

FAMILY CARE COUNCIL FLORIDA

PATTY HOUGHLAND, CHAIRPERSON

Holiday Inn Select Orlando Airport

Orlando, Florida

March 15th, 2008

MEMBERS PRESENT:

Patty Houghland, FCCF Chairperson
Joy Frazier, FCCF Secretary

Ann Millan, Past FCCF Chairperson
Lynn Carper, A1 Chair
Lynn Daw, A2 Representative
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast West Region Chair
Donna Rauber, A7 Co-Chair
Sharon Berry, A8 Representative
Phil Pearson, A12 Chair
Betty Kay Clements, A13 Chair, FCCF Vice Chair
Laura Tacinelli, A14 Chair
Nancy Moody, A15 Representative

STAFF & GUESTS

Stephanie Khan, APD Central Office
Terri McGarrity, APD Central Office

Lynn James, Area 8 Guest
Maria Eash, Area 8 Guest
Manny Champavannarath, A14 Guest
Amelia Rauber, Area 7 Guest
Rosalind Murvin, Area 7 Guest

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

I. CALL TO ORDER

Chair Houghland welcomed everyone to the FCCFlorida meeting and asked for introductions. She asked that everyone share the area they represent and something positive either with their council or in their personal life. Chair Houghland reviewed the FCCF information packet contents. Items include the following:

- FCCF Agenda
- MRSA Information
- The PAD-CO (Parents of Adults with Disabilities – Colorado) – Parent’s Viewpoints on Colorado’s Developmental Disability Delivery System – An on-line survey for parents by parents. The survey can be found at:
<http://members.aol.com/padcoweb/PADCOSURVEYFINALALL.pdf>
- ARC Florida campaign concerning the waitlist – www.endtheline.org - Chair Houghland shared The Arc of Florida has undertaken a public relations campaign by purchasing advertising “End the Line.Org” on 4 billboards in Tallahassee.
- National Waitlist Initiative – National grass-roots group known as National Organization to End the Waitlist (NOEWAIT) - <http://www.noewait.net>
- A Inspirational Paper titled: Some Things to Think About
- March 7th APD’s Legislative Digest
- A Newspaper Release titled: Governor Crist Announces Task Force on Autism Spectrum Disorders. Chair Houghland advised the first meeting is April 2nd & 3rd in Tallahassee. She has been appointed to the task force. APD Director Jane Johnson and Dan Marino are co-chairs.

Waitlist: Terri McGarrity shared that APD is working with the DD Council to create a survey that will be used to determine the needs of each individual on the waitlist.

CDC+ Program: Frank questioned the following wording found in the March 7th Legislative Digest: “Consumers are very pleased with the new, more efficient system”. Terri shared a memo received by Rhonda Sloan, who has a full time position in the CDC+ program and is a parent. She has been charged with assisting in the transition. She stated “from a parent and consumer representative perspective, this transition was truly a success. After going through each of the transitions in the past this is the first time a process is in place where problems are easily fixed without the individuals needed supports being affected by having to wait a long period of time to get an answer”. Frank shared the people he spoke with were pleased with the fact that APD employees were at work and taking calls that one weekend. Will that continue? Terri advised they are there this weekend. Terri mentioned after having lived through 2 previous transitions this one was 2000% better.

Gift from Chair Houghland – Chair Houghland shared she has a book for each council titled “The Race, Life’s Greatest Lesson” by Dee Groberg. It’s about a father supporting his child with a disability who was participating in a race. The boy keeps falling but he keeps remembering what his father said about keeping the end in mind, keep the goal in mind. She shared as we’re racing through this legislative session and racing through all the cuts, etc. she hopes the book will be a reminder to you and to encourage others that the goal is not to save money, the goal is to make sure the **individual with a disability** is going to be safe and have what he/she needs.

