

## **FAMILY CARE COUNCIL FLORIDA**

### **PATTY HOUGHLAND, CHAIRPERSON**

**Holiday Inn Select Orlando Airport**

**Orlando, Florida**

**May 19th, 2007**

#### **MEMBERS PRESENT:**

Patty Houghland, FCCF Chairperson  
Bob Wessels, FCCF Treasurer  
Ann Millan, FCCF past Chairperson  
Joy Frazier, A1 Chair, FCCF Secretary  
Frank Carroll, A3 Representative  
Beverley DeStories, Suncoast Region Chair  
Donna Rauber, A7 Representative  
Maria Eash, A8 Chair  
Maryellen Jones, A9 Chair  
Jean Sherman, A10 Co-Chair  
John Montalvo, A11 Representative  
Phil Pearson, A12 Chair  
Betty Kay Clements, A13 Chair, FCCF vice Chair  
Pete Wesley, A14 Representative  
Todd Decker, A15 Chair

#### **STAFF & GUESTS**

Jane Johnson, APD Director  
Stephanie Kahn, APD Central Office  
Terri McGarrity, APD Central Office  
Lynn Carper, A1 Guest  
Michelle Passidemo, A8 Guest  
Diane Ciccarelli, A15 Guest

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

### **I. CALL TO ORDER**

Chair Houghland welcomed everyone to the FCCFlorida meeting. She began the meeting by reviewing what is included in the FCCF information packet. Items include the following:

- The Agenda
- Medicaid Reform article
- APD Central Office Telephone list
- FCCF Financial Expenditure Reports - discussion followed expressing concern that FCCF is currently showing a deficit amount. Questions were asked if area councils who have not used any of their monies could be transferred to FCCF. Also, emphasis was placed on the need to encumber monies now as any delay will result in purchases not getting paid with current funding dollars. Travel expenses to/from Family CAFÉ should be turned into area program office immediately after the conference. Otherwise, will come out of next year's budget. Chair Houghland expressed the need for area councils to show their support of FCCF by increasing the amount they donate and making that decision at the beginning of the new fiscal year. Without additional monies, FCCF will have to limit the number of meetings from six to four. She expects council approvals by July meeting. Ann shared that Chair Houghland has traveled to and from Tallahassee attending workgroup meetings and other conferences on behalf of FCCF. This will continue into the next year. Currently the Advocacy Center has paid her travel expenses. This is clearly a conflict of interest and at some point they're going to refuse to pay it. These expenses should be paid by FCCF. She believes it's time to request funding dollars for FCCF from APD. It was suggested to create a spreadsheet with projected budget expenditures to support and include with the request to APD. Bob advised he

would do the budget projections for next fiscal year to include 6 meetings. Maria suggested including in the proposal letter the educational advantages received by all in attendance at FCCF meetings due to the trainings, mentoring and guest speakers. Chair Houghland will wait for budget information from Bob and asks people for any ideas for future FCCF considerations to be included in the proposal.

- Overview of FHFC (Florida Housing Finance Corp.) Purchased Subsidized Loans
- First Time Homebuyer Program information
- APD Website Additions
- Supported Living Area Liaison contact information

Chair Houghland shared the procedure that will be followed during the question and answer period with Ms. Johnson.

## II. INTRODUCTIONS AND FCC UPDATES

Chair Houghland advised that she is allowing additional time per council to share with Ms. Johnson what their area councils are doing. Also, each person was given an opportunity to share some personal information about them and/or the person within their family who is responsible for their interest in developmental disabilities and the Family Care Councils.

**Frank Carroll, Area 3** shared they are currently working on getting all the information from the last legislative session and from APD for the purposes of developing an information forum for families in their area which will take place sometime this summer. The forum will include representatives from the area APD program office, support coordinators and others to answer the families' questions. They are in the process of writing a summary of the changes. They are currently working on establishing their next year fiscal budget to discuss at the next meeting.

**Maria Eash, Area 8** shared they have accomplished a lot this year. They established five committees with the strongest being their policymaking/legislative committee. They were very active with the E-mail process, attending DD Awareness day in Tallahassee and providing training for self-advocates who attended DD day. The other committees are operations, outreach events, membership and media/communications committee. They meet every month. They held a meeting this past Tuesday which resulted in the largest attendance (standing room only, she stopped counting at 55) they have ever had. Maria shared the flyer they sent which announced the meeting agenda subject being "New 4-tiered Waiver system, Wait List for Service, Where Do We Go from Here". She shared they have a new local community resource called Foundation for the Developmentally Disabled. 145 families have signed up to start working with their local FCC. Maria shared the various people who attended the above mentioned meeting. During the meeting they discussed the APD talking points. It was a great group discussion. Families really do want to learn what is going on within the APD program. It is the goal of their FCC to eliminate the fear of the unknown. Ms. Johnson shared how much she appreciates their concern for reducing the fear and de-mystifying the upcoming changes to the various programs. That is the main concern of the agency as well. She advised the bill isn't even signed yet and they really don't know the finality as yet but she plans on going through it today and provide as much information as she can so it can be shared with families. She advised to please let them know of anything that APD can do to help at the local level. Maria advised they have 2 follow-up meetings already planned, in Lee and Collier Counties.

Chair Houghland took this opportunity to introduce Jane Johnson, the new Director of the Agency for Persons with Disabilities (APD). She shared FCCF presented her with a good luck welcome gift and Ms. Johnson mentioned it sits on her desk and she gets inspired every time she looks at it.

