

FAMILY CARE COUNCIL FLORIDA

PATTY HOUGHLAND, CHAIRPERSON

Hampton Inn Orlando Airport

Orlando, Florida

July 15th, 2006

MEMBERS PRESENT:

Patty Houghland, FCCF Chairperson
Bob Wessels, FCCF Vice Chair, Treasurer
Ann Millan, FCCF Past Chairperson
Joy Frazier, A1 Chair, FCCF Secretary
Frank Carroll, A3 Representative
Beverley DeStories, Suncoast Region 5 Chair
Jeannie Forthuber, A7 Chair
Sheryl Soukup, A8 Representative
Maryellen Jones, A9 Chair
Jean Sherman, A10 Co-Chair
Phil Pearson, A12 Representative
Betty Kay Clements, A13 Chair, FCCF Vice Chair
Pete Wesley, A14 Chair

STAFF & GUESTS

Denise Arnold, APD Central Office
Stephanie Khan, APD Central Office
Randy Wilcox, Children's Medical Services
Jonathan Forthuber, A7 Guest
Amelia Rauber, A7 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. CALL TO ORDER

Chair Houghland called the meeting to order and welcomed everyone. She asked for introductions and area represented. Chair Houghland reviewed the materials found in the packet of information which includes:

- FCCFlorida Agenda
- Roadmap for Medicaid Reform
- Florida ARF White Paper on Medicaid Reform
- ARC handout on Medicaid Reform
- Evaluation Survey of FCCFlorida meeting
- APD 2006-2007 Substantive Legislative Proposal Form
- Listing of new state travel expense reimbursement rates
- List of important websites. FND and FDCC both have E-mail servers. Anyone can add their E-mail addresses to these servers. Therefore, Chair Houghland as chairperson will not forward on these E-mails. She reviewed the remaining websites listed.

Also, included under separate folder is information that Denise Arnold will be sharing during the APD Update, a copy of the FCCFlorida 2006 bulletin, and a hard copy of a Medicaid Reform powerpoint from Randy Wilcox, guest speaker from CMS.

Chair Houghland mentioned that during lunch a short piece of a CD developed by APD for training on Core Competency will be shown. She advised that all providers were required to take this training by June 30th, 2006.

Joy asked about the 24/7 DVD and VHS. It was determined Todd may still have the VHS version. She gave the DVD to Frank who was next on the list.

II. FCCF FUTURE

Chair Houghland advised there was a working group meeting on Friday which included much discussion about FCCFlorida – where the council has been and what was accomplished this past year. Following is a list of accomplishments:

1. FCCFlorida has a face to face contact with APD Leadership at bi-monthly meetings
2. FCCFlorida collaborated with state agency and organizations on issues which included:
 - Incontinence Supplies
 - Autism Issue on Waitlist
 - Delmarva Initiative
 - Employment Initiative – Celebrate Employment booklet
3. FCCFlorida Website:
 - Posted trainings and events on a regular basis
 - Area Links to other websites including APD
 - Current information posted to area web pages
4. FCCFlorida recognized as important family representation throughout state.
 - AHCA
 - ARC and FARF are recognized at major conferences but as providers (John Hall, Terry Farmer). FCCFlorida is now recognized at major conferences as the only family based entity (Ann Millan)
5. FCCFlorida has received support from the individual councils in shared experiences:
 - Purchased FCC screens for participation in exhibits
 - Published FCCFlorida 2006 Information Bulletin for Family CAFÉ
 - Published FCCF statewide brochure
 - Purchased BOSS manuals distributed throughout the state

Chair Houghland elaborated on the above. She shared the council has made great strides and has recognition and what is shared as FCCFlorida carries weight. Providers want to connect with us. Chair Houghland asked all in attendance to share any additional comments that may have been left out. Ann Millan mentioned the need to remember the FCCFlorida year-end reports which have been a helpful tool in showing legislators, agencies & providers what FCC's accomplish throughout the state. It's important to be recognized, that the council and families expect to be included in meetings that are affecting individuals with developmental disabilities. An example was asking AHCA to include FCCFlorida in their research projects. Chair Houghland mentioned she did E-mail Beth Kidder on the issue of having family representation on committees. Beth replied she did have family representation on committees. Chair Houghland shared when you say Medicaid to AHCA they are not thinking of persons with developmental disabilities. They do have Medicaid recipients on their committees but what hasn't been done is identify recipients who either have a developmental disability or family members of individuals with developmental disabilities. That is the missing piece. In her E-mail reply to Beth she indicated what she thinks is missing is the developmental disability Medicaid population because of the uniqueness of their needs, of their method of aging, of that type of issues. Chair Houghland shared at least we've started the dialogue but need to be persistent on this to make it happen which includes asking APD for assistance.

Chair Houghland asked if any other items should be added to the list. Ann mentioned through the help of Wilma and now Stephanie the local councils have been able to attempt to spend FCC money. Two years ago, all councils had difficulty spending their money because of numerous problems at the local level. Additional items:

6. FCCFlorida Year-end reports summarizing area council's accomplishments
7. FCCFlorida has provided assistance to local councils having problems spending their funding dollars.

