

FAMILY CARE COUNCIL FLORIDA

ANN MILLAN, CHAIRPERSON

Amerisuites Orlando Airport

Orlando, Florida

November 19th, 2005

MEMBERS PRESENT:

Ann Millan, FCCF Chairperson
Patty Houghland, FCCF Past Vice Chair
Joy Frazier, D1 Chair, Secretary
Frank Carroll, D3 Rep, FCCF Past Chair
Beverley DeStories, Suncoast Region 5 Chair
Donna Rauber, D7 Chair
Rob Holl, D7 Vice Chair
Sheryl Soukup, D8 Chair
Bob Wessels, D10 Chair, FCCF Vice Chair, Treas
Margarita Montalvo, D11 Chair
Betty Kay Clements, D13 Chair
Pete Wesley, D14 Chair

STAFF & GUESTS

Kerry Schoolfield, APD Central Office
Marilyn Volker, Guest
Melinda Brown, D13 Guest
Sharon Berry, D8 Guest
Amelia Rauber, D7 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 AND INTRODUCTIONS

Chair Millan called the meeting to order. She advised guests, Kerry Schoolfield from Central Office and Dr. Marilyn Volker, Sexologist will be in attendance. 2 hours will be devoted to each on the agenda. She reviewed the packet of information which includes the agenda, a copy of the FCCFlorida legislative platform, a copy of a letter sent to Melinda Coulter at Central Office pertaining to the FCCFlorida committee's review of the yellow book, a list of questions sent to Kerry Schoolfield, a paper on Medicaid Reform by the National Governors Assn., Florida Medicaid Reform questions and answers, a document on Current Threats to Ventilator Users, 2 documents prepared by Florida Developmental Disabilities Council pertaining to Sexuality Education for Children and Adolescents with Developmental Disabilities, a document titled Seeking Personal Impact on Public Policy and the 2006 legislative calendar. You can view the Medicaid Reform Application for 1115 Research and Demonstration Waiver at the following website:

http://www.fdhc.state.fl.us/Medicaid/Medicaid_reform/waiver/index.shtml

Sheryl added another good source for Medicaid Reform information is at the Winter Park Health Foundation website, www.wphf.org. She mentioned they had a really thorough presentation by their area Medicaid representative. The Medicaid Rep.'s response to the many concerns expressed during the meeting was that her counterparts in other areas throughout the state are not hearing of these concerns. They are not hearing from the developmental disabilities population. She suggests that every Family Care Council invite their AHCA Medicaid Representative to give a presentation on Medicaid Reform at a future meeting.

Chair Millan asked that everyone fill out the evaluation survey and return before leaving the meeting today. Chair Millan shared she has a CD from the Alliance for Full Participation conference she attended and will make available to anyone wanting to review. After viewing the CD, she has copies of the handouts and she'll copy for anyone interested. She ordered from the National Institute for People with Disabilities a video titled "Running an Effective Meeting" for

area FCC reviews. Joy will keep a sign-in/sign-out list so all area chairpersons will have an opportunity to review if they choose.

II. INTRODUCTIONS

Chair Millan asked for introductions and area updates.

Pete Wesley, Area 14 shared they have met with individuals from other parts of their district who are unable to travel to Lakeland. They are looking at ways to arrange a sub-group within the district. She also shared that Lou Brown gave a presentation in Bartow and they were able to display their new FCC screen. They also displayed it at a meeting held in Avon Park.

Rob Holl, Area 7 shared he has been extremely busy in his new job. He was asked about his new job and shared the company is looking at expanding into home modifications. He shared his 24/7 video was presented at the Reno Film Festival and won best documentary.

Frank Carroll, Area 3 shared they are busy purchasing materials and equipment to improve their information and outreach capabilities.

Joy Frazier, Area 1 shared they are having to re-do their budget as they learned a few weeks ago that items purchased at the end of last year have been deducted from this year's funding dollars. Also, travel to attend FCC Florida meetings has doubled due to increase in plane fares. In October they had a Social Security forum. They are working on a day long forum on Supported Employment for next year.

