

## FAMILY CARE COUNCIL FLORIDA

### FRANK CARROLL, CHAIRPERSON

Amerisuites Orlando Airport  
Orlando, Florida  
September 20<sup>th</sup>, 2003

#### MEMBERS PRESENT:

Frank Carroll, D3 Chairperson  
Patty Houghland, Past Chairperson  
Joy Frazier, D1 Chair  
Janet Graham, D2 Chair  
Cathy Mitchell, D4 Chair  
Ann Millan, Suncoast Region 5 Co-Chair  
Rhonda Sloan, Suncoast Region 6 Co-Chair  
Donna Rauber, D7 Chair  
Judy O'Halloran, D8 Chair  
Maryellen Jones, D9 Chair  
Joan Hinden, D10 Chair  
Martha Sheldon, D11-A Chair  
Yolanda Herrera, D11-A Substitute Chair  
Pat Hawk, D13 Co-Chair  
Diane Ciccarelli, D15 Chair

#### STAFF & GUESTS

Wilma Lefler, DD Dept. - Guest  
Beverley DeStories, FND Guest  
David Vaughn, Suncoast Guest  
Stan Hinden, D10 - Guest  
Roger O'Halloran – D8 - Guest  
Judy Senick – Suncoast Region Guest  
Margaret Watkins – Suncoast Region Guest  
Milton & Berthy Aponte – D10 Guests

*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 Frank Carroll called the Family Care Statewide Council September meeting to order. He welcomed everyone to the meeting and asked for introductions.

### II. DISTRICT UPDATE

**Donna Rauber, District Seven** shared that her council has been very busy. Unfortunately our district DD program administrator accepted a position in another district which means the dept. is looking for a replacement. At a previous council meeting, the current District Administrator attended and was asked if an FCC member could participate in the interview process for the new DD program administrator. The suggestion was taken into consideration and approved by the DA. An FCC council member was one of 4 interviewers of 6 candidates for program administrator. A feature writer with the Orlando Sentinel attended our last meeting. She is doing research on writing a series of articles on persons with developmental disabilities and their families. Our October meeting will be a presentation by 2 attorneys focusing on Guardianship Advocacy and Special Needs Trusts. Donna shared she has created a newsletter announcing the event that will be sent to approximately 2900 families in the district.

**Joy Frazier, District One** shared they participated in a community network night at one of the district schools. They had a table set up and it was well attended. They added 13 names to their E-mail list and mail list. Unfortunately most of them have aged children who are ready to leave the school system and not many of them are receiving services. She is hoping to bring them into the Family Care Council. Next week they are sponsoring a financial planning seminar night and will

have a speaker there to discuss special needs trusts, college, how to save benefits once the consumer is working, etc.

**Janet Graham, District Two** shared there has been a lot of statewide department projects going on with the public hearing on the service directory, etc. She has been trying to increase the FCC presence in the other sub-group 2A and attended the support coordinators meeting in that sub district. She shared a former member who is a wonderful advocate has been trying to establish an additional 8-bed Autism unit at Sunland. As a result of the change in DCF Secretaries, the previously approved program fell apart. Thus, this lady is trying very hard to get the unit re-approved. Janet shared that she recently toured Sunland. Recently the council had a guest speaker on guardianship.

Janet was asked what her impression was of Sunland. She shared she was quite impressed. They are having their fall festival October 25<sup>th</sup> where they sell some of agricultural & horticultural products. They have recycling and canning operations, carriage rides, etc. She shared they have a beautiful location with 525 acres in the country. They have around 300 residents. The residents seem happily employed. Patty shared the Autism unit is wonderful because a family set it up. It is completely separate from the institutional part. The question was raised, why isn't the autism house in the community? Janet shared the family has tried every community setting, in their home, in supported living, in-home supports, they have tried it all. Probably the main reason the home is not in the community is the difficulties in maintaining staff. When in the community, the staff was not vigilant enough to keep the son from going out in the middle of the night, he fell and broke his leg but it wasn't diagnosed for about 10 hours and the staff tried to hide that he had fallen. No one has tried harder than these parents to keep their son in the community.

**Cathy Mitchell, District Four** shared they have been quite busy with community legislation. They have identified people in need of guardianship because families had passed on. They identified \$20,000 in Jacksonville community dollars that was used to help families access siblings/relatives who were willing to assume the responsibility of guardianship/special needs trusts for the persons in need. There is a transportation pilot project in the works whereby a transportation provider is taking residents out to shop for groceries, etc. It's free to the consumer. It's paired up with elderly affairs so the residents are participating in the community more often now. She shared they just sent out their latest newsletter which announced the upcoming ICG training the end of the month. She also shared that through ASK (Advocacy Support and Knowledge) letters were sent to dentists and oral surgeons asking them to sign up as Med-Waiver providers in the area as there is a terrible need for dental services. The voting issue for self advocates was presented to the new mayor who was very receptive to this and promises it will be in place prior to the end of his term. She shared they are always going to the school board requesting persons with disabilities be integrated in the schools. She thinks they will be successful this time as several members of the school board have family members with disabilities.

