

FAMILY CARE COUNCIL FLORIDA

FRANK CARROLL, CHAIRPERSON

Amerisuites Orlando Airport
Orlando, Florida
November 1st, 2003

MEMBERS PRESENT:

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

STAFF & GUESTS

Wilma Lefler, DD Dept. - Guest
Jadene Ransdell, Suncoast Guest
Beverley DeStories – FND Guest
Dave Vaughn – Suncoast Guest
Robin Millan – Suncoast 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 Frank Carroll called the Family Care Council Florida meeting to order. He welcomed everyone to the meeting and asked for introductions and district updates.

II. DISTRICT UPDATE

Diane Ciccarelli, District 15 shared they are having a town hall meeting on December 6th in conjunction with the Project Connect funding received. She has asked the district to provide a list of items such as durable equipment, diapers, etc. as they plan on placing a full page ad in the newspaper around Thanksgiving requesting donations from the community. These donations will be provided to persons on the waiting list.

Joan Hinden, District 10 shared that DCF met with support coordinators and providers to discuss the rate changes. They invited family members to attend. They had a transition meeting with the Autism Society. She also attended a transition meeting with the ESE advisory group. She shared they received a one year renewal of the Juntos Podemos (Together We Can) grant. The grant director is now Laura Prado.

Maryellen Jones, District 9 shared they are working on the March conference which will now consist of three paths, 1 being devoted to IDEA, path 2 devoted to transition from high school to work, path 3 devoted to older people. They are receiving some help from elder agencies to determine what happens to persons with developmental disabilities when they get older. The United Way received a grant for disabilities so they will be helping the FCC. Also parents and support groups will help.

Judy O'Halloran, District 8 shared their meetings will focus on preparing for an area conference on services, what's out there, how to access them and what can you expect. They are moving forward with creating the handbook of services available that she mentioned last meeting. The Best Buddies program associated with Gulf Coast University is moving forward. She shared it was interesting they have more volunteers to be buddies than disabled individuals. They did have a supported living training last week that went well. She shared they have a couple of people from the school district that have been attending their meetings.

Charm Thometz, Suncoast Region shared they are working on the Pathways in Partnership conference scheduled for March 15th. It will focus on the entire Suncoast Region and Polk County. All the school systems are moving forward with this and in collaboration with the DD program. In addition they will have a provider fair. They are also preparing a Pathways in Partnership conference in Sarasota County. She shared they have been working very closely with Sarasota and Manatee Counties. The theme of the March conference will be Exploring Possibilities. This will be their sixth conference and each one gets bigger and better. She shared Hillsborough county commissioners did a \$500,000 line item in their budget for respite for children up to age 18 with developmental disabilities. They expect the money to be available the first of the year. She suggested that other districts go to their county commissioners asking for the same. Advise them that Hillsborough County is doing this. Joan asked if Charm could write up a summary or action plan that we could present to our commissioners. Charm agreed to do so.

Cathy Mitchell, District 4 shared they are working with the ASK (Awareness, Support, Knowledge) program. They have received a few grants from the community. They are using these dollars to help with legal fees so that individuals they have identified who don't have guardians can obtain guardianship from relatives or friends who are willing to take on this responsibility. Last week they did an ICG training for self advocates and families who missed the original training. They prepared and mailed a newsletter. A few more self advocates have joined the council.

Pat Hawk, District 13 shared they lost their DD program administrator to District 7. She doesn't know if he will be replaced because of the possibility of districts becoming zones by July of 2004. She shared they are working on dental issues and respite. She shared her co-chair Ann Klein has been trying to see the Governor with no success. She has a residential facility called Independent Living for Retarded Adults (Shady Acres) and her funding was cut by \$50,000 a year. She serves about 15 consumers and these dollars covered the cost of the live-in manager. She shared that Governor Chiles had an "open door" policy. If anyone has any ideas or connections that would help Ann please let her know. She shared District 13 is participating in the ARC rally on November 12th. Their district waiting list is 1300. They are serving about 1000. She asked if anyone had the figures yet on the dollars being spent on Maximus and Delmarva.

Joy Frazier, District 1 shared they had a financial planning workshop with a guest speaker. They had a good turnout. He gave them information on how to work around the system and continue to keep benefits. ARC has asked their FCC to join with them in support of their legislative platform. They are attending regular meetings with ARC. They participated in an ARC town hall meeting. They had an ICG training workshop which no families attended. They are working on changes to increase their participation. Because they cover such a wide area they are looking at holding meetings in just two locations rather than going all over the district. They participated in a redesign information seminar with UCP. They are working with other organizations hoping to increase the awareness of Family Care Councils.

