

FAMILY CARE COUNCIL FLORIDA

Pauline Lipps, Chairperson
March 19, 2016 Meeting Minutes
Embassy Suites, Orlando Airport

Members Present:

Pauline Lipps, FCCF Chair, SC East
Mary Smith, FCCF Vice Chair, FCC4
Jean Sherman, FCCF Past Chair, FCC10
Ruth Wingate, FCCF Interim Secretary, FCC15
Dan Bayley, FCCF Treasurer, FCC7
Elizabeth Hill, FCC3
Paula James, SC West
Patricia Oglesby, FCC8
Karen Oberg, FCC9
Gilda Pacheco, FCC10
Rosa Maria Barbara, FCC11 (by phone)
Mary Ellen Ottman, FCC12
Betty Kay Clements, FCC13
Laura Tacinelli, FCC14
Melody Hearn, FCC15

Guests:

Howard Fetes, FCC7
Patricia Bell Kennealy, FCC9
Tina Ciecierski, SC West
Stephen Ciecierski, SC West
Sara Brothers, FCC7
Daniel Hosack, FCC7
Martha Stuart, FCC9

APD FCCF Liaison: Stephanie Rogers

APD CENTRAL ROM: Clarence Lewis

GUEST SPEAKER: Karen Hagan,
APD Chief of Staff

CALL TO ORDER:

FCC Chairperson Pauline Lipps called the meeting to order at 8:38 a.m., adding Jean Sherman's presentation made at the Florida Symposium on Aging with Developmental Disabilities titled "Caring for the Caregivers to the agenda. The Chair introduced Interim Secretary Ruth Wingate who identified folder contents:

- FCCF March 19, 2016 Agenda
- FCCF January 16, 2016 Meeting Minutes Draft
- FCCF FY 2015/2016 YTD Expenditures
- ARC of Florida "Maximum Potential Kids" Applied Behavior Analysis training flyer.

Chair Lipps presented the inspirational DVD "Pulling Together" from the collection available at Simple Truths.com online. Councils can allocate funds to purchase these educational tools.

Introduction of members/guests were made. Ms. Elizabeth Hill asked that she be identified as Chair in Area 3, replacing the former "Vacant" status on FCCF's letterhead. Ms. Paula James asked that she be identified as Chair of SC West Area. By consensus, changes approved.

II. BUSINESS:

Moved by Ms. Clements, seconded by Ms. James to accept the minutes of January 16, 2016 as submitted with the amendment that Mr. Bayley and Mr. Fetes be identified as residing in Area 7. Motion passed without dissent or discussion.

FCCF Budget Report: Howard Fetes assisted Treasurer Dan Bayley in reporting, stating that FCCF's 2015/2016 expenditures YTD are \$8,429.40. Largest expenditure of \$1,000 was for community booklets. As of January 1, meeting room rental has increased 25%, and an increase of 10% on individual rooms. A total of \$6,571 remains unexpended.

III. AGENCY FOR PERSONS WITH DISABILITIES CHIEF OF STAFF KAREN HAGAN

Chief of Staff Hagan stated that after the FCCF meets, a team at APD convenes, including the leadership team member present at the meeting, to discuss issues raised by FCCF members and

community. This information is also vital to other agencies connected to APD, such as AHCA, DCF, Vocational Rehabilitation, Department of Health and others. She complimented FCCF for producing the "Part of Your Community" booklets. Chair Lipps noted that the FCCF's efforts such as this project, started at the FCCF level then moved locally with its message.

The Agency achieved success in both policy and budget this legislative session. Policy highlights included HB1083 which updated many provisions of F.S. 393, including revised priority classification for clients on the waitlist, required APD to provide waiver services through community-based care to individuals who need extended foster care services, provided requirements for increases in iBudget for clients needing certain transportation services or with extraordinary needs, and provision for services to an individual if their parent or legal guardian are active duty military and move into the state of Florida having had services in a prior state. APD is also required to contract with a qualified evaluator to annually conduct reviews of the status of individuals admitted involuntarily to residential services provided by the agency. Bill 628 includes the reduced fee for background screening for agency providers. Fees will now be charged for this service to equal those paid by DCF.

