

**FAMILY CARE COUNCIL
APD AREA 13
APRIL 13, 2009**

IN ATTENDANCE:

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

MEMBERS ABSENT: Anna Brynild, Sandy Dayton, Sandy Shorey, Michael Payne

ASSOCIATE MEMBERS: Stephanie Hopper, Eva Knowles

ASSOCIATE MEMBERS ABSENT: Karen Huscher,

APD STAFF: Brenda Stevens, David Johnson

VISITORS: Bill Reidy, self advocate on waitlist

Quorum Present

Meeting called to order at 10 AM by Chairperson Isabel.

MINUTES REVIEW/APPROVAL: Chair Isabel asked for review of meeting minutes of last month. Eileen made a motion to approve the minutes as written, seconded by Phyllis. Motion Approved by consensus.

BUDGET REPORT/BUDGET REVIEW: Norm reported that the FCC Balance is \$5,428.07, with APD report of \$5,440.53. These reports remain close. So far, he reported, that there are only \$519.00 expenditures in from the Forum. He has prepared the 3rd quarter expenditure and 4th quarter projection and they are ready for submission to Tallahassee Central Office. He will send to Brenda. There was a discussion about budget balance and suggestion of considering a new FCC Computer, tape recorder etc. Discussion will follow.

AREA ADMINISTRATOR REPORT/UPDATE: David Johnson shared that appx. 1800 QSI's were 100% completed on schedule. Now Area 13 has been assigned to do appx. 400 QSI's of individuals on the waitlist. Stephanie said she advises many on the waitlist of the QSI and there are various responses. There is concern about how this has been explained to parents as many are saying they do not see it as necessary. David said they are aware of this and are looking at ways to accomplish this. They will express how important it is to them. Could they be taken off the list if they refuse, she asked? Before that would occur, David said they would revisit once others assessed. He stressed there are legitimate reasons that people would not want to do at this time, and this will be taken into consideration. Some discussion whether the QSI picks up the prioritization being discussed in the Senate. It may need another tool to pick up that criterion was suggested. Stephanie stated concern for those she sees aging out of school. Some are on the waitlist or the lowest waiver she added. She tries to get them on crisis, as this is a major life change. She also expressed concern about the necessity of working closely with the State Coordinator for Citrus County. His movement back to the main office has become an issue. Crest school has offered space and she would like to see this considered. When he comes to the county he does not have the tools to access information needed to answer questions. He is available as needed in the County David

stressed. He will get with him to discuss issues. There may be telecommuting possible as well as computer access in the future, he added.

David reported that appeal hearings are ongoing regarding tiers and rebasing. Legislators have added rebasing again for the next year.

He reported that WSC's are going to have access to ABC for cost plans etc. reinstated May 1, 2009. There is training starting this month. This should speed up the process of input.

CDC+ is slated for 2500 additions this year. They have met with WSC companies and a June training is scheduled. Training is also being scheduled for APD staff to get them up to speed on this program. Questioned as to how the role of the WSC is impacted, David said the consultant is similar to WSC role. He does believe there will be enough consultants. Asked about the role of WSC and consultant on purchasing plans, he said the WSC/Consultant is one role. Isabel said that she was discouraged by this topic at the last FCCF meeting when Dr. Robinson addressed it, and will need to understand more about it for tier 4. Betty Kay read from notes from the FCCF meeting. It was explained that 42% of consumers are in Tier 4. The average expenditure in Tier 4 is \$8,500 less 8% discount is \$7,500 less administrative fee of 4% equals \$7,000; this could present a problem to accessing this program. This was a concern for Isabel. More explanation is to be forthcoming, David said. Not sure when program will be available. It will not be available in group homes. It will triple the CDC + census at Area 13 David said. Asked about relationship to Individual Budgeting, David said it is his understanding, at this early stage of discussion, that Individual Budgeting is a variation of CDC+ and would probably be based on QSI's and a funding tool.

David said that the prioritization of the Waitlist is being looked at in legislation this year. It is believed they will attempt to address based on need. Betty Kay shared some of the current discussion and recommendations being shared with APD and legislators. David said that the Area office is processing about 10 crisis/month off the waitlist, with high success to date.

David shared that the APD Area offices are tracking significant occurrences and will be online soon. Example would be that deaths for any reason of waiver or waitlist individuals will be tracked.

Eileen asked about getting Medicaid. David said that if you have SSI, you have Medicaid. You must be Medicaid eligible for the waiver. You may not be getting Medicaid but individual must be eligible. APD office talks to those that are most familiar with DD eligibility in assisting with Medicaid eligibility. Area 13 is having training on all Medicaid possibilities. Stephanie said the Center for Independent Living can accompany families to answer questions, so it is good to suggest to parents getting their assistance. Isabel handed out the Center for Independent Living folder with contact information.

Discussion of transfer from ICF/DD to Waiver for Individuals: Stephanie had asked for this agenda item to discuss a problem some families are experiencing with ICF/DD living arrangements for individuals and inability to transition to the HCBS Waiver. She is among the families concerned as this does involve her son currently. She explained the personal

situation with her son, who was in an ICF/DD that had for some time provided well for his needs. With new ownership many problems occurred, such as staff changes made that had been promised would not occur. She gave other anecdotal examples, resulting in concerns for his health and safety. This resulted in his moving out of the ICF/DD. Once it was observed that the caregiver (ICF/DD) was no longer providing safe and adequate care, he was essentially forced into homelessness. He is living now based on temporary charity. As a result he is now on the APD Crisis list.