**Judy O'Halloran, District Eight** shared at their August meeting they broke into small groups and generated questions to be passed along to their district office. The questions pertained to support coordination, cost plans, med-waiver availability, non-med-waiver services, residential rehabilitation, etc. Their by-laws committee met and developed the final draft of the revised by-laws to be presented and voted on at the September meeting. The September meeting program consisted of a four-member panel from the district office. They reviewed eligibility requirements for DD program, the crisis tool, prior authorization and an introduction to office personnel and their responsibilities. Their outreach committee is developing a full-day forum which will focus on bringing various agencies/organizations together in one location so consumers and families can be educated on services available in the district. Then their goal is to develop a handbook that would be presented similar to a navigation tool with an overview of services available based on needs pertaining to a consumer's various stages in life.

**Maryellen Jones, District Nine** shared they are moving their meetings from every third Monday at one of the rehabilitation centers to the program office during the day because they are having a problem with attendance. They have a lot of consumers ready to transition out of high school that doesn't have any services. They are planning a transition forum in March. They are looking to go out into the countywide communities looking for services available besides med-waiver services. She is working with other organizations like Parent to Parent and FND to make parents aware there are other options. They are promoting micro-enterprises as an option. They are having a disability awareness weekend at a local mall in Boca Raton because October is disability awareness month. She is getting newspaper coverage of the event. They are working hard to get more people involved, promoting community awareness and find jobs for consumers.

**Joan Hinden, District Ten** passed around and shared a flyer for their upcoming conference titled "The Emerging Workforce Conference" to be held February 8 – 10, 2004 in Weston, FL.

Yolanda and Joan are recruiting people to attend the conference. They are asking for a mailing list from each district. It's very important that we attend as the National Council on Disabilities will be meeting there also. This is a great opportunity to attend their meetings. The Wyndham Hotel is the most accessible hotel in south Florida. They are hoping to arrange for bus service from the airport to the hotel. She shared she has forms if anyone wants to sign up to give a presentation specifically related to employment. She urges each district to send Jill the name of a contact person so conference information can be sent out statewide. She shared her experience with trying to find work for her daughter over the years. Laura now has a clerical job in an office. She shared she is working to get Laura a job in the justice dept. Why should parents have to go out on their own and look for employment for their loved one? Parents can't hire job coaches or employment specialists. Tons of money is being given to different agencies that are not doing their job. One of the worst offenders is Vocational Rehabilitation.

Joan also shared they were the first district to participate in the redesign/ICG workshop. She and her husband were the only parents to attend the portion of the program allowed for family participation. She asked the presenters to attend their Family Care Council meeting the next night. Joan contacted all the providers she could and only 1 person other than council members showed up. Something needs to be done when workshops are announced to give districts more than a one day notice.

**Martha Sheldon and Yolanda Herrera, District 11.** Yolanda shared that she will be reporting on school issues and Martha adult issues. Yolanda shared that the FCC through PTA and parent to parent will be conducting transition training for parents of high school kids. She and other FCC members serve on a transition task force made up of representatives from various agencies associated with employment. They plan on providing information to parents earlier through the school system so transition after high school can be addressed during individual IEP's. Through the transition task force they are pushing for curriculum changes at elementary & middle school levels to include reading skills. Yolanda shared she has the support for this endeavor. She shared she visited Southern Memorial College, an incredible program geared towards work and employment skills. The only requirement to participate is good behavior. They also require parent participation. Yolanda shared she participated in the master training program for the ICG training sessions. At their scheduled meeting, no parents showed up. Due to the serious changes that are taking place, she & the other trainers are holding a session similar to the SC's for parents in October.

Martha shared she wears many hats. She works for the Miami Center for Child Development, a program for children with profound disabilities. Her other jobs are in advocating as Vice President of People First. They have their board meetings at her house. What she sees around her are disabled adults with not-caring parents who put themselves first. For example, an individual has been put in supported living. However, his behavior is such that he ended up in jail. That is her worry; incidents like this will result in going back to institutionalization.

**Diane Ciccarelli, District 15** shared they are doing a town hall meeting in December and working with Project Connect. Project Connect which is funded through the University of Florida is a grant their county received. They are going to re-establish their interagency council so that all agencies are back working together on transition issues. The town hall meeting will encompass transition and establish a special wish list of persons on the wait list which will be published in the paper in hopes of acquiring some local donations.

**Pat Hawk, District 13** shared they are concerned about respite. They receive a lot of calls from parents who are maxed out taking care of children, many of which are adults not being served. They sent a representative to the respite convention for information and are looking for possible respite situations that might already exist in their district. They want to organize a group of people on the wait list to take to Tallahassee in early 2004 to advocate to the legislature that the wait list is an issue that must be addressed. They are concerned about the cut in funding for the psychological type services. She shared they do support something similar to Sunland for persons with severe autism. There is a tremendous need for settings other than a group home as a community setting is not always the right choice for individuals with severe autism. She shared a phone conversation with a parent from Polk Co. whose autistic son was wrongfully accused of incidents because a neighbor was out for revenge. The autistic adult has ended up in jail twice as a result of something he did not do. This is an example of a family who has worked so hard to get their son at a level where they want him to be in the community and then they're punished for it.

