

1

**Family Care Council
Sun Coast Region, Pinellas & Pasco Counties**

www.fccflorida.org

July 17th, 2006 Minutes

Council Members Present:

Louise Reinecke, Brian Simpson,
Virginia Ruf, Beverly DeStories,
Sandy Carpenter, Rob Mochrie

Absent or Excused:

Judy Senick, Tyler LeClair,
Barbara Ireland,
Ronald Hutchins, Margaret Watkins

APD Liaison:

Zoharah Peters
Carl Littlefield

Board Meeting

Beverly DeStories called the meeting to order and asked those present to introduce themselves at 6:45pm. Sandy Carpenter was asked to lead the Pledge of Allegiance. There was a total of twenty-three present. Beverly DeStories asked the board members to stand up and they identified themselves. There wasn't an APD (Agency on Persons with Disabilities) Liaison present.

Business

Secretary's Report: May minutes were handed out to board members and are tabled until read and will be voted on next month.

Treasurer's Report: Per the APD Liaison and her handout, "Family Care Council Treasurer Report Fiscal Year 07/01/05 to 6/30/06 as of 6/30/06 – UPDATED 07/17/06 for FCC West and FCC East," FCC West has an unused balance of \$597.70.

Zoharah Peters needs a breakdown of what FCC West needs for funding this year. Beverly DeStories recommends for money to be set aside for the statewide FCC for: Financial Resources (to be set aside to help keep the website going; to pay for hotel rooms because they have increased so much; to pay for the brochures for the Providers Fair. Beverly DeStories would like to see more money from FCC West go to the Florida Statewide FCC. We need to see how is in charge of the money from the East. Zoharah Peters suggested that she get together with Beverly DeStories to make a list of needs with justifications. Zoharah Peters offered to come to Beverly DeStories to do it. Zoharah Peters can conduct some of the members from the East and see where they want the money to go.

Co-Chairperson's Report: Beverly DeStories was at a conference this weekend that Randy Wilcox from Children Medical Service attended as well. He represents the newborn-to-three-year-old population of Children Medical Services. Denise Arnold brought up the ABC System that has not been well maintained; for example, one-third of the yellow books were returned as undeliverable. Beverly DeStories state that the mailing list needs a concerted effort to bring it up-to-date. Funding needs to be set up to help keep it updated. Zoharah Peters said that we need to notify the families that they need to notify the APD that they are moving. This occurs with people who are on the waiting list and the people who are receiving services. Nancy Seiler suggested we should put a little change of address post card with self-addressed mailing post cards in our brochures. We need to help get it out. There are also a lot of individuals who are unable to read the information in the brochures.

Discussed the brochure that was printed up for CAFÉ by FCC. 20,000 more is what they would like to print up to give to people on waiting lists.

Old Business: Prior months' minutes were discussed. The minutes are typed up by the secretary and are current but require editing. The issues surrounding why getting them edited has been so difficult was discussed...personal reasons, issues with her NRSS provider not being able to go into Louise's home to work with her on the minutes due to the job description; the person who used to voluntarily edit the minutes no longer has the time to do so due to an illness in her family; etc...It is hoped that a new Administration Assistant is found, approved by the council and the state; and will be able to help the secretary with this.

(Continued on Page 2...)

2

**Family Care Council
Sun Coast Region, Pinellas & Pasco Counties**

www.fccflorida.org

(Continued from Page 1)

The Governor's appointment of FCC board members was discussed. Board member applications need to be notarized and scanned/copied. Beverly DeStories stated the status is that she turned in four letters of recommendation to Zoharah Peters for board members. Carl Littlefield has to write letters of recommendation for Beverly DeStories application.

How to get more people aware and interested in FCC was discussed. Delmarva does quality reviews. Inter-council gives points to providers who bring a consumer/family member because it needs to be about the families. Carl Littlefield suggested looking at other successful organizations. He gave an example of fishing and not just putting out a welcome sign to the fish but putting out bait. Beverly DeStories said food draws people. Nancy Seilor said there is still a block of confidentiality at the school levels. Zoharah Peters said she got invited to a social workers' meeting in Pasco County and Desoto meeting. When asked how was she invited to these meetings, Carl Littlefield said that it is because he made Zoharah Peters' position of Community Liaison; "She is the bait." Zoharah Peters said she has been asked to go to different agencies to speak about APD. She has also attended different fairs. Virginia Ruf suggested that we put together a short video/DVD to show for FCC utilizing a college. Nancy Seilor said a high school like Lakeland or Gibbs. Carl Littlefield said that this is a good example of a justification for money to go to Florida Statewide FCC.

Administrator Assistant: Angie Wulf-Liles voluntarily continues to send out announcements for the FCC, checks the FCC voicemail on the 800 phone line and returns calls until a new Administration Assistant is found and has time to apply for the position.

Program: No program, we had a discussion instead.

