

FAMILY CARE COUNCIL FLORIDA
FRANK CARROLL, VICE CHAIRPERSON
Holiday Inn Select Orlando Airport
Orlando, Florida
July 18th, 2009

MEMBERS PRESENT:

Frank Carroll, Vice Chairperson, A3 Chair
Patty Houghland, Past FCCF Chairperson
Lynn Carper, A1 Chair & FCCF Secretary
Tracy Stewart, A2 Chair
Joanne Rydzewski, Suncoast East Region Rep.
Beverley DeStories, Suncoast West Region Rep.
Donna Rauber, A7 Representative
Jean Sherman, A10 Chair
Phil Pearson, A12 Representative, FCCF Treasurer
Manny Champavannarath, A14 Representative
Nancy Moody, Area 15 Chair

STAFF & GUESTS

Jim DeBeaugrine, APD Director
Patricia Hayston, Suncoast Region Guest
Ruth Wingate, Area 15 Guest
George Boulahanis, Area 15 Guest
Brian Boulahanis, Area 15 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

Vice Chair Carroll called the meeting to order and welcomed everyone. He asked Patty to review the contents of the information packet, which includes the following:

- National Assn. of State Directors of Developmental Disabilities Services (NASDDDS)
Patty shared there is a great deal of information on their website <http://www.nasddds.org>
- Copy of Powerpoint presentation titled “Supporting Families who Live Together” also from NASDDDS website
- Response to SB1660 – Wait List Priorities
- FCC12 Suggested Recommendations for revising APD Wait List Maintenance Procedures
- APD Waiver and Wait list data – Source: ABC Database as of 9/1/08
- Legislative Time-line from FCCF Legislative Committee
- Legislative Talking Template from FCCF Legislative Committee
- Wait list data by Age and County – Source: ABC database as of 6/1/09
- FCCF Financial Information

Vice Chair Carroll asked for introductions and include any FCC news they would like to share.

II. BUSINESS

Review of Minutes – Vice Chair Carroll asked if there were any corrections to the minutes. Patty asked Donna if she received any corrections. Donna advised 2 typos which have been corrected. Phil makes a motion to accept the minutes as corrected. Beverley seconds the motion. There was no discussion. The minutes were approved by consensus.

Treasurer’s Report - Phil referred everyone to the FCCF Financial Information sheet in their information packet. He has summarized the projected 2009/2010 budget into Income and Expense categories. Total income for the year is \$9,096.00 which includes beginning year FCC donations and pre-paid room from some areas. Total Expenses for the year is \$15,071.64 which includes meeting room and miscellaneous expenses. This results in a negative balance of \$5,975.64. He is requesting that all councils consider an additional donation to the FCCF. It’s

important to make this additional donation as soon as possible as it takes time for the transfers to be made. The earlier the donation is transferred the better opportunity of using the dollars before year end. He asks each council to consider donating an additional \$500 or \$1,000. Phil advised that hotel expenses to the FCCF meetings are prepaid for areas 5 (Suncoast Region West) and 13. Both areas need to get approval from their councils to transfer dollars to FCCF to cover the hotel expenses. Jean suggested that it be required that each council who can donate additional dollars makes the transfer no later than September.

Patty shared that Stephanie is contacting all the hotels in the current area where we meet to see if FCCF can get a cheaper rate. The stumbling block could be the individuals that uses the APD PO card. Many of the hotels no longer accept this type of payment. Discussion followed indicating satisfaction with the current hotel. Manny asked if they could find a hotel with a decent accessible public restroom. The one here is not accessible for people using wheelchairs.

