

FAMILY CARE COUNCIL FLORIDA

PATTY HOUGHLAND, CHAIRPERSON

Holiday Inn Select Orlando Airport

Orlando, Florida

September 15th, 2007

MEMBERS PRESENT:

Patty Houghland, FCCF Chairperson
Joy Frazier, FCCF Secretary
Ann Millan, Past FCCF Chairperson
Lynn Carper, A1 Chair
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast Region Chair
Donna Rauber, A7 Co-Chair
Michelle Passidomo, A8 Representative
Belkis Almeida, A10 Co-Chair
Phil Pearson, A12 Chair
Betty Kay Clements, A13 Chair, FCCF Vice Chair
Pete Wesley, A14 Representative
Todd Decker, A15 Chair

STAFF & GUESTS

Stephanie Khan, APD Central Office
Brad Hunt, FASC
Kathy Burton, Department of Education
Sandy Carpenter, Suncoast Region Guest
Chris Dugan, Area 7 Guest
Nicole Coratti, Area 8 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 Houghland welcomed everyone to the FCCFlorida meeting and asked for introductions. She began the meeting by reviewing the FCCF information packet. Items include the following:

- FCCF Agenda
- FCC Schedule of Expenditures – 9/12/07
- Medicaid Rule Making Process
- Website address for Pennsylvania Waiting List Campaign
- Flyer announcing FASC Annual Conference – Oct. 17 – 19, 2007
- The Family CAFÉ Planning Committee Summary – provided by Maria Eash representing Family Care Councils
- 2007 Case for Inclusion Report, a ranking of all states on how well they are providing community-based supports to individuals with developmental disabilities being served by Medicaid. The entire report can be found at <http://www.ucp.org/medicaid>.
- Article titled “Advocates for disabled Floridians will be lost” from Daytona Beach News Journal
- Article titled “State Money woes to continue, panel told” from the Florida Times-Union – It provides general information on the financial woes of Florida.
- A Fact Sheet from FASC regarding the Waiver Support Coordination issue
- A map of Florida Counties
- A list of Family Care Council Chairperson with contact information

II. WORKGROUP REPORTS

Overview of FCC Orientation Manual – Ann Millan

Chair Houghland advised a copy of the manual is in the dark blue folder provided by APD. She thanked Ann for all her efforts in revising/updating the manual. She thanked Stephanie for her efforts in working with Central Office representatives to see that the manual got through the

legal process and approved. Ann also thanked Stephanie. Stephanie shared that Ann received some great compliments from legal dept. Ann asked that one thing to think about when reviewing the manual is her concern regarding the FCC liaison giving the training. She is afraid it won't get the support it needs to families. She would like people to consider offering a one day workshop on a Saturday. There is a lot of valuable information in the manual which if reviewed extensively will reveal how much power Family Care Councils have. By doing piece meal or having people take home to read won't serve its purpose. Ann made reference to Jane's cover letter where she states "a good FCC is made up of more than board members. We encourage everyone's involvement". There is a lot of information in the manual pertaining to establishing committees that anyone can participate on including APD staff.

Ann provided the following highlights in the manual:

- FCC Guidelines (page 7) provides an interpretation of the law. It is broken down by Florida Statute number (Law) on left side and APD interpretation on the right (Action). She made reference to several of the action items. Ann emphasized these guidelines are probably the most important section in the manual. Trainings are to be completed within 90 days from today's date. Betty Kay mentioned that she and Area 13 FCC Liaison worked together on training their council members. **They used an old power point presentation.** She shared it went very well doing it that way.
- FCC Guidelines, Page 10 (Meetings): **"All expenditures should have prior approval by a vote of the FCC members."** Ann recommended for clarification each FCC add to their bylaws **"The chairperson has authority to approved budgeted expenditures."** This way, a vote is not required for unexpected expenses between meetings.
- FCC Guidelines, Page 10 (Meetings), within last bullet Ann referenced "Notification of meetings should be provided to all individuals with developmental disabilities, their family members, and legal guardians". Each council must have a mechanism of how they are going to advertise their meetings.
- FCC Guidelines, Page 10 (Assist in providing information and outreach to families); within last bullet Ann referenced "Make sure information provided is the information needed, accurate, and understandable".
- FCC Guidelines, Page 11 (New Councils), within last bullet Ann referenced "A dissolved council may be reinstated with **4** members appointed by the Governor". That can include members in the process of reinstatement.
- FCC Guidelines, Page 12 (Respite and family care subsidy expenditures; funding) Betty Kay asked Stephanie to please get a clarification of what this means. Many questions have been asked in the past. It's part of the law and yet nobody can explain what it is. Stephanie was asked to get the clarification in writing.
- Family Care Council Legal Responsibilities, Page 13 – Ann made reference to the HIPPA Regulations – all council members are to participate in their area program office HIPPA training. It's important they attend at least one session.
- Family Care Council Legal Responsibilities, Page 14 – Ann referenced the need to understand the Vendor Registration procedure.
- FCC Legal Documents, Page 16 (Minutes) – Ann referenced the need for minutes to be promptly recorded and open to public inspection. According to Roberts Rules of Order, the minutes only need to include attendees, motions, all budget decisions, appointments, committee reports. Ann shared it's more important the minutes get published of what the actions were rather than what was said.
- FCC Legal Documents, Page 16 (Budget) – Ann referenced the fact that each council's budget consists of **tentative** expenditures. "Bylaws may state that the FCC chairperson has the authority to approve spending in the approved budget, even if it was a draft". This should be added to all councils bylaws.

