

FAMILY CARE COUNCIL FLORIDA

Mary Smith, Chairperson
July 16, 2016 Meeting Minutes
Embassy Suites, Orlando Airport

Members Present:

Mary Smith, FCCF Chair, FCC4
Patty Houghland, FCCF Vice Chair, FCC1
Pauline Lipps, FCCF Past Chair, SC East
Ruth Wingate, FCCF Secretary, FCC15
Mary Ellen Ottman, FCCF Treasurer, FCC12
Betsy Hill, FCC3
Joanna Rydzewski, Suncoast East
Paula James, Suncoast West
Dan Bayley, FCC7
Patricia Oglesby, FCC8
Martha Stuart, FCC9
Marty Norris, FCC10
Karen Huscher, FCC13
Laura Tacinelli, FCC14
Tony Mancuso, FCC15

Guests:

Betty Kay Clements, FCC13
Patricia Bell Kennealy, FCC9
Howard Fetes, FCC7
Reshawna Owens, FCC7
Sheryl Soukup, FCC8
Brian Rothly, APD Liaison, Suncoast Region
Stephanie Weis, DCF Areas 7, 13, 14
Clarence Lewis, ROM, APD Central Region

APD FCCF Liaison: Stephanie Rogers

Guest Speakers:

Barbara Palmer, Director, Agency for Persons with Disabilities
Mike Carroll, Secretary, Department of Children Families
Elizabeth Perkins, Florida Center for Inclusive Communities, Waitlist Project

CALL TO ORDER:

FCCF Chairperson Mary Smith called the meeting to order at 8:42 a.m. She welcomed guests and went over housekeeping details. Ruth Wingate reviewed the folder contents, including:

- July 16, 2016 FCCF Agenda
- May 21, 2016 FCCF Draft Meeting Minutes
- 2015/2016 Year to Date Expenditures
- 2016/2017 Approved Spending Plan
- Chair Mary Smith FCCF letter to members
- "Why Meet" document
- Vice Chair Patty Houghland Inspirational handout
- FCCF Member Directory
- Family Care Council Table of Accomplishments
- APD Carlton Palms Statement, Background and Talking Points document

II. BUSINESS

A motion was made to accept the minutes of the May 21, 2016 FCCF meeting with the amendment to remove a sentence fragment on the third page, third paragraph by Pauline Lipps and seconded by Patricia Oglesby. Motion approved.

FCCF Treasurer's Report: Mary Ellen Ottman noted FCCF's annual budget is \$15,000 per year. The final Council expenditures for 2015/2016 were \$13,658.77 with a surplus of \$1,341.23 that will not roll over into 2016/2017.

Mary Smith distributed the new "Manners Matters" pamphlet describing how to appropriately interact with individuals with developmental disabilities. She then described the proposed Council family education initiative "Welcome Packet", following the design of the Rish Park informational packet for easy addition and deletion of material. Initially planned for newly enrolled Medicaid Waiver families, distribution could expand to waitlist families. Completion of the project is anticipated in June, 2017. Committee members for this project are Mary Ellen Ottman, Patty Houghland, Paula James, Pauline Lipps and Mary Smith.

Mary Smith also noted that as part of the branding for FCCF, Kimberly Tharpe of APD will refresh and update the Council's letterhead. She also discussed her letter presented in today's folder regarding the role of Council members working as an advocacy team for the most effective voice. She acknowledged that the Council represents all Floridians with disabilities. She reinforced the Council's awareness of their power to effect change partnering with APD. FCCF and FCC members have first-hand experience with disability issues to pass on to their local communities, and Florida at large.

Karen Huscher asked that the Bylaws committee, comprised of herself and Mary Smith, be included on the September, 2016 meeting agenda..

Introductions were made including the personal mission statements of members. A team-building activity of puzzle assembly was done while introductions were made. Mary Smith noted that when the activity was finished, the pieces missing from the puzzle correlated to members absent from Council meetings, their absence making the group, like the puzzle, incomplete.

