

FAMILY CARE COUNCIL FLORIDA

ANN MILLAN, CHAIRPERSON
Hilton Garden Inn Orlando Airport
Orlando, Florida
May 20th, 2006

MEMBERS PRESENT:

Ann Millan, FCCF Chairperson
Bob Wessels, FCCF Vice Chair, Treasurer
Patty Houghland, FCCF Past Vice Chair
Joy Frazier, A1 Chair, FCCF Secretary
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast Region 5 Chair
Donna Rauber, A7 Chair
Maryellen Jones, A9 Chair
Belkis Almeida, A10 Co-Chair
Jean Sherman, A10 Co-Chair
Margarita Montalvo, A11 Chair
Edith Kegle, A12 Chair
Betty Kay Clements, A13 Chair
Connie Carter, A14 Vice Chair
Todd Decker, A15 Chair

STAFF & GUESTS

Denise Arnold, APD Central Office
Eileen O'Brien, APD Central Office
Melinda Brown, A13 Guest
Lynn Carper, A1 Guest
Vickie Smithee, A1 Guest
Robin Millan, Suncoast Region Guest
Louise Renicke, Suncoast Region Guest
Betty Behm, Suncoast Region Guest
Rosalind Murvin-King, A7 Guest
Amelia Rauber, A7 Guest
David Alexander, APD Guest
Anne Buechner, CQL Guest

The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities, to bring quality services to individuals for dignity and choice.

I. WELCOME

Chair Millan called the meeting to order. She provided a list of contact information for each area chairperson/representative and asked all in attendance to verify the accuracy and make any changes necessary to bring up to date. She reviewed some of the documents in the information packet which includes the evaluation survey to be completed by everyone before leaving the meeting. Also included is a list of Calendar of Events taken from the FCCFlorida website. Not listed is the ASPE conference on August 24th & 25th. Maryellen shared the hotel is about 5 minutes from her house and she is inviting anyone attending to a barbecue the evening of the 24th. David Alexander mentioned the FASC conference is October 12th & 13th at the Hilton Inn in Ocala. Chair Millan advised there was no evaluation form provided to attendees at the Council on Quality and Leadership (CQL) training session the day before. She asked those in attendance who participated in the training session to list their comments about the session on the back of the evaluation survey of today's meeting. She will then compile them as funding dollars were spent for a two day session and it's important to know what people thought of the training.

II. INTRODUCTIONS AND AREA UPDATES

Chair Millan introduced herself as FCCFlorida chairperson. She announced her chairperson role ends with today's meeting. She mentioned it's time to pass the torch which is a good thing for the organization.

Donna Rauber, Area 7 shared their council met on Wednesday and she is happy to report the council will continue on even though her term as chairperson ends in June. We have a slate of officers for next fiscal year. Council member Jeannie Forthuber has agreed to take on the chairperson role. She currently has more on her plate than she can keep up with but feels the

importance of Family Care Councils and doesn't want the council to disband. Donna shared she has offered to provide any assistance she can and will continue on as the council's information coordinator and do some administrative duties.

Joy Frazier, Area 1 shared she brought 2 people, Lynn Carper & Vickie Smithee with her to attend the CQL training session and today's meeting. She shared they are actively looking to increase their membership. Two current members are making application for re-appointments and another person is submitting their application for membership. She is participating and on the planning committee for the Supported, Competitive, Integrated Employment training. She is also participating in the QSC transportation forum in their area.

Maryellen Jones, Area 9 shared she is having a difficult time recruiting new FCC members. Her term as chairperson ends next year. They will not have a DD Awareness day this year as APD was unable to obtain the amount of insurance the shopping mall required. She is currently working with Ruth Archer and her son who has autism to create 2 informative DVD's, one on supported employment and one on supported living. She is working with their area program office to recruit more non-residential service (NRSS) providers.

Beth Kidder introduced herself. She is the Bureau Chief for Medicaid Services with the Agency for Health Care Administration (AHCA). Her area of responsibility is development of policy for all the Medicaid services including all the Home and Community Based waiver programs and every other medical service except pharmacy. She shared she is happy to be attending the meeting and hopes to answer our questions but if not will get back to us with the answers.

Frank Carroll, Area 3 shared they will be spending all of the FCC funding dollars this year. Their area APD office held a yellow book training with Melinda Coulter from APD Central Office. It was a 2 day session with Friday being attended primarily by providers and staff and Saturday attended by residential facility staff. Area 3 co-sponsored the event and sent notice to consumers and families including people on the wait list. They had a very good turnout and Area 3 FCC was given some time to provide an overview in hopes of recruiting new members.

Edith Kagle, Area 12 shared they have a new website at www.fcc12.org which is linked to the FCCFlorida website. Their area council will be participating in a workshop with United Cerebral Palsy (UCP) ARC. They have 3 families attending Family CAFÉ.

Eileen O'Brien introduced herself. She is Program Administrator for the APD Family and Individual Partners Unit. She represents the Family Care Councils in Central Office. She shared they have been working very closely with the governor's office in hopes of speeding up the FCC appointment process.

Bob Wessels, Area 10 shared some changes in officer positions have taken place within their council. The co-chairs in attendance will provide the area update. He is currently FCCFlorida vice chairperson and treasurer.

Patty Houghland, Area 1 introduced herself. She is currently FCCFlorida past vice chair and consultant.

Jean Sherman, Area 10 newly elected co-chair shared at their last meeting a change was made to their by-laws to allow for the serving of co-chairpersons. She has been with the Family Care Councils since its inception in Broward County. She served a six year term, stepped down and is currently in her second go-around. An upcoming event in their area is the Quality Symposium/Provider Fair on June 16th. They are always looking for new members. They have an active and very verbal council. They are involved with the quality assurance steering committee. Bob shared that Jean was recently elected to the advisory committee of the Interagency Quality Council.