**Rhonda Sloan, Suncoast Region** shared they are having 3 ICG trainings and just completed the second one. There was poor parent attendance. She did the second training and they had 2 parents signed up so they moved the training to the Family Care Council meeting the following evening. There were 32 in attendance that evening. Some of the feedback from support coordinators based on the evaluation sheet filled out is that they don't need to know anymore about redesign and self determination. They would prefer administering the ICG assessment tool without being face to face with the focus person. She really does hope the ICG accomplishes what the dept. expects it to but as a parent she will have concerns until she sees her daughters completed ICG. Rhonda shared they are also participating in the first pathways in partnership in the Bradenton/Manatee area November 8<sup>th</sup>. This is exciting as it's the part of the region that is not active in the FCC. They are having more meetings in that area in hopes of developing more participation, interest and support. There will be a pathways in partnership conference in late March or early April for the entire Suncoast region. Their council is concerned about the poor participation from younger families in the FCC so they are developing a program to go to them. They are identifying all the support groups within the school system. FCC representatives will start attending their meetings. Rhonda shared in Hillsborough County, the county commissioners have allocated \$500,000 for this fiscal year to provide respite for developmentally disabled children, whether they're on the waiting list or not. Next year they have allocated \$750,000. This will not pay for adult respite. A company has been hired to administer the monies and develop the criteria. These are projected dollars. **Patty asked Rhonda if she could obtain a copy of the criteria and send to Ann to distribute to each district chair.**

**Ann Millan, Suncoast Region** shared that her Board is sending a letter to specific zip codes of families and individuals on the wait list. Their ARC has requested this letter and they are going to try to identify and create programs for these individuals, similar to what was accomplished 10 years ago. Other areas in her counties are going to do the same thing. Diane asked how did she accomplish that? The dept. will be doing and putting on the labels and mailing for the FCC. Ann also stated the providers have questions for the dept. and are coming to the FCC for answers. It's taking her awhile to get the answers but she shares this as success when providers realize the FCC's have that kind of amity with the dept. Beverley and Ann went to a Center School and gave a presentation on the Family Care Council & wait list. She shared that one of the functions of Delmarva is to provide consumer and family training sessions throughout the state to educate

people as to Delmarva's function. The training session became a part of their FCC meeting. Her concern is that the dept. made no effort to advertise/promote the training session so more families could be involved. She shared in our packet of information is a sheet their dept. liaison distributed which is a great overview of the med-waiver program. It's directed to their region but could be used by any district. She's in the process of creating their yearly FCC bulletin which will focus on the ICG and guardianship. She shared there has been no ICG training for the focus person. She wants to make that a project for their FCC. They meet monthly, have at least 20 people in attendance each month, and have over 400 e-mail and mailing addresses of families and individuals wishing to be kept informed.

**Frank Carroll, District 3** shared they are currently in the process of organizing a CDC support group. These are people who know nothing about FCC and in general don't know anything about DD. They believe a collaborative effort sponsored by their FCC will give them some structure as to how to address the state on training issues and newsletters promised but never received. There are a host of things promised and these people are still waiting not realizing that they're not going to get them. This is a new group of people they're working with who seem excited about becoming educated.

### **III. BUSINESS SESSION**

#### **Review of July 12<sup>th</sup> Minutes:**

Chair Carroll asked if there were any changes or recommendations to the minutes. Judy makes a motion to approve the minutes as submitted. Ann seconds the motion. The motion was approved by consensus.

#### **Financial Report:**

Diane shared they don't have a financial report at this time. Chair Carroll asked that Diane meet with Wilma and advise him of a procedure on how that's going to be addressed.

#### **Old Business:**

July minutes follow up. Ann advised there is a sheet in our packet which is an overview of follow up items from last meeting. Not sure it needs to be addressed at this time but as we go into committees and during the rest of the meeting these are questions/concerns left over from last meeting.

#### **New Business:**

No new business to report.

### **IV. Presentation – Working Group Report on Guardianship – Roger O'Halloran**

Roger is an attorney and was asked to review the Governor's Report on Guardianship which was submitted by the working group he established to review the guardianship process in this state. He shared that he and Judy have a son Casey, age 22, who has Down Syndrome. As a result, he and Judy have become experts as Casey goes through the system. As an attorney, he does a lot of work in family law, divorces and adoptions but also has a practice in probate guardianship. He shared a lot of attorney's don't know there are new, better alternatives to the "old fashioned" form of full guardianship. The working group was to focus on these other alternatives. He shared with the group an excellent background of developmental disabilities over the past 40 years from the days of institutionalization, through the improvements in education and civil rights of persons with disabilities, then deinstitutionalization and individual rights, choice, independence and responsibility followed by the current laws and regulations relative to community based services.

He shared the reason for establishing the guardianship work group. The group started the process with goals based on the Governor's orders. They figure out what the facts are and then make recommendations as to how to meet the goals set. The group submitted their final report in August and it's been turned over to a larger task force established by the Dept. of Elder Affairs. This task force will take the recommendations and see how to put them into effect. Roger then shared the work group findings and recommendations of which a portion is included in a summary located in our packet of information. The entire report can be found at the FCC website ([www.fccflorida.org](http://www.fccflorida.org)) under breaking news.

Discussion followed regarding the option Client Advocate. It is a simple process that doesn't require an attorney. It appoints a family member or friend of the individual to become an official client advocate when the need for this is recognized. It relates specifically to services provided through the Developmental Disabilities Program. Ann shared this is an excellent choice but wanted everyone to be aware that as part of the ICG tool under "Your Legal Status" the client advocate appears buried towards the bottom of the listed choices. Also, it was shared that support coordinators in the training sessions were having a difficult time with the legal status question as it asks for the paperwork to back up whatever choice is checked. Janet wanted to share the importance of making sure you're distinguishing between a client advocate and guardian advocate. They are two very different options. She thinks the client advocate is a wonderful tool for families and genuine friends. You must be very cautious though because group home providers/facilities really like client advocates. They tend to designate retired staff or staff not assigned to the person. You have to be careful. When you're trying to circumvent a law then the possibility of abuse exists. You have to consider the setting and the individual circumstances when making a decision of the type of guardianship most appropriate for the individual. The "Planning Ahead Handbook" created by the FDDC is a wonderful tool which offers an excellent description of the guardianship options. Every one of the levels is appropriate for someone. If client advocate is appropriate for your family member that's great but you need to realize there are other people who are trying to find ways to not have to do the right thing. Martha shared to remember there are a lot of adults who don't have an involved person like us in their lives so they fall through the cracks. She has been in a situation where she didn't want to be in.