Patty Houghland, Area 1 shared they participated at the University of West Florida disability awareness day. They had one of the nicer looking booths and received many compliments.

Bob Wessels, Area 10 shared they had to cancel last months meeting as a result of Hurricane Wilma. He shared most in Broward County were without power for 2 to 3 weeks and having lived in Florida for 25 years he has never seen such devastation. The next meeting will be held the 2nd week in December. He shared the conference "Exploring Options for Independence" which their FCC co-sponsored was very successful with about 135 in attendance. He also indicated that items purchased during last fiscal year appear to have been deducted from current year funding dollars.

Sheryl Soukup, Area 8 shared they are moving forward with current year plans. As mentioned previously they had a representative from Medicaid attend a meeting. Also, the area provider enrollment person attended a meeting to help with starting a provider development committee. They continue to be involved in AQL (Area Quality Leadership), the steering committee and planning their upcoming annual conference.

Beverley DeStories, Suncoast Region (Pasco, Pinellas Counties) shared they have had some wonderful presentations on trusts and social security. She praised their co-chair for keeping the FCC running smoothly while she was away for 30 days. They are looking for a secretary to help with sending out flyers and E-mail notices of meetings.

Betty Kay Clements, Area 13 introduced their FCC vice chair, Melinda Brown. They are currently working on 3 family forums in hopes of reaching out to more families by concentrating in certain counties. The first will take place in Marion County in January. They have brought a consultant on to coordinate the program. A person who received an FDDC grant is coming to their next meeting to use their members as a focus group to put together a "how to" book based on the Planning Ahead and yellow book documentation to make them more disability friendly. They have been involved in some school projects.

Betty Kay shared the APD Uniform Practice team visited their area office. Their purpose is to visit each area office and bring them all into compliance so that all areas are working off the same page. They called Betty Kay to arrange for her and several other FCC members to meet with them at a specified time. They spent several hours with them and had a list of questions specifically related to communication between area office and FCC. She shared it was an excellent opportunity for them and was very impressed with the meeting. They were definitely interested in Family Care Council future plans, how they are involved in the community and how active the council is. Frank added

that at their meeting the team was most impressed with the fact that their area PA attends every FCC meeting.

Donna Rauber, Area 7 shared they are currently working on a newsletter, updating their brochure and a legislative platform. She shared they are looking into holding some night meetings in hopes of reaching out to younger families. The council is in desperate need of more participation.

John Stone, Area 2 was unable to attend. Chair Millan reported in his absence. John represented FCCFLorida at a summit in Tallahassee dedicated to developing a legislative platform. He indicated of the 60 providers/agencies invited about 20 attended. It was sponsored by FARF and ARC.

Edith Kegel, Area 12. Chair Millan shared that Edith had the flu and was unable to attend today's meeting. Edith wanted Ann to share with the council that Area 12 is planning to mail out a flyer to individuals in the school system in special education to inform them of the services available, including those who might qualify for APD. Chair Millan told the council we should all watch the success of this in Area 12 because they are targeting the very individuals most difficult to find.

III. PRESENTATION – Developing Healthy Sexuality - Dr. Marilyn Volker, Sexologist among young children, adolescents and adults with developmental disabilities