Old Business:

FCC Appointment process – Patty shared that Stephanie has worked very hard to get a clear understanding of the appointment process. She passed around a copy of the letter that is sent to members whose term is about to end. Patty indicated that each council who has seen the Governor's Appointment office list of FCC members has seen names of people that haven't been involved in the area councils for years. The names had not been removed for whatever reason. Jean asked if there was a protocol in writing. Patty shared whoever you see on the membership list who no longer participates must write a letter of resignation and send to the Governor's Appointment office. That name will then come off the master list. Jean asked that all Council Chairs be sent a copy of the Governor's Office of Appointments list of FCC members, so that we might review these names locally. Discussion followed stating there is nothing within the letter to indicate that if a person doesn't want to continue on the council they need to send a resignation letter. There needs to be written procedures. Patty added that if a member is at the end of the six years he/she has the option of resigning or the option of staying on the council until replaced. Patty advised each council needs to review the list and if there are inactive members on the list to contact them asking they write a letter of resignation. Patty explained this procedure is for all Governor appointed councils or boards.

III. APD UPDATE - Jim DeBeaugrine, Director

On Conference Call: Stephanie Rogers, Liesl Ramos & Hilary Brazzell

Vice Chair Carroll introduced Jim and thanked him for taking the time from his weekend to meet with the council. Jim began by sharing how much he values the Family Care Councils, which is why he is at the meeting. The Councils are the lawfully established group set up to give APD input from consumers and families across the state. He believes that is the most important perspective of them all. It's a relationship he wants to continue to nurture, have good communication back and forth and he believes it's important that he attend FCCF meetings whenever he can. Jim shared he had the pleasure on Friday of interviewing three finalists for the Area Seven Administrator. He introduced his choice, Merari Perez who has been the acting administrator since February and has done a great job in Area Seven. He mentioned she is very supportive of families. Jim wants APD to become more a part of the community. He wants to see a little more emphasis on networking with grassroots and charitable groups as a way of becoming part of the community not just an isolated bureaucracy. Jim shared it is a real pleasure to have Merari at the meeting today. Donna shared with Jim she represents area Seven on the FCCF council and on behalf of Area Seven FCC he made a good choice.

Jim advised there is a lot going on within the agency. They are working feverishly on the legislative mandates.

CDC+ Expansion - Jim advised they have a fairly well defined work plan in place right now for expanding the CDC+ program by 2500 people. He asked Liesl to verify the dates of enrollment.

Liesl advised right now they are planning to announce open enrollment on August 1st. They hope to receive feedback from interested people by September 15th. The dates are subject to change depending on completion of the rule development, which is being developed with AHCA. Liesl mentioned the letter will be sent to over 20,000 people. Jim mentioned if more than 2500 people reply they will need to do a random selection. The current plan then is to begin the process of enrollment on October 1st. The savings that will result from people changing to the CDC+ program will be used to get people off the wait list.

Flexible Benefit – Jim shared the flexible benefit is kind of like the CDC+ program as it provides an opportunity for some flexibility. It will be more like a voucher than a bank account. In the CDC+ program the person in essence becomes a small business. The flexible benefit would be different in that it would still be through the traditional Medicaid payment mechanism. You would continue to use a regular Medicaid provider but could work with the provider to specifically negotiate a package of service within the array of designated services. The services include ADT, supported employment, in-home supports, respite, companion and supported living. They would take the aggregate value of services requested less 8% then put that into a flexible benefit which would allow the person to vary the precise mix of services without having to go through a prior service authorization. Jim shared that he plans on asking for approval to allow people in tier 4 to use the flexible benefit for dental.