APD Liaison Report: New phone number and mailing address is: Agency for Persons with Disabilities Suncoast Region: 1313 North, Tampa, FL (813) 233-4313. She also distributed copies of "Reimbursement of Travel Expenses" memo and "FY 05-06 Waiver Enrollment - July 11, 2006." As of July 1st, 2005, there were sixteen thousand (16,000) on the waiting list. Ten thousand six hundred and forty-one (10,641) have been contacted so far; forty-six hundred and two (4,602) have not responded or declined. "This number includes people who are currently on FSL and did not wish to apply for HCBS or did not triage for the HCBS. Also reflected are people who decline enrolment by individual request, are not eligible for Medicaid, have moved out of state, passed away, or did not respond to our letter offering them enrollment." FCC board members would like to know the number/percentages of families how have to decline because they want to keep their individual at home instead of supported living and still receive big waiver funds and services. Ninety-nine percent (99%) of almost six thousand (6,000) have been enrolled. Legislation will still serve crisis cases and some Department of Children and Families cases, but beyond that very few will be added to the waiver.

New Business: Nancy Seilor read the following letter:

Family Care Council
Suncoast Region
Pinellas & Pasco Counties

To Whom It May Concern:

Re: single source provider of consumable incontinent supplies.

(Continued from Page 2)

At the June 2006 meeting of our Family Care Council there was a discussion about recent attempts to create a “single source provider of consumable incontinent supplies.”

Concerns expressed were:

1. “Nothing about us without us.”
That this effort to create a change that would effect families, people with developmental disabilities, and providers happened with none of us having an opportunity to inform AHCA of issues relevant to our needs.
2. Consumer choice:
In an era when we are emphasizing the importance of choice and self-determination such a move would reduce or eliminate choice for people dealing with incontinence in an area that is very personal and is a constant issue for anyone dealing with incontinence.
3. Elimination of competition:
We moved away from the single source provider of telephone services because of a belief that such monopolies reduce evolution of technologies and increase price. Incontinence briefs, etc. are a constant experience for these people and different brands feel very different on the body. It was suggested that we challenge AHCA and the legislature to spend a week in incontinence briefs. While in the short run it is believed that using a single source system might reduce price, we suggest that such a monopoly would halt the evolution of these products by eliminating consumer preference as a controlling factor and would eventually increase price by eliminating competition.
4. Service and individualization:
People who use incontinence supplies are each unique in their needs. In addition, each person varies from time to time in their CMS needs. Sometimes illness, bad days, etc. increase the rate of consumption. Local suppliers are better at being able to support people and families through these times. They can respond quickly to changes in needs. It is reported that some suppliers individualize delivery. They may deliver supplies to the home and to the day program if that is needed by the person/family. This kind of support is important to people dealing with incontinence and developmental disability who already have a lot on their plates as it is. This kind of individualized help validates the enormous contributions made by families. It says, “Let us relieve you of this one task; you deserve it.”

The conclusion at this meeting is that single source provider systems would be detrimental to the people we support and to the visions society has been pressing all of us to pursue. Certainly lowering costs is an important goal – one that government agencies, providers, families and people who are directly affected need to work on together.

No one had any questions and the letter was received by the council. Beverly DeStories entertained a motion to put on FCC letterhead and send to Shelly Brantley and the head of ACHA. Sandy Carpenter first and Rob Mochrie seconded it. All were in favor; it was voted unanimously.

Citizen’s Time: Ray Talicman said he would like to become a member of the Family Care Council. He was instructed on how to do this. A parent shared some Medicaid letters that were duplicates to show a form or waste in the government. There is no purpose for this and it is a waste of tax dollars. There was a brief discussion on how sometimes there is a problem with the limits placed on what a

**Family Care Council
Sun Coast Region, Pinellas & Pasco Counties**

www.fccflorida.org

(Continued from Page 3)

provider can do with a consumer. Louise Reinecke is currently having this as an issue as are other consumers. Louise is an FCC board member and Secretary. She received NRSS and has personal goal to advocate for persons with disabilities. She is to receive assistance with her role with FCC for her NRSS provider per her support plan to help meet this goal; but is only limited to keep the assistance out in the community. Louise has had computer training at the library from her NRSS in the past but would like to utilize her own computer at home to work on the FCC minutes. Louise requires training to be done in her home to show her how to transfer what she learned on the computers at the library onto the computer in her home, but her NRSS provider cannot do this and bill for this because NRSS is only to be done in the community and not in a consumers' home.

Non-Agenda Announcements:

Our next FCC Meeting will be on Monday, August 21, 2006, at 6:30 PM at UPARC, The Long Center. (1501 North Belcher Road, Clearwater, FL 33765.) All are invited to socialize at McDonalds after the meeting to fellowship and discussion.

Beverly DeStories entertained the motion to adjourn the meeting. Sandy acceded and Brian seconded it. All were in favor; it was voted unanimously. The meeting adjourned at 8:30 pm.

Respectfully submitted,

Louise Reinecke and Carisa Boyes

(Edited by Carisa Boyes after the fact.)