

**FAMILY CARE COUNCIL
APD AREA 13
SEPTEMBER 8, 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, Sandy Dayton

MEMBERS ABSENT: Anna Brynild

ASSOCIATE MEMBERS: Stephanie Hopper, Caryn Jones, Karen Huscher, Eva Knowles

ASSOCIATE MEMBERS ABSENT:

APD STAFF: Brenda Stevens, David Johnson, Joyce Leonard

VISITORS: Linda Travis WSC, Amy Miller self advocate, JoAnn Quackenbush of Moving Mountains, Eileen Carlton family member,

Chair Isabel welcomed everyone and had visitors introduce themselves. A quorum was present. Packets for meeting were passed out. Newly appointed members, Sandy Dayton, Eileen Reidy and Phyllis Novak were congratulated. Michael Payne and Caryn Jones have been contacted and need to return call to Governor's appointment office, for agreement with appointment. Michael as a reappointment is still a voting member at this time.

MINUTES REVIEW/APPROVAL: Motion was made by Jennifer and seconded by Michael to accept the minutes as written. Motion Approved by consensus.

BUDGET REPORT/BUDGET REVIEW: Norm reported State financial shows an encumbrance for secretary still appearing, but is to be removed and \$600 for FCCF hotel should be added. A budget balance of \$8,403.54 was reported.

AREA ADMINISTRATOR REPORT/UPDATE: David Johnson addressed the group and had Joyce Leonard assist with questions on Tiers. Letters have been sent out and those not delivered will be followed up on. He addressed the Appeal process. They are working with WSC, s and need amendments to cost plans back by Sept. 24. By Oct 10 amendments are to be processed, and Oct 13, the adjusted cost plans are due. They were advised on a conference call with Central office that tier assignments with a 30% cost plan reduction are to be reviewed by Central Office for error. He stated that Brenda Stevens is working with emergencies and significant life changes and is reviewing for tier change. These issues can be supported up to 30 days by Area office while PSA goes forward. Joyce Leonard is the lead on reconsiderations and there are 50-60 with no decision at this time. They are gathering information on outliers. Advising families with concerns on appeal procedures and stressing that they need to show the error they believe has occurred. David stated that the Area office will assist getting the appeal to Tally if requested.

Cost plan discussion revealed there are individuals and families not wanting to adjust the plan as they appeal the tier. David advised that the cost plan can be appealed as well when it is

returned to them from the WSC. Doing the exercise of reducing cost plan to fit tier does not stop them from appealing and cannot be used against their appeal.

Stephanie spoke of families she has spoken with where their children were put in Tier 3, with one losing \$35,000 services because lives in family home. She asked if this would be addressed quickly. Response was that family should not lose opportunity to file appeal within 10 days. Encourage families to make their concerns known. She had another question about an individual waiting for a group home but had not found an appropriate opening yet. They are in Tier 4. She asked how difficult that would be now. If needs are being met now, probably life change would be necessary was the answer. Discussion followed of moving up to a higher tier, and an example was given that to move from family home to group home could take a significant life change, not just desire to move to group home at this point. It would involve justifying the need and the due process availability if denied. These situations will be on a case-by-case basis David stated. Concern expressed by a FCC member that this has become a question of civil rights being denied, not being allowed to make choice of where they live is discriminatory. Another question asked was if limited SC could be used if not able to afford ADT and transportation, as that would be about a \$700 saving. Answer was that this is the individual/family choice in the family home but not in a Group Home. Transportation a great concern by members. \$9.00 round trip Citrus County transit for instance, but if living at home on the waiver, it is \$1.00. Not available in all counties or all areas, also not something that all individuals can do. Everyone agreed that this is seen as a crisis for individuals and community inclusion.

David confirmed that Dental in Tier 4, is not available at this time. He did address that if there is an emergency need individuals can seek Medicaid State Plan. This does have limitations and availability issues. There was discussion to encourage movement by APD working with Tacachale on a dental program that was talked of under Jane Johnson.

Discussion of situations some members voiced regarding acute needs of families or individuals had them asking for direction. David stressed that families need to be encouraged to get with SC for emergencies, fill out papers and get to the Area office for consideration of 30 day assist. Beyond that time PSA must be done. David also stressed when asked about Mother with child and spinal surgery who has not rec'd letter that it is when it is received that 10 days starts. Someone asked what to do if calling a SC who does not respond, and they were told to file report with Area office, and also can request change of SC.

During discussion of tiers, Norm stated that it would not be as difficult to adjust cost plan if providers would tailor services but many providers are not flexible. Concerns expressed by members that providers may close and though there is empty bed space in Florida, those beds are not always equal or accessible for families. Also a concern that group homes will only want those with intensive rates and tier that individual is in could make placement more difficult now. Rate changes especially on transportation has had dramatic impact. Members see a perfect storm.