II. WORKGROUP REPORT

Topic E-lists: Chair Houghland advised that because of the extensive amount of information on all subjects being distributed and people becoming overwhelmed with trying to keep informed, the workgroup has created some “Topic” E-lists. Topics include Guardianship, CDC+, etc. She is asking everyone who has a particular interest in subject topics to sign its sheet with name, E-mail address and phone number (if agreeable). She will create a master list of all topics and contact information and send to the FCCF E-list. This will be a better way of conversing very quickly with the folks who have particular questions and interest in a certain subject. She advised each council can add any of their members who have a particular interest in any of the topics.

Legislative Bills: Chair Houghland explained how difficult it is to keep track of the legislative bills pertaining to developmental disabilities. She emphasized the importance of keeping track of SB 2278, Senator Lynn’s bill that would transfer APD from the Department of Children and Families (DCF) to the Agency for Health Care Administration (AHCA). She is very concerned there will be a “strike all” that we will not like. The bill has no house sponsor yet.

FCCF Platform: Ann suggested the need to add FCCF support of the CDC+ Program to the platform. Chair Houghland asked for a motion. Betty Kay makes a motion to add a “bullet” to the FCCF platform stating its support of the CDC+ Program. Beverley seconds the motion. Discussion followed. Beverley wants it noted in the platform language that CDC+ represents a civil right which is the consumers and parents are in control. It’s their civil right. It was agreed to use the wording “keep it as an option”. The motion was approved by consensus. Chair Houghland asked for 3 volunteers to work on the language during lunch break. Frank, Beverley and Lynn James volunteered.

III. CONFERENCE CALL - Jane Johnson, APD Director

Chair Houghland introduced Jane and asked her to share what she can with the group.

Legislative Session - Jane advised the most pressing issue at this time is the legislative session taking place now. They just finished the budget cutting exercise. The first two weeks focus was taking a half billion dollars out of the current year budget. APD did not take a big hit there. There were no cuts to services because APD had taken a hit at the October special session. They feel good about this. The remainder of the session will be directed towards cutting every agency

budget. They do not know where those cuts will come from. In general the legislature is hesitant to cut programs that draw down federal funds like the Medicaid Waiver. Jane shared what support she has received from House representatives, especially Rep. Galvano, but not as much from the Senators. APD will be looking at administrative cuts and possibly further reductions in staff. She stated they just don't know at this point.

Task Force on Autism - Jane shared the exciting news that Governor Crist has announced his new Task Force on Autism. Jane will be co-chairing with Dan Marino. The task force is being charged with issues pertaining to causes, prevention, treatment, services and insurance coverage. It will be a fairly broad scope of responsibility that they are charged with. She is very pleased with the people who have been named to the task force. Jane added that the Governor's Commission on Disabilities continues to meet. She serves on that committee also. They have a final report due to the Governor by July 1st. She shared about the Mental Health Parity bill which would create mandatory insurance coverage for families who have children with Autism. The Commission has endorsed this bill.

CDC+ Program - Jane shared the transferring of the fiscal intermediary role for the CDC+ program from an outside company to APD. It took place about 2 weeks ago with staff working around the clock on Saturday and Sunday. The first payroll was an unqualified success by comparison with PPL's payrolls. She shared they have not perfected it, however, they have certainly developed a system that they think will be successful in to the future. They are very encouraged with what has taken place so far. The new system will allow families to enter their time sheets on-line or via telephone. She praised the entire APD staff for taking on this project and making it a success.

QSI Assessment Tool - Jane shared they are continuing to conduct the assessments at the area level. They have at last count just over 1400 completed. They have hired 70 new OPS employees who have been trained to conduct the assessments. They had to establish inter-rater reliability which is going along on schedule. They still need to develop a formula for taking the assessment results and turning them into a budget or cost plan. That will be done within the next month or two. That will also play a role in determining the tiers each person will be assigned to.