**Phil Pearson, Area 12** shared their council is struggling with attendance and determining what to do. They are moving their meetings on a quarterly basis to different parts of the 2 counties. He created a newsletter announcing the meeting and 15 new people attended. Many of the

people acknowledged this is the first contact they have received in years. He plans on issuing newsletters on a quarterly basis as a way of communicating with families. Phil shared they provided the wait list number information in the newsletter and the phones rang off the hook at the APD program office. They used some of the funding dollars to support the local libraries in Flagler and Volusia Counties by purchasing 2 sets of training tapes from the Stansfield Company. The kids love to watch these tapes which relate to behaviors. Their FCC got involved in the Duval Home evictions by meeting with families to help with some kind of resolution. They have a good E-mail support list to go along with their website.

**Stephanie Kahn, FCCF Liaison with APD**

**Donna Rauber, Area 7** shared they have struggled this past year with FCC members being very involved with caring for their loved ones, work and other commitments. Consequently, we haven't accomplished as much as we would have liked to. She shared they did send five people including 2 self-advocates to DD Awareness Day in Tallahassee. They have established a mailing list of about 500 families which allows the council to communicate more effectively with them. Also, the council purchased a large quantity of the FCC "Believe in the Future" bulletins. She is happy to report that their local APD office staff attached the mailing labels and it was sent to 1500 people on the wait list. We are very grateful to them for doing this.

**Joy Frazier, Area 1** shared she has been chairperson for 6 years and will be stepping down the end of June. She advised that Lynn Carper will be the new chairperson. Lynn has been attending the past few FCCF meetings in order to make a smooth transition. They're local FCC has been working with their area APD office to re-develop a park that has been given to their area. It was ravaged by hurricanes and they are making it totally accessible to persons with disabilities. Their council meets every month. They have had a lot more success with better attendance this year which has included many providers. They are trying to increase their membership which is currently at 4 or 5 members. Their council does participate with the school system in the community service fairs, exceptional Saturdays in the different counties, etc. The council has a large E-mail list which results in many questions from families and she tries to point them in the right direction. She is also on the Supported Living work group with Deb Blizzard.

**Betty Kay Clements, Area 13** shared their council is very active. She shared her concerns, along with everyone else, about the very slow process for FCC member applicants to be approved by the Governor and his appointment staff. The gubernatorial appointments have just been non-existent. She shared people are interested in becoming members but the delay in obtaining approval results in them leaving the council as the appointment is important to them. Betty Kay currently has 4 self-advocates who have applied for appointments. There council has never had this number of self-advocates wanting to become members. They are so excited about becoming members but become frustrated with the long drawn out process. She has one individual who has been waiting for over a year and has still not received notice of approval or disapproval. Betty Kay emphasized this is not just a problem in area 13; it's a problem in all councils. Ms. Johnson expressed her concerns for the delay and advised she would check into the issue with the Governor's office. Betty Kay shared their council has been having some sessions with families regarding the proposed changes to the various programs as a way of reducing the fear factor. She shared at one meeting there were 30 people in attendance. She was prepared with the APD talking points. Unfortunately, only 1 person was on the waiver, everyone else was on the wait list. It was a good group discussion with everyone wanting to be a part of the solution. She learned it's very important to get the necessary information and resources to these people while they are on the wait list. Their council is very active in the legislative process.

**John Montalvo, Area 11** shared he is substituting for his wife, Margarita who is area 11 chairperson. He shared their 2 children's disabilities and the concern they have with the cutbacks, specifically the therapies they are currently receiving. As a substitute, he is unable to provide a council update. He is attending the meeting to observe and report back to Margarita.

**Jean Sherman, Area 10** shared they have been fortunate in Area 10 to have a very close working relationship with their area APD office, even prior to it becoming APD, since the inception of the Family Care Council. This year they are in a situation of having their FCC shrink for 2 reasons; (1) A lot of second term members rotate because the term has come to an end and (2) They share the same problem with Betty Kay as 4 FCC member applications have been sitting in the appointment office waiting for approval. As a result they have serious concerns about re-invigorating their council. On the other hand, they have more self advocates coming to meetings. Jean mentioned that self-advocates are able to attend the meetings because their NRSS service provider brings them to the meetings. The hope is with the service going away it isn't going to change their ability to attend meetings. They are very enthusiastic and will be good advocates who really want to be a part of the council. They have a very large contingent of providers who attend their meetings. Jean shared their council was very active in the legislative process with excellent responses from the letter campaigns, they sent 10 – 12 people to the rainy day rally in Tallahassee and several who attended DD day. Their council is involved in monitoring the Medicaid Reform since Broward is one of the pilot counties. They want to continue the same spirit and cooperation with the area but they need support from the state level to make sure the membership stays current so they can continue doing the educational work they do.

**Pete Wesley, Area 14** shared their focus the past several months has been on the Law Enforcement video. They were fortunate to obtain Dennis Debbault, the creator of the video, for a day long conference in Lakeland. The morning session was devoted to teachers, the afternoon for law enforcement and the evening for families. They had over 100 in total attend the conference. It was most helpful as there were many questions for Dennis to answer. They are currently working on establishing a satellite group in Highlands County. They also had a session at their last meeting on emergency preparedness for persons with disabilities as it's so important for them to get their names on a list for special shelters in the area. They are always recruiting for new members and currently have 2 in the application process. They will be sending people to Family CAFÉ and purchasing training equipment with the remainder of the funding dollars.

