

# THE CAMPAIGN TRAIL

## NEWSLETTER OF THE PENNSYLVANIA WAITING LIST CAMPAIGN

4540 BEST STATION ROAD, SLATINGTON, PA 18080

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

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## URGENT! CALL YOUR STATE LEGISLATORS!

The PA Waiting List Campaign has been working hard to ensure that our citizens with mental retardation, including 800 young adults graduating from High School who are waiting for community services and supports are funded. We are supporting the request for funding of a program for Autism and a Cost of Living Adjustment (COLA.) The state budget calls for funding of the waiting list for mental retardation and Autism. You need to call your state legislator to make sure funding stays there.

### Why Do We Have to Call Again?

Each year the state budget begins at zero. It is easy for state legislators to become complacent when they hear the same wants over and over again. The PA Waiting List Campaign was recently shaken to its core when we visited homes of families who had three and four family members with mental retardation who were waiting decades. They were one caregiver families. The adults they care for are in their 40's and 50's. The mothers or fathers were worn and tired. Their eyes begged us for relief. Yet, they stood steadfast in their commitment to be there for their adult children while expressing worry over who will take care of them when they are gone.

Every group and organization is asking for limited state funding as well. If we are not loud enough, we could lose it all. Let's pull together and end the wait. Your one call could make the difference.

### THE PA WAITING LIST CAMPAIGN IS WORKING TO ENSURE THE WAIT WILL END.

1. People with mental retardation and their caregivers from across the state held a meeting 10/23/2007 with state Budget Secretary, Michael Masch, Secretary of DPW, Estelle Richman

and Deputy Secretary of the Office of Developmental Programs, Kevin Casey to discuss the need for funding of the community waiting list that affects 21,128 vulnerable people across the Commonwealth.

The officials were informed of the need for crucial funding to 4,407 people on the Emergency Waiting List. A homeless man, whose parents are in a nursing home and is reliant on the goodness of others, was among those present.

Babyboomers and aging adults continue to provide the bulk of care for their sons and daughter, saving the state and mental retardation system billions of dollars. Health issues and physical decline make it necessary for caregivers to turn to the system for long term care for their sons and daughters in the form of residential supports, such as Life Sharing or supported care in their own homes. The educational system graduates  
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# Remarks to Appropriations Committee

By Representative Thomas P. Murt

## RE: Waiting List for Services (Adults with Special-Needs)

Mr. Chairman, I believe that one of the most painful situations we face as elected officials in Pennsylvania is watching families who struggle to care at home for an adult child with special needs. The plight of these special families does not appear on the front page of any newspaper, but to these families, this issue is vitally important. These families are to be commended for caring for their adult special-needs children - themselves - at home, and I think that those of us who serve in state government should examine ways to make their jobs a little easier. Simply stated, the state resources that we dedicate to caring for the adult members of our families who have special-needs are not ample and need to be increased further than they have been in the preliminary budget. According to the Department of Public Welfare, a total of 21,475 adults with mental retardation are currently on the waiting list for help. These special members of our families come from every community in the Commonwealth. Governor Rendell's proposed budget designates \$28.8 million to reduce that waiting list by 1,818 individuals for Fiscal Year 2008-2009. This funding is much appreciated and badly needed - however, I believe we cannot turn our backs on the thousands of Pennsylvanians who would not be helped in this scenario. With that in mind and on behalf of these families and all special-needs Pennsylvanians, I respectfully request that the committee see fit to provide supplemental funding so that even more families who care at home for an adult with special-needs can get the helping hand they so desperately need.

Mr. Chairman, I strongly encourage

the continued support of the 800 special-needs students graduating from high school each year by making this allocation a permanent line item in the budget. I add that providing support for special-needs adults at high school graduation prevents regression, and maintains vital connections to community, while empowering parents to continue working to support the household. This action also severs the waiting list at the source. Mr. Chairman, state law requires that up until 21 years of age, special-needs children with an I.E.P. be educated in public schools or in another appropriate setting. Once these special members of our families leave the public school system, however, they and the families who lovingly care for them are frequently left to navigate an underfunded system that requires them to wait for services for their adult child who has special-needs. Additionally, after these special needs children leave school, many do not have opportunities either socially, educationally, or with suitable employment due to a lack of funding and programming. Many of these special needs members of our communities must stay at home and are under-stimulated and sometimes develop even more health, emotional, and other mental health problems due to a lack of services. Some special needs adults will only be given a housing placement outside their parent's home if their parent-caregiver dies.