Residential Oversight Initiative - They had teams from Central Office go out into each area to visit group homes to do additional monitoring on top of the 30 day monitoring that areas are currently doing. The teams went to group homes unannounced and double checked what goes on in group homes to determine what the quality of care is like. Also, they wanted to determine if the monthly monitoring is effective and what, if any, additional tools could be given to the area staff so they can do a better job. Jane shared they will be continuing to do this on a regular basis. APD has more than doubled the number of provider terminations in the past 10 months, compared to the prior 3 years. During the group home initiative they found incidents where they had to contact the abuse registry or report findings which they took action on. They will be developing a tool for the area offices to use when they visit group homes so they know what to look for. Everyone will be conducting the same type of monitoring and collecting the same data so they are holding all group homes accountable to the same standards. The recoupment that was finalized late last year is getting some good results. They are using the Delmarva data they have to go back and recoup overpayments or recoup from providers where they find that services have been billed for but the service has not been provided.

Waiting list - Jane shared that OPPAGA has reviewed the waiting list. The Senate has been very critical of the way APD has been managing the waiting list. They are probably going to be asked to move to a system where APD triage the waiting list based on the urgency of a person's needs. They are currently breaking down the waiting list into separate lists as follows:

- People who have been offered services and turned them down,
- Lists based on age brackets,

- People in school on one list,
- People 16 and over on another list because they would be more likely to need services
- People who have been contacted but unable to reach because they haven't kept contact information current.

They aren't quite sure how the new triage will work. Due to the deficit they aren't serving people on the waiting list anyway but if this is the direction the legislature is going to require APD to take she wants to be ready in order to get the word out as soon as possible. When they do start serving people on the waiting list, which she thinks can happen soon, people are forewarned so it's not a surprise for someone who thought they were at the top of the list may no longer be at the top.

Questions for Jane:

Group Home Visits - Chair Houghland asked if a report was going to be developed based on the outcomes of what was found when Central Office visited the group homes. If so, can that be made available to FCC chairs. Jane advised yes but they are still pulling together the data. Once it's complete they will share with FCC's. She would like input from FCC's on additional things they can be looking for.

Recoupment Dollars - Ann asked if Central Office planned on going after the areas that have shown minimal recoupment dollars. Jane advised yes, they are working with the area staff in those locations.

CDC+ - Frank mentioned there is a lot of confusion among CDC folks as to if CDC+ is still considered a program. Jane advised the CDC+ is still a program. The big change they are waiting on is that AHCA has submitted an application to move it from an 1115 demonstration waiver to a 1915 J Waiver. It makes it a permanent waiver so it's no longer considered a demonstration or time limited waiver. APD expects it will gain its permanent status with the federal government in the next couple of months. At that time, APD's plan is to expand it and open it up to more people. Frank suggested rather than opening it up to people already on the HCBS waiver, consider asking the legislature to create slots for people on the wait list.

Redefining 10% Density Rule - Manny asked if it was true that supported living would only be available for people in a congregate living arrangement. Jane guessed that this issue has to do with a provision in the current supported living rule that states in order to get supported living you can't live in a community where more than 10% of the people in near geographical area have developmental disabilities. She shared there are several communities being developed around Florida where families and non-profit organizations have gotten together to build affordable housing for people with developmental disabilities. The current rule doesn't allow APD to pay for supported living in this type of setting. They received a lot of public testimony and pressure asking APD to pay for supported living services in those kinds of environments. They wanted the 10% restriction removed from the rule. Jane advised APD is willing to remove it but in exchange for that they want to tighten up the requirements for supported living. There concern is if you have someone who develops a community, they don't want the developer (or the person who owns the home) to also be the person who provides the supported living because it could limit a person's choice of providers. They don't want people being told they have to use their company to get supported living services. They will remove the 10% restriction but create language in the rule to restrict who can provide the supported living services. Jane shared she has a lot of background in affordable housing development and knowing the market as it is, she thinks it's really unwise of APD to restrict or discourage affordable housing development that is happening now because in many cases it's the only option for people with limited income. She believes APD needs to support that. She believes from an affordability standpoint it is an important option and she thinks it's great they aren't using public dollars and state resources to build these homes. It's a great opportunity for people to get the supports they need in a

community where people understand their needs and enjoy socializing with their friends. Ann commended Jane for working so hard on this issue.

