

FAMILY CARE STATEWIDE COUNCIL

PATTY HOUGHLAND, CHAIRPERSON

Amerisuites Orlando Airport
Orlando, Florida
September 14th, 2002

MEMBERS PRESENT:

Patty Houghland, D1 Co-Chair
Joy Frazier, D1 Member
Janet Graham, D2 Chair
Melinda Morrison, D3 Substitute
Cathy Mitchell, D4 Chair
Ann Millan, Suncoast Region 5 Co-Chair
Dean Parker, D7 Co-Chair
Donna Rauber, D7 Co-Chair
Mary Ellen Jones, D9 Chair
Joan Hinden, D10 Chair
Yolanda Herrera, D11-A Interim Chair
Kathy Rafanan, D12 Co-Chair
Pamela Wainwright, D13 Chair
Diane Ciccarelli, D15 Chair

STAFF & GUESTS

Jadene Ransdell, DD – FCSC Liaison
Myrna Winter, Guest
Louise Parker, D7 Guest
Judy O-Halloran, D8 Guest
Beverley DeStories, FND Guest
Norm Davis, Mercer
Liesl Ramos, State DD Program Office

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, September meeting to order. She welcomed everyone to the meeting and asked for introductions of attendees.

II. Review of June 8th, 2002 Minutes

Correction to June minutes: Beverley DeStories is attending as a representative of Family Network on Disabilities not Suncoast Region. A motion was made to approve the minutes with above correction. A motion was made to second the motion. Let the record reflect that the minutes have been approved. The question was asked if the minutes could be distributed during the first 30 days after the meeting rather than the last 30 days before the next quarterly meeting. Donna advised she would do this.

III: Solution Forum Issues

There was much discussion between the chairs regarding the selection by FDDC of the new Solutions Forum employee. At issue was the hiring procedure instituted by the FDDC which seemed to not follow the original guidelines established by them. Also at issue were conflicting comments made at the statewide conference by the executive director to various FCC members. This showed a lack of professionalism by that individual. It was supported by all chairs that the solutions position would have been better served by an FCC parent. A contributing factor that should have been taken into consideration was each FCC candidate had many years experience advocating for persons with developmental disabilities. They have the knowledge whereby the candidate hired does not have the experience and is not a parent of an individual with developmental disabilities. It was discussed that FCSC should write a letter. **Ann makes a motion to write a letter to Joe Krieger at FDDC.** Pamela seconds the motion. The motion was approved by consensus. Pamela volunteered to write the first draft

and submit to chair Houghland. Janet asks if we couldn't use some of our funding dollars to create and print some FCSC stationery. Discussion followed that it would be nice to have each district chairs name included on the stationery. Ann agreed to create FCSC stationery.

IV. Folders of Information

Chair Houghland asked to take some time, in case unable to get to later, to share with the chairs the following information folders:

1. A hard copy presentation by Bobby Silverstein which was put on a CD to train family or self advocates on "how to be an effective advocate". Included in this documentation are some items she especially wanted to share:
 - a. Under New Paradigm, Items 3 – New core precept – disability is a natural part of the human experience that in no way diminishes a person's right to fully participate in all aspects of American life.
 - b. Item 4 – Goal of public policy is to determine how society can "fix" the environment to provide effective and meaningful opportunities.
 - c. Top Ten Tips for Disability Policy Change Agents on How to Influence Policy Makers and the Policy Making Process.
 - d. Guidelines for Meeting with a Policy Maker.
 - e. Principled Negotiation: A Tool for Getting to Yes

She is sharing all of these tools so that we can share with our Family Care Councils.

2. The Florida Department of Education. Subject: Changes in the School Code Regarding Student Progression. This is state policy then each district has its own pupil progression plans.
3. A sheet describing 4 videos that are available for sale pertaining to Self-Determination. The Videos are titled "Whose Decision is it Anyway". One video per subject: (1) Young Adults Working on Self-Determination; (2) Parents Prompting Self-Determination; (3) Educators Encouraging Self-Determination; and (4) Services Providers Supporting Self-Determination.
4. A folder which contains a copy of Florida Statute 393, Developmental Disabilities which includes the "Bill of Rights for All Persons with Developmental Disabilities" and "Client Rights".
5. A CD titled "Fight for your Rights: Take a stand against violence" issued by the U.S. Department of Justice.

V. By-Laws

It was decided to start at the beginning, take each Article, review, and make changes. Much discussion followed. Donna volunteered to make all changes to current by-laws document and submit to Chair Houghland for review.

