

FAMILY CARE COUNCIL FLORIDA
Pauline Lipps, Chairperson
September 20, 2014, Meeting Minutes
Corrected Nov. 15, 2014
Embassy Suites, Orlando Airport

MEMBERS PRESENT:

Patty Houghland, Chair FCC 1
Margie Garlin, Rep. FCC 3
Mary Smith, FCCF Vice Chair, FCC 4
Jackie Aikens, Rep. FCC 7
Patricia Oglesby, Chair FCC 8
Elaine K. Scola, Rep. FCC 9
Jean Sherman, FCCF Past Chair, FCC 10
Gilda Pacheco, Co-Chair FCC10
MES, Rep. FCC 11
Karen Huscher, Chair FCC 13
Betty Kay Clements, FCCF Secretary FCC13
Many Champavannarath, Rep. FCC 14
Melody Hearn, Chair FCC 15
Ann Graybeal, Rep. FCC SC East
Nancy Simmons, Chair FCC SC West

GUESTS:

Rosa Llaguno, APD CRC & FCC 11 Liaison
Ruth Wingate, FCC 15
Laura Edmunds, FCC 4
Lisa Lupi McGlone, FCC 15
Paula James, FCC SC West
Lynn James, FCC 8
Stephanie Rogers, APD FCC Liaison
Clarence Lewis, APD Central ROM

GUEST SPEAKERS:

Tom Rankin, APD Deputy Director of Operations
Suzanne Sewell, President and CEO Florida ARF
Tom Rice, APD, via Web Cam
Meghan Murray, APD, via Web Cam

CALL TO ORDER: FCCF Chairperson, Pauline Lipps, called the meeting to order at 8:30 am. She welcomed everyone, and had all in attendance introduce themselves.

The contents of the FCCF information packet include:

- FCCF September 20, 2014 Agenda
- FCCF July 19, 2014 Meeting Minutes (Draft)
- FCCF FY 2014/15 Spending Plan
- FCCF AREA Summary Balance Report by Region as of August 31, 2014
- 2014 FCC Statute 393.50 with Grandparent addition to membership
- Motivational Quotations
- September Updates for the Family Care Councils
- iBudget 90 day Emergency Rule
- Copy of letter to AHCA from FCCF with iBudget handbook comments
- APD update on Admission Moratorium on Provider
- APD Operating Procedure : Residential Care Payment Rates-July 1, 2014
- Kathie Snow-"In Employment, Who's talking the talk, but not walking the walk"

FCCF Chair Pauline Lipps asked members to review the 2013-14 FCC Summary of Accomplishments and send comments or changes to the Secretary by Monday September 22. She said she will be sending a letter with the document to the Governor and legislators. Following discussion, a decision was made to also include a 2014 profiles booklet and FCCF brochure with the letter. The Chair gave a brief review of the profile booklets history and intent for new members and guests. An updated edition will begin by January 1, 2015 she said.

Chair Pauline shared that she had made a recent visit to APD's Rish Park. She showed pictures taken and gave a personal overview of the grounds and facilities. The park is managed for APD by the Sunland Center in Marianna, and has a full time caretaker. There is a charge of \$15/night/person. It is totally accessible and legislative dollars are paying for more work that is expected to be finalized in March 2015. She stressed that

scholarships should be considered for waitlist families to spend time at Rish Park. For more information the website is: <http://apd.myflorida.com/rish-park/index.htm> or contact J R Harding at 850-922-5220.

II. APD UPDATES: Tom Rankin, Deputy Director of Operations, introduced Stephanie Rogers and Tom Rice assisting with the APD updates. Stephanie shared the packet: agenda; employment update; iBudget update; waitlist enrollment; updated resource directory; power point presentation for Human Trafficking, and a Who's Who at APD Operations, Programs, and Regions. Tom Rankin addressed the following:

- **Director Palmer's Directives :** Tom stressed that APD Director Palmer feels strongly about the housing options and service delivery system initiatives. He shared that over 1000 stakeholders have participated on three APD workgroups. He indicated that if new waivers are sought, APD will need to work with AHCA and legislators, as legislation may be needed. Requests for Information (RFI) are in development to move forward on the initiatives. Some of the comments he addressed about the initiatives were:
 1. The **Dual diagnosed and Intensive Behaviors (IB) model** has a mental health overlay. A blending of dollars and services between agencies, with a waiver or an agreement could be a possibility. A DD assessment FACT TEAM is a consideration for short term stabilizing in home setting, short term placement or other long term option needs for IB. An increase of Smaller IB homes are needed across the State he said. They would need to meet CMS guidelines for integrated settings, he stressed. The redesign includes an optimized training component and a certification process is a possibility.
 2. The **Forensics workgroup** has stressed the need for support workers to have an understanding of the clients they are working with. The availability of different levels of specialized housing are needed he said, as well as smaller settings. APD is looking at it with an actuary for high level services. A short term plan is to reach out of state for both Forensic and IB home operators with a good history who might want to expand into Florida. APD is also approaching providers in Florida to seek their interest. He shared that creative transitioning has increased forensically over the last year with success.
 3. The **Aging and Alzheimer's workgroup** addressed **Aging in Place**. The need occurs due to aging factors that may involve one person or both the APD client and family members. Combining service delivery is a consideration for a parent and individual with DD to remain at home. An example of a successful placing of family members needing services staying together was shared. Agencies such as APD, Elder Affairs, and DCF collaborating and/or combining waivers might be a real possibility he said.

All of the above initiatives have significant **Transitioning and Training** components that need to be addressed he stressed. APD wants the FCC's to be a part of these initiatives as APD continues to need input, he said.

- **iBudget Florida Update:** Tom said that Legislatively resolving the iBudget Rule issues is an APD priority.
- **Progress of Wait List to Waiver Enrollment:** Waitlist data available was discussed. In response to questions, Tom said that he will have the report broken down by Area as well as region. Information on how changes in category levels are revisited, for movement to the Waiver, will be sent to FCCF he said.
- **Agencies Faith-Based Initiative:** Tom Rankin introduced Tom Rice, who spoke via webcam. He is in charge of APD zero tolerance, licensing rule, and enhancing or fostering the growth of faith based initiatives among other duties. Tom Rice shared his background and said that he has two children with Developmental Disabilities. He related how he and his family became involved in assisting the start of a special needs ministry at their church. It evolved beyond a respite night to include volunteers, community involvement, transportation and companions as well as respite services. He said that APD is creating a category on the APD Resource Directory for Faith Based programs. They are also developing a package to distribute for awareness of what can be accomplished within the ministry. He showed a video on "The One Roof Initiative Team". It is an organized effort to show churches and others how it can be done and what can be accomplished. They do not want to segregate those with special needs, but programs must be individualized, he said. He is seeking FCC input. Attendees shared programs they are aware of in their local areas. Tom took the ideas for the APD directory. He can be reached at Tom.Rice@apdcares.org. He was thanked by all in attendance.

Attendees at the meeting began an extensive discussion with Tom Rankin of issues regarding the recent media news of abuse, and even the death of a child while residing in a licensed facility. It raised many questions and concerns about verified and non verified abuse findings and prosecutions. Concerns were expressed by attendees about those who have not been prosecuted and how that works. The concern is that individuals with DD are not listened to, or their claims are not pursued because law enforcement does not believe they can make the case. It was stressed that training is needed for the justice system. Tom said that APD and the Director are very concerned about this issue. He stated that Director Palmer has made it clear that APD wants to be notified at the front end of any claims whether verified or not. Chair Pauline shared with Tom that the response from the group shows that FCCF would appreciate more information on this issue and how APD deals with these serious issues. He said that Lisa.Robertson@apdcares.org could be reached for more information. He also said to email him with questions on any of the topics discussed today or materials in the packet not discussed. Tom.Rankin@apdcares.org. Members thanked Tom for attending and sharing the APD updates.