- Financial Responsibility and Reimbursement, Page 22 – Ann referenced the valuable knowledge that can be gained by attending conferences. This being a good source for use of FCC funding dollars. The manual states that “Committee members and affiliate members can also access these funds to further their education for the benefit of the area FCC”. If the area administrator states that a person can’t access these dollars to attend a conference because they aren’t a FCC member, which is not true.
- Individual Best Practices, Page 22 – Ann and Chair Houghland both emphasized the following: “When making comments of ANY kind be sure to clarify you are speaking as “the parent of ____.” Do NOT speak on behalf of your Family Care Council unless the subject has been approved by the board and is in the meetings minutes”. Chair Houghland stressed that a member can attend council meetings, etc. but if it isn’t what the council voted on and this is what they believe as a council then it can’t be signed as Family Care Council. Beverley shared it’s very important to communicate with the chairperson what is at issue so they aren’t blindsided. The chairperson can then determine if the issue should be taken to the council for a vote or it remains the individual’s point of view. If the latter, it must be stressed to that person to speak or sign on his/her behalf not the FCC.

Ann shared the Orientation Manual is on the FCCFlorida website. Chair Houghland mentioned the area program office should help with printing the manual for members. Trainings must be done within 90 days. Ann mentioned the manual also states that the area administrator should help the councils find members. Donna mentioned the previous manual had been done in powerpoint for FCC orientation training. She wondered if that would be done with this manual. Chair Houghland and Ann indicated they would check into it.

Direct Staff Support Certification - Frank Carroll

Chair Houghland asked Frank to be the FCCCF representative on this planning committee. She asked him to update the council on what has taken place to date. Frank mentioned the meetings are being done via teleconference calls. He shared it’s the National Association of Direct Care Staff and what is taking place within the planning committee is whether the state of Florida wants to participate. They are in the preliminary stages of trying to decide what constitutes a group, what constitutes membership in the Florida group, etc. Participating on the conference calls are Agency Providers, Support Coordinators and FCCCF. The purpose of the organization is to offer a direct care staff certification process. It is a web-based training offered by an on-line college. It’s a way of providing credibility to direct care staff employees. It provides that population with a network and a status symbol with certification. Frank mentioned he was most impressed with the training process. It is quite extensive, well documented and requires a lot of testing from the student before he/she can be certified. It’s been noted that people who have participated in this training process are more knowledgeable about how to care for individuals which has resulted in a better quality of work from staff and a lower turnover rate. Michelle asked what service providers fall into this category. Frank and Chair Houghland shared any provider of direct care services; PCA, In-home supports, respite, behavioral analyst, supported living coach, etc. Patty shared she would send out a link to the website via E-mail to everyone.

CDC+ Update:

Chair Houghland shared that Tammy Smith, CDC+ program Administrator is leaving. Sherry Jackson will be acting PA beginning September 20th. Chair Houghland contacted AHCA for an update on CDC+ program. They are working on the J Option which is supposed to be the same as the current program. Beverley asked for an explanation. Chair Houghland advised that AHCA is not putting the CDC program into the 1115 demonstration waiver. It will be put into what Medicaid Feds. are more inclined to approve as a J Option to the Medicaid program. AHCA has sent a draft for the J Option to the Federal Medicaid program for feedback. AHCA is looking at reviewing the Operational Procedures Guidelines. Chair Houghland asked if FCCCF could review it. The AHCA representative indicated she would make that suggestion.