The core of this problem is that ICF/DDs are not funded by the HCBS Waiver, but by a Medicaid program administered directly by ACHA, and that money does not follow the individual. She added that Funding was \$114,000/year in the ICF/DD, and in an APD group home, even on Tier 2 (\$ 55,000), his care needs would be met and ultimately save the State money.

Another basic issue is that AHCA oversees the ICF/DD's and this presents an oversight concern, shared by her and several other families. They would like a proposal to have ICF/DD under the oversight of APD. This is seen as the logical, effective place for oversight for Individuals with DD. Since the APD and State of Florida philosophy is for those with DD to be living more independently and inclusively within their community, it also makes sense that if they no longer need the ICF/DD they should be able to move into Waiver services, she stated. There is no prioritization for moving from an ICF/DD to the HCBS Waiver. He had been on the Waiver and had to give that up when he entered the ICF/DD, as his needs had increased at that time. Stephanie would like FCC to investigate how ICF/DDs could move from ACHA to APD oversight.

Betty Kay said she will seek information about ICF/DD and the Waiver regarding obstacles faced, but offered her opinion that it would take legislation to make a difference. Stephanie submitted a copy of the packet she has sent AHCA, APD staff, legislators and Gov. Crist. A documented copy of this issue was provided to the FCC to address at whatever level considered appropriate. A formal complaint has been sent to AHCA regarding the ICF/DD situation.

AOL/LENS PROGRAM REPORT: Brenda Stevens reported on the Lens training still has a few openings, room for 32 people. Days and dates are Wed. May 13, Thurs. May 14 and ½ day Friday May 15. They will be asking experts in the areas of employment, health care, housing, social capital and others, going into the community to gather information. Confirmed are Housing VR, Protective services, City of wildwood, Sheriffs department, Health dept., Langley, etc. a list of questions will be asked. Work will be done in Sumter, but information being collected from all counties in Area 13. An Electronic Resource book will be put together, and a name chosen for it. She also reported that Dr. Garvey has a dental pilot program at Tacachale. Information handout distributed. Asked about funding, it is the Waiver, private pay, and she will check on insurance payment availability.

ACTION STEPS FOR EFFECTIVE ADVOCATING WITH LEGISLATORS: Betty Kay distributed information FCCF put together from a presentation that Rep. Proctor did at an earlier meeting. FCCF is setting May as the time to set up their legislative committee. She is

recommending Area 13 FCC follow these guidelines as well. Members are to review and discuss at the May meeting. Members agreed that summer is the time to start activity, and take advantage of all opportunities to meet with legislators in their areas. Isabel stated that she had 80% response from Forum invitations sent to legislators. There were some personal responses and with session it was understandable they could not attend. She stressed that keeping in touch will now be the task that each member needs to do and to counsel others of the importance. It is important to make sure legislators realize that individuals with DD have a lifelong disability, but also realize how much can be accomplished with services and supports that meet their needs.

FAMILY FORUM-DISCUSSION: Summary of discussions and planning. Forum went well, over 150 attendees, Chair Isabel said. Next year work will be started earlier. Donations from Vendors and others covered refreshments. Very positive comments about Director DeBeaugrine's presentation and interaction with attendees. Thanks goes to everyone, as well as Aaron for all of his assist. She noted that Hernando commissioners responded to forum invitation, Sumter seemed disinterested, Lake and Citrus did not respond.

After a great deal of discussion there was a decision to do a Hernando Forum in September. That will allow good lead time for planning and avoid the end of the fiscal year crunch that occurs. Phyllis and Eileen will seek information on sites. Plans will be addressed at each meeting. It was expressed that basic programs of FCC and APD need to be presented. The distance is a concern that it has created a disconnect and that needs to be changed.

NOMINATION COMMITTEE REPORT: Sandy, Phyllis and Eileen committee members. Eileen reported that Chair Isabel and Vice Chair Norm agreed to continue if elected. Isabel stated that the election would be next month and at that time nominations from the floor would be solicited.

MEMBER DISCUSSION/ACTION: Discussion of inadequacy of FCC Tape recorder and inability to get tapes any longer. It was thought by members that a new one should be ordered. Chair Isabel described one she has seen for around \$150-200. Jennifer made a motion to purchase a tape recorder in that price range. Tina seconded the motion and the motion passed with consensus. Members agreed to continue monthly meetings throughout the summer. Stephanie invited everyone to a program FFRA is having this upcoming Friday from 9a-11p at the Key Center, Lecanto. The Citrus Safety Crime Task Force is speaking.

VISITOR/CITIZENS INPUT: No comments or questions

ADJOURNMENT: No further business meeting was adjourned at 11: 45 am. Next meeting May 11, 2009 at the APD office from 10:00 am –12:00 pm.

Respectfully submitted,

Betty Kay Clements
Area 13 FCC Secretary