Waiting List - Phil shared with Jane that he is glad to see that APD is looking at revising the waiting list from a chronological order to priority order. He would like to request that APD do something for people on the waiting list right now. His suggestion would be to designate someone from each area to act as a benefit counselor for those folks on the waiting list. These families are alone trying to negotiate how DCF, Social Security, Medicaid, food stamps work and APD already knows how to do all of that. He doesn't think it would cost much to do that. Jane advised it ties in with a grant they received that has allowed them to do training and they already have some staff trained as benefits counselors. She agrees they should have someone in each area office that can do that but she will have to work with the area administrators to figure out how to designate who would and how it would be accomplished. She believes it's a good idea. It was mentioned the need to advertise who the current benefit planners are in each area and not just on the website. This information needs to be made available to people on the wait list. Beverley suggested using 211 to advertise those type things would be very beneficial. Jane shared that is a good idea.

Chair Houghland thanked Jane for her time. Jane thanked everyone for their support and feedback. She added to say your prayers and hope this legislative session works out well for APD. Everyone thanked Jane.

IV. APD UPDATE – Terri McGarrity, APD Community Development

Terri reviewed the APD Information packet contents. They include:

- The new Fight Medicaid Fraud brochure
- QSI Brochures – In English and Spanish
- QSI Priority Order of Assessments – A question was asked about Carlton Palms. Terri shared they are being done. Betty Kay mentioned only because another OPS position has been filled. She thought they were on the priority list. She shared they assessed her daughter before they even began Carlton Palms. Terri advised some of the residents at Carlton Palms were in the initial 600. Terri mentioned Area 13 is leading the state in number of assessments they have completed. Terri reviewed the priority process. Lynn Daw shared the assessment process used by the assessors in Area 2. Terri shared that people can receive a copy of the assessment results from the assessor. Beverley wanted to commend Terri and Lynn for making the family an incremental part of the assessment process.

Wait List Survey Tool - Chair Houghland asked where APD is on developing the survey tool. Terri advised she brought one copy with her. She will E-mail the final to Chair Houghland. Terri reiterated they are working with the DD Council to do a preliminary survey just to see what kind of tool would work. They are doing a telephone survey for APD. They are contacting a group under 21 living in the family home and over 21 living in the family home, 800 in each group. They will do the data analysis to determine what services people are waiting for as well as the immediacy of people's needs. They have taken some of the data received from the Alaska survey. Terry will E-mail the following to Chair Houghland:

- The Alaska Survey
- The position papers adapted from the Alaska Survey
- The final wait list survey tool

Contents of Information packet continued:

- Status Report on APD Assessment Process – This was shared with the Senate staff. They are happy with where APD is going with the assessment.

- A notice titled Supported Employment – A certain “pot” of 2008 GR funding will be used only for supported employment or employment related transportation services for individuals who qualify who are on the wait list only.
- March, 2008 Monthly Employment Report by State & Area – Terri reviewed the report. Ann shared her concerns with the number of dollars being put into supported employment and no more people than appear on these reports are employed. They are paying \$40.00 per hour to supported employment people because APD was convinced with good quality people APD would be able to employ more of the DD population. She doesn’t see it happening. Terri believes APD is doing a good job with employment considering the 5 year target is 5,800 which ends in 2009. Discussion followed with many concerns including Sharon explaining the difficulties she has experienced with regards to her son and Manny sharing her personal experience with trying to obtain employment. Joy mentioned what is not put into the plan is that Supported Employment coaching is supposed to fade over time. It’s not specified. Terri advised the handbook requires that but she will take that back to J.B. Terri mentioned there are some people who need that level of support and people that need to keep that safety net in place.
- Process for Residential Monitoring Quality Review
- Supported Living Data
- Summary of Recoupment Activity Data
- A document prepared by the Center for Disease Control (CDC) titled “Strategies for Management of MRSA in the Community
- FY0708 Provider Termination reports