Donna Rauber, District 7 shared their October meeting was dedicated to presentations by attorneys speaking on Special Needs Trusts and Guardianship Advocacy. A newsletter was sent to consumers families and the meeting was a big success with 73 in attendance. She shared the district has hired a DD program administrator who comes from District 13. She thanked Pat and Pamela for being gracious enough to provide references which were forwarded on to the interview committee. He comes highly recommended and we look forward to working with him. The FCC is preparing for the second annual “Stepping Forward into a Better Tomorrow” seminar which is co-sponsored with Osceola County Support Group for children with disabilities scheduled to take place on Saturday, December 6th. She also reminded the group that we did send a letter to Shelly regarding Delmarva and that we did receive a reply which was forwarded on to all of you. The council is in the process of writing a reply.

Frank Carroll, District 3 shared they are in the process of preparing for their next family information forum which will be held in Lake City on November 22nd. The focus will be on guardianship. He shared information on Prepaid Legal Services.

Ann Millan, Suncoast Region shared they just sent out their latest newsletter to 3500 people. They had two meetings last week in the outlying area, one in the morning, and one in the evening. She shared the information in the newsletter on guardianship. She shared in our packet is an article titled “Five Wishes”. They went to the county legislative delegation. One of their members spoke to the National Epilepsy Foundation. They still don’t have the provider list from their department. She shared that her travel expenditures documentation had been returned as not being filled out properly. She presented Wilma with a packet of all the detailed information required. There needs to be some better way for FCC’s to access our funding dollars. Joan advised the document in the “Five Wishes” information is NOT A LEGAL DOCUMENT.

Housekeeping - Ann asked that we use the agenda in the packet of information and also be sure and fill out the meeting evaluation survey. Also she handed out blue slips for questions to Shelly. She wanted to know if Tom Rice would be attending the meeting. Wilma shared as far as she knows, yes. Chair Carroll shared that he learned yesterday that the stakeholders meeting scheduled for November 19th & 20th has been cancelled.

III. DEPT. LIAISON UPDATE - WILMA LEFLER

Wilma provided the group with a packet of information which included a copy of the updated FCC orientation guide which Jadene will discuss later. Also included are a copy of the Quick Reference Guide to the ICG and a description of how to calculate the new rates with copies of the rate schedules for Res-Hab and ADT programs which was prepared by the DD dept. for circulation to the district offices. Wilma shared she wants to see that FCC chairs receive the same information that is sent to the districts. She also shared that if we have questions for the Central Office to E-mail her and she’ll try to get the answers. She shared her vision is to see the families in the forefront of all their meetings, not the afterthought. Her E-mail address is Wilma.Lefler@dcf.state.fl.us. Also in the packet is a description of the Flexible Support Coordination Summary. **Ann asked what the status is for getting each chair a copy of the Supported Living manual. She will check into this.**

IV. FCC DISTRICT CONCERNS

District One - Joy Frazier passed out a document titled “ARC Gateway Legislative Issues Summary”. She shared ARC asked there district FCC to join in the grassroots meetings. She advised they did attend a meeting and ARC’s vision is very similar to our FCC vision. They want a cohesive group to meet with legislators to educate them that people with all disabilities, not just one form of

disability, are affected by programs/services. They are compiling a “picture book” which consists of profiles and pictures of individuals with disabilities which will include the FCC, ARC & UCP logos. It will be sent to all the legislators in their area. The majority of individuals featured in the book will be those on the wait list and those not receiving appropriate services. Patty shared that a copy will also be sent to ARC Florida who will distribute it to all legislators. ARC Florida is hoping that other district FCC’s will compile a similar book to be distributed to the legislators. It’s not a difficult process. You just need a signed consent form from a family member to include the individual’s picture. As this is a statewide ARC project, FCC’s could contact their district ARC for further information. Also ARC Florida would like FCC Florida to consider working with them in support of their legislative issues. The summary included the issues of the Wait List, Early Intervention and Medicaid Ticket to Work Buy-In. Joy shared ARC’s vision is that we all come together and support the same issues/goals. A question was raised asking the status of the Medicaid Ticket to Work Buy-in program. It has never gotten off the ground as no funding has ever been approved. Questions were asked regarding Olmstead. It was shared that Florida is one of several states that hasn’t initiated an Olmstead plan as is required by the federal legislation. Joan shared that even though the state hasn’t developed a plan, the basis of Olmstead is beginning to move people from institutions into the community is taking place within our state. Patty shared that Gary Blumenthal is no longer with the Advocacy Center. The board is doing a national search for his replacement. The acting director is Pat Wear. Chair Carroll also passed out the ARC Florida three year legislative platform. Ann shared what their district did last year in creating their legislative brochure.

V. TELECONFERENCE CALL - SHELLY BRANTLEY

Patty began by asking Shelly if she would like to start with an update. Shelly stated she did have a few minor changes to her portion of last meeting minutes which she would submit later. As a follow-up to last meeting, she and the Governor met with the Social Security Adm. and the Center for Medicare and Medicaid this week in Washington, D.C. and received a very positive response from them regarding the grant for the Florida Freedom Initiative. They indicated they would do everything possible to help the dept. get the waiver they are requesting by February.