VI. New Business

Chair Houghland shared that we need to decide on what to do about the December meeting. December is a very busy time of the year. We need feedback and suggestions for December meeting. Donna made the suggestion that we consider moving our meetings to the months of January, April, July and October thus eliminating the problem altogether with holidays. Jadene advised this would not be good because of the way the budget works with year end being June of each year. We would not have the funding in place in time to obtain voting from each council for approval of portion of funding to remain in central office for future year and unable to create purchase orders in time for July meeting. Ann suggested that we move just the December meeting to January as we need to plan for legislative session. It was decided to meet on December 7th. As Donna is not available to take minutes that day, do we have a volunteer? Jadene suggested she could tape the meeting then Donna could transcribe from the tapes.

Dean wants to make a motion that the Family Care Statewide Council purchase a recording device to be used at the quarterly meetings. Ann seconds the motion. Motion was approved by consensus. Jadene will be responsible for determining how to do this and advise on how to purchase. It needs to include a microphone extension.

VII. Old Business

Diane asked to continue discussion from last quarterly meeting regarding the **respite and family care subsidy expenditures**. She read the following Florida Statute 393.503 which states:

“The Department of Children and Family Services shall determine the amount of expenditures per fiscal year for the respite and family care subsidy to families and individuals with developmental disabilities living in their own homes. The information shall be made available to others requesting the information. The Family Care Councils shall review the expenditures and make recommendations to the Health and Human Services Board with respect to any new funds that are made available for family care.”

She wanted to share that this is not being done. We are not receiving this information from the department. The subsidies do exist although most have been eliminated as they were being funded by General Revenue dollars. The question was asked “What about the \$5 million in current proviso language designated for respite?” Diane is asking that we as a statewide council inquire as to exactly how much money is there and specifically how much per district. The question was asked “if there is \$5 million allocated in proviso language for respite, doesn’t that mean those dollars cannot be used for any other purpose?” If it’s not there anymore what happened to it? Many districts have families in need of nothing more than respite. These families may or may not be on the waiting list for services. Who knows how long before they receive respite they so desperately need. Chair Houghland asked if we need someone to draft a letter to Susan asking these specific questions. Ann volunteered to write the draft and submit to Chair Houghland for her review and subsequent review from all chairs.

FCC Statewide Conference

Mary Ellen asked that each chair ask their district members to approve \$1,000 each for next year’s Statewide Family Care Conference to be held in Palm Beach County. The question was asked if we had approved having a statewide conference next year. Ann made reference to the location as we have had conferences in South and Central Florida but none in northern Florida. Cathy indicated that she had volunteered before to take on the responsibility of creating a statewide conference next year in District 4 (North Florida). Janet shared that if the conference is going to become a yearly event and sponsored by the statewide council with district monies going towards this annually and the council is going to be depending on these monies as a funding source we need to establish a standing committee of the council who will report directly to the chair and submit quarterly progress reports. Ann shared that she feels annually is too often as it looks like we are competing with CAFÉ. Every other year would be plenty. It’s a huge task to prepare for a conference. Joan shared that we don’t have to make it an elaborate event each year but it does offer a chance for families to get together. Several chairs indicated they would rather have forums and use monies in their own districts. Diane asked if we could get an accounting of how the \$12,000 was spent for the statewide conference in Tampa. Chair Houghland suggested we could ask Charm for a breakdown of how the monies were used. She would ask her to submit to all chairs before the December meeting. Judy suggested we should have a summary of the conference which would include if goals were achieved, any recommendations that would help with future conferences and any feedback Charm would like to share. Then we can have a discussion at the December meeting regarding when, where and how often to commit to an annual statewide conference.

Website Update

Chair Houghland asked Ann if she was able to talk to Jadene about setting up a conference call with her website committee. **Ann would like to make a motion that the FCSC sponsor the cost up to \$500 for payment of telephone conference calls with her website committee to work on website.** Kathy seconds the motion. The motion was approved by consensus. Joan shared that the most important information to include on the website is the legislative issues. We need to establish our legislative priorities. Ann shared that we need to spend time at our December quarterly meeting preparing for the upcoming legislative session.

VIII. FCSC LIAISON UPDATE

Jadene shared the department is in the process of developing curriculum for training direct support professionals and she has asked for photographs of persons with disabilities with and doing things with their caregivers. She would like you to E-mail the photographs with permission to use them. If unable to E-mail you can send them to her with name, address on back so she can return them after they have been scanned. She needs them now. The curriculum will be in a web based format. It will be in an instructor like classroom type format.

