

**FAMILY CARE COUNCIL
APD AREA 13
OCTOBER 13, 2008**

Meeting called to order at 10 AM by Chair Isabel S de Martinez in the APD Training Room.

IN ATTENDANCE:

MEMBERS: Tina Renwick, Isabel S. deMartinez, Sandy Shorey, Norman Price, Betty Kay Clements, Jennifer Knowles, Michael Payne, Eileen Reidy, Phyllis Novak, Caryn Jones

MEMBERS ABSENT: Anna Brynild, Sandy Dayton

ASSOCIATE MEMBERS: Stephanie Hopper, Karen Huscher, Eva Knowles

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APD STAFF: Brenda Stevens, David Johnson,

VISITORS: Coleen Spillman provider, Judy Pastore/Carlton Citrus School Board, Pat Hawk parent and past FCC Chairperson,

Chair Isabel welcomed everyone and had visitors introduce themselves. A quorum was present. Packets for meeting were passed out. Michael Payne has been reappointed and Caryn Jones is a newly appointed member.

Isabel started the meeting with a positive note. She reported on a project her daughter is involved in that was recently in the news. It is a butterfly garden therapy, started with a grant. It is now a wildlife certified habitat. It started a little over 2 years ago. She also reported on an ADT recycling center/club project that her fellow employees assist with and it is feeding families with a certificate from a church. There is a special project for Thanksgiving. She encouraged all to get involved and encourage others to get out and about in their communities; it has had a very positive effect on her daughter.

MINUTES REVIEW/APPROVAL: Chair noted that the minutes are now only being sent online for review prior to meeting. A copy will be available at meetings as necessary. Motion was made by Michael Payne and seconded by Sandy Shorey to accept the minutes as written. Motion Approved by consensus.

BUDGET REPORT/BUDGET REVIEW: Norm reported that travel was the only expense. A budget balance of \$8,204.18 was reported. He reported that \$600 for FCCF hotel has not been taken out by Tally yet and the encumbrance for last year's secretary has not been removed yet. Question on some delayed checks for travel expected to be resolved shortly according to records.

AREA ADMINISTRATOR REPORT/UPDATE: David Johnson addressed the group. Staff are very busy with tier changes. APD is still receiving them and that is expected to continue for awhile. The Area office was notified that 177 appeals rec'd within 10-day period and no changes to service at this time for those individuals are to be made. David expects a larger list soon. Betty Kay did receive a letter saying the appeal request for her daughter was received within the 10-day period and services would continue, exactly as David stated. It is reported

that appx. 5000 appeals were filed for hearings. They meet daily on significant changes, and the Area office can provide for emergencies for 30 days and request goes to APS for possible tier change. They are sending to WSC's today to encourage notification of needs to Area office. Many changes were made to tiers and moved to a higher tier from notifications. Stephanie asked where DOAH hearings are held. They are held in the jurisdiction of request, David said, at least in regards to the ones he has participated in. He stressed that DOAH is more formal and may not happen quickly. This is not the only Agency that they work with, particularly do regarding Medicaid. APD was a smaller portion of their work but they will now be busier with the amount of Tier appeals.

Stephanie stated that the parents of some of the students she works with are being notified that the individual will be having a QSI done soon. She asked when the QSI will be used for cost plans. David reported that they are validating the tool now to be sure it is reliable and accurate. All Waiver individuals in the State are to be done by March 2009. After that time there will be determinations on how it will be applied. Another question was who makes a decision on whether there will be a hearing or not. He stated that a Lawyer from APD would determine if an appeal meets the criteria. The individual or representative and APD both give testimony at the hearings. Judges are not sitting judges but work for the state of Florida, and they hear for licensing, and other departments as well as APD. Betty Kay stated it has been reported that individuals have been more successful with DOAH hearings than previous APD hearings. There was a question about recourse if appeal not sent to DOAH and Betty Kay read a statement from John Newton General Counsel for APD saying that "if the Agency issues an order dismissing or denying request for a hearing, the Order will include notice to the client of the right to appeal to the First district Court of Appeal or the district court of Appeal where the client is located." This information did not address it, but it has been reported that services do not continue at current level at that time. No known denials yet.

David reported that over 50% of Area 13 reconsiderations were changed and Tally made the decision based on information Area sent to them. Stephanie said that the Key Center is having a meeting on what to do to prepare for a hearing, Stephanie will notify of dates. Betty Kay stated that the Advocacy Center is looking at many cases and are particularly interested in the Children. They also want to hear from individuals that are denied a DOAH hearing by APD. An alliance in Jacksonville has at least 30 lawyers working on a grant to assist individuals pro bono with tier appeals. Other smaller groups around the state exist but none known in Area 13. Norm noted that cases are individual and that is why there has not been a class action. Karen expressed her real concern that discrimination needs to be looked at for those under 21 years of age. They are denied the choices that those without disabilities can access, like moving out of parental home. There is no equity for those without disabilities. Betty Kay said that question was addressed to the APD Director at the FCCF meeting and he said the lawyers have been instructed by him not to discuss this issue. There was no further comment on that issue. Norm asked if Crisis admittances were admitted to a specific tier and David said they are being assigned a tier according to criteria.