III. AGENCY FOR PERSONS WITH DISABILITIES DIRECTOR, BARBARA PALMER

Barbara noted that during the individual mission statements, there was a common thread of outreach, learning, sharing experience and the sense of what community inclusion means. She discussed the transition of individuals with very complex medical or behavioral disabilities from the Carlton Palms facility into the community. Some individuals also have forensic involvement. Carlton Palms houses 250 residents on the Medicaid waiver and 50 others from a variety of states and countries. The community capacity to absorb this influx of transferees at this time is 11 residences. Barbara said movement of these individuals consequently could only go as fast as individualized complex needs planning is completed. It will be an ongoing, challenging process, supported by many Central Region APD employees as part of a 15 member team that includes nurses and behavior analysts. APD went directly to settlement agreement instead of through the administrative complaint to move this transition as quickly and safely as possible. The Agency will bring in a professional entity specializing in transitioning individuals from large to small facilities. This new entity will provide oversight of the facility and supervise the transition. The process is expected to take up to 2 years, with planning for 16 individuals already completed. The Agency's strategic planning process determined category by need for those transferring and transfer deadlines, and will meet with out-of-state entities Benchmark, Liberty and Columbus as part of the selection process. Carlton Palms will pay for the transition and APD will be in charge of the contract. However, all families are afforded the choice to have their individual stay at a newly configured Carlton Palms. They will operate either 4 to 6 bed residences, or three bed medical homes exclusively as a group home model, following group home licensure requirements, and no longer as a Comprehensive Transitional Education Program (CTEP). Barbara will decide among the three transition companies within the next two weeks. She asked that FCC's assist APD with the successful movement of individuals by welcoming them into their local community. Secondly, she noted a desperate need for foster and adoptive families for children with special needs, and

feels fostering and adopting could be promoted by FCC members that have met these challenges within their own families.

Discussion about the nursing shortage in the state of Florida became a recommendation that the Council educate the legislature on this issue. Families with experience in raising special needs children must have access to sufficient nursing care for their natural born children with disabilities before considering a new family member with medical needs who also require this service. Barbara suggested that she, Secretary Mike Carroll from DCF, and Secretary Elizabeth Dudek from the Agency for Health Care Administration (AHCA), participate as a panel at a future meeting since this, and other concerns raised are cross-system issues.

She also discussed the need for Adult Day Training (ADT) center incentives to encourage movement of their clients into competitive employment, rather than being ADT clients until retirement.

Paula James, Howard Fetes, Marty Norris and Martha Stuart volunteered for the "Work Incentive Committee" to address movement from ADT's to competitive employment.

Barbara also discussed APD's work on a Florida Navigator project for families to use as a roadmap to services within all of Florida's systems of care.

IV. SECRETARY OF DEPARTMENT OF CHILDREN AND FAMILIES, MIKE CARROLL

Mike Carroll explained that managed care networks are required to prove they have enough providers to offer sufficient care to families enrolled in their plan. He also noted that sometimes the solution can be increasing salary rates, but is not always the case. His goal is to maintain continuity of care and a real family home for those under his supervision, including those with disabilities. He welcomed the opportunity to discuss provider issues preventing experienced families from welcoming another member into their family through fostering or adoption. He plans to participate in the panel suggested by Barbara Palmer, including Elizabeth Dudek, where the Council can suggest solutions to solve some of the agency silos, managed care, Medicaid and provider challenges. He also agreed to return to the Council in the future, and supports the participation of a Liaison to the Council, Stephanie Weis of DCF's comparable APD Areas 7, 13 and 14 to participate on a regular basis at FCCF meetings.