Questions for Shelly:

1. Explain what is taking place with Res-Hab and ADT rates? Shelly advised that of the 34 services offered Res-Hab and ADT rates are the only ones that have 96% of the paid claims data entered. She shared the concerns that have been expressed in weekly meetings with ARC and FARF over the last few months about early trends of utilization that were seen specifically with res-hab which is the bulk of what they project will be a \$27.5 million deficit if the adjustments are not made to the rates. On average, even with the adjustments, the providers will still receive about a 5% increase this 2003-2004 fiscal year as compared to what was received during 2002-2003 fiscal year. She explained it’s based on what your cost is per unit of service and how many units you are serving. It won’t be as significant as what they have received the last 3 months. Ann asked why did the redesign and Mercer raise the rates in July without projecting that this was going to happen. Shelly advised that Mercer did project both the increase in provider rates and utilization. She shared as an example about half of the districts had in their service agreement a cap of 240 days that they could bill for res-hab and ADT. The reason being that federal guidelines indicate they don’t expect people to get training more than 5 days a week. They don’t expect people to work more than 5 days a week. When the rates were implemented, looking at all the providers, keeping in mind that half of them (res-hab providers) had the 240 day cap, on average it was only about 212 days. The Mercer projections anticipated when the cap was lifted there would be some increase in utilization and they projected an increase in provider rates but not to the magnitude it happened. Prior to July 1st the average number of days billed was 21 days. Beginning July 1st it increased to 29 days. That in large part is what drove the significant increase and cost. They anticipated utilization would increase approximately 300 days,

they certainly did not expect the providers to bill almost every day. Another question: Does this increase affect every county or are some counties (providers) receiving less money than last year. Shelly stated these are all based on averages. There are some districts (Suncoast Region, an example) where the provider rates are higher than other parts of the state. They estimated there are about 5 – 10 % of providers who did receive a decrease over last year. However, the majority of providers did receive an increase over last year. One of the major challenges in standardizing the rates was that even in one district providers offering the same service had a significant difference in rates. A major reason for this was shortly after the Governor took office there was a huge influx of dollars that went to the program. The dept. needed to find additional providers quickly and what happened was new providers were paid significantly higher rates over those providers who had been in the system for a long time. She shared that for all 34 services there were thousands and thousands of different negotiated rates. The question was asked if there was a mechanism in place statewide that would show in actuality which providers had to take less dollars this year than last. Shelly shared it would take some time to do that type of analysis but they are working on that now as they receive information from providers. It could be done based on a particular provider. She shared they want to work with the providers as much as they can and they certainly don't want to lose any of them. They do have a number of providers willing to contract statewide and currently over 1000 vacancies are in group home beds. She shared it's always very challenging with any Health and Human Services program to balance and try to actually solve affordability. They are doing everything possible to do that but obviously they have major concerns. Significant dollars have gone into provider rates over the last year (about 80 million dollars) and yet the dept. hasn't made an appreciable dent in the waiting list. She shared how they receive letters and phone calls daily from families who are desperately waiting for services. The waiting list is now at 12,500. **Patty asked for clarification, if individuals here want data regarding a provider/agency in their area, they can E-mail Shelly and she'll check into it. Shelly agreed to do that.** She requests that we let her know the specific service we're interested in because some providers might have received an increase in one service and a decrease in another. In other words, the overall rate they may have negotiated for res hab may have been higher than a lot of other providers, they may have received a decrease but then they may have received an increase in ADT. The other pattern seems to be in transportation although they don't have enough claims in yet but when unbundled they think significant increases will be seen. Some of the providers received an increase in both ADT and transportation or some variation of that. **Also, a list of questions and answers have been documented and sent out. She will see that it is sent to the group. She also shared she had asked Delmarva to do an analysis in relation to the inter quality council. She would see that we get a copy of this also. This is an analysis based on year 1 and 2 outcomes in various settings and some of the services.** The analysis indicates the smaller the setting and the more integrated, the outcomes are much better. The data supports this and there is no value to your quality assurance data if you don't expect change based on that. She feels we will understand even better when we see the outcomes.

She is currently working on putting out a memo to all the districts regarding ADT programs and individuals wanting to work or receive supported employment opportunities. They are asking the dept. to work on getting at least 5% of persons in ADT programs out into the workforce. The dept. is meeting with a lot of the district staff and they believe a lot of the people are ready, willing and wanting to work. This was certainly reported in the FDDC employment survey which indicated 75% of those surveyed wanted a real job in the community. She stressed they have to make some changes and get the outcomes up. **Patty asked Shelly to please copy Ann Millan as the FCC Florida contact person.** Shelly shared it's an all out effort to get everyone involved in this not just the districts. She shared they have some providers who are really interested in making some changes related to employment issues. They want to do anything possible to promote employment. If we all work together to get people in the most integrated settings when they choose to, some progress can be made with our outcomes. The dept. is spending more money but the outcomes on average are lower

than last year. She is not happy about this. When reviewing the analysis, it becomes very apparent where changes need to be made. It won't happen overnight but the focus must be in these areas. She is also working with Vocational ReHаб and they are putting out another memo which will provide districts with additional clarification and best practices in working with individuals in our programs. Ann wanted to emphasize the importance of seeing that we receive copies. She shared with Shelly that the recent ResHаб/ADT rate documentation came to the FCC via a support coordinator, not the dept. **Shelly will try to make sure the FCC gets copied on everything.**

