

FAMILY CARE STATEWIDE COUNCIL

PATTY HOUGHLAND, CHAIRPERSON

Amerisuites Orlando Airport

Orlando, Florida

February 15th, 2003

MEMBERS PRESENT:

Patty Houghland, D1 Co-Chair
Joy Frazier, D1 Member
Frank Carroll, D3 Chair
Cathy Mitchell, D4 Chair
Ann Millan, Suncoast Region 5 Co-Chair
Charm Thometz, Suncoast Region 6 Co-Chair
Dean Parker, D7 Co-Chair
Donna Rauber, D7 Co-Chair
Judy O'Halloran, D8 Chair
Mary Ellen Jones, D9 Chair
Joan Hinden, D10 Chair
Yolanda Herrera, D11-A Interim Chair
Pamela Wainwright, D13 Co-Chair

STAFF & GUESTS

Jadene Ransdell, DD – FCSC Liaison
Shelly Brantley, DD Director
Beverley DeStories, FND Guest
David Vaughn, Guest
Lois Smith, D7 Guest
Louise Parker, D7 Guest
Roger O'Halloran, D8 Guest
Linda Lee Koch, FND Guest
Betty Busbee, SAC Guest
Carolyn Shell, D7 SAC Guest
Nell Knott, D8 Guest
P.J. McKay, SAC, Guest
Roger DeShaies, Mercer
John Villegas-Grubb, Mercer

To unite the Family Care Councils in the State of Florida to represent/advocate for all persons with disabilities and their families.

I. WELCOME AND INTRODUCTIONS

Chair Patty Houghland called the Family Care Statewide Council, February meeting to order. She welcomed everyone to the meeting and asked for introductions of attendees.

II. Review of December 14th, 2002 Minutes

There was one correction to the minutes. The word "Pathway" was added on Page 2 under Charm's report of activities. Joan makes a motion to approve the minutes. Mary Ellen seconds the motion. The motion was approved by consensus.

III. Legislative Issues

Chair Houghland turned this portion of the meeting over to Dean. He shared with the group the efforts of the District Seven FCC in bringing together a group of advocates in our area for the purpose of developing a plan of major issues of importance to all of us. Once agreed upon, this plan consisting of three major issues would be used by all during the upcoming legislative session. Dean shared that Mike Ertel, a professional consultant who has experience in the disability community attended our meeting and made some excellent suggestions.

As a group, three major issues were decided upon to advocate to our legislators. They are: **(1) Greatly Minimize the Waiting List; (2) Preventative Adult Dental Services, (3) Maintain Current Funding Levels.** The Family Care Council then asked Mike if he would put together a plan of action. The legislative committee and Mike worked together and he developed a plan that we were all very impressed with and chose to follow. Dean then shared that he and Mike went to Tallahassee and met with legislative members of the Health and Human Services Appropriations committees. Dean also met Jerry Regier and Lucy Hadi. Mike is not a lobbyist. He does know the legislators, aides and knows his way around the capitol, senate & representative houses. As a result Dean was able to meet many legislators that day. He shared that once introduced to the legislators as a Family Care Council member, they were very supportive and pleased to meet him. He spoke to several legislators who advised him the best means of communication with them is face to face. They will even have their aides call them out of session to meet with us. He shared that we definitely need to meet with the legislators during the session at times in addition to DD day.

Dean asked Mike to come to the meeting today as several chairs had indicated their interest in wanting to be included in District Seven's agenda. District Seven is paying Mike a small sum for his efforts. Dean talked with Shelly Brantley this morning as he was concerned about using FCC funding dollars for the purpose of hiring a PR consultant. He shared the three issues with Shelly and she thought they were excellent and emphasized the need to have everyone advocating to the legislators on these three issues as compared to numerous issues. The legislators get confused when we approach them with a variety of issues. By supporting a platform of three issues, our efforts will be much better received.