Margarita Montalvo, Area 11 shared they are working on new membership. They have 5 current members working very hard to recruit consumers to the council. She has been going around to various agencies and speaking to families about the Family Care Council. She is pleased that many families are interested in learning more about FCC. Many of these families

are on the wait list and received the \$2,500 one time IFS offer. They are planning a family forum in their area and are looking for a location.

Betty Kay Clements, Area 13 introduced their vice chairperson, Melinda Brown. She shared they recently held their third family forum. Also included during this forum was an initial yellow book training presented by J.B. Black from APD Central Office. Many in attendance had not received their book yet. J.B. assured they're in the mail. Betty shared they are involved in the Quality Symposium to be held in Ocala on June 13th. They've been busy doing inventory and end of the year fiscal responsibilities.

David Alexander introduced himself and representing APD. He is one of the state pre-service trainers for new support coordinators. His term as FASC chairperson will end this year.

Beverley DeStories, Suncoast Region West shared she has taken over the responsibilities of reorganizing or attempting to put into place an active Suncoast Region East FCC. She was recently named chairperson of the Interagency Quality Council (IQC). She mentioned to Beth Kidder in her new role as IQC chairperson she would like very much to meet with her about policy of AHCA regarding the developmental disabilities program. She welcomes the opportunity to spend some time with her.

Belkis Almeida, area 10 newly elected co-chair shared the reason the council has elected new co-chairs is that Bob Wessels, the prior chairperson is now working for APD. Belkis shared a situation brought to their attention from another board member who along with a sister group has a support group for parents of children with Down Syndrome. They believe the sign-up process to be on the wait list for children with disabilities such as Down Syndrome and other disabilities that make them eligible under the category of mental retardation is unfair. A child who has been diagnosed with a mental disability can qualify for the wait list at age three but schools are refusing to test them until they are six. If they go through the process of intake they are usually given a high-risk category and by age five that disappears and they have to sit in limbo for 2 years, time which they could have been on the wait list. The board member is working closely with area parents and is finding the area 10 intake process improving. They have found that APD has been offering non-verbal tests to some of the children and parents are happy with the tests and the outcome. Belkis shared the board member would like input from area FCC's, if they are finding the same problems. She would like to see statewide a more streamlined process for children in this situation. Belkis suggested that this could be an item FCCFlorida would consider taking on at a future meeting.

Connie Carter, Area 14 vice chair shared she is sitting in for Pete Wesley today. Connie mentioned they are working on recruitments. They now have an FCC liaison to the support coordinators who attends the monthly SC meetings. They also have an FCC member participating in the area quality assurance steering committee. They have been attending area agency fairs and schools with their exhibit table. Their major focus has been disaster preparedness and guardianship. She mentioned they would be very interested in learning from other areas what kind of financial assistance is available for setting up guardianships. It is a huge issue because in Polk, Highlands & Harding there is nothing. Chair Millan asked Connie to add that to her evaluation form as a subject to bring up at a future meeting.

Todd Decker, Area 15 shared he will continue on as FCC chairperson. He mentioned they are also looking for new members and getting out in the community promoting the Family Care Council. He briefly shared there has been an allegation made of misconduct in his district, it is purely an allegation between a client and a support coordinator. At this time, as far as he knows, nothing officially has been started yet but is probably in the process of being researched. He shared things are going well in his area. They are looking for a new location to have their meetings. He reported they have also spent all their FCC funding dollars.

Chair Millan asked the remaining guests seated around the room to introduce themselves.

Louise Renicke, Suncoast Region FCC is their secretary and board member. Chair Millan shared Louise began attending FCC meetings with her NRSS person. The NRSS person has helped her with minutes and other FCC duties. Louise is making speeches all over their area. **Robin Millan**, Suncoast Region FCC shared she will be attending the APSE conference in Boca Raton in August.

Jim Miller shared he is the person FCCF hired to re-vamp the FCCFlorida website.

Melinda Brown, Area 13 vice chairperson shared she has been out of the loop for a while with her son's medical issues. She mentioned within three to six months she will be moving to area three. She praised Betty Kay for always being there for her and helping with anything she needs during these difficult times with her son.

Betty Behm, Suncoast Region shared she plans on helping Beverley with FCC duties. She is a local provider and her agency is taking on family care in the Clearwater area.

Vickie Smithee, Area 1 attended the CQL training on Friday and is happy to be attending the meeting and looking forward to getting a lot of information.

Lynn Carper, Area 1 attended the CQL training on Friday and is also happy to be attending the meeting.

Donna introduced her sister Amelia.

III. FCCFLORIDA UPDATES

Officer Nominations - Chair Millan advised at the last meeting officer nominations were announced. Patty Houghland and Bob Wessels were elected Co-chairs, Betty Kay Clements, Vice Chair, Joy Frazier, Secretary and Bob Wessels, Treasurer. Since then, Bob Wessels has accepted a position with the APD. As a result, Bob has resigned as co-chair. Chair Millan, speaking for the council said we understand his need to resign as co-chairperson and accept his resignation, but do not accept him leaving the council. Bob shared he appreciates the council's support in the past and that he was considered co-chair at the last meeting. However, he projected his time study after accepting the position with APD and it revealed there just wasn't enough time. He will continue on as treasurer of FCCF and support Patty and the group.

IQC - Chair Millan took this opportunity to congratulate Beverley DeStories, the new chairperson of the Interagency Quality Council (IQC). The audience applauded with enthusiasm. Bob Wessels has been elected to the IQC as a family member. Jean Sherman has been elected to the advisory committee. Patty Houghland will be attending as FCCFlorida chairperson. Chair Millan expressed how exciting it is to have such strong support on the IQC.