Medicaid Reform - Chair Houghland shared she attended the Developmental Disabilities Council's summit on Medicaid Reform. What she learned from that summit is they are not looking at developmental disabilities and it's scary. All speakers, except for one, talked about disabilities and managed care for people with disabilities. They advised they do excellent case management. She asked what is their ratio. They replied 300:1. Chair Houghland questioned how they can case manage 300 people. Their mindset is on 300 people who have Medicaid. These people don't have the problems with daily living as people with developmental disabilities. They aren't thinking about the day programs, the need for a companion or a person's quality of life. They are only thinking about the individual seeing a doctor and solving the problem as cheaply as possible. Every time they tried to bring it around to the quality of life, it wasn't an issue. The other issue Chair Houghland and others frequently brought to their attention during the meeting was that individuals with developmental disabilities have managed care, probably the highest level of managed care. We have Maximus, APS, APD, and Support Coordinators who are managing the individual's services. Chair Houghland is asking all chairs in attendance (Joy will contact chairs not at the meeting) to consider forming a sub-committee in each council to focus on Medicaid Reform issues and keep membership informed of what's taking place. It's a huge issue and very important for council's to learn and share information. Hopefully we can provide enough information to keep families educated. Its possible FCCFLorida will have to take a stand at some point of what we will or will not support. In that perspective, it's very important that all councils are united. Ann added that FARF has already taken a stand that the DD population is already in a managed care system and don't need another managed care system. ARC is looking at a pilot to try in two areas which could expand rapidly throughout the state. The DD Council wants to take the lead on hosting all the summits. All council's must be strong and educated enough in Medicaid Reform to make informed decisions.

III. BUSINESS

Review of May Minutes: Ann gave Chair Houghland an addition to the minutes. The addition is: "Chair Millan put the Delmarva figures on the flip chart she received from the meeting she and Patty attended in response to FCCFLorida letter to APD with concerns. Review figures: 844 providers, 442 technical assistants, 210 regular follow-up, 452 WISC review, 400 technical follow-up to them, 975 desk reviews, 1417 POM's and 160 longitudinal (seen 4 times) in 15 months. Chair Millan expressed concern regarding the best use of Delmarva, less than 1% of individuals receive POM's annually." Chair Houghland asked Donna if she received any corrections. Donna replied no. If there are no other issues, Chair Houghland asked for a motion to accept the minutes with above addition. **Maryellen makes a motion to accept the minutes.** Beverley seconds the motion. No discussion. The minutes were approved by consensus. Bob asked if a revised version with the addition would be sent to the chairs. Chair Houghland advised yes. Ann will make the change and send out to chairs and post on the website.

Treasurer's Report: Bob advised he was looking at a report dated June 30th but due to last minute expense vouchers, invoices and travel reimbursements that the state must submit, pay or be encumbered by June 30, it's not an accurate report as not all expenses have been posted. The report he is looking at still shows an available balance of \$48,000 which can't be a true figure. He advised that he and Stephanie will be working closer on this in order to provide a final figure. They will also be developing a template that can be used on a monthly basis to show not only FCCFLorida expenses but also verify where each council is on an area by area basis. Maryellen asked who would get the monthly reports. Bob advised he would send to the area chairs and Stephanie will submit to the area liaisons. Ann asked to remind chairs that any items purchased over \$2,500, you must get 3 bids on. Also, anybody/company you plan on paying with FCC dollars must be registered in myfloridamarketplace.

Old Business: Chair Houghland turned this portion of the meeting over the Ann to finish some issues started last year. Ann asked that Chair Houghland send around the listing of chairs contact information for any updates.

Website: Ann praised Jim Miller for doing an incredible job of updating the FCCFlorida website. She has been updating what information she has received from area councils for their web pages. Ann reminded everyone to pay attention to the current Calendar of Events page which lists all upcoming conferences. Bob mentioned if any of us learn of a conference to let Ann know and she'll update the page. Ann shared a decision needed to be made later is if the council wants to continue the website. She gave Chair Houghland an estimate of \$2,000 to keep the website maintained for the year. Bob praised Ann for all her efforts and Jim Miller for a fantastic job on updating the website. It's much better than it used to be. It's important to maintain it and keep it current. It provides a wealth of information.

Year-End Report: She has prepared a cover letter to submit with the report. She and Chair Houghland received a request from APD on June 30th that FCCF submit a legislative budget proposal to Lucy Mohs for 2006-2007 legislative year (copy in information packet). They asked for 3 requests: (1) Membership be approved by APD director instead of governor appointments and include grandparents to the list of qualified members, (2) Allow FCC's to use a non-profit fiscal agent that adheres to APD spending guidelines, (3) Request funding to hire a director to work with areas requesting help to develop and meet legislative statute. They did not request that FCCFlorida be legislated. There will be time to enhance or change the LBR but the need was to be proactive and get something done by the deadline. Chair Houghland advised that Lucy Mohs did E-mail her that she did receive the LBR. It's necessary to discuss with Denise what is the next step in the process? It's important that FCCFlorida have a representative on the Statute 393 committees. Ann mentioned she added our 3 requests to the year-end report cover letter that will go the legislators. She added she will send the letter to the chairs for approval the following week. Each area council had the opportunity to write a paragraph on what they accomplished during the year. It will be too expensive to mail the report to all the legislators. It will be noted on the cover letter that area council dialogue will be available on the FCC website. She sent around the report and asked chairs that had submitted dialogue to review for accuracy and any she hasn't received yet to submit by Friday, July 21st. It's important for all council's to participate.