Ms. Hagan acknowledged that successful funding of APD's budget for next year came through a team effort. Funding of \$1.31 billion funding is budgeted for APD, a \$100 million dollar increase over prior years, and the largest appropriation the Agency has received. \$36.4 million is available for waiver enrollment for individuals with critical needs in priority category 6, who reside in their family home and are at least 30 years old and have been on the waitlist for at least 10 years. This funding is anticipated to serve 1,300 new enrollees. The budget includes \$2.5 million to offer waiver enrollment to about 55 people with a genetic disorder involving Chromosome 22 called Phelan-McDermid Syndrome, a newly qualifying disability for Waiver services

. ROM Clarence Lewis noted that if information is available through school records or other supporting documentation identifying the special need, an individual could be considered for Waiver services.

The budget also included \$25 million for Adult Day Training 1-3 staff ratio rate increases, and a 3% increase across the board for Adult Day Training, Personal Supports and Residential Habilitation categories of service. \$37 million is budgeted for provider rate increases for 1-1 services for Personal Supports Life Skills Development 1 (Companion), Respite and Residential Habilitation Live-in complying with the Department of Labor Home Care Rule. An additional \$9 million was allocated to begin the rate increase effective April 1. \$500,000 will be available to continue the enhanced employment project for year 4, which includes internships and employment placement. APD budget allocations for the upcoming year can be viewed at www.apdcares.org.

Ms. Hagan suggested that FCCs could be a good resource to assist with the enhanced employment project. She asked Ms. Rogers to document for the Council the number of individuals who have successfully participated. APD has a continuing and enhanced relationship with Vocational Rehabilitation through this project, to avoid service duplication and gaps for a better continuum of support. She suggested that APD staff member Megan Murray address the employment project at a future FCCF meeting.

Vice Chair Smith noted that a tool used to inform employers, discussing hiring incentives, such as tax credits could be disseminated throughout the community. Ms. Sherman noted the Developmental Disabilities Council has produced videos for employers, but some felt employment services have morphed into a less effective system, with practical implementation remaining a challenge. A continuum for successful employment of those with developmental disabilities remains disjointed, identified specifically when individuals choose to leave employment, with program rules producing less than person-centered results. Business culture change in perception of employees with disabilities is still in its infancy. It was noted by Chair Lipps that in five other states, plans to address employment have been implemented in a cohesive method. It was suggested that APD training on supported employment covering paperwork, goals and person-centered planning be integrated with Dale Dileo's training which focuses on a hands-on approach and employer incentives.

Ms. Hagan also identified the appropriation of \$1.3 million to Rish Park and \$2.2 million to continue working on the client data base. She noted that web-based training will be implemented this spring. Topics available include Zero tolerance, HIPPA and Core Competencies. Classes are free with certificates of completion awarded. A Supported Living Coaching training is in development, and input heard at the meeting will be communicated to Pam London who is developing this module. The client data management system is being addressed through solution mapping sessions discussing software

configuration changes to accommodate APD requirements during numerous meetings held jointly with APD field and Central office personnel. In April, the topic of key data exchange, including AHCA's FEMIS and DCF's FLAIR, will be discussed by the Agency and vendors, regarding interface and compatibility. FCCF was asked for comments on the revamped Support Plan. There was concern that there was not enough family and guardian involvement, which was reflected in the tenor of the draft version. Also the document seemed written for those who could make decisions for themselves and could provide narrative answers. However, two thirds of individuals on the Waiver have an intellectual disability where this format would be challenging without family/guardian support in the process

Six QSI stakeholder focus groups were held in Orlando on February 16-18. On March 3, nine members of Area FCCs attended a QSI phone-in meeting. Much information from the call reinforced the Orlando focus group input. On March 29 a statewide call regarding QSI will be available for all stakeholder participation. APD will send out the current QSI to members. The purpose of the six Orlando focus groups was to gather information as a part of a three year project to examine the integrity of the QSI, to discuss algorithm statistics with the creator of the tool, Dr. Foster, and report back to leadership with recommendations. Next year's focus will include a small scale field test of the adopted refinements, development of electronic support refinements, concluding with the 2017-2018 implementation of a large-scale field test, refinements and updated independent validity and reliability studies. It was suggested to use a survey to gather information prior to meeting, or a FAQ produced to avoid duplication. Vice Chair Smith suggested the QSI should first identify the specific disability and how it affects answering the QSI questions. The questions must be established under guidelines of how the disability is manifested in each individual to make this a valid tool.