FCCFlorida – Chair Millan advised the council has been very active these past 2 months. Betty Kay Clements as new Vice Chairperson has been brought into the daily activities of the council and has done an excellent job. Betty shared she had no idea the daily statewide involvement.

Incontinence RFP - Sheryl Soukup wrote an excellent letter to AHCA on behalf of FCCFlorida regarding the incontinence supplies RFP. She provided detailed examples of reasons why one supplier of these supplies would be devastating to families in our state. Beverley asked if FCCFlorida received a response to the letter from Secretary Levine. Chair Millan advised no.

Letter to Governor - Chair Millan informed the council never received a response from the letter sent to the Governor asking for 1% of individuals with developmental disabilities to be employed in state agencies. The FDDC has an RFP out for 20 state jobs for people with developmental disabilities which recognizes this void.

FSL & HCBS Concerns - Chair Millan advised the council she sent a letter, based on chairpersons' responses, to Governor Bush, Legislators, Secretary Levine, and Director Brantley with concerns regarding the limited triage with the FSL and HCBS waiver. There are many individuals who are not having their needs met. She included some examples. The letter is posted on the website.

ARC Proposed Legislation - Chair Millan reported they had received information from the DD council that ARC had in legislation pro-viso language for 2 satellite sights for HMO's for persons with developmental disabilities. She is very proud that FARF, FASC, ARC and FCC all signed the letter objecting to that being in legislation and requesting it be removed. Chair Millan shared FDDC also sent a letter (copy in information packet). She read the first paragraph of the letter. Their letter was sent separately as they wanted to be in control of research on successful Medicaid models of care for persons with developmental disabilities in the country. They have announced a conference to be held on June 5th. Patty will be FCCFlorida's representative.

Letter for APD - Chair Millan reported they received a letter from APD dated May 12th (copy in information packet) regarding identifying legislative proposals and legislative budget request (LBR) items for the 2007 legislative session. Anyone interested in participating on the FCCFlorida committee should include their names on the evaluation form.

IQC Letter & Subsequent Meeting - Chair Millan reported a letter was sent to Pamela Wainwright regarding FCCFlorida concerns about the direction and goals of the IQC. Linda Mabile invited Chair Millan and Patty to attend a meeting in Tallahassee to discuss ways of meeting the concerns of the FCCFlorida council. In attendance were Denise Arnold, Bob Foley from Delmarva, Bob's boss from Maryland, Pam Kyllonen, Pam Wainwright, Ed Rousseau, Eileen O'Brien, and Steve Dunaway. Unfortunately APD neglected to invite Beverley DeStories, new Chairperson of IQC. Chair Millan shared there was really good dialogue between all those in attendance. Linda Mabile is to follow up with Chair Millan regarding a procedure for FCC's to have outside evaluations of individual concerns brought to the FCCFlorida attention seeking review. FCCFlorida funds paid for travel expenses for Patty and Chair Millan. Chair Millan reminded the council that this was a good use of our funds.

FCCFlorida participation at DD Day - Chair Millan asked Eileen if FCCFlorida was represented at Florida Developmental Disabilities Day at the Capitol. Eileen advised yes with an exhibit table that included FCC brochures and information by the Family Care Councils and the statewide council.

Family CAFÉ - Chair Millan asked Joy to talk about Family CAFÉ. Joy reported that FCCFlorida will be represented with an exhibit table. She asked for persons planning on attending CAFÉ to volunteer an hour or two of their time to "man" the exhibit table. She will contact those who sign up to schedule times.

Family2Family Project - Chair Millan asked Bob to bring everyone up to date on the Family2 Family project, a joint effort between APD, Challenge Enterprises of North Florida and PSI Family Services. The important goal of the program to help participants and their families use natural community supports, increase the participation of non-disabled community members in natural support networks. Their mission as stated in the grant is to promote self-advocacy and community involvement for individuals with developmental disabilities. Specifically, they are reaching out to people on the wait list to help them to identify what community services are available in the community to provide assistance. The statewide area consists of five pilot sites, Broward, Duval, Gadsden, Lee and Polk Counties. It's an \$180,000 grant. It began in March, 2006 and expires in June, 2007 and they anticipate it will be renewed. They are reaching out to the Family Care Councils in those respective areas for assistance. Bob is excited about the project because it's a way of providing some assistance to people on the wait list who otherwise just sit back and wait for their number to reach the top of the list. This provides a way of reaching out to families to educate them on what community services are out there. Anyone interested in any more information can contact Bob.

Law Enforcement/Autism Video - Bob mentioned FCCFlorida is still trying to purchase 15 of the Law Enforcement videos. He is waiting for word from the vendor that he has completed the state vendor application process through myfloridamarketplace.com. Joy asked if there was a copy that could be circulated among the group until the videos are received. Bob advised he

gave Ann his video to share. We are having difficulty because vendors do not want to spend 45 minutes to 1 hour signing up on myfloridamarketplace.com for one purchase. Bob tried to purchase the videos through FICD but APD would not approve.

Chair Millan asked Denise Arnold to introduce herself. Denise shared she is with the Central Office in Tallahassee with the Agency for Persons with Disabilities. She is one of the Bureau Chiefs in charge of Community Development which includes all of the waivers, quality assurance, support coordination and offers Family Care Council support.

