

**FAMILY CARE COUNCIL FLORIDA**  
**BETTY KAY CLEMENTS, CHAIRPERSON**  
**Holiday Inn Select Orlando Airport**  
**Orlando, Florida**  
**November 15th, 2008**

**MEMBERS PRESENT:**

Betty Kay Clements, FCCF Chairperson  
Patty Houghland, Past FCCF Chairperson  
Lynn Carper, A1 Chair & FCCF Secretary  
Susan Creek, A3 Chair  
Frank Carroll, FCCF Vice Chairperson  
Maria Quinones, A4 Co-Chair  
Beverley DeStories, Suncoast West Region Rep.  
Pauline Lipps, Suncoast East Region Chair  
Donna Rauber, A7 Chair  
Jean Sherman, A10 Representative  
Laura Tacinelli, A14 Representative  
Nancy Moody, A15 Chair

**STAFF & GUESTS**

Sonja Bielecki, Area 15 Guest  
Margaret Watkins, Suncoast West, Guest  
Aaron Nangle, Waiverprovider.com, Guest  
Dixie Sansom, Florida ARC, Guest

*The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring quality services to individuals for dignity and choice.*

**I. CALL TO ORDER**

Chair Clements called the meeting to order and welcomed everyone to the meeting. She began by reviewing the FCCF information packet contents. Items include the following:

- AAIDD Publication – Toxic Exposures and Developmental Disabilities
- APD Cost Plan Rebased data
- Article titled: “Does God Make Garbage?” by Johnny Seitz
- Presidential Quotes
- FCC Schedule of Allotment Balances – 11/7/08
- Article announcing Geraldo Rivera’s initiative regarding National Waiting List Crisis
- Copy of Powerpoint presentation given at DD Waiver Workshop titled: “Taking a Look at Florida: Responding to the Need of People with Developmental Disabilities”. The workshop was attended by Chair Clements, Patty and Frank.
- APD Legislative Budget Request, Fiscal Year 2009-2010 dated October 31, 2008
- FCCF meeting agenda
- News Release announcing Tamara Yang Demko has APD Chief of Staff. She is also the Executive Director of the Autism Task Force.
- FCCF September 20<sup>th</sup>, 2008 minutes
- Copy of Florida Statute 393.502 Family Care Councils

Chair Clements mentioned that Vocational Rehabilitation has developed a PowerPoint presentation explaining how individuals with developmental disabilities will be added to a new wait list titled Order of Selection. She will E-mail it to everyone. The reason for this is that VOR has received so many requests and are unable to fill all the requests. Therefore, a wait list has been established effective August, 2008.

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

## **II. FCCF BUSINESS**

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

**2009 Meetings dates** - Beverley asked for the 2009 meeting dates. They are: January 16-17, March 20-21, and May 15-16.

**Treasurer's Report** – There is no update at this time as the APD budget information did not get to Phil in time for him to analyze it. Included in the packet of information is a listing of expenditures per area through November 7<sup>th</sup>, 2008. Stephanie is currently tracking down the transfers from area councils to FCCF, which have not been done yet.

## **III. APD UPDATE – Conference Call - Terri McGarrity, Linda Mabile & Stephanie Khan**

Chair Clements asked everyone to share their name and council number. Terri began by giving some APD updates.

**Medicaid Infrastructure Grant** - She shared that APD was awarded a Medicaid Infrastructure Grant fourth year funding that will begin in January 2009. That will continue some of the FBIRN work with the benefits counselors. There will be more information released about this in the coming weeks. Central Office staff was very excited to receive this grant for another year. The grant is for \$750,000. Terri was asked if there was a focus to the grant. Terri advised it is to develop more targeted consumer/family education and to train support coordinators on benefits planning activities.

**QSI Update** - Terri mentioned they are continuing on with the QSI's. They have completed close to 17,000. They are beginning a pilot to train support coordinators on how access the synopsis reports which will start this coming week in area 2. They are using the training tools that FCCF helped them develop. Terri shared that she was unable to get the data reports FCCF had requested in time for the meeting. She will work to see if they can be sent to Betty Kay next week. Betty Kay asked Terri if she would send her a link to the QSI PowerPoint. Terri advised yes she would. Patty asked Terri to elaborate on the purpose for training support coordinators on how to access the synopsis reports. Terri advised that support coordinators are doing a web based training individually and when that is completed they will be E-mailed a form that they will take to their area office for additional training. APD wants to encourage support coordinators to use the information in support planning and to use it as a way of learning of any changes in the individual that they may not be aware of.