The CMS survey was discussed by Ms. Hagan during the Operations update. In November, APD compiled a list of all 1,797 licensed residential facilities and 184 Adult Day Training sites to survey. A sample of 323 residential facilities and 123 ADTs will be reviewed. As of March, 39 residential and 13 ADTs reviews were completed. The sample deadline is June 30, 2016 per CMS requirement.

APD is setting up six regional meetings with APDs leadership staff, support coordinators, waiver providers and FCC members. A similar meeting was held last year in Orlando. The first will be held on May 5 in Tallahassee, to continue through July. Included will also be stakeholder groups such as FARF and ARC. The leadership team plans to spend the remainder of the meeting day with Regional staff. Priority agenda items are requested and can be emailed to Ms. Hagan.

APD's Lifespan Project is spearheaded by Tom Rankin and assisted by an APD MSW intern and Ms. Rogers will identify who, when and with what resources are individuals served. The intent is to chart a path through service acquisition including categories of early years, school, work and family years and retirement, along with an Other Assistance tab that includes resources such as WIC and cash assistance. Chief Hagan noted that APD has met with Elder Affairs to discuss their "No Wrong Door" initiative and will continue that conversation with coordinating agencies. APD is considering what tool is best to make this information available, potentially an online piece with updating capability. It was suggested that both clients and service providers receive training to use this process. Ms. Hagan noted the research phase is complete but not disseminated since coordinating agencies have not signed off on this information and format. When the document is approved by participating agencies, she will share it with FCCF.

The Comprehensive Transition Education Program identified in FS 393 that provides services for individuals with serious behavior issues is currently only available at the Carlton Palms facility. New CTEPs can now be licensed in Florida through statute revision, and new providers must be fully compliant with CMS Waiver guidelines for licensure. These include limiting length of stay for newly admitted residents to a maximum of 2 years with extension of stay only through clinical review, clarifying the types of residents served, types of programmatic components offered and complying with any settlement agreements in place between Carlton Palms and APD. Some of the settlement language will be added to Florida Administrative Code, which is the Agency's licensing rule. Public comment will be held for every setting identified as a presumptive institution, noticed by AHCA. APD and AHCA completed a joint survey on March 3 at ARC of Jacksonville Villages to ensure compliance with the CMS rule. The survey indicates it does not meet the criteria for presumptive institution, so Waiver funds could be expended at this facility. Ms. Hagan noted that APD diligently follows federal guidelines regarding funding this type of residential facility. APD and AHCA will jointly perform follow up to ensure continuing compliance with CMS rule. Denise Arnold from APD will speak at the May FCCF meeting, joined by Shevaun Harris from AHCA. Specific information requests from the speaker should be sent to Chair Lipps prior to the meeting.

The modified CMS transition plan will have no public comment, the format is to answer questions about the draft document. The plan will go through a 30-day public comment phase in August.

Ms. Hagan noted that pending Governor's Office appointments to local FCCs are anticipated by the end of March.

Ms. Rogers discussed the Medicaid Waiver Waitlist documents. In November, 2015, APD offered enrollment for Waiver services to 2,502 individuals in priority category 3, 4 and 5. As of March, 2016, 1,124 of those were enrolled. These figures represented slightly less than half of those receiving offers. There are various reasons why individuals do not enroll at the time of offer, including that they have current resources to meet their needs, have opted to enter Intermediate Care Facilities or are school-age and are receiving services in that setting. Some are going through the Medicaid enrollment process, which can take 60 or more days, delaying their enrollment. Regional offices follow up with those not taking advantage of the offer. Sometimes families have not updated contact information and addresses with the Agency, so APD occasionally cross-references other agencies to locate the family electronically.

IV. DIRECTOR OF PLANNING/DEVELOPMENT, BRANDON GOEKE, MOORE COMMUNICATIONS GROUP, ABLE UNITED

The predecessor to the ABLE Act, the Stephen Beck, Jr. Achieving a Better Life Experience Act became federal law in December, 2014 and created regulations in Section 529A of the Internal Revenue Code. This original legislation encouraged individuals with disabilities to save private funds to support health needs, to foster independence and improve quality of life. Florida's "Achieving a Better Life Experience" Act (ABLE) became law in July, 2015, creating an ABLE Program modeled after and overseen by the Florida Prepaid College Board. July 1 2016 is the program start up date for Floridians.

