

FAMILY CARE COUNCIL FLORIDA

ANN MILLAN, CHAIRPERSON
Hampton Inn – International Airport
Orlando, Florida
March 18th, 2006

MEMBERS PRESENT:

Ann Millan, FCCF Chairperson
Patty Houghland, FCCF Past Vice Chair
Joy Frazier, A1 Chair, Secretary
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast Region 5 Chair
Donna Rauber, A7 Chair
Sheryl Soukup, A8 Chair
Maryellen Jones, A9 Chair
Bob Wessels, A10 Chair, FCCF Vice Chair, Treas
Yolanda Herrera, A11 Representative
Edith Kegel, A12 Chair
Betty Kay Clements, A13 Chair
Pete Wesley, A14 Chair
Todd Decker, A15 Chair

STAFF & GUESTS

Eileen O'Brien, APD Central Office
Stephanie Kahn, APD Central Office
Denise Arnold, APD Central Office
Rhonda Sloan, Suncoast Region Guest
Sara Romine & Mother, Guests
Rosalind Murvin-King, A7 Guest
Kendra Gambles, A7 Guest
Amelia Rauber, A7 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. WELCOME

Chair Millan called the meeting to order. She mentioned the next meeting will be held at the Garden Hilton Inn on Augusta National Drive. She presented the "Walk on the Moon" award to Stephanie Kahn, APD Liaison who has been an incredible support to the council. Chair Millan praised Stephanie for providing the council with information via E-mails and her efficiency with regards to accounting issues. Chair Millan passed around a survey from Central Office requesting information on the working relationship between each council and their area program office. She asked they be filled out and returned to her so that she can send back with Stephanie. Chair Millan reviewed the documents in the information packet received by all in attendance.

II. INTRODUCTIONS & AREA UPDATES

Donna Rauber, Area 7 shared their provider fairs were very successful with a good turnout of consumers and families. The council held their second night meeting this week. Betsy Taylor from Family Network on Disabilities gave a TILES presentation on employment. A consumer was in attendance that is currently looking for employment and the interaction between the two was excellent. She advised no decisions have been made yet with regards to what happens to the council after June with five current members in their sixth year who must step down for a year. So far, no one is coming forward to takeover the chairperson role.

Stephanie Kahn, APD Liaison for FCCFlorida shared the packet of information she provided to all in attendance which included 2nd quarter area expenditures and projections for remainder of fiscal year. She mentioned if there are any questions to let her know.

Maryellen Jones, Area 9 shared her concerns with their council as all of their members will be in their sixth year and have to step down in a year. She shared their council currently doesn't have an APD liaison. She keeps communicating with the area program manager the need to find

new people interested in becoming FCC members. They were supposed to hold an area DD day next week but it was cancelled as they were unable to get the necessary event insurance policy in the amount of \$1 million required by the venue. They are working on obtaining necessary insurance and hope to reschedule the event in April. She is working with Rosalie Archer on creating DVD's of success stories of persons in supported employment and supported living. Her focus audience is parents of adult children ages 22 – 25. Maryellen has found jobs for many of these individuals but because they don't work five days, six hours a day the parents are pulling them out of the jobs and sending them to adult day training programs. She is working with their area coordinator trying to find NRSS programs that will appeal to the parents.

Sheryl Soukup, Area 8 shared their council's nominating committee is choosing a slate of officers for next year. She advised she will not remain as the chairperson but has offered to continue representing Area 8 at FCCFlorida meetings if the new chair wants her to. She attended the area provider fair which was poorly attended by families. They expressed concern to the area administrator that sending a notice of the event out 2 or 3 days prior to was not sufficient notice for families. In the future if they want better attendance they should work on improving this issue and offered FCC's assistance. They are working on their annual conference which is focusing on transition in employment. They have applied for an FDDC grant. They are continuing to work on their satellite groups and have someone to chair one in Collier County. They are sending six individuals to DD Awareness Day.

Pete Wesley, Area 14 shared their mini-café was very successful. They used \$700 of their funding dollars to bring Dr. Jill England from Michigan who gave a wonderful presentation on inclusion. She spoke about what is taking place in her state and surrounding states. They had provider fairs in Lakeland, Bartow and in Highlands County because the area is so spread out. The attendance was about 60 in Bartow and less at other fairs but probably still a good thing. They also participated in a "family fun day" at one of the schools.

Edith Kagle, Area 12 shared she is excited they have someone working on their website. She feels bad because he's doing all this work and it was determined that his membership application has come under the new rule of governor appointment so he has yet to be approved. She is hoping he will receive his letter of appointment soon. She shared they attended a couple of transition fairs, one in Flagler which was not well attended and one in Deland which was very well attended.

Bob Wessels, Area 10 shared they had their first provider fair in February. It was small as they were limited in space due to using the state building. They were only able to invite 20 providers. He thinks approximately 300 people walked through the event that day. The agency in conjunction with Family Care Council has decided to plan provider development days 3 or 4 times a year. They have one planned for April in conjunction with the CQL (Council on Quality and Leadership) symposium at one of the local hotels. Their FCC has partnered with APD to do a provider development workshop on May 23rd. It will consist of 4 components. They plan on inviting people who want to become providers. Also they're inviting existing providers and once they have completed the day's activities, they'll receive a local certification which they can in turn use as a credential when going through the interview process with new potential consumers. The 4 components are: (1) Basic DD Awareness 101; (2) Self Determination; (3) Handling Challenging Behaviors presented by UM CARD; (4) Provider Application Breakout Sessions which include: IP services, non-IP services, Medical/Product/Behavior and Fingerprinting. They have invited SNAC (Special Needs Advisory Council) which is part of the Children's Services Council to become a member. In working with them the goal is to bring together unique and different perspectives, philosophies, values and cultures and to create ventures in development and awareness in Broward County. They believe this will be another asset to the community. They have 13 members and have received a couple of applications waiting for approval.

