



# Family Care Council Florida

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## Who Are We, Anyway?

By Phil Pearson

Here I was, worried about what to write about for this newsletter. I guess that I shouldn't worry so much because the "ugly" always raises it's head. Just like bad behaviors, you can only hold them down for a while, then something happens.

In 2007, when Senator King was still alive and my senator, I was on a letter writing campaign to bring attention to the waiting list issue. I wrote to Senator King who promptly forwarded the letter to APD in Tallahassee. The letter was in reference to legislation putting foster kids ahead of those already on the waiting list. I didn't understand it and wanted to know why King voted for it.

Well, someone from APD wrote me indicating that if they get these kids early, they could fix them. This is funny in itself because it was the first time that I had someone tell me that they could fix mental retardation.

But, that's not the point. The point was that Senator King washed his hands of my questions and passed the buck on to APD. In a later meeting that I had with him, he pointed out that DD

was not his expertise and that I should go to another Senator for help. He did not get it. He was my senator and, as such, should develop the expertise and work the issue, whatever it was.

I just saw this happen again with another legislator, one that I know and one that supports us.

I went to a local advocate meeting where we had quite a discussion. All of the parents were upset. Apparently a child of one of the parents there was expelled from his day work program. Now, this person is on the wait list and has no other day activity. He would get up during the day and walk around so the staff had to get up and go get him and tell him to sit down. A really tough job but apparently the staff person

didn't like it. Bottom line is that he was out because of a behavior. No hearing, no alternatives, no nothing!

Parents at the meeting were scared to death that if they could do it to one student, no student was safe.

A few months earlier we had a Family Care Council meeting where our AA introduced his new behavioral specialist. That parent was there and explored the idea of the specialist stepping in and providing some behavioral counseling to both the staff and his son.

For whatever reason this did not happen. An opportunity lost for the local APD. They could have helped someone on the wait list. But again, that's a story for another day.

I also suggested to the par-

## ibudget—Wa(i)ve(r) of the Future

By  
Hilary Brazzell, APD

Unbelievably, it's been just *one year* since APD first gathered a group of 16 stakeholders—individuals with developmental disabilities, family members, waiver

support coordinators, large and small providers, and advocates—to begin building a new waiver system. What happened during this

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### This Month's Action Items

- Visit your legislator
- Attend your local FCC meeting and the FCCF meeting
- Start working with your local Arc
- Support ibudget
- Don't give up!
- Think about highlighting your local FCC in the next newsletter

**MY LOCAL Arc**  
BY  
PHIL PEARSON

I joined my local Arc a few years ago so that my son could take part in some social and entertainment opportunities. Another reason was to introduce these parents to our local FCC. Attending the meetings gave me an opportunity to both meet the people and give them an update on what was happening (or not) with legislation and other issues pertinent to them.



enjoyment to people who need it. I suppose that this decision will be continually revisited as we move into the future but for now, that is who we are.

The impact was high-lighted to me when Sandy and I and our son, Bill, attended our ARrcs yearly dinner/dance. It was held at the Portuguese-American hall in Palm Coast. I just couldn't believe the attendance. It was a large hall and was filled wall to wall with all kinds of folks.

It is a great group of parents who work very hard to provide these opportunities for our kids.



What a great time. It made me proud to be a part of the group.

Our Arc is a bit different from others. We are not a service provider. We only provide entertainment opportunities for our "special friends". Not very earth shattering and we certainly don't make any money but we sure help provide a lot of

You can visit our website at:

[www.arcflagler.org](http://www.arcflagler.org)

**President Obama Signs Rosa's Law**

Contributed by Deb Linton, Florida Arc

President Barack Obama has signed into law Rosa's Law, which will change references in federal law from *mental retardation* to *intellectual disability*, and references to a *mentally retarded individual* to an *individual with an intellectual disability*.

Rosa's Law replicates a law recently adopted in the state of Maryland. The family of Rosa Marcellino, a nine year-old girl with Down syndrome, worked with their state representative to pass the legislation in the Maryland General Assembly. Shortly before it passed the Assembly, Senator Mikulski met Rosa's mother Nina Marcellino at a roundtable on special education. Senator Mikulski promised that if Rosa's Law passed in Maryland, she'd take it to the Senate floor.

Legislation will be introduced in Florida to change terminology in state statutes as well.