Support Plan Training – Patty attended the pilot project on support plan training with Janice Phillips group in area 2. It's being piloted for future distribution to the whole state. Enclosed in the information packet for the 1st days training handout titled "Hear my Voice, Support Plan for Florida Citizens with Developmental Disabilities". Patty felt the training went very well and was done the right way. The next day everyone used computers to work the actual program. Patty missed that session but Janice met with her the following day to view the program on the computer. Patty shared her concerns with operating the program. She mentioned the completed support plans using the computerized program went to APS with quick turn-around and approval but that's because the program is structured so it can be approved by APS. They still need to have completed documentation for behavior and the behavior plan. There are still many computer glitches. This is an APS form copyright. Maximus has agreed to use it but she wonders if they have seen the printouts. The printout is very hard to read. In order to print some of the documentation it has to be copied to a Word Document which means you go outside the secure system. Patty praised Janice and the area 2 agency for the hard work they have done on this project. Her overall impression is the quality of the program was written using low technology. There is technology out there to make the program much more user friendly. Chair Millan expressed her gratitude to Denise for allowing Patty to participate in the training session and to Patty for taking the time to participate. Patty mentioned included in the information packet is a document titled "Wellness Interview Support Notes". The support coordinators use this and update it on a regular basis. Also included is a copy of the "Person's Plan Draft-Part A-Draft" for review.

Delmarva – Quality Assurance meeting - Patty made reference to the flip chart which provided a list of numbers regarding Delmarva's quality contract requirements. Chair Millan went through the numbers and discussion followed. The procedure for determining the consumers Personal Outcome Measures has changed from being picked by the support coordinator to Delmarva picking the consumer. David mentioned that Delmarva notifies the SC of their choice usually a month in advance so the SC has plenty of time to make sure the file is in order. Denise mentioned the scheduling needs to be done in advance. It was mentioned that all providers are touched within 15 months either through provider review (core), a waiver support coordination review or a desk review. Many of the service options require just a desk review. Denise noted that one problem they are concerned about is the number of POM's continues to go down. The current figure of 1417 is out of 33,000 consumers. Patty shared that in the meeting they asked if FCCFlorida could have between 15 to 30 consumers that they could ask for Delmarva to do a POM. Patty asked Denise if they were working on such a procedure. Denise advised yes. Chair Millan explained the procedure FCCFlorida is requesting. It starts at the local level when someone learns of a consumer who is not meeting or being denied his/her personal outcome measures. The issue can be brought to the area FCC council and if they agree the issue needs further review, then it's brought to a committee at FCCFlorida. FCCFlorida can request the case be reviewed. If the Agency agrees, additional follow-up will be done outside of that area office, probably by another area office. Linda Mabile is working on the protocol for this to happen. Denise expressed the need for the program administrator to be involved in the process.

Beverley expressed her concerns with what is happening to SAC and the local LAC's. Where has their money gone, where has their responsibility gone, who is heading it up? They were able to do investigations and be impartial because they did have autonomy. She is concerned the APD is not putting enough energy into assisting the LAC's to be effective organizations to do the work they used to do. It was shared that some LAC's are still very effective, it varies by areas. Patty shared for the next meeting she will meet with Denise and Bob's wife to develop a fact sheet which provides information on the LAC's charge, where it is, etc. Beverley mentioned it's a concern that needs to be addressed by APD because it affects the health and safety of individuals out in the community. Bob shared the LAC's vary by area and is a function of who is involved because once out of Tallahassee it's all strictly voluntary. Chair Millan requests Beverley to report on FCCFLorida's request to review some POM cases with the IQC. Beverley advised in her role as chairperson, it should be presented by someone else. Chair Millan agreed. Jean asked Denise about the CQL's training of Delmarva in doing their POM's, tools and the people who do the WISC have been accredited and certified by them. But that's not the case with the CORE, that's a derivative being used. And yet Delmarva is constantly referring to interrelated reliability but her concern is what is the "peg" that the interrelated reliability is being hooked to. Denise advised they have had that concern with Delmarva as well. That is being looked at either with the contract amendment or renewal. What they did with the WSC's is focus and make sure it was as clean as they could get it. They couldn't do that with the CORE, it's close to the same kinds of information but those people that gather it are trained but don't go through the same interrelated reliability that a reviewer who does the support coordinator. Jean mentioned they have heard responses from families that they are not always involved during the interviews even when they are legal guardians of the consumer. Denise indicated the two are different processes. Jean was surprised to hear the CQL point out that difference. Patty felt the CQL was trying to distance themselves from the CORE which raises concerns. Chair Millan encouraged Denise that these issues should be brought up at the time the Delmarva contract is up for renewal. Chair Millan put the DELMARVA figures on the flip chart she received from the meeting she and Patty attended in response to FCCF letter to APD with concerns. Review figures: 844 providers, 442 technical Asst., 210 reg. follow up, 452 WISC, 400 technical, 975 desk reviews, 1,417 POM's, 160 longitudinal (4 times), 15 months--100% desk reviews (touched). Chair Millan expressed concern regarding the best use of DELMARVA . Less than 1% of individuals receive POM's annually.

IV. BUSINESS

Review of March Minutes - Chair Millan asked Donna if there were any corrections/comments to the March 18th minutes. None were received. Chair Millan asked for a motion to accept the minutes as submitted. **Joy makes a motion to accept the minutes as submitted.** Betty Kay seconds the motion. No discussion. The minutes were approved by consensus.

Treasurer's Report – Bob reported an available balance of approximately \$4,400.00 pending 2 transfers from Area 12 and Suncoast Region. Several of the area councils have not notified Central office if they have monies to transfer. They are area 1, 10 and 14. Those councils represent approximately \$3,600.00 of unspent funds. If they would agree to transfer to FCCF there would be a balance of approximately \$8,000.00. Joy shared the problem with area 1 is they show a balance of about \$700.00 but the area program office says they have spent all their money and are in the "red". Bob reported the expenditure report dated April 30th showed area 1 with a \$4,400 balance. Beverley shared the problem in Suncoast Region area office is FCC gets dumped on people who don't want it and can't handle it. That process needs to stop and FCC's need to be given more respect. Other FCC's experience the same problem. Bob mentioned the problem occurs when the area budget person doesn't communicate with the FCC liaison. Frank

mentioned their area budget person attends all FCC monthly meetings. Many shared their liaison's don't attend meetings let alone the budget person.