Also, in regards to the Delmarva letter, she met with them last week. She shared that this ties in with the questions referred to in the district seven FCC letter with reference to trying to communicate with families. Apparently they are concerned that in some of the FCC councils there aren't ten people attending the meetings. She tried to convey to Delmarva that they must understand the complexity of the lives of the families who serve on these councils and they're all volunteers. They try to get everyone to attend but it's not always possible. She also mentioned to them the problems with getting the information out to the families. She mentioned receiving information from Donna regarding this matter and also HIPPA has created some additional challenges. Shelly felt the meeting with Delmarva was productive and she thinks they understood some of the challenges. **She stated she asked them to set up a meeting with her which would include some FCC members to discuss any of the concerns they have.** One of the suggestions they had was using FCC funding dollars to pay for transportation to and from meetings for self-advocates. Some districts currently do this. In regards to sending out newsletters, she wondered if the districts can't send out the newsletters. Yes they can but they don't do it in a timely manner. Shelly advised then that she would follow through with Ed Harris, who is the operational person. He communicates with all the districts. Shelly asked Donna approximately the timeframe needed for mailing to families. She replied it all depends on the circumstances and then shared additional information pertaining to the large mailing promoting the guardianship/special need trusts presentation which mailing labels were affixed by "DCF volunteers". When she asked for volunteers to affix mailing labels to a much smaller group of families, she was advised the volunteers were unable to help. **Shelly stated she would follow up with their legal counsel to see if there is anyway, because of the unique status of the councils, to get around the problem.** It was shared that since the FCC chairs have received the HIPPA training and are certified that maybe what needs to happen is a notification from the department to the districts that FCC chairpersons are HIPPA certified and fall within compliance to affix mailing labels at the district office. Another option is FCC members fill out the same application as DCF volunteers to become a "DCF volunteer". However, they would have to go through the background check and the cost involved in being fingerprinted.

Questions for Shelly:

1. What are the legislative goals of the department? Shelly replied it has not been finalized as yet. They are looking at proposing legislation on abuse issues related to our DD population. They are also working on legislation related to supportive employment. Also, working on proposed legislation related to guardianship & alternatives to guardianship. **As soon as she gets approval on these, she'll send out to the group.**
2. Does the Governor support MICASSA? Shelly doesn't know how familiar he is with it. Shelly hasn't looked at it recently. She wondered if this was something we were really interested in. The response was that we are curious as to what upper management's position is and whether it's something we need to get involved in.
3. When will the zones be implemented and is the plan already a fact? Shelly shared they are doing workgroups right now but they haven't finalized a lot of the details. She believes they are planning on moving forward with it. What is not known yet within the workgroups is discussion of excluding some programs and the DD program might be one of them. She indicated that she would like input from our group as to reasons why we are not in favor of

- the zones. Any concerns as well as any suggestions that could improve the existing structure can be E-mailed to Shelly.
4. How are rates determined for group home, res-hab and ADT transportation? What is the purpose for the providers having to coordinate with the community transportation coordinator? The rates for these services are determined the same as all services. Transportation in some districts previously was included in the ADT rate. The major change they unbundled with the new rate structure. Now they are looking at possibly making changes to that. They're still trying to review the analysis. The major reason they must work with a community transportation coordinator is because of a law that relates to coordinated care system. Anyone outside the coordinating care system, they have to approve the rate for that provider. Also if they have access to the state plan, they have to access that first. In some cases that coordinator provider may be a state plan provider.
 5. We would like a quarterly report of the number of providers/number of consumers by district in order to track availability of utilization. **Shelly advised they can provide the group with quarterly reports that they do on the rate implementation.** They don't have enough claims data. **She stated they can provide a listing of providers.** If we're looking for the before and after scenarios of specific providers, she can look that up for us. She believes the quarterly report will give us good information. She was asked when we could count on receiving the quarterly reports. She advised the one just completed does not show all the services as rates for ADT and Res-Hab began in July and rest of services in August. Based on the early trends they have seen some changes they are concerned about but nothing to the magnitude that took place with ADT and Res-hab.
 6. Shelly was asked if she could appoint a permanent appointee from her office to attend the FCCF meetings when she is unable to attend. Shelly agreed to do this. She indicated she would ask Denise Arnold whom she thinks would enjoy doing it.
 7. At the town hall meeting you stated provider rates were based on the GNP, a national group. If there is a rate reduction, where will this bring us? Our rates are in line with other states that have implemented similar rate structures and have similar demographics such as California and Arizona. She thinks there is also information in the question and answer document she will be sending the group. She shared she has seen some data out there that is only related to one portion of the rates. She advised it's important to note they get paid based on four components of the rates.
 8. Where are we on the supportive living waiver? Shelly stated they have it and it's under review with the feds. right now. They are very interested in expanding that waiver. They want to expand it by about 1500 people. Right now the dollar amount is \$500,000. Is there money right now to support new people? No, she doesn't believe so. The only way would be if new people came through as a crisis if they qualified for that waiver. She shared this month they had only 20 crisis applications so they are bringing on 10 people from the wait list.
 9. Is there a possibility of having a child vs. adult waiver? Shelly advised absolutely. She shared that most states have separate waivers particularly the DD population for children and adults. Often times waivers for children only include certain services such as respite. This is a result of children under the age of 21 have access to a broader array of services through the state plan.
 10. Mental Health type providers say they have been cut to ½ of what they received previously. Will their rate be improved in the future? If so, how much? Shelly shared they looked into this one and again it's a matter of some areas received an increase while others a decrease. As shared before, they are really in no position where they can increase anyone's rates until they get more claims data. Another thing found was that there are some mental health providers who should be billing Medicaid state plan, particularly psychiatrists.