Meeting with Shelly: Ann mentioned FCCFlorida did not have the funds to print an updated statewide brochure or to do the mail out that was approved to send to everyone on the waitlist. Chair Houghland was involved in a meeting also attended by Shelly Brantley. Shelly asked to meet with Chair Houghland and Ann. Upon arriving in Tallahassee, Ann & Patty met with Suzanne Sewell from FARF. Ann wanted to introduce Suzanne to Chair Houghland as FARF has been very supportive of FCCFlorida and it's a good provider source. That afternoon they met with Shelly. Shelly is concerned that CAFÉ is not meeting the needs of people in the local areas. She is very concerned with the illiteracy of the families of consumers on the waitlist. Illiteracy is a 2 prong thing, its people who are illiterate but also people who are on the waitlist and illiterate in trying to understand APD. Jean added an additional prong being the people whose primary language is other than English. Shelly would like Family Care Councils to be involved in something similar to the CAFÉ Bistros (information fairs) that took place a few years ago. Sheryl mentioned that APD has just spent lots of money on the Family to Family project that is supposed to be addressing the needs of educating families. Bob mentioned it's not APD money, it came from a grant. Ann continued what Shelly is looking for is a personal contact with the families on the wait list which could be provided by FCC members. Ann shared the 2006 bulletin with Shelly and suggested they add a postcard in the center that asks for contact information that can be filled out by families and sent to their local FCC representative. Ann asked Shelly to encumber the money needed to print a bulletin for everyone on the waitlist.

Shelly felt she could find the money to pay for it. Ann mentioned the Bulletin has been very well received especially because much of it is written specifically for the consumers and families on the waitlist.

Ann mentioned she wants to thank Denise for adding the FCC link to the APD website. Also mentioned she has developed a survey that is posted on the website. It's an interactive survey that will eventually be put on the front page of the website. It currently appears on the District 1 webpage.

FCC Updates (Conferences attended):

Family CAFÉ - Chair Houghland asked Joy to report on Family CAFÉ. Joy reported FCCFlorida's booth was right behind the APD booth. The booklets went fast. Other organizations sent families to the FCCFlorida booth to pick up a booklet. Excellent feedback was received on the booklet. She mentioned approximately 40 people signed the sign-in sheet. She is currently sorting by area the names and will forward in the next few weeks. Joy indicated she felt the majority of people stayed at the conference rather than going off to theme parks, etc. Many people commented they felt Family CAFÉ is getting too big. There were about 10,000 in attendance and many were farmed out to other hotels in the area. Too many break-out sessions per hour, too many to choose from.

IQC Conference - Jean mentioned there was discussion about the draft support plan that is still being revised. Delmarva made their presentation which included that they have received funding to review FSL clients in the future. They were not clear about staff and how soon they will be ready to begin those reviews. AHCA did comment on having to pull back the consumable medical supplies RFP but it hasn't gone away. They are still looking at a soul source bid on these supplies. It's being re-worked and under discussion. The IQC asked that they have more participation in these type discussions from the IQC/Interagency perspective and they agreed it was something they should be doing. Jean believes they are learning they need to involve more end users who are going to be directly affected but it's unknown how they will implement that. Beverley mentioned the importance of having an AHCA representative attending FCCFlorida bi-monthly meetings as APD is now doing on a regular basis. Ann shared that FCC has good representation now with several members on the IQC board and advisory committee. Chair Houghland mentioned she would work with AHCA asking for representation at the next FCCFlorida meeting.

Chair Houghland asked for any other updates:

Area Seven - Donna shared their new chairperson, Jeannie Forthuber will be attending the afternoon session so everyone will have the opportunity to meet her.

Area Nine – Maryellen shared she has received funding for the Supported Employment and Supported Living DVD which will include a segment on Family Care Councils. Also included in the package, Rosalie Archer will be doing a TV program on the Family Care Council. Ann asked if the council could recommend what area councils she should interview. Maryellen said sure. Ann suggested Area 13 and 14.

Area Twelve – Phil shared their website is up and working good. They have created a new brochure which is on the website. He indicated he still doesn't understand why they couldn't use their remaining end of year funding dollars to pay for printing the brochure.

Area Eight - Sheryl shared their FCC has a new chairperson. Her name is Maria Eash. She'll be attending the next FCCFlorida meeting.

IV. PRESENTATION - Randy Wilcox – Bureau Chief Children's Medical Services (CMS) Network Administrator CMS Managed Care

Chair Houghland introduced Randy Wilcox. Randy shared it is a pleasure to have been invited to the meeting. He praised all in attendance for all they do as family members with very little resources and still taking the time to get involved. He mentioned he had been a lobbyist for

