

FAMILY CARE COUNCIL FLORIDA
Pauline Lipps, Chairperson
September 19, 2015, Meeting Minutes
Embassy Suites, Orlando Airport

MEMBERS PRESENT:

Pauline Lipps, FCCF Chair, FCC SC East
Mary Smith, FCCF Vice Chair, FCC 4
Jean Sherman, FCCF Past Chair, FCC10
Dan Bayley, FCCF Treasurer, FCC7
Laura Edmunds, FCCF Secretary, FCC4
Patty Houghland, Chair, FCC1
Betsy Hill, Rep., FCC3
Paula James, Rep., FCC SC West
Patricia Oglesby, Chair, FCC8
Karen Oberg, Chair, FCC9
Marty Norris, Co-Chair, FCC10
Gilda Pacheco, Co-Chair, FCC10
MES, Rep., FCC11
Mary Ellen Ottman, Chair, FCC12
Karen Huscher, Chair, FCC13
Melody Hearn, Chair, FCC15

GUESTS:

Howard Fetes, FCC7
Lisa Lupi, FCC15
John Patrick McGlone, FCC15
Ruth Wingate, FCC15
Tom and Jackie Aikens, FCC7
Maryann Sarra, FCC7
Margarita Garlin, FCC3
Diane Agrusa, community member

APD FCCF Liaison: Stephanie Rogers

APD FCC14 Liaison: Manyone Champavannarath

APD Regional Operations Manager: Clarence Lewis

GUEST SPEAKERS:

Barbara Palmer, APD Director
Margaret Hooper, FDDC

I. CALL TO ORDER: FCCF Chairperson, Pauline Lipps, called the meeting to order at 8:45 am. She welcomed everyone, shared basic housekeeping information, passed around attendance, and asked that introductions be held until Director Palmer joined us. A Simple Truths inspirational video about courage was shared with all. The contents of the FCCF information packet include:

- FCCF Sept 19, 2015 Agenda; FCCF July 18, 2015 Meeting Minutes (Draft)
- FCCF Aug 20, 2015 Phone Conference Notes
- FCCF FY 2015/16 YTD Expenditures
- FCCF Spending Plan for FY 2015/2016
- FCCF Letter to Governor Scott
- FCCF Website Policies and Procedures
- FCCF Media Release Form
- FCCF 2014-15 Accomplishments
- World Suicide Prevention Day insert

Many Resource materials and pamphlets were made available to all on a side table

II. BUSINESS:

July 18, 2015 Meeting Minutes: Draft minutes sent to members prior to the meeting were reviewed. **A motion to accept the minutes as written was made by Mary Ellen Ottman. The motion was seconded by Patty Houghland. Motion passed.**

FCCF Budget Report: Howard Fetes reporting for Treasurer Dan Bayley stated that FCCF's FY 2015-2016 expenditures YTD are **\$1919.01**, as of 9/8/15. Included in the budget expenditures were expenses for

the Waiver Support Coordinator meeting. Those who attended shared their experience from the meeting.

III. APD DIRECTOR BARBARA PALMER: Introductions were made for Director Palmer.

The discussion began with policy changes and language clarifications being made by the Agency for Persons with Disabilities (APD) in Bill 393. Priority items include proper staffing and QSI assessments. PASSAR & Utilization Review in regards to nursing care – money will be requested to contract nursing work out to allow APD nurses to focus their care on individuals with developmental disabilities. QSI assessments must be done correctly. 30 full time positions have been requested for new QSI assessors. APD is requesting a fund shift to make monies available to assist with individuals in transition, to comply with CMS changes and requests for behavior analysis. APD will request FCCF's assistance in the development of the Client data management system (CDMS) system. The goal is to ensure that the system is user friendly for consumers and their families. It is expected to take two years to complete the new data system due to its complexity.

APD is continuing to ask for dollars to take individuals with critical needs off the Wait List (WL). The Agency is also requesting rate increases for personal supports providers, as indicated in the Department of Labor (DOL) lawsuit. The actuary reviewed and reported on what would it take for APD to be in compliance with DOL requirements. APD submitted the report to the House and Senate, who in conjunction with the Governor's office, felt the report was not complete. According to the report, it will require \$61 million to pay people the necessary income as according to the DOL. The report was reverse engineered and it was determined that people are earning \$4.05 per hour. APD wants to make sure businesses remain whole and that travel time is added in. They are advocating for a full day at 12 hours. Director Palmer expects that by January, enough data will be collected to show the legislature what amount is really needed. APD didn't include any additional fund requests in the Legislative Budget Request (LBR). The goal is to work out the rates and have hard data to support the request of additional funds. APD would like for providers to have all of their rates reviewed – residential habilitation, ADT, dual diagnosis. Personal supports requires the most funding, including respite care. It cannot be expected that staff will work with our more behaviorally or medically fragile individuals for low wages, below minimum wage.