11. How many DD clients have been incarcerated this year (02/03)? She believes the number that she sent to Ann was 53. One thing she is excited about regarding the ICG is more timely and accurate information on people's legal rights. This will also help with the efforts in response to the guardianship report and legal decision making in general. The question was asked if the 53 were part of the mentally retarded defendants program. It's highly probable that these people identified are now in that program.
12. What is the average per year direct cost per consumer being served? It's on average above \$25,000 per person.
13. What are the base rates in the ICG? They are still working with Mercer which is why they haven't released them.
14. When will the Independence Waiver be approved? She brought this up when meeting with the Center for Medicare and Medicaid. As she understands, they did do a sight visit which went very well. ACHA sent them the final information they requested a few weeks ago. No set date as yet.
15. What is the % or number decrease of consumers in DD program? Example: Overall DD population in Suncoast region was 20% is now 16%. Shelly asked if we were talking about the overall number being served. The answer was yes. She replied it's still about 25,000 people. **Shelly asked if she had given us all a copy of the "wait list" information. The answer was no. She'll send it to us. It shows how many people in each district are waiting for services.**
16. Can we see an employment agency that specializes in placing DD clients? She would like to see us invite Susie Hutchison from Tri-County to an FCCF meeting. She could really enlighten the group on the possibilities of individuals with developmental disabilities who want to work. Another person is Jill Houghland. She has a wealth of knowledge in employment and is located in Broward County.

At this point the telephone connection with Shelly was lost.

VI. ZERO TOLERANCE PRESENTATION – TOM RICE, DD PROGRAM OFFICE

Tom Rice was unable to attend the meeting so the presentation was done via a teleconference call. He provided us with an update as to where they are on the zero tolerance initiative. He gave a brief overview of the incidents that have occurred particularly in recent months within group homes, transportation, ADT programs involving sexual assaults and rapes of some of our individuals with developmental disabilities. He shared it's not a problem unique to Florida but a national problem. Some of the statistics found in their researching and developing the initiative were scary. The results indicated that somewhere between 70% and 90% of persons with DD are likely to have at least one incident of sexual abuse or assault at some point in their lives. He shared that all the information can be found on the DD program website. He suggested we check it periodically as they are updating it frequently.

The initiative consists of three areas:

1. Training and education – The goal is to get information out to all persons who have any association with individuals with developmental disabilities. The information is to make persons aware of the signs and symptoms that sexual abuse is occurring. They are looking to partner with Family Care Councils, providers, support coordinators, Dept. of Education to name a few, to help with the educational process. The FDDC has donated monies to purchase 50 training kits specifically related to this topic. The group that produced the kits will be providing a train the trainer session for the dept. There will be 2 sessions in Orlando on December 10th & 11th. A flyer will be sent out on Monday. Day 1 will be devoted to all state staff participants. Day 2 will be devoted to everyone else, Family Care Councils representatives, provider organizations (FARF & ARC), support coordinators and self advocates. Ann asked the question since this is all related to