Beverley DeStories, Suncoast Region shared they have held regular meetings the past 2 months. They had a situation occur whereby an APD employee has suspended operations of the Hillsborough, Sarasota, Manatee and DeSoto Counties Family Care Council which they had no legislative right to do. They have been told they can't have meetings because of lack of membership (they have 4 members), they can't have a quorum, etc. She shared they plan to work through this issue and the Pinellas, Pasco FCC is going to assist in redeveloping the membership and activities for that council. Beverley shared that Ann Millan had been hired by the APD as an OPS employee to develop their wonderful provider fair. It was truly a wonderful event held at a local hotel much like a CAFÉ conference with providers having booths. It was estimated about 1,000 people attended. There were 155 participating providers. Ann created a wonderful newsletter which was sent to all consumers and families giving them plenty of notice about the fair. She passed around copies of the newsletter. Ann developed a program distributed to all consumers/families that listed all the providers that participated, APD facts, helpful information to consumers and families on how to work with providers, some success stories on employment, and a listing of Medicaid Waiver Services. It was a very successful event. Almost every member of their FCC worked at the fair. In the future, all area FCC's will have an opportunity to utilize the knowledge that was gained from their effort. They also did a recruitment effort by providing cards for consumers and families to fill out with their contact information for future mailings, etc. Ann mentioned the council approved hiring an NRSS person who attends their monthly meetings to be their administrator.

Yolanda Herrera, Area 11 shared she is attending for Margarita who has been very disappointed on lack of payment of her travel expenses. Their council activities have been minimal with a lack of scheduled meetings. Margarita has had some personal family health issues which have prevented her from working on FCC. But the work is continuing on by other members. They had their provider fair last week. The area agency personnel came through by taking on all the responsibilities of the planning, etc. The FCC assisted any way they could. They charged \$30 for the provider tables and 50 participated. They had about 112 consumers and families attend. Many group homes brought their residents. She shared how they received most of their monetary assistance from the little providers. The larger providers didn't offer any assistance. The fair proved to be very successful especially for the little providers.

Frank Carroll, Area 3 shared they worked with their area APD office and participated in 2 provider fairs in Gainesville and ? . For their rural area it was well attended and FCC was represented at both meetings. It was a good learning experience for everyone. It gave them the opportunity for families to sign up for more information and possibly get involved in the FCC. They are hoping to recruit some new members. Their first newsletter is scheduled to go out the first of April. They are in the early planning process of developing a forum with a few break out sessions. They have a new applicant anxiously awaiting notification of FCC approval.

Betty Kay Clements, area 13 shared they have been very busy. They have held 2 combination forum/provider fairs which worked out very well. They have one more scheduled. They were very successfully attended and one of the highlights was 2 consumers did programs. Their area APD office worked closely with FCC. They are preparing to do a media blitz to recruit new FCC members. They have a new applicant anxiously awaiting notification of FCC approval. Betty Kay shared that an FCC member is a good friend of a state senator who is very interested in the fair hearing process. She participated in a conference call with the Children's and Family Committee Chair, Senator Campbell and Senator **Argenziano**. As a result of their conversation on the fair hearing process and what families have brought to them as a council and voicing their concerns, she has been invited to appear before the committee on Monday to discuss this issue.

Todd Decker, Area 15 shared he is pleased to announce his area council now has an active and updated set of by-laws. With the help of their area APD they had a provider fair in January at the local community center which was well attended. From his perspective it appeared there

were more providers in attendance than consumers and families. They have decided on how to allocate the remainder of their FCC budget. Most will go to sending consumers/families to Family CAFÉ. He shared that he did an interview with a local TV station as part of a talk show and mentioned the Family Care Council. He plans on creating a FCC powerpoint presentation which he will take to local civic and community groups. This month was his first year as FCC chairperson and he is pleased that the council is becoming more structured. He is very happy with his relationship with their area APD. Some of their councils concerns include the due process hearing, fair representation for consumers, the incontinence supplies issue and a severe lack of dentists that accept Medicaid Waiver. Todd shared that he is now an Uncle. He has begun the business plan writing process for starting his own handicapped services business which will include employment of individuals with disabilities.

Joy Frazier, Area 1 shared they have been actively attending trainings and other events. They participated in 2 provider fairs in Crestview and Pensacola. The area program office seemed very pleased with attendance but from FCC point of view it was very disappointing. The Pensacola fair had about 10 – 12 providers and maybe 20 consumers/families attended. Patty shared the reason for low attendance was the area APD only invited people who were eligible for the IFS dollars. The Crestview fair was even less attended. Joy & Patty have been attending the POM trainings sponsored by the area APD. Joy shared that ARC Gateway was granted a supported employment pilot seminar training which she has been attending. The training participants are Dale Delio and Dave Guido. They are very interested in input from Family Care Councils. She is a team support member on the working group. She and Patty participated in the Exceptional Saturday forum sponsored by the ESE department. Joy is participating in the Disability Mentoring Day and ADA Torch Relay. She shared they are involved in a lot of community activities but are having a difficult time with gaining FCC members. Chair Millan asked the guests to introduce themselves. She passed around the FCC contact information sheet and asked each chair/representative to review, make changes if necessary and check for accuracy of counties listed.

