

FAMILY CARE STATEWIDE COUNCIL

PATTY HOUGHLAND, CHAIRPERSON

**Amerisuites Orlando Airport
Orlando, Florida
May 10th, 2003**

MEMBERS PRESENT:

Patty Houghland, Chairperson
Janet Graham, D2 Chair
Frank Carroll, D3 Chair
Ann Millan, Suncoast Region 5 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
Diane Ciccarelli, D15 Chair

STAFF & GUESTS

Jadene Ransdell, DD – FCSC Liaison
Beverley DeStories, FND Guest
David Vaughn, Suncoast Guest
Stephanie Shepherd, D2 Guest
Pat Hawk, D13 Guest
Roger O'Halloran, D8 Guest
Linda Davis, Maximus
Karen Rogers, D7 Guest
Linda Herring, D7 Guest
Tracy Rackensperger, D7 Guest
Rosella Jones, D7 Guest

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

II. GUEST PRESENTATION FROM MAXIMUS – LINDA DAVIS

Linda began with a brief description of Maximus, a national company whose business is with state, federal and local government. They perform a variety of duties in the field of developmental disability and human services. Linda then shared a brief description of her experience. She has an extensive background in developmental disabilities. She has been with Maximus since late 2001. She provided us with a hard copy of her PowerPoint presentation. She will be happy to answer questions during her presentation. The presentation included an overview, legislative directive, contract requirements, deliverables, key elements of PSA review process, current selection criteria, medical necessity conditions, services limitations, other funding sources, general procedures, district review, PSA unit review, due process procedures, reconsiderations, and activities report. Many questions were asked throughout the presentation. As each chair has a copy of the presentation, for the purpose of the minutes, questions and answers will be the primary focus.

Question: Diane asked about previously requesting documentation to support accountability dollar-wise for Maximus service. To date, she has not seen any. Linda advised she would address that later in the presentation. She can share exactly what they do as far as accountability and the types of reports they provide to the state.

She felt it important to emphasize that the Maximus role is based solely on the rules and regulations the state asked them to implement. The only guideline they use is the Medicaid-Waiver handbook.

Question: The perception in the Miami area of the Maximus staff is they don't know or understand the needs of the developmental disability population. Could you address this?

The contract requires six professional reviewers, one doctor and one dentist. Linda shared they have a lot more than that. The workload has been such they needed additional staff to do the quality work

expected of them. She reviewed who the members of the staff are and their experience with developmental disabilities. The staff are all persons hired within the state of Florida.

Question: Is the denial process a way for the department to save money as the majority of families aren't familiar with the appeal process and consequently just give up rather than fighting the system? The denial determination reduction rate percentage (no matter the cost) runs at 11%. Over 70% of everything that comes through their office is approved. They do have a very simple process for reconsideration within the agency.

Linda shared that a lot of the current selection criteria will change once the redesign and new rate structure take place. She thinks that it will change what comes to them as much is based on the dollar amount now which is a rate issue.

Question: Would you please review the medical necessity conditions? The Medicaid and Medicaid Waiver programs are required to meet a medical necessity criteria before the state can pay for them. That is a federal requirement. She then explained the conditions which are part of the handout.

Linda stressed the importance of good documentation. Support coordinators (as they work for you) should be expected to document a clear representation of your family and child's needs.

Linda shared that waiver support coordinators need a lot of tools. They need to thoroughly understand the handbook; they need to know what Medicaid State plan will pay for and how to help families find the billing codes for that. They need to understand what the school systems responsibilities are. Just because a child turns 18 and chooses to exit the public school with a special diploma, that does not relieve the school system from continuing to provide services like pre-vocational, transitional services and they can even fund adult day training. The waiver cannot pay for ADT programs for individuals under the age of 22. Families are under the impression that once the child receives the special diploma the school system has no further obligations. That is not true and school systems will let families believe that. Another thing schools don't do and families don't know is that they should be planning for transitioning the child at the age of 14.