Mike said Florida has 23,000 children in care. When moving individuals from a skilled nursing facility to a medical foster care setting, sometimes medical professionals may step in and say the child can't be supported in that type of environment. DCF will not go against a medical recommendation when another professional feels it's the wrong decision for the child. He has 14,000 employees that make life-changing decisions every day, in real time situations. In the field, DCF and APD timelines don't align. The challenge of necessarily removing children immediately by DCF because of a dangerous situation, and the extended period of time it takes to enroll an individual on the Waiver by APD remain very different. It creates friction and frustration in the field when workers don't understand another agency or department's program requirements. DCF and APD are committed to cross-training their employees to reduce these issues. About 450 kids currently in their system are served by both DCF and APD through waiver or waitlist. 80% of CPI's (Child Protective Investigators) have been with DCF for less than two years. Of those two years, it takes one year to be trained and certified. The level of employee turnover remains challenging, and cross-training is constant for new employees. Mike is thankful that Florida has increased funding for social services in the last couple of years. Workers are also in need of training regarding the State Medicaid plan, to supplement the dollars both DCF and APD spend to support children. Media pressure is high for DCF to remove more children after a publicized incident. Mike feels that it's not that more children should be removed, but that the right children be removed. In 2003 there were 30,000 kids in the foster care system, not including those receiving services in their original home. Then the numbers shifted to a low of 16,000. After incidents, in some counties the removal rate tripled. DCF can not adapt quickly with resources to accommodate this huge increase, putting stress on the system. Extreme increases in need for care can

cause children to experience inappropriate settings. Group care is not appropriate for children who do not need it. DCF is striving for homes that are with individual families, rather than with shift care employees, such as group homes. DCF's process only begins when children are removed, the goal of the Department is successfully integrating children into their permanent home. Now statewide numbers are about 23,000, approximately 25% less than 2003. He feels a child coming into care should be placed with a family that understands individual needs such as a disability or medical issues. DCF is looking for diversity in families to meet these needs. Sometimes foster families are available but are not able to welcome a child with challenging, persistent and lifelong needs. Mike and Barbara have partnered to recruit foster/adoptive families that match this diversity of need. He distributed materials related to foster family recruitment for children with disabilities for Council members to discuss with their local communities.

Mary Smith suggested that the Council's "Profile Book" distributed yearly to legislators focus on the positive aspects of individuals, but also the continuing challenges.

V. ASSOCIATE DIRECTOR AND RESEARCH ASSISTANT PROFESSOR OF THE FLORIDA CENTER FOR INCLUSIVE COMMUNITIES, ELIZABETH PERKINS

Elizabeth Perkins described FCIC (Florida Center for Inclusive Communities), as an entity whose mission remains unfamiliar to some Floridians. Their 5-year plan includes an Agency for Persons with Disabilities waitlist initiative to raise awareness through a social media campaign. They want participants who reflect the diversity of the state and different geographical regions to reach the largest number of legislators who represent these families. The FCIC chose this activity because similar campaigns in other states have had positive results. Funding under the Federal Developmental Disabilities Act allows FCIC to use resources to advocate for system change, but Elizabeth stated that this project also requires an investment in system funding. They are coordinating with the DD Council (Developmental Disabilities Council) waitlist workgroup so efforts are not duplicated, along with coordinating legislative platforms to highlight continuing need. This project will be a tool to make the community-at-large aware of the waitlist issue. Elizabeth indicated that individuals deemed eligible for services but don't receive them until many years later is not a sustainable system. The waitlist initiative is expected to be operative in the Fall, and will continue throughout the remainder of their 5-year plan. Elizabeth said that once the community is aware that 40 percent of people qualified for services are not receiving them, the question arises if this is really a service Florida is providing. She noted that she and Pauline Lipps will compile stories from Floridians that describe the value of Waiver services by those who receive them, and stories from those still waiting. Pauline Lipps asked that stories be sent directly to Elizabeth Perkins, and she will send media release forms to members to allow use of these stories. Elizabeth can be reached at eperkins@usf.edu. The website for FCIC is flicic.org. Clarence Lewis, Central Regional Operations Manager, APD, noted that although individuals may not be on the Waiver, it doesn't mean they are not receiving services. Also, some families counted as waiting aren't ready to accept services at this time. There has been progress in the last two years, but Florida hovers around a consistently unserved group of 20,000.

She spoke about caregiving for individuals as a natural resource. She noted many quality of life issues experienced by families providing lifelong care. The University of South Florida, Tampa (USF) is a University Center for Excellence in Developmental Disabilities (UCEDD) and is funded similarly to the Developmental Disability Council and Disability Rights in Florida. The UCEDD's were formed in 2005 and focus on working with school systems to address positive behavior supports, intervention and early education. They have online certification training for positive behavior supports. They also offer an online Master of Science in Child and Adolescent Behavioral Health. A small part of their mission involves employment, and a health mission that examines the lifespan of individuals with disabilities, which is Elizabeth's focus. They are one of such 67 UCEDD's across the country that do interdisciplinary training to professionals to provide an understanding of individuals with developmental disabilities. They primarily

support, coach and train systems field personnel, along with technical assistance and research dissemination activities. Their governing body is The Association of University Centers on Disabilities, which has a broad range of archived webinars, and all 67 UCEDD's interact back and forth with the AUCD. The AUCD website is aucd.org.