III. PRESENTATION - Sara Romine, Florida Youth Council

Chair Millan introduced Sara. She began her presentation by sharing some highlights and lowlights of her very young life which included the following:

- She spend the first two years of her life in a Romanian orphanage
- Her Mother adopted her at age 2 but developmentally she was about six months and very sick and mal-nourished. Her Mother was successful in bringing her to this country.
- She was diagnosed as being developmentally delayed.
- Her Mother received assistance for Sara from local Developmental Services, became her advocate, participated in Partners and Policymaking and learned about IDEA & inclusion.
- She was told she would never attend regular schools. She and her Mom proved them wrong. Although very frustrating at times, Sara has excelled beyond expectations through kindergarten, middle school and currently in high school. She auditioned and was accepted in her school's musical/theater department. She wants to be an actress. She is a straight A student and very happy.

She decided to apply and was accepted in the Florida Youth Council. She shared with the audience the essay she wrote as part of the application process. She mentioned the FYC is a grant for ground breaking federal assistance change. Florida is one of 3 states involved in the program. The council consists of 15 young people ages 15 to 17 and emerging leaders ages 18 to 30, all with disabilities. Their goal is become better leaders and represent other young people with disabilities. One of their projects is writing a proposal to create a disability history and

awareness week in Florida. They would like for the FCC to help with their efforts. She enjoys attending their area FCC meetings. She is learning through the FYC many advocacy skills which are beneficial throughout the world. She learned the law in Romania had stopped all international adoptions. She wrote a letter to a Romanian newspaper reporter which was included as the feature story. She expressed how much she wanted to change the law. She ended her presentation and received applause and a standing ovation from the audience.

IV. FCCFLORIDA UPDATES

FCCFlorida in Legislation – Bob explained they originally planned to get FCCFlorida in legislation this year. At the same time the agency tried to include the Citizens Support Organization. This created a conflict of interest. The Agency withdrew the CSO language and requested the council not pursue putting FCCFlorida in legislation at this time. At this point both Senate and House bills have been filed. The long term objective of the council should be to get FCCFlorida in legislation. Bob wants to establish a working committee of FCCFlorida members to work on a plan directed towards the legislators. He believes it's an obtainable goal for next fiscal year.

Asset Summit – Chair Millan advised she attended an Asset Summit sponsored by the Florida Developmental Disability Council. It covered the CDC+ and Florida Freedom Initiative. It's working with banks to develop ways that individuals employed or not employed can have assets and not be limited. It was very well attended and included some very good speakers. One of the speakers was with the FDIC (Federal Deposit Insurance Corporation) who shared they have developed computer training modules to teach individuals with disabilities how to manage their monies, design budgets, etc. It has been done in a way that is very basic, even for children. This needs to be recommended to individuals in supported living and employment.

Legislative Committee – Patty attended and represented the FCCFlorida at a Chapter 393 meeting in Tallahassee. Patty shared they spent an extended period of time with the 3 agency attorney's explaining the changes and the reasoning behind each change. What she was unable to learn was exactly what was included in the Senate and House bills and if any recommendations from that meeting which was held on February 20th were included.

IQC – Bob mentioned the next quarterly meeting is scheduled for March 29 – 30 in Tallahassee. He shared the IQC council makeup is supposed to be more consumers/families than AHCA and APD members. They are currently in need of consumers and family members. He and Yolanda have applied to become members. Elections are scheduled for next meeting. The IQC is responsible for providing oversight to contracted professionals (Delmarva) with the primary focus of the interagency group being of quality improvement. Bob believes the IQC has lost sight of its purpose. With more consumer and family involvement it could be re-directed back to where it should be.

Family CAFÉ – Chair Millan shared that Yolanda has been participating in the organizational planning meetings and providing the FCCFlorida with information only. Yolanda shared she participated in a conference call on Thursday. As of Thursday just over 8,000 people have registered. They will be providing financial assistance to about 3500 families. Registration will continue and include on-site registration. CAFÉ is inviting individuals in self-employment to set up exhibit tables at no charge. Chair Millan asked if they would be able to sell their merchandise. Yolanda was not sure but would ask that question. Maryellen shared she will be presenting a Micro-Enterprise workshop at 1:00 on Saturday, June 3rd.

Housing Newsletter – Yolanda shared the ADA working group at one time had a very good agenda for affordable housing. It was recognized at the Aging and Disability conference that many barriers still exist. She is concerned that with the Governor leaving office this will stop because it was one of his initiatives to remove these barriers. She believes the council needs to become more knowledgeable on this issue. She passed around copies of the newsletter. Yolanda

shared the keynote speaker at the Aging and Disability conference was the person in charge of hurricane preparedness. It is a very serious issue. Information developed by her office needs to be received and distributed through each APD area office. Another focus at the conference was aging adults with developmental disabilities who will acquire over time medical issues related to aging. This issue is not being recognized. Guardianship is another important issue discussed at the conference and needs to be addressed, not ignored. The council needs to get involved with obtaining the information and passing it along to consumers and families. Bob shared that each area APD office has an emergency preparedness/disaster staff person. Each council should contact their person and invite them to attend the next FCC meeting.