many years and can share legislators really do want to hear from families. Our voice really does count and makes a difference. He began by defining Children's Medical Services. It's a state program within the Department of Health. They have a Deputy Secretary who by statute must be a pediatrician because they serve children age 0 through 21. They have been in existence for 75 years. There are 2 divisions within CMS, (1) Child Protection Needs. These are the teams that do medical evaluations of children who have been abused. (2) CMS Network Division. Randy is a bureau chief within this division. His primary function is the administrative side of CMS. Operations and Early Steps program also fall under this division. Early Steps is the zero to three early intervention program. It's funded primarily through federal resources and some state resources. It serves approximately 40,000 children. Their role is early intervention to attempt to make a child who is at risk of having a developing disability or working with a disabled child at an early age in hopes that the disability does not become an impairment to the extent it would have without early intervention. It's an entitlement program. Chair Houghland asked for verification of the 40,000+ in the early steps program. About 50% of them are Medicaid recipients so under state Medicaid Plan they get the therapies. If they aren't a Medicaid recipient they get the therapies through early steps program. Randy agreed. Chair Houghland mentioned there is some dissatisfaction with the therapies availability. Randy agreed that is an issue and the reason is they are restricted by statute to paying state Medicaid rates whether the child is a Medicaid recipient or not. A lot of therapists don't want to take Medicaid rates which results in a lack of qualified therapists. Sheryl mentioned personal experiences within area eight of the differences between therapists/providers seeing recipients on Medicaid vs. early steps program. It's a huge problem with providers in their area because of the way the local early steps program is working. Randy mentioned there is a federal requirement that the service be provided in the natural environment. Therapists must go to where the child lives, plays, or day care as compared to the child/family going to the therapist's office. Many therapists don't like this as it requires additional expenses for them that wouldn't exist if appointment was in their office. Sheryl mentioned that many families in her area would prefer taking their child to the clinic where possibly appointments for more than one therapy could be arranged on the same day. Many don't want the therapists coming to their homes. Randy agrees it would be better that families have a choice but they're mandated by federal policy. Ann asked if families are included in the learning/therapy process within this program. Randy advised yes, it's all part of the program. They assist the family in learning about the potential disability, learning how to care for the child, learning stimulation activities and if physical therapy is involved they learn range and motion exercises and other activities that are appropriate for the child's developing process. Randy mentioned other programs within CMS which provide a wide range of children's needs. They have 20 area offices within the state. The bulk of the services they provide on behalf of individual children are done through insurance type payments. They approve a variety of different physicians across the state to be CMS providers. They have three primary categories of financial status for children. They are:

- Title 21 Kidcare program - They are a managed Kidcare system. They receive a capitated rate per month per child. They manage that service on behalf of those children with special needs. There are about 9,000 currently in this program.
- Safety Net Population – A group of children and families that are not eligible for Medicaid, are not enrolled in Title 21, have no other kind of insurance and are indigent with no health care coverage. There are about 14,000 in this program.
- Medicaid Children - They service approximately 46,000 children with special health care needs.

Randy mentioned the Children's Medical Services Florida statute is 391.

Medicaid Reform as it relates to Children’s Medical Services – Randy provided all in attendance with a hard copy of his powerpoint presentation.

Assignment Process – Current Enrollees:

- Choice of managed care plan or Medicaid opt-out within 45 days. Sheryl asked what is Medicaid opt-out? Randy advised it’s a new component of Medicaid that will allow a person to take the equivalent value of their Medicaid benefit and use it towards a private health insurance that would be available to that person. You can use the Medicaid resource to pay that premium. Therefore allowing you to opt-out of Medicaid and buy into a commercial market premium.
- No Choice – Automatic assignment occurs
- Current CMS Medicaid recipients with “C” flag (internal to Medicaid process) will be assigned to CMS/PSN unless they choose another plan. Children that are currently enrolled in CMS right now have a “C” indicator on their Medicaid record. Those children will be assigned to CMS or their PSN (Private Service Network plan) unless the family chooses another option.

New Enrollees:

- They have 30 days to make a choice on which plan they want to enroll in.
- If no choice is made they will be assigned to a plan. This is done either by previous experience the family has had with a physician and whether that physician is enrolled in a particular plan. Other factors can determine a rational assignment choice. Otherwise it’s whatever the next number is goes to the next HMO on the list.
- In the choice period, only emergency services are provided to the adult population. For children, because of the federal provisions, they will still be able to access all the medically necessary services. Sheryl mentioned how important this is because when she attended a previous Medicaid Reform conference several months ago this was not included and it was feared that children would lose their medical services during the choice period. Also, families with special needs children moving from another state wouldn’t have access to medically necessary services. She praised CMS and advocates speaking up for this provision being added to the program. Randy advised CMS does have the opportunity to play advocate at times with Medicaid as they work with issues pertaining to children and they did remind Medicaid of this federal provision.

Lock-In / Disenrollment Process:

- There is a lock-in process for the choice made within the 30 days. You’re in a plan for the first 90 days, you can leave that plan voluntarily and choose another plan. That will allow a family who has enrolled in a plan, finds out the plan doesn’t offer the specialized services that their child or family member needs, they can opt to leave that plan and enroll in another plan that would have that service availability.
- Rest of disenrollment processes is consistent with current policy. This is important to children with special healthcare needs because many times a new Medicaid recipient family will enroll in a plan or auto assign in a plan because they didn’t understand it. They find themselves in a plan 120 days later after the lock-in period starts and that child needs a level of care that is not in the financing as a particular HMO option for that plan. That child/family can be disenrolled voluntarily and request an assignment to CMS because they are one of the few plans that provide special healthcare needs to children. Presently CMS is the only applicant in the 2 pilot counties. Randy advised it’s very difficult to qualify as a special healthcare plan.