APD 2007 Strategic Planning:

Ann and Betty Kay attended a day long symposium in Area 14. They were both very impressed with the event. Ann shared that Betty Kay did an incredible job doing the FCC presentation. Ann mentioned in the APD packet is a draft copy of the APD 2007 Strategic Planning. She made reference to the APD Vision statement on page 2. Her concern is with using the words “national leader” in the statement. Discussion followed, pros and cons, to the use of the words. Chair Houghland indicated that it appears at this time the council cannot come to a consensus on this issue.

Rules for teleconference call with Jane: Betty Kay shared that Jane has questions that have already been submitted to her. Each area representative at the table will have an opportunity to ask her a question. There will be a sergeant-at-arms. Each person will be allowed 3 minutes for question (be specific and to the point) and answer. There will be no interrupting.

III. APD UPDATE – Teleconference Call with Jane Johnson, APD Director

Chair Houghland greeted Jane and shared with her that those in attendance consisted of area council representatives, Brad Hunt from FASC, and 3 FCC guests. She advised that Betty Kay would be leading the call from the council’s side. Jane began by answering the questions submitted to her.

Assessment Tool: When will it be implemented? Which group of individuals and how soon? Who will do the assessment? Jane advised their staff is currently working on developing the assessment tool and integrating into a web-based format. It will be an electronic tool and will be a combination of the SIS (Supports Intensity Scale) with elements of the FSTS integrated into it. They will begin testing it in October and the plan is to assess the individuals living in the Res-hab settings first. They are hoping that the Governor’s recommendation to allow APD to hire 75 state employees will be approved by the legislators. They will be trained to conduct the assessments on a full time basis.

Is it necessary to hire 75 employees? Would it not be better to have OPS positions? Jane advised they could do OPS. That would be a budget decision that they could be flexible on but they would prefer to hire fulltime employees. She is concerned that many current employees have been on staff for many years and within the next 5 to 10 years they will be losing very knowledgeable staff. One of the priorities for the agency is to begin training younger and newer employees so they aren’t left with a skeletal crew in 5 to 10 years.

What is included in doing the cost plan which is part of the assessment process and the responsibility of the person doing the assessment? Once the assessment is completed and the budget established the APD staff will review the existing support plan, for people already on the waiver, to determine their service needs using the budget established based on the results of the assessment. For most people they don’t anticipate a need for the PSA (prior service authorization) process. Cost plans will be updated annually but if there are any life changes or medical need, the support coordinator can ask for an update.

Personal Care Assistance: AHCA is to provide under state plan Medicaid for children, however, we all know the reimbursement rate is the barrier for AHCA. What is being done to correct this issue? Jane advised they know that AHCA’s rate of \$9.70 an hour is not competitive and they do not have a provider base available to pick up the PCA services for the individuals under 21 that would transition off the Med-Waiver onto the State Plan. Jane advised this is a personal priority of hers as she would like to see the state become compliant with requirements under EPSDT. That would mean AHCA would have to get competitive provider rates and have a meaningful service delivery system under EPSDT which is the Medicaid program for children under 21. She is working with the Governor’s office and AHCA to develop a plan. She does not anticipate this would happen within the next six months. She believes it’s a systems change

issue where the state historically has not adequately offered services to kids under 21 through state plan. She thinks this is one of the contributing factors that has created the APD deficit. APD is picking up services for agencies that should be covering it. They understand the limitations that AHCA has now and they are not planning to push people onto state plan until they know that there are services available for them. She is asking the FCC and DD Council to help APD advocate for this. She explained the difference between the Medicaid Waiver which is by definition a limited discretionary program as compared to the Medicaid State Plan which is considered an entitlement. Example: Under the waiver PCA hours can be limited to 6 hours per day or 180 hours a month. Under state plan a person is entitled to the services that they need as long as they're medically necessary. Therefore if someone needed 12 hours PCA per day and it was medically necessary under EPSDT, the state couldn't deny it.

Wait List: What is the latest enrollment date of someone given services from the wait list? Jane advised they haven't had any enrollment of people off the wait list, except people in crisis, since June, 2006. Individuals enrolled from the 2005/2006 waitlist enrollment had a waitlist date of 2003 or before.