Workshop on Residential Rule - Patty advised she has reviewed the changes pertaining to the proposed amendments for Administrative Rule 65B-6.001 – 6.014. Most pertains to the licensing of group homes/foster homes, staffing ratios, background checks, etc. Your packet of information includes Florida ARF's comments/concerns. She advised if anyone has an interest in this subject that it is still open for comments.

24/7 Video – Bob shared the council has purchased 2 copies of the video at a cost of \$439.20 in both formats, VHS & DVD. Bob asked Joy to coordinate a list of people interested in borrowing the videos. Donna added the video is scheduled to be shown at the Florida Film Festival in Orlando on Sunday, March 26th at 11:00am. Beverley mentioned the film received an award from the Reno, Nevada Film Festival.

Law Enforcement/Autism Video – Bob mentioned he was unsuccessful in his efforts to get a discount on the purchase price. The cost is \$155.00 which includes the video and handouts. Chair Millan makes a recommendation that the FCCFlorida buy one for each council. She thinks it's important for each area council to see that it's shown to the law enforcement community. It was mentioned that some CARD offices have the video. Sheryl suggested rather than spend FCC money, check with area CARD offices and borrow from them. Discussion followed questioning how successful FCC's would be in approaching local law enforcement for their consideration. It would be better if a contact could be made and request they order their own copy. Chair Millan asked for a show of hands for those who want to purchase the video. Joy made a list. It was decided that Bob would wait 10 days for others to check with their councils before he places an order.

FICD – Patty mentioned a meeting was held the day before. Two additional members have been added to the board, Betty Kay Clements and Edith Kagle. They have selected a logo for their letterhead and received a financial report update.

CDC+ - Rhonda Sloan reported the APD recently held 3 focus groups; (1) Parents with children under 18, (2) Consumers and representatives for participants of CDC+ over 18 and (3) Liaisons and consultants. The purpose of the focus groups was to receive input from the participants on what is working, what is not working for them and share ideas of how to improve the program. The information is being used to develop a survey which will be mailed to every participant on the CDC+ program. Currently there are 987 people in the program. Each will have an opportunity to give their input. Hopefully this will result in some positive changes and in the future be opened to everyone receiving services. Rhonda shared she is the trainer/coordinator for the CDC+ program. She held her first training at the hotel Weds. and Thurs. It went well. They do have some new consultants. There is a real shortage of consultants throughout the state. She will be going around the state helping with developing area peer support groups.

V. BUSINESS

Treasurer's Report – Bob shared with the audience this is the first meeting the council has had a treasurer's report and it's all because of Stephanie's efforts. He mentioned she is doing an excellent job of providing the information requested and if unknown going to the source to get the information. He complimented her and advised all is working very well. Bob introduced

Eileen O'Brien. Bob advised that each chair/representative received in their packet of information a summary of area FCC expenditures to review. If there are any errors please contact Stephanie and copy Eileen and Bob. Also included are 3rd quarter area projections. He indicated it appears that combined there is about \$95,000 unspent dollars for fiscal year. That doesn't include the projections. From the FCCFlorida report they have enough funds to cover the hotel/conference room expenses through May. Taking this into consideration the FCCFlorida has about \$4,100.00 plus whatever any council's would like to transfer to FCCF. Bob advised regarding paying a Secretary to transcribe minutes that Stephanie has structured a purchase order whereby FICD is transcribing the minutes, FICD bills the agency and the agency reimburses FICD. FICD in turn has contracted with Donna to transcribe the minutes.

Review of Minutes – Chair Millan asked if there were any corrections/comments to the January 21st minutes. None were received. Chair Millan asked for a motion to accept the minutes as submitted. **Frank makes a motion to accept the minutes as submitted.** Joy seconds the motion. No discussion. The minutes were approved by consensus.

VI. COMMITTEE REPORTS

Working Group Committee:

End of the year Report – Chair Millan reminded everyone that last year the council developed a year end report which was submitted to the legislators. It provided a listing of activities each area council participated in during the year. She strongly recommends this be done again this year. It provides everyone with an answer to “What is it you do?” She mentioned that on many occasions she has shared this report. Everyone agreed it should be done again this year.

Governor Appointments – Bob advised that no one has been appointed since our last meeting. Part A - A protocol for a procedure to submit applications has been established and submitted to Shelly or Kerry for approval. Part B – Bob has asked Eileen's office for permission to meet with the Governor's Appointment office when in Tallahassee the end of March. Stephanie advised she will be meeting with Nicole on Tuesday and will let Bob know Weds. morning if a meeting has been arranged. Discussion followed emphasizing the frustrations within councils regarding the inability to get applicants approved. Something must be done or we're going to lose more councils.

FCCFlorida Brochures – Chair Millan advised the council will be printing updated FCCFlorida brochures. She will need the contact information of the chairperson or representative each council wants represented in the brochure. She indicated if any area council is in need of brochures to E-mail her.

Chair Millan advised the council would like to purchase a Spider phone for future meetings.

Bob makes a motion the council authorize the APD to purchase a spider phone. Joy seconds the motion. No discussion. The motion was approved by consensus.