Mike shared his Powerpoint presentation which included a handout of information. His plan includes a full-force public information campaign about the existence of the waiting list by focusing on those at the bottom of the list. The plan also includes focusing and praising legislators who support our issues. An example, if a legislator introduces Dental legislation, media coverage in support of the legislation and special attention will be given to that legislator. The plan will also include special consideration to legislators who support the maintaining of current funding levels. A suggestion would be to present to a non-freshman legislator a "Champion of Individuals with Disabilities" award. Included would be media coverage of the event. In addition, announce that an award will be given to a freshman legislator at the end of the session. Throughout the months of March, April and May produce news releases and letters to the editor supporting the maintenance of funding developmental disabilities programs. The communication plan is time-lined with activities for each month. The time line allows for maximum exposure for the FCC and its goals, while being conducted when the exposure will most effect attitudes and affect change.

Dean shared the above plan requires some money. In addition to what District Seven has committed there are a couple of other options. The statewide chairs funding dollars and possibly other district FCC's could commit some of their funding to the plan. It was shared the importance of needing to be speaking as "ONE VOICE" when advocating during this legislative session. Chair Houghland asks if the statewide council wants to partner with the efforts of this legislation and work with Mike Ertel, consultant. Does the council want to look at committing any of our statewide funding dollars for this purpose? It was asked how much money is left in our budget. Jadene is unsure but thinks about \$5,000. Chair Houghland is still asking if there is an interest in this.

Ann makes a motion that the council accepts the three goals presented by District Seven as the goals of the statewide family care council. Joan seconds the motion. Joan asks if it becomes all of the districts goals, will the consultant contact other districts for input. He has to be with the media throughout the state. The motion was approved by consensus. Dean shared he asked Mike the cost involved in doing this statewide. Mike shared \$1,500 per month through June. This would be a total of \$6,000. **Frank moves that the statewide family care council chairs agree to participate in District Seven's outreach and education endeavors contingent upon funding and authorization from the Department of Children and Families.** Ann seconds the motion. Ann suggested that if ten FCC's could each agree to \$500 that would be a total of \$5,000 then statewide council could add the additional \$1,000. It was shared that some districts just will not have the funding dollars to contribute. Judy from District eight shared that monies are available from her district but she needs the support of all district family care councils to help with establishing her council. The motion was approved by consensus. The council will need to determine the percentage of remaining funding to be used for this purpose. Once the percentage is determined, the balance needed will be requested from the district family care councils. It was decided to table determining the percentage until other items are discussed within the agenda. A motion for % can be handled by E-mail. Jadene will find out the balance in FCSC account.

IV. Committee Reports

Nominating Committee - Joan and Yolanda have nominated themselves as co-chairs. Janet Graham has agreed to be vice-chair. Frank brought to our attention that the by-laws state our officers consist of a Chairperson, Vice Chairperson and Treasurer. We can't have co-chairs as chairpersons. Frank shared the function of the nominating committee is to nominate, the function of the council is to accept or reject. Frank continued with educating the council on the proper procedures for placing names into nomination. It was determined that the nominating committee did not have a report. **Joy makes a motion asking the council to accept nominations from the floor.** Judy seconds the motion. The motion was approved by consensus. Yolanda nominates Frank. Kathy seconds the motion. Pamela nominates Ann. Several of the council members encouraged Frank to accept the nomination because of his leadership qualities and parliamentarian knowledge. Frank shared that he thinks the council could be something special. It will take a while and a lot of work. He believes that any good organization must have 3 things. They are: (1) Organization, (2) Focus and (3) a Mission. He shared that he will accept the nomination but as chairperson he will expect a lot of work from the council. Many agreed that the council is ready for this. All agreed that Patty has done a wonderful job. By choosing a permanent chairperson for an extended period of time has brought us to the next level. Jadene shared that at the state office she feels the support as liaison that she can give will be much more evident now as compared to in the past. She continued by saying she knows that in the past the FCC's have not been a priority at the state level but is very confident that will change with the new leadership in place. Judy asked that Frank share with the group a short biography of his experience. Frank shared that a lot of problems discussed among the group should be delegated to committees to solve and then report to the group. Groups such as this require a structure. He can provide this. Ann withdraws her nomination in support of Frank. Frank was asked to leave the room so a vote could be taken. Patty asks those in favor of voting Frank as Chairperson for the next year raise their hands. The vote was unanimous.