**Attend a Legislative Debate**

By Phil Pearson

Last year our local FCC held a legislative forum. We had a few legislators, and some aides but, overall, not a lot of attendance by legislators. We had about a dozen or so people attend and we got to tell our stories but we didn't feel that we had the impact that we should have. We vowed to do better next time.

We thought that part of our problem was that we had the event at the end of January so we decided to move it back to October before any elections. This, we reasoned, would give info to our families about how to vote.

Scheduling went fine until we got an

email from one invited candidate that he was booked at the same time on the same date, in the same building in another room for a legislative debate for the Palm Coast Civic Association. It never dawned on us that other organizations were doing the same thing.

To make a long story short, I cancelled our forum (after writing invitation letters to 12 candidates) and our FCC send post-cards to all of the Flagler families in the APD system inviting them to the Civic Association forum. In addition, we generated a set of questions for the association to pass on for the judges, school board and legislative candidates.

This worked out great! We had our questions asked, we had our folks at the meeting and the civic association set it all up.

I wondered how this would all go during the debate.

I showed up early and met my counterpart for the civic association and took my seat. I was later joined by Rosemary and Irene and Fred and our AA, Ed.

First up was the judges. The decision was made to not allow audience questions for them. I am not sure I understand this but that is the way that it was.

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Join and support your local Arc!

*(Who are we, anyway? Continued from page 1)*

ent that they contact their legislator and ask him to help with the issue. I figured maybe a phone call to the day program or the local school. After all, the legislator approves the adults with disabilities grant that funds this program.

Boy, you guys are smart! You guessed it again. The legislator's staff referred the parent to APD. It is like a cat chasing its tail.

This prompted me to write a letter to the legislator pointing out that he should not just refer families in trouble to state agencies, like APD. APD only provides help to families that have Medicaid Waiver funding. Those that don't are told—sorry, no funding, no help.

So, there are a few things that need to change here.

First, our legislators must never just refer our citizens in need to a state agency without following up personally. They seem to have the impression that just because they created the Agency for Persons with Disabilities that they would naturally help someone that asked. I guess that we need to change the law so that this actually happens.

And the second is that we DO need to change the legislation so that APD actually helps families that ask.

So, now you know the rest of the story. Who are we anyway? Certainly the legislators don't know. They don't even understand the detailed workings of their own agencies.

Did you make your appointment to talk with your legislator? You need to because it is the only way that they will know who we are.

*(Legislative debate Continued from page 2)*

This debate was fun. Put 4 lawyers in a line-up and hear them take positions on issues and it quickly becomes clear who you will vote for. I didn't think that it

would be this easy or obvious. I don't know if the result is correct but it made the decision making process easy.

Only one judge really knew what a developmental disability was. One was a "strict constructionist" who answered every question by saying that he would go back to the constitution to figure out his rulings. There was not even a hint of a heart in this person. Another one sneered and made faces during the entire debate. Another was obviously a "sleeze". You get the picture.

During the legislative part of the debate we had legislative and senatorial candidates. None of them had a clue except for Representative Proctor who has been working with us for the past couple of years. One of the candidates pointed out that he was an expert because his transportation company had given some of our people rides in the past. Kind of like "I had a friend that was one".

When the senators spoke, we got to see some real political footwork. It was really entertaining watching them try to cover their tracks. I don't think that they have ever had to answer these types of questions before.

I sat there and was thinking to myself—"my God!". But, I must say that there were a number of good things that happened here.

First, for the first time, I knew who to vote for amongst the judges. Second, our issue of DD was raised at these debates. Third, some candidates were visibly embarrassed because they didn't know anything about the issue. Fourth, our people were there watching what was going on.

This only a start! We need to keep going and keep asking and keep

bringing up our issue.

*The debates were informative, and entertaining to say the least!*  
**Schedule and/or attend one in your area!**

Schedule and/or attend a debate in your area!

### Highlighting Area 1 FCC

By

**Michelle Gross, FCC1 vice-chair**

Area 1 FCC held their monthly meeting on October 21st at the Silver Sands School in Fort Walton Beach with a local attorney, Tracy Strom as our guest speaker highlighting information everyone needs to know about guardianship and less restrictive options.

Area 1 encompasses the four counties of Escambia, Santa Rosa, Okaloosa, and Walton. Since almost all meetings are held in Escambia County it was important for us to venture east and try to include the folks who normally are unable to attend. We hope to increase our Council membership thereby increasing our ability to reach further into the service community.