Choice Counseling – Information to be provided: (Also covered in May minutes)

- Benefits
- Network Information
- Contact Information
- Cost-sharing requirement (does not apply to children)
- Performance information
- Hospitals under contract to specific plans
- Specialty care focus

Randy suggested if interested in finding out how this will work to call the statewide phone number already available which is 1-866-454-3959.

Marketing - (Also covered in May minutes)

CMS will not do any marketing. They will provide educational information about CMS only.

Benefits - Randy provided information on the three different types of structures which include comprehensive care, comprehensive plus catastrophic care or under a provider service network which is still a fee for service model. All capitated plans assume risk for comprehensive care. Plans may assume risk for catastrophic care. Catastrophic equals expenditures or hospital days over a certain threshold (yearly) per member. PSN plans may choose to be fee for service and not at risk for capitated premiums for up to three years. These plans are at risk for cost savings or loss. He reviewed the enhanced benefits (also covered in May minutes). Some examples of indicators for children include making sure the child gets to all scheduled appointments, that they are getting their immunization shots and if the child is obese that they are involved in a weight loss reduction program. These type indicators would qualify them to earn points towards the enhanced benefit. The enhanced benefit for the coming year has been set at a maximum of \$125 value. He reviewed the following:

- Types of Premiums
- Eligible Providers which includes CMS Network
- Minimum Provider Requirements
- Quality and Reporting Requirements

Sheryl made reference to “Provider access and timeliness of care”. She asked how CMS network will be measuring the amount of time for a patient to actually see a physician or provider in their network. Randy advised there are standards established as part of the application that they have to meet. He briefly reviewed a few of the standards. Sheryl mentioned complaints from many families in her area relates to appointments at local CMS clinics require a parent to take a full day off from work in order to take their child to the clinic. The backlog time results in delays, it takes hours to be seen for a 10 minute appt. Randy advised that will be part of the measurement and also appears on the customer satisfaction rating document. Sheryl advised it’s a chronic problem and should be recognized as such and improved when CMS is re-vamping their whole system. She really wants an answer to how they plan on improving this measurement and asked Randy to E-mail the council with answers on how they plan to improve and monitor the situation over time. Ann mentioned the need to establish a customer satisfaction survey with questions that allow the consumer/family to make constructive criticism rather than questions that will result in what appears to CMS as high customer satisfaction. Randy advised that’s a good criticism but CMS doesn’t write the questions.

Ann replied that’s another reason for the comment. Sheryl mentioned families should be included in the design of the survey.

- Potential Reform Effects on CMS
- CMS Strengths – Statewide network of care coordinators, Statewide provider network

that meets standards of care, Long history in managing the care of children special health care needs.

- CMS Challenges:
 1. Lack of an information system impacting ability to measure outcomes and clinical interventions (disease management).
 2. Inability to add or shrink staff, or make quick budgetary/expenditure adjustments.
 3. Insufficient provider network for some services (dental, mental health, etc.).
 4. Expansion of risk: Under capitation network assumes risk for all of its providers. This was a key issue for them in determining whether to become a PSN plan or a capitated at risk plan. He explained why with examples including current Duval and Broward county pilots. They are discussing with Medicaid a managed care format under their current statutory authority as a way of moving faster towards managed care activities on behalf of their current CMS families in a broader area than waiting for the rest of the reform.
 5. Tied to Medicaid rate structure – No readily identifiable source of funds to provide increased payments.
- CMS Options
- Current Strategies – Includes participate initially as a fee for service PSN and retain current benefits package which includes mental health and dental.
- Possible Legislative Changes – Legislature approved CMS network in statute as a managed care plan. They obtained legislative authority for CMS to use an external Third Party Administrator and authorize establishment and retention of reserves.
- Current Status with reference to Broward and Duval County Pilot programs.

Randy also provided everyone with a document titled “Key Points – Medicaid Reform and the Children’s Medical Services Network – CMS Medical Director’s Meeting – June 3, 2006.” He shared they did a lot of evaluation and leg work before they decided how to position CMS programs as related to Medical Reform. It was determined they wanted to be a part of the Medicaid Reform plan and work directly with the people at AHCA and with the legislature. They felt in order for CMS to survive they had to be an entity within that structure. Chair Houghland thanked Randy for his time and presentation. The audience agreed with their applause. Randy expressed it was a pleasure to be a part of the meeting. He suggested the council might want to invite Janice Kane from the Early Steps program.

The meeting was adjourned for lunch. Chair Houghland presented portions of the Core Competency training CD, a requirement for all APD providers.

V. APD UPDATE - Denise Arnold, APD Bureau Chief of Community Development Chair Houghland introduced Denise who began by asking everyone to refer to the information packet she provided. The documents include the following:
OPPAGA Draft on APD Wait List – Denise mentioned the function of OPPAGA (Office of Program Policy Analysts & Government Accountability) is to do special requests by the legislature for reviews. They also tend to get tasked with the review of each agency. She shared over the legislative session many concerns were expressed with regards to the wait list, including the current enrollment because this last year they will have enrolled 6600 consumers. Also of concern, was how to deal with funding the rest of the wait list. This is an informational review. The review provides a lot of background information on the wait list and how the process works. Included at the end are the OPPAGA recommendations which were summarized as the headline of the report “APD Waiting List Should Be Improved for Agency’s Planning and Budgeting Purposes”. It referenced that APD has a difficult time contacting people on the wait list because

they don't have the right home address, they move and don't leave forwarding address, and they have no other contact information, all examples. There is a lot of difficulty using the wait list as a way for the legislature to know how many persons should be funded for services. Denise made reference to the chart (Exhibit 8) breaking down the source of services received by individuals on the wait list and number of individuals. The report recognizes APD should be looking more at the number of people who need immediate service vs. who is on the list for the point of time when they need services. Denise advised that is kind of their challenge, how can they improve that. The recommendations include:

- The agency should obtain more current information on the location and status of individuals on the wait list.
- The agency should maintain better information on the expected need for waiver services. They suggest the agency should determine the level of services received from these other sources (Exhibit 8) and the estimated time when individuals may need services on the HCBS waiver. Denise mentioned this is their challenge within the application process. Discussion followed with numerous examples to support the difficulty in addressing this recommendation. Denise mentioned the report made reference to Georgia's use of the Support Intensity Scale (SIS). APD has scheduled a representative from Georgia to give a presentation on the SIS. Ann mentioned FCCFlorida would like to have a representative there. Denise made reference to the ICG (Individual Cost Guideline) used as APD's assessment tool. Joy mentioned the report suggests a contact be made each fiscal year, she thinks maybe 6 months would be better, and couldn't at that time the family be asked to update their situation/needs.
- Once this information is available, the agency should develop a multi-year plan for addressing the state's waiting list for waiver services. The plan should consider the length of time individuals have been on the waiting list, how soon the individuals are expected to need waiver services, the level of expected services to be provided, and whether the individuals are receiving services from other waivers or programs. Denise believes this is a good recommendation. She's not sure what all of this means but would like everyone to think about it and offer suggestions. Joy suggested a need to offer a training session to individuals/families on the wait list who are close to being offered services whereby the process could be explained in detail to them before they make the decision. Denise shared how extremely difficult and time consuming it was for the agency to enroll the 6600 this past fiscal year, in fact they're still enrolling the last of them. Maybe something a little more predictable and controlled would help. A training session say for the next 100 on the list made good sense to her. She also stated, this year they could be lucky to get anybody enrolled except for crisis cases. Chair Houghland asked if the agency is limited on the number of crisis case this year. Denise advised they are limited by the dollars.

General Revenue Support Coordination Workgroup - Denise mentioned what they are trying to do is to clean up their internal world. The document refers to the agency intake workers, the people who determine eligibility (General Revenue Support Coordinators) within all the field offices. They are the ones who help people go from the wait list to the waiver. They want to establish some minimums which means revisiting what to they do when someone comes to the agency, how often are they contacted, what is it they do for an intake, are they required to see them before they determine eligibility. The first workgroup meeting was held on July 11-12. They also mentioned the need for twice a year contact to determine what needs to be established as a minimum. The handout provided a listing of tasks/goals. Denise advised they would provide the council with the completed list. Discussion followed with regards to documents that should be shared with the individual/family at the time of the application process. They would

include FCC materials such as brochure, statement authorizing release of contact info. to FCC and several community resource contacts. The APD letter includes more of a helpful packet indicating yes you're eligible but currently unable to access APD services but enclosed information may be of assistance. Ann indicated most helpful item needed now is APD website address on APD letterhead. Denise also indicated the need to include the FCC Florida bulletin distributed at Family CAFÉ. It needs to be determined if it should be mailed to everyone on the wait list or given to new applicants or both. Denise mentioned they could probably do both but need to discuss some timeframes. She is committed to helping FCC's and will do her best to find funding to help with the printing costs. Ann mentioned she could probably get 20,000 printed for \$3,000. Denise thought that was great. The number one priority is the people just coming on the wait list. Beverley mentioned the need for the Agency for Persons with Disabilities to be listed under state government in telephone books. Sheryl shared the resource guide Families First produced for the Family Care Council's regional fair. Denise was very impressed. Ann mentioned the need for APD to provide more consumer friendly literature. She referenced how limited the information in the Meaningful Day brochure. It could provide so much more information on services available to the consumer. Also, the E-bulletin is not written for the average consumer to be able to read or understand. Denise wants to continue the E-bulletin but asks for more comments and suggestions for improvement. Discussion followed regarding all the yellow books that were sent to people on the wait list that were returned with insufficient addresses. Also, there was no cover letter attached to the book explaining to families they aren't yet eligible for services, you're just getting the book.

Eligibility Issues – Denise explained they are trying to finalize their eligibility procedures. One issue is people applying with children under the age of 3. If they allow them to apply (but really no way to allow them not to apply) the challenges are either to say “I'm sorry you're not eligible because your child is not 3” or “When your child turns 3 they will be eligible” but then it's on the agency to remind them at the age of 3 to get on the wait list. Ann suggested the family be informed they need to re-apply when the child turns 3. They shouldn't be told they're not eligible for services because of the disability but they haven't met the criteria yet.

The other issue is related to high risk and not being eligible for the wait list until you get a qualifying diagnosis. She thinks Shelly is having their general counsel review to see if there is a way to remedy this but not sure if possible. The other issue is why isn't Downs Syndrome as a whole categorically eligible. Discussion followed because not all individuals have mental retardation that meets the IQ criteria.