Shelly Brantley joins the group via conference call. Patty asks if Shelly knows where we stand on the family involvement dollars (\$500,000). Shelly first shared that Senate Bill 2568 passed without any of the redesign language. She advised that both Senate and House budgets didn't include the \$500,000. If it doesn't get picked up in the special session it could be picked up in the conference at the end of the session. If the dept. does get the dollars they will go to the statewide advocacy center. Because the DDP doesn't have control over that she can't tell us for certain where the monies would be spent or distributed. She is fairly confident that if this goes through a portion of those dollars would go to the Family Care Councils. At this point it looks like about \$150,000. This is not for certain but they are hoping to secure those dollars for a number of community development type activities with FCC's. Patty asked if these dollars were in addition to what we normally receive. The answer is yes. She indicated there might be an advantage to having these dollars in SAC as it could help expedite the ability for FCC's to access those dollars.

Back to Maximus - Linda shared information regarding the Reconsideration process which is an internal process they built into the program which gives the family and consumer an opportunity to present more information. She emphasized this does not protect your due process rights. The only thing that can protect those is if you request a fair hearing. She advises that families request both. To request a fair hearing doesn't mean you have to go to one because if they receive a reconsideration and the service is then approved, you don't need to follow through with due process.

Linda then shared an activities report. The information is from November, 2001 through April, 2003 and lists the number of reviews received; approvals; terminations, denials, reductions; Form #2's and number closed. She was asked what is the percentage related to high cost plans? Shelly advised there

have been rapid increases this year in utilization despite the fact they aren't bringing in many new people. On average there is about 15% of the population who on average have costs that exceed \$25,000 a year. Of those there are about 5% whose costs exceed the costs of the average ICF/DD. Probably less than 10% of the total population they serve would fall into any of the high cost categories.

Diane questions the Maximus approach on evaluating the combinations of services. This is a problem in her district as supports are being disallowed because the effect appears to be a duplication of supports. An example being a consumer attends an ADT program during the day and NRRS on nights and weekends as a means of reinforcements. As a means of transitioning, if you have a goal in one place you should continue that goal in another. That's how the goal is reinforced in different environments. Diane shares she is finding in her district that 2 different providers working towards the same goal for continuity and reinforcement purposes are being turned down. Shelly advised that when looking at costs and they put the freeze on the rates they noticed that utilization started to climb at unanticipated rates. One of the things they found was they were not only paying for ADT and Res-Hab but then NRRS on nights and weekends. They are used to providing NRRS and ADT in combination but with limits on number of hours and they aren't going to pay for it on the weekends. It's not that they don't support meaningful day activities but there are just limitations on how many hours a week they can afford to pay for them. Meaningful day activities were really intended for during the week not nights and weekends. Diane asked about companion services. Even if it's a companion they need to be working towards the same goals. Shelly agreed she could see instances where a companion could be used on nights and weekends. She indicated that maybe they needed to focus more on the service planning process to make sure the providers are all working towards the same goal and maximizing the resources they have available. Shelly shared we must be mindful of the fact we have over 10,000 persons waiting for services. Our utilization rates have climbed significantly over the past 2 years and the dept. has brought on less than 1000 people. There are limits to what the dept. can pay for and limits to what our federal partners (Medicaid and Medicare) are willing to pay. It's better for us to approach it proactively than be in situations that some other states are in where they have recouped dollars from the state. The federal government pays 58% of everything dollar we spend so if anything were recouped it would be a significant loss to our program.

Linda shared that of the total of number of reviews received on an average of 35% of the time Maximus needs to request more information. The result being an additional round of paperwork for Maximus employees, it holds everything up on the other end and people tend to blame Maximus. When documentation isn't there or the support plan isn't adequate they are required to go through the process of asking for whatever is missing. They really hope to address this through educating the family and support coordinators. Patty added as out-going chair it is the chair's responsibility to disseminate this information to our families and no one else is doing it right now. She suggests that each district FCC have a meeting devoted to educating our families on the process of learning about their cost plan and the importance of having accurate information because they don't have this information available to them. The only people that are going to do this are Family Care Councils who will have to walk them through the process. Linda shared she would be willing to help us with planning an agenda and providing the information we should have to present to families. Patty has her contact information.

Linda continued on with the statistics generated from the Reconsiderations (Informal Internal Process) to date report and the Fair Hearing report which is included in the hard copy each chair received.