Bob reported the process of having a purchase order submitted to Tallahassee to pay for the rooms has worked very well the past 2 months. However, beginning next fiscal year, in order to fund it, it must come from each council's funding dollars. He has determined the cost would be about \$1,000 per council if you want the state to put your room on a PO for the next 12 months, over and above each council's usual contribution. He advised the need to present this issue to each area councils for approval. Chair Millan reminded everyone the rooms are costing \$100.00 per night compared to the previous rate of \$59.00 per night. Bob mentioned the executive committee has agreed to abide by each council's vote. If all councils agreed to transfer the additional \$1000 the PO will be issued for all councils, if 6 agreed then the PO will be issued for the 6 councils and the other councils would continue the way they have done in the past. Patty requested the councils vote prior to the July meeting. She will take consensus at that time.

Chair Millan shared she thinks its excellent councils are able to use their money at the local level, that's what it's for. However, she feels personally slighted when chairpersons report the attitude there FCC's don't want to give any money to FCCFlorida. All monies transferred to FCCFlorida are used on projects that benefit all Family Care Councils. She shared FCCFlorida has accomplished a lot this year and reminded the chairs that FCCFlorida has no funds. An example of money well spent for all was Patty and her trip to Tallahassee for a face to face with Linda Mabile and Delmarva because they felt it important for all consumers and families. FCCFlorida voted on 3 or 4 things to do with the projected dollars from the councils but the monies didn't come in to support them. One example is scholarships to attend the ARC annual conference. There isn't money to cover that. Also, she has created a booklet to be sent to the wait list people and distributed at CAFÉ. There are many drafts involved in creating such a booklet. She passed around the latest draft for comments, suggestions & content. It's imperative it be completed this week as it must get to the printers. She was asked if the money is there. Chair Millan mentioned she thinks there is money for CAFÉ booklets but hopes the agency with Denise's help can offer some assistance. In conclusion, the statewide can benefit by spending what money they receive for all the areas. Jean asked if their council approves the transfer of \$1,000 for travel expenses to FCCFlorida meetings but doesn't use it all, can they request a rebate of unused dollars. Patty, as future chairperson, answered no.

FCCFlorida Website – Chair Millan introduced Jim Miller who has been hired to improve and update the FCCFlorida website. He has been working on the website since March and has yet to receive a check for hours invoiced. Chair Millan expressed our appreciation to Jim for his patience and continued work on the website while waiting for his first paycheck. Chair Millan and Jim advised they are changing ISP's which has created some problems with having to go off-line at times. Everyone thanked Jim for his work and shared how impressed they are with the new look and how easy it is to navigate through the website. Included on the website is a more user friendly link to the AHCA and APD websites.

V. PRESENTATION - Beth Kidder, Chief, Bureau of Medicaid Services - AHCA

Chair Millan introduced Beth and asked everyone to hold their questions until after Beth has finished a subject area. Beth began by sharing she is very glad to be attending our meeting.

Legislative Session – Beth mentioned this was the first year they haven't had an avalanche of new projects and initiatives to implement. She shared a few good things came from the budget this year allowing funding to restore adult vision and adult hearing services. They also received funding to cover partial dentures for the first time. She reminded everyone the Governor hasn't signed the budget and there is a line item veto so anything within the budget is subject to veto. Also included but buried in AHCA's expense budget is an expansion to the Delmarva budget in the amount of about ½ million dollars. The purpose of that funding is to be able to cover with

Delmarva quality assurance services for the FSL Waiver. The contract with Delmarva will be amended to include the addition. Bob asked what is the total budget for the Delmarva contract. Beth did not know but would get that figure for the council. A few bill highlights:

Senate Bill 1278 – The Integrated Service Committee for Youth in Transition – This bill is a result of work being done in the Blue Ribbon Task Force implementation working group and the National Governor’s Association alliance committee. They learned how some other states were in some ways institutionalizing interagency relationships to work together on transition issues. Beth shared the task force has made some really good relationships with agencies involved in this process. The bill gives them an opportunity to make it more formal and do additional reporting back to the legislature. Denise added the membership of that group will likely include the same working group & NGA members. It will probably need additional family or self advocate people added to the committee. Eileen suggested adding a representative from the Florida Youth Council.

House Bill 241 – Refers to the Medikid’s program (Children’s Health Insurance Program for people who don’t qualify for Medicaid because of income). Up until now they could qualify with incomes up to 200% of the federal poverty level for subsidized premiums. There is now a full pay option which means a family over the 200% of federal poverty level can pay the full amount of the premium and get health insurance coverage. They don’t know what the premiums will be but it will offer families an opportunity who can’t get coverage elsewhere due to a pre-existing condition or lack of insurance to buy into.

House Bill 1247 – Expands the statutorily-required HCBS waiver serving children who are diagnosed with Familial Dysautonomia to include adults.