**Tiers** - Linda advised she doesn't have much to report about the tiers except that APD is continuing to work on them. There are no new developments. They are still working through the hearing process. APD is still doing reviews although not as many error reviews. Beverley shared her personal experience with her daughter who was placed in an inappropriate tier which was even more evident due to her experiencing a major life style change due to Beverley's illness. Beverley filed an appeal and has not received any indication that it has been reviewed for an inappropriate tier placement let alone the life style change that occurred for her. Linda advised Beverley to be patient. She shared that she is doing a number of reviews for Suncoast region and she doesn't recall doing a review on Beverley's daughter yet. Linda reminded everyone APD had about 5,000 hearing requests. They have quite a ways to go to get through the hearing requests. She suggested that Beverley could request at the area office for them to send up an error request in addition to what Beverley has already submitted. Linda advised that Beverley could send the error request directly to her. Patty advised that some of the confusion regarding error reviews could be that area offices are only notifying parents if a change has been made. Otherwise, their request is being assumed that it is going forward for a hearing. Patty asked if any of the hearing requests have gone to DOAH (Dept. of Administrative Hearings) yet. Linda doesn't know if they have gone to DOAH or not. She advised she could check on this and let us know. Patty advised it would help FCC's be

prepared to answer questions families may have if they know that the assignments have been received at DOAH.

**Cost Rebasing** - Linda advised APD is very close to having their procedures and data finalized on rebasing to send out to area offices. They are hoping for Director DeBeaugrine to approve on Monday. The procedures are not that dissimilar from what they did with the Tiers. APD will be sending out notices just to people who are affected by the rebasing. They will be asking them to work with their support coordinators to bring the plan into the rebasing amount. APD will be sending spreadsheets out to each area office which will identify the expenditure levels for 2007-2008 plus 5%, the current cost plan amount for the individual and what the reduction is. That information will be shared with all the coordinators. APD will be mailing the notices from the Central Office and have targeted a date of November 21<sup>st</sup>. APD has prepared a handout for support coordinators that reviews the steps, the process and gives hints on how they can work with individuals and families in this process. They will be providing copies of the notice of hearing. Kathy Bedell has created a request for hearing form that she thinks will help families when they are submitting for a hearing to make sure all the necessary information is provided so the request won't be sent back to them for additional information. They should have information regarding the hearing process available by mid-week. Beverley asked Linda when referring to the hearings is that the appeals process to the rebasing. Linda advised yes. Patty mentioned that all the folks who have requested a Tier hearing are in limbo and their cost plans are in limbo. How is that going to work with the rebasing? Linda advised they are being considered as this is a statute and there are no exemptions from it. She shared it is confusing. They will be subject to a rebased amount and their cost plans will be changed. However, then they have the right to file for a fair hearing and go through that process. It could result in two hearings opportunities going over two different issues for the same individual. Betty Kay asked if they have any projections on the amount of money saved by cost rebasing. Linda advised from what she understands this cost rebasing is more of a cost containment initiative than a cost savings initiative. Additional discussion followed regarding questions pertaining to specific examples of rebasing and hearing procedures. Linda advised as they send out the procedures & letters, she will make sure Betty Kay receives copies to forward on everyone. Several in the audience shared that most people including waiver support coordinators have no knowledge at this time of the cost rebasing issue. Most families affected will be totally in the dark when they receive the letter.

Betty Kay asked for an update on the future budget reductions of 4% and possible 10%. Linda advised the 4% reduction will be taking place. Linda mentioned at this time it's uncertain about the 10% affecting the next fiscal year budget. She did advise that statewide it's looking really grim. Terri advised that Central Office has not heard anything definitive about what will take place in the future.