Patty shared she read the working group report and wanted to make one distinction. We are talking about several different groups of people who need different levels. She panicked when reading some of the recommendations because they had a narrow focus. They were looking only at those people who don't have involved families, that don't have someone to speak to/for them and are going to be in a crisis situation. She wants to address that part of the population who has some kind of a support system. They have family members, close friends, somebody involved in their life that really concerns themselves with the focus person. Her information comes from workshops, teleconferences and learning of innovative ways other states have approached the problem. Some state legislatures have taken the initiative to put through state statute a cap on how much money attorneys can charge to set up a DD guardian advocate. There is no cap in Florida. There is nothing to prohibit a group (if it was to be us) to lobby the legislature for a change in the statute to say the cost for a guardian advocate will not exceed a certain amount. It's a possibility that could be examined. Another possibility that another state has done is if you're under a guardian advocate or guardianship and you're the representative payee, the state has elected to weigh the yearly financial reporting. None of this costs the state anything. She shared that some states have a recognition titled "assisted competency". The argument is "how can you declare a person incompetent if they have an assisted family unit to assist in making the decisions". It would work wonderfully in those situations where the family is involved and until the family dies off or the situation changes, for that time period. This is another option. Another great idea which will take a little work and planning is something called "Micro Boards". Micro board is a board that is set up to support an individual. Micro boards receive Medicaid funding just like an agency for that person they support and disburse

those funds. The micro board then acts as the guardian of that person. A micro board is an entity with by-laws. It's stated in the by-laws that the board maintains x number of people and when one dies a replacement must be found. The board is constantly perpetuating itself. They look out for the welfare of the person through everything. This is being done in Tennessee, website address is [www.tnmicroboards.org/index.htm](http://www.tnmicroboards.org/index.htm). It's thinking beyond guardianship. She shared some of what the work group has proposed the state can't afford to do. There won't be money for it. If it's not done in statute because of Medicaid Waiver, legalities, etc. and the person is not competent and signs an "X" for the Medicaid waiver, the state is in violation. Patty was asked about the guardian. The need for the guardian goes away as the micro board speaks for the person. Does someone act as the chairperson of the board? Yes in Tennessee & 4 other states the board has a chairperson.

**Judy shared she attended a presentation on micro boards at the self-determination conference. She brought back a powerpoint hard copy of the presentation which she thinks Jadene may have as she was given the package of information received from the conference. Judy will search for it.** Ann makes a motion to the chair to recommend that the council create a guardianship committee. Chair Carroll agreed and asked Patty to be chairperson. Committee members are Janet Graham, Pat Hawk & Yolanda Herrera. Roger O'Halloran has agreed to be a consultant. **Chair Carroll asked the committee to have a meeting and present in the next 35-40 days an outline of issues with time frames for implementation.**

## V. TELECONFERENCE CALL – SHELLY BRANTLEY

Shelly apologized for not being able to attend our meeting in person. She shared they just announced yesterday a new initiative titled "Zero Tolerance" for the abuse and exploitation of individuals with developmental disabilities. She has been working since February with the FDDC, provider agencies and the Florida Association of Support Coordinators to develop a program from a training aspect, monitoring and mandatory training of providers. They secured from the FDDC about \$12,000 to purchase nationally recognized training materials and also bring in national experts from disability services ASAP program which is actually run by a disabled woman who was a victim of sexual assault. They are scheduling a 2 day conference to be held in December in Orlando. She is hoping for as many FCC members as possible to attend the conference. Possibly the statewide council meeting could be scheduled around the same time as the conference. A key piece of the initiative will be engaging the family care councils in the training of the family members of individuals. It's really important to understand this is a societal issue.

It's assumed the problem exists mostly in group homes but actually the published rapes in family homes are the highest. Up to 70% of sexual assaults occur in family homes. She is hoping to obtain at least one set of training materials for the FCC. **She would like to request that maybe if the council could set aside a couple hours at our next meeting, she would like to do a "train the trainer" session with us to kick off the training that could be done at our local council meetings.** Her goal is to train as many self-advocates as possible. She really sees the family care councils as being huge leaders in this effort because nobody can reach out better than families. Some of the provider organizations and FASC will be partnering to assist with the training. Probably second to self-advocates and families the training of support coordinators will be most important as in their role they are in an ideal position to find where abuse exists.