Questions to Shelly: What is your vision for the DD program? She is very interested in moving forward with the complete redesign which she hopes to finish by end of the summer. She wants the individual with a disability to have more choice and control over the services that they receive. She also wants providers to offer things that people want to purchase. That is what is so important about people

receiving their own individual budgets. She shared they look at the outcomes coming from Delmarva and she's concerned the dept. is spending all this money and yet there are a lot of people who aren't happy with their outcomes. We need to make sure that people have a right to self-determination and they choose the services they want and providers are held accountable for the outcomes that these individuals are trying to achieve. Ultimately her goal, the depts. goal as a program is to support their mission for community integration. The two areas she wants to focus on, as they have a lot of room for improvement, are to try to insure that more people they serve on the waiver have greater opportunities for integrated employment and integrated living arrangements. She feels that many people living in group homes could live in supported living arrangements and have a lot more independence and choice over their lives and their goals. In addition, one of the areas she really wants to work together with the FCC's on is community development. There are many resources and ways that we can build on our local communities that are not being done now. It's possible we can spread out our state dollars by tapping into resources in the community that aren't necessarily paid for by the waiver. By working together with local schools and local voc-rehab centers and really trying to establish some relationships there to have better integration. She wants the department to work very closely with the FCC's because she sees that as being an area where they should be the leader. The department would like to provide support for the FCC's which is why they hope to secure some additional dollars to help with this effort. Linda wanted to share the need for after-school resources especially during the adolescent years when after school programs that will take children with disabilities until they become ineligible because of their age. There has never been a concentrated effort to develop these resources through the provider community. She hopes someone will put this on their agenda. Judy wanted to share that it's very important that families with young children understand at an early age that you can't always depend on government. Self-determination needs to be taught at a young age. She is glad to see the concept of community development being considered. Pamela shared it had been discussed among the chairs at one time about setting up a foundation that would allow FCC's to receive more funding for the purpose of not being so dependent on the waiver. It was discussed but fell by the wayside. Shelly shared that it was something to continue to look at possibly if we could secure some of the dollars this year that could help start a foundation to look at some other avenues. FCC's might consider using dollars to pay for grant writers. Both Shelly and Linda suggested the FCC's work with the DD council. Pamela shared their district will be conducting a seminar with the help of instructors from Rollins College on grant writing in June. She will send out an E-mail as all chairs are encouraged to attend. The price will be \$25.00 for a two-day session. Joan would like to see the chairs work towards creating a video showing individuals with disabilities out working in jobs within the community. The video could be distributed to chamber of commerce all over the state.

Question: What is the timeline of the redesign? Shelly advised they have provided ACHA with revisions relating mainly to the rate structure. They are looking at the end of May. There is much information on the dept. website and agency website including about 200 Q&A that were gathered during the public rule-making/workshops. If published by the end of May she would expect a final rulemaking hearing in June. Is this just for the rates? Yes, but there are some policy changes also which will assist with our effort to implement the rate structure.

Question: Where are we with the Independent Plus? They are waiting for approval on the operational protocol from the first amendment that was approved in February. The agency did provide responses to them but haven't heard back as yet. On the bigger amendment which is to allow individuals who are enrolled in CDC program who are in the control group to choose the cash option. The problem at the federal level is the waiver is not currently cost neutral. The 1115 waivers are different from the 1915 HCBS waiver. With CDC waiver you have to demonstrate it doesn't cost anymore for the dept. to provide this cash budget then to service under the traditional waiver. Right now they are spending more per month on persons on CDC project then they are for persons on the traditional wavier. The Office of

Management and Budget who work with the Center for Medicare/Medicaid are asking the dept. a great deal of questions about that and the dept. has to demonstrate a plan to insure that if they expand this waiver that it will be cost neutral. The dept. is working on two primary strategies to insure that the dept. meets the cost neutrality test. Shelly was asked who could participate in the waiver. It would be those who were part of the choice and control project and those who participated in the control group. Once the people are moved from the control group and are given the option of getting the cash, the dept. can submit another amendment to the federal government to request larger members. It could be everyone in the waiver would have the option which is what they would really like to see.

Question: Can the DDP develop an incentive program to have families who aren't using all their services or return money they don't need? If possible then can those dollars be directed to providing services to individuals on the wait list. Shelly shared that automatically if any savings has been accrued and are not being spent for something specifically those dollars would go to people on the wait list. Patty added that what they were hoping could happen is that maybe the dept. could come up with an idea (incentive) that would help families to find ways to cut down on costs so their support plans wouldn't be so high. Shelly shared that is part of what they are working on now.