Bob Wessels introduced Dr. Marilyn Volker and shared with her the council's appreciation for her taking the time to meet with the group. Dr. Volker passed around her business cards and advised that she would leave the powerpoint CD with the council. She began by honoring her good friend Martha Sheldon who worked with her on this project. She and Marty gave this presentation many times. The presentation was developed for the University of Miami, Mailman Center. She provided some background information which included 36 years in the field of teaching sexuality and developmental disabilities. She has degrees from several universities in deaf education. She shared how she became involved in sexuality issues of children with developmental disabilities. She pursued her doctorate degree in California at the Institute for the Advanced Study of Human Sexuality associated with the University of California. She shared her personal experience included one of her daughters became a foster parent for an autistic young man. Michael, from age 5 to 15, was part of their family and taught them a tremendous amount. Her experience includes teaching in group homes, classrooms, teachers and children. She teaches sexuality classes for counselors at 2 medical schools and 4 universities. Teachers and Special Education teachers aren't required to have any sexuality classes. Her dream is to see such classes, particularly in area of Special Education teachers. She has a sex therapy private practice. She works with many people with body changes, disease and disabilities. At this time she opened up the presentation to include audience participation. She asked the audience to think of something in the area of sexuality with people with developmental disabilities where there is a critical need. She suggested listing them, then addressing some of the strategies involved. Concerns include masturbation, an incident reporting system within APD process whereby if a provider walks in on 2 consenting adults having sex in a group home, it must be reported as on an incident report. Other listings were sexual abuse, ways for non-verbal individuals to communicate, hormones, educating parents in how to teach sexual language, care giving issues (an example, a father finding a comfort level when bathing, clothing and caring for his daughter as her body develops into a young woman), body image, and fear of sex. It was stressed how nobody has ever addressed these issues with parents. Dr. Volker advised this is why there needs to be a specialized team of sex therapists within the state. Her group trains sex therapists and educators in the state of Florida. They need to be triaging with parents to look at each individual and how to develop body image. Dr. Volker explained there are educational materials available that help with teaching about the development of the body. They include images of family, books, videos and anatomical dolls. Her belief is that corporations need to be buying these dolls for families of children with disabilities or at least providing some within all the districts.

Pharmaceuticals need to get involved by sponsoring conferences or speakers. Examples of personal situations with sons and daughters of audience participants were shared with Dr. Volker providing solutions to the issues. She mentioned several times that strategies used to change the behavior, no matter what the behavior, in persons with developmental disabilities normally take between 2 and 5 years. She suggested any attempt to change the behavior should be taught by someone other than the parent and the person needs to be rewarded when he/she remembers. She talked about using picture books that includes, for example, pictures of persons it's OK to hug, or pictures of persons it's OK to kiss. With the use of picture books the person learns when it's OK and when it's not OK. Another example is making a video of the person when using appropriate behavior and receiving the reward. By showing this to the person over and over again, he/she learns what is appropriate. Dr. Volker expressed she always refers to the adult child as young man/young woman, never child. She mentioned that when looking at the social skill development, which needs to be in each IEP, it should be referred to as sexual health and relationship, which gets away from just the sex part. She provided examples of ways of addressing body images. It was mentioned that much of what Dr. Volker has talked about is teaching vocabulary and the ability to communicate and the use of pictures but what about assistive technology, communication devices. Are there symbols developed for this language on communication devices and where do you get them? Dr. Volker advised it's very limited but the Stanfield Company and the YAI have developed some. Dr. Volker shared that she does provide training to certified behavior analysts but it is not a requirement of their certification.

Throughout the presentation, Dr. Volker referred to portions of her powerpoint presentation. She has made the CD available to the council. Bob volunteered to make copies for anyone who is interested. Below is a brief summary of issues presented in the powerpoint.

Purpose:

- To understand the need for healthy sexual development among individuals with developmental disabilities
- To provide a framework for promoting a healthy sexuality for individuals with developmental disabilities

Sexual Myths about Individuals with Disabilities:

- Individuals with disabilities are asexual.
- Individuals with disabilities do not feel a need for sexual expression.
- Individuals with disabilities are not able to engage in intercourse.
- Disability will breed more disability
- Individuals with disabilities have perverse sexual desires.
- Individuals with disabilities are the eternal child.
- People with disabilities are "Holy Innocents".

Sexual Exploitation and Individuals with Disabilities (Some General Facts)

- Based on the figures it is very conceivable that between 15,000 and 90,000 individuals with developmental disabilities are raped per year in the U.S.
- Studies suggest that 40%-70% of girls and 15%-30% of boys with developmental disabilities will be sexually abused before the ages of 18.
- Studies also suggest 90% of criminal cases involving developmentally disabled adults were sex related crimes.

Reasons why people with disabilities are at risk for exploitation:

- Dependent
 - Physical - Need help with personal care (i.e. dressing, bathing)
 - Emotional – (isolated, not involved with community program)
 - Financial
- Lack of a sexual identity (i.e. not understanding what is happening)

- Non-assertiveness & lack of social experiences - are not taught that they have rights and that saying “no” is one of their rights.
- Lack of the vocabulary to report because of no formal sex education
- Low self-esteem. Looking for love, care and attention
- Isolation and no opportunities to meet people.