**Maryellen Jones, Area 9** shared their council participated in the APD conference last week with their exhibit table. She held a workshop titled "Got a Minute, Let's Talk" which focused on educating consumers and families on the importance of getting to know their local state legislators. The workshop included how to make the connection, how to know who they are and how to communicate with them about disability issues. The workshop was very successful. She shared their council is always looking for new members. She mentioned her second term ends in September and she is grooming a consumer to take her place. Maryellen shared that she and Rosalie Archer are creating a DVD on supported living and supported employment. The DVD will be available to other FCC's. She shared they interviewed a consumer the day before who is in supported living. She is a diabetic and it was most fortunate that her dietician and supported living coach were there to explain services. The purpose of the DVD is to provide examples of people living on their own with supports or working in the workforce with supports as a way of educating families in hopes of eliminating some of the anxiety level. Their Council is working closely with Special Olympics because they feel what is learned in SO can be helpful in teaching job skills. They are taking 20 consumers, 10 older adults & 10 adults coming out of school and creating powerpoint presentations on each to present to employers in the area. They are calling it a "reverse job fair" for employers to attend. Supported employment coaches and BLN representatives will also be participating.

**Beverley DeStories, Suncoast Region** shared their council is co-sponsoring with area APD a reception in Tampa on Sunday for Jane Johnson, APD Director. The event will include an information fair for consumers and families. Beverley shared the council was fortunate to have Ann Millan organize the event and she has done a wonderful job. Beverley also added her concerns with Betty Kay and others regarding the Governor Appointment issue. She has been

waiting 1-1/2 years for her appointment to be approved. She recently received a phone call but no documentation yet. She shared with the staff person from the Governor's office that prior to 4 years ago FCC appointments were automatic after 45 days. She asked why not consider going back to that method. It was pointed out that currently this process is not in statute and it would take legislative approval to change back to the automatic 45 days. Terri McGarrity advised she would contact the Governor Appt. staff person to see if the change could be made. Ms. Johnson mentioned it should be a legislative priority for next year. Beverley shared they have been very proud for the past 8 years to have over 50% of the council represented by self-advocates. They make sure the advocates share in the meeting agendas and discussions which results in excellent input from them. The minutes are being transcribed by a self-advocate with the help of her supported living coach. Providers also attend their meetings. Beverley shared that she currently serves on the Interagency Quality Council (IQC).

**Todd Decker, Area 15** shared he has been chairperson for a couple of years. He also introduced Diane Ciccarelli who is on their council, a support coordinator and very supportive of consumers. He shared they just received the Law Enforcement video so they will be going to law enforcement agencies in their area to give presentations in hopes they will purchase the video. He shared he was successful in working with a charity and radio station to purchase a van for a family who has several children with multiple disabilities. He was also successful in helping a parent make application for the Medicaid waiver and is now on the wait list. They just held their last meeting for this fiscal year and are always looking for new members. He will be promoting the Family Care Council through PR with local TV and radio stations.

**Bob Wessels, Area 10** shared he is employed by APD in Broward Co. as their Employment Coordinator, Florida Freedom Initiative Liaison, FCC Liaison and community outreach. He is also FCCFlorida treasurer.

**Ann Millan, Suncoast Region** used her time to share some FCCFlorida accomplishments. FCCFlorida created the "Believe in the Future" bulletin of which a box was sent to each area office for distribution but she believes they are just sitting in the offices because of no money for mailing. Terri mentioned Central Office is working on getting mailing labels of people on the wait list to the area offices. Ann added a lot of volunteer time and money went into creating the book. Ann shared the Law Enforcement video needs to be seen by everyone. It provides excellent examples of how to interact with people who have disabilities. Ann mentioned the need for Ms. Johnson to view this video. Terri advised they do have a copy at Central Office. Ann also mentioned that she and others have noticed recently and at FCC meetings that as a result of the law changes and the deficit there has been a resurgence of interest in support groups and families wanting to get involved. This can be a very positive thing.

Ann mentioned that Suncoast East currently does not have a Family Care Council. She attended their meeting last month. She advised they have a lot of FCC member applications sitting at the Governor's Appointment office. They can't form and become active until the appointments are approved and they have a membership.

Chair Houghland asked the guests to introduce themselves and share a little about the person within their family who is responsible for their interest in developmental disabilities and the Family Care Councils. Chair Houghland shared about her daughter.

### **III. APD PRESENTATION – Jane Johnson, APD Director**

Chair Houghland introduced Ms. Johnson and requested that she be given the time to share her comments of things she thinks are important for everyone in attendance to know whether it be legislative or how she envisions working with the Family Care Councils, what she would like to see from the Family Care Councils, etc. After her time, the role will be reversed allowing council attendees to ask their questions.

Ms. Johnson thanked everyone for allowing her to attend the meeting. She shared it has been a really helpful morning to listen to what we do and what is taking place in the area councils. She

mentioned her participation on the outside as an advocate with various disability work groups & task forces over the years. She provided the council with some background information about her so everyone would have an opportunity to get to know her better. She believes strongly in the Family Care Councils and is asking everyone for their trust and support. She wants us to feel good about who we are putting our trust and support in. She has a commitment that is heartfelt and long term and she knows she can't do this job without the support of consumers and families. She shared her personal awareness of disabilities came from her father who had polio and her sister whose son was diagnosed with Asperger's Syndrome. She was previously employed as Executive Director of the Florida Alliance for Assistive Services and Technology (FAAST), a statewide assistive technology program. She understands how important it is to rebuild APD programs to make sure the families who need help are getting the help and to make sure the children who have so much potential get their opportunities. She shared she didn't apply for the APD position, she was approached. While she was director at FAAST she shared some of their accomplishments which included successfully bringing the agency out of financial trouble. As a result she understands what it takes to bring in funds to establish fiscal accountability. She shared her respect and admiration for Governor Crist and the direction his office is taking with regard to APD is very different from what it was. She is very excited to be part of the turn around.