To stir up interest this past year, Area 1 has brought in speakers on a variety of topics such as transition services, recreation opportunities, Social Security, transportation issues, guardianship and other legal options. In November we will host guests from local support groups such as UpSideToDowns, Autism Pensacola and the Civitan Club. In December we will hold a business and planning meeting.

The majority of the Area 1 council members are "newbies" and while we may have struggled a little this past year, we are hopeful for a more successful 2011!

(I-Budget Continued from page 1)

past year, and where are we today?

We had 5 in-person, 2-day stakeholder meetings, and 4 conference calls to develop the ibudget Florida plan and policies.

We wrote a 216 page plan (online at [www.apdcares.org](http://www.apdcares.org); click "ibudget Florida" icon on the right) describing our vision for the new system.

We had 12 public meetings across the state to get feedback from individuals, families, waiver support coordinators, providers, and advocates on the ideas and draft plan.

The Legislature approved the ibudget Florida program, and the Governor signed it into law!

We wrote an application for a new waiver and gave it to the federal government, which has already begun reviewing it.

We chose the initial phase-in area—Area 2B (Leon, Gadsden, Wakulla, Taylor, Franklin, Madison, Liberty, and Jefferson Counties). We began sharing information with the individuals, families, waiver support coordinators, and providers in these counties.

We created a video to tell people about ibudget Florida—view it at <http://apd.myflorida.com/ibudget/video/index.htm>.

We almost finished the first phase of a new online ibudget Florida system. This system will help individuals, families, and waiver support coordinators have more choice and control over services and help speed the process of service planning and approval.

We've begun the rule development process.

So what does this mean? It means that APD is well on its way to making ibudget Florida a reality! Since ibudget Florida is in state law (s. 393.0662, F.S.), APD can expand ibudget Florida across the state. Once the federal government approves our waiver, the agency will begin transitioning people in the first eight counties mentioned above to ibudget Florida. After APD has tested and refined its processes and policies with the first group, the agency will begin expanding across the state. When ibudget Florida is fully implemented, the tier system will go away.

What is ibudget Florida? It's a way for APD to better manage the waiver system, while giving customers more flexibility. Individuals will get an allocation of funds, or budget, at the beginning of the service plan year. They will choose how to spend it on waiver services. Waiver support coordinators will still assist individuals and families. With our new online system for developing and reviewing cost plans, in many cases service approval will take as little as one day.

ibudget Florida is designed to give individuals more self-direction and to be simpler, more equitable, and sustainable into the future. Will it give individuals and families more choice and control with how they use their waiver funds? Yes. Will it help them get their chosen services faster? Yes. Will things be perfect for individuals under ibudget Florida? Unfortunately, nothing is perfect. Will ibudget Florida fix the funding problems due to Florida's tough economy? No. Will it help the waiver program be around for the long term so it can serve individuals with developmental disabilities far into the future? That is the goal!

ibudget Florida will be for individuals who are currently enrolled in a waiver. Individuals in CDC+ will receive an ibudget Florida allocation but will follow CDC+ policies in using the funds.

APD will continue to provide information to customers about ibudget Florida in the future. In the meantime, visit our website at [www.apdcares.org](http://www.apdcares.org) for more information or to submit questions or comments.

### ibudget—my take

By

Phil Pearson

I was part of the original team that worked on the development of the ibudget along with Betty K, Patty and many others. I really liked the way that Jim D. included all of the players and I wish that the legislature could do the same with other issues that affect us.

I see this ibudget as a way to fairly and equitably distribute the funds that APD has control of to families on the Medicaid waiver and is, essentially, the second part of the grand plan of support for our community in Florida. The first was the re-prioritization of the waitlist and the third is mobilization of our families to support getting more funds as we come out of this economic recession.

In addition, as APD proves that it can do a good and fair job, I am hopeful that the legislature will see this improvement in credibility through new eyes and votes to give us more funds, which will, of course, go to families on the waitlist in the new priority order as established by the legislature a few years ago.

So, I think that we all need to support this new ibudget, both on and off the Medicaid waiver. It is in all of our interest.

The questions that now need to be asked are how ibudget relates to managed care. I would sure hate to see a good plan thrown out for something that we don't have a clue about how it will affect our folks.