Role of Medical/Mental Health Professionals facilitating Sexual Health Care:

- Create Milieu conducive to discussion of sexuality issues
- Include questions/permission about sexual health
- Validate individual experience
- Educate – cognitive, attitudinal, & behavioral
- Model communications re: sexual health
- Counsel/offer a variety of strategies
- Provide intensive therapy
- Refer to/consult with other professionals

Comprehensive Sexuality Education for Individuals with Development Disabilities

- Assessing Individuals Sexuality Needs
- Addressing Misconceptions and Sexuality & Developmental Disabilities
- Tailoring Sexuality Education for Children, Youths and Adults
- Facilitating Social Skills Development
- Presenting a Variety of Body Images
- Discussing Masturbation
- Preventing Sexual Exploitation
- Considering Reproduction/Contraception Concerns
- Including All gender & orientation feelings
- Identifying/creating specific resources
- Providing information & support for Teachers, Parents, Group Home Professionals, Aides, Transportation Staff, etc.
- Focusing on Safety – Physical, Emotional and Sexual

RESOURCES – Websites/Training Materials (Video, Booklets, etc.)

- National Institute for People with Disabilities Network – YAI training videos
<http://www.yai.org/trainingstore/>
- Sex Education and Relationships from the James Stanfield Publishing Company
Videos and work materials –
<http://www.stanfield.com/sexed.html> and
<http://www.stanfield.com/sexed-2.html>

Dr. Volker provided many examples of individuals she has worked with and the successful strategies used in each situation. There was a lot of interaction and brainstorming between her and the audience. She conveyed her life passion is working together with parents of individuals with disabilities as a team. She really wants to work with the council, whatever suggestions there are in determining who to contact. She praised the audience by sharing how totally in awe she is of everyone for the time, energy and commitment devoted to their loved ones with disabilities and what we teach her and the professionals in her field. She would love to see a forum created with parents, special education counselors and students. Chair Millan thanked Dr. Volker and shared with her the council’s appreciation for her time and exceptional presentation. The audience responded with applause.

IV. APD UPDATE - Kerry Schoolfield, Director of Operations

Chair Millan introduced Kerry and asked those in attendance to introduce themselves.

Treasurer's Report - Chair Millan asked Bob Wessels, FCCFlorida treasurer to give the treasurer's report. He advised Kerry that the council requests each meeting a treasurer's report from the state's standpoint. He presented Kerry with a paper with a very large "question mark" as no report has been received. He reminded Kerry that the council relies tremendously on Central office for input on FCC funding, how the dollars are being spent, if it's being applied properly, etc. It's becoming more and more difficult to obtain any information out of Central office in a timely manner. He mentioned that the council is trying to work through this via FICD to eliminate these problems. An example is many expenses that were to be certified forward did not take place resulting in beginning this fiscal year with expenses that should have been deducted from last year's funding dollars. Kerry asked for an explanation of how the procedure worked in the past. Bob advised through Wilma, the APD liaison. Chair Millan advised Eileen requested the current report from finance and said she would have it by Wednesday. Never received. The council has discussed the situation and feels that certain staff at Central Office really do not care about us. We're just a group of parents, volunteers. Kerry advised that's not true. Bob provided an example of how finance dept. works. Ann submitted a certified forward voucher on June 30th, it was approved by Central office on October 10th. Another example, Donna who transcribes the minutes is still waiting for payment for July and Sept./Oct. minutes. Kerry asked her for the procedure she follows to receive payment. She replied. Kerry advised he has learned a lot this week through E-mails and finding out what FICD was and what the council is trying to accomplish. Bob presented to Kerry a package of invoices that were being held until FCCFlorida dollars could be transferred to FICD. Since that hasn't occurred he is requesting payment for all these invoices from Central office. Sheryl explained that she was unable to attend the TASH conference because she couldn't get authorization for travel from Central office. She contacted both Wilma and Edith but no one would reply. Kerry commented obviously the coordination between Central office and FCCFlorida needs to be fixed. Kerry advised they have a new employee named Barney Rey, the APD finance and accounting director. He has looked at the FICD proposal as well as the legal dept. He has proposed to set up a special tracking of all FCCF invoices if FICD proposal is denied. Kerry understands the reason for FICD becoming a fiscal intermediary. It was the state comptroller's office questioning the validity of the proposal as FCC members are volunteers, how can they have an organization to do this. He personally thinks it can be done but it hasn't been resolved yet. He proceeded to explain a procedure being considered under the contract which would allow 3 advance payments through the year totaling the \$14,000. Chair Millan suggested establishing a committee to continue this discussion as the meeting needs to move forward. Kerry provided everyone with a paper titled "Options for FCC Funds". Margarita shared her frustration with not receiving approval from her area PA to attend today's meeting. Kerry stated that he would meet with Eileen, Terri and Barney to come up with some solutions.