Mr. Chairman, one very serious condition that has evolved in Pennsylvania is where parents who have worked hard for many years to care for their special-needs adult child at home, start to experience serious age-related health problems themselves. In these heartbreaking cases, in addition to having to care for themselves and

worry about their own healthcare, these older parents must also continue to care for an adult special-needs child. Many of these families have parents who are in their 80s, and an adult child with special-needs who is in their 60s or older. Needless to say, these special-needs adults start to experience their own health challenges relating to age or years of under-stimulation. Providing supports to aging caregivers and older adults with mental retardation are of the utmost importance. Many aging parents simply can no longer provide care for their special-needs sons and daughters living at home and they need relief. The challenges of caring for a loved one with special-needs at home are already painful and the aging process exacerbates these challenges even more.

Mr. Chairman, I am not pressing the panic button, but if the waiting list issue is not addressed in the near future, these adults with special-needs could very well end up in other systems within the state such as state hospitals or even in the corrections system. This would be much more costly to the state than taking action now, and certainly much less prudent. Supporting our most vulnerable citizens is a core function of our government and should be a top priority for us. Thousands of Pennsylvanians and their families anxiously await the supports they need to be healthy and productive citizens in their communities.

Mr. Chairman, as you well know - this issue is quite complicated and requires much effort in order to simply understand its magnitude. Essentially, I am requesting you to reconsider the budgeted amounts and to appropriate even more badly needed and deserved

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# QUICK SELF-ASSESSMENT

By Lisa Tesler

How can you be sure you have taken all the necessary steps to access supports and services through the Mental Retardation System? Ask yourself the following questions to make sure you have all the appropriate paperwork completed.

Are you Registered?

1. Have you contacted the County Program/AE and asked to register for services?
2. Did you have an intake meeting to submit all the needed paperwork, including: Social Security Card, Birth Certificate, Proof of Address, Psychological evaluation, etc.?
3. Were you sent a letter stating you were eligible for services?
4. Have you been assigned a Supports Coordinator?
5. Have you met with your Supports Coordinator and have they helped you understand how to access the supports and services you need?

Is your PUNS form completed?

1. Did you complete your PUNS form with your Supports Coordinator to describe all the supports you may need within the next 5 years?
2. Did you check all appropriate situations that apply to you?
3. Do you know what category of need you are; Emergency, Critical or Planning?
4. Were you honest about your needs to make sure the PUNS form is an accurate, complete record of what you are waiting for?
5. Do you have a copy of your PUNS form? If not, call your Supports Coordinator and ask for one.
6. Have you reviewed and updated your PUNS form every year?
7. Were you given information about what you should do if you disagree with your PUNS category?

Are you on the waiting list for a Waiver?

1. Did you fill out a Waiver application?
2. Do you have a copy of the letter stating whether or not you are eligible for services?
3. Have you discussed all the services available through the Waivers with your Supports Coordinator?
4. Have you applied for or asked for Family Driven Supports while you wait?
5. Did you get a copy of your Right to Fair Hearing, which explains what you can do if you disagree with the County/AE decision?

Do you have an Individual Support Plan (ISP)?

1. Have you had your annual planning meeting with your Supports Coordinator and your team to discuss the supports and services you need?
2. Do you have a copy of your ISP?
3. Does your ISP reflect the “Every Day Lives” values and philosophy?
4. Does your ISP describe all the supports you need to live successfully in the community, both paid and unpaid?
5. Do you have a copy of your approved plan and budget?

If you have gone through and answered yes to all these questions, you are in good shape! Having all your paperwork up to date and complete is essential to accessing supports through the Office of Developmental Programs. If you are not sure about any of these steps or need additional information, contact your Supports Coordinator or your local County/AE office for help. You can also call the Office of Developmental Programs toll free at 1-888-565-9435.

# The Office of Developmental Programs: WAITING LIST UPDATE

By Patty McCool, ODP

In September of 2007 the Counties/Administrative Entities received the allocation letter that contained the waiting list initiative information including the slots for each of the three initiatives (PFDS non-residential, PFDS Graduates and Consolidated non-group home) and the funding amount. The funding was for an average of six months. The allocation letter also included the proposed annualized cost of the initiatives. Due to the wonderfully large size of the waiting list initiative, it was necessary to have the process of enrolling and serving people start as early as possible. The allocation letter was provided in September to allow the programs to begin to enroll the individuals into the waivers, identify providers and secure staff for in-home services as soon as possible.