An ABLE account is one allowing individuals to choose savings or investment options, with earnings from the account identified as tax-free and used for qualified disability expenditures. These accounts are excluded from SSI means-testing as assets for the first \$100,000. Medicaid benefits are not lost if SSI is suspended for assets in this account of over \$100,000. However the standard \$2,000 asset ceiling must be included in this \$100,000. Other federal programs such as Section 8 do not count assets in these accounts as a resource.

The ABLE United Program is overseen by Florida ABLE, Inc., which is a direct-support organization of the Florida Prepaid College Board which manages \$15 billion in assets. Individuals who meet the disability and severity requirements for SSI or SSDI can open an account, even if they are not currently receiving those benefits, or if they have a condition on the List of Compassionate Allowances. The disability onset must be before age 26, with no restriction on age when applying, and the individual must be a Florida resident at time of application.

The IRS categories to qualify for ABLE accounts are developmental disorders, intellectual disabilities, psychiatric disorders, nervous disorders, congenital anomalies, respiratory disorders and others not identified above.

The individual with a disability is the ABLE account owner, and may have only one account nationwide. They may open and manage the account independently or a parent or guardian may assist if the individual cannot or chooses not to manage the account. Persons managing this account with the beneficiary must certify their signature authority to act on the individual's behalf, such as a power of attorney. This account can be managed online via a secure customer portal. Online enrollment can be completed in approximately 10 minutes, and deposits can be made during that process. It is not necessary to upload documentation. An individual with a disability needs to provide authority to open the account, as the owner or for parent/guardian management, with Social Security number, name, address and date of birth, categorize the disability and that onset was before age 26. Individuals are required to self-certify that application information is accurate. Banking information will be needed if electronic payments/expenditures are chosen. If person is not receiving SSI or doesn't have a condition listed on the Compassionate Allowances, the person will need to provide the date of diagnosis with treating physician's name and address as part of the application.

Anyone may contribute to this account, but no rollovers are permitted from IRAs or 529 College Savings Plans at this time. Money can also be moved from pensions into these accounts. There is a \$14,000 per year limit for these after-tax contributions, and one-time or recurring contributions are accepted in a variety of methods such as online, by automatic withdrawal, payroll deduction or by check remitted to customer service. The maximum balance for this account is \$418,000, and additional

contributions can backfill the account as funds are expended, at the same limit of \$14,000 a year. Contributions from a third-party are not considered income to the individual, but as completed gifts, are not considered an asset for the purpose of federal means-testing and allowed from the individual's wages after taxes. This does not reduce taxable income, nor income for federal means testing, but does reduce assets for means-testing.

Savings options can be chosen to focus on capital preservation or investment options that can include U.S bond funds, U.S. stock funds and international stock funds. An individual selecting the investment option can also decide whether they prefer a conservative, moderate or growth portfolio. By law, ABLE United cannot provide financial advice to individuals regarding their ABLE accounts. They do provide updates by statement so individuals can examine how their account is performing and can be informed what other options are available within the program. The ceiling fee for buy-in to this account is currently suggested as \$50.00 with maintenance of ½ of 1% monthly, or 6% annually. There is no upfront fee for investment options, just the monthly maintenance fee.

ABLE account funds can be withdrawn at any time, for any reason through electronic transfer or check. All expenditures for qualified disability expenses, including basic living expenses, are tax-free. Non-qualified withdrawals will have income tax assessed, plus 10% on the earnings. ABLE United reports contributions, expenditures and earnings to the IRS (annually) and Social Security (monthly). If audited or reviewed, individuals would need to document qualified expenses under IRS regulation. ABLE United does not question if the expense is qualified, nor give approval or denial for withdrawal. Qualified withdrawals include expenses for health, education, housing, transportation, legal fees, financial management, employment training and support, assistive technology and personal support services, oversight and monitoring, funeral and burial and other expenses approved by Treasury regulations. The expenses do not have to be for medical necessity.