Adult Day Training (ADT) was addressed. Individuals are placed in an ADT and employment outcomes are not being achieved. Individuals are staying in ADTs for a long time. The Governor supports APD's goal of creating an incentive program to reward programs who are successfully creating and maintaining outcomes for individuals. Other States' models are being reviewed for best practices. A discussion ensued regarding "sheltered workshops". However, workshops can be worthwhile options for individuals for whom competitive employment is not a goal or ideal.

Ms. Palmer also discussed the future of services for individuals with a Mental Health/Dual Diagnosis and those in the Forensics System (not included in this year's LBR): The goal is to create a crisis team of experts that can go into homes and assess the situation and determine what level of need is present. This will ideally prevent or reduce the use of Baker Acts. The hope is to eliminate large facilities housing individuals with Dual Diagnosis needs, creating smaller residential homes around the state so physicians/experts would be able to serve the individuals in the same areas. Education will ideally be addressed locally within the school systems. In regards to the forensic system, the goal is for individuals to be gradually phased into the community under appropriate supervision before fully releasing them. A discussion on the importance of personal choice in regards to employment, living situations and quality of life ensued.

A folder of APD documents was shared, containing:

- “New Way of Doing Business at APD: Changing Business Processes to Achieve Measurable Outcomes”
- Waiver Support Coordinator (WSC) Statewide Advisory Workflow Draft (9/4/15)
- DRAFT WSC Advisory #1 – iBudget Handbook one-pager
- Individuals with Home and Community-Based Services Waivers
- Individuals on the Waiting List by Region
- House Appropriations Committee membership
- House Health Care Appropriations Subcommittee membership
- House Health Innovation Subcommittee membership
- House Health Quality Subcommittee membership
- House Children, Families, and Seniors Subcommittee membership
- House Health and Human Services Committee membership
- Select Committee on Affordable Healthcare membership
- Senate Appropriations Committee membership
- Senate Appropriations on Health and Human Services Subcommittee membership
- Senate Health Policy Committee membership
- Senate Children, Families, and Elder Affairs Committee membership
- 2016 Agency Legislative Platform
- APD Legislative Budget Request (LBR) for Fiscal Year (FY) 2016-17

A copy of the 393.002 bill: to be entitled “An act relating to the Agency for Persons with Disabilities; providing an effective date” was also provided to FCCF members.

- Underlined portions represent new language.
- Portions that are stricken through are being deleted from the bill.
- Highlighted portions represent changes that have occurred.

*A copy that is color coded with proposed changes will be shared with the FCCF.

*The entire packet of information will be sent electronically.

Person-Centered Planning is discussed in the bill. Training will be necessary and curriculum is being developed. The Florida Department of Health’s TRAIN online training program will be the delivery system for the curriculum for person-centered planning.

Individuals living independently were discussed, specifically regarding their safety and vulnerability to exploitation. Concerns were made about difficulty getting assistance from support coordinators and other APD service providers. FCCF and FCC members can assist families with connecting to the appropriate persons in APD offices who can provide the assistance needed to help families.

QSI assessments were completed on individuals on the Wait List, people were classified or re-classified. APD contracted with a vendor to send out the letters informing individuals of the results of these QSI assessments. During the mail merge process, 721 out of 3000 letters were sent out with incorrect address information on the letter. Letters were addressed correctly on the envelope so were mailed correctly, however individuals saw another person’s address on the actual letter. This was not a HIPAA violation.

- FCCF requested an updated APD directory from each region. The APD website is being updated with new hire information. APD directories will be updated and shared with FCCF.
- FCCF requested Wait List to Waiver information by county.