V. BUSINESS

Treasurer’s Report – As Phil needs to leave early it was necessary to do the report out of sequence. Phil advised he doesn’t have enough information to report at this time but is working on it. Stephanie shared the reason for the large deficit was the encumbrances were not clearing out every time they were paying items off. As a result the actual encumbrance is only \$2,265 which brings it from a negative \$4,000 to a negative \$29.03. Chair Houghland asked if any other council’s had voted to give the statewide council some money and it hasn’t been done yet, please contact Stephanie. Also, if any council knows they will have extra money, March is the time to commit any unused dollars to FCCF. Ann shared a good source for using each council’s funds is to take advantage of the great conferences in the area. Someone should prepare a notice with information on upcoming conferences. Chair Houghland asked Phil if she gets the information together would he post on the FCCF website. He agreed to do so.

CDC+ Addition to Legislative Platform - Chair Houghland shared the language created by the committee members during the lunch break. Discussion followed with changes. Chair Houghland asked for a motion to accept the addition to the platform. Frank makes a motion. Phil seconds the motion. No discussion. The motion was approved by consensus. Chair Houghland will add to the legislative platform and send out via E-mail to everyone.

VI. AHCA UPDATE - Pam Kyllonen, AHCA, Medicaid Services

DD Waiver - Pam shared it’s time to renew the waiver with the Center for Medicare and Medicaid Services (CMS). She is in the process of updating the waiver document to ask for a renewal. She advised the process for renewal is routine and simple. She was hoping the 2 new tiers would have been implemented by now so that she could reduce the number of individuals that are on the caps for the waiver but that won’t happen this time. She’ll have to do an

amendment later on. Chair Houghland asked if the total number would then be the same as current number. Pam advised yes, it's about 26,000.

HCBS Handbook – Pam shared they had a lively discussion at the public hearing on March 3rd. She shared 70 people attended. They received many good comments. The 3 major issues were, (1) 10% Density Rule; (2) 300 maximum hours for personal care assistance; and (3) new language regarding staffing ratios in residential habilitation.

They have been working closely with APD to make appropriate changes. They hope a notice of change will go out this week which will appear in the Florida Administrative Weekly (FAW) on March 28th. They will hold that for 20 days and then submit a final unless another protest is filed. They have received one filing of a protest on the handbook. It relates to the 300 maximum hours for personal care assistance. AHCA attorneys advise they are taking care of that protest since AHCA is taking out the maximum hours.

Rule Hearing on Rates for Providers – This took place on the same day. They now have 2 rate rules, 1 for residential habilitation in a licensed facility and the second is rates for everyone else. She shared some provider groups are still not happy with the rates. They have 21 days (March 24th) after the hearing to protest.

Tiers - Tiers 2 and 3 were approved by the CMS. They have an effective date of February 14th. She understands that APD is looking towards a July 1st implementation date. Chair Houghland asked if a number of recipients were included for each tier. Pam advised yes. They are:

- Tier 1 – 5,800 – Unduplicated Participant Count
- Tier 2 – 4,200 – Unduplicated Participant Count - \$55,000 cap
- Tier 3 – 16,000 – Unduplicated Participant Count - \$35,000 cap
- FSL Waiver – 6,300 – Unduplicated Participant Count - \$14,792 cap

Frank asked how were the numbers determined. Pam advised these numbers were based on projections from APD based on current cost plans. Terri added it was based upon claims data. Pam shared she was told the first pool was based on cost plans, then they looked at where and with whom they lived and claims data. This formula provided the best possible estimation.