Website – Bob shared the website hasn't been updated because it has become time consuming. The working group thinks it's time to upgrade and make it into a first class website. The APD has agreed to link their updated website to the FCCFlorida website. Since FCCFlorida will have some excess funds this year, it has been suggested to hire a professional to work on updating the website. Bob has found a professional who is willing to do this at extremely reduced rates. Some of the features will be very proactive. They have decided to go through FICD who will contract with the person, then FICD submit a purchase order to the APD. The work will be done in phases. The rate charge is \$25.00 per hour. Bob asked for a motion. **Beverley makes a motion to authorize the expenditure for Phase A of the website not to exceed \$2,500.00.** Betty Kay seconds. Chair Millan advised the need to start this soon as it must be completed by June 15th. The motion was approved by consensus. Bob asked for another motion. **Beverley makes a motion for Phase B not to exceed \$2,500.00.** Betty Kay seconds. No discussion. The motion was approved by consensus.

Family CAFÉ Booth – Chair Millan asked who would be willing to take on the responsibility for the CAFÉ exhibit table this year. Rhonda has sent the forms in. Sheryl will check with Lori to see if it has been approved. Joy volunteered to take on this responsibility.

Guardianship Advisory Group – Chair Millan advised that Jean Sherman from the University of Miami has received a grant from FDDC to do several guardianship trainings throughout the state. There are four meetings scheduled, two in Fort Lauderdale and two in Tampa. Betty Kay, Yolanda and Bob will be participating on this project. Betty Kay will represent FCCFlorida.

FAAST – Chair Millan advised that FAAST (Florida Alliance on Assistive Services and Technology) has requested on several occasions they would like an FCCFlorida council member to participate on their advisory committee. Todd expressed interest.

FCCFlorida May meeting – Chair Millan received a letter from the Council on Quality and Leadership (CQL). They are inviting the FCC councils to a training session. She explained that knowing the difficulty in FCC traveling she asked them if they would be willing to do a mini-training at a future FCCFlorida meeting. They were very interested. She believes this is an excellent opportunity for FCC's to learn about this group. The meeting will take place at the Garden Hilton, our May meeting location. 50 people will be invited to attend. Discussion followed to determine if the training session should be on Friday or Saturday. The session is open to all FCC members, not just chairs/representatives that attend regular FCCF meetings. The session will include experimental learning value exercises, discussion presentation of the generic use of personal outcome measures and how to use them in Florida and a presentation on introduction of social capital and community life and how they tie into quality of life. **Chair Millan asks for a motion to confirm the training session be held on Friday, May 19th from 10:00am – 4:00pm. Pete makes the motion.** Beverley seconds. No discussion. The motion was approved by consensus.

September FCCFlorida meeting – Chair Millan reminded everyone that at the last meeting it was discussed to travel to Tallahassee for the September meeting. This would be a great opportunity for FCC chairs/representatives to interact with APD and AHCA staff, tour the APD offices, etc. Sheryl expressed her concerns with the timing as nothing legislatively is taking place in September. She believes if the councils are going to use a substantial portion of FCC funding dollars for this event the time should be used to maximize the educational opportunities. By going when the legislature isn't in session you're missing out on a huge reason why you even go to Tallahassee. Patty commented there are other opportunities for consumers and families to meet their legislators in Tallahassee during session. Examples include, DD Awareness Day and ARC Florida. Her concern is that FCCFlorida has not made an overt offer to become more intertwined with the APD. One problem with combining both in the same weekend would be that it's too much for such a short period of time. September is the time when agency attorneys begin their work on updating Chapter 393. The council could play a role in this process especially with our attempt in legislating FCCFlorida. Discussion followed expressing concern about the financial issues with FCC funding dollars. The priority should be meeting with the legislators rather than APD. It was suggested to hold an APD day for any council members that would be interested but not make it a priority. It was recommended whatever is decided it should be devoted to just FCCFlorida members. Bob emphasized the need for the executive committee to meet with APD in September or October because of Chapter 393 rewrite for next session.

Edith makes a motion for the FCCFlorida executive committee to develop some strategic planning and travel to Tallahassee to meet with APD staff in September. Todd seconds the motion. Frank asked if the executive committee meeting would be separate from the regular FCCFlorida September meeting in Orlando. Chair Millan advised yes. The motion was approved with 2 opposing.

Nominating Committee - Chair Millan advised she received a letter from Edith Kegel, Area 12 FCC chairperson, requesting a motion to amend current by-laws dated March 17th, 2006. Secretary Joy Frazier read the contents:

I propose to amend Article V: Section 1 of the Family Care Council Florida By-Laws to allow for the Chairperson position to be filled by either one individual as Chairperson or two individuals as Co-Chairpersons. In addition, any references to "Chairperson" shall be amended to "Co-Chairpersons" as applicable.

Joy seconds the motion. No Discussion. The motion was approved with 1opposing. Chair Millan asked for a report from the nominating committee. **Betty Kay, chairperson of the committee makes a motion to nominate Bob Wessels, and Patty Houghland, as Co-Chairpersons.** Joy seconds the motion. Chair Millan asked if any other nominations from the floor. There were none. Frank mentioned in the by-laws it states the chairperson speaks for FCCFlorida. He asked with co-chairpersons, who will speak for FCCFlorida. Edith shared that she has no problem with either co-chairpersons speaking for FCCFlorida. Chair Millan shared that she did nothing this past year without Bob and Patty's input. No further discussion. The motion was approved by consensus.