- APD is asking FCCF how they can disseminate information, especially to other agencies.
- APD is asking for assistance with individuals receiving Supported Living services, especially in regards to emergency response systems and assisting those who may become stranded or in need of assistance during an emergency (i.e., hurricane, etc.).
- FCC 4 invited Director Palmer and APD staff to represent the Agency at the Connecting the Dots conference on April 16, 2016

IV. LIFESPAN RESPITE: Jean Sherman shared briefly about a federal seed grant for lifespan respite that was sought and achieved under lead agency, Department of Elder Affairs. (She will provide a more in depth presentation at a later date.) This grant will serve caregivers of individuals of all ages with all types of disabilities. A grant partner, The Florida Lifespan Respite Alliance will soon be incorporated. A Board is in the process of being established. The project's intention is to work collaboratively across disabilities, seek future local grants and eventually develop legislation for a demonstration respite program for the State of Florida.

*At this time, they are hiring a consultant to do administrative work, a half time position that can be carried out anywhere in the State. Interested candidates are asked to contact the Ounce of Prevention agency. Responsibilities will include the development of new resources for respite care and setting up a website to exchange information among a wide range of respite stakeholders and educate the public about the critical importance of respite care to families.

V. MARGARET HOOPER, FDDC: Public Policy Coordinator for the Florida Developmental Disabilities Council, Margaret Hooper, has worked with individuals with developmental disabilities since the 1980s. Ms. Hooper shared a training PowerPoint about advocates learning how to speak to their legislators and the press, as well as for those interested in hosting Developmental Disability (DD) Days in their local communities. A video of the training is available on the FDDC website or via YouTube. Although DD Day events can be held anytime during the year, Ms. Hooper shared that months already acknowledging DD, such as in October (Employment of People with Developmental Disabilities Month), March (Developmental Disabilities Month), or April (Autism Awareness Month), may be a good time to host an event. Ms. Hooper will send information regarding upcoming trainings to FCCF Chair, Pauline Lipps. Ms. Hooper is available for technical assistance, workshops, etc. Contact her for handouts.

Key points made during the training:

- Decisions about you should not be made without you
- Legislators are available at their local offices after session – during summer and fall
- Use email to send letters, copy the legislator's Aide to ensure they see it – US Mail delivered letters take one month to get past the clearance process
- Pick your priority issue: State the main point, Explain its importance, Re-State the main point
- See where your legislators went to school, where their memberships are, if they have children/a spouse – seek commonalities
- Tell your legislator you are a constituent of theirs
- Leave them feeling inspired and wanting to help you
- Ask: "Do we have your support for this issue?" and say "Thank you" no matter what their answer is
- Ask: "Is there any additional information we can provide?"
- Take a photo and send it to them afterwards
- Leave handouts

Ms. Hooper shared some information about what the FDDC may present as part of their legislative platform:

- Provider rate increase for Community Living
- Individuals in Categories 3, 4, 5 to be removed from the Wait List
- Deinstitutionalization plan involving stakeholders and outcomes
- Education: continuing work on restraint and seclusion in schools
- Education: protecting Early Steps and Post-Secondary Education
- Health: Help Me Grow screenings and reducing number of children in nursing homes
- Transportation
- Employment First

VI: COMMUNITY BOOKLETS COMMITTEE REPORT: Hard deadline for booklet submissions of new profiles is October 1, 2015 @ 2pm. Submit to Mary Smith or Pauline Lipps. Submissions will be formatted to fit the booklet. Editing will be done as needed to clean up language/grammar.

VII: LEGISLATIVE PLATFORM COMMITTEE: A phone conference will be held for committee members on October 6, 2015. A Draft will be ready for review on October 15 for the FCCF conference call.

- FCCF has requested a legislative calendar from APD
- FCCF and FCCs will be updating legislative phone trees with new Officers' information to prepare for legislative alerts

VIII: LOCAL FCC UPDATES: FCC7 is collecting stories regarding issues faced when in the hospital. The concern is when an individual's services are discontinued while they are in the hospital, causing them to lose companion/personal care assistant services which can put them at a disadvantage, especially when hospital staff are not adequately trained in how to work with individuals with special needs. They are working to create a training that can be provided to hospital staff to improve the hospital experience for individuals with developmental disabilities. An email will be shared to provide more information.

IX. CITIZENS TIME: There were no speakers signed up for citizen's time.

X: COMPUTER TRAINING REVIEW: An online training session will be held for those interested in receiving additional assistance.

XI. COUNCIL INPUT/MISC. INFORMATION

There being no further business, the Chair adjourned the meeting at 3:45 PM.

Respectfully submitted,

Laura K. Edmunds,

FCCF Secretary

The next meeting is November 21, 2015

Embassy Suites Orlando Airport, Orlando, Florida