the sexual abuse part of it, what about the exploiting part of it vs. self determination. It will not be a part of this particular module. Diane asked if this training could be incorporated with the training teachers currently receive in the school district. Tom stated they will be contacting DOE to obtain a copy of their training and borrow from it if need be. The dept. training curricula will be given to the DOE, ESE. The question was asked about the foster care program, if training will be incorporated into their training curricula. Tom stated yes. Patty asked what is the name of the company providing the training? It's called Austin-Safe Place. He will send Ann the website address so we can review the modules. The second part of the training piece which is not going to be focused on as much in the December train the trainer session is actual training and information to self advocates themselves. Patty shared her concerns regarding scheduling sessions with one type of individual attending one day and another type the next day. If you have all the same interest level people in the training, dept. staff people, DCF people, etc., they're only coming with one perspective and you're not going to get the questions that you would get from a very heterogeneous group of people to present to and the interchange in the dialogue she hopes will be available is going to be so limited. If you're concerned about space, open up the sessions to everyone and when day 1 is full, the remainder to day 2. Tom shared they had discussed that but it was decided to designate day one to state people as they would be more likely to discuss specific incidents that have occurred. Jadene reminded him of the problems with the ICG training because support coordinators were not included. They were inundated with questions from SC's that they had no answers. It's critical that if the state really believes in partnering with families and providers, the message that's coming out by segregating this training, for whatever the intent is not a good message. Tom shared he would share that with Shelly and Kerry. Ann, as a parent, shared she feels employees in Tallahassee lead a very sheltered life. She continued by saying the majority of staff don't get the full reality of what's going on, just what hits the newspapers. The consensus of the Family Care Council statewide is it needs to be a heterogeneous training. The operative word here is "partnering". It's going to be difficult enough getting people there during the week, they need to have a choice. Tom shared, good point. It was shared again the December train the trainer sessions are specifically for individuals who will learn the materials for the purpose of training the public in the future.

2. Address through monitoring and quality improvement - This entails training the district staff that are out doing monitoring. This includes medical case management nurses and LTRC monitors in residential facilities. This type of information will be included on the checklists they use. Looking and identifying potential signs or symptoms of sexual abuse and environments that would indicate possible "red flags" would create a need for follow up.

3. Look at possible rule and statutory changes – Tom indicated the general counsel had researched some exciting things going on in other states. The legislation they are proposing which is being done in 30 other states, it makes it easier to allow the submission of testimony from a person with a developmental disability, it allows that testimony to be submitted into evidence during court cases. They're looking to make some other changes in rule that take the licensed residential facility side, treat licensure as a privilege instead of a property right which is kind of how it is now. Basically that gives greater flexibility in insuring the dept. has quality residential providers. That's how it works with family safety/foster care. They're looking at allowing employers to have greater access to previous abuse information on prospective employees during the hiring process. They want to specify clearly the definitions of sexual misconduct, sexual abuse, and sexual exploitation in Florida Statute 393. Also document the reporting requirements. Ann shared the necessity of including persons in supportive living. She doesn't see how you can address sexual abuse and not address exploitation because of those in supportive living sexual abuse starts with exploitation. Tom agreed. Pat asked when training begins and abuse cases are identified supposedly there would be more reporting of abuse cases. Is the dept. putting anymore into follow up where

you'd have more investigators? In the past when she has reported any kind of abuse to the 1-800 number, the box is full and she doesn't believe there is any follow up. Tom shared they have been working with the people from the hotline and they are aware with any kind of abuse initiative they would expect more calls. He shared they follow their statute requirements but if we learn of situations where the call wasn't followed up on to call him. He shared they have a good relationship with them. Pat asked if they were also going to train the law enforcement on how to question a person who has been abused. Tom shared they have specific materials which include interviewing techniques. Patty asked if the group has additional suggestions, can they E-mail them to him. He agreed. His E-mail address is [Tom Rice@dcf.state.fl.us](mailto:Tom_Rice@dcf.state.fl.us) .

Chair Carroll suggested that if Pat was willing we would ask her to serve as our state representative in the discussions pertaining to zero tolerance. If the group has any questions, comments, suggestions you can contact Pat directly. She will then get the answers for us and periodically we'll ask her for a report. Pat agreed to do this.

VII. BUSINESS SESSION

Review of September 20th Minutes:

Chair Carroll asked if there were any changes or recommendations to the minutes. Patty advised Donna that Shelly has some corrections to the minutes that she hasn't sent yet. Ann makes a motion to accept the minutes. Mary Ellen seconds the motion. Chair Carroll asks if there is any discussion, changes, modification or errors that need to be address.

Page 6 - a typo, eight lines from the bottom - the word "weigh" should be "wave".

Page 9 – five lines from the bottom - change "ready for school" to "ready to leave school".

Page 10 – Item 11 first sentence – change "modern" to "moderate".

Page 12 – Line five under Policy and Procedures Committee – change "process" to "progress".

It was decided to table approval of the minutes until next meeting in order to receive Shelly's corrections. Ann asked if Shelly could give her the corrections, she would send them out to all the chairs and vote via E-mail to accept as corrected. Chair Carroll agreed to this. Chair Carroll asks that if you find typos, grammatical and structure changes to the minutes E-mail them to Donna prior to the meeting. She can make the changes and send out a final just before the meeting. The only items that should be discussed at the meeting prior to approval pertain to content within the minutes.

Financial Report:

Diane shared the chairs council was allocated \$7,500. To date, actual expenses total \$399.03.

As we don't have a structured budget as yet, any expenses will need to be approved by line item.