Individual Budgets – Jim advised another mandate required by the legislature is to develop a plan to transition the financing for the APD program to individual budgets. What it basically does is turn the current assessment and budget setting process upside down from its current process. They have determined, using a few different models that with individualized budgets they can actually predict with a great deal of accuracy how much a person spends. What has been used to determine this is the 3 score elements of the QSI assessment tool, where a person lives, the person's age and the primary diagnosis. Jim advised how this gets turned upside down is they will take a statistically valid model which results in the person getting the budget up front. A dollar amount will be assigned based on the individual characteristics of the person. Once the family gets the budget amount they will work with the support coordinator to develop a support plan. This is another way to incorporate the principles of CDC (self directed part of that) without forcing everyone to be a small business. It also promotes equity in families because there will be much less opportunity and incentive for people to game the system. Phil mentioned if APD can get predictable costs from those four areas, that means APD can look at the wait list and give legislators a prediction of what it will cost to take care of wait list people. Jim agreed. Beverley asked about behavioral issues and where does that factor come in to the projected budgets. Jim and others mentioned through the QSI assessment. Beverley indicated she is not comfortable with the behavioral assessments within the QSI. Jim asked Hilary to address the issue. Hilary advised the QSI behavioral section is defined to address some of Beverley's issues but it's only one element. Another element will be through primary diagnosis. Hilary mentioned it's a good question and she has made note of it to research. Jim emphasized the details of actually what's going into this model are still being worked on. There will be a public and open discussion as to the variables that should go into this process. Hilary mentioned they are trying to find more variables and ones that center on people with intense behavioral needs are some of the factors they are looking for. She welcomes suggestions. Jim advised APD is required to have this plan to the legislature by February, 2010. They would be looking at some smaller pilots to start with which conceivably could be implemented in the next fiscal year. Jim emphasized the one thing you don't want to do with something like this is rush it. It must be done right to begin with. He doesn't expect full implementation until the following fiscal year. This is for the future. This is for creating a benefit within the system that will be there 10 – 30 years from now so they want to take the time and do it right. Jean wondered while the tiers are still in existence as APD comes up with this model, will it have to be considered within the tier framework, or totally separate

and a part from it? Jim advised he plans on showing the legislators what it will look like without the tier framework. This new process should show them that it's an actual, accurate assessment, if done properly. Patty asked Jim if this plan needs to be presented to the legislature by February, how do you plan on getting family and others input. Jim advised there will be six public hearings around the state. Hilary shared they are still planning and hopefully there will be more. There will be 2 sets of hearings, one hopefully in August and early September to introduce people to the concept and get general ideas. Later in the fall they hope for another set of hearings to provide more concrete options for people to react to. Hilary mentioned they will have a website and their own E-mail address. Jim shared the name for the process will be called iBudgetFlorida. He also mentioned they would like to get feedback from a smaller group of stakeholders. He suggested that FCCF sponsor that workgroup. APD would agree to pay for any travel expenses. He believes FCC is a good forum to have that stakeholder's discussion. It would include representatives of the provider community. Ruth asked how pilot sites would be determined. Jim advised it would depend on multiple items. He mentioned wanting either a small area such as Northwest Florida or a small random sampling from across the state.

Senate Bill 1660 – Wait list - Jim advised another issue that will result in public hearings around the state is a SB 1660 – Wait List Prioritization. Phil actually helped draft this law. It will create a new way of prioritizing the wait list. It will no longer be based on chronological order. It will put people on the wait list based on one of seven categories. These categories will then determine the order of priority among different groups of people. Within the categories it will be based on chronological order. Jim briefly reviewed the categories. They will have to do rule development and promulgate to implement this. Even though the legislature enacted this into law, it will not be implemented until July 1st, 2010. This gives APD the opportunity to go out during the rule development process and if there is something APD or the legislature didn't think about that could be an unintended dire consequences it would be revealed during the process. If this were to happen they would have time to go back to the legislature and he believes they would work with APD to tweak the process. Unless they come up with a better idea, come July 1st, 2010 this will be implemented the way its written now. Jim advised that is why it's so important to get the word out to people whose interests are going to be affected by this. He shared because of this how important it is for area offices to become more involved within the community. He really wants to develop and nurture partnerships with groups in the community that have the resources that are able to bring those to the table and collaborate with APD. It is so important to bring the interests of the wait list people into the discussions with outside groups. Jim is asking the Area Administrators to create a full time position to help them go out and identify resources and communicate with families on the wait list. Or, another solution would be to look at current staff and reprioritize positions in each area office. Patty asked Jim that when they have a person identified in each area office to share with the FCC's so they know which person they could partner with in finding these resources. Jim agreed to do this.

Supported Living Workgroup – The purpose of this is to identify where there are redundancies, where they can possibly streamline things better than they are doing now. That is something they will take back to the legislature.