**CDC+** - Frank asked Terri for an update on what is taking place with the transfer of savings dollars from the previous fiscal agent. He appreciates the monthly report that was received but it doesn't include the amount of dollars in individuals' savings accounts. Terri will check with Sherry for an update and E-mail Betty Kay and copy him. Terri mentioned that there has been a request to expand CDC+ by 900 folks. Nancy asked if CDC+ families are going to have their budgets reduced by 10%. Terri asked Nancy to E-mail the question to her. She will give to Sherry and make sure she sends a reply.

**Waiver Monthly Statements** - Beverley asked Terri why she hasn't been receiving monthly statements of expenditures lately. Terri advised because they will be generated by the new AHCA fiscal agent, EDS. EDS still has a number of issues they are working on and they haven't gotten to monthly statements yet. Possibly they will issue a quarterly statement then monthly thereafter.

**FCC Governor Appointments** - Jean asked Stephanie for an update on the status of Governor Appointments and re-Appointments to Family Care Councils. Stephanie advised she has not heard anything official but has contacted them on the ones that are pending. They are backlogged with

checking background checks, etc. and waiting for Governor approval. Jean advised she can understand for new appointments but why would it be an issue for re-appointments. They have 2 including hers that have been pending for 6 months. Stephanie advised it's the same process for re-appointments. Donna mentioned Area Seven has two that have been pending for over a year. Dixie Sansom, Legislative Lobbyist for Florida ARC advised that there is a backlog with Governor appointments because there are just so many pending appointments throughout the state. She mentioned there is no problem or controversy with the council. Terri advised APD is fortunate in that Stephanie has been working with the same contact person at the appointments office for over a year.

**APD Chief of Staff** - Terri shared the agency has a new Chief of Staff. Her name is Tamara Yang Demko. She started on October 31<sup>st</sup>. Terri mentioned that when she has an opportunity to meet with her, she would like to discuss FCC with her. Betty Kay shared that she would send Ms. Demko a letter of congratulations and an invitation to attend an FCCF meeting, if travel is allowed. Betty Kay thanked Linda, Terri and Stephanie for taking the time to talk with the council this morning.

#### **IV. AARON NANGLE – WaiverProvider.com – Communications, Resources**

Betty Kay introduced Aaron and shared with the council she had the pleasure of having him attend an Area 13 council meeting. He has been doing some wonderful things with his websites. Aaron shared he owns an internet company, Clear Choice Web Solutions. He began creating the waiver provider websites because his wife is a support coordinator. He has a brother with a disability who lives in Indiana. He shared you can go to one of his websites titled WaiverInfo.com which will give you links to the waiver programs in all 50 states. Also a website he created is FloridaGroupHome.com which gives information on statewide group homes. Group home providers can place an ad on the site. The two most recognized websites he created are WaiverProvider.com and SupportCoordinators.com. He advised they have a waiver news blog. He has invited several different companies and organizations to provide news related to the waivers and various things going on throughout the state. He suggested that any FCC council can be invited to go on the site and write about what's taking place in their area. It's a great way of getting recognized for free. Anyone interested can E-mail Aaron and he'll add your name and send you instructions. It's very easy to do. The E-mail address to send to him is:

[Clearchoice07@aol.com](mailto:Clearchoice07@aol.com). Aaron shared that he has sent out newsletters via computer to over 20,000 people around the state of Florida by the push of a button. Sure some people don't have access to computers and the technology but consumers/families on the waiver all have support coordinators, providers, and people caring for them that do have access who can print a copy a give to them. The internet is a very powerful tool. Aaron shared that all FCC's need to get their E-mail addresses together into a statewide E-list. Put them all in one long list. Once that is done, name a contact person who can meet with Aaron and he will show the system and how easy it is. Beverley is volunteering to become the contact person. Aaron shared his wife actually started the support coordinators website because she was unable to find resources and get information. As his wife took on more caseloads, etc. she became frustrated with not enough time to work on the website. Aaron then agreed to take over the website as it was a great tool to help people with disabilities throughout the state of Florida. Then he created the waiver provider website. He started calling providers himself asking them if they would be interested in having a listing on the website so people can see their information for \$20.00 a month. Many agreed which resulted in an active, beneficial website for people with disabilities. He does screen the providers and if there is something on a listing that he doesn't find appropriate, he will delete their listing. Patty mentioned to the chairs, and share with chairs not in attendance, if anyone feels they need training on any computer program, it's definitely within the purview of the FCC to fund that cost. Aaron advised that during an upcoming meeting he would be glad to bring up the system to show everyone how to