FCC Appointments: What is the status of the applications submitted by area 12 for FCC membership? Since the last FCCF meeting there have been 14 appointments (4 in Area 4, 3 in Area 8 and 6 in Suncoast Region East). There are currently 21 pending FCC applications. Jane commented on what a great job Stephanie has done keeping up with these applications.

APD Vision: Do you have any plans to work on a vision for the DD population? Jane mentioned they have recently conducted a strategic planning and visioning exercise with all of the area administrators. A copy is in the APD folder. They are in the process of trying to vision where they want to be and if they didn't have a deficit where would they be and how would they be serving people. She advised that is a very important priority for them. She shared that when she first came to the agency that was something the staff begged her for because they felt the agency lacked a vision. They have engaged a facilitator and have a draft they're still working on. They are very excited to at least have a blueprint for the next five years.

CDC+: How and when will a replacement for Tammy Smith be selected? Jane advised they have an interview scheduled with someone next week. They are advertising the position and hope to hire someone ASAP. In the meantime, Denise Arnold is overseeing and monitoring the program. She shared the transfer to the new fiscal intermediary did not go smoothly. They have had many problems the past few weeks with providers not getting paid. She offered her apologies. It's difficult when you contract with outside providers and they "drop the ball". She emphasized they still have just as much of a commitment to the CDC+ program. It is a very successful program in the sense that families really like it. They do want to expand it in the future but obviously they can't until the infrastructure is reliable.

Personal Care Assistance: Betty Kay asked Jane if she had a conversation with Senator Nan Rich in which she gave approval for someone to receive 300 PCA hours. Jane advised no she has not had any conversations with Senator Rich regarding adults getting 300 PCA hours. She has not approved any services for anyone. She has completely removed herself from that process. She would never have made a "deal" for certain people to receive services.

APD Area Offices: Why does the local APD office draw such a boundary between folks on the Medicaid Waiver and the folks on the wait list? It is like they don't want any contact with the families on the wait list. Since APD is the Agency for Persons with Disabilities they should be helping everyone, including those on the waitlist. Maybe they can't provide funding but they should at least provide some form of counseling so that it doesn't feel so hopeless for these individuals and their families. Jane shared she agrees with whoever made the statement. She personally has heard from very few people on the wait list but from a lot of people receiving services. She emphasized that at least since she has been at the agency the main focus has been the waiver. She mentioned it does concern her because she doesn't want to lose sight of the vision for the future. She did agree they can do a better job of providing some counseling and

referring people to other local programs & services. She will take this very seriously and try to work with the staff to see if they can do a better job.

PCA Reduction of Hours: Donna asked regarding the reduction of hours from 300 to 180, what constitutes a substantial change in circumstances? Jane advised they don't have the definition written yet. Since this was the subject of a lawsuit, they must be very careful on the wording and their attorneys are working on that now. Examples would be:

- If someone graduated from school, turned 22, and was no longer receiving services,
- If someone's parent or caregiver passed away or became incapacitated,
- If someone moved from a family home into supported living or a group home.

Jane stated the actual definition it must be legally defensible and clear enough to understand that it won't open itself up to all kinds of challenges.

Agency Budget Cuts: Beverley asked what other advisory councils or boards are taking the 4% budgetary cuts besides the Family Care Council? Jane advised she didn't know the agency was cutting the FCC budget. Betty Kay mentioned in area 13 they have been advised by Central Office that FCC will be taking a 4% cut. It just hasn't been administered yet. Jane said she would check with Terri McGarrity. She mentioned they're taking the 4% cut from other areas such as supplies, travel, etc. She said it doesn't make sense to her because the agency needs the FCC's now more than ever to help with getting information out to the families. Ann mentioned to Jane that Margarita Montalvo from Area 11 is not at the meeting today because her FCC liaison could not get the travel approved and it's not the first time she has missed FCCF meetings for that same reason.

