

**FAMILY CARE COUNCIL FLORIDA**  
**Patty Houghland, Chairperson**  
**September 15, 2018**  
**Embassy Suites, Orlando Airport**

**Members:**

Patty Houghland, FCCF Chair, FCC 1  
Patricia Oglesby, FCCF Vice Chair, FCC 8  
Mary Smith, FCCF Past Chair, FCC 4  
Ruth Wingate, FCCF Secretary  
Paula James, FCCF Treasurer, Suncoast West (5)  
Dina Justice, FCC 1  
Denise Torres, FCC 4  
Pauline Lipps, Suncoast East (6)  
Susan Andersen Moore, FCC 7  
Jean Malacko, FCC 9  
Gilda Pacheco, FCC 10  
Ernie Martinez, FCC 11  
Charlene Greene, designee for Chris Spears, FCC 12  
Karen Huscher, FCC 13  
Laura Tacinelli, FCC 14  
Lisa Lupi, FCC 15

**FCCF Liaison:**

Stephanie Rogers

**Guests:**

Howard Fetes  
Dan Bayley  
John Patrick McGlone  
Diane and Chris Ciccarelli  
DarLing Malacko  
Krystal Sims  
Vicki Kurkimilis  
Fawn Moore  
Hannah Moore  
Lucia Berry-Kniceley  
Dr. Jackie Briceno

**Speakers:**

Jeannette Estes, Esq., APD counsel  
and Acting Central Region ROM  
Denishia Sword, Bureau Chief,  
Florida Dept. of Financial Services

Meeting called to order at 8:33 a.m.

**Council Action and Committee/Member/Liaison Activity:**

- Moved by Jean Malacko, seconded by Dina Justice to approve the July 20, 2018 FCCF minutes as presented. Motion passed.
- Moved by Patricia Oglesby, seconded by Ernie Martinez to approve the July 21, 2018 FCCF minutes as amended. Motion passed.
- Received the report from Paula James as presented.
- Agreed by consensus that Dina Justice perform revisions as recommended on logo.
- Patty Houghland reminded members to return the 1-800 FCCF calls timely as possible.
- FCCF advised Agency for Persons with Disabilities about service discontinuation due to conflicting expiration dates regarding time-limited Behavioral Service Assistant service, and that requires the Local Review Committee (LRC) review extension requests two months prior to expiration, performing the same perceived function as Significant Additional Needs Request (SAN). A lack of required due process notice was also reported in this matter. Jeannette Estes said that Behavioral Assistant service is time-limited in the Waiver Handbook. Its purpose is to train caregivers to help individuals in their environment, then services fade out and are discontinued. If ongoing training/support is needed, a request for renewal of service may be submitted, and can be done through the SAN process. APD follows Rule 65G-4.009, and 4.010 in the Florida Administrative Code (FAC) related to behavioral services. Behavioral plans are required to include fading plans to assist individuals in being more independent with their behavioral challenges, the rule also brings in the oversight of the LRC. The iBudget

requires review every six months, not tied to support plan dates. She agreed that iBudget 6-month reviews and support plan dates do not coincide, and noted the situation brought to APD's attention is known by the Agency to exist for other families. She recommended notifying the Waiver work stream lead in the Region so if there is an error it may be resolved within the confines of the law, and also to file a hearing request when this arises. She acknowledged that families need an updated contact list provided by APD to address Notice of Intent of Agency Action (NOIA) regarding service discontinuation or change issues when due process notification is not received. Jeannette Estes will compile a summary of this information for distribution to members.