Family Supported Living Waiver – Pam shared it is time to renew this waiver. Ann asked if they are planning on opening this waiver up to all services. Pam advised probably not all services because there are some services that are not appropriate for this waiver doesn't apply to such as residential services. Pam advised that Jane wanted to open up this waiver up as much as possible which would include therapies, nursing, etc.

Legislative Bill Analysis - Pam shared hearing about the bill wanting to move APD's administration responsibilities from DCF to AHCA. She advised AHCA does not have the same infrastructure as DCF to handle things like the data system.

Staffing Additions - Pam shared the new staff and what positions they will have with AHCA.

Delmarva Contract - Pam shared that Kelly Hensley will be in charge of the Delmarva contract. Ann asked when the contract is up for renewal. Pam advised June, 2009. Ann mentioned the need for a future FCCF meeting to be devoted to discussion of the Delmarva contract. FCCF needs to be included in the input process. Pam advised there will be discussion at the next IQC meeting on May 20 – 21 in Tallahassee. The first day Delmarva will be present and AHCA has asked Delmarva not to be present on the second day so they can talk about the future of the contract. She mentioned it would be good if a representative from FCCF could participate at the meetings or provide written comments. Chair Houghland mentioned the need for all chairs to see the list of recommendations prepared by Delmarva presenting their thoughts on how to improve the program.

Medication Administration Rule (69G-7.001-009) – Terri advised this rule has been filed and will become effective March 30th, 2008. That gives the guidelines for the administration of medications.

Reactive Strategy Rule (65G – 8) - Terri advised this is the Behavior Analysis rule regarding restraints. It was published as a proposed rule in the FAW and a hearing date has been set for March 20th. Terri will forward to Chair Houghland copies of both bills.

Chair Houghland thanked Pam for taking the time to travel to her office to call in. Everyone is very appreciative to Pam for her time, efforts and keeping the council updated on AHCA issues.

VII. OTHER REPORTS

FDDC Stakeholder Meetings - Chair Houghland advised the DD council has been hosting stakeholders meetings since before the legislative session began. APD was not included. Frank & Chair Houghland have been representing FCCF at the meetings. The group includes: Florida Association of Rehabilitative Facilities (FARF), Florida ARC, Florida Association of Support Coordinators (FASC), Family Care Council Florida (FCCF), UCP South Florida, Autism Society and Advocacy Center. They originally began by trying to get a consensus from the group. They held a conference call on Friday and FARF took the lead. They asked for FCCF opinion. Chair Houghland advised she shared the council has talked about it and referred them back to the FCCF legislative platform. During the call there was much discussion about freezing rates as a possible solution to reducing monies. Chair Houghland advised that AHCA rejected all of FARF's suggestions that appeared in their published report. Discussion followed regarding issues pertaining to other states solutions that appeared in the FARF report. The next call will be March 23rd.

VIII. BUSINESS (Continued)

Review of Minutes - Chair Houghland asked if there were any corrections to the minutes. There were none. She asked for a motion to approve the minutes. Joy makes the motion to approve. Lynn seconds. No discussion. The minutes were approved by consensus.

Nominating Committee Report - Chair Houghland explained the nominating committee presents a slate of officers at this meeting. In May, nominations from the floor are accepted as well and then a vote is taken. Joy advised the slate of officers are:

- Chairperson – Betty Kay Clements
- Vice Chairperson – Frank Carroll
- Secretary – Lynn Carper
- Treasurer – Phil Pearson

Partners in Policymaking – Ann shared with everyone that Partners is advertising for people to sign up for their next training. She mentioned what a wonderful training this is for anyone who hasn't participated.

IX. ADJOURNMENT

Chair Houghland thanked everyone for attending the meeting. With no further business to come before the council, Chair Houghland adjourned the meeting at 3:00.

The next meeting will be held on May 17th, 2008 at The Holiday Inn Select.

RESPECTFULLY SUBMITTED,

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