Mary Smith was invited by Elizabeth Perkins to become a member of the FCIC community advisory committee that includes eight state agencies, eight family members and 5 self-advocates.

Caregiving research information in the 2013 report from stateofthestates.org noted that 76% of those with disabilities live with family caregivers, 21% in a supervised residential setting and 17% live alone or with a roommate. She cited that 32% of those with disabilities lived with caregivers under the age of 41, 35% lived with caregivers age 41-59 and 33% lived with caregivers over the age of 60. It is projected that the number of individuals with disabilities over the age of 60 will double by 2030. The life expectancy of individuals with Down's Syndrome has gone from 25 to 55. Globally, by 2017, people over the age of 65 will surpass the number children under the age of 5. Life expectancy used to be 65 in the 1950's, now it is 78 or 79 in the United States.

Elizabeth suggested that reports should also focus on aging caregivers of those with developmental disabilities to augment previous studies describing caregivers of those with dementia, cancer or stroke. In those studies, generally the individual receiving care was older than the caregiver and was not expected to survive that disease. Those with a lifelong commitment to caregiving have experience very different from the above model. The differences are not just long term, but often for the duration of the caregiver's life. Both can go through the aging process at a similar time and because of extended life expectancy, there is concern about the future of care, such as quality residential supports for the recipient when the caregiver is gone. She noted that long-term caregivers have a measure of expertise and feelings of mastery of the caregiving process due to their length of experience.

Caregivers experience a balancing act between stressors involved in their job and how they cope with those stressors. The concept of "Compound Caregiving" was identified as caring for a lifelong special needs individual concurrently with a relative, that due to illness or age, requires significant support needs. 68% of individuals indicated they are a compound caregiver, sometimes cycling in and out of these caregiving responsibilities. 34% anticipated they would become a caregiver in the future for a family member. The average time of concurrent caregiving was 3 years. Support for these caregivers should include lifespan respite because their role does not start with a family member over the age of 65. She also noted that when respite is received for only one of the "compound care" recipients, but not the other, there is no real respite from caregiving responsibility. The concept of reciprocity was identified as when the caregiver actually becomes supported by the person receiving care.

Elizabeth went over the health disparities for people with disabilities. She noted that 87% with disabilities report at least one secondary condition, whereas 49% without a disability report one secondary condition. Individuals with disabilities report an average of four health conditions, as compared to those without disabilities report only just over 1 additional condition. Due to the time it takes to discuss additional issues with their doctor in a time-limited situation the "Health Passport" was developed by Elizabeth and a med student holding a Master's in Public Health to promote effective communication during visits to medical providers. The "Passport" includes education for Lifelong Mental Health, addressing anxiety and depression, cancer, cancer treatment, diabetes, osteoporosis, good health and hygiene with additional information on how to speak to medical providers and a personal health report history, and the passport document itself that gives information specific to the individual's needs during a medical visit beyond health statistics. All these FCIC-developed health resources are available as free downloads, without limit for community distribution.

VI. OTHER COUNCIL BUSINESS

Area 10's Marty Norris discussed their Council looking into sponsoring local families for respite services through private funding, and greatly needed respite services for individuals over the age of 22.

Area 15's Tony Mancuso noted he met with the Indian River County School Superintendent. That School District is interested in partnering with the FCC to have advocate families speak at an Exceptional Student Education event. Also presenting will be Vocational Rehabilitation, Social Security and Abilities Resource Center (ARC). The goal is to have families share information with others present, as well as videotaping for families unable to attend. Orientation packages will be offered those without computer access. Mary Smith noted that Nicole Torres of the Family Network on Disabilities would be a good resource to support this type of event.

