This makes up the long-range plan. Patty mentioned the legislators need to evaluate their policies so that it promotes the above concept. She shared that she, Frank and Betty Kay have been attending the stakeholder meetings.

Advocacy Action Plan – Chair Clements advised the Action Steps for Effectively Advocating with the Florida Legislature was adopted by the working group. She will forward on to Phil who will make some format changes and post on the website.

Area 13 Forum – Isabel shared she made special invitations and sent to each of the legislators in their area. They have received some responses.

FCCF Website - It was discussed the need for each area FCC to keep their webpage updated.

VII. NOMINATION COMMITTEE -

Pauline spoke on behalf of the nomination committee that consists of Patty Houghland, Jean Sherman and Pauline Lipps. The nominating committee contacted each of the present officers and all have agreed to serve a second term if elected to do so. The present officers are:

Betty Kay Clements – Chairperson
Frank Carroll – Vice Chairperson
Lynn Carper – Secretary
Phil Pearson – Treasurer

This is the slate of officers presented by the nominating committee. The vote will take place at the May 16th FCCF meeting. Prior to the election there will be a request from the floor for any additional nominations. Pauline submitted the nominating report to Chair Clements.

VIII. ADJOURNMENT

With no further business to come before the council, Chair Clements adjourned the meeting at 3:15.

The next meeting will be held on May 16th, 2009 at The Holiday Inn Select.

RESPECTFULLY SUBMITTED,

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