Ms. Johnson shared she has come to APD at a time when they're projecting \$156 million deficit in the Medicaid HCBS Waiver. She shared the various ways and separate categories in which APD receives their funding. The legislature is very specific when they allocate funds. The Medicaid Waiver dollars must remain in one category as that's how they draw down the federal match. It's \$.45 cents state, \$.55 cents federal monies to equal \$1.00. She mentioned the success of the Family and Supported Living Waiver (FSL). Monies left over from this waiver as well as any monies left over in the Individual Family and Supports General Revenue fund will be transferred to the big Waiver to offset the deficit. Diane asked Ms. Johnson what exactly is the budget deficit based on. Is it based on allocations in ABC or monies spent? Ms. Johnson advised there are three sets of numbers; (1) AHCA, (2) Economic and Development Research, and (3) APD's estimate. It's based on annualized spending over a 12 month period factoring in a level of utilization (a rate of growth per client for the total expenditures). She shared a chart was presented in one of the Senate committee meetings showing the total number of consumers served over a period of time compared to the cost of those services. APD has continued to serve the same number of people or slightly less but the costs of serving those same families as increased dramatically. The original cost plans have grown to a point that it's become impossible for APD to predict what spending will be from first to last part of a year. It results in uncontrolled or unpredicted growth. Ms. Johnson shared there were more than 65,000 cost plan amendments submitted during the year. They only serve 25,000 on the big waiver. What this means is either the original cost plans are not being done correctly resulting in not accurately accessing what a persons needs are or there are a lot of major life changes taking place. She hopes this helps everyone to understand APD has uncontrolled growth, a system that needs reined in. A lot of areas need to be reviewed very carefully. Ms. Johnson spent a few minutes praising the APD staff, many of whom have dedicated there whole lives to working for the agencies responsible for developmental disabilities. Ms. Johnson emphasized the importance for everyone to concentrate on the facts and manage the message. It's of utmost importance to educate families and providers with correct information. It does no one any good to over sensationalize. All parties involved need to act with a united voice which will show true credibility, especially with the legislature.

Ms. Johnson advised that APD did not support the 4 tiered waiver program. She shared she came before the legislators on multiple occasions and advised them the agency didn't think a tiered waiver system was the way to go. They would rather use a plan that could be implemented internally with input from stakeholders and work forward from there. They did ask

for full funding of the deficit but when it became apparent they weren't going to do it, they asked for at least enough money so with the savings they project they can finish the year in the black. She mentioned the bill that passed was very much provider driven. She shared it was very discouraging for the agency as they had no input on the 4 tiered waiver. She indicated that language was added to the bill stating if the bill didn't pass APD wouldn't get their money. Ms. Johnson emphasized the priority within the agency is helping families and getting people off the wait list. At this time she offered additional information based on the Talking Points on Budget and Session document. Contrary to what has been said in the press by some advocates and providers, the legislature didn't cut the APD budget, they actually received an increase. The reason it looks like a cut is the projected expenditures are so out of control but compared with last year APD got 15% more in the Medicaid Waiver. It's not enough to cover the projected expenses but it is an increase. Overall there was a 9% increase in the APD budget. She shared some of the increase is in non-recurring funds which means those dollars will not be received next year. Consequently APD either needs to get more dollars or cut back on spending. Otherwise they will end up in another deficit.

**SENATE BILL 1124:**

Ms. Johnson advised that everyone has a copy of the Legislative Wrap-Up Report which includes the Senate Bill 1124 language. She mentioned that none of the adjustments will cause anyone to become institutionalized. She wanted it to be clear and hopes the council can get the message out that APD is not a state bureaucracy; it's not budget people sitting behind desks. APD consists of a lot of social workers, doctoral students, service providers, family members of children with disabilities; it's a really unique agency. They are not about to cut off services to the very people they have dedicated their lives to.

Ms. Johnson advised the agency has tried to incorporate as many safeguards as possible in the plan for basic supports. She understands there are still questions regarding NRSS, companion services, etc. that need to be addressed. She shared the APD working group met on Thursday walking through every aspect of the plan, sharing with providers, consumers, families and the DD Council to make sure they're not doing something inadvertently that will be harmful to families. She advised, however, everyone will be affected. Hopefully it won't all be negative affects. She mentioned the services that will be eliminated; Chore, NRSS, Homemaker services but they are going to change the definition of In-Home Supports to incorporate some of those services into one package. She addressed the remaining service changes that are listed in bill 1124. Discussion included the Medicaid Waiver picking up services that are really the responsibility of other agencies. Examples include Voc Rehab and the school districts, specifically relating to IDEA. They need to be held accountable. Ms. Johnson shared every child is entitled to a free and appropriate public education through IDEA not through Medicaid. IDEA has the funding and should be picking up the costs for services and equipment the child needs. Two of the items included pertained to cost plan reviews and support plans being extended to one year beginning July 1, 2007. The purpose of both is to bring utilization under control and eliminate the need for thousands of cost plan amendments throughout the year. Discussion followed which included reference to the revised assessment tools, ICG & FSTS, which will result in a more accurate description of actual services needed which will improve both the support plan and cost plan implementation, provide an overall cost savings and improved program. Ms. Johnson mentioned an unanswered question at this time is who will administer the assessment tool. They don't think support coordinators should be administering the tool. They want a third party who does not have a personal or financial interest in what services a family receives. She credits Linda Mabile and Terri McGarrity on this one as what they are trying to do is make sure the administration of the assessment is a Medicaid Waiver service so they can get the federal match. They are trying to be as fiscally responsible as possible.