Updates from previous Legislative sessions:

Incontinence Supplies RFP – Beth reported AHCA withdrew that RFP this week. Beverley asked if it’s been permanently withdrawn. Beth advised that has not been determined yet. Beth mentioned AHCA had a number of formal protests to the RFP. Beth made the commitment if the RFP should go out again she will work closely with APD and other waiver programs impacted to provide more outreach and education to insure quality and choice of products. Discussion followed requesting that families of individuals who use these products be included up front in the thought process as a way of providing assistance in offering possible alternatives prior to the release of the RFP. Chair Millan added the needs of the individuals with developmental disabilities are different from those of the elderly population particularly in size of items, etc. It’s assumed that the DD population is the same as everyone else but it’s not, every person is different. Beth indicated within the RFP there was nothing in there that lumps together and believes that everybody who needs incontinence supplies are the same. It was expressed that the way this RFP was handled contributed to a lot of fear within families that sometime in the future the state would determine they aren’t saving enough money and stop providing consumable supplies. Also it takes away choice for families to purchase the type of supplies that works best for their loved ones needs. Beth reiterated that during their research they did find interested organizations that would provide more individualized assistance to families so the effort was not just cost savings but to improve quality and customer service. Patty shared that individuals with a lot of medical needs and need for supplies will develop a relationship with their provider who will then offer free supplies that Medicaid doesn’t have to pay for, they do it as a thank you for the business. The personal attention is very important. Beth thanked everyone for their comments and indicated they are currently working on responding to all the letters and E-mails received.

Statewide Program of Therapies for children - Therapies include Speech, Respiratory, Physical and Occupational. This has been put out for bid twice before. The bid is out for the third time. It’s structured so the preferred response would be for a capitated model, somebody bidding on a risk based model for capitated payments for all therapy services statewide. If they

don't receive satisfactory responses for that model then AHCA will review responses and choose a prior authorization model. She is unsure of the latest timeline but it's still out there. Beth was asked for the number of the RFP. It's an Invitation to Negotiate. She will E-mail the ITN # and a summary of the timeline to Chair Millan. Discussion followed requesting families of individuals who are in need of therapy services be included in the research process of this ITN. Chair Millan wants to be involved in this.

Nutritional Supplements – Beth reminded everyone of the Miami Herald articles dealing with Medicaid's payments for nutritional supplements and children being denied medically necessary services. She reported they are not allowed and never intend to not give children medically necessary services. She indicated back last summer they did do some changes to the authorization process. Before their bureau of Pharmacy services had handled prior authorization and due to federal changes related to Medicare Part D and some other changes they were required to shift that to the durable medical equipment program. Changes that were done to prior authorization just did not work but they didn't know they weren't working. It was their mistake in thinking all was OK. Once learning of the Herald articles they dug deep to determine the process just was not working and Secretary Levine suspended the authorization process. They convened a workgroup of professionals to review the policies and are currently re-working the policies which will include a very comprehensive outreach plan. Patty asked that families be included in the outreach process.

Medicaid Reform –

Enrollments - The first enrollments in Broward and Duval Counties will start September 1, 2006. Starting July 1 choice counseling will be available to individuals. On July 20, the first round of materials will be sent out to individuals enrolled. Chair Millan mentioned this does not include DD. Beth answered correct. Beth indicated individuals with developmental disabilities are a voluntary population, they can enroll but don't have to until such time as the plans are certified to meet specialized needs of the DD population. She shared the DD Council is taking the lead on helping AHCA determine what standards are important. AHCA has been working very closely with APD and the DD Council. The DD Council contracted with a research organization to look at what has been done for individuals with developmental disabilities in managed care and what's been successful and what hasn't been in other states. She advised the early drafts were not helpful enough as it doesn't get specific enough. What they need to know are there special types of network standards you need to have for specialists for individuals with developmental disabilities that are different from what they have for standard HMO recipients. Are there special services that are particularly important? The most recent report she has seen does show very specific case studies of states and programs that have done this at some level, be broad or very narrow, and been successful and what hasn't been successful. The next step is the forum on June 5th where the DD Council has invited professionals that have been involved in these programs around the country to talk with AHCA representatives.

The way AHCA is intending to exclude persons with developmental disabilities from the enrollment process is they have arranged to get from APD a listing of everyone on the various waivers and those on the wait list. They will not receive choice counseling materials. She shared the importance of making sure APD has the correct mailing address for everyone.

Choice Counseling – It's particularly needed in this case because instead of all managed care organizations offering the same benefits which they do now, in this case they be able to offer some differences in benefits. For the first time there is an opportunity to opt out of Medicaid and buy into an employer's health insurance program. New eligibles to Medicaid will only be able to receive emergency services until they sign up with a plan or are enrolled. The sooner they are enrolled the sooner they can receive primary care and all other benefits. These are all very important reasons for providing choice counseling. It's a critical step for Medicaid reform to work. AHCA has selected ACS State Healthcare to provide the counseling. Some of the

requirements of these contracts are they must make choice counseling available through a number of different means which includes face to face counseling, telephone access, web access, written materials, etc. They have to hire and train choice counselors who are representative of the state's diverse population. Also they have to have a component where they need to work on promoting health literacy through outreach. Another part of that is to provide information that helps reduce the disparities in minority healthcare access. They have contracted with Florida State University to develop the choice counseling materials and counselor certification program which includes multi hours of training and pass a competency test that shows they can apply what they have learned.

Enhanced Benefits - This is new to Medicaid. When a recipient participates in healthy behaviors they are able to earn credit which can be used to pay for services or products that they can't otherwise pay for through Medicaid. Specifics include a panel has been formed to determine which healthy behaviors will be the qualifying behaviors, how much they can earn for each behavior and what items the credits can be spent on. Beth gave examples.

Applications for Managed Care Plans - The number of applications for managed care plans in Broward County as of May 10th includes 11 HMO's, 3 provider service networks (fee for service networks) who over a 3 year period of time convert to full managed care and 1 plan to serve children with chronic conditions, Children's Medical Services. The number of applications in Duval includes 5 HMO's, 2 provider service networks and 1 plan to serve children with chronic conditions also Children's Medical Services. They have completed the initial reviews and on site visits will be scheduled in the next few weeks. Final determination will be made by July 1, 2006. Chair Millan emphasized that individuals with developmental disabilities have needs that don't fit the normal criteria outlined by Medicaid. There should be exceptions outlined within Medicaid Reform to allow for the medically necessary changes that take place in the individual's lives. Chair Millan provided a few examples. Beth indicated it's helpful that AHCA know this now. If fee for service issues are being denied because of age or service needs and there are policies that need to be looked at to allow for exceptions for certain circumstances they have a unit that all they do is medical reviews. She indicated they are aware that individuals with developmental disabilities have special needs and that is why they are asking for more specific guidelines and feel the participation in the DD Councils study on individuals with developmental disabilities and managed care is helpful. They want provider standards, coverage standards, exception standards because they need to understand. Chair Millan expressed her appreciation to Beth for attending the meeting. The audience agreed with their applause.