Noah's Ark Housing Alternative - Ann shared she went to Noah's Ark on her way to Orlando yesterday to visit Noah's Nest, a group of rental homes developed for individuals with developmental disabilities. She expressed to Jane how very impressed she was with this housing alternative for our DD population. She shared how a church made this their mission and the parishioners completely refurbished these homes. Jack Kosik has been creative in finding money so these homes are no cost for individuals. They can afford to live in the homes and pay rent. But yet they can't get services from APD. Ann emphasized this is an excellent example of a community coming together and trying to help the needs of our individuals. She asks for Jane to take a stand on this issue. Jane shared she appreciates that and has met with Jack. She agrees they are doing some phenomenal things but this is one of those really tough issues. It strikes up the all inclusion debate because in the minds of some of her staff and a lot of vocal advocates, that is not inclusive living because it's people with developmental disabilities living together and people from the community can't live there. She advised the current rules disallow supported living services if living in a setting where there is a predominance of people with developmental disabilities. She thinks it's a great model of using public/private partnerships with lesser reliance on state government (on the waiver). Ann emphasized this is different from group homes, it's literally a house set in a city, in a community within walking distance of all daily needs. Jane advised the supported living rules require a person has to either own the home or have their name on a lease so they can control where they live. She reminded everyone of the inclusion advocates who feel that no one else should be able to control where a person lives if it's truly supported living. She did share that she hopes to work something out with Jack because she realizes he is doing some great things and is truly committed. She did mention the agency can't afford to take that stand as if they can afford to let everyone live in their own homes (with 24 hour supports) because they can't. This is a more affordable alternative, it's not fully independent but it is much more affordable. This is the kind of flexibility they need to embrace so they can be spending less than they are spending now.

Tiered Waivers – Todd asked if the legislators have talked about any alternatives to the tiered system that's currently being considered. Jane advised that several legislators have agreed to consider eliminating the tiered requirements. APD would be very supportive of that. APD will be advocating with the legislators that they can be responsible with the money and they can

achieve the same goal of predictability of costs without the tiers though accurate assessments and established cost plans that don't get changed for 12 months. She doesn't believe there would be an alternative, they would just eliminate that requirement. The applications for the 2 new waivers have been submitted to CMS. Because it was mandated by law, AHCA had to submit the applications. She thinks there will be time between now and the spring session to prove to the legislature they don't need the tiers.

Waiver Support Coordinators: - Belkis mentioned to Jane that their FCC held a meeting yesterday and the main concern was the increase of consumers to 1:50 was too high for support coordinators to take on, especially with limited support coordination being basically 2 for 1. That could lead to a total of 100 consumers. How was the number determined and what exactly will their duties be? Jane advised their duties would remain the same except they would not do the assessment or develop the cost plan. As a result they would have fewer responsibilities on the "front end". Any ongoing changes that would require an additional assessment would be done by APD staff. Working with the families and the advocacy role will remain the same. Belkis mentioned it needs to be taken into consideration Florida's waiver offers 33 different services which is much more than other states offer resulting in much less of an SC role for them. Jane advised they are really examining this whole proposal very carefully because they don't want to diminish the quality of services people are receiving.

APD Area Offices: Phil asked to expand on the issue of the boundary between the wait list and those receiving waiver services. He thinks the policy from which the area offices and how folks treat people on the wait list should come from the top. His suggestion would be to try to make the area office staff friendlier than they are currently. He believes there could be counseling within the APD office to help point people on the wait list in the right direction. Jane advised that Phil is absolutely right. She offers her apologies that he is not having a good experience. She shared that she will talk to the Area 12 office.

NRSS Services: Frank asked Jane if families can still receive NRSS services. Jane advised technically yes. AHCA submitted the revisions to the waiver that would eliminate NRSS on July 17th. They have not heard back from CMS yet. They don't as yet have permission from CMS to eliminate the service. Once they hear from CMS to eliminate it, a letter will be sent to people giving them 30 days notice that the service will be eliminated.

Disaster Information Program: Jane advised they have made an offer to the person they hope to become the statewide disability coordinator. He is a person with a disability.

Massage Therapy: Belkis asked if there is any truth to the agency reconsidering the elimination of massage therapy. Jane advised that personally she considers it a very important service. She would be willing to advocate to any legislator who asked her about the importance of this therapy for individuals with developmental disabilities. In the long run, the physical problems that arise from not having the therapy will be more expensive than the therapy itself. Chair Houghland asked if there was something FCCFlorida could do to help get that therapy reinstated during regular session. Jane advised it would be difficult because they would have to submit a waiver amendment to add it back in. She doesn't know if that's doable. She suggested the FCCF develop a Fact Sheet with examples of the benefits of therapeutic massage for persons with developmental disabilities and what happens when the person doesn't get it. Show how it limits their functioning capabilities. No one provided the legislature with a good argument as to the medical value of therapeutic massage.

