

Family Care Council Florida

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YOUR FCCF AND THE LEGISLATURE

By Phil Pearson, FCCF Vice Chairman

OK FCC's

During the last 2 years we have been trying to figure out how to get more involved with the legislative happenings. Boy, this is tough! The political game is take no prisoners and if you don't do or say the right things to the right person you can't get anything done.

We started by creating a Legislative Committee. I took on the position of chair with members being Patty Houghland, Betty Kay Clements, Sharon Berry, Tracy Stewart and Frank Carol.

Then we invited Representative Proctor in to give us a "primer" on what to do and how to do it. Very Enlightening and too much info to mention here but the single most important message that we got was that we must increase our visibility with our legislators. If we don't, we are a non-issue.

Last year we brainstormed with the Arc of Florida and came up with an idea for a bill that would create a special lottery ticket for our people on the waiting list. It has to be limited to educational

things but there is still a lot that we could do with that money. Representative Proctor agreed to introduce the bill so we were successful up to that point.

Bottom line is that it didn't pass because the economy is so bad and the representatives were afraid that our lottery would take money away from the schools. I find that hard to believe but that's politics. We could have used a lot more people asking their representatives about this bill.

We were successful, however, in defeating a number of tries to push out the implementation of the bill that re-prioritizes the wait list.

That along with our success at defeating the push for managed care was well worth the effort.

Mobile Dental Unit or "Miles for Smiles" Initiative

By Deborah Linton,
Executive Director, The Arc of Florida

Last March a small group of families and professionals met early one evening to once again discuss waitlist initiatives to be undertaken.



Representative Proctor

What we need now is more people ready and willing to call their legislators to encourage them to support or not support bills that we identify as important to our folks.

So, the bottom line is that we all need to get more involved with your legislators.

One area of continued concern for all persons with developmental disabilities was dental services.

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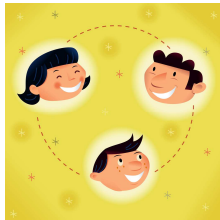
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- Make an appointment to speak with your legislator today!
- Check out the FCCF website, www.fccflorida.org for more info and talking points for legislators
- Join your local FCC
- Join your local Arc

A VISION & PLAN FOR FLORIDA

BY PHIL PEARSON

When we moved to Florida 6 years ago, we had no idea that the DD system would be as underfunded as it is today. It is disgraceful that we have a waiting list of almost 20,000 people. Having lived in New Hampshire with no sales or income tax, yet still able to provide services when needed, I figured that it couldn't be worse than that. Boy was I wrong!



My introduction to the system (APD) was met with no hope and no helpful direction from anyone. If you weren't already on the Medicaid Waiver, no one wanted to even talk to you. Not only that, but when I investigated hiring my own support coordinator, I was met with exorbitant up-front costs that made that totally impossible. Providers are so spoiled at receiving the state rates that they don't even want to talk with you for less. I then had the same experience with behavior annalists. I hired two of them and they made sure that they got their assessment money up front but then didn't deliver. They gave the impression that they were much more interested in the money than the peo-

ple that they were supposed to help.

So I got involved mostly through the Area 12 Family Care Council. I learned a lot and by working cooperatively with many people, I think that we actually have a long term vision taking shape for Florida.

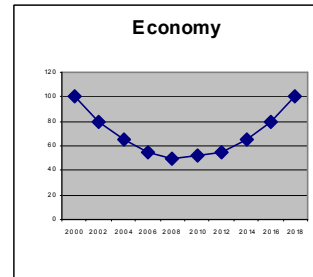
First, we need to understand that we are in an economic down turn. This means exactly what it says, implying that there economy will go up. This is a blessing in disguise which means that we have this lull in activity to set up what we want. We need to get all of the policies and procedures in place so that when the available monies increase that we will be ready to effectively use them.

more effectively use the monies that we have (and will have) than ever before.

These 2 bills have set us up for a great recovery. As we get more monies, we now know who to spend it on and we can also do a good job of allocation.

Couple this with our efforts to increase

our exposure with the legislature and I see a big win over the next 10 years.



But notice please, that it all depends on our efforts with the legislature.

If we take our eye off the proverbial ball, we will be forgotten as quick as you can shake a stick! We can't let that happen!

One example in our own house was not having a legislative strategy session right after the legislature adjourned for the year. We needed to do that to plan legislative visits and future possible legislation. We lost focus and now are behind the "8-ball" for the next session.

But, I think that we are still OK, overall, because the economy hasn't come roaring back yet. We still have time.

Couple this with our efforts to increase our exposure with the legislature and I see a big win over the next 10 years.

Now re-

member that we passed a bill 2 years ago to reprioritize the wait list based more on need than it was before. Next, thanks to Director DeBeaugrine, we passed I-budget which will allow us to

MANAGED CARE

BY PHIL PEARSON

Well, I must say that I am confused and I'll bet that most folks are when it comes to managed care. There is misinformation everywhere.

Managed care is the most confusing, political hot potato to come down the pike in a long time.

When I think of managed care, I think of health insurance plans like HMO's. Now, I am not a great fan of these when it comes to health care and don't have an HMO myself mainly because I can afford something better. But, who am I to judge for other people that can't

afford what I can.

The legislature looks at managed care from another perspective. They look at it as a panacea for beating Medicaid fraud. Apparently, the way that we have it, Medicaid is a fee for service plan that pays first and worries about fraud later. HMO's, on the other hand,

do a good job of making sure that claims are legit. If we had managed care (according to some people) we would save enough money on fraud to pay expenses and actually cover more people.

So fine! Let them put healthcare for our

people under HMO control. Why not! After all, they are getting the service for nothing!