Joan as a member of the nominating committee nominates Janet Graham for the vice-chair position. From the floor, Pamela nominates Ann Millan. From the floor, Ann nominates Patty Houghland as vice chair. Frank shared the original plan was for the nominating committee to make its report at this meeting and then take a vote next meeting. Therefore, what should happen with the vice chair position is accept the nomination made by the nominating committee then next meeting additional nominations can be added from the floor. Thus the additional two nominees mentioned above are removed at this time. Janet Graham's name has been placed into nomination. A nomination for treasurer has been put on hold until next meeting as the nominating committee was unaware of this office.

Statewide Outreach Committee - The council asked the outreach committee to prepare a short presentation to be used at conferences by all district FCC's. Maryellen presented us with a hard copy of a Powerpoint presentation she has developed based on Family Care Council orientation information. Some of the information was questioned as being outdated and in need of some changes. Chair Houghland suggested that we all review and any corrections send to Maryellen via E-mail. Maryellen will make necessary corrections and present at next meeting.

Yolanda shared information regarding the purchase of a display table. She shared the costs depending on simplicity as compared to a more professional look which would run from \$948.00 to \$1142.00. The cost of a table skirt with our logo would be \$150.00. Yolanda shared she would like to research the possibility of obtaining donations for the cost of the table so the council won't have to pay for it. Judy asked who was on the state outreach committee. The committee consists of Maryellen, Yolanda and Jadene. Also what is the purpose of the state outreach committee? It's to provide outreach across the state to the whole population. The outreach material would be available for use by all Family Care Councils. Whoever would want to borrow it would just be responsible for the cost of shipping to their location.

Web Site Committee - Ann shared the committee has met twice via conference call since the last meeting. She provided each chair with a summary information sheet. She wanted to share with all how beneficial the conference calls have been. It would be nice to pursue this type of communication in the future between meeting dates. She shared the letters to not-for-profit and state agencies have been mailed. She has received support from several including FND, CAFÉ, ARC, FDDC and the Advocacy Center. Yolanda is translating the FCC definition and sight headings to Spanish. The Florida Map has been moved to the home page. It's faster and better access to the district web pages. Additional information sites to consider as part of the redesign are: Transition, Self-Determination, School Resource, Frequently Asked Questions, Consumer, Statewide Bulletins/e-mails of interest, newsletters from other organizations. ARC Florida has requested their newsletter be posted on our site. We would like software that would allow consumers access to the website via voice activation. Dave Vaughn has researched and been unable to find another website that offers voice activation to the disability community. Diane has the software. We would need to purchase the upgrade at approximately \$1200 in total. **Ann makes a motion asking for \$1200 to purchase the Macromedia Authorware Software program to make our website interactive.** Maryellen seconds the motion. Discussion followed to determine if we have the funds to purchase the software as we are considering other projects that require funding dollars. Donna asked Ann if she thought the software could be up and running by end of fiscal year. If not, possibly we could hold off purchasing until July, 2003.

It was decided to table this for now. Jadene will try to set up a conference call with all members once she is able to determine the amount of funding the council has left. All agreed this was a good idea. Ann makes a motion to rescind her first motion. Frank seconds the motion. The motion was approved by consensus. **Ann makes a motion asking the FCSC to commit to purchasing the Macromedia Authorware Software upgrade pending fund availability.** Maryellen seconds the motion. The motion was approved by consensus.