- FCCF advised APD that they request an APD acronym definition list to educate families and themselves on APD terminology.
- FCCF advised APD that they request a legislative budget request (LBR) report from the Agency. Stephanie Rogers agreed to send the LBR in advance for review/questions.
- Received and recommended changes to Stephanie Rogers' Family Care Council survey for all FCC members.
- Received and recommended changes to the Waiver Support Coordinator brochure for action by Stephanie Rogers.
- Stephanie Rogers will meet with Lisa Kuhlman to devise a mechanism to provide for timely review and advice from FCC on APD rules in their statutory advisory capacity, prior to public comment, revision and enactment.
- Revised the Waiver Support Coordinator brochure by adding the Facebook icon, new FCCF logo, APD logo, using alternate pictures and revising spelling of advocacy.
- Legislative Committee reported on the proposed 2019 Legislative Platform, with changes by consensus from members. Are writing a talking points fact sheet for this Platform.
- FCCF member Gilda Pacheco volunteered to continue translating information for Spanish-speaking individuals when they call the FCCF 1-800 number. Patty Houghland will send this contact information to FCC Chairs.
- FCCF advised APD about timeliness of their communications to the community on availability of new or changing services. An example of a three year gap between APD receipt of transportation to work funding and support coordinator/family knowledge of this funding was discussed.
- Members questioned whether FCC can attend Developmental Disabilities day using FCC finances, as it is not a FCC statutory requirement. Jeannette Estes will clarify this question within the next two weeks. Howard Fetes asked that FCCF contact him to gain his personal experience in New York State regarding a similar situation before requesting an opinion by APD on this matter.
- FCCF advised APD that FCCF members need Waiver Support Coordinator meeting and training schedules in their capacity to educate families.
- FCCF advised APD that Council needs clarification on APD's request that FCC partner with them in the Foster Care project.
- FCCF advised APD that Council needs clarification on APD's prior requests of them to help acquire funding from the legislature. FCCF attendance at meetings with other organizations also needs clarification.
- FCCF advised APD that some waiver support coordinators/consultants continue to need training on courtesy, respect and listening skills as a requisite for employment with APD. Members feel that suggesting families employ a different coordinator, as is their option, does not relieve APD of the obligation to train coordinators to acquire these basic skills.
- Members agreed to remove "advocacy" from FCCF materials, and identify their efforts as education and empowerment.

**Speaker Jeannette Estes, Esq., Acting Regional Operations Manager and Counsel for APD – [Jeannette.estes@apdcares.org](mailto:Jeannette.estes@apdcares.org)**

- Training of direct care staff on choking issues is not presently required by APD, only CPR first aid training. Heimlich maneuver is not part of first aid. ARC of Florida and APD discussed anti-choking initiatives last week and ARC of Florida is providing \$50,000 for training on this issue. Cutting boards have also been developed to indicate portion size to avoid choking, and were distributed to all APD licensed facilities. The issue of choking was initiated when FCCF met with Deborah Linton of ARC of Florida.
- The Agency for Health Care Administration's criteria to select dental plans for the statewide Medicaid Managed Care Program is (1) Where they operate, (2) Which plan will provide services, (3) Who must enroll, (4) when plans are available and when recipients are notified, (5) who will pay for services, (6) coordination of services between health and dental plans and (7) continuity of care requirements.
- Discussed Waiver waiting list figures distributed in handouts. 34,344 currently receiving Waiver services, 31,098 through iBudget, the remainder 3,246 on iCDC+.
- One hundred and thirty-five APD-sponsored residents and 17 private pay or out-of-state residents of Carlton Palms have transitioned out of Carlton Palms, with 28 APD and 11 private pay residents remaining in Carlton Palms care as of September 11, 2018.
- The APD Recovery Toolkit was distributed, a resource document for waiver support coordinators and providers to meet their own and customer needs, during disaster, and is available at [www.apdcares.org](http://www.apdcares.org).
- FCCF has 17 membership appointments pending, which may be announced shortly.
- A FCC liaison call included the FCC survey, governor appointments, FCC and FCCF bylaws update for statutory compliance and updating FCC training. September call may discuss preliminary survey results, bylaws and possible appointment announcements.
- She noted that APD held a hearing on FAC Rule 65G-5 on Supportive Living on August 22, 2018. APD presented recommended revisions to the Rule and received questions/comments from the public, along with written comments. APD will revise as appropriate.
- A guest recommended using the peer support specialist initiative, utilized by NAMI substance abuse providers to connect systems and reduce gaps to use limited finances effectively. This initiative could be tailored specifically for developmental disability.
- Fawn Moore noted that Children and Families has improved department communications to allow review and advice on proposed rules, and offered to assist Council with this matter.