Only the first \$100,000 is excluded in the account balance for SSI. Funds over this amount are considered an asset by Social Security. Another SSA regulation regarding housing expenditures requires money must be spent in the same month as withdrawal or the funds count as assets. Individuals will not lose Medicaid benefits if SSI is suspended due to ABLE account balance or housing expense distribution a month or more after withdrawal.

Medicaid repayment is federally required in all states to recover Medicaid expenditures from the Medicaid recipient's estate. Upon death, the state may request reimbursement for Medicaid benefits paid, less premiums paid to a Medicaid Buy-In program. This repayment request excludes benefits paid by Medicaid before establishing the ABLE account, and has priority only after payment of all outstanding qualified disability expenses. There are also recoupment restrictions if survived by a spouse along with rules regarding limitations on Medicaid repayment. The state is a creditor of an ABLE account, not a beneficiary of that account, meaning payback is not automatic. Prior to the account owner's death, the account can be transferred to a qualifying sibling with a disability. If funds are left in the account after final disbursements and Medicaid recoupment, they pass to the individual's estate.

ABLE funds are easy to access without the need to involve trustee approval, and have tax-free earnings, as compared to tax rates for trusts. An ABLE account can complement a special needs trust through a reduced tax burden, and individuals can save for certain expenses such as food or shelter. Dated deposits and withdrawals from the account will be itemized by online statement. It has not been determined if there will be a fee to disburse funds by check.

A presentation will be made at the Family CAFÉ conference in June, 2016 with a supporting exhibit and hosting room. Questions can be addressed to Brandon J. Goeke, MBA, Director of Planning and Development, Florida Prepaid College Board at brandon.goeke@myfloridaprepaid.com or by phone at (850) 488-8514. Latest updates on the ABLE program are available at www.myablesavings.com or info@myablesavings.com.

VI. FCCF Nominating Committee:

Ms. James presented the nominating committee's recommended slate for 2016-2017 FCCF's executive officers. Nominated were Vice-Chair Mary Smith for Chair, Ms. Patty Houghland for Vice Chair, Ms. Ruth Wingate for Secretary and Mr. Dan Bayley for Treasurer. Nominees from the floor will be taken and election held at the May 21, 2016 meeting.

VII. FCCF Family Care 2016 Presentation:

The FCCF will be presenting at the Family CAFÉ conference on Friday, June 10 at 1:30 p.m. Ms. Huscher chairs this committee, and six FCCF members have volunteered. A committee meeting will be held in about 2-3 weeks.

VIII. Other Council Business:

Community Booklets previously ordered by Areas will be mailed to individual Councils or Regional Offices. No new FCCF brochures are currently on order. Chair Lipps asked for a volunteer to attend and relay information to FCCF from the Delmarva Quality Council meetings three or four times a year in Tallahassee. Members include representatives from Delmarva, AHCA, APD, consumers, families, provider representatives, etc. All are welcome. Chair Lipps agreed to ask member Ms. Lou Ogburn from Area 2 to consider assuming this responsibility.

Area 11 Chair Rosa Maria Barbara announced they have a new APD employee in Area 11 to serve Monroe County throughout the Keys where services are greatly needed. They are planning a legislative forum for various stakeholders. A forum was also held by the Center for Independent Living on transportation and accessibility in South Florida. Florida International University has a college option designed for people with developmental disabilities, including the autism spectrum, to achieve certification in a variety of employment options that slowly integrate the individual into an employment situation. The model also includes medical services for participants and hopes to expand nationwide. They are also organizing a housing forum because of the high need for this service. The Association of Agencies has been expanded and remains focused on matching needs to services across their community. Three applicants to FCC-11 have remained interested throughout the long appointment process.

Moved by Vice Chair Smith, seconded by Ms. Pacheco to expend up to \$500 to reprint FCCF brochures. Motion approved without dissent/discussion.

Moved by Ms. Oglesby, seconded by Ms. Ottman to expend up to \$750 for a projector for FCCF use. Motion approved without dissent/discussion.