### Questions for Shelly:

1. Can the Family Care Council be an agenda item at Waiver Support Coordinator monthly meetings? It is understood that the agenda for these meetings is generated in Tallahassee. Shelly answered not necessarily although they do offer a lot of information that is shared at the meetings. She is meeting with the DA's this week to discuss some of the new initiatives and will ask them to include FCC's on support coordinators monthly agendas. Also FCC's want to attend meetings to share concerns that the dept. may be hearing from other families

or people the dept. serves. She has a couple thoughts on the issue of fiscal intermediary. One is if it's something the family care councils want to do it's definitely do-able. For example the FND could provide that service as they do with the Family Café. The downfall is a 5% charge for the service. The other option would be work with the DA's and try to set up some guidelines to help the FCC's obtain uniformity statewide in the use of their funding dollars. She is very troubled by the fact that some FCC's have such a difficult time obtaining their funding dollars. Patty shared it depends on the relationship the FCC has with its district DD office. It's also still not clear even at the district level what FCC's can spend their monies on. Shelly was concerned that the FCC was having difficulty purchasing software as this would be acceptable because the use of technology would make the councils more effective and efficient in their operations. She sees no problem with the statewide council purchasing software to improve the statewide website.

2. Does everyone in a group home get their own ICG? Yes.
3. Grant Writing - Shelly suggests going through the FDDC council. Also, she suggests using FCC dollars to hire someone to do grant writing for us. She shared she could help as she knows some grant writers in private practice.
4. There was a resolution going around and vote on at the ATSE and Self Determination conference that \$5 million be set aside for supported employment and 4 other targeted services this year. Do you know where that issue is now? She isn't sure but offers a couple of ideas. A priority is employment opportunities. She is really interested in pushing for new legislation related to employment. They are also working at the federal level to remove some of the barriers. One possibility is looking at legislation to set aside a certain amount of waiver dollars from the ADT service specifically for employment. Another possibility, she is anticipating there will be some legislative budget requests for supported employment that would be set aside for individuals to tackle head-on the issue of transition from high school to employment. Another area for legislative changes is the federal law already dictates to VR to target those with the most significant disabilities. Maybe we want to consider some companion language in the state law that specifically targets individuals with developmental disabilities. If you're serious about doing any kind of legislative proposals, now is the time to be talking to lawmakers. Martha asked if there is anyway professionals with CP can make a decent living without losing their Medicaid benefits. Shelly shared they are anxiously waiting to see if their grant proposal to the Centers for Medicare & Medicaid is approved but even if not they are working on an initiative. They are looking at proposing an expansion of the Independent Plus waiver to include the ability to use waiver dollars for housing costs which is something that is currently prohibited under federal law. Also to obtain a companion waiver from the Social Security Administration which would allow individuals to maintain more of their income and also not risk losing their benefits if they start earning above a certain amount of income. The Governor, Lt. Governor Jennings and Shelly met with a representative from the SSA who is very interested in their proposal.
5. Was a Delmarva evaluation ever done on the rape victim in Orlando? She was in a group home and just getting LTRC. She didn't go on the waiver until 2001. She doesn't know whether Delmarva did a review. She did share that she has been meeting and working with Delmarva on the zero tolerance initiative. Any of the cases the dept. finds where there is suspected or questionable abuse, Shelly personally contacted Delmarva and asked them to review those individual settings or providers or both to make sure there is a very close and diligent effort to determine any and all possible warning signs. She shared they are in the process of finalizing a new amendment with the Delmarva contract and moving more intensely from compliance reviews to outcomes and to assist in the depts. efforts to encourage providers and support coordinators to assist individuals with their personal goals.

- They are also asking Delmarva to partner on zero tolerance efforts and take a much closer look at any and all potential vulnerabilities that any of the clients could be experiencing.
6. How many consumers are being served in the state? In 1998 the dept. was serving around 10,000 people. The program now serves about 30,000 people. Can we get a monthly total of the number who have left the state or died? Shelly doesn't know if she can get that but will try. They are in the process of making some enhancements to the ABC system in connection with the ICG.
  7. Has anything changed regarding RES-HAB rates or is it still 365 days present? With respect to the rate structure for purposes of determining what to put in the cost plans, districts were told to use 365 days. However, since then the dept. has conducted another provider survey based on utilization of res-hab. On average there was about 212 days of res-hab used by individuals in the last fiscal year. In their projections, they took the highest possible average days used (292 days). Now suddenly providers are saying they used many more days than that. Actually what they found providers doing is putting an attendance policy in place which discourages individuals from going home with their families so they can bill the state the maximum amount possible. Shelly shared they can't do that because it won't be within the budget. The dept. is expecting to make changes within the next 30 days. She is giving the provider organizations a choice, either cut the rate and bill 345 days or increase the rate and cap at 260 days. She shared the dept. has to stay within its budget. The legislation will absolutely not tolerate the dept. going over its budget.
  8. How many consumers are monitored by the jail system? Do we know how many consumers we have in jail? Shelly doesn't know. She should be able to give us a number at a given point in time. Shelly asked if there was a particular reason why we wanted to know that. It's to recognize there is an issue with individuals with disabilities getting into legal problems and how to best address that. Shelly is concerned from a fiscal standpoint as well as the individual's quality of life that some people with severe behavior issues are being kept in the community with enormous, costly supports. It's almost comparable to being held in a "holding tank" type environment. This is not the best way of using our dollars especially when the dept. has families, law abiding citizens waiting for services. She is interested in working with providers on this issue. She visited Sunland's office and they have some residents with some long criminal backgrounds that are really thriving and she thinks there are some components of that program that could be brought to the community.
  9. Who is the contact person someone can call to determine what number they are on the wait list? A person needs to call the district office who in turn will contact Shelly's office. Margie Collins is the point person in her office that maintains the wait list. Judy asked if after contacting the district and they say they don't have that information, are they supposed to have it. Shelly will bring this up with the DA's. Janet asked Shelly how many people are on the wait list. About 12,500. Shelly shared the list really grows at the end of the school year. She shared it would be a good area to focus in on anticipating growth to determine how many kids are in ESE classes that will be graduating. The primary trends they are seeing of people coming on the wait list are either aging out of the school system, they've maxed out on their insurance, they have aging parents or something has happened to their caregiver. Also a lot of people moving to the state. Judy shared another trend that will increase in numbers is the individuals aged 3 and up. School liaisons are telling parents to put their kids' names on the wait list now because if you wait until they're ready for school you'll never get services. Shelly shared they have seen a number of referrals of this age group from the Dept. of Health. She discussed this with lawmakers last session that this is one of the populations to be considered in future planning. Yolanda shared that Miami's transition task force is making it their year's goal to pass the information to parents of children as early as age three.