Ann shared with the group that there is a \$500,000 line item in the Governors budget for families and CAFÉ has written a business plan for that \$500,000 which has not gone out for bid. The Business plan was dated August, 2002. She read the plan and was very concerned about it because it's just stability. She thinks for \$500,000 we should see some vision of what can be done. Yolanda shared that her understanding is that Lori Fahey is taking a position where she would be enhancing, educating and carry on the tradition that the FCC's are doing at a very high salary. No disrespect to Lori as she had done a wonderful job with CAFÉ. This is a lot of money to be spending on something that Family Care Councils are currently doing with minimal funding. Pamela shared that she has been invited to work along with them as a grant manager and director of research. It is her understanding that it is not going to be anything duplicated. She suggests that we have Lori discuss this with us. Ann's major concern is this should go out for bid. It would be an incredible way of enhancing and improving our website. It would also allow for a statewide newsletter. There are many visionary ways the Family Care Councils could use this amount of money. Frank asks if the budget item listed is discretionary dollars. Jadene shared they could not find the \$500,000 anywhere. It's not showing up as a specific item titled family information network. Frank wondered if we ask the governor's budget office where the money is would they tell us. Jadene indicated we could ask. There are certain categories in the budget that are discretionary under certain headings. If that be the case it's discretionary and they can spend it anyway they want. If it's for a specified goal purpose they shouldn't be able to fund it without a contract. It's in the new budget which hasn't been appropriated yet. Chair Houghland shared she has read the plan and it's exactly what we as Family Care Councils have been doing for years. Over half of the \$500,000 is designated salaries/benefits. Remember, we have a 10,000 person wait list. These dollars have nothing to do with the CAFÉ conference. Jadene gave an explanation as to how CAFÉ conference originated. Frank recommends that we make a phone call and ask about the \$500,000 listed in the E-budget priorities under Developmental Disabilities. Find out what it's for, if FCC is entitled to any of it, what are the perimeters. Beverley shared that someone has made a presentation before the appropriations committee this past week for the \$500,000. Chair Houghland has delegated Frank to make the phone call. We can discuss the outcome during the upcoming conference call.

Statewide brochure - Jadene shared that she had offered to take the lead on the development of the brochure. Things have been so hectic she has not had the time to work on it. Jadene gives Ann a huge thank you for putting together a very nice first draft of a statewide brochure. It will need to be edited and pictures added.

Adopt-a-Policymaker - Chair Houghland shared that FND has asked the statewide council to support the project. They want to use the FCC logo and there is a minimal amount of clerical work involved. She asks that each chair read the letter and we can discuss during the conference call.

Conference Call - Chair Houghland will E-mail the chairs with the time and phone number to call. Please pick one line per district. It was decided the conference call will be Thursday, late afternoon. The following will be discussed during the call:

1. Amount remaining in FCSC budget
2. Percent of budget to commit to outreach consultant
3. Possible purchase of Macromedia Authorware software
4. Adopt a Policymaker
5. Governor's budget recommendation of \$500,000 for family information

Chair Houghland included in our package copies of Chapter 419 which includes the 1000 ft. rule and SB178 introduced by Anna Cowin which states no group home within 500 ft. of a single family dwelling.

Frank has agreed to create a Policy and Procedures manual. On the committee with Frank will be Beverley and Cathy. Frank asked if we had any rules in place at this time. If so, it's unknown. Donna shared that she is in the process of tracking down all the minutes since the group began. She is missing May, 2000 and December 2000. Once received, she will combine into a folder as a history of our council. Jadene asks to have a copy once completed. She will then make copies plus keep a copy at the state office. Once past minutes have been reviewed, it may be determined we have established some rules which should be incorporated into the policy and procedures manual.

Our guests from SAC asked if we could each introduce ourselves and include what district we represent. Ann asked for our guests to introduce themselves.

The next meeting will be May 10th, 2003.

V. ADJOURNMENT

With no further business to come before the council, Chair Houghland officially adjourned the meeting at 3:45.