IX. Presentation by Past Chair Jean Sherman:

Past Chair Jean Sherman discussed her recent presentation at the Florida Symposium on Aging with Developmental Disabilities, titled "Caring for the Caregivers". She noted that in 2015, 43.5 million individuals served as family caregivers in the United States across all ages and disabilities. Thirty-nine percent of all U.S. adults are caregivers, and an emerging population of youth caregivers are assisting their families. Nationally there are 3.5 million individuals with developmental disabilities who reside with their family. Of the 39% of caregivers, 850,000 are over age 60, and by 2030 it is anticipated that 1.2 million of those cared for with developmental disabilities will also be over age 60. At that time 70% or more will live with family caregivers, which is expected to continue to rise.

In 2013, U.S. economic value of family caregiving was \$470 billion, greater than funding Medicaid or the value of the Walmart Corporation. 2.5 billion hours of care were provided by 2.7 million Florida caregivers, equaling a value of \$29.7 million per year. Caregivers sometimes don't identify themselves with this title because caregiving is often viewed as a natural and unpaid resource and a family responsibility. It was noted that generally, caregiving can be either temporary or long-term, but with an individual with developmental disabilities, caregiving is a lifelong responsibility for families.

At 3:30 p.m. it was announced that the Council opened Citizen Time and asked those calling in to identify themselves for the opportunity to speak.

Ms. Sherman noted that resources to support caregivers can include paid in-home services, day programs and respite care. The informal/voluntary resources for families can include local support groups, unpaid respite care and caregiver organizations, websites, tip sheets and blogs that provide information and supportive experience. Paid resources can be accessed through the assistance of Waiver Support Coordinators and Consultants with iBudget funding. Private funding can also be used to

pay for day programs, in-home services and respite care that can benefit both the family and the individual with the disability.

The informal or natural supports and voluntary services can include support groups that can be disability-specific or those sponsored by provider agencies. Parent-to-parent, Family Network on Disabilities and local communities also assist families with support groups, and faith-based, hospitals and others can offer support group opportunities. The informal support of respite care can be found in faith-based organizations, fraternal organizations, the APD Resource Directory. The Developmental Disabilities Council is refining this resource as some listings were self-nominated, and might not provide the specific service they identify as available. Also the Area Agencies on Aging can provide respite. Although originally intended for caregivers of elderly individuals, it could include grandparent caregivers of younger family members with disabilities.

Supporting yourself or others as caregivers is important. Asking for help when needed, being a part of a support group and taking breaks, whether with friends or independently away from the caregiving process is necessary. Ms. Sherman suggests that remaining connected to interests and hobbies, exercising and maintaining a healthy diet, and good medical care will allow caregivers to continue their important work. She suggested keeping health, legal and financial plans up to date in case of emergency, and telling someone where they are.

If you know a caregiver, help them remain connected to the community by visiting, calling or reaching out through social media regularly, and supporting them with a meal or dessert to provide a well-deserved break. Supporting caregivers can also include assisting with grocery shopping, something as simple as picking up mail or trash management, helping with yard work, offering an hour of your time to give them a quick break and being a friend by taking both the caregiver and cared for family member out for a ride or a simple lunch away from their normal surroundings.

Ms. Sherman noted caregiving organizations such as www.aarp.org under the title "Family Caregivers", the Family Caregiver Alliance at www.caregiver.org, the National Alliance for Caregiving at www.caregiving.org, the APD Resource Directory at www.apdcares.org/resourcedirectory and the DoEA for ADRC (Area Agencies on Aging) in your area at www.elderaffairs.org. The Florida Lifespan Respite Alliance, a newly created group addressing cross-disability, cross-age resources for respite that Ms. Sherman currently works with as President is also a burgeoning organization as a resource. Disability-specific resources include www.nia.nih.gov/alzheimer's/topics/caregiving, and by phone at 1-800-438-4380, military resources such as TRICARE, EFMP which includes Army, Navy, Air Force personnel, the Coast Guard Mutual Assistance Respite Care program, The Department of Veterans Affairs, CARD Centers for Autism, the National Cancer Institute and the MS Society, along with others related to specific disability. Much information crosses disability identities as the need to support caregivers is universal.

Members asked that the powerpoint of Ms. Sherman's presentation be shared with those not present. Chair Lipps will assist with this request.

There being no further business before the Council, Chair Lipps adjourned at 4:10 p.m.

Respectfully submitted,
Ruth Wingate, FCCF Secretary

**The next meeting of the Family Care Council Florida will be held on May 21, 2016 at
Embassy Suites, Orlando Airport, Orlando, Florida**