Eileen had questions about an individual with DD having entitlement to a free lawyer. Her Niece has told her that legal services would be free to her son if available. David advised that the Advocacy Center should be able to inform of resources across the State. She had asked if

the WSC is to fill out and assist with appeal, and most said that many are helping but it is not their responsibility. She knows someone who did not get a letter, and David said he would talk with the person and let her know if he has any information. Discussion about the hearing process ensued. A question was asked if client needs to be present at the hearing. David advised that Advocacy Center or DOAH office should be able to give details.

Karen discussed the issue of concern over intense behaviors, as in autism, and the fact that so much has been accomplished with her son and costs are lower now due to the services he has received. So much will be lost and denied now due to tiers, and service needs will increase she said. Legislators need to be advised about the plight of below 21. Question of why some States can do more, whether it be taxes or not. Disagreement about how much other states do based on experiences of others having moved to Florida. Norm said in Florida DD has always been first to be cut and last to receive funding. Loss of Federal funds a concern also. Karen related her dream is that APD would actively advocate for individuals with developmental disabilities. Norm says you need to prove the client is at risk for health and safety. Group needs to get together and visit legislators Karen said. Isabel stressed that the community does need to get involved and individuals and families need to involve community.

Phyllis and Eileen visited Rep. Schenck office and related Autism statistics with him, dental issues with tier 4 and asked specifically if tiers were done to help budget or open up the waitlist. He did not know the answer and said he would get back with them.

Discussing Tier 4 and dental, Betty Kay said the APD Director shared with FCCF that APD is working on that for this next year. Concern even then is with Dental providers willing to work with the Waiver or with individuals with special needs. A dentist told Eileen her son did not feel pain, for example. Many said that Pediatric dentists do work well and some continue to do so beyond childhood. Eileen suggested that FCC get the new American Dental Assn. Chief to come and speak at Forum. All agreed that was a good idea and would be pursued.

FAMILY CARE COUNCIL FLORIDA UPDATE: Betty Kay reported that there is a 3:30pm call today about the 10% budget reduction exercise for the governor. Tally staff, Area offices and stakeholders have sent ideas. Jim has said that there is only a 3.6 APD overhead in budget so nothing can really be done without cutting into the Waiver. He will discuss some of the recommendations being considered. This must go to Governor by this next week. It is expected that the 4% being withheld will not be returned this year. On Friday, Betty Kay is attending FASC (Support Coordination) meeting in Ocala at the Sheriff Substation. Usually they have been more formal but this year doing 3-4 regional conferences to brainstorm concerns and status in today's political climate. There is a rule hearing on Restraints, the 24th in Tally. On Oct. 29th there is a stakeholders and APD workshop in Tally on Waivers and projecting how it may look over the next few years. It will be facilitated by someone familiar with other States and Waivers. Betty Kay will report back to FCC and FCCF. She also reported that HMO's continue to be around this year looking at DD and the legislature, so will bear watching.

GENERAL DISCUSSION/ Isabel led stating the need to do informal/sub committees for resources. Draft Resource list from Citrus serves as an example; so encouraged to bring some

from other areas. She gave examples of holiday plays that are free, or low cost. Bring any information for local area to next meeting. Watch the papers. Horseback riding was a great resource while her daughter was on the waitlist. They do various payment or other arrangements and they do more than just ride.

Stephanie brought up what she called the category of black humor with VR employment services. They have been a great support in many areas but they are now working to save money and in fact have tier like categories for application around age 14. If you need help and then apply, must prove the disability, then you will be put on a waitlist according to need. So when individual is ready they will hopefully be able to receive services.

Isabel referred to a copy of planning for the future that gives good timely information. It is helpful for providers for instance, to become familiar with the individual. You are to be explicit and make the document a part of your planning or guide on things such as a favorite color that could be pertinent to an individual.

Tina asked about Colleges, Isabel will get information. She will also send out calendar of downtown activities such as Leesburg recently did. Stephanie told of activities that Moving Mountains does on a regular basis. They will be having a picnic, and winter ball. Isabel said to let her or Betty Kay know what is available in their areas. She suggested they could carpool to other areas to attend. She acknowledged it is a stressful time and individuals pick up on it. Action is the only thing that helps us through tough times, she said. She named a book she was given at work on practicing personal accountability. It has a lot of ideas on changing instead of complaining. QBQ (Question behind the Question) John G. Miller.

Eileen told group of an incident with an older parent who became ill and had information on her that led them to her daughter at home. She also had a file of life that Eileen shared. Hernando County Sheriff is looking for a sponsor to assist this program. It is on the Internet. If an individual were traveling on a bus, this information and a picture would be most helpful. Group was encouraged to check with their County. This could be considered for a forum.

Betty Kay suggested discussion about the Forums for this coming year next month. Consider having resources as exhibits in particular. Isabel also suggested legal information and guardianship, as well as unique sessions for individuals such as budgeting.

Orientation scheduled after next meeting. New members and those interested to attend.

No further business or discussion at this time. Michael moved for dismissal and Jennifer seconded it. Meeting adjourned at 11:35am. Next meeting November 10, 2008.

Respectfully submitted

Betty Kay Clements
Area 13 FCC Secretary