The nominating committee on behalf of Betty Kay makes a motion to nominate Betty Kay Clements as Vice Chairperson. Sheryl seconds the motion. Chair Millan asked if any other nominations from the floor. There were none. Frank mentioned if there are co-chairpersons, shouldn't there be co-vice chairpersons to be trained to take over when co-chair term is over. It was indicated that is not in the by-laws for vice chairperson. No further discussion. The motion was approved by consensus.

The nominating committee has submitted and makes a motion to nominate Bob Wessels as Treasurer. Frank seconds the motion. Chair Millan asked if any other nominations from the floor. There were none. Sheryl thanked Bob for offering to take on 2 officer positions, that's really commitment. No further discussion. The motion was approved by consensus.

The nominating committee has submitted and makes a motion to nominate Joy Frazier as Secretary. Bob seconds the motion. Chair Millan asked if any other nominations from the floor. There were none. No discussion. The motion was approved by consensus.

The new slate of officer's for fiscal year beginning July, 2006 and ending June, 2007 are:

Bob Wessels and Patty Houghland, Co-Chairpersons
Betty Kay Clements, Vice Chairperson
Joy Frazier, Secretary
Bob Wessels, Treasurer

Bob questioned aren't elections to be held in May? Discussion followed including Frank's concern that it appears on many issues if there is one or a few whose viewpoint isn't in agreement with the majority they are just passed over and ignored. There is no room for free and open discussion with the council anymore. Chair Millan offered an example to the contrary. She dismissed the issue at this time.

VII: OLD BUSINESS

No old business to report.

VIII: NEW BUSINESS

Telephone Directory – Edith advised of her concerns that the Agency for Persons with Disabilities (APD) is either not listed or very difficult to find in phone books. She asked if anyone found a listing in their phone books. Betty Kay mentioned it was listed in all their counties phone books under State Government, Persons with Disabilities. Discussion followed that it was listed in some areas under Children and Families, Developmental Services, Program

Office but not APD. It wasn't listed anywhere in Orlando phone books. Others couldn't find a listing either. Edith asked how to resolve this issue so that APD is listed in phone books statewide. Bob expressed this is a serious discrepancy and his recommendation is to appoint a committee to research (a) determine what is the best way for the agency to advertise (b) take the results to the agency advising them of FCCFlorida's recommendation and (c) someone with the agency and/or FCC work with the phone book providers. Chair Millan asked Edith if she would like to chair the committee. Edith said yes but also indicated she believes the agency can fix it themselves because it's their job. Beverley contacted their AA who advised he would contact Central Office regarding this matter. The committee will consist of Edith and Beverley.

IQC – Chair Millan shared that Patty will be attending the March meeting as FCCFlorida representative in Tallahassee. Beverley is currently on the council. Chair Millan mentioned her involvement with the IQC this past year. She has serious concerns regarding how the IQC is being run. She mentioned she wants to write a letter and would like input from anyone. She shared some of her concerns with IQC which include Delmarva issues and the AHCA RFP on incontinence supplies. Yolanda shared her thoughts after attending the last meeting in Miami. Chair Millan understands the IQC purpose is to the quality of what Delmarva provides but somebody needs to be picking up the rest of the quality issues in the state. Patty mentioned to Chair Millan that it's obvious she is compelled to write this letter but suggests that it not come from FCCFlorida (as all may not be in agreement) but from her personally as a member or past member. Chair Millan indicated she would be doing it as an advisory member for the FCC. Bob felt it important that Ann do this.

Booklet for Family CAFÉ – Patty mentioned in previous years we have provided the Celebrate Employment booklets for distribution on the FCCFlorida exhibit table at Family CAFÉ. As we currently don't have anything to distribute this year, the executive committee has talked about creating a resource booklet for consumers and families. She is asking FCCFlorida to consider taking on this project. It will be based on availability of funds. The intent would be to have the booklet available for distribution at Family CAFÉ. They want to start by using the articles that appeared in the Suncoast Region Newsletter and Provider Fair Program. They are: Consumer, Family, and Provider Relationships (Respect, Team Work, Collaboration), Code of Conduct, Interviewing for APD Provider Services, and information pertaining to the Wait List and how to find the consumer wait list number. Patty advised they are looking at other items to include in the booklet. She asked if the council should move forward with it. **Edith makes a motion that the executive committee move forward with developing the booklet.** Pete seconds the motion. Sheryl asked if people have suggestions for items to be included in the booklet to notify Ann. Chair Millan indicated her desire to include some success stories on NRSS program, etc. No further discussion. The motion was approved by consensus. Pete shared that she has a page of acronyms with no idea what they stand for. She is certain that many consumers and families are unaware of these. Chair Millan thought it a great idea to include acronyms in the booklet. Bob added it would be great for the website also.

Chair Millan asked if any other new business. Yolanda shared their consumer directed care support group is requesting information on Medicaid Reform. If anyone has any information to share please let her know.

Rhonda asked that area Family Care Councils please encourage the consumers and families on CDC+ to fill out the survey being sent to them. She reminded the APD is open for suggestions for improvement.