Howard Fetes suggested the members consider that FCCF hold a meeting or retreat at Rish Park in the future. It was noted that accommodation is in dorm format, with a cafeteria facility, remotely located from provisions and the majority of Council members, an hour away from Panama City with no phone service. Pauline Lipps made a visit within the last 2 years and noted it is 400 miles from Sarasota to Rish Park and Sunland facility is the contact for reservations, even for day visits.

Sheryl Soukup discussed the ROOF (Residential Options of Florida) program and asked members to distribute brochures to their FCC's to share with the community. ROOF connects individuals with developmental disabilities to housing opportunities. They hold workshops and training, and is a resource to refer people to help with locating homes and renovating. They also provide technical assistance to groups of families and providers considering building inclusive housing. ROOF is planning a joint conference with APSE (Association of People Supporting Employment First) on housing and employment for people with developmental disabilities from October 12 to October 14 in Orlando at the Florida Hotel. Registration is available on the ROOF website. Pauline Lipps will send conference information to all FCC Chairs. Mary Smith noted that she will be joining the Board of ROOF, along with current member Patty Houghland. In Sheryl's local office they manage a project for FDDC (Florida Developmental Disability Council) on abuse and neglect as part of the Abuse and Neglect Task Force, to reduce incidence throughout Florida. One strategy is to increase the value and respect for individuals with disabilities through a public awareness campaign called "Respect Every Ability". They will be promoting the positive contributions and leadership roles that individuals with disabilities have assumed in their community. She asked the Council to help in the arenas of housing and abuse/neglect by "liking" both the conference and the campaign on Facebook, then sharing posts locally.

Betsy Hill noted that access to dental care remains a critical problem. It is vital to reimburse professionals at a rate to acquire and retain independent, not just institutional providers. She feels the managed care entities have an unfair advantage in providing care to Florida's Medicaid clients and is not the answer for children in foster care, those with developmental disabilities and other, because there is no incentive in large institutions to see patients if they are late. Late clients are told to go home, whereas in private practice, they are worked into that day's schedule, because private businesses have the incentive to pay their bills. Managed care entities also have distance challenges for clients, who may travel two or more hours to receive dental services. She notes it is not financially feasible for private practitioners to exclusively have individuals with disabilities as patients because of the time required to offer specialized care for this population. Especially costly to a professional is the need to provide general anesthesia for individuals who need this provision to receive care.

Mary Smith agreed this information would be a good addition during the panel discussion comprised of the Council and Barbara Palmer, Mike Carroll and Elizabeth Dudek. The Executive Board may schedule this panel either prior to the Council's Friday Workgroup meeting, or 30 minutes during the workgroup. The Board could also travel to Tallahassee. It was noted that more input from a variety of members would likely be offered if the panel was available to FCCF in Orlando. The Executive Board will examine both options and determine how to bring concerns/solutions to APD, DCF and AHCA. They may decide that both options will best serve the needs of the community.

Patty Houghland noted the only individuals who can opt out of managed care services are those who are on the Developmental Disabilities Waiver, the DD Waiver waitlist, and a small group of others.. It was noted that Medicare recipients can choose traditional Medicaid services, and they are being actively pursued as clients by managed care companies. Families continue to experience long travel times and challenges to get timely appointments with specialized providers when utilizing managed care.

VII. CITIZEN TIME

Tony Mancuso spoke about creating a legislative initiative to amend the use of McKay vouchers for individuals on the waitlist identified as having severe/profound disabilities to allow an educational experience up to age 26. Mary Smith gave a brief description of state Medicaid dollars accessible to those on the waitlist depending on family income. She then referred him to the upcoming Wright's Law Special Education Law and Advocacy Conference, sponsored by the Family Network on Disability, on September 24 in Dunedin from 8 a.m. to 4:30 p.m. for technical advice on pursuing this project. Pauline Lipps will forward registration information to members as it becomes available.

There being no further business before the Council, Mary Smith adjourned at 3:22 p.m.

Respectfully submitted,
Ruth Wingate, FCCF Secretary

**The next meeting of the Family Care Council Florida will be held on
September 17, 2016 at Embassy Suites, Orlando Airport, Orlando, Florida**