

# NEWSLETTER # 3 - 2

AREA 12  
FAMILY  
CARE  
COUNCIL



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## RESULTS OF OUR 2009 LEGISLATURE

Boy, what a lead-in to the legislature this year! We met with a number of senators and representatives and got some very good advice from Representative Proctor.

I hope that you met with some. If you didn't, I expect that you will next year.

Whether you realize it or not, you will be impacted by legislation passed this year.

One piece of legislation that passed was SB1660. It sort of "snuck" though the legislature without a lot of fanfare or notoriety. I have yet to see anything about developmental disabilities on the

Sunday morning Florida news shows.

One thing that SB1660 did was create a study committee to investigate the possibility of creating a pre-paid service plan similar to the pre-paid college plan. Definitely an interesting concept. Too late for us old folks but the younger generation should definitely be following this.

Affecting the older folks, however, is part of the bill that re-prioritizes the waiting list for Medicaid Waiver services. Up until now it was "first to sign" up was the first to get services. This will end during July of 2010. Since this is

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## Waiting List Email Addresses Wanted

In order to more effectively advocate for our folks on the waiting list, we need to know your contact information and at present, APD is prevented from providing us that information.

Now, I know that we have a good email list for sending out issues but when I started that I did not do a good job of keeping track of who is on the waiting list and who is not.

It would really help if you would send me that information.

I would like your name and whatever contact information you are willing to share, including your email address. Also anything that you can share about your position on the waiting list and what new priority you might fall under.

You can email it to me at ppearson1@mindspring.com or send it to me snail mail at:

Philip Pearson  
32 Oasis Circle  
Palm Coast, FL 32137

## Your Newsletter

We're having a heck of a time with our newsletter. We realize that it is the only news that you get from our district about developmental disabilities so we are trying to keep it going. Seems like every time we turn around we have some glitch!

We are shifting our newsletter by a month, targeting July, October, January, April for publication. June is the end of APD's fiscal year and it is becoming more difficult to get the finances straightened in June.

The other issue is that the printer we use no longer wants to do business

with our Tallahassee main office. We are getting help with this and also searching for a new printer. What a pain. Our current printer was doing a good job at a good price.

Hopefully we will get this all ironed out in the next few months.

News Flash! Actually, since you are receiving this by regular mail means that we have successfully found a printer. Hope you like the format.

Send comments to ppearson1@mindspring.com

**WAITLIST  
FAMILIES  
PLEASE  
SEND  
ME  
YOUR  
CONTACT  
INFORMATION**

**Wait List Priorities**  
**Created by SB1660**  
**To go into effect**  
**July 2010**

Category 1 - which includes clients deemed to be in crisis as described in rule.

Category 2 - which includes children on the wait list who are from the child welfare system with an open case in the Department of Children and Family Services' statewide automated child welfare information system.

Category 3 - which includes, but is not required to be limited to, clients:

1. Whose caregiver has a documented condition that is expected to render the caregiver unable to provide care within the next 12 months and for whom a caregiver is required but no alternate caregiver is available;
2. At substantial risk of incarceration or court commitment without supports;
3. Whose documented behaviors or physical needs place them or their caregiver at risk of serious harm and other supports are not currently available to alleviate the situation; or
4. Who are identified as ready for discharge within the next year from a state mental health hospital or skilled nursing facility and who require a caregiver but for whom no caregiver is available.

Category 4 - which includes, but is not required to be limited to, clients whose caregivers are 70 years of age or older and for whom a caregiver is required but no alternate caregiver is available.

Category 5 - which includes, but is not required to be limited to, clients who are expected to graduate within the next 12 months from secondary school and need support to obtain or maintain competitive employment, or to pursue an accredited program of postsecondary education to which they have been accepted.

Category 6 - which includes clients 21 years of age or older who do not meet the criteria for category 1, category 2, category 3, category 4, or category 5.

Category 7 - which includes clients younger than 21 years of age who do not meet the criteria for category 1, category 2, category 3, or category 4.

**Setting Wait List Priority Procedure**

Within categories 3-7 the agency shall maintain a wait list of clients in the order of the categories first and the order of the date that the client is determined eligible for waiver services second.

**SB1660**

*(Continued from page 1)*

such a big change, the legislature wanted to give a year's grace period to make changes, if need be, before the law actually is used.

A summarized view of this prioritization is shown on the previous page.

Categories 1 and 2 are basically the same as they are now. Category 3, however, is an attempt to factor in the needs of the family by recognizing that there are some families that are in trouble or will be. Category 4 recognizes that family caregivers over 70 years of age have a shortened life span and are concerned about making sure that their children are properly cared for. This continues on to category 7, which are younger families with children receiving services through their school system.

This law does a few things from a big picture viewpoint. First, it recognizes that older families have a shortened lifespan and are concerned for their children's care after they (caregivers) die. It also recognizes that the older families have put a lifetime of effort into support that the state probably should have done in the first place. The younger families have not. This re-prioritization also puts the advocacy pressure on the younger families. It is hard to argue that they are younger, and have much more energy to advocate than the older families. The older families, in many cases, are worn out! This will also force the younger families to more effectively advocate for their children through their school systems. Now I understand that this can be like pushing on a wet rope but we can't give up on the schools. We must fix them and their support structure.

Another interesting item is priority #5, which basically puts children about to graduate ahead of older children who have already graduated. I'm not sure myself, if this is the way that it should be.

At any rate, older families should be happy about this bill. Younger families, however, who were low on the waiting list number are bound to be upset, As will priority #6 families.

The name of the game, however you feel, is to get involved and speak your piece. Call your legislator, join your Family Care Council. Let's make sure that this bill is a good one when it goes into effect in 2010.

The Flagler ARC has a new website, [www.arcflagler.org](http://www.arcflagler.org).

Check it out. We are trying to get more info out to members. The Flagler ARC sponsors outings and entertainment for DD members in Flagler County. You might consider attending a meeting or coming to an activity.

**Look for an FCC legislative session in the October time frame.**

**WAIT LIST MEETINGS**

I went to a Florida Family Care Council meeting this weekend and the new head of APD, Jim De-Beaugrine, was there. Boy, what a pleasure! He is enough of a geek to be able to get a really good handle on all of the data available about our consumer, clients, families, wait-list, you name it. He mentioned that they have developed a cost modeling system that predicts cost with a remarkable degree of accuracy. This will really boost APD's credibility with the legislature which should really improve our chances of getting more funding for the wait list.

He is also very "in tune" with the family situation for us families on the wait list and has charged each area with having quarterly meetings with families on the wait list.

The first wait list meeting for our area is on Thursday, August 13, 2009 from 6:00 PM to 8:00 PM (Registration begins at 5:30 PM) at Daytona State College, Mori Hosseini Center, 1200 Internat'l Speedway Blvd., Daytona Beach, Florida 2114. We can look for them to move between different parts of our 2 counties for the follow up meetings.

I hope to see you there.

- 7/9/09 3-5 pm, APD
- 8/13/09—Cancelled, conflict with WL meeting
- 9/10/2009 3-5 pm, APD
- 10/8/2009 7-9 pm, Florida Hospital in Palm Coast
- 11/12/2009 3-5 pm, APD
- 12/10/2009 7-9 pm, Florida Hospital in Palm Coast
- 1/14/2009 3-5 pm, APD

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