So, think hard and keep asking good questions. And, of course, keep meeting with your legislators. They still don't know who we are and, I think, would really wish that we would




## MEMORANDUM

DATE: November 9, 2010

TO: Family Care Council Members

CC: Area Administrators  
Area Family Care Council Liaisons

FROM: Tamara Demko   
Chief of Staff

SUBJECT: Updated Family Care Council Travel Policy

Thank you for your ongoing commitment to our mission and willingness to "advocate, empower and educate" individuals with developmental disabilities and their families.

As you know, the Agency for Persons with Disabilities (APD) has designated a portion of its funds to assist the Family Care Councils (FCC) in fulfilling their mandated purpose.

Due to the state's current budget situation, strict guidelines have been placed on state agencies to limit the amount of taxpayers' dollars being spent on travel costs. Additionally, the Executive Office of the Governor clearly expresses that state funds shall not be used to pay for travel to foreign countries, other states, or conferences unless the Agency Head has approved in writing that these activities are critical to the agency's mission.

Although FCC travel is deemed critical to the mission of APD, all councils must comply with state expenditure requirements (Section 393.502(9), F.S.). APD is committed to supporting the FCC in accomplishing their statutory obligations and will continue to approve travel requests related to attending the local and statewide FCC meetings.

Travel request for conferences and out-of-state meetings require Agency Head and Governor's office approval. Please submit these travel authorizations (following Area Administrator approval) to Stephanie Rogers, of External Affairs, a minimum of two weeks prior to the date of travel. This includes in-state

conference requests as well. External Affairs will inform the area office and traveler once a decision has been made.

Please note that all authorizations must be approved prior to making any travel arrangements. Also, FCC members should make every effort to limit the costs of travel including but not limited to the following:

- 1) Members should consider sharing either a rental car or vehicle when traveling for the same purpose.
- 2) Always compare the cost of a rental car to the mileage costs of driving one's own vehicle. Often times, the rental car is a much better deal for the taxpayers.
- 3) Hotel costs should be the most economical possible which may or may not be where the actual meeting or event is being held.

Thank you for your prompt attention to this new approval process. Together we will continue to advance the mission of APD to better serve persons with developmental disabilities in living, learning, and working in their community. If you have any questions, please feel free to contact Stephanie Rogers of my staff at (850) 414-6558.

## FCC Travel, an editorial

Phil Pearson

Well, last week we received the memo detailed to the left of this column. It was generated after a few of our FCC members attended a conference in another state.

Their plans and proposed expenses had been approved by their local counsel and local office so it was assumed that everything was AOK. Guess not. Shortly before taking off, word came down that things were not approved. What a mess!

Bottom line is that we think that the travelers will be reimbursed for their efforts but aren't quite sure just yet. This kind of hassle has been going on in various areas for quite a while and it is about time that it got fixed.

Now keep in mind that we have talked about creating a set of policies defining how we and APD interact.

So-o-o-o, this is actually a good thing. Before, we didn't have anything written down about what we could or could not do regarding travel. Now we have something that defines it. We may not like the restrictions, but we have something to work from and change.

Since we receive our funding from APD and since it is taxpayer funds, we really do need some oversight on what we spend our money for, how much, etc. Everyone is accountable to someone. We may not like it but it does make fiscal sense.

We do, however, need to continue to question and define exceptions to this policy, especially when it comes to working with the legislature. In that case, we will not have 2 weeks in which to get permission to attend.

So, let's suck it up, resign ourselves to now having a written policy, and start a dialog with APD about what changes need to be made.

Then move on to the next policy that needs to be written down.

Onward and upward.

Florida Family Care Council  
PO Box 300100  
Fern Park, FL 32730-0100  
800-470-8101

We're on the web,  
[www.fccflorida.org](http://www.fccflorida.org)



## CALENDAR OF EVENTS

11/2/10—Election day

11/16/10—Legislature meets for purposes of organization

11/19-20—FCCF Meeting, Sheraton Suites, Orlando

1/14-15/2011—FCCF Meeting, Sheraton Suites, Orlando

3/8/2011—  
Legislature Convenes

- Attend your local FCC meeting. It could mean the life of your child.

3/18-19/2011—FCCF Meeting, Sheraton Suites, Orlando

5/7/11—Legislature Adjourns

5/20-21/2011—FCCF Meeting, Sheraton Suites, Orlando—FMA of legislative session and plan for 2012