Individual Budgets - Several states use the Supports Intensity Scale (SIS). Denise believes Georgia uses it to predict their budget. She reminded everyone about the Individual Cost Guideline (ICG). FCC's were going to help families with learning how you work with an individual budget and have some flexibility. Shelly wants to pull a group together for Medicaid Reform that relates to the DD world. Denise asked everyone to think about this. They need to have a validated tool that Florida stakeholders will accept for that purpose. Ann thinks the ICG looks pretty good. The challenge is they will have to find funding to purchase the SIS or they have to put money into validating the ICG. The question is how can APD offer a type of managed care that really works without APD having to find a way to fit what is known into Medicaid Reform rule. Frank mentioned the CDC program. Denise agreed. What CDC offers is the ability to use non-Medicaid providers and allows monetary flexibility.

Support Plan Module – Ann mentioned in their review of the module it appeared that many of the questions looked like those on the ICG. Denise advised yes, they were pulled from there. Chair Houghland mentioned she talked to Janice about the form that APS had constructed, they're finding that they are still getting denials which require additional justification of services. The feeling is they aren't asking the right questions in the asking order to get the information out of the support coordinators to show it is justifiable. It's hard to create a general form that will do

that. Denise mentioned the electronic system includes support plans A & B. A is more the planning information and B is justifying the kinds of services needed. There has been a lot of testing of the system. The electronics of the system are still not right, the stability of the system is still not right and the time factor is still not right. They have made more changes and testing. It's still not ready but they are seeing improvement. Ann mentioned and Denise agreed there has been a trend of problems within supported living. Denise advised Lorena Fulcher is the contract manager for both APS and Maximus. Any concerns should be directed to her. Chair Houghland also noted APS doesn't have enough technical staff to have efficient assistance when needed. Her concern is that APS doesn't have the capability to develop a program that fits the need and to make it functional for the number of users, for the amount of information and to provide the technical assistance that it will require when everyone is on it.

Provider Rates – Included in the packet of information is the Provider Rate Increase Procedure and draft Implementation Plan. Denise mentioned the Waiver Support Coordinator increase is 8.9% and all other service providers will receive 2.81%. They were given specific appropriation for the provider rate increase which resulted in separate percentages. The increases also apply to a couple of negotiated waiver services which include the intensive behavioral service and transportation rate which will still get the 2.81% increase even though it's not a standard rate. The increase doesn't apply to waiver providers of commodities or equipment or service providers whose rates are established through bid or "market" costs. These services are: Adult Dental, Consumable Medical Equipment, Durable Medical Equipment and Supplies, Personal Emergency Response. The "caps" for these services will be adjusted to accommodate the rate increase. They met with the providers last week and reviewed the procedure in great detail. Denise reviewed the procedures. Providers will have to sign all new service agreements. It will require a lot of administrative work for area offices, support coordinators and providers. She explained the families role in the process is making sure the providers are estimating correctly what their needs are from now to December. Frank asked if the increase will result in some cost plans going to Maximus. Denise advised, no, they plan on raising the cap of high cost which is currently at \$77,000 to the appropriate amount to account for the increase. Denise explained both documents are still in draft form so are not official as yet.

Pre-Service Training Manual - Included in the packet is information from David Alexander providing a brief summary of his plans on changing the waiver support coordination pre-service curriculum. It includes some timelines and outline for a pre-service training manual for the council's review. She is requesting feedback and wants to schedule a time to meet with council members and David possibly via conference call. Chair Houghland asked who should get our comments. Denise asked to send to her and copy David and Terri McGarrity. She mentioned they are trying to standardize the area office training.

Application for Services - Included in the packet is a copy of Instructions for Completing the Application for Services and Application for Waiver Participation. She specifically made reference to the page the applicants must sign. It includes a paragraph explaining the applicant's responsibility for advising of any change in contact information and failure to keep the agency informed. Also added is contact information of someone who can be contacted if the agency is unable to contact the applicant. The area offices will start using this version. Council members offered some suggestions for improvement.

Request from FCC for POM Reviews – A copy of a proposed draft procedure is included regarding FCC's concerns about people the councils hear about or work with who are not scheduled for a Delmarva POM review or in addition to Delmarva's. This procedure would result in another mechanism to help the person obtain the supports needed to reach his/her potential and notify providers that this is what really needs to happen. The draft is a summary of what was discussed at the meeting with Patty and Ann and also at the May 20th FCC Florida meeting. Denise reviewed the draft and asked that council members define its criteria. She

would like to know how councils see this procedure working at the local level. She suggests adding this issue to the next FCCFlorida meeting agenda to discuss and finalize the procedure. **Additional items in the packet** include the latest APD Waiver Enrollment Status effective July 11, 2006 and information on the Familial Dysautonomia Waiver which will be administered and operated by AHCA.