Chair Houghland thanked Jane for taking the time out of her Saturday to speak with the council. She shared how much the council appreciates her and we'll continue to work together.

IV. WAIVER SUPPORT COORDINATION & MANAGED CARE – Brad Hunt, FASC
Chair Houghland introduced Brad and shared how much she appreciates his attending the meeting on such short notice.

Brad shared he is the owner of Exceptional Partners, a Medicaid Waiver Support Coordination Agency in Area 1. He was chair of FASC for 4 years. He has been working very closely with current chair, Janice Phillips and the FASC board. He is very active both in advocating for and collaborating with FCCF and other advocacy groups on DD issues.

Managed Care: Brad shared how he and FASC became involved in the managed care issue. He explained what took place during the last legislative session when a speaker bill (from out of no where) was introduced on managed care reform and passed three committees. In spite of the “hard ball” politics placed on this issue, FASC representatives and others were able to defeat it. As support coordinators, they are very concerned about what happens to individuals receiving their services when they go up against a managed care entity that may or may not be benevolent without someone to help them advocate. Therefore, they felt the role of a WSC is even more critical to have in place under a managed care arrangement. FASC and ARC Florida decided to contract with HMA, a consulting group with expertise in managed care, to give them some recommendations on what to advocate for in the event the legislature went this course. A document prepared by HMA with results from this research study will be released soon. Brad advised it’s a great source of information on managed care. He urged everyone to keep their eyes open, be informed and respond when managed care is mentioned because it is seriously being considered by the legislators. Brad was asked to elaborate on the document being prepared by HMA. Brad also made reference to the Florida Developmental Disabilities Council’s “White Paper” on managed care. He believes it’s available on the DD Council website, www.fddc.org. Chair Houghland asked Brad to forward the paper to her via E-mail and she will forward on to council members. Ann provided information pertaining to the meetings she attended that included representatives from Amerigroup. She believes independence will fall by the wayside because it’s too much for anyone to manage what APD is currently managing. Chair Houghland mentioned that Florida ARC has asked her, as FCCFlorida, to give a response to the HMA draft. Can they use Family Care Council Florida’s name in any part of the draft. She plans to write a letter explaining strongly that FCCFlorida in no way cares to initiate or support a managed care initiative. FCCFlorida was part of the meetings for information purposes only. The council agreed to support Chair Houghland. Brad advised FASC was there strictly for information.

Waiver Support Coordination: Brad mentioned that FASC is meeting on Tuesday with Jane to discuss APD’s plans for support coordination. FASC is still very concerned about the 1:50 ratio and some sort of triage process for limited support coordination. He shared his concerns with the council. The council shared their concerns with Brad. Several had questions about the rationale behind Jane’s consideration of limited support coordination for people in group homes. Brad explained the rationale used is that APD is currently going into each group home on a monthly basis to do a Long Term Residential Care (LTRC) review. This is a monthly monitoring of group homes by APD staff. It includes a check list of charts, any incidents, dietary issues, check for cleanliness, etc. Ann expressed concern that what it doesn’t show is any turnover in staff. Chair Houghland asked Stephanie to send her an electronic copy of the LTRC review document and she will forward on to the council members. Ann mentioned she learned that the check list form includes a reference to having the CHAMPS form available for people to complete. That program no longer exists. Brad was asked about the hiring of 75 full time employees by APD to perform the assessments. How will that save the agency money? Brad explained the savings will come from changing the ratio to 1:50. He provided dollar figures to back up the agencies logic. Brad adds he believes there is a fundamental flaw with their plans to hire 75 FTE’s. APD projected it will take 2 years to complete the needs assessment of 31,000 consumers. They don’t have 2 years to get the program under control. WSC’s could do the needs assessments in a much timelier manner. Example: They completed the ICG assessment process in 3 months. Discussion followed offering other examples of how WSC’s doing the assessments would result in more cost savings. Brad shared FASC certainly appreciates the support of Family Care Councils. Considering the demoralizing affect of what has occurred for support coordinators

over the past couple of months, he suggests it would be nice to send a thank you card from time to time to your support coordinator. Several consumer guests in attendance expressed their concerns for the possible change in the support coordinator role. They want to keep their support coordinators.