IX. CONFERENCE CALL - John Hall, ARC Florida

Chair Millan mentioned that included in each information packet is a document titled: "ARC/Florida Concerns with SB 2012 and Proposed changes to Chapters 393 and 39 are not in the best interest of people with disabilities." John advised that on Monday, March 20th, the

Senate Committee on Children and Families will be meeting regarding Senate Bill 2012 and propose a committee substitute for that bill. The House bill has not been introduced yet. Representative Galvano will be sponsoring that bill known as HB1503. John shared that Rep. Galvano invited a number of stakeholders to meet with him last week. He reviewed the issues listed on the handout, provided comments and ARC Florida's recommendations. The issues include: Family Court Jurisdiction, Service Definitions, Epilepsy deleted, Client Representation, Inability to pay protection, Restricted access and Certification programs. All are changes the APD is recommending under Chapter 393 and 39. John indicated the latest information regarding the Autism definition issue is the Agency is removing the proposed change. Budget Issues – John advised the Senate version includes the Governor's recommendation to provide a cost of living adjustment to Support Coordinators. Unlike the Governor, the Senate version also recommends a 3% cost of living adjustment for all other services under the waiver. He asked families to support this recommendation with their legislators. John also advised the Senate version did not pick up the Governor's recommendation for additional funding dollars for removing people from the wait list and crisis list. Chair Millan asked John about the consumable medical supply issue. John suggested the FCC's research the RFP and write a letter voicing family concerns with examples. Chair Millan mentioned the main problem is it appears the bid could go to one provider which eliminates choice. John mentioned he would offer ARC Florida's support. He thanked Ann and FCC chairs for their help and keeping him informed.

X. APD UPDATE - Denise Arnold

Wait List – Chair Millan asked Bob to share his frustrations with trying to determine the actual number of persons on the wait list. He reviewed the total numbers from various sources between July, 2005 and March, 2006, all of which were different. The one number that really stood out came from the ABC & Wait list dated February, 2006 totally 16,781. He determined the reason the number was so much higher than the others was because it includes the individuals on the FSL waiver who are still considered on the HCBS waiver wait list. He expressed a real need for the numbers to be separated so that an actual wait list number can be determined. Bob shared the number does increase by about 250 each month statewide. He received some statistical information to back up the wait list numbers prior to leaving for Orlando and will forward on to all chairs. Bob then took the March 1, 2006 total of 11,395 and broke it down by disability category. The majority are in the 22-44 year age group. As of March 1, 2006, the total number of people enrolled on the HCBS waiver is 25,423 and the FSL waiver is 5,635 and CDC+ is 987. Discussion followed expressing a real need to determine an actual wait list number, who has been contacted and declined, who has been contacted and currently not eligible, who can't be found and who has yet to be contacted. Also, some type of educational/training process be developed for persons who have declined services or are considering declining because they are unaware of what's available or what they're eligible for. Denise reviewed the current process used to contact people on the wait list. It was suggested that APD area staff follow up with a phone call a week after the initial call to determine if they have reconsidered their decision. Also the initial contact process needs to be Spanish friendly. In summary, it was suggested the agency look into improving the initial contact process with consumers/families on the wait list. Denise was asked if the declines are kept separate with the reason for decline. She advised yes, there is a separate report. Chair Millan asked Bob to keep the chairs updated monthly on the wait list statistics.

Chair Millan welcomed Denise to the meeting. Chair Millan asked all in attendance to introduce themselves. Denise provided everyone with a packet of information that includes a DD Awareness Day flyer, APD legislative priorities and bill tracking chart, Provider Development Plan, Best Practices Around the State, APD Provider Development Plan, Waiver Enrollment

Data, Individual & Family Support Service Budget Protocol, Announcement of New Family-to-Family Grant, Memo from Kerry Schoolfield regarding Handbook Clarification on Relatives as providers, Florida Initiative Freedom Update, Medicaid Infrastructure Grant Update, Uniform Practice Reviews and Employment Initiative Update.

IFS Service Budget – Denise shared IFS handout includes a chart showing 3,774 people offered services, 980 still to process, 1924 have accepted and should be in the process of getting some services. This is just the people being offered the one time GR dollars. Also included is a chart showing the number of remaining individuals per area as of July 1st, 2005 on the wait list. Each area office has the flexibility based on the needs in the area and how much money the area has left to spend after finishing the one time offers and after taking care of any emergency needs. The remaining list of individuals can be contacted if the area determines they have the time and money left in their budget to offer more services. It's a matter of spend but don't overspend. Chair Millan asked if we know of somebody on the list prior to July 1 who hasn't been contacted can we suggest they call the area office. Denise advised yes, please do. Anyone on the wait list as of July 1, 2005 who hasn't received a letter or is in emergency need should contact their area office.

Sheryl commented that it would be wonderful if each AA or area Liaison could provide FCC's with the type of information Denise brought with her today. It's exactly what FCC's would like to see at each monthly meeting. Denise indicated at the next leadership meeting she would share with the AA's the information packet and suggest they share this type of information with area FCC's.

Legislative Issues – Denise mentioned her concerns regarding items in the Governor's budget recommendations that have not been picked up in SB 2012. She realizes, however, that it's very early so changes will occur in the next few months. She expressed how important it is for families and advocates to contact their Senator's and share with them the need to include these items in their bill. The issues include no new money for wait list, crisis, utilization increase for medically necessary services and updating ABC computer technology. Discussion followed regarding the increase for support coordinators. Also, the de-certification process for providers which includes SC's. Denise advised the agency has improved that process. She indicated the importance of families to share any concerns with providers/SC's with their local area office. She shared the process that takes place with a bad Delmarva review of a provider/sc. She advised the area office can terminate a provider/sc within 30 days without any notice. That is how the Medicaid system is set up. Chair Millan asked Denise for a list of providers and support coordinators that have been terminated. Donna expressed her concerns regarding companion services being abused by some providers. Denise suggested these type concerns should be directed to area office staff.