Supported Employment – This change is required by statute and is directing APD to develop a means of scaling back supported employment service if a person has been in a stable job placement for 3 years or more. Phil mentioned that currently SE is available only for people on the Medicaid Waiver. He suggested APD consider using SE services to help people not on the waiver. Jim shared his point is very well taken. Ruth Wingate asked Jim if there was any way to waive the SE requirement of scaling back SE services after 3 years of stable employment. She knows of people in her area that have been employed for many years solely as a result of the SE service available to them. Jim advised it's the statute that requires them to come up with a plan. He will pass this along to the people working on the plan.

CDC+ Expansion – Liesl mentioned they would like to request the assistance of Family Care Councils. When they send out the CDC open enrollment letters they would like to include in the letter a list of area Family Care Council meetings in August and/or September that can be devoted to a forum/training of the CDC+ program. They would have APD staff in attendance to answer questions about the program. If the councils are in agreement could they send her a list of times and locations to be added to the enrollment letter. Patty asked when they are planning on sending the letter. They are hoping to mail it on August 1st but that's contingent on AHCA's ability to post a notice of rule development. Beverley asked Liesl to send an E-mail to all the FCC chairs requesting dates, times and locations of meetings. Liesl agreed to do this. Patty asked Liesl to make sure the information on the CDC+ website is up to date. Liesl advised they are currently working on a redesign of the website to make it more consumer & user friendly. Jim suggested in the meantime they can go to the current website and pull things off that are no longer applicable.

Wait List/Waiver Statistics – Phil asked Jim if the council could start receiving electronically statistical information on the wait list and waiver that had been provided in the past. Jim asked Phil to send him an example of the documents and he'll see that it gets done.

Vice Chair Carroll shared with Jim how much the council appreciates his taking the time from a very busy schedule to attend our meeting. The audience agreed with their applause. Jim turned the meeting over to John Newton, APD Legal Counsel who joined the group via conference call.

APD Hearings - Patty shared with Mr. Newton that a couple of council members are in limbo, along with other parents statewide, who requested a fair hearing. It was acknowledged that the request had been received but they haven't heard anything since. They are concerned that possibly their information has been lost or misplaced. Mr. Newton advised the volume of request for hearings has slowed them down considerably. If people have a request for hearing and haven't heard something that means processing of the request is not complete. The key is if there has been a change in services. If someone has a request for hearing and haven't received notice yet and somebody is trying to change their services APD needs to know about it. The process is slow and he apologizes but the volume is unprecedented. People will receive a notice that their request for hearing has been referred to the Division of Administrative Hearings or they will receive an order from the Agency advising of their rights to amend or appeal to a District Court of Appeals. In any event, they will have plenty of time to work with their waiver support coordinator on any decision the agency makes that requires a change. Jean and Beverley shared with Mr. Newton the problems they have experienced with the hearing process. Mr. Newton indicated to both to contact him and he will pursue the issue from his end. Patty thanked Mr. Newton for taking the time to call in and answering questions. Mr. Newton emphasized that lawyers in his office are trying to get through the process as quickly as possible. They realize it is an extremely stressful time for individuals and families. He stressed that any time you believe there has been a mistake in any form, please let them know.

IV. WORKING GROUP AND OTHER MEETING REPORTS

Patty distributed copies of the area Legislators by area. She thanked the legislative committee for doing this.

Meeting with representatives from other organizations - Vice Chair Carroll turned this portion of the meeting over to Patty. Patty advised in attendance representing Florida ARC was Deborah Linton, Dixie Sansom and a couple of other attendees. Representing FDDC was Debra Dowds. The purpose of the meeting was to discuss issues and concerns that we have in common. Issues all three groups could partner with and present a united front. They agreed to support the following issues:

- The Wait List - Phil suggested a separate lottery to fund the wait list. It could be either a one time lottery ticket or a special scratch off ticket. Patty advised that Phil and Deborah

have the lead on researching the issue. It was agreed upon by all they need dedicated funding for the wait list.

- During next legislative session DD funding needs to be held harmless.
- Flexible and Individualized budgets – They all agreed these are good ideas that should be pursued.
- Use QSI Assessors to provide Case Management services to wait list families. Patty shared the QSI assessors are about half way through the wait list. Once they are through the wait list, what will they do? It was decided at the meeting it would be a good idea for them to be assigned as coordinators for people on the wait list. It would result in more personal attention or they could do the research for finding community resources.