Question: Frank asked Shelly when she was talking about the cost neutrality part when his son went on the CDC they took his med-waiver cost plan from the previous year and automatically deducted 8%. Where is his money? If we're not cost neutral with an 8% cost savings up front where did the money go? Shelly answered that in some cases that is true. Where the challenge comes in is that at the same time CDC waiver became operational that was when all of the funding was going into the waiver program. There were a lot of people who requested additional services so there were two tests, one based on your previous budget and another one based on a new cost plan. Keep in mind there were some people on the waiver getting more services and new people coming on the waiver who also chose CDC. A lot of those service plans particularly those new to the program were significantly over-inflated so taking 8% off the top really didn't make that much of a difference. Once they received the full data from the last 2 years, those trends really started to change. In a large part it was from people who were new coming into the system, they didn't have any cost experience with them. Frank shared he thought in the future when talking about this subject to make a distinction between those originally on the experiment group and how they managed with a lesser amount of dollars being spread out, being able to be creative and using savings in a creative way by shifting them around that they were not able to get on the waiver which is a plus. In generalization what you were originally saying was making it sound like the original consumers that went on the CDC were actually costing more which they may over time but in the front end they gave up big bucks. Shelly will make the distinction in the future. She believes the new assessment tool will help a lot to get this under control. She would like to see some CDC families participate in the upcoming training sessions to share with families and support coordinators some of the creative ways they have used their dollars.

PRESENTATION – SELF-DETERMINATION – KAREN ROGERS, LINDA HERRING AND TRACY RACKENSBERGER

Karen Rogers and her sister Linda Herring attended the Self-Determination Immersion Conference in Las Vegas. They provided us with a well thought out, organized and very interesting slide presentation, accompanied with handouts, about the conference. They shared several stories of self-advocates they had met which were very impressive to them. It was obvious that the knowledge they gained and the friendships they made are priceless. They provided hard copies as well as audio tapes of presentations for our review.

Tracy Rackensperger attended the Self-Determination conference last year through her involvement with the Florida Developmental Disabilities Council. She shared what a great learning experience it was

to attend this conference. Her part of the presentation was dedicated to Micro Enterprises. Micro Enterprises are simply small businesses that produce income for people with disabilities. The purpose of creating Micro Enterprises is to promote a stream of income for people with disabilities to use for whatever they want. Micro Enterprises can also help generate income for people with disabilities who experience difficulty obtaining other employment opportunities. It focuses on individual's abilities and desires. They stress the principles of self-determination. Tracy brought along some information for anyone interested in learning more about Micro Enterprises.

III. NEW BUSINESS:

Election of Officers: Last meeting we elected the new chairperson – Frank Carroll – District 3. Officers still to be elected are Vice Chairperson and Treasurer.

Vice Chairperson - At the last meeting a slate was established by the nominating committee. Their selections were Janet Graham and Ann Millan. The nominating committees' slate is amended to withdraw Janet Graham's name upon her request. There were no nominations from the floor. A vote was called and Ann was elected by unanimous vote.

Treasurer – No names from the nominating committee. Nominations will be accepted from the floor. **The responsibilities are: Prepare and present a quarterly statement of accounts and prepare an end of the year fiscal report.** In the future, by-laws will probably be amended and additional duties may be added to the treasurer position. Diane Ciccarelli has volunteered. A vote was called and Diane was elected by unanimous vote.

Purchasing Guidelines - Jadene provided each chair with a notebook containing the Florida Department of Children and Families Operation and Travel Procedures. It includes guidelines on purchase of information technology and purchasing and travel procedures. She highlighted some of the most pertinent information for our review. This included the information pertaining to when or when not is a written bid needed. Also information on how to fill out a purchase requisition which includes a list of restricted items. Jadene shared that Paul Mauck in the purchasing dept. at Central Office would be someone we could E-mail with questions. We might consider having someone from fiscal office do a presentation at a future meeting. Included in the documentation are all necessary forms and procedures pertaining to travel. The critical thing is that travel must be approved prior to the travel. Donna asked if FCC's could use their funding dollars to give small grants/donations to FCC members who have their own support groups and/or functions that provide activities to our DD population. Jadene said no to donations. She shared that Diane does a purchase order where she purchases outreach services for her Parent to Parent group. Jadene advised she really doesn't know but her main concern is that this is what family care councils are charged to do. Donna questions this because as an outreach this is what our FCC members are doing, providing outreach to our DD population through groups and activities. Jadene shared these are the kinds of questions we need to pull together so that we can sit down with somebody who can provide us with answers. Jadene suggested to Frank that maybe a committee could be established to look at some alternatives to how the FCC funds are allocated out to the local councils. These could be presented to Shelly or whomever it needs to be presented to. Frank stated that what we need are the operating procedures. The process of transferring family care councils funds to another category, where more accessible, is on his list to discuss with Shelly.