#### **FOUR TIERED WAIVER SYSTEM:**

Ms. Johnson advised there is no such thing as a four tiered waiver system. In talking with CMS they can't have a four tiered waiver, it has to be four separate waivers. That is why they have such a problem with the legislative bill because from a logistical and problematic standpoint it will be very complicated. What they will have to do is submit amendments to the FSL waiver (tier four waiver). The current waiver will be the tier one waiver (unlimited, no cap on services). The initial concern with this is the Medicaid waivers are designed to provide institutional level of care services in the community to people who would qualify for institutional care but don't want to live in an institutional setting. The only way it can be approved is if it's cost neutral. Cost neutral means the cost of providing those home and community based services must be equal to or less than the cost of providing the same care in an institutional setting. Ms. Johnson's initial concern is with four different waivers, cost neutrality is looked at for each waiver, not four in the aggregate, so you have tier four (FSL) waiver which is no problem as it clearly is cost neutral. There is no problem with the \$35,000 and \$55,000 capped waivers as the ICF rate is about \$120,000 a year. Her concern is whether they would get cost neutrality with the tier one waiver where you have the higher end consumers consisting of over 800 people receiving services costing more than \$100,000 a year. She shared how CMS arrives at determining cost neutrality and if that number is significantly above the institutional cost of care they will not consider the waiver cost neutral and reject it. If they reject that tier the other three tiers will be fine but what will they do with all the people with the most significant disabilities who are the most needy. If CMS would reject it the agency will have to go to the legislature advising they can't implement this. The legislature certainly is not going to want the most vulnerable individuals left without any services. Ms. Johnson shared it can take up to 180 days for CMS to approve a waiver application. AHCA submits the waiver applications not APD. Another piece of this process the legislature didn't think about and APD wasn't given the opportunity to explain is that every waiver has a provider application process. APD has 10,000 Medicaid waiver providers for the current waiver. With 4 waivers, each provider has to submit a separate provider application for each tier. That is a lot of processing for AHCA to do. Diane mentioned that in the federal waiver it states that family members can work and get paid, the CDC+ allows for this, she would like to see this in the regular waiver. As a support coordinator she sees far better services provided by family members than from people out to make a dollar. Ms. Johnson agrees with that but she really wants to see an end to the waiting list and one of the ways to get there is to really look critically at natural supports and not sub-planting natural supports with paid services and not contracting out for things family and community would normally do. She believes that is an important piece for APD getting to a place of equilibrium. Diane gave examples of situations that are not natural, a 65 year old Mother taking care of a 35 year old child or a sister devoting her life to caring for her sister. Ms. Johnson agrees and is not saying that it should never happen but she doesn't want to completely rely on paid services and ignore the important value of community and family supports can bring to persons with disabilities.

Ms. Johnson advised they do not have the applications written yet. They are working closely with AHCA. As mentioned CMS has 180 days to approve so it's difficult to say when these tiers will take effect. Before then, APD will be pulling together the assessment instrument for use. They will triage that process and work on different areas one at a time. The first area they plan to look at is residential habilitation. That's where most of the dollars are spent and where most of the people receive the service. They will conduct the individual assessment and come back with a new cost plan which may be more or less than what they are currently receiving. It will then become that person's budget and that person can choose the services they want to receive as long as they don't exceed the budget amount. Chair Houghland questioned when you say in the budget they choose the services, it sounds very open. She stated you still have to follow within the handbook. Terri advised there still will be the handbook and services will still have to be determined to be medically necessary but where the flexibility comes in is the individual can

make the changes within their own budget without having to go through PSA with a cost plan amendment. Chair Houghland is hearing within the community that this will result in CDC+. Terri advised it will not be CDC+. Ann voiced her concerns that APD is not going to hear the concerns of families. She is afraid providers will be telling families what to do. Providers will be losing dollars in their group homes. Ms. Johnson advised they have the same concerns as providers do have a lot of control and influence. She hopes they can rely on support coordinators and their ability to make sure the family is getting what they need. Terri suggested questions be sent to her and Linda. Any questions/answers can be put on the website. Frank mentioned that regarding any correspondence with families APD needs to rely on a family member, specifically Rhonda Sloan or someone like her, to communicate with families. Rhonda knows how to tell parents exactly what APD wants families to know so that families understand it and don't get mad. Ms. Johnson mentioned that communication with families is very important to her. She met with the IT person to discuss making the website more user-friendly. They plan on devoting much more time and money in developing better communications so that APD is the families' first line of information.

Ms. Johnson advised the first goal within APD is to get their financial house in order so they can accurately predict their spending so they aren't running a deficit. They have to demonstrate to the legislature they implemented the fiscal controls APD has been asked to implement. The second most important issue is the waiting list. It's stated that 300 people get added to the wait list every month, however, the numbers don't reflect accurately the need. Families are encouraged to place their family member on the wait list as a "place holder" so that when they age out of high school they can get the services they need. A lot of the people on the waiting list are not Medicaid eligible but they're still on the waiting list because at some point they may qualify. There are also people on the waiting list that can't be found. Every effort has been made over the past two years to notify them. They're still on the waiting list. They need to be moved off the waiting list. Parents need to be informed it is their responsibility to keep the agency informed of any change in contact information. If after a year, there is no contact then APD should be allowed to remove them from the waiting list. There are also people on the waiting list that are currently receiving some services on the FSL waiver. They need to be put into a separate category so that the legislature doesn't think they aren't receiving any services. They can still retain their spot on the waiting list but they shouldn't be counted in the total number. Then there are the people who decline when their number comes up because they are place holding. The child doesn't need services now but will in the future. The end result is they need to show the legislature that the number of people on the waiting is really smaller than they think. APD needs to ask the legislature if they can increase the dollars every year by a certain amount, within five years they may get to where they need to be. Terri presented Ms. Johnson with a proposal to re-do how they manage the waiting list. They would like to stop using numbers and just use dates people came on the waiting list. Phil shared his concerns, which are the concerns of many parents over the age of 60, as to what will happen to his son (who is on the waiting list) if Phil dies. His son is not in a crisis situation now but would be if Phil is no longer here to care for him. Chair Houghland advised the death of the individual's caregiver is automatic crisis. Phil advised the point is that folks his age don't understand that. He suggested if there was some written documentation that would assure them that when the parent dies the child will be placed somewhere and receive services, it would be very helpful. Ann asked where the crisis money comes from. Ms. Johnson advised the process and monies will come from the Individual Families and Supported budget. Ann asked for a dollar amount and would like that E-mailed to the councils as the crisis list is one of the major concerns of Family Care Councils.