Diane makes a motion to allocate \$50 per meeting to cover material costs which includes purchase of office supplies such as folders, etc. Pat seconds the motion. The motion was approved by consensus. Another item to consider is the cost to rent a post office box in the amount of \$90.00. The purpose is to create a central FCC address. Discussion followed sharing some of the disadvantages to a PO Box. Another possibility would be to contract with another organization such as FND or a mail and copy center. Judy shared when thinking of communication issues, the subject of grant writing was discussed at the last meeting. It would be advantageous if the council would seriously consider obtaining grant monies to pay a director whose responsibilities would include maintaining of a PO Box, 1-800 phone number, public relations and communicating on behalf of the state FCCF. It was decided to table further investigation of renting a PO Box. **Diane asks for a motion to allocate \$450.00 for teleconference call expenses.** Ann seconds the motion. No discussion followed. The motion was approved by consensus. The council is planning on creating a 1 page document with the FCCF legislative platform listed to be sent to each of the 180 Florida legislators. **Diane makes a motion to allocate \$103.60 for postage stamps to cover the cost of**

mailing the platform to the legislators. Ann seconds the motion. It was asked who was creating the document. The communications committee will do this. The motion was approved by consensus. **Chair Carroll requested the budget committee present a recommendation on the expenditure of all available funds at the next meeting.**

Old Business:

Chair Carroll indicated it was his understanding that previously the Family Care Council has participated with Family CAFÉ in their planning process. It was shared this took place a number of years ago. Ann suggested that we offer a representative to be on that committee this year. Chair Carroll asked if the invitation still holds would anyone like to volunteer. It was shared the meetings take place in Tallahassee. Beverley pointed out the need for FCC participation to offer a voice representing adult children with disabilities. So many of the workshops are devoted to families with young children. Cathy shared the difficulties in communicating with Family CAFÉ in regards to the recently held Café Bistro series in Jacksonville in which she was asked by CAFÉ to participate on the planning committee. Chair Carroll advised with the consensus of the group, if an invitation is received and it makes sense, he will meet with them. Joan shared at the last Family CAFÉ there were no programs for consumers. There were no programs for families with adult children. She shared about 50% of the workshops dealt with transition. Judy suggested that we not wait for an invitation and contact them. **Chair Carroll offered to find out whom to contact and discuss with them preliminary matters. He will advise the council at the next meeting.** Ann shared that Rhonda Sloan has agreed to do the FCCF display table at CAFÉ again this year.

New Business:

Chair Carroll asked if anyone was attending the ADA conference in Orlando. Donna shared that she was attending the day of the FCC “train the trainer” program. He asked those who plan on attending might want to give an overview of the conference at the next meeting.

VIII. COMMITTEE REPORTS

Nominating Committee:

Judy advised the nominating committee will be sending out an E-mail and present a hard copy form for nominee suggestions at the January meeting.

Strategic Planning Committee:

Chair Carroll advised as a reminder the officers and committee chairs are members of the Strategic Planning Committee. He shared the Friday afternoon meetings are very constructive and open to all chairs if they want to attend. Chair Carroll shared a lot was accomplished in the committee meeting the day before. It was agreed upon that Family Care Council Florida needs a Mission Statement, a Vision and a Legislative agenda. Following is up for discussion among the council:

Mission Statement:

The mission of the Family Care Council Florida is to advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the department to bring quality service to individuals for dignity and choice.

Chair Carroll asked if there was any discussion. Everyone agreed it was a good statement. **Ann makes a motion that we approve the mission statement.** Cathy seconds the motion. There was no discussion. The motion was approved by consensus.

Vision Statement:

The American dream for all individuals with developmental disabilities.

Chair Carroll shared it's a given the American dream means different things to different people. A vision is different from a mission statement. The vision is like a "tag line" to our name, Family Care Council Florida --- The American dream for individuals with developmental disabilities. It's basically the council's "advertisement" slogan. **Ann makes a motion to accept the vision statement.** Mary Ellen seconds the motion. There was no discussion. The motion was approved by consensus.

Legislative Agenda - The strategic planning committee came up with a list of ideas. They felt the whole council should make the decision. Chair Carroll reminded the group the qualifiers were it needs to be two no more than three issues that the council can agree upon as a group to advocate, support and submit to Florida legislators statewide. Following is a list of ideas developed by the committee which are up for discussion:

1. Bill services
2. Wait list
3. Funding for DD needs
4. Guardianship
5. Vocational Rehabilitation
6. Supported Living Waiver
7. Transportation
8. Law Enforcement
9. The DD department should be a separate department of the state of Florida
10. Supported Employment/Medicaid Buy-in/Ticket to Work

Chair Carroll asked the communications committee to condense the above into three legislative goals, send out to all the chairs for approval/disapproval and once they are totally agreed upon by all in the group, prepare a 2004 legislative platform statement that once agreed upon will be sent to all legislators by the end of the year. He reminded everyone to remember to think about these issues from the legislative standpoint not your individual point of view. This will be a one page document from the FCCF that states the issues simply, 1 short sentence with a 1 to 2 sentence explanation. He emphasized the importance of studying the document, make sure you're in agreement with it, if not provide suggestions for improvement to Ann.