Individual and Family Services Project: Kerry provided everyone in attendance with a **DRAFT** copy of a proposed onetime expenditure project for individuals on the wait list. Kerry explained they are working with the Governor's office to get approval to spend some of the funds they received that will be non-recurring next year. He provided some background information on the process that takes place on July 1 when funding dollars are received. They determined they could enroll an additional 6,600 individuals due to accountability measures in place which include the rate structure, prior services process and primarily the gatekeeper. It's impossible for all of these individuals to begin receiving services on July 1 at a full cost plan amount. As a result, over the year it creates a surplus of funding as people get enrolled and services begin. It's a non-recurring surplus as it will only be a surplus during that one year because next year they all will have been enrolled and receive a full year's services. They are planning on taking about \$18 million from the waiver category and move into the non-recurring category of Individual and Family Supports (IFS). They have determined they have enough money to give to 7100 people who are on the wait list as of July 1, 2005 who will not be receiving a letter this year offering the waiver. This would allow a

one-time \$2,500 for each of these people to spend on a variety of service and/or equipment options by June 30, 2006. This has not been approved yet. They go before the legislative budget commission on December 8th to be approved. APD feels strongly it will be approved. Kerry reviewed the draft copy which included the purpose, a list of available services which was taken from Chapter 393, and implementation procedures. Discussion followed pertaining to services listed and how they will be implemented considering the time element of must spend by June 30th. They will send a list of names to the area offices the first week of December in order for them to prepare the letters. Shortly after December 8th, the letters will be sent. His goal is for all of the contacts to be made before Christmas so that beginning January 1, 2006 staff can begin preparing short version of support plan and finding providers. Kerry advised the agency will be hiring additional OPS staff to help with this project. They will be working one on one with the families. It's a massive project to undertake and a very short period of time. Providers are not limited to med-waiver providers. Any provider can be used but must be a registered vendor under myfloridamarketplace (<http://dms.myflorida.com/dms/purchasing/myfloridamarketplace>) in order to get the bill processed for payment. Kerry is asking Family Care Councils to help the area offices with setting up provider fairs, asking all local providers to participate and inviting families receiving the letters to meet with them in a centralized location. He asked if Family Care Councils would like to take a leadership role? He believes the area offices would really appreciate FCC's participation. It was decided this would have to take place sometime in January or early February. Questions were asked pertaining to specific items not mentioned or needing clarification on the list of services/equipment. It was suggested that in a search for new Medicaid waiver providers that during the provider fairs area offices make available enrollment packages for any new providers participating at the fair that might be interested. Several expressed concerns with allowing current fulltime staff to work overtime on this project. Their current workload might suffer or not be considered as important knowing they can get overtime working on this project. Kerry assured everyone that won't be the case. They are looking at employees who will be finished with current enrollments by the first of the year. They might have some time available to help with this project. He asked for advice on the draft letter to be sent to families. Chair Millan suggested creating a committee for this purpose. Beverley and Patty volunteered. Anyone else with comments can send to Chair Millan and she'll forward on to Kerry. Margarita asked if the documents will be translated into Spanish. Kerry advised a good point, a Spanish version will be needed in several areas. He asked Margarita for her assistance. She will ask for Evelyn's assistance. Frank brought to Kerry's attention an inaccurate statement in the support plan under Individual/Guardian consent. Considering these dollars are based on one-time services, the sentence "I agree that this plan identifies **all** my needs for supports and services" is misleading. Kerry agreed. Patty suggested naming it a "one time expenditure" support plan in place of "short version". Kerry liked that idea. Several mentioned the need to add to the list purchase of a generator for individuals with medical needs whose equipment requires a power source especially as it relates to hurricane prone areas. Chair Millan asked that we move on and send any additional comments to her and she'll forward on to Kerry. Kerry advised as soon as possible and thanked everyone for the many comments he received..