**Additional Questions for Ms. Johnson:**

**FCC Reference in Medicaid Waiver Q&A:** Maria mentioned on the APD website under the APD about Medicaid Waiver, APD Questions and Answers on the Medicaid Waiver, Item Number 11 - **If I have a service cut under the new law, where can I get information to help**

**me replace the service elsewhere?** The answer mentions contacting the Family Care Councils about the new law and where to get replacement services. Maria questioned how does APD expect FCC's to do that without more resources. The opinion within area eight is this is a stretch, leading people to believe FCC can direct them to replacement services. Chair Houghland believes the thought was directed towards FCC's having developed some resource directories in the past. Terri advised she would ask that it be re-worded, made a little clearer. Terri provided everyone with a copy of these questions and answers and encouraged everyone to discuss this with their councils. Any additional questions not covered should be sent to Central Office, they will get answers and add to the website.

**Organizational Chart:** Chair Houghland asked Ms. Johnson if she could share the names of staff and their positions within APD that will make up the organizational chart. Ms. Johnson did provide many names and their positions within all the departments.

**Area 15 Administrator:** Todd mentioned that currently there is an interim director in their area 15 office. He asked if Ms. Johnson is planning on hiring someone to fill that position. Ms. Johnson advised they are planning on hiring someone permanently. She advised the person to contact would be Mac McCoy who is the Deputy of Operations.

**CDC+ Question:** Todd mentioned the CDC+ waiver is due to be renewed in 2008. He wondered if at that time additional consumers (specifically him) could be added to the waiver. Chair Houghland advised that will be addressed during the "J" waiver Discussion.

**Lack of Behavioral Homes:** Diane mentioned the lack of behavioral homes in her area. There is only one with 4 consumers with no step down program. Consequently they have people not getting the services they desperately need because of long wait lists for these services. People are sitting in jails and mental health facilities costing huge dollars because APD doesn't have placement available. Chair Houghland mentioned the same problems are in other areas including area one. They have never had behavioral intensive so those individuals end up in area 13. Ms. Johnson advised that is a tough issue. She talked to folks about possibly turning Sunland Mariana into a specialized center for Behavioral Focus and MRDP which would provide different levels of behavioral services. She doesn't have a solution at this time and it would require more money to make it happen. Another issue she struggles with is learning that within the state there are almost 2,000 empty group home beds. This is important to know as when providers threaten to send people to institutions or out on the street, it won't happen as there are plenty of empty beds currently available where they can be placed.

**Direct Care Staff Certification:** Frank expressed his and others concerns about the ongoing issue of direct care staff at ADT programs, NRSS, companions and in group homes. They can hire anyone off the street to do that kind of work. He has been asking for a long time that direct care staff who directly care of our children should undergo a mandatory certification and training process. He feels its well within the means and legal obligation to require this. Ms. Johnson shared the comparison with nursing homes where the average cost of care is \$31,000 a year. Nursing homes have much more regulatory requirements than group homes. They do it for less per month than group homes. Terri mentioned what Frank is asking for is more of a competency based training to demonstrate skills necessary in caring for individuals with developmental disabilities. Discussion followed sharing reasons why the nursing home comparison is not a good one. Ms. Johnson mentioned she is looking at different economic models where you have congregate care. Diane mentioned the comparison should be more towards the Juvenile Justice System where they have their secured and unsecured beds. That's really more like it and much more expensive. Chair Houghland summarized the ability of direct care staff on the needs of people with disabilities is very lacking. Licensing requirements only require direct care staff to have an eighth grade education which results in minimal pay. She shared she went to a group home and couldn't pick out the staff. It needs to be recognized and is a long term one that must be changed as to what direct care staff is required to do. It is very sad that the most important people in the lives of our people with disabilities are the least paid and nobody fights for them.

Ann believes the Interagency Quality Council (IQC) should take on the research of this issue. Ms. Johnson shared in reading the Delmarva studies the environment where outcomes are least likely to be met are group homes. She believes it's directly related to the staffing and level of staff. She also read where this includes abuse, neglect & exploitation within group homes. Jean mentioned she participates on an IQC committee that has researched data which shows that independent living and supported living have the highest rate of abuse, neglect and exploitation, not group homes. This data comes from actual interviews done with the consumers and the reporting of their concerns as well as from reported observations. In some circumstances Delmarva consultants called in abuse reports based on what they observed. This falls in line with elder abuse as well. Most elder abuse occurs in the family home not group settings.