HIPPA - Jadene provided each chair with a hard copy of the slide presentation given to all DCF employees regarding the federal Health Insurance Portability and Accountability Act (HIPPA). DCF has to insure that it meets HIPPA standards because it is a health care provider which is a covered entity. The HIPPA Privacy Rule provides safeguards to protect privacy health care information, sets boundaries on the use and release of health information and holds violators accountable if patient rights are violated (civil and criminal penalties). As volunteers and persons working closely with the department, FCC

members have the same responsibility to comply with this regulation. Jadene highlighted the most important parts of the presentation. It is very important that we learn and share this information with our members. FCC members must be extremely careful when discussing a consumer's health information that they have permission from the parent and/or legal guardian of this individual. If necessary, get a signed written document. Talking directly to the parent/legal guardian is OK. Jadene shared that she would ask the person assigned to the HIPPA regulations within the dept. exactly what protects FCC members as well as continues to protect the rights of people we are serving.

IV: Review of February 15th, 2003 Minutes

Mary Ellen makes a motion to approve the minutes as is. Joan seconds the motion. The motion was approved by consensus. Judy asked if upon completion of the minutes if an "action" page could be developed showing who and description of follow-up information.

V: FCSC Funding Dollars

Patty shared that the FCSC still has funding dollars to spend. Jadene shared that she is afraid it's too late to get a purchase order started. Jadene's recommendation was that we contact Shelly. Patty will E-mail Shelly advising her of how we want to spend the remaining dollars. We agreed upon the following: (1) Purchase Authorware Software for Website; (2) Purchase a display board and (3) Create a Statewide Brochure. She will ask Shelly if we can get this done or is there a process by which we can take care of this. Yolanda shared that she has letters out in her community requesting fund raising dollars for the purpose of purchasing the display board. She doesn't have anything positive to report but she is not giving up on this effort.

VI: FUTURE MEETINGS

Frank Carroll, our new chairperson beginning next meeting, wanted to share some ideas for moving forward. He suggested that because of all that needs to be done that we consider meeting every other month instead of every quarter. He also suggested that we consider meeting Friday afternoon and Saturday. It's difficult to get everything accomplished in one day. He shared that we will be forming standing committees consisting of **Budget, Policy and By-Laws, Communication & Strategic Planning and Nominating**. Ann will chair the Communication & Strategic Planning Committee. If you want to volunteer for any of these committees contact Frank. We should begin working on committee structure and how to get things done at our next meeting. The communications part of that committee is on-going but we need to focus on the strategic plan with certifiable goals that the group agrees on for at least 3 years. What needs to be added this year is some structure to the group. Frank will specify the committees and their responsibilities. He will work with all committees as a non-voting member. All issues we work on will relate to statewide chairs council issues only. Patty asked to expound on this point. She cautioned us to please be very careful when in meetings or places that what we are stating is your district family care council position. Please be sure you know that is the position of your FCC. Just because you are a member of the statewide council does not mean you may speak to those issues as the statewide embracing that issue. Only those issues that the FCSC has come to consensus on should you say the FCSC embraces. It's causing a little dissension among the ranks. After some discussion it was decided to try meeting bi-monthly this next year beginning in July. Meetings will begin promptly at 8:30 AM. It was mentioned that we need to go back to a working lunch at the hotel. Donna will check on in-house lunch options. It was also mentioned that we spend too much time listening to speakers. That leaves us with little time for our business meetings. Frank shared the next meeting will be more of group training session. Most of the next meeting will be committee assignments, committee training, form a structure, goals of committees, and set work timelines. A

budget committee is absolutely critical. In order to spend our money in a cohesive and logical manner, you must create a budget with cost categories.

VII: ADJOURNMENT

With no further business to come before the council, Chair Houghland officially adjourned the meeting at 4:00.

NEXT MEETING - JULY 12, 2003

RESPECTFULLY SUBMITTED,

DONNA RAUBER