III. ICF/IID PROGRAM: Suzanne Sewell, President and CEO of Florida ARF (FARF) addressed the attendees and shared a packet of information regarding Florida ARF and ICF/IIDs. There are 66 member agencies on the Florida ARF side and 54 RESPECT groups she said. Florida ARF also manages the RESPECT of Florida Program which works with nonprofit organizations around the state to employ persons with disabilities and produce products and services that are sold to state and local government agencies. She described the ICF/IID Community Residential Program. It differs from the HCBS waiver, as it is comprehensive care. There are 86 ICF/IIDs, with 2068 licensed beds federally funded at \$150,000/year/resident. That covers all the needs of the individual. There has been a moratorium on ICF beds since 2003. They are licensed and monitored by AHCA as an institutional, medical model. The model features an “active treatment loop” of consistent, specialized training, treatment and health services. Individuals tend to be severely disabled and may have respirators or feeding tubes, as an example. Their occupancy level is about 95% across the state, she said. There are several six bed homes similar to group homes in residential areas in the community. Twenty three Clusters have homes in close proximity to each other. There are six 64 bed Campuses, and twenty one others have a variety of models. The Sunrise campus in Homestead FL is a residential community with 120 beds in a variety of housing choices. She was questioned about whether an ICF/IID could be an alternative to an extended facility if needed. She said it must be approved by APD, but it could be possible. Asked about entitlement of individuals’ placement in an ICF/IDD placement, it was acknowledged that Sunland, Marianna and Tacachale cannot refuse placement of a qualified individual. However, the private ICF/IID beds may have a waitlist or could decline placement. If a client on the HCBS waiver enters an ICF/IID they retain their ability to return to the HCBS waiver within a year. An individual in an ICF/IID may also retain a slot on the APD waitlist for the HCBS waiver. Suzanne shared that most of Florida ARF’s member agencies are APD Medicaid Waiver providers as well. She said 98% of the services provided by Florida ARF member agencies are to clients on the APD Medicaid Waiver. A member may be providing both APD Medicaid Waiver services, and ICF/IID residential services. She also addressed the Florida ARF legislative platform that is to be approved next week. She stated that more Medicaid Waiver waitlist money is needed, but provider rates are a key issue that needs addressing this year. She related the history of the Mercer rates, comparing how rates have gone down 14% compared to 2003. Minimum wages have increased 54% and are going up again. The Consumer price index has increased 32%, along with agencies overhead, unemployment and workers compensation insurance, liability insurance and other costs of doing business. Sewell said about 20 providers want to do IB homes, but the cost of set up has no guarantee of clients so that is a concern. In closing, she said to get more information on issues she spoke about today visit www.floridaarf.org hit the grassroots link or contact her ssewell@floridaarf.org. She was thanked by all for attending and for the information presented.

IV. INCLUSIVE HOUSING COALITION UP DATE: Sheryl Soukup will be attending the November FCCF meeting to report on the housing coalition with the latest updates.

V. Progression of Respite Coalition: Past Chair Jean Sherman reported that the coalition was unable to agree on board membership. Therefore, Debra Dowds of the DD Council is working on this issue. A conference call will be held to form a statewide coalition pulling from the summit held earlier. APD is still expected to take the lead and apply for the Respite grant next year. She also reported on the "Living Longer" conference she attended. She said that about 500 persons attended with mostly direct care and some administrative staff. Speakers addressed aging in Down's syndrome and disabilities in general. She said it is not inevitable that those with Downs will get Alzheimer's, as there are many factors involved. Lengthy environmental tips were discussed she said. She was asked to provide a summary to share if possible. Elizabeth Perkins from UCF also attended, she said. The two of them have submitted an application for a grant to do training on aging/DD. They will know by Nov. 3, 2014 if it is granted. They will involve FCCF if they are awarded the grant. It would start January 1, 2015, and will be a 3 year project. Jean also addressed a new FDDC book on *Stress and What You Can Do About It* for self advocates. A Spanish version is available as well. Samples of the books were distributed to the Councils in attendance. To order go to <http://www.fddc.org/publications>.

VI. BUSINESS: Meeting Minutes July 19, 2014 reviewed: **Patty Houghland made a motion to accept the minutes as written. Nancy Simmons seconded the motion. Motion passed.**

VII. FCCF BUDGET REPORT: In the absence of FCCF Treasurer, Dan Bayley, the Chair reported on the FCCF budget expenditures. Balance YTD is appx. \$14,421.07. FCC's summaries of budget balances were reviewed.