**Non-Residential Support Services (NRSS):** Jean mentioned her concerns with the elimination of the NRSS program. She shared how beneficial the program has been for her son. She moved him out of an ADT program and it took about a year to find an appropriate NRSS provider where he is volunteering in a couple of community settings. What happens now as she doesn't see a companion taking on the same role as an NRSS provider. Terri mentioned the companion role can but it goes back to the qualifications of who is doing the services and what is expected from the service. Ms. Johnson wondered if NRSS providers might migrate into companion or other areas where they could continue what they are doing. Jean advised the pay is not at the same level. NRSS is a training goal with things associated with it. Companion is just a person to accompany a consumer.

**Provider Invoices:** Jean realizes this is an AHCA policy but providers have 12 months to submit invoices for payment. Isn't there some way to tighten that policy? How are you ever going to know what's been spent if you're constantly waiting until the last minute for provider invoices to be paid. Ms. Johnson mentioned another big initiative they are taking on is fraud abuse and false claims. They are currently working with the Inspector General's Office. Secretary Butterworth has offered his help also.

**Monthly Invoice Statements:** Jean mentioned that parents who are legal guardians do not get copies of the monthly invoice statements. Ms. Johnson shared she wants families to get a copy of the approved cost plan and monthly invoice statements. Families are the agencies best line of defense in terms of determining if services are being billed that weren't provided or if items are listed on the cost plan that you didn't request. Jean mentioned the monthly statements (summaries that come from the fiscal agent) are targeted to the representative payee by AHCA. Jean asked how can families' monitor it if they don't get the summary. Terri advised AHCA is getting a new fiscal agent so maybe the agency can work with them to see that families, legal guardians and SC's receive the summary in the future. Terri mentioned that she and Linda plan on working with SC's to see that families receive a copy of the **approved** cost plan.

**Governor Appointments:** Pete expressed how much it meant to her to receive a letter from the Governor's office advising of her appointment to the Family Care Council. It was important to her. She is concerned if the procedure for FCC members reverts back to automatic 45 day approval that we all go back to being second class citizens. Ms. Johnson shared she believes there is a lot to that. She doesn't believe the Governor is aware of the problems councils are having with appointment approvals. Terri advised from now on Central Office will be doing the press release when there is an appointment.

**Service Eliminations:** Maryellen mentioned her concerns with regards to the elimination of Chore, Homemaker and Supported Living Coaching services. Will there be a transition program established to allow current providers of these services to train the consumers on how to perform these services themselves? Without providers to do these jobs, consumers could find themselves living in filthy conditions. Ms. Johnson advised families need to be aware of these service eliminations in order to provide some guidance or make sure arrangements are made to fill in the gap when the service is no longer available.

**FCCFlorida funding:** Frank mentioned that area family care councils receive a yearly budget allocation. He shared that everyone attending FCCFlorida bi-monthly meetings are dedicated volunteers. He would like to request an increase in the area council's budget allocation but with that increase being designated to FCCFlorida. Chair Houghland advised she has already discussed this with Ms. Johnson. Ms. Johnson mentioned she thinks it more than reasonable. She asked the council to prepare a budget proposal.

**“J” Waiver:** Terri advised she spoke with Pam Kyollen and Daniel Rutherford about the change. She advised that currently the CDC is an 1115 demonstration waiver that is going away. AHCA has advised the feds. are not approving many 1115's any longer. What they are allowing states to do is to add the CDC option as a state plan service and narrowing the focus of the target group. Consumers currently on the CDC would move into this option under the 1915c waiver (current HCBS waiver). They will have the same amount of flexibility in terms of selecting their supports and services. There is no cost neutrality feature. Diane asked if consumers can be added on. Terri advised they certainly can at some point. When you add a state plan service it's available to anybody who gets Medicaid unless you design your target group. The target group would be consumers who are on a 1915c who have elected the “J” (CDC) option. It will be up to APD to expand the group when they do open enrollment again. Discussion followed with suggestions, current issues, and summary of latest developments within the CDC+ program.

Chair Houghland thanked Ms. Johnson for taking the time to travel to Orlando to meet with the council in person. Everyone is very appreciative of her time and efforts. Everyone is excited to have her as the new APD director and wishes her well. All agreed with their applause.

#### **IV. FCCF WORKGROUP REPORT**

##### **FCCF 800 Number:**

Chair Houghland advised the workgroup met the previous day. The FCCF 800 number that is being answered by a live person in both English and Spanish has been successful. Out of 30 calls they have taken and E-mailed to FCCF committee, 20 were returned in Spanish by Margarita Montalvo. Because this is a statewide number, Margarita is returning the calls using her personal phone or cell phone. Chair Houghland thinks it's the responsibility of FCCF to purchase phone cards for this purpose so Margarita is not paying the bill personally. Chair Houghland asked Bob if he could do this. Bob asked Stephanie if APD can purchase phone cards. Stephanie advised she would have to ask Barney. Terri advised she would ask purchasing what the ground rules are regarding phone cards. It was also suggested that Margarita could mark her phone bill to indicate which are FCCF calls and submit the bill with a request for reimbursement. Terri will research and get back to Chair Houghland.

Chair Houghland advised the procedure for distributing the calls to local area councils is as follows:

- The answering service sends an E-mail of notification to the core committee that a call has been received. The core committee consists of Chair Houghland, Bob Wessels, Joy Frazier and Betty Kay Clements. Of the four, whoever has duty, will look at the E-mails and send them to the area FCC chairs.
- The Area FCC chairs will receive an E-mail with the persons name, address, telephone number, county and a brief summary of the call. The area council, whether it is the chair or someone assigned, it is now their responsibility to return the calls.
- It is the area council's responsibility to keep a log of all calls made. The log will contain the contact information from the E-mail, the date and time the call was made to the person (if unreachable or left message), the date and time you actually speak to the person and a brief description of the phone call.