Financial Committee:

Diane asks that when anyone submits a bill to Wilma for payment, please send a copy to her.

Policy and Procedures Committee:

Beverley shared that the by laws state a time limitation on the length of the chairpersons reign. They felt it should apply to the other officers also. They will be working on that and submit a revised version by next meeting. They are still working on policy and procedures. Chair Carroll emphasized as indicated previously in the meeting the importance of having policy and procedures. It's an on going process as it's important they are done correctly the first time.

Communications Committee:

Ann shared to remember to turn in the evaluation survey sheets. The committee received some good comments from those turned in after the last meeting. They are adhering to these comments and trying to change the structure that the chairs suggest. The committee has three letters that have been planned through the strategic planning committee to be sent this month. One is advising of the council's name change which will include our new mission statement. The second one is to Shelly expressing the need for dept. representation if she is unable to attend our meetings. It will be

suggested in the letter to request Denise Arnold as her backup. At the moment it was unclear as to the subject matter of the third letter. Ann brought up the subject held over from last meeting pertaining to approval of teleconference calls by chairperson or vice chairperson. She stressed the importance of being able to communicate with the group between meetings. Chair Carroll expressed his concerns regarding teleconference calls. He feels this is where mistakes are made if things are done too fast. If it's something simple then OK but anything of a substantial nature will be held at council meetings with total group participation. Teleconference calls will be made only if it's something that needs urgent, immediate approval. **Ann makes a motion that the chairperson or vice chairperson may approve teleconference calls as needed for committee or board business.** Joan seconds the motion. Chair Carroll asked how the dollar amount approved in the budget for teleconference calls was determined. Diane will need an expense requisition per call. Ann shared probably the less expensive method would be to go through the dept. The cost would also depend on whether it's a full council or committee member call. The motion was approved by consensus.

Guardianship Committee:

Patty shared they feel that some of the issues in the working group report are on going and to be acted upon by the task force. She indicated they want to get in contact with the task force, determine who is on the task force, and see what kind of representation we have and where they are going with it. Also they plan on speaking to individual legislators to determine what knowledge they have of the issue. Also Patty indicated they are looking at it being a very long term task force for the council as this is not a quick fix.

IX. PUBLIC COMMENT

Joan asked if chairs could get a copy of provider and support coordinator lists from each district office. Diane shared the providers are listed on the state website. You can find them by your district and pull the information down yourself. It was shared that information is not accurate as it's not kept up to date. It was asked of Wilma if this information is available. Wilma advised she has been told yes it's available. **She shared she will work on getting these lists for us.** Joan also asked if the FCC district councils can get permission to do mailings. **Wilma shared she would follow through on this.**

Jadene asked Wilma about the **powerpoint presentation** Judy received from the Self-Determination conference pertaining to **Micro Boards**. Wilma advised she thought she had copied that information for us. The council remembers receiving conference documentation but the problem may be that this particular document was not included. **Wilma will check on this.**

Beverley asked if it would be possible to have meeting materials available to visitors who attend the meetings. Chair Carroll advised our meetings are open to the public and therefore extra copies of all meeting materials should be available.

Jadene provided each of the chairs with the updated Family Care Council Orientation Manual. She is concerned that some pages haven't been replaced with updated information. **She and Wilma will have to get together to determine if some documentation hasn't been included.** She shared after 3 years they now have revised FCC orientation materials. She shared that on November 18th, she and Wilma will be doing a training with the District 8 council. Included with the manual will be a powerpoint presentation which includes pieces of each of the chapters. She will also have a very short curriculum to be given to the district staff so they can train new FCC members. The intent was that the state office would create the training materials, then turn them over to each district office and they would be responsible for training new council members. They are trying to set it up so it's a one on one session rather than a group. She shared that JB has been talking with Teresa Davenport who has been doing some web based training for the dept. He would like the material turned into a one hour web based training for new members so it could be done over the web. She was asked if the intent is that each new member would receive an orientation manual. Jadene advised her thought was

the dept. would send 15 notebooks with dividers to each district because each council is allowed up to 15 members. After that it would be up to the district office to make copies for new members. This is still in draft form. She then went into a brief description of each chapter. Ann asked if HIPPA training was included. Jadene stated the manual has been set up in a manner for including future chapters, thus it would be easy to add a chapter on HIPPA training. Everyone thanked Jadene for all her efforts in creating the manual and for all her contributions while employed with the dept.

A welcome back party with decorated cake was held in honor of Jadene's return to the Family Care Council. Chair Carroll shared that Jadene is always welcome at our meetings and in the future we would like her to be in some capacity a part of the council.

X. ADJOURNMENT

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

NEXT MEETING - JANUARY 10TH, 2004

RESPECTFULLY SUBMITTED,

DONNA RAUBER