10. Are their additional slots for supported living waiver? Yes. How many? They only have federal authority right now for up to 200 people. The problem is for years they haven't received any additional appropriations for supported living. She is very interested in expanding the supported living waiver. She wants employment and independent living to be major priorities. One of her big concerns with the DS waiver is that they are investing over half of their dollars on res-hab which is primarily serving people in group homes. A lot of these providers have made huge real estate investments in addition to what they receive from res-hab. Their mission is for people to live as independently as possible. She wants to see the American dream for individuals with developmental disabilities. She's been working with local housing authorities to find out ways to help persons with disabilities tap into their programs. She wants to see that it become a priority for individuals with developmental disabilities get stipends for housing. Many of the federal laws dictate this but it's not materializing in the real world, at least not in Florida.
11. The ICG rates are categorized as standard, modern, intense. What is the dollar amount for personal care? She doesn't have the figure but suggested going to the DD or ACHA website and look for the modified version of the draft rules handbook. It outlines what the personal care policy is. **She thinks she may have singled out that portion, if so she'll forward it on to us. She shared that the personal care rates and service was basically developed by families and she is very proud of them.** Diane asked how FCC chairs can be notified immediately when there is a rule promulgation with regard to developmental services. Shelly said that everyone who has attended public workshops or shown an interest has been put on their master E-mail list. She believes that all FCC chairs are on that list. **Diane shared that because it is legislatively mandated that FCC's monitor the effectiveness of services, once the utilization and ICG is implemented, we would like to get copies, per district, of all the reports with regard to utilization of the ICG tool. She shared they are amending their contract with Mercer who is assisting in that effort and once the contract is finalized they hope to get more of that information (utilization patterns) which could be shared with FCC's.** She shared she has learned a lot about utilization since the provider rates went into effect. They have some really interesting & creative ways of increasing the volume of services.
12. **Can we get a copy of providers and support coordinator lists from each district?** Shelly shared that's a great suggestion. Ann shared that the districts have the list, it's just FCC getting access to it. It can be categorized by individual provider/service and by City. **Shelly shared she will include this on her list to discuss with DA's.**
13. When CDC changes to Independent Plus, will the same principles be followed such as unspent money rolling over into the next year? Probably but she doesn't know for certain. She shared the feds just came down this week for an on site review which is the final stage of operating protocol. It will probably be a certain %. They will have to review if they're not planning on using those dollars for long term care purposes. Considering the wait list, they can't afford to have monies that aren't being spent. Once they receive final approval, a major initiative will be training. They are noticing CDC consumers are requesting additional dollars when they actually have money in savings. She thinks this may just be an educational thing. Currently the project is not cost neutral. Chair Carroll shared that part of their problem is the perception of what that money is for. He shared they were originally promised if they participated in the CDC, so the state could accumulate some data benefit from it, they could roll over un-used dollars so they wouldn't be lost into the next cost plan. Then it was suggested that those dollars be rolled over into savings. He has rolled his over into a savings category. If he is told he can't do that at the end of this year, then he can't get what he's saved the past 2 years. Shelly shared this is one of the challenges. In order to maintain the 1115 it must be cost neutral. It's a much harder waiver to get because of that.

She thinks having the ICG in place will help with that because it will provide greater predictability of cost. She shared they have talked with the federal partners about how important it is that families keep these savings. She anticipates though that it's going to have to be cap or % of savings. She doesn't know that for sure but wants to make us aware there may be some type of change in that area.

14. Can any of the billion dollars sent Florida by the Feds that the Governor is holding back be used for DD? This past federal fiscal year they adjusted the Federal participation rate. In Florida it was adjusted upward. She doesn't know the exact amount but thinks it's in the hundreds of millions. Per Florida statute 216, the state department can't spend anything that was not appropriated by the legislature. When they appropriate dollars for the Medicaid program they appropriate within a revenue based on what they know the amount to be. Since the federal government is on a different fiscal calendar year she believes it goes into the dept. of revenue, a bigger pot of funds. The legislature will have to re-appropriate those dollars in the next session.
  15. Do you project there might be cuts as a result of the ICG? They don't have any anticipated savings associated with the ICG. There are some high cost people who are over the cost of institutional care who won't be able to use the ICG. They will continue to be reviewed through Maximus. There is another group of people in the budget that will continue to have to be reviewed individually.
  16. How many group homes are being closed based on the new rate structure? Where are those residents being placed? She thinks it's only 2. She shared the reasons for both.
- Chair Carroll and Patty both thanked Shelly for taking the time to conference with us. Shelly shared she really is anxious to meet with us to do the zero tolerance training. As soon as she confirms the conference dates in December, she will let us know. She encourages all of us to attend if at all possible. She asked that we help get the word out to self advocates so they will be able to attend.