The meeting was adjourned for lunch. During lunch everyone enjoyed an Employment video which shared a young man's daily routine in high school. From this video he was hired because it showed his employment skills. The video was produced by: David M. Bliesner, Ph.D. Director, Research and Development, Florida Learning Curve, Inc., P.O. Box 487, Indian Rocks Beach, FL 33785, 727.421.8722 Phone www.floridalearningcurve.com All agreed it was very a very well produced video and would be an excellent tool for employing individuals with developmental disabilities. Chair Millan told everyone they had information about FL Learning Curve in their folders.

Also, everyone shared their appreciation to Chair Millan for all her efforts and hard work as chairperson over the past 2 years. She was presented with an appreciation plaque, a scrapbook of thank you cards and several "walk on the moon" awards.

VI. APD UPDATE – Denise Arnold, APD Chief of Community Development

Denise passed around an information packet to all in attendance. Denise shared from the state's perspective the Family Care Council has really become a group that is well respected. She

expressed her appreciation to Chair Millan's leadership and many others who have worked so hard especially as volunteers. She expressed how much she enjoys attending the meetings and hopes to make them more of a priority. Denise shared they are looking at some organizational changes within Central Office. Eileen has been employed about 2 years and has some personal goals they want to support. They want to place more emphasis on self-advocacy. Eileen shared that she has been asked by Central Office to expand her focus to self-advocates. They offered her a position as a self-advocate statewide liaison in the Tampa office. In order for her to take on this endeavor she must leave her current position vacant at Central Office. She has requested that Family Care Councils remain in her job description. She plans on assisting the Suncoast Region East in recruiting new members. Denise shared Stephanie will continue to work with FCC's and even expanding her duties with the councils.

Denise shared the items in the information packet which includes the latest APD enrollment status. She does expect they will meet the 6600 enrollment target. A copy of the E-mail from Tammy Smith regarding the APD's announcement of an RFP to contract with a Fiscal/Employment Agent for the CDC+ program. The current fiscal agent's contract is ending soon. She wants to talk further about the CDC+ program but not enough time on this agenda. She'll see that the power point presentation which includes data learned from the various surveys compiled by a consultant they hired is sent to us. Maybe next meeting some time can be allocated to discuss and answer any questions. Chair Millan asked if this meant it was staying in Elder Affairs. Denise advised no. The whole program will be moving to APD and they are putting out the RFP. They hope to complete the transition process by June, 2007. Also included in the packet is a copy of the letter from APD to Ann regarding the 2006/2007 legislative proposals. She mentioned they are still looking for suggestions regarding updates to the HCBS handbook. Send to Denise with a copy to Chair Millan by the end of June. The remaining documents all relate to the legislative package which includes the Legislative Budget, Chapter 916, F.S. – APD Bill, Summary of APD Ch. 393 Bill, the 2006 Session Legislative Substantive Wrap-Up Report and 2006 Session Legislative Administrative Wrap-up Report.

APD Legislative Budget – Denise explained this one includes the pro-viso language. She reviewed the first paragraph which states the APD has to submit quarterly reports to the legislature about its ability to spend within budget. This year it also includes reporting IFS dollars. She reported the legislature pulled \$1.7 million of general revenue out of the IFS budget because APD didn't spend it all. The second paragraph states they have to submit a plan on how they will implement the budget. There are a number of items in the budget that money is attached to but there were a number of items they were not funded for that they asked for. The APD statute has language added this year that states they cannot overspend. She reviewed the various items on the budget.

Under 296I – Home and Community Based Services Waiver appears the language stating “The Agency shall serve all autistic clients through the HCBS wavier”. This means they have pulled the autistic clients out of the FSL waiver to be added to the HCBS waiver. Chair Millan asked who did this. Denise advised it came from the Senate but they don't know who including Shelly. Chair Millan mentioned she has a real problem with this. FCC's represent ALL individuals with developmental disabilities and she can share from personal experience how expensive a person with autism is but so is an individual with other developmental disabilities. She indicated she received a phone message to call the Governor's office and spoke with Charles Leim expressing her concerns pertaining to this piece of legislation. He is very curious how families feel about this. Later on during the meeting she hopes to get a position statement from the council. It was expressed this was something that got through the legislative process at the last minute. Denise shared that anyone with concerns should let the Governor know of their concerns. Discussion followed asking about persons with autism on the wait list, can this item be vetoed, and the need for individuals with autism to get behavioral services before the age of 18, early intervention is

the key. Patty shared that DD cannot share everyone's problems. If behavior is the issue with any disability in a school age child the first and primary responsibility is the school system. Also, it is never ever fair to carve out and make one disability more than another disability. Denise continued on with the budget items. It appears they were allocated \$24,000 million to serve additional clients from the wait list and clients in crisis but what wasn't funded was the utilization growth for the wavier. Also, they have added clients in crisis to the FSL waiver which presents a challenge. The whole caveat to this budget is you have to stay within the appropriation. They know they don't have enough dollars to cover it all. The budget includes appropriations for support coordinator increases and provider rate increases which totals about \$28 million. She shared there is a lot of budget analysis going on because they have to submit a plan. She admits at this time it's confusing to say what they will be able to commit to. Bob asked Denise if the \$5,000 supported employment initiative was picked up in the budget. Denise advised no the \$1.5 million for this initiative is not in the budget but she said they would figure out how to pick them up out of the IFS monies. Denise reviewed a few of the legislative bills listed in the Legislative Substantive Wrap-up Report. She made reference to the summary of items in the Budget Update which includes the increases in state per diem and travel costs. Also is non-recurring funds in the amount of \$1 million to the Agency for Workforce Florida, Inc. (AWI) to be used for services for persons with disabilities. It's a resource outside of VR. Included in the report is a budget comparison.