But wait! What about the other services that our people get on the Medicaid Waiver. What does it have to do with Medicaid anyway. Well, Medicaid...Medicaid Waiver. They do kind of have the same name and, well, they both do come from Medicaid.

So managed care will, in addition, take on the job of providing ADT, PCA and all of those other services that our folks need in order to live a healthy, respectful, useful life. I, for one, don't see the

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MILES FOR SMILES (CONT.)

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The Arc of Florida had written a paper for The Agency for Persons with Disabilities, APD, on how they may be able to attract more dentists and provide more dental services in the state. Michele Poole, the Arc of Florida President suggested that an easier way to get services to everyone might be a mobile dental unit, in other words, using an RV to travel around the state.



Members of the Family Care Council, some Arc Board members and APD Director Jim DeBeaugrine all thought the RV idea might be an answer.

Director De-Beaugrine from APD, was able to find funding to

People on the wait list will have first priority when the new dental van comes to town.

purchase the RV. A group has continued to meet and the Florida Developmental Disabilities Council was asked to conduct a needs survey. The survey had a short turnaround time of only one week, but results demonstrated a need for more dental care around the state. The mobile dental unit or a.k.a., *Miles for Smiles* RV, would be used to serve individuals on the waitlist who have dental needs as well as those on the waiver.

Payment for dental services on the RV would most likely be through a sliding fee scale, Medicaid reimbursement or for free if the individual has no resources.

The Family Care Council has stressed how important it will be to reach out to those on the waitlist and will need to work closely with Area Offices to make certain that efforts are made to reach out to these individuals and families. The Arc wrote an operations manual for the project and The Family Care Council

of Florida will be asked to assist in volunteering for the van when it visits various communities.

The Agency for Persons with Disabilities is working on the specifications for the design of the RV, has been meeting with dentists who specialize in dental practices for persons with developmental disabilities and basically covering all the details of trying to get the RV on the road!

So, stay tuned, hopefully a 40 foot, "*Miles for Smiles*" RV will be rolling into your community sometime next year.

(Managed Care—Continued from page 2)

HMO's having the expertise to know how to do this.

What a scary thought!

Apparently, all Medicaid monies get lumped together when managed care takes over. If so, then here's another thing. What happens to folks on the wait list? They qualify and are getting Medicaid too. Does this mean that the waiting list will go away? Does this mean that the legislature will fully fund (to the tune of an additional \$1 billion) all of the folks getting Medicaid?

Anyway, I don't think that we know all of these answers and I don't think that the legislature knows all of these answers either. I also don't think that they know the ramifications of what they are considering.

So what do we do. Well, the advice that we are getting is to assume that eventually, managed care for our folks will pass and we will have to deal with it. What we need to do is figure out

how it is structured and understand all of the ramifications so that we can influence the legislation as it is created. It is in our interest and our children's interest to have this done correctly!

Your FCCF is actively involved in trying to understand this important issue. We are attending meetings and inviting speakers to our FCCF meetings just so that you can understand and, therefore, be in a position to influence your legislator.

What you, as FCC chairs need to do is come to the meetings, get educated, educate your members and then go out to influence your legislators.

"Get-er-done!"

INCONTINENCE SUPPLIES PROJECT

BY BETTY KAY CLEMENTS

Back in the summer of 2009, As FCCF Chair, I was contacted by Brian Darling, CEO/President of Woodbury Products with an idea he had for helping people on the APD Waitlist. That idea was to offer incontinence supplies to families on the Medicaid Waiver Wait List who had the most critical need. After talking with FCC members and APD staff, a plan was put into motion for a fair and equitable distribution initiated by the individual or family with Woodbury staff. Since then I have had the pleasure of working closely with Brian, Linda Michelle Prell, his staff supervisor of this project and the many APD Staff members who worked very hard to make this project a success. Brian expressed his thoughts to me in the following comments:

" I had the privilege of learning more about the Family Care Council in the summer of 2009. The Family Care Council represents everything that is great in our state and our country as they truly work the hardest for those who do not always have a voice. I knew that Woodbury Health Products needed to continue the philanthropic work that my father in law started in 1977 with our company. The current Wait List for proud citizens in the State

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We're on the web,
www.fccflorida.org



YOU AND YOUR FCC(F)

BY PHIL PEARSON

We have to get involved! You need to get involved! You need to energize your FCC's. You need to come to the Florida Family Care Council Meetings. I am sorry but that is the bottom line! Without you and your help, our children will be left picking out of garbage cans for food. Do you want that.

OK, OK, I know that you are busy and don't like being lectured to but we have no choice. I DON'T WANT MY KID EATING OUT OF A GARBAGE CAN when I am gone!

We are the most influential political organization for our folks. If we are not,

then we should be. We have 50,000 families with relatives which possibly pushes our voting block up into the many hundreds of thousands. We represent the families. We are not a special interest! We have a responsibility! That's what separates us from the animals in the jungle.

We must stop just complaining and organize better. We need to show the legislature that we count. We need to demand that the legislature step up and pro-

- We are the most influential political organization for our folks in Florida (or we should be)
- I don't want my kid eating out of garbage cans when I die.

(Incontinence Continued from page 3)

of Florida continues to rise, and although it is difficult to help every single family out there, Woodbury wanted to do its part to assist those on the Wait List who may need incontinence products. So we pledged in 2009 to join with the Family Care Council to provide adult diaper products for 50 families in each of the FCC Areas in Florida who are at the greatest need. What is the most rewarding of our collaboration with Betty Kay and the Family Care Council Florida is to simply hear in a family's voice that they are not forgotten and there are many who care about them."

This project continues across the state and FCCF thanks Woodbury Products for "making a difference" and would like to have others step forward to assist individuals on the waitlist.