Patty shared another issue discussed related to the DOE prone restraints rule. She mentioned there is a conference call pertaining to the rule on Monday afternoon for anyone interested in participating. It has been proven that the use of prone restraints can lead to accidental asphyxiation or sudden cardiac death.

HCBS Waivers - Patty shared The Centers for Medicare and Medicaid (CMS) are announcing proposed rulemaking to consider amendments to the regulations implementing Medicaid home and community-based services waivers under section 1915(c). They want to open up the waiver so it doesn't have to be disability specific and could include the aging population. Patty advised comments must be received no later than August 21st. She will re-send the E-mail with the information and instructions for sending comments.

Wait List - Phil mentioned at the last meeting he sent each council member back with two items pertaining to the wait list. He asked they be shared with each council, report any suggestions and be ready to take a vote at July meeting for FCCFlorida to support or not support these issues.

- **Response to SB1660 – Wait List Priorities** – This pertains to the re-prioritization of the wait list. He shared some background information of how he became involved in the process. He wanted to see it based more from the families' perspective, specifically on age and how it affected the family. Phil has asked the FCCF council to support this legislation. Tracy mentioned she has a couple concerns. Beyond age (caregiver or person) there really isn't any ways to grasp need. She believes there has to be a better way so that in addition to age it includes medical, behavioral, or whatever the persons' needs are. Everyone is different but there are some real complex cases out there. She believes the current list of categories is a really good start at prioritizing but she doesn't feel it's complete. She is concerned about a sub-group of children with significant disabilities that might need catastrophic needs, which under the current list would fall into the last category. Her other concern pertains to any person that moves into the state that is over the age of 21 automatically bumps past every single person whose age is 20 or less on the wait list. This doesn't seem fair. If you have a child that has been on the wait list for years, an adult that moves to Florida from another state shouldn't have the right to immediately trump them. Tracy shared she really can't support it at this time because it really doesn't capture the risk and the need completely. It's a good start. Beverley reminded everyone that Jim did mention that input and workshops are going to be promulgated over the next 12 months. The concerns expressed by Tracy will come forward at these venues for discussion and change. Because it is such a good start, Beverley shared that she will support it from that point and let the process that is in place bring out the concerns. Tracy shared she understands and agrees with everything Beverley is saying but she is not willing to support it as is. Donna mentioned that at the last meeting Phil had asked each council member to share the wait list priorities with their councils and E-lists. He wanted comments. She asked Phil what kind of response he received. Phil replied he received numerous comments that ranged from thanking him

for taking on an attack at re-prioritizing the wait list to the need to switch category 5 and 6. Older people have commented sharing they believe with the change there is hope. Phil would like to see the council approve this as a good start, stating we support re-prioritization. Then go back and work on seeing what ways it could be changed. Phil asked to call for a vote. It was determined there is a quorum. Phil makes a motion that the council support the wait list priorities position and address changes later. Beverley seconds the motion. Discussion followed making sure changes can be made and presented to the council at a later date. No further discussion or questions. The motion was approved with one negative vote.

- **FCC12 Suggested Recommendations for revising APD OP 04-004 – Med waiver Wait list Maintenance Procedures – 1/3/09** - Phil stated a part of the FCC charter is to review and give feedback on APD procedures. The Area 12 FCC looked at the APD procedure for the wait list. There was nothing in the procedures on how they treat people on the wait list. Their council voted to brainstorm on procedures they would like to see APD do for people on the wait list. They wrote a letter to Jim DeBeaugrine sharing suggested recommendations for revising their wait list procedures. He would like to see FCCFlorida support these recommendations. Phil expressed this is a living document that can be changed. Discussion followed with some suggestions for change. Several people had a problem with using the word “will” in each category (ex. APD will...). It was suggested maybe to change to “should” or remove APD and replace with We (ex. We will...). Vice Chair Carroll reminded everyone the council can recommend any and all of these but it doesn’t preclude the agency from writing their own which may or may not include any of these recommendations. Phil asked if everyone wanted him to rewrite it and tone it down a bit. Everyone agreed the items are good but not be so directive. Phil asked if the council would support a set of recommendations to support the wait list procedures based on this list. Everyone agreed they would. Phil agreed to rewrite it and send out to everyone via E-mail. He stressed that this type of editorial conversation needs to come prior to the council meeting. It becomes to time consuming. He needs these types of comments prior to the meetings. He hopes that all the changes can be made prior to the September meeting so the final document can be voted on. Vice Chair Carroll urged everyone if they have ideas for change send to Phil.