use it. Aaron shared that he has developed several information fairs in the state. The most recent was in Area 8 and was a big success. He sends out invitations to everyone on the waiting list and the waiver. He has called various companies advising if they would be willing to pay the cost of stamps, he'll include a business card ad for the company on the invitation. He charges providers \$50.00 a table. He provides free tables to groups and organizations such as Family Care Council, Special Olympics, APD, etc. He does the major legwork to put on the fair himself, buys door prizes, food, DJ for dance afterwards, etc. Aaron advised if Family Care Council wants to have an information fair with him, contact him. Betty Kay shared the need to start finding outside community resources. Aaron advised there are many things the Family Care Council could do to get recognition, as many people don't know about the councils. Beverley shared that Aaron has been responsible for the positive impact and the changes in her daughter's life just since May. She really commends Aaron for all that he does because it's the right spirit. Aaron shared with everyone the Five Wishes pamphlet and what a wonderful, inexpensive tool for families to use to document their wishes (decisions for future care, medical treatments they want or don't want, how they want people to treat them, etc.) for the future of their loved one. This is particularly beneficial for individuals who are unable to make decisions for themselves. It is a legal document.

Aaron was asked to give some information about the chat room. He started the chat room where everyone to come, without giving their names, and communicate with one another. Unfortunately, he has seen a bad trend over the past few months where people are giving other people a hard time and chasing them off. He doesn't like this so he has locked the chat room. He is asking for any thoughts from the audience. Patty shared it was a good beginning but went downhill from there. Aaron shared it is a good tool if people treated it properly. The only way it will work to everyone's advantage is if there are one or two people on the call each week that would identify themselves as the host. That person's responsibility would be to help answer questions and keep the call on a positive note. He wondered if FCC's would be interested in doing this. It would be another way the FCC could get their name recognized. Betty Kay asked Aaron to keep FCC's in mind as to anything he thinks would be of benefit to the councils. Aaron advised his main goal is getting the news and information out there for individuals and families so they can learn how to advocate for themselves.

Betty Kay thanked Aaron for attending the meeting and providing everyone with some great information and ideas. She also thanked him for the great work he is doing for people with disabilities. Everyone agreed with their applause.

## **V. DIXIE SANSOM – Legislative Lobbyist for Florida ARC**

Chair Clements introduced Dixie. Dixie shared she is currently the Legislative Lobbyist for Florida ARC. She shared some background information about her, which includes a variety of employment positions within the disability community. She became involved with the state legislature by being a reporter while working on disability issues with state legislators. She shared that developmental disabilities and ARC have a very special place in her heart and life. She mentioned that Betty Kay has asked her to speak about the importance of contacting legislators, formulating positions, attending legislative committee meetings, writing letters and discussing the ARC legislative platform. Dixie provided everyone with a copy of the most current listing of State Senators and House Representatives, which includes their name, district, party affiliation, and Counties they represent. She mentioned the importance of working with the legislators. She advised the asterisks on the sheets indicate new legislators. The six new State Senators have all previously served in the House of Representatives. Therefore, they are not new to the legislative process. She shared that State Senator Andy Gardiner from Orlando will be a great supporter of DD issues. He was the lead person on the House side who chaired the select committee that worked on the Autism Spectrum legislation. The House bill was approved over the Senate version, which was inclusive to all developmental disabilities. Dixie shared that committee assignments have not been issued of yet in