Concern voiced about those on the waitlist who have nothing and so much has been available up to now for those on the waiver. New member, whose child is on the waitlist, shared that in

State she had moved from there was little available after age 21. Others voiced that they often hear from other States that they have more than Florida. It was agreed however that it is difficult to compare, as States vary so much in their programs and how they address this population. Some agreed that since it took a lawsuit to help the waitlist a few years ago that may be what could occur again. It was also agreed though that the economic climate was very different then.

There were no further questions for David. He was thanked for his report and asked to keep FCC updated.

AQL REPORT: Brenda addressed the Lens project. A date or provider has not been picked yet. She will ask some of the larger providers. She gave an overview for new members regarding Lens project and identification of Natural Resources and development of resources to be able to access. Isabel looking at resources as a FCC and personal priority and would like to be part of that initiative. AQL will host the Lens program, pick a county and areas of interest, e.g., housing, transportation etc. Eventually this will be moved out to all counties. There are 6 areas with specialists who will consult, research and develop a plan for a company to set up a program. Isabel stressed that we need to leave no stone unturned, need action, not just studying the issue. She is going to seek certification as master gardener to do something for individuals as an example.

GENERAL DISCUSSION/INFORMATION: Isabel brought up Guardianship another serious issue for individuals where family may need to be able to assist the individual or have legal status to make decisions. In Marion County a Guardianship Grant is available. Person to contact is Nancy Ackerman, ph. 352-629-8800.

Isabel also shared some links for information on different issues: Guardianship Advocacy recorded message- Florida Call a Law- 850-561-1200 for menu and choices. She referred to Online Sunshine for POA Statute 709 link to find statute at www.leg.state.fl.us/statutes, forms www.uslegalforms.com/findlaw. Other general help for caregiver websites www.caringconnections and www.lotsahelpinghands.com

Stephanie referred to a “Planning Ahead” booklet, forms and guidance she uses with families. Betty Kay will bring to next meeting. Isabel told of www.lookiris.com where she took part in program offered. Discussing Guardianships further, it was learned that some are told that Guardianship from another State is good in Florida. Others questioned this, as most had experienced changes that must be made in Florida. Therefore people need to look into this in order to be sure that the guardianship will be honored in a crisis.

Discussion of developing a 501c(3) or something similar in order to develop resources. FCC could write for grants, and would need bank account to deal with monies not thru APD. This money could be used as FCC determined. The degree of responsibility necessary voiced as a concern. Decision to not pursue at this time but to identify grant opportunities and advise those who would write and obtain for the DD population. Chair asked for comments and suggestions to be brought forth.

SUPPORT PLAN 2008-2009: Stephanie presented draft of plan edited and updated. See attached for detail. Members agreed that use of specific dates might not be practical for items such as forums. It was suggested that “to be determined” be entered instead. Key activities of the plan revolve around resource identification in each County, with committees to follow up on. Recruitment activities, information and education activities addressed. Survey to be worked on with Anna for families and WSC to determine how services are viewed, and should be area specific. Motion was made by Norm to accept Support Plan with 2 changes of dates to be determined, Phyllis /Michael seconded. Motion passes by consensus. Members asked for Fact Sheet and brochures that will be brought to next meeting.

FAMILY CARE COUNCIL FLORIDA UPDATE: Update by Betty Kay of continued activities of FCCF on connecting with legislators. They are very busy getting information to individuals and families as Tiers are rolled out. She attended the Arc Conference in Daytona with the hurricane. It was a good conference with very good speakers, though some had cancelled because of the storm. Also, Stakeholders meetings have begun with looking at individual groups/agencies plans and positions for this year legislatively and with APD. Waitlist is a key issue for FCCF and desire to keep APD as stand alone agency. Tier concerns being followed up on and significance of appeals to be done within 10-day period. Members encouraged to check out the FCCF website, Area 13 has been updated and has FCC minutes on it. Resources and more can be added to site as desired by the members. Next FCCF meeting is Sept. 19 and 20. Pam Kyllonen of AHCA will attend with updates and Jim DeBeaugrine will be on conference call. Meeting will be reported on next month.

MEMBER AND VISITOR INPUT: Having joined the general discussion and questions and answers, there were no comments or discussion at this time.

ADJOURNMENT: No further business, the meeting was adjourned by the Chair at 12 noon. Next Meeting scheduled for October 13, 2008, at the APD office from 10am- 12noon.

Respectfully submitted,

Betty Kay Clements
Area 13 FCC Secretary