Kerry provided another handout with regards to the Bridges project. He shared that Family Network on Disabilities (FND) has terminated their contract with APD at the request of FND Chair Richard LaBelle. They have contacted the next contractor who bid on the project which is PSI Family Services partnering with CCAR Services, both located in Jacksonville. APD will be meeting with them in early December. They are very interested in picking up where FND left off.

Chair Millan asked for an update on the yellow book with regards to the letter of comments with concerns sent to Melinda. She has not received a reply. Also, when will it be released and is their

any re-evaluation going on at this time? He isn't aware of any problems but will check with Melinda and get an update from her. He asked for examples of our concerns. Several stated it was so comprehensive to the point of being overwhelming. In its current form, it's 387 pages long. It needs to be broke into modules, separate books. Chair Millan mentioned items not covered such as crisis qualifications, Medicaid eligibility, and AQL information. Chair Millan shared how impressed she is with Shelly's legislative presentation, orientation and summary of programs that is currently located on the APD website under the "In the Spotlight" link. It's very well done and needs to be made available to families. Kerry was asked if printer friendly copies could be made available as the way it's presented on the website cuts off the right margin. He shared he would see that each chair received a hard copy. Chair Millan shared there is no consistency in the new version and there are a lot of pages that could be left out. Patty suggested seriously consider leaving out the Planning Ahead and Compass sections from the yellow book but distribute at the same time in their own separate books. It's too overwhelming in its current form. It was very difficult getting support coordinators to distribute the last book.

At this time the questions previously sent to Kerry were discussed.

1. Chair Millan asked about the budget request for next year and if there are any changes to 393. Kerry advised he will see that she receives a copy of the legislative package which includes changes to 393. It's very similar to what was submitted last year. Also, the Governor's budget package has already been released so he'll see that she gets this also.

2. Chair Millan advised the council has some concerns about the crisis committee. It was learned that no one from AHCA is on the committee. Kerry advised the reason being that person retired. He stated the core of the group is pretty much the same. They want some rotation so that people don't get in a rut. The crisis committee reviews and makes the recommendation then a separate person who isn't sitting on the committee, usually Linda Mabile or Terri McGarrity is the decision maker. They take all the recommendations and make the decision for the agency. He was asked if there was a family member on the committee and if not could one be appointed. Kerry advised there isn't at the time but would ask why that hasn't been done. There may be a problem with having a non-employee on the committee. Chair Millan said she believed Janet Graham has served on this committee in the past.

3. Chair Millan asked if there was any provider development for providers on FSL and HCBS. Kerry advised yes. Recently they had all area offices send in an assessment of their provider needs by service, by waiver. The staff is developing an exercise for them to go through to develop providers in those gap areas. Chair Millan asked if we could see the report. He shared the major gaps were in behavioral analysis, transportation and the biggest was waiver support coordinators. He reminded everyone there is a reason for a shortage of WSC's as they're bringing on an additional 7,000 people.

4. Chair Millan asked if there was a corrective action plan for CDC+ program. Kerry asked if anyone had attended the CDC+ trainings that took place throughout the state. Margarita attended, said it went well, it didn't resolve the issues but was good to have key personnel in attendance to answer questions. Kerry advised that FDGS still has problems with their system. He wished it was resolved, it's better but some problems continue to flair up. He advised there continue to be too many errors in the system. He believes FDGS is under a corrective action plan through the Dept. of Elder Affairs who has the contract. Kerry advised the agency is hiring a consultant who will be looking at how to improve CDC+ for the future, where does the project need to go and how to avoid current problems. Many on the program have complained it has become too complicated. They also want to get a national perspective as most other states have consumer directed care programs as a means of improving the program.