either the Senate or House. She shared the organizational session will begin this coming Tuesday, Nov. 18<sup>th</sup>. She advised that usually it's around the 1<sup>st</sup> of December before committee assignments are made. She mentioned 36 of the 120 members of the House are new members. Dixie stressed how important it is to make arrangements to meet with your legislators, especially the ones that have been newly elected. She shared the two legislative website addresses: The House website is [www.myfloridahouse.gov](http://www.myfloridahouse.gov) and the Senate is [www.flsenate.gov](http://www.flsenate.gov). An important source of each website is the individual bios of each Senator and House Rep. Much information can be learned about the legislators from their bios. Dixie shared if at all possible within each area council, it would be very beneficial to send a personal letter to the legislators, especially and most important, the newly elected legislators. She would recommend not sending E-mails as they get lost in the hundreds each legislator receives. Dixie shared it is also important to get to know the legislators staff. You will be working more with them and they can be very helpful to you. The most important thing is to develop and cultivate your ally system as soon as possible. There is much pro and con talk among the powers that be about declaring a legislative special session in January. Dixie mentioned another important thing that she can recommend is to keep your legislative platform as concise and limited as possible. She shared that the ARC has identified four top issues to advocate for during the session. Their platform includes listing the issue on the left side of the paper and the ARC's suggestion for a solution on right side. The solutions are:

- Funding for children and adults with developmental disabilities must be held harmless this year by the Florida Legislative.
- Create a system supported by dedicated revenue streams.
- Mandate a full review of the current system and remove unnecessary rules and regulations, which increase the cost of services and consumers resources.
- Move the service system to individualized budgets with a more cost effective means for families to access the most necessary services.

Dixie shared that Wednesday, March 18<sup>th</sup> will be the ARC of Florida Legislative Day in Tallahassee. This is a great opportunity to visit personally with the legislators and their staff. If at all possible, plan to attend the event. Dixie reviewed the ARC's legislative platform. Dixie asked if everyone was familiar with The Advisor, a listing of all state legislators in booklet form created by the Florida United Businesses Association. It is a very valuable resource. Another resource is called the Clerk's Manual and costs \$5.00. Periodically you can make a phone call to the Clerk of the Florida House, phone number 850-488-1157 to find out when it will be available and order it. It won't be available until the 1<sup>st</sup> of the year. It includes each legislator's bio information, in book form, that appears on the websites. She mentioned that House Rep. Peter Nehr has a son who has a developmental disability. He's from Pinellas County. Chair Clements asked how to order the FUBA directory. Dixie suggested contacting Debra Linton at ARC or the phone number is 850-681-6265. Dixie hopes the information she has shared has helped everyone in some way. Everyone agreed that it has. She shared again the importance of getting to know the legislators. They may not always agree with us but at least if we can get them to at least think about us. We all have to make individuals with disabilities and their families' needs personal to as many legislators and their staff as possible. Patty shared her concern that in the future she sees a big division coming between developmental disabilities and autism, not just in Florida but across many of the states. Autism Speaks has the money backing them and they are part of the Autism task force. She feels they are driving everything to the same Autism Speaks desire. Dixie compared what is happening with Autism, in developing its face for itself, to what took place years ago with Mental Retardation. She reminded everyone the official name of the task force is Autism and Other Developmental Disabilities, although the other DD has unfortunately started sliding off some. Dixie mentioned the high profile people who have come on board to support the Autism cause, Dan Marino & Jimmy Buffet to name a few. Developmental Disabilities need to find high profile people

to be of support. Jean Sherman mentioned that Gloria Estefan is a supporter of Best Buddies. She might be someone to ask. Frank mentioned all that Jerry Lewis has done for Muscular Dystrophy. Chair Clements asked if anyone had additional questions. She shared having Dixie speak and share the ARC platform is a great lead in for everyone because FCCF needs to develop their platform. She has provided us with excellent information on how and the importance of meeting with our state legislators. Dixie shared the waiting list over arches everything. Chair Clements thanked Dixie and everyone agreed with their applause. Dixie shared that on behalf of Debra and the ARC, they all look forward to working with Family Care Councils.