Everyone expressed their appreciation to Brad for attending the meeting. Brad thanked everyone for their thoughts, views, concerns and support. Everyone wished Brad good luck with the meeting on Tuesday.

V. BUSINESS

Review of Minutes - Chair Houghland asked if there were any corrections to the minutes. There were none. Phil makes a motion to approve the minutes as submitted. Beverley seconds the motion. The minutes were approved by consensus.

Treasurer's Report – Chair Houghland mentioned a copy of the expenditures from APD is in the FCCF folder. Stephanie advised any transfer of monies to FCCF have not been done yet. Ann asked Stephanie to research why Area 11 is not at the FCCF meeting. This is an ongoing problem that needs to be solved. Joy asked about the tax exempt form. Stephanie will send Chair Houghland who will forward it on to FCC chairs only. It allows for an exemption of sales tax when purchasing items.

Old Business - Chair Houghland mentioned at the workgroup meeting yesterday they discussed Pennsylvania's wait list procedure. It's titled "Prioritization of Urgency of Need for Services" (PUNS). It's a way of categorizing people on the wait list. Phil visited the website (www.pawaitinglistcampaign.org) and did some research on the subject. Phil was impressed with the process. He felt it validated that a person on the wait list is somebody and has expectations and someone is paying attention to them. It isn't a difficult document and could be used for generalized predictions. Chair Houghland would like to pursue this with the Waiver Support Coordinators and APD to see if they would consider looking at this. She asked for a committee to evaluate the program and report at the next meeting. Committee members: Phil Pearson, Nicole Coratti, and Michelle Passidomo. Discussion followed concerning how to determine priority. Chair Houghland stressed we need a better picture of the wait list.

FCCF Conference Calls - It was suggested that FCCF consider having conference calls on the months between meetings. It could include FCC liaisons and APD. Chair Houghland will discuss this with Jane.

VI. FCC UPDATES

Chair Houghland asked for area updates and to include 1-800 return calls on messages they have received.

Donna Rauber, Area 7 shared their last meeting was devoted to the budget issues and Steve Roth, Area Administrator was there to answer everyone's questions. They had hoped to spend the meeting on developing this year's Family Support Plan but due to other priorities, it was tabled until the next meeting. She shared several FCC members met with a local house representative last week to discuss the councils concerns which included the PCA issue, Waiver Support Coordination and Provider rates. Donna couldn't report on the 1-800 numbers as Jeannie receives them.

Betty Kay Clements, Area 13 shared her 1-800 calls have been pretty good. She described a couple of the calls which included one from an 81 year old man with a disability. They had a very good conversation and he was very appreciative to have someone to talk to about his issues. Betty Kay shared their area administrator arranged a meeting with Senator Lynn from their district and asked her to attend the meeting. She shared what took place during the meeting. Senator Lynn voiced her objections to APD and Waiver Support Coordination issue. She is very much in favor of the new assessment tools. Betty Kay shared with her that families have talked about taking an across the board 10% reduction in services as a solution to the budget issue but it

was not considered. Senator Lynn was very interested in that and wanted to know who to contact. Senator Lynn expressed an interest in wanting to meet with FCCFlorida because she wants to hear from families.

Michelle Passidomo, Area 8 shared that Maria has organized IEP trainings locally for families with school aged children.

Lynn Carper, Area 1 shared they still have only 4 FCC members. She indicated they have received 2 1-800 calls. They are doing their QSC (Quality Steering Committee) Symposium on Monday. They have a variety of different sessions scheduled including supported employment. It includes a session on how to advocate for transition in an IEP. They will have a mini-job fair. They have about 200 school aged children registered to attend. She mentioned seeing a hot link on the APD homepage to the FCC website. She researched and discovered that the area office web pages do not have such a link. She requested this to their AA and it has been done.

Pete Wesley, Area 14 shared their symposium was very successful. They had about 175 participants. It included a number of well-attended sessions which included Betty Kay & Ann's session on the Family Care Council. They had asked Senator Dockery to attend their last FCC meeting. She wasn't available but her legislative aide did attend, took many notes and seemed very interested.

Phil Pearson, Area 12 shared they have 2 members but do have several applications in the appointment process. He shared they received 2 1-800 calls. They were interested and have been added to the FCC E-mail list. They held a meeting last week with 12 people in attendance. He did get volunteers to contribute to the council's third newsletter which includes articles on the differences between SSI, SSDI, etc. Also, an article on IEP's. They are planning an FCC social in February, 2008.