5. Chair Millan asked if there are any OPPAGA reviews currently being done. Kerry advised yes. The legislature directed OPPAGA to look at the Maximus contract with the specific question in

mind of is the current process doing what the legislature intended it to do. The review should be completed before session begins. Chair Millan asked for an update on the FARF and ARC lawsuits. Kerry advised the lawsuits are still ongoing and as a result he can't talk about them but said he was in deposition last week.

6. Chair Millan asked about the Governor Appointments. Currently she is no longer a member, others will be going off soon and many prospective new members are waiting for approval. The current applicants hesitate to get involved until they receive approval. It would be a real insult if a member applicant became involved and then was turned down by the Governor's office. Some consumers have even been turned down.

7. Chair Millan mentioned there are 3 BLN's (Business Leadership Networks) in the state and has heard the agency is planning on 3 more. Kerry advised yes but is uncertain of their locations. They have the funding for it and will be doing an RFP in January.

8. Chair Millan asked if APS is still on corrective action plan. Kerry advised yes and he met with the President of the company last week. The good news is they have caught up on the backlog. Now every APS is processed within 10 days. Several advised that's not happening. Kerry advised he will check with Lorena on that. Any issues should be directed to him or Lorena Fulcher. She is contract manager for APS.

At this time, Chair Millan asked that each FCC chair or representative share with Kerry any comments or questions. Everyone shared with Kerry how appreciative they are of his input, thanked him for attending and expressed how much they would like for him to attend future meetings.

Frank asked about the Uniform Practice Reviews. How many areas have been done and will other areas be included. Kerry advised 2 areas have been completed and they will be doing all of the area offices. Kerry mentioned he has not seen the reports yet. He was asked if FCC chairs could receive a report. He advised yes. He was asked if a schedule of dates per area could be shared with FCC chairs. He advised yes. The future plan is that it be done every year. Kerry shared he visits every office at least once a year but goes to 1 or 2 a month. He meets with staff and some area providers. Beverley shared her appreciation and also asked as a way of keeping FCC's closer by involving them in the planning process of future issues. He advised he would try to do this.

Betty Kay asked if APD has had any involvement with the dual eligible situation with Medicare Part D. Kerry advised that Becky Mcguire, their nurse has had the most involvement in this issue. He has not but if she has certain questions to direct them to Becky.

Margarita specifically thanked him for 2 issues that he helped her with. One of the issues was related to a family in desperate need of power after the hurricane. Margarita asked Kerry what happened to the Hurricane Crisis group, is it still working on hurricane issues. Chair Millan mentioned to Kerry that the council has been trying for over a year to get Sheryl Soukup on that committee. Kerry advised that's a good idea. He asked Chair Millan to follow up with Kerry on how to get her on the committee.

Donna had a question pertaining to area FCC funding dollars. Currently the area program office requires that all FCC purchases be done through their office. This creates a problem as staff is overworked and orders placed aren't received on a timely basis which really creates problems at year end. She has learned that some area program offices allow the FCC chairperson to purchase items such as supplies, postage, etc., present the receipts to the area office and then be reimbursed. What is the policy? Kerry thinks it can be done, it's just the area office hasn't given permission yet. As he is meeting with Area seven PA on Monday, he suggested discussing at that time.

Chair Millan thanked Kerry for attending the meeting.

V. COMMITTEE REPORTS – Working Group

BOSS Manuals - Chair Millan reminded everyone to distribute their BOSS manuals. She still has 100 cases in her garage. She suggested mailing a case to each of the FDLRS in the state with a

cover letter asking them to give to families with consumers interested in starting a business. Sheryl shared she thinks that's the problem. There aren't many people with an interest in doing this. Chair Millan mentioned that if we had known that the University of South Florida would be holding MINTA sessions throughout the state, the council wouldn't have published the book. One problem is that the councils aren't incorporating a training session along with the book as MINTA is doing. Joy mentioned sending to Benefit Planners and Margarita mentioned the CIL's. It was suggested to take them to the Partners in Transition conference next year.