- The area councils will then submit that log at the FCCFlorida bi-monthly meetings. The core committee will be in quality control to make sure the phone calls are being returned. Terri asked if Central Office could receive a summary of the calls. It was decided to add Stephanie's E-mail address to the core committee and she'll track the calls for Central Office. Joy asked if Chair Houghland would be preparing a log template for area councils to use. Maria shared she has an Excel spreadsheet she uses for their log that she can send to Chair Houghland.

## V. ELECTION OF OFFICERS

Frank Carroll participated as moderator during the election process. Joy, chairperson of the nominating committee announced the slate of officers. The committee's recommendations are: Patty Houghland, Chairperson, Betty Kay Clements, Vice Chairperson, Joy Frazier, Secretary and Bob Wessels, Treasurer. Bob Wessels shared that at the last meeting he agreed to continue on as treasurer but since then has given it a lot of thought and due to a busy schedule and possible conflicts as an APD employee, he would like to withdraw his name for nomination. Frank advised the nomination committee's report with Bob's announcement stands as a motion to the council. The council will vote on the following officer positions:

**Treasurer** – The floor is open for nominations for the office of treasurer. Bob asked to nominate Maria Eash. Frank asked if Maria was willing to accept the position. Maria advised yes. Frank asked for any other nominations. There were none. Frank called for a vote. The vote was unanimously approved.

Frank asked for any further nominations from the floor for each remaining officer position. There were none. The remaining officer positions of Secretary, Vice Chairperson, and Chairperson recommended by the nominating committee were unanimously approved by the council. The officer positions for the next fiscal year beginning July 1<sup>st</sup>, 2007 and ending June 30<sup>th</sup>, 2008 are:

- Chairperson – Patty Houghland
- Vice Chairperson – Betty Kay Clements
- Secretary – Joy Frazier
- Treasurer – Maria Eash

## VI. BUSINESS

**Review of Minutes** - Chair Houghland asked if there were any corrections to the minutes. There were none. Chair Houghland asked for a motion to accept the minutes as submitted. Beverley makes a motion to approve the minutes. Phil seconds the motion. The minutes were approved by consensus.

## VII. CONFERENCE/MEETING UPDATES

**APD Business Plan** - Chair Houghland asked Frank to give a report on the APD Business Plan meeting he attended. Frank advised that Terri McGarrity invited him to attend the meeting in Tallahassee. He was there representing families. Meetings are also being held in Ft. Lauderdale and Tampa. APD hired North Highland, a consulting group, to review the system to determine where there were any log jams. With this information, APD is looking to develop a plan to operate internally more efficiently. The two programs involving the most discussion were the HCBS Waiver and Support Coordination. Frank shared with the group his concerns on needing to find an effective way to get rid of a bad support coordinator. Currently there is none. They need to find a way to get them out of the system. The plan is for APD to take all the recommendations from the three group sessions and combine them for discussion at another set of regional group sessions within the next few weeks. Terri advised there may be more follow up meetings in the future. Bob attended the session in Ft. Lauderdale. He advised, and Frank agreed, how impressed they were with the caliber of the people representing the North Highland

group. They were very well organized. Terri shared they spent numerous hours with APD staff getting to know the current system and where staff thought problems existed and changes needed to be made.

**Supported Living Planning Group** - Joy is representing FCCF at these meetings. Joy shared she attend her first meeting last week. Enclosed in everyone's packet of information is the following:

- Florida Housing Financing Corporation overview of Purchased Subsidized Loans in 2005 and 2006 – Utilization by Persons with Disabilities. She advised it's a breakdown of pertinent information pertaining to subsidized loans for people with disabilities. 57% of the loans were issued to residents in Orange, Gadsden, Escambia and Leon Counties. The information also included the average loan, down payment assistance and home purchase price of these loans.
- An information sheet pertaining to the First Time Homebuyer Program which includes a website link to the FTHB Wizard which allows people to input pertinent information per county to determine eligibility for home loans, how much can the person afford, and lender contact information.
- An information sheet from APD showing website additions pertaining to the supported living program.
- A listing of APD Supported Living Area Liaisons contact information

Bob asked to clarify that the information sheet from FHFC that provides information on subsidized loans for people with disabilities refers to all disabilities. Joy advised yes.

Joy shared the group consists of individuals representing various organizations including FFAST, FDDC, Florida Housing Coalition and a group representing the homeless. She is representing self-advocates and families. The purpose of the group is to find ways for making it easier for people to identify the necessary resources needed to access housing availability.

**Medicaid Reform Conference** - Bob attended the conference and shared the report provided in the information packet is well worth reading even though it pertains to Broward County as it's going to expand to other counties. The Jessie Bell DuPont Fund commissioned researchers from Georgetown University's Health Policy Institute to examine the impact of changes to Florida's Medicaid program. Bob is anxious to see the state's report to see how it compares to this report. Bob shared it doesn't look good because Doctor's are dropping out and patients aren't receiving services they need. Fortunately the developmental disability population is not included at this time. It would be disastrous based on current program.

Betty Kay shared how much the council has appreciated all that Bob has done for the council. Everyone agreed with their applause. Also a huge thank you to Patty for all she has done as our current chairperson and what she will continue to do this next fiscal year. Again, everyone agreed with their applause. Bob shared how much he has enjoyed being a part of the council. He assured the council he will assist anyway he can personally or professionally.

## **VIII. ADJOURNMENT**

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

The next meeting will be held on July 21, 2007 at The Holiday Inn Select.

**RESPECTFULLY SUBMITTED,**

**Donna Rauber,  
Florida Institute on Community and Disability (FICD)**