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**MEETING WITH SENATOR LYNN
BY PHILIP PEARSON**

On Tuesday, Jan 15, 2008, I was honored to be able to meet with Senator Lynn to discuss the state of developmental disabilities in the state of Florida. We covered a number of topics including the future of APD, the waiting list and support for the Family Care Council.

I pointed out that we were over 16,000 on the waiting list and she said that she was appalled that APD had not been able to address this. As a matter of fact, she wasn't sure that APD should remain an independent agency and maybe should be supervised by AHCA (Agency for Health Care Administration). I sure don't want to see APD dismantled because we will lose our DD identity if we are lumped in with all other disabili-

ties. However, it is hard to argue the point that APD doesn't appear to be able to manage it's budget.

She promised to help get some much needed FCC appointments approved.

Another issue that I raised is the difficulty that we have in working with DCF to obtain benefits that our folks are entitled to. It is a nightmare calling their central number and stepping through 6 levels of touch-tone levels to either be put on hold or told by a recording to call back another time. She gave me the name of a contact that she had and I am in the process of following up.

I think that I am still on hold!

WAITING LIST PRIORITY

The waiting list is currently ordered by the date at which the family applied for services with APD. The numbers are currently over 16,000.

The problem with using the actual number is that most of the folks on the list don't really need or want services right now but want to be on the list for when they do. This really distorts the problem for everyone. Folks on the list don't have a clue about how far down they are and the legislature has no idea what the real needs are which means that they have no idea how much it will cost.

The other issue is that need is not factored in. the only exception is if a crisis situation exists. So if a young family applied for services in January of 2008 and a very elderly, about to die, caregiver applied for services in February of 2008 and a position on the Medicaid waiver opened up, the young family would get it. Doesn't make sense to me!

Personally, I think that the waitlist should be prioritized according to need, not date. Of application.

Priority 1 should be those whose caregivers are very old and ready to die. Older

**WORK OPPORTUNITY NETWORK (WON)
BY JOAN MANNIX-VOLUSIA ARC**

In September 2007 **Work Opportunity Network** was formed. The **Work Opportunity Network (WON)** is a consortium of public and private stakeholders in the economic wellbeing of the community through the employment of people with disabilities. **WON** brings business, human ser-

vices and government together to create a business environment that values the contribution of persons with disabilities as citizens which are vital to the economic health of the community. The group strives to address the disparity in the income level and underemployment of people with

Work is critical to our

Folks—Not only does it increase self-esteem but it paves the way to future benefits

disabilities and to satisfy the mutual interests of all of the network's members.

Although the network

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is newly formed, it has already demonstrated how this collaboration works for the community. In May 2008, WON will occupy a table and give three 1 hour instructional presentations on Best Practices in the workplace regarding disability related issues in the workplace, at **The Business Express Connections on the Go Business Summit** sponsored by The Center for Business Excellence (CBE). The audience will consist of managers and HR representatives from more than 200 area businesses. CBE is a member of WON, as well as disAbility Solutions for Independent Living, who's Executive Director will be presenting on behalf of WON at the summit. The table will provide information about WON and its members as well as information regarding Tax Incentives to businesses that hire the traditionally underemployed, support available to businesses as regards workplace modifications and accommodations for employees that have disabilities and a range of other information.

This activity is but one of many that WON will generate to help bring those with disabilities fully into the workforce. With the Baby Boom generation retiring, those with disabilities represent a human resource that is ready, willing, and able to address the workforce needs of the future in our com-

munity.

Members of WON include:

- ACT Corp.
- Area 12 Family Care Council
- Brevard Achievement Center
- Center for Business Excellence
- Covenant Support Services
- Daytona Beach College
- Daytona Beach/Halifax Area Chamber of Commerce
- disAbility Solutions for Independent Living
- District 12 Agency for Persons with Disabilities
- Florida Dept. of Ed./ Division of Blind Services
- Florida Dept. of Ed./ Division of Vocational Rehabilitation
- Strategies, Inc.
- The Arc of Volusia, Inc.
- UCP Central Florida
- Veteran's Administration
- Volusia County Schools

Any Business, Agency, or individual that has a vested interest in employment for people who have disabilities and is eager to share ideas, resources, and talent is welcome to attend a meeting, join the network, or get on the mailing list. WON is looking for members from the Westside of Volusia County and Flagler

County so that efforts can benefit everyone in the area. WON meets the last Friday of every month at a location determined at the previous meeting. For more information contact: Joan Mannix at 386-274-4737 or joan-arcv@cfl.rr.com

Who's who at APD

Sandra Mills



I have worked for APD for two years. Prior to securing a position at APD I was a Support Coordinator for four and a half years. I am a graduate of the University of Central Florida with a bachelor's degree in Psychology and minor in Criminal Justice.