VIII. HUMAN TRAFFICKING IN FLORIDA: Meghan Murray, APD Operations, presented a power point via Lynx that addressed human trafficking as modern day slavery. She gave a detailed overview. She spoke about the federal law "The trafficking Victims Protection Act of 2000". She stressed that at the federal level there must be the use of force, fraud or coercion for the purpose of subjection to involuntary servitude, peonage, debt bondage or slavery. The Florida Statute Chapter 787.06(2)(d) includes transporting, soliciting, recruiting, harboring, providing, enticing, maintaining or obtaining another person for the purpose of exploitation of that person. (Transporting or smuggling alone is not considered human trafficking she said.) It is a \$32-\$34 billion industry that enslaves appx. 27 million people worldwide. Florida is ranked number 3 in the nation. People with intellectual, cognitive, or developmental disabilities have 7 times higher risk of becoming victims. Some kinds of trafficking are in the areas of labor, agricultural, sex and domestic servitude. Traffickers have varying profiles. They recruit victims with gifts, compliments and promises. They move on to breaking them with abusive techniques, coercion, humiliation and enticement. The traumatic stress has a lasting change as it alters the brain and is the reason they stay. Fear is a big motivator in trafficking. It happens in broad daylight, and is accepted because outside people do not know what to look for. She presented Red flags to be aware of that will assist the protection and prevention of trafficking. She reviewed signs of sexual abuse, exploitation. How and where to report was discussed: DCF Abuse Hotline, National Human Trafficking Hotline (Polaris), Department of Homeland Security and local law enforcement. Everyone in Florida has a responsibility to report known or suspected abuse, neglect or exploitation she said. Failure to report known or suspected cases of abuse, neglect or exploitation is a 3rd degree felony. Curriculums on trafficking are being introduced in some schools and with special education students as well. Law enforcement is increasing their efforts. Calls to the Polaris project go to law enforcement agencies that are being trained, and many agencies now have a human trafficking unit. DCF investigations are then initiated. The APD office is to be notified, or victim services etc. Email Meghan at Meghan.murray@apdcares.org. Meghan was thanked for her presentation by attendees.

IX. FCC ACTIVITIES: Patty Houghland shared that Area 1 FCC hosted an Employment Enhancement Project (EEP) forum, with APD staff presenting to families and providers. Melody Hearn shared that Area 15 is participating

in an Expo at a state college with APD, DRF, and others. Gilda Pacheo reported for Area 10 FCC that on Oct 11, a Disability Expo at Nova University is open to anyone interested. Nancy Simmons said that SunCoast West FCC is having an event at their FCC meeting with Jeff Smith, the new SunCoast regional manager and Michael Taylor on Friday. Waitlist families and exhibitors were invited to meet the new Regional Director. She also shared that her AFIRE 501C3 program raised funds of \$1000/person for 7 individuals to attend an ADT program of their choice. Betty Kay reported that Area 13 FCC has an EEP forum being scheduled. They are participating in a resource fair in Ocala Sept. 27, and on Oct. 3 and 4 will take part in a Sportsability weekend. Area 13 FCC paid for mailings to waitlist families for the event and Margie Garlin, Area 3 FCC said they may approve funds for mailings as well. Ruth Wingate, Area 15, asked if other areas were having difficulty recruiting WSC's for the CDC+ program. Discussion actually centered on why WSC's would not want to support those on CDC+, since the work is done by the family or a representative.

X. COUNCIL INPUT/MISC. INFORMATION: Chair Pauline addressed the need for a Legislative Platform committee and appointed FCCF Vice Chair, Mary Smith, to chair the committee. Mary asked for volunteers and Karen Huscher, Lynn James, Gilda Pacheo, and Patty Houghland volunteered. Mary encouraged others interested to contact her. She will be having a conference call with interested participants. A draft platform will be put together for sharing and discussion at the November workgroup day and the meeting. The Secretary advised that the Bylaws should be amended to include the change to the F.S. 393.50 that includes membership for grandparents. A draft will be prepared to present at the November meeting.

XI. CITIZENS TIME: There were no speakers signed up for Citizen's time.

There being no further business, the Chair adjourned the meeting at 3:30 PM.

Respectfully submitted,

**Betty Kay Clements,
FCCF Secretary**

**The next meeting is: November 15, 2014
Embassy Suites Orlando Airport, Orlando, Florida**