Donna shared the subject of FCC councils being unable to communicate with people on the wait list because HIPPA law requires APD not to release contact information that came up a few minutes ago as well as at last meeting. She wanted to share with everyone the document they used to establish their own FCC mailing list. The document was given to intake coordinators and support coordinators who gave it to families who filled out and returned to the council. She mentioned the same type document could be used for contacting people on the wait list. She was asked if it could be E-mailed to everyone. Donna advised she didn’t have it in her computer. Lynn shared she would scan it and send out to everyone via E-mail. Patty advised APD will be having quarterly meetings with people on the wait list. They have to mail out notification. Area 1 FCC council is providing a stamped postcard in that mail out and inviting them to become a member on their E-mail and mailing list. Beverley suggested that a recommendation be made to Jim DeBeaugrine to include a postcard in the mailings through the state. The local FCC’s could pay the postage. She stressed this is a great opportunity for all councils to build their FCC’s.

V. LEGISLATIVE COMMITTEE REPORT

Phil, chairperson of the committee, advised the committee has had a number of meetings. In addition to Phil, members of the committee are Patty Houghland, Anna Brynild, Sharon Berry and Tracy Stewart. The following is included in the information packet:

- Legislative & FCCF Time-line – A description of important dates and duties to accomplish beginning in March, 2009 and continues through May, 2010
- A list of Key Players within the Legislature
- Legislative Talking Template with attachment Florida Statute 393.502 – Family Care Councils
- FCCF Legislative Platform 2009-2010

He suggests meeting with your legislators, share with them what appears on the template and talk to them about the FCCF platform and any other issues of importance. He asks every council as a goal to meet with a legislator (either Senator or Representative) in your area. It was suggested to take your loved one with you if controllable. Phil wants to see at next meeting a report from each council of the legislators they have met with. It should include a brief summary of the visit. Jean asked if Phil would send the documents to everyone via E-mail. Phil mentioned he has met with a number of legislators and in each situation he was given a half-hour of their time. Jean mentioned if it becomes a problem of being able to meet with the legislator, meet with their legislative aide or chief of staff.

Phil advised the legislative committee will continue to meet via conference call. They will be developing the FCCF position. At the next meeting, they will present a new set of data. They want to be in a position to support or suggest a bill. Jean suggested the council focus on one main priority.

Beverley shared how proud she is of Phil and his committee on the amount of work they have accomplished to provide the councils with this information.

Vice Chair Carroll advised they were told at the workgroup meeting yesterday that legislative committees will start in October 2009.

Vice Chair Carroll asked if there was any further old business before the council. He asked if there was any new business. Tracy asked about the Prepaid Services Plan group. She wondered who is representing FCCF. She would like the subject added to the September agenda.

Donna asked for clarification of Mr. Newton's reply to her question regarding the hearing process and judges denying ADT programs for some individuals because it is not medically necessary. It is being excluded as a service that will be used as a basis for tier placement.

Discussion followed.

Nancy asked to bring to the attention of the council a resource. It is called Parenting Special Needs and is only on the internet. The editor is from Area 15. She wants some input from parents of older children. The website is <http://parentingspecialneeds.org>

Patty mentioned another good website is <http://disabilitycoop.com>

VI. ADJOURNMENT

Vice Chair Carroll asked if there was any further business to come before the council. Phil makes a motion to adjourn the meeting. Beverley seconds the motion. The motion was approved by consensus. Meeting adjourned at 2:30.

The next meeting will be held on September 19th, 2009 at The Holiday Inn Select.

RESPECTFULLY SUBMITTED,

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