Questions submitted by Patty and Ann - Ann asked about the status of the triage. Denise explained the triage language which appeared only as one sentence was vetoed by the Governor because it was part of the Autism language which was vetoed. She mentioned it really doesn't have any meaning when there isn't much enrollment. What is different is they can now enroll crisis people on the FSL waiver in addition to the HCBS waiver. Ann made reference to a family who is devastated because they were put on the FSL waiver and only wanted language therapy for their child. Can they get a Doctor's prescription for language therapy on the FSL waiver? Denise replied no, not on FSL waiver. Since there is no enrollment this year, only crisis, the only alternative for this family is to re-apply for HCBS waiver as a crisis case which means meeting the 3 criteria for crisis. Donna asked if there have been any additional services added to FSL. Denise replied they're looking to add Durable Medical Equipment. They have to raise the FSL cap because of the provider rates increase. There is no plan for adding language therapy but she will check again. Ann emphasized the importance of language therapy because it's available for children under Medicaid State Plan but nothing for adults 21 and over. Denise said they would re-visit the issue. Denise mentioned the FSL waiver official "rule" handbook should be coming out soon. She shared there are some priority issues on the HCBS waiver. They have some rule making authority this year that allows them to write rule crisis enrollment, how they handle children in the DCF system and application and eligibility. Any suggestions for HCBS handbook changes can still be sent but probably won't be addressed this fiscal year.

Reimbursement for Travel Expenses – Chair Houghland mentioned that several FCC councils (8 and 13) have been required by area personnel to sign up as a vendor to get reimbursed for their travel expenses. Denise questioned this as it shouldn't pertain to travel reimbursement. She will follow up with those area offices. Bob mentioned the challenges families face dealing within the different area offices. There is no continuity about how operating procedures exist in one area vs. another. It's very frustrating.

Chair Houghland thanked Denise for attending the meeting and for her time and efforts in keeping FCC's informed on APD issues. The audience agreed with their applause.

VI. NEW BUSINESS

FCCFlorida Funding Issues - Bob explained FCCFlorida receives a total of \$7,500 based on a \$500 donation per area council every year. He mentioned the current year budget includes travel expenses to FCCFlorida meetings for Patty, Ann and himself based on 2 days, 1 night totaling \$2,000 per meeting multiplied by 6 totals \$12,000. Another expense to consider is the website. In order to keep it maintained during the year will cost \$2,000. With just these 2 items the council is over budget. There is no money for anything else, attendance at state conferences, etc. A decision must be made. Are councils willing to provide additional funding to the statewide council just to continue the meetings & website or will the council have to cut back on the number of meetings this year, or is there something the agency can do to assist the council. A major reason for the dilemma is the increase in travel expenses. Several of the councils advised they had already voted on additional dollars over the \$500 to FCCFlorida. The question was asked if another meeting place could be found that would be less expensive. Bob replied not in current area as they had already researched that. Jeannie mentioned she works at UCF and on weekends it's not as busy. It's a 20 minute drive from the airport and there are hotels across the street. She would have to check on hotel rates and if they provide shuttle service to/from the airport but there would be no charge for the meeting room. Bob asked Jeannie if she could

investigate the costs and submit to him. Denise asked how the councils did this past year in spending their funding dollars. It was shared by several that it's totally unknown. The councils think they have spent all but according the financial data from APD they haven't. Dollars were to be transferred to FCCFlorida which never happened. Denise asked if the councils could determine an estimate/percentage of the costs associated with the increase in travel rates. There is also the increase in airfare to consider. Denise mentioned she would look at the issue from her end, she can't make any commitments, but will look at it. Joy mentioned the frustration with spending the dollars because the figures have always been so far off between the councils, the districts and APD. It's impossible to know how much money the councils have at any given time. It's an ongoing yearly problem. Jean asked if there was a better way of keeping the accounting of FCC funds. Chair Houghland advised that was part of the budget request that they sent in asking to use a non-profit organization as fiscal agent. Area council commitments previously mentioned total an additional \$2,000. Bob will contact the area chairs via E-mail requesting figures on their upgrade in travel costs. He asked Denise if she could work on something from her end. He asked Jeannie to prepare a proposal on what the costs might be to meet at UCF. Discussion followed emphasizing how successful FCCFlorida has been the past 2 years in making great strides at being recognized at conferences throughout the state. The costs to attend the conferences came from FCCFlorida dollars. It would be horrible for the council to take a step backwards. Meetings are so important not only for receiving information but in turn educating and reaching out to families. Maryellen asked Bob how much money is needed. Bob advised in quick, round numbers to have 6 meetings a year, \$2,000 for the website, administrative fees, and for Patty and/or Ann to attend a couple conferences you're looking at about \$1,400 total per council. Chair Houghland mentioned we know what the problem is, we don't have a solution today, however, we need a consensus on whether to have a September meeting or not. It was decided to have a meeting in September. To summarize, each chair will go to their councils, explain the problem and E-mail Patty with approved additional donations to FCCFlorida so a plan can be put together to present at the September meeting. Also each council needs to determine the percentage of increase in travel costs to the meetings and submit to Bob so that he can inform Denise. Bob, with Stephanie's persistence, was able to purchase the Law Enforcement videos and gave one to each council. Chair Houghland asked if there was any other business that she had missed. Stephanie was asked to give an update on FCC governor appointments. She mentioned there were 6 approved appointments from Area 4 and 14. She reviewed the names of applicants currently at the Governor's office

X. ADJOURNMENT

Chair Houghland asked to return meeting evaluations to her. She asked for a motion to adjourn the meeting at 3:45. Maryellen makes the motion. Sheryl seconds the motion. The motion was approved by consensus.

The next meeting will be held on September 16th at The Hampton Inn.

RESPECTFULLY SUBMITTED,

FICD

Florida Institute on Community and Disability