Celebrate Employment – Bob advised it was discussed during the working group meeting that Chair Millan has solely created the Celebrate Employment booklets with Patty and Beverley doing the editing. The group came to the consensus that it's been an advantage to the agency but with very minimum involvement from the agency and no stories. Chair Millan mentioned to J.B. Black recently that the council may not be interested in doing another book. J.B. seemed shocked. Chair Millan indicated to him that if the council doesn't see job carving and creative employment stories then it serves no purpose. The working group decided that FCCF will work with the agency in possibly publishing another book but FCCF can no longer provide volunteer hours and publish. It was estimated the cost would be about \$7,500.00. Chair Millan reminded the council if the agency says they are not interested, then FCCF will not do another book. Bob will proceed forward and discuss with J.B. Black.

Legislative Committee - Bob reported on behalf of John Stone who wasn't able to attend the meeting. Bob talked to him this morning via cell phone. John is working on creating a Family Care Council Day in Tallahassee. He sees it happening one of two ways:

1. Either the FCCFlorida original suggestion of sometime in March which would be a low key type function for Family Care Councils. He feels confident he can get the Observatory at the Capitol.
2. John is involved in the big bend BLN (Business Leadership Network) and they suggested to him that BLN partner with FCC's. They would help FCCFlorida sponsor Family Care Council day. They want to do it during legislative session, sometime in April. An advantage of partnering with BLN is they can track many more legislators to visit us. Everyone in attendance was in agreement with this. Frank asked if this would take the place of an FCCFlorida March meeting. Discussion followed if there should be a March bi-monthly meeting and FCC day in April. It was decided to have an FCCFlorida March meeting and the April date will be solely dedicated to FCC day in Tallahassee. Chair Millan asked for everyone's opinion on teleconference calls. Most agreed it's not an efficient way of doing business unless an emergency situation. It was the consensus of everyone in attendance that John and area two FCC council along with BLN should begin planning for Family Care Council Day. Chair Millan asked that a date be determined ASAP. Bob will call John after the meeting.

Donna will call Amerisuites and see if March 17th & 18th are available. Donna shared the booked meeting dates are January 20th – 21st, May 19th – 20th, and July 14th – 15th.

Chair Millan mentioned that we have a problem with Amerisuites not accepting a purchase order. APD is requiring a PO and is asking us to check out other locations in the area. We have done this and cost wise nothing comparable and wheelchair accessibility is better at Amerisuites. Still an ongoing problem. Donna shared the regular room rate at Amerisuites is \$129.00 per night. Beginning in January the room rate at Amerisuites will increase from \$59/69 to \$83.00 per night.

FICD – Bob reported FICD is officially a 501(c)3. He has applied for and received a sales tax exemption, he filed the annual report. He's ready to vendor with myfloridamarketplace. A bank account has been opened with the residual funds leftover after the donation of \$3,227 from Parent to Parent of Pinellas County. The current bank balance is \$1,842. The decisions made during the

working group include Sheryl volunteering to create our policies and working on writing a concept paper for the speaker's bureau.

VI. NEW BUSINESS

The Employment Work Group has suggested that APD request Governor Bush encourage job carving in state agencies. No action has been taken to date. The FCCFlorida executive board is asking for a motion to write Governor Bush requesting a proclamation that he charge all state agencies to hire 1% developmentally disabled individuals and encourage job carving. Sheryl makes the motion. Frank seconds the motion. The motion was approved by consensus.

Chair Millan asked for suggestions for future meeting presentations. Medicaid Reform was mentioned. Sheryl advised she would look into that. It was suggested to contact Winter Park Health Foundation as they are located in the area.

VII. ADJOURNMENT

Chair Millan thanked everyone for attending the meeting. With no further business to come before the council, she officially adjourned the meeting at 4:00.

RESPECTFULLY SUBMITTED

DONNA RAUBER