

# Family Care Council Florida

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## FAMILY CAFÉ 2011

Last year I gave a presentation at Family Café for our FCCF that focused on making sure that we do a good job of advocating for our people. You can view the actual presentation at

<http://fccflorida.org/fcc/family%20cafe%202010.pdf>

I figured that this year I would give, basically, the same presentation. Well, it didn't quite work out that way. I received a letter from Family Café informing me that we would be presenting not a separate session but part of a panel discussion, hosted by the DD council.

After much deliberation we all agreed that we would include the DD council (Margaret Hooper, FCCF (Phil Pearson), Disability

Right of Florida (Sylvia Smith) and the Florida Arc (Deb Linton). A formidable group of advocates! Next, we needed to find a moderator. We settled on Tom Nurse and sent him a request asking him to do it. Thankfully, he agreed.

We  
all



piled up our brochures and handouts at the back of the room. We discussed a number of topics, including the waitlist lawsuit, I-budget,

family advocacy and the results of the 2011 legislative session.

We had 27 people sign our attendance list which was very encouraging.

We got some good questions and hopefully helped a number of people.

I think that if we do a panel discussion next year we need to push for a 2 hour slot instead of 1 hour. We were just too pressed for time. And with the kind of questions that we got,

they all just had to be answered.

It was good to see all of our FCCF friends at the session so keep coming.

## WEB EX CONFERENCE CALL WITH APD

A few weeks ago, APD scheduled what is called a "web ex" conference call with the FCCF. My first reaction was not good and my expectations were pretty low. I knew that the content was not going to be pretty

because we were talking big budget cuts.

Even though we did talk budget cuts, I thought that the meeting logistics were pretty good.

Basically you call into a con-

ference number like usual but, in addition, you also log onto a computer conference service called web ex. On this service you can view the power point slides being shown as well as a video

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### Summer is here!

- Now is the time to visit your legislator
- Now is the time to re-energize your FCC
- Now is the time to join your Arc

# WAITING LIST LAWSUIT

A few months ago, I received a call from Patty Houghland asking me to come to Tallahassee to talk with their panel of experts on the wait list lawsuit. Immediately upon hearing the word "Tallahassee", my stomach said ugh!, not again. But on second thought it certainly would be worth it to help those on the waitlist.

First, I was surprised to hear that someone has actually launched a lawsuit against the state. Second, I was also surprised to be asked to talk with anyone about it. Betty Kay and Deb Linton were also asked to testify.

The organization pulling it all together is Disability Rights of Florida, or what used to be the Advocacy Center. They have a long history of representing the disabled and their rights.

A snippet of the plaintiffs and defendants is shown here.

Most folks on the wait list have been there more than 5 years and have little hope of being served in the least restrictive environment until they enter "crisis". This, of course, is inevitable when their caregivers die or become too sick to take care of them or themselves.

Consider the trauma of ripping the disabled person out of the family home when the caregiver dies. Consider the emotional damage done to the elderly child under these circumstances. Consider the trauma and damage done to

the elderly caregivers as they struggle to take care of their children and the fear of what will happen to their children when they pass on. Cruel and unusual punishment if you ask me!

Consider also the plight of those in an ICF who in all likelihood will never be integrated into the community with the state policies currently in place.

And just think about how unfair it is to create a new set of classes of Florida citizens. Those that have the waiver and those that don't.

names of the experts, but they were a group of about 6 people chosen because of their expertise in helping with similar lawsuits around the country. Very knowledgeable and personable folks.

They were easy to talk with and wore out numerous pencils taking all of our info down.

Oh, and another thing. This is a federal lawsuit, not a state lawsuit so what is at risk for the state is the federal funding that they get. Hopefully this should be enough of a concern that the state will consider settling and enrolling all of our waitlist families on the waiver.

*(Web ex Continued from page 1)*

feed of those presenting. Add to that the real time chat feature with other participants and I thought that it was pretty neat.

Of course, it can't beat the regular meeting, but to save money and present info it was pretty good.

I look forward to more of them. Here is a screen shot of the conference.

UNITED STATES DISTRICT COURT  
NORTHERN DISTRICT OF FLORIDA  
TALLAHASSEE DIVISION

JOANNA DYKES; DAVID WALKER,  
by and through his next friend, Michele  
Beauregard; HEATHER YOUNG, by  
and through her next friend Robert Stark;  
MICHELLE CONGDEN; AMANDA  
PIVINSKI; and DISABILITY RIGHTS  
FLORIDA, Inc., a Florida non-profit  
corporation,

Plaintiffs,

v.

CASE NO.:

ELIZABETH DUDEK in her official  
capacity as Secretary of the Florida Agency  
for Health Care Administration, and  
BRIAN VAUGHAN in his official capacity  
as (Interim) Director of the Florida Agency  
for Persons with Disabilities, and  
RICK SCOTT in his official capacity  
as Governor of the State of Florida.

Defendants.

Taken directly from the court document:

13. The plaintiffs seek to remedy the pervasive systemic and continuing failure of the defendants to provide necessary services in a reasonably prompt manner to meet their needs, as required by the integration mandate of Title II of the Americans with Disabilities Act ("ADA"). See 28 C.F.R. § 35.130(d).

14. The plaintiffs seek a declaration that denial of adequate services with reasonable promptness and the denial of freedom of choice of those waitlisted persons violates Title XIX of the Social Security Act, 42 U.S.C. § 1396a *et seq.*, 42 C.F.R. § 431 *et seq.*, the Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.*, and 42 U.S.C. § 1983.

The Disability Rights Travel folks did a great job of setting up the hotel and other logistics. All that we had to do was get there. I don't remember the

*Just think about how unfair it is to create 2 classes of citizens, those who are on the waiver and those that aren't.*



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We're on the web,  
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