Wait List - Denise reported they have OPPAGA looking at their wait list. They are reviewing the wait list enrollment procedures. A major concern is the decline rate or no responses. They have sent out to all area offices some instructions to try to re-contact the people who were no responses due to not responding within the 15 days. They don't know if these people are just not interested or not at the address or moved out of state, etc. Area office personnel will re-look at these files, make a personal visit to the last known address, talk to relatives (if known) to try to find these people. They have revised the application form to include a name of a secondary contact and a statement the applicant must sign which states they have a responsibility to inform the agency when moving or any change in contact information.

Intake Process - Much discussion was shared with Denise regarding numerous problems with agency offices pertaining to the intake process, people calling and receiving bad information, people being turned away from offices because staff is too busy, etc. In Area 10 an automated telephone line has been set up for intake calls only. People can call the number, leave information and within 24 hours they will receive a call from the area office. It was suggested developing some type of one page intake information form. Bob mentioned a main problem is there is no commonality between the different areas. Denise advised she would send the revised application to Chair Millan for distribution to area chairs for their input. Chair Millan shared her appreciation to Denise for taking the time to attend our meetings. The audience agreed with their applause.

VII. OLD BUSINESS

OPPAGA Report on Wait List – Chair Millan mentioned OPPAGA is still looking to interview some families eligible for the IFS monies. They wanted to know the problems experienced with getting access to the IFS monies.

Core Competency Training - Chair Millan asked Denise for an update. Denise advised it should be going pretty well. All the providers have received the discs with the core competency curriculum on them. The website is up and running through TCC. Area Office personnel have received some training. Support Coordinators are included as they are direct service providers. Chair Millan asked if every provider within an agency is to take the training. Denise advised

yes. The deadline for accessing the training is June 30th. David shared for the new provider it should be considered a pre-certification training. Denise thought that was a good idea.

Year End Report - Chair Millan advised she will be doing a year end report again this year. She mentioned she'll be sending out the form and asked all councils to participate by filling in the dots on what activities they have participated in this fiscal year. It's a very impressive document for others outside the councils to see our accomplishments. The attached letter to the legislators will point out all we have done at the statewide level and emphasize council's unity.

Gubernatorial Appointments - Edith shared a draft of a cover letter required by the Governor's office to be sent to APD Central office with applications for FCC governor appointments. It's a form that can be used by all area family care councils which accurately addresses the information requested.

VIII. NEW BUSINESS

Autism Legislation – Chair Millan shared her conversation with Charles Leim at the Governor's office who stated they are very concerned and want to hear from families regarding the Autism legislation. Based on previous discussion she shared Edith's concerns are very legitimate, however, she thinks the problem with the FSL is the triage language not with isolating conditions. She asked to go around the table asking chairs/representatives to state if in agreement with her or in opposition. All were in agreement with one opposition. Connie shared personal reasons for her agreement. The consensus reached is to write a letter to the Governor from FCCFlorida.

IX. PRESENTATION - PRE-SERVICE SC TRAINING INPUT – David Alexander

David reported he is now employed in an OPS position with APD as Trainer/Counselor for Support Coordination. His primary function at this time is to re-write the training manual used to train new support coordinators. He has used the manual on a regular basis in his capacity as a pre-service trainer. Currently, there are five pre-service trainers, each with their own manual, each being slightly different. They are looking at more consistency so that everyone trained will be using the same manual. He is asking for the council's input as families to determine what we think might be missing as the training is currently being set up. They are also considering taking the district training and re-vamping it. Several indicated the problem with asking for the council's input is they are not sure how SC's are being trained now. David shared his training begins with discussing values and challenges the prospective SC's to look at their own. He includes an overview of Family Care Councils and how important it is for SC's to network with them. He mentioned talking with Anne Beuchner with CQL the need to incorporate POM trainings into the SC training. Patty shared the need for SC's to be more knowledgeable in people skills, listening to what consumers and families are saying to them. Connie mentioned the need for some accountability and follow-up with SC's. Issues are not resolved because the SC doesn't follow through with their responsibilities to the consumer/family. David suggested maybe the need for developing some new trainings for SC's who have been around for a long time that focus on these type of issues. He plans on developing a mailing to families asking what kinds of problems they have with their SC. Chair Millan mentioned the need to include in the training materials the definition of "CHOICE" as many SC's don't understand what choice is. Also, goals need to be reviewed every three months. It was mentioned the need to consider extending the SC training time beyond a week because all of the responsibilities can't be consumed in a week's time. Interactive training encompassing exercises and activities need to be included in the process. Discussion followed with suggestions for when trainings should be administered to SC's and how often. It was suggested that some on-going training could be included in the monthly support coordinator meetings. Also, it was suggested it would be worthwhile for David to visit monthly SC meetings around the state.

David thanked everyone for allowing him some time on the agenda and for providing him with good suggestions for the manual.

X. ADJOURNMENT

Chair Millan asked that everyone submit their evaluation forms. With no further business to come before the council the meeting was adjourned at 3:55.

The next meeting will be held on July 15th at The Hampton Inn.

RESPECTFULLY SUBMITTED,

FICD

Florida Institute on Community and Disability