My unit is Provider Development. As a part of this unit I am the Family Care Council Liaison. I am the Area Quality Leader for Area 12, which means I help with quality assurance. I work with Delmarva reviewing the consultation reports for each provider reviewed and provide technical assistance where needed to providers in relation to their review and overall. I work with new providers to understand what they need to have in place to provide quality service to the people they support. I assist with auditing, recoupment, training, and the Steering Committee.

(Continued from page 1 - Waitlist priority)

caregivers should be able to go in peace, knowing that their DD children are well taken care of. Priority 2 could be for DD children that are a danger to themselves or others. Priority 3 might be for families that might break up if they don't get help. Priority 4 might be for caregivers over 60, Priority 5 might be for caregivers over 55 and so on down to children in school who should be getting services through the school system anyway.

It would be really good if we could get you folks to send in your opinions about this waitlist prioritization. So far, I have received feedback suggesting that a family where the caregiver is also disabled should be priority 3 and somewhere in the priority list should be folks in institutions. At any rate, I don't really know what the priorities should be but we need a lot more suggestions to come up with an effective one. Please send suggestions to:

FROM THE EDITOR



Another thing for you to think about. APD is the Agency for Persons with Disabilities, not the Agency for Persons with Disabilities on the Medicaid Waiver. So, in my opinion, APD should be helping our folks on the waiting list as well. After all, we pay taxes and these taxes are used to pay the salaries of our APD folks so an equal portion of their work day should be spent helping our folks. Granted, we can't demand the same kind of services provided by the Medicaid funding but they certainly could take a small percentage of their work day.

One example might be for APD to provide benefit counseling for those on the waitlist. As you all probably know, it is a nightmare trying

to figure out what you are entitled to, when you should get it and how to apply for it (DCF again). We need more folks asking for this.

Maybe a brochure listing family life stages and what the corresponding benefits are should be developed and available for all of us.

What do you think?

We recently purchased a speaker-phone to allow folks that can't attend our meetings to call in and participate in the conversations.

Assuming that we have a phone line in the meeting room (and have the line reserved), all that you have to do is call

Again, we need your help.

Last month we purchased 2 copies of the book, Mental Wellness in Adults with Down Syndrome but Dennis McGuire, Ph.D. & Brian Chicoine, M.D. We are donating one to the Volusia public library in Daytona Beach and one to the Flagler public library in Palm Coast.

We purchased this book at the suggestion of Covenant Support Services so thanks to them for the recommendation. One of our members, Ray, took the book home and started reading it. Come to find out a number of his daughter's problems were pretty well spelled out in the book along with recommendations for solutions.

URGENT!
We should all be camping out on our legislator's doorsteps telling them to fix the waitlist

New Call-in Number

1-888-808-6959, enter the conference code of 4146558 and follow the prompts to be connected.

Try it out for the next meeting. Assuming that we have a line in the meeting room, we should be good to go!

Looks like it was a useful purchase.

So go to the library and check it out.

Also send us suggestions for books and or videos that we should purchase and donate to the libraries.

FCC UPCOMING MEETING SCHEDULE WWW.FCC12.ORG

- 4/10/08—7-9 pm, Florida Hospital, Flagler 60 Memorial Medical Parkway Palm Coast, FL 32164 Education room A
- 5/8/08—3-5pm, APD office, 210 N. Palmetto Ave., Suite 312 Daytona Beach, FL 32114
- 6/12/08 -3-5 pm, APD office, 210 N. Palmetto Ave., Suite 312 Daytona Beach, FL 32114
- 7/10/08—7-9pm, Volusia ARC, 1738 Patterson Ave. Building K, Deland, FL. 32724. The building is in a business park behind Lowe's off 92.

WAIT A MINUTE!

I just received a letter in the mail from APD asking if I would like up to \$5,000 in funds for my son for supported employment. This MUST be completed by June 30. This only affects folks on the wait-list.

Pay attention, now, because you must act immediately!

I know that many of you think that your folks are not employable but they really probably are. Think about the barriers that your son or daughter has that prevents them from working.

Do they need transportation? Do they need behavioral services so that they will fit in at the workplace?

I'll bet they do.

Do they need a supported employment coach?

Please follow up. Our folks need to be working and we shouldn't let this money get away.

Chiropractic Outreach

One of our families stumbled onto this opportunity. Apparently Palmer Chiropractic Clinics has an outreach program that will provide free chiropractic services for our DD folks.

The contact number is 386-763-2776

It is on Clyde Morris Blvd in Port Orange.