**Speaker Denishia Sword, Bureau Chief, Bureau of Education, Advocacy and Research, Division of Consumer Services, Florida Department of Financial Services – [Denishia.sword@MyFloridaCFO.com](mailto:Denishia.sword@MyFloridaCFO.com) and [www.MyFloridaCFO.com](http://www.MyFloridaCFO.com).**

- Discussed the My Money program for individuals with developmental disabilities. Goals are (1) teach financial literacy skills, (2) empower individuals and caregivers, (3) make information accessible as a self-paced and user-friendly program and (4) ease of use as a responsive web-based program. Lessons include (1) money basics, (2) money and making a plan and (3) sources of income and savings with lessons available under each category.
- Other financial literacy programs are available to the public including Your Money Matters, On Guard for Seniors, Operation Safe – Be Scam Smart, Financial Frontlines, Serve-Save-Succeed -- Tools for Financial Success, S.T.A.R.T. (Save Today and Retire Tomorrow), Your Life – Learn Individual Financial Empowerment, CLIMB (Children

Learning the Importance of Money Basic), Family Foundations – Building a Strong Financial Future and Finance Your Future.

- Denishia Sword provided handouts, and will send her Power Point presentation to the Chair for distribution.
- Denishia Sword is available to make presentations to local groups, including Area FCCs and self-advocates to provide education to the community.

#### **Area Updates:**

- Paula James of Suncoast West (5) will represent FCCF at the Qlarant meeting on October 11th in Tallahassee. Discussing national trends on developmental disabilities.
- Area 1 has changed meeting time and location. Johnathan Martinez of “Supported Decision Making” will speak at the ARC building from 5:30 to 7:00 p.m. Patty Houghland will forward information about law enforcement sponsored bingo for people with disabilities to members.
- Area 14 is considering evening meetings along with a day and location change to encourage membership.
- Area 7 has changed meetings to 6-8 p.m. on Wednesdays and attendance has improved, including younger members. They distributed the CAFÉ presentation and are holding more educational meetings that have produced greater participation.
- Area 13 will hold their meeting on Tuesday, November 13 from 6-8 p.m. They did a livestream of the APD update. Their March and May meetings will include outreach forums separate from their regular meeting.
- Area 4 included training on transition for individuals and on intellectual disabilities from pediatric to adult at their meeting.
- Area 11 is working on local law enforcement training and renewing their Area website. Miami received \$98.5 million for housing for 12,000 non-elderly people with disabilities.
- Area 9 received information on ages 0-3 on mental health, and attended presentation on human trafficking, noting that 30% of Florida girls trafficked are identified as those with developmental disabilities. Agency meetings are assigned to individual members.
- Area 10 attended a sex education webinar and two-day training on racial issues. On December 13, 2018 they will hold their first night meeting, hosted at Ann Storck Center.
- Area 12 meets every second Thursday from 2:30 to 4 p.m. They will attend the Jacksonville Bank of America disability awareness event as presenters.
- Suncoast East (6) has changed meeting location to a library. They are aware new members need education/information at each meeting by guest speakers, provided at different times and locations. A newsletter is in the works along with events such as a beach or picnic Christmas party for families.
- Area 8 is holding a community awareness day at the Fairfield Inn. Present will be APD, and a waiver support will speak along with the “Our Voice” coalition on September 18 from 6:30 to 8:00 p.m. In October they will hold Lifescape counseling. Denishia Sword will speak on money education and finances for individuals with disabilities in November. The FCC “Family Celebration” sign is available for FCCs to use.
- Area 15 held an informational event, including three legislators from the Area. Krystal Sims, a self-advocate is currently participating in the Partners in Policymaking program.

There were no requests to speak during Citizen Time.

Meeting adjourned at 3:32 p.m.

Respectfully submitted, Ruth Wingate, FCCF Secretary