RESPECTFULLY SUBMITTED,

DONNA RAUBER

VI. Guest Presentation

Roger DeShaies, Mercer

Roger shared with the group the latest version of the assessment tool. The version is fully automated, all calculations built into the program. There will be three hard copy versions, English, Spanish and Asian Creole. The automated version is currently using Microsoft Access software. It will be web friendly. It should take no more than 20 minutes to complete the tool if you know the person. There is some controversy about the tool being that a person's disability is not taken into consideration. The tool is created to look at the supports and needs of a person rather than the disability. What matters is the staff associated intensity needed for the person to live as normal a quality of life as possible. He shared they will be testing the program to be sure it's as accurate as an indicator as it can be. It does still need some fine tuning. The programming, logic and all the tools will be left with the DD dept. so changes can be made without having to bring in a consultant. Roger shared that Arizona (the most recent actual experience) has many of the same similarities as Florida. In Arizona 65% of people being supported live with parents. The average age of the caregiver was 62. From anticipation of planning that was very significant information. What they started to see was as parental caregivers got older, the number of hours of services for in-home support increased, not because the acuity of the individual changed but because the caregiver's ability to care started to diminish. This resulted in the escalation of costs because of the increased number of units of care. They spent years educating the legislators that what was going on wasn't the change in acuity but the change in the caregiver. The same dynamics are seen in Florida. A major difference between Arizona and Florida was that when he left they had about 22,000 people being served. Of those only 150 were in an ICF. They were out of the ICF market. Therefore the majority of the community budget was related to community services. Medicaid is the prime provider of a lot of services and pays a lot of bills. Medicaid is more flexible than what we have now. The bad news is it won't do everything you want it to do. The bottom line of Medicaid is it's a health insurance program for people who are poor.

Roger spent some time explaining and guiding us through the various parts of the assessment tool. He was asked if there was a protection built into the tool to prevent anyone from tapering with someone's assessment tool. The support coordinator will have access to only his/her individual client caseload. The district will have access to all tools. He was asked if the parent could access his child's tool from his home computer. The answer is yes if you have the software and the password. If a change is made to the tool, it will tell who and when the change was made. He was asked if the program builds an historical database. Yes it does, whenever you make an entry into the tool, it keeps it as a record. Roger proceeded to give some examples by entering data into the program which then showed how dollars are calculated. What the examples proved was a significant difference between the costs of supports in the family home compared to the costs associated with living in a group home. He was asked about the difference between the group home budget and the supported living budget. Right now, the supported living budget and living at home budgets are identical. What they are trying to do is pull enough costs out of your experience in order to calculate what the supported living costs are. They are having some problems with this but are still working on it. He was asked about SSI monies. The tool is only designed to allocate the home and community based waiver resources. Anything on top of that is not considered in this tool. An individual living in a group home who decides to

move into an apartment or supported living program, their group home budget doesn't follow them so then the individual must be re-assessed, correct. That is correct. He was asked if the money follows a person if they move from one group home in one part of the state to another part of the state. What might change would be a cost of living adjustment. The department will need to determine what happens to fixed costs associated with one group home compared to another. One concern was shared that what could be scary is that Medicaid, the state or feds could come in and take the same approach as with ICF's that group homes are too expensive, what % of clients can you get out a year, we expect you to put so many into supported living when in fact the consumers are not (in the families mind) potential for supported living. As a community this could be very dangerous. Roger shared that expectations have changed. Over time the system of services has changed. Institutional settings used to be the approach. Then it was decided to move individuals into smaller settings. Nothing much was changed except for making the living arrangement smaller. Now as people are moving out of the school system and have had opportunities to experience things that are very different, what in fact is happening is that an evolution of expectation is changing. As they are leaving school they are not looking at sheltered environments whether it be work settings or group settings they are looking at individualized settings. The challenge to all is that you have a reality, a growing wave expecting something that needs to be accommodated. But you also have an established "institutionalized" structure where people expect and are comfortable with group home settings, you have to manage them both until one dominates the other. Over time the new wave will dominate and what the systems are trying to do is accommodate, support the existing structure but also start accommodating the new structure coming in. What he thinks we will see in five years the management group home setting will diminish. The market will start redefining what the provider network offers. Several in the audience disagreed with this theory as individuals with developmental disabilities age much sooner. You may think group homes are disappearing but what is happening is people who are aging in the disability community are going into group homes because they need additional healthcare needs. To say group homes are disappearing is unrealistic. Roger clarifies he agrees there will still be group homes, just be far fewer. The option of group homes should always be a choice especially for the older adult individuals who have lived their entire lives at home with parents. In the minds of legislators we can't be saying you can save a lot of money by doing away with group homes. Roger continued to explain the remaining parts of the assessment tool.