Chair Millan asked what is the status of the Medicaid Waiver Handbook? Denise mentioned they are working internally to identify some changes. She asked for input from families on any changes they would like to see. There is no official process at this time. She added that Linda Mabile is the lead on this workgroup. Chair Millan also inquired about the Florida Supported Living Handbook. Denise advised they are open for suggestions on changes for that handbook also. Chair Millan asked everyone to share with their councils the agency is excepting input from families at this time.

Denise advised there is a rate rule hearing on Monday, March 20th and wondered if anyone knew about it. No one knew of it. She mentioned that previously the rates for both waivers were part of the coverage and limitation handbook. When it was challenged and they went to court it was agreed they would be pulled out and made their own rule. A public hearing was requested and it will focus on the actual rates effective November, 2003. Chair Millan asked if written comments are allowed and if so until what date. Denise would check on this and forward to Chair Millan. Sheryl voiced her concerns with the lack of rate increases for skilled nurses and others affiliated

with the Medicaid State Plan. She shared the consumer medical supplies issue is another very important service provided by Medicaid State Plan and families had no opportunity for input. How can families obtain information on the Medicaid side vs. Medicaid Waiver? Denise advised she didn't know what Medicaid's structure was on that. Frank suggested inviting someone from Medicaid to a future FCCFlorida meeting. Chair Millan advised she has invited Beth Kidder from AHCA to the May meeting. Sheryl asked Denise if she could find out the Medicaid State Plan process for any family input. Are there any councils or workgroups sponsored by Medicaid that consumers can participate in? Denise indicated she didn't know of any but would check on it.

Yellow Notebook – Chair Millan asked the latest on the yellow notebook. Denise gave one to Chair Millan. The note from Melinda indicated she is shipping 10 to each FCC chairperson for distribution to their members. Donna asked how the books are to be distributed. Denise advised they will be mailed directly to the area offices for distribution by support coordinators. Also some will be sent to the DSI's.

Support Plan – Chair Millan mentioned there are definite issues and concerns about the support plan. Sheryl is working on one piece of it. Chair Millan advised they hope to get with Linda Mabile the first of the week to share their issues and concerns. Denise asked to be copied on whatever is given to Linda. Patty asked if there are plans to pilot the support plan using actual consumers. Denise advised yes, it will be piloted in area 2 she believes the first 2 weeks of April using Janice Phillips group of SC's. The piloting will be of the person centered planning training and how to use the check list. Chair Millan asked if someone from FCCFlorida could go to Tallahassee and participate in the training. Denise advised yes.

65B-6 Licensure Rule – Chair Millan asked Denise to explain. She advised it's their licensure rule that governs how they license group homes. There were some workshops offered throughout the state on this rule and some additional ones to be scheduled. The purpose is to tighten some of the requirements on how they license facilities. It is currently a very old rule that needs updated. Chair Millan voiced her concerns regarding our consumers being admitted to ALF's where there are no rules governing the DD population. Discussion followed regarding group home providers who are terminating residents with 30 days notice who are aging and taking on other medical issues or becoming more difficult to handle. The person has no where to go but an ALF or nursing home. There needs to be some safety net for these individuals.

Family to Family Grant – Chair Millan asked Denise what counties will be included in the PSI grant. Denise was not sure but indicated she could find out. Bob asked if Family Care Councils have any buy-in on this project. Chair Millan mentioned FCC's need to be represented on this committee and involved in the project. Denise suggested that Marjorie Swindell could schedule a conference call with FCCFlorida reps. to provide more specific information. She would see what could be done to get FCC's more involved.

Provider Fairs – Chair Millan asked if Denise would like to hear from the chairs/representatives about the provider fairs in their areas. Denise advised yes she was very interested. Each shared their experiences, provided numbers of providers/attendees, what went well and what needs improvement.

Provider Development Plan – Sheryl mentioned the day before they discussed how cumbersome the application packet is for providers. It was suggested that it would be very helpful if someone in each area office could be hired or designated staff assigned to specifically walk a potential provider through the application process. The recruitment process needs to become more user friendly as currently some providers become frustrated with the application and decide not to continue with the process. Also, it was learned the screening for fingerprints is being done electronically now. She suggested that maybe some way the agency in Tallahassee could get together with other agencies and see if there is some way to prevent multiple fingerprinting. Each agency seems to charge a different rate for fingerprinting. Denise

indicated good suggestions although some of this is AHCA's rules but maybe it's time to review the process with them again.

Denise indicated at some time in the near future that Central Office needs to inform the FCC's about the CDC+ transition. Also, she indicated they are making some changes to the Individual Cost Guidelines (ICG) to make it more of a needs assessment tool. They don't use it for the resource allocation it was initially designed for and they couldn't use it now if they wanted to because it was never validated. The new design's focus is on what level of support is needed regardless of who provides the support.

Chair Millan thanked Denise for attending the meeting and providing those in attendance with excellent information and assistance.

XI. ADJOURNMENT

Chair Millan asked that everyone submit their evaluation forms. With no further business to come before the council, she asked for a motion to adjourn the meeting at 4:05. **Todd makes a motion to adjourn.** Betty Kay seconds the motion. The motion was approved by consensus.

RESPECTFULLY SUBMITTED,

FICD

Florida Institute on Community and Disability