Frank Carroll, Area 3 shared he doesn't have a report on the 1-800 numbers yet. He shared their council is currently trying to get organized. He mentioned at their last meeting they had more support coordinators than members/associate members. He shared he just learned that his 23 year old nephew is teaching ESE to six and seventh graders at a school in Sanford. A major reason his nephew decided he wanted to teach ESE was because of his relationship with Joey, Frank's son. Frank is very proud of his nephew.

Belkis Almeida, Area 10 shared their council met yesterday and support coordination was an issue. Another issue pertained to a family member voicing her concerns regarding the PCA issue and the letter sent to families. Her concern was that it appeared that some families who should have received the letter never got it. Chair Houghland explained there were two different letters sent at different times. Belkis shared they have received some 1-800 call requests but have not had a chance to make the calls yet. Chair Houghland stressed the need to make the calls.

Beverley DeStories, Suncoast Region shared they have received quite a few 1-800 calls. Most of the calls were from people with disabilities other than developmental and mental health issues. She shared that Virginia Ruff is doing a wonderful job of organizing a provider fair in Pinellas County.

Todd Decker, Area 15 shared the same 4 or 5 people show up at every meeting. They met last meeting and discussed the legislative budget issues. He has written letters to their newspaper, Governor Crist and Jane at APD sharing his views on why support coordination should remain as is. He is trying to recruit new members.

Area 2 - Chair Houghland shared their council is meeting on a regular basis now. Lynn Daw, the program administrator is running the meetings. She invited chair Houghland to meet with the candidates that are currently in the appointment process. She praised Lynn for taking on these duties and she is also making the 1-800 calls.

Chair Houghland is real pleased that the 1-800 number seems to be an important resource for families.

VII. DOE BUREAU OF EXCEPTIONAL EDUCATION - Kathy Burton, Program Specialist

Kathy began by sharing one of the biggest problems families have is getting information. She passed around a copy of the Bureau of Exceptional Education and Student Service website homepage. It includes the following links: Publications, Resources, Services, Directory and Organizations. The website address is: <http://www.fldoe.org/ese/default.asp> .

She provided statistical information on the percentage of children within the ESE program and the percentages per each disability. She indicated the growth rate of students being identified as being ESE is going down but the growth rate for students between the ages of 19 and 22 is going up. In 2000 they had 4,339 and in 2005-2006 they have 6,238. There is a real growth there which affects APD, Voc Rehab and Centers for Independent Living. Kathy provided a lot of helpful information regarding the ESE program. She provided the following handouts:

- Resources for Parents and Teachers which includes websites for Assistive Technology Educational Network (ATEN), Career Development and Transition, Clearinghouse Information Center, Family CAFÉ, Florida Department of Education, Florida Inclusion Network, Florida Instructional Materials Center for the Visually Impaired, Parents Educating Parents in the Community, Positive Behavioral Supports, Resources Materials Center for the Hearing Impaired and Transition to Independence Process (TIP).
- Florida ESE Process System – The focus of the project is to develop and implement statewide standardized processes for the provision of exceptional student education services. Website address: <http://www/ecgnet.org/FLIEP/index.cfm>
- Draft Technical Assistance Paper pertaining to changes in Rule 6A-6.03016, Florida Administrative Code (FAC), Exceptional Student Education Eligibility for Students with Emotional/Behavioral Disabilities.

Much discussion took place with regards to the IEP process. They are creating a web based IEP which will be on the internet. Kathy believes there is real potential with this system to more accurately determine the needs of children in the ESE program. It is currently being piloted in a district. Kathy provided a wealth of information on the various different categories of disabilities within the ESE program. Also discussed was the FCAT and an alternate assessment from the FCAT. Most of the success or lack of success depends on the school districts, ESE programs within the schools, ESE administrators, teachers and their backgrounds.

Chair Houghland thanked Kathy for attending the meeting and to DOE for paying her travel expenses. Kathy shared she is really trying hard to change the system. Her E-mail address is: Kathy_Burton@fldoe.org. She highly recommends families contact FDLRS in their local areas for information.

VIII. ADJOURNMENT

With no further business to come before the council, Chair Houghland adjourned the meeting at 3:50.

The next meeting will be held on November 17th, 2007 at The Holiday Inn Select.

RESPECTFULLY SUBMITTED,

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