She has received several calls regarding the planning guide titled “Community Development of Before and After Care for Children and Youth with Disabilities” Each chair has received a guide and she would like for us to share with her anything we are doing with this project.

Also, let her know if you have any issues you would like covered in the E-Bulletin. Joan shared how much she liked the question/answer portion of the bulletin. Those are nice to include in district newsletters.

IX. MISCELLANEOUS

Chair Houghland passed to each chair the first newsletter created by the Self-Determination Movement. They are working on sponsoring another self-determination conference.

She also brought the four self-determination videos titled “Whose Decision is it Anyway”. Since we did not have time to view them during the meeting she gave each tape to a chair who was interested in one of the particular subjects.

Diane asked about the Dental Grant Workgroup. To recap we are still looking for an FCC member to participate on this workgroup. Janet had indicated she thought she knew of a member who would be interested. Evidently that person is already part of the workgroup. Jadene brought us up to date that the grant was submitted and Florida was not selected as one of the pilot states.

Judy asked what is the best way of getting information to and from each of the chairs? Jadene advised she would update the current contact information which includes all chair information.

X. ADJOURNMENT

With no further business to come before the council, Chair Houghland adjourned the meeting at 4:30.

REPECTFULLY SUBMITTED,

DONNA RAUBER

GUEST PRESENTATIONS:

Norm Davis, State Director, Mercer

Mercer is part of Marsh and McLennan Companies which is the world's largest insurance underwriter and Putnam brokerage house. Mercer previously until early 1990's focused on benefits and pension management. In the early 1990's Medicaid state agencies began asking Mercer to help them set their rates. They are a state actuary for 27 states. Mr. Davis joined Mercer in 1998 and they began a Developmental Disabilities practice. Mercer actuaries have a contract with the state DD office to help with our redesign. He indicated that our state has made so much progress with the system redesign that Mercer has become the general contractor. Mercer is responsible for creating two parts of the system redesign. First being an individual needs assessment tool and the second is a standard rate schedule. He shared with us that the greatest predictor of cost is (1) family supports; (2) transition phases and (3) aging parents. He was asked if they were working with the redesign committee or with DD staff. The answer is both. They meet weekly with DD staff. They meet every 2 weeks with redesign committee. The timeframe is that most everything must be done by October 31st, everyone needs to be trained by year end and all must be tested and ready for use by July, 2003. Mr. Davis indicated the direction of the redesign is very solid. As a consultant, they will build rates that will allow families to hire the people we want to hire, they will define the services that allow families to purchase the services they want to purchase, they will put the service levels so that families get as much as they want. They can do all this but the main drawback is they can't balance the budget. They will present the case proving these are all the pressures that are very real and needed, here is the price tag. He was asked if when building this "wish list" is it being done based on a reference budget of some type. Does he know what our budget is? The answer is "yes". It is being built based on current budget or best case? He answered it's based on best case and that is what the department asked them to do. Their job is to give the department tools to balance the budget not to balance the budget. Another interpretation of the process is: When a needs assessment tool is applied to a person it will give that person a "pot of money". Then when the family or supports that person has decides how they want to spend the "pot of money", that's where the flexibility comes in. How the money gets awarded is based upon a published rate. The subject of the term "medical necessity" was brought up because a lot of the services our population require have more to do with maintaining the individual's health and quality of life not necessarily medical needs. The term is inappropriate for the developmentally disabled population. The more appropriate term would be "developmental necessity" which would be less restrictive and provide the necessary kind of supports needed. Mr. Davis shared that in the research they have done mobility, behavior and health were the three drivers of cost. These required the most staff assistance. He shared they wanted to create some focus groups with families throughout the state. He was asked to include some families who are on the "wait list". Mr. Davis shared that basically what they are doing will have no effect on the "wait list" unfortunately. He was asked upon how rates will be defined. It will be based on geographic location. It will be done by metropolitan service area (MSA). They use housing cost, cost of living scale, labor statistics and US census data sources. Also, they look at and predict costs on a long term basis. What will costs be 5, 10, 20 years from now. These predicted costs will then be provided to DD program office so they can estimate and advise legislators in advance as to what funding is needed in years to come. People stay in supports for disabilities longer. The legislators tend to look at long term care as related to aging. The length of stay for people who are elderly is about 7 years, for persons with disabilities it's 45 years nationally. He was asked about transitioning as the individual ages. How easy will it be for the family to change services or get increased rates once the needs change? They will set aside the monies for these transitional changes. They cannot predict the emergency situations that might occur. They have been asked to build emergency conditions into the plan. Unpredicted costs will more than likely need to be requested. He was asked about numbers being put together for the state, are they looking into the people who are not on any list for services? The state doesn't have a realistic figure at this point of individuals in need. The answer is yes through a scientific percentage based on population