A PARENT'S PERSPECTIVE ON ADVOCACY

BY CHRISTINA PINTO

I am a parent of a 19 year old son that was born with cerebral palsy and just last October diagnosed with autism. With that being said, I have to stress the importance of advocating for your loved ones that have disabilities. I have fought so many battles for my son and so many times I have wanted to give up because I feel like I am the only one out there fighting for him or I am just tired of fighting. But I cannot give up because if I want my son to have a productive and fulfilled life then I have to continue fighting and being his voice. That is something we all have to remember. If we want changes for our loved ones and others we have got to

be their voice, we have to tell their stories. We have got to be the ones meeting with schools, legislators, committees, and whatever organization or person it takes to make them hear how everything affects our loved ones' lives along with the family unit. When we have someone else act on our behalf the people that need to listen do not see the whole picture and we so desperately need them to see the whole picture. We must remember that most of the people in our Legislature, committees, boards, etc. are not affected by budget cuts to the disabilities program. They don't have a family member with a disability so they do not have to live a day in our lives and face the struggles that we face every day. That is why it is so important to plead your own case whenever possible. Now

that is not saying that you have to be the only one going in front to speak, take a group of families or individuals with you that are in the same situation. Numbers speaks volume. Remember it is the squeaky wheel that is heard the most. Therefore, I am challenging all of you to become that squeaky wheel and be heard for your loved ones and others that need your voice. If anyone out there is reading this and would like another squeaky wheel just let me know, for I will become that wheel. You may reach me by email at noles-fan4ever@cfl.rr.com or phone 386-437-2175.

"When we THINK differently, we ACT differently."--Kathie Snow

Christina Pinto

Believe it or Not!

When it comes to Advocating, Families have the most powerful voice

By Barry Pollack

We, the “professionals” in the field of disabilities find ourselves every year in the position of advocating on behalf of those we have committed to serve, those that have not or could not speak for themselves. Yet time and time again, we hear from our elected officials, our legislators that the voice of one consumer, one parent or caregiver is worth a hundred of ours. Never underestimate the powerful impact that your voice has when heard by our elected officials. Tell your story, share your life, speak on behalf of your loved ones. This is how we got the funding and services that exist today. This is how we will keep it and protect individuals with disabilities and the services they desperately need.

Barry Pollack

President & CEO

UCP of East Central Florida

***Your Voice Counts: Tips for Powerful Advocacy
How to communicate effectively with policymakers
and legislators
Thanks to Barry Pollack***

Advocacy is not hard. Still, it is estimated that only 10 percent of all Americans will write to their congressperson or state legislator in their lifetime. But your representative knows that if you feel strongly enough to contact him or her about an issue, there are many others who feel as you do. So when you take the time to contact your legislators, you're raising your voice not just for yourself but also for many others!

There are three basic advocacy tools: letter writing, calling, and visiting. Regardless of which method you use, there are some basic points to remember when communicating with policymakers. First, your credibility is vital so be truthful and fair. Second, always be courteous. This goes without saying, of course, but some of us do get a little hot under the collar when talking about issues we feel strongly about. Keep in mind that your message will be better received if you can make your points firmly but politely. It pays to remember that your opponent today maybe an ally on

another issue tomorrow so you won't gain anything by burning bridges.

Tips for Effective Letter Writing

A personal letter from a constituent is a very powerful advocacy tool. Here are some tips to help you get your message across:

Be Brief. Remember that policymakers often have a lot to read. Therefore, try to get your entire message on one page. If writing longhand, take care to write legibly.

Be focused. Address only one issue per letter. In a short first paragraph, state the issue and your position and use the rest of the letter to support it. If the subject of your letter is a bill, cite it by name or number if that information is available.

Be personal. Try to help your representative understand your position by giving him the personal side of the issue; tell your story.

Be factual. Write your policymaker from a strong knowledge base. Where necessary, use key facts to support your position.

Be original. Letters are more effective when they are original. But if you don't have time to start from scratch, use sample letters which are often prepared by advocacy organizations. Consider personalizing the letter by adding information about how the issue affects you, your family or community.

Be persistent. Legislators need to be able to tell their colleagues that they have been inundated with calls and letters supporting a particular position.

Be grateful. Thank your legislators if they have a good record of support. Our friends need to know that their support is appreciated.

Be confident. Your voice counts.

What about Email?

Email is a fast and easy way to contact your representatives. However, you need to consider a few things if you're going to use email. First, recognize that it's easy for your message to get “lost” in email clutter. After all, how many times do you just quickly glance at your own email? Be cautious about the informal style most of us use when writing email messages; such a style is not well suited to communicating with legislators. Generally, a mailed (or faxed) letter makes a better impression and is most likely to get the attention of legislators and their staffers. However, it's more important to get your message out than to wait until you have the time to compose a letter -- especially if you know that time will never come! When sending an email, keep in mind the letter writing tips noted above. If time is short, you may want to consider calling your legislator (see below).

We'll cover more in the next newsletter.

Area 12 Family Care Council
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Daytona Beach, FL 32114