## **VI. WORKING GROUP UPDATE**

**FCCF Fact Sheet** - Chair Clements shared it had been previously discussed the need for FCCF to develop a Fact Sheet that would include some items such as Tiers. She had sent out a request for people to send her some impact statements on how they thought the Tiers would affect them. It obvious the process within APD is still happening. Chair Clements asked Jean to give a summary of what was discussed during the working group meeting. Jean shared that because there was so much information going around during the legislative session last year, it became overwhelming to the legislators. It would be better to come up with something consistent that could be used throughout the year with our contacts with legislators whether now, during session or anytime. Since the tier implementation is having such an impact statewide that having information from one district is fine but showing how it's affecting the whole state is much more impactful to these legislators to see what they actually accomplished by doing this. The problem is because this is just starting to be felt and seen now and many families don't yet understand what the impact is going to be until the hearings begin and the process going on in Tallahassee. In order to begin collecting this information, families have been asked who understand if their loved one has been placed in a lower tier what they have lost and what it means to the lives of the individual and the family. And now the cost plan rebasing will be another impact that wasn't even known when they talked about developing the fact sheet. What is needed is some real, selected, concise statements of the impact of what has been happening to the people being served on the DD waiver as a result of the action of the legislature last year, we can very least help for stall any further cuts and get them thinking about un-doing some of what they have done. She shared the legislative platforms are different from the proposed fact sheet. Chair Clements mentioned that Aaron shared that what he is finding is people thinking that they sent the appeal and that will take care of everything. That may well be the reason that more people have not contacted FCCF with their impact stories. Jean shared that she asked at her council last week for people to list some basic facts which includes, no names, age, sex, disability diagnosis, what services they were receiving, what tier they have been placed in, what the loss was and what it will mean to the person. The parents in attendance agreed they would get the information to Jean. Chair Clements suggested that everyone do the same thing with their councils and also include support coordinators. This is not going to be an easy task and the council is not going to have much time. Jean stated the sooner the better, but most likely since the hearing process hasn't started yet, the earliest could be February. Frank shared it's very important that we obtain accurate information for the fact sheet. It may be more logical to find the people who have been denied a hearing. Lynn asked if families can write their personal stories and deliver to their legislators themselves. Jean mentioned that is what was done last year and it didn't seem to have any impact. Patty mentioned that individuals can do whatever they feel necessary to do. What is being suggested here is what the statewide council can do.

**Legislative Platform** – Chair Clements asked how the council should handle developing the FCCF platform. She mentioned we have the ARC's as an example. She shared that Maria attended a consortium made up of many agencies that brought with them 3 different ideas that specifically related to their platforms. Chair Clements will gather the additional information and send out to everyone via E-mail to review. Any ideas can be sent to Chair Clements. Next step will be a

working conference call to develop a draft of ideas to be included in the platform. Chair Clements emphasized the need to have this so it can be voted on by the council members. Jean suggested making a list of topics, send them via E-mail and have everyone rank the most important ones. Then focus on the top 5 or 6. Frank mentioned the importance of including a solution as ARC has done. Everyone agreed they liked the ARC's format. It was mentioned that area Family Care Council's may want to use, and should be encouraged, to use the FCCF platform.

**Family Care Council Florida By-Laws** – Chair Clements advised that yesterday during the working group meeting the attendees reviewed the By-Laws. There is a copy in everyone's folder. The only change recommended is listed under Article VI: Meetings, item 3. It was agreed to change "A quorum shall consist of 50% of the participating councils" to "A quorum shall consist of a **simple** majority of the participating councils". The following sentence shall read "A **simple** majority of members present and voting is required to take official and final action on a matter before the council". This also results in a change under Article IV: Membership, item 3 which now reads "a quorum shall consist of a **simple** majority of voting area/region Family Care Councils. Beverley makes a motion to add simple prior to majority wherever it appears in the by-laws. Frank seconds the motion. No discussion. The motion was approved by consensus.

**PCA Hourly Rate** - Patty wanted to bring to the attention of the chairs. It's important to pay attention to any complaints you may receive. She shared in working with APD and AHCA there was a Home Health Agency that was providing PCA and when they failed they were only being paid \$9.70 per hour for PCA. The PCA hourly rate is \$15.00 per hour. If they can't get the billing to go through they are to call Sherry Jackson at APD or Pam Kyllonen at AHCA.

**World Congress On Disabilities** - Maria reminded everyone the World Congress on Disabilities Expo will be held in Jacksonville on November 20<sup>th</sup> and 21<sup>st</sup>.

## **VII. ADJOURNMENT**

With no further business to come before the council, Frank makes a motion to adjourn the meeting. Beverley seconds the motion. No discussion. The motion was approved by consensus.  
Meeting adjourned: 3:30

The next meeting will be held on January 17<sup>th</sup>, 2009 at The Holiday Inn Select.

**RESPECTFULLY SUBMITTED,**

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