they try and predict the individuals that are unaware services are available. Another question pertains to our middle-aged DD population who are showing signs of pre-mature physical aging which will require more costly medical needs in the future. Will the plan take this into consideration? The answer is yes. As indicated previously one of the transition packages pertains to the aging population which they average at 45 years of age as their parents can be considered 20 years older. With the DD population you really have to predict long term funding to present to the legislators rather than what costs will be for the next 2 years.

Mercer has budgeted three state focus groups. They want to talk to people with supports and those who have not received supports. Maybe our FCC's could help form these focus groups. Mercer has timelines to follow which have been delegated by the legislature. They really need to talk with families during October. Mr. Davis is going to propose that the FCSC help with establishing three focus groups in the middle of October. Chair Houghland asked to know ASAP dates of availability. The project group will advise of dates and contact Jadene.

Liesl Ramos, Operations & Mgmt. Consultant II, State Developmental Disabilities Program

Liesl's purpose is to explain to us the prior service authorization process which is currently being administered by Maximus. The contract is in accordance with the 2001 legislative appropriations act. It was mandated via proviso language by the legislature. The purpose is to ensure services are medically necessary, ensure identified services meet individual's needs and ensure services are delivered at the appropriate intensity, frequency and duration. The provider (Maximus) has two functions, program design and program implementation. Liesl provided each chair with a power point documentation which explains what was accomplished within program design and implementation. The documentation also includes staffing requirements. Of those on staff, the nurses, CBA's and QMRP's are full time staff. The Physicians and Dentists are consultants. All of them have experience in Developmental Disabilities. Liesl then shared the review process which is also in the documentation she provided. She was asked about how the process will continue after the redesign. She advised it would have to be changed. She provided us with a copy of the Selection Criteria plus all forms used in the process. In reviewing the cost plan if one service meets selection criteria but other services do not, Maximus will only review the one service and if they find it not to be medically necessary, they will issue a denial, due process letter for just that service. The district will review the rest of the services which do not meet selection criteria. If it's determined that any of those services meet selection criteria and are found to not be medically necessary, a separate denial, due process letter is issued for that service on the same cost plan. It was asked what documentation is included as back-up to PSA request. Liesl shared that Form 1 includes a list of all items needed as backup information. Liesl proceeded to explain what the additional forms 2 through 6 represent. Liesl also explained the timelines involved in the process which are included in the documentation we received. She then shared the current status as of August 31, 2002 which includes a total of 6,159 requests. The contract with Maximus expires December 31st. She is currently writing the Request for Proposals which she is hoping to release by the end of September. Hopefully by end of November they will be able to award a contract, write and have executed by January 1st, 2003. She was asked how many denials go to hearings. Liesl didn't have that information with her but advised she would forward it on to us. Diane asked for some total dollar figures that represent the 646 denials, terminations or reductions. The total contract was \$2.5 million. How much is the savings? Liesl advised she needed to research her numbers and would forward information to us via E-mail. These numbers represent only what Maximus has denied since the beginning of the contract. All chairs agreed it was important to get documentation which shows a comparison of what has been saved vs. total amount of contract. Diane shared that we need to write a letter with this information so that we can advocate to ensure that the funds aren't needlessly spent. Chair Houghland shared this was a good plan coming from the statewide council as we have a united voice that should be powerful enough but not yet that recognizable with our legislators. What will be more noticeable is this information coming from individuals as well because it's the individuals doing the voting. So as we develop our thoughts at the statewide council we need to pass these thoughts on to our district family

care councils and individuals within the community so that we are all advocating the same message to our legislators. Diane shared that in their district they invite the local state representatives and state senators to their meeting so that their council can sell themselves as a resource. They develop a relationship with them so that when they receive calls pertaining to DD issues they call FCC asking for help in locating whatever the support/need may be. In turn when FCC has an issue they want them to listen to, they are more responsive. Pamela asks to nominate Diane to research the issue and write a letter. Diane agreed to do this once she receives the cost figures from Liesl.