## VI. DEPT. LIAISON UPDATE - WILMA LEFLER

Wilma provided each of the chairs a listing of supplies that are approved from the state, a vendor list, updated purchasing guidelines and a manual of DCF travel rules and travel voucher preparation. **Wilma suggested sending the request for purchase of software to her.** Regarding the issue of hiring a fiscal agent to take over the accounting process of our funding dollars, that is up to us. If we choose to do so, Jadene requests that a proposal be submitted to the Individuals and Families Partners Unit for review. Wilma asks us to remember if we do get a fiscal agent we will be subject to audit and still have to abide by the state guidelines. Also, you'll have to pay a fiscal agent 5% whereby the central office does it for free. **Chair Carroll asks who should our treasurer call to find out how much money the state council has and where is it. We have to know how much money we have in order to create a budget. We need to know how many districts have donated their share. Wilma said she will get the information and send to Diane.** Wilma shared the report from Jadene which included her resignation.

## VII. COMMITTEE REPORTS

### Finance Committee:

Chair Diane shared that until we receive the actual revenue amount from DD dept., her estimation of the budget is as follows:

Total Budget amount:	\$7,500.00	(Estimate)
Less Allocated Expenses: Meeting Room	636.00	
Secretary	1,800.00	
Past Chair travel expenses	<u>1,614.00</u>	
Remaining Balance:	\$3,450.00	

Recommendations for balance include:	\$700.00	Website development
	455.00	conference calls expense
	175.00	telephone expense
	70.00	post office box expense
	100.00	1-800 telephone number
	<u>2,500.00</u>	grant writer
Total	\$4,000.00	

As the expenses total \$550.00 over budget, Diane suggests the council could ask each district for an additional \$50.00 to be used towards cost of website development. Another suggestion would be to drop the grant writer fee to \$2,000.00. Also, as Martha shared many times grant writers will include their fee in the total grant amount. Diane also mentioned that when looking at last year's budget it was determined that approximately \$30,000 of district FCC funding dollars went back to general revenue because districts didn't spend all their dollars. Chair Carroll asked if individual councils project a budget. Some yes, some no. Chair Carroll suggested that what should be considered is those districts councils that know by the end of March that they will have money left over, maybe those councils would vote to transfer to the state council to be used for "wish list" items such as software for the website. Discussion followed as to the appropriateness of the proposal as the legislature mandated these funds to be used in each district for families. An item such as money towards improvements to the website would be considered beneficial for all districts. There is a real concern about lack of family participation (example: ICG training sessions). Wilma shared that FCC monies can be used for public service announcements. This could be another way of getting information to families. However, Rhonda shared the information would have to get to us in time for us to arrange for the announcement. It was also shared the cost of public service announcements can be expensive. Diane shared we have \$3,450 of disposal income. At the next meeting a list of recommendations will be presented for discussion.

### Policy and Procedures Committee:

Chair Beverly shared the committee has developed its draft of the FCC by-laws which was distributed to each chair. Upon review, please E-mail her with any recommendations/changes. The 2 positions have been added. She has started a draft of the policy and procedures manual. She has isolated 6 different new policies that need to be incorporated into the draft. This is a work in process. A final product will be delivered at a later date for the council's consideration. Once the council has reviewed the by-laws, discussion will follow and a vote taken to approve at a later date. **Chair Carroll added that any recommendations/changes be directed to Beverly and her committee for discussion.**

### Communications Committee:

Ann began by asking everyone to locate in their packet of information the draft prepared by the communications committee to the strategic planning committee. She shared the committee's goal

and purpose. As the committee worked on its purpose and establishing its goals, they found it was necessary to go into other committee's territory and it became difficult to not include those as communication leans on one thing to another so if one thing is left out it makes a difference on moving forward. We recognize that some of these goals are not communication goals. Ann shared the Short Term Goals which include internal housekeeping within the state council. This includes the establishment of an executive committee consisting of the Chairperson, Vice Chairperson, Past Chairperson and Secretary/Treasurer. A list of their responsibilities is included. Also included is FCSC representation at other board/agency/organizations and communication methods to include prepaid phone cards, teleconference calls, a 1-800 number and a post office box. The second part of short term goals is titled FCC Awareness Goals. Ann reviewed the list. Also shared with the council was the committee's goals relating to Reaching Individual and Family Members, Public and Other Support Groups and Long Term Goals.

Motions:

1. **Ann makes a motion to change the name of the council to Family Care Council Florida (FCCF).** Joan seconds the motion. No discussion. The motion was approved by consensus.
2. **Ann makes a motion the FCC Florida logo to remain the same.** Judy seconds the motion. No discussion. The motion was approved by consensus.
3. **Ann makes a motion to establish an Executive Committee, consisting of Chairperson, Vice Chairperson, Past Chairperson and Secretary/Treasurer shall be established in the By Laws.** Joy seconds the motion. No discussion. The motion was approved by consensus.
4. **Ann makes a motion that the Chairperson or Vice Chairperson may approve teleconference calls as needed for committee and board business.** Discussion followed suggesting that committee chairs should be able to make teleconference calls with their committee members. It was limited to chair and vice chair for financial reasons. Diane suggested that considering the limited budget allocation any teleconference calls should be run by the finance committee first. Chair Carroll suggested the motion be modified to: If using FCCF funds for teleconference calls, the finance committee should be notified for approval first. Others suggested using the prepaid phone cards instead. Ann agreed to take back to committee for further review. **Motion has been tabled.**

Ann shared that Dave has decided not to be chairperson of the communications committee. However, he will remain on the committee.

#### **Nominating Committee:**

Chair Judy advised at this time there is nothing to report.

#### **Strategic Planning Committee:**

Chair Carroll advised the committee met Friday afternoon. The council needs to get serious about developing a legislative platform for the next fiscal year. All chairs should be thinking of ideas for discussion. It is recommended by next meeting the council come to a consensus on 2 or 3 legislative issues. The issues need to be simply understood, one or two sentences. The legislators want to see something simple with some backup information. He suggests that other disability related organizations will have platforms as well. If it is determined that our issues are in agreement with others then we should join forces to create a more united front in our advocating efforts to the legislators. By November, we should have the information from other organizations to see how similar they are to our platform. **Once you're satisfied with your ideas and it meets the criteria, send to Ann and mark to Strategic Planning Committee.**

Patty added each FCC council will have issues of their own that might be different from the statewide council issues. It's important to make sure that any legislative issues that are agreed upon

by local districts should be specified when advocating to be supported by your local FCC council not the statewide council.

Rhonda mentioned when the statewide council was originated years ago, the purpose was for all FCC's to meet and share information. Why would you have a brochure promoting the state council? Ann answered the brochure identifies the county and which council it is. It's another avenue of reaching out to families in order to lead them to the council in their district. Some district FCC's already have toll free numbers. Maryellen shared when participating in conferences where FCC could exhibit information, it would be easier to have one brochure with all contact information as compared to a separate brochure per each district because not all districts have brochures and many times people forget to bring them. Ann reminded Rhonda the communications committee report is a draft, a work in process. Chair Carroll stated once more that anything this group votes to do as a majority vote does not preclude, does not inhibit or restrict the chairs and their local district family care councils from any project or issues you wish to undertake.

### **Statewide Updates:**

Ann shared when we do the district updates, there are some real significant things going on statewide that need to be addressed. Ann proceeded to share the revised supported living handbook has been released. It was written for parents who are considering supported living. It includes all the requirements of the supported living coach and should give parents confidence in making the decision for their loved one to go into supported living. In addition to the handbook there is a training manual and a side manual by district which gives a list of people already in the supported living program who are willing to be interviewed. Support coordinators have these manuals. This is a project of the DD Council and the dept. has copies. The question was asked if these materials have been posted on-line. Ann shared not yet but will be in the future. **Wilma stated she would see if she could get one set of materials for each chair.**

### **FCC District Concerns:**

**District Seven** - Donna shared her council was most disappointed in the Delmarva family and consumer training session. Also they were aware of some disturbing issues from families who had participated in the person centered reviews. Therefore the council chose to take advantage of our legislative mandate which is to review the effectiveness of developmental disabilities program and make recommendations with respect to program implementation. Several council members researched the problems and created a letter to Shelly advising her of concerns with some possible recommendations. Donna shared the letter was sent Friday with copies to various persons familiar with the program. She gave an overview of the issues and recommendations presented in the letter. Donna shared she would forward a copy of the letter to all the chairs.

**District Eight** – Judy has some questions concerning the availability of qualified providers and the insufficient training of them. In her county there are only 4 agencies that provide supported living coaches. In a 3 week period of time she did not receive one call back from any of the agencies. She is asking if this occurs in other districts. Martha shared an experience she had with a supported living coach. Ann shared she has had no support since the first of August. She lost her daughter's NRSS person as a result of the rate changes. She has called everyone there is to call and receives no answers back. It's obvious this is a bigger problem that needs to be addressed. Judy learned from her district representative that there had not been a supported living coach training session in their district for 2 years. She asked why not. He shared it's almost a conflict of interest because the individuals doing the training are the ones who already have agencies. She finds this reprehensible that at the state level issues like this are not being addressed. Diane shared it's a district issue as the agency in her district is wonderful. Diane shared in Judy's situation she needs to document the lack of provider call backs and report that information to the district office. Judy asked what the

council should do since one of our functions is to monitor the effectiveness of programs. It was suggested they meet with the program administrator. Also submit the problems to CHAMPS.

Beverley provided each chair with a flyer from ASCEND announcing they would provide assistance in starting a Parent to Parent Information and Support Group in your area. There are stipends available to start up this program. Contact Diane Hefferman Joslin at the FND office.

Joan introduced Milton and Berthy Aponte who were in town attending the World Congress on Disabilities expo. Milton is currently on the National Council on Disabilities. Berthy is on the National Council on Ticket to Work. He suggested that some of our FCC monies could be used for training projects/workshops. He asked that we all become involved in the upcoming Emerging Workforce conference scheduled for February, 2004. Berthy is very pleased with the projects and things the councils are doing currently. She applauds our efforts. She is so happy to see a self-advocate on the statewide council.

Chair Carroll reminded everyone to fill out the evaluation form in our packets and give to Ann.

## **VII: ADJOURNMENT**

With no further business to come before the council, Chair Carroll officially adjourned the meeting at 4.00.

**NEXT MEETING – NOVEMBER 1, 2003**

**RESPECTFULLY SUBMITTED,**

**DONNA RAUBER**