Three individuals were identified at the Office of Developmental Programs to manage the process. Toni Richardson is a consultant who assists ODP on several projects. Dana Olsen and Patty McCool are at Central Office ODP. In December of 2007, Toni and Patty traveled to all four regions to meet with the fifteen counties who had been identified as having the highest numbers of individuals to serve through the initiative. One purpose of the meetings was to ensure that these counties had a solid plan of approach to enroll and serve all the individuals on their list. Another was to learn from the counties barriers they had identified to implementation. Finally, the team asked the counties to identify ways that ODP could help them in the process.

All of the counties identified ways they were planning to track the progress. Some were having weekly meetings,

some monthly. Most had set enrollment goals and had tracking systems to ensure they would meet those goals. ODP also has a tracking system and on a monthly basis receives reports from the counties on their progress.

Barriers that were identified at that round of meetings included difficulty getting the paperwork processed through the local County Assistance Offices, having the background checks for providers completed in a timely fashion by the State Police and the technical difficulties attaching services to Individual Supports Plans because of the categorical funding streams. The additional work overall for the supports coordinator was also identified as a barrier, although counties had plans to address the issue. ODP was able to identify a strategy for the counties so that the technical difficulties due to the categorical funding streams were eliminated. Counties are working with their local CAO to address the issue of the slow paperwork.

One other issue was identified by the counties as a barrier to implementation. There were individuals on the county lists who declined services when offered, even though the individual was in the emergency category of PUNS. The reason most often cited for the refusal was that the individual and/or family were not ready for services. Those individuals were moved to the Critical Category of PUNS and the counties were able to substitute another individual from the Emergency Category. This has slowed the implementation of the waiting list initiative somewhat. ODP is tracking this issue and may address it with changes to the PUNS system in the future.

A second round of meetings in the regions was completed by the end of March. These meetings included all counties, not just the top fifteen. It was a great exchange of ideas and resources. Dana Olsen provided some information on Everyday Living scenarios to help individuals, families, supports coordinators and providers as they develop new living options for people. Some of the same barriers identified remain, although there has been some movement addressing them. The counties remain confident that they will be able to serve the number of individuals identified for their individual program. Some counties have identified an ability to serve more people if the slots and funding become available.

ODP has been tracking through monthly reports the progress of the counties. As of the beginning of March, 37% of the individuals had been enrolled. There are still a couple of larger counties who are behind, but the strategies they have in place should ensure they will meet their targets. ODP has committed to move funding and slots to other counties in need if it is clear that some counties will not be able to serve all the people in a timely fashion.

ODP remains committed to ensuring that the hard work of all the people who championed the waiting list initiative will not have been in vain. The number of individuals identified in the waiting list will be removed from the Emergency Category of PUNS and begin services by June 30, 2008. The strategies employed this year for the waiting list initiative will continue for future years when initiatives are funded.

## **The PA Waiting List Campaign is Working to Ensure the Wait Will End.**

*...continued from page 1*

an estimated 800 young adults into the mental retardation system each year. State funding in recent years has allowed this body of people to continue their lives after high school. It has also allowed their families to continue their lives and work. The funding of high school graduates is a vital part of the state budget and holds potential to end the waiting list. The mental retardation system must evolve to support the people in their care from cradle to grave.

People present at the meeting were representative of those waiting for community services and supports were from Philadelphia, Bradford, Westmoreland and Dauphin counties.

2. House Resolution (HR)159 is being written by the Joint State Government Commission to look at the issue of waiting lists and what can be done to address them. The PA Waiting List Campaign met with Representative George Kenney to implement the study and is part of the team on the Joint State Government Commission. The work has been a collaborative effort of many groups and the report should be available within a few months.

3. You will be seeing television advertisements over the next few months meant to educate the general public over the social injustice of waiting lists. Most people believe all our needs have been met. You know this isn't true. We thank families who traveled far and families who invited us into their homes. We thank people and staff who went over and beyond expectations to help make is project a success.

## **SIS Assessment – NEW to PA**

**By Lisa Tesler**

The Office of Developmental Programs is now using the Supports Intensity Scale (SIS), developed by the American Association on Intellectual and Developmental Disabilities (AAIDD), as the standard needs assessment for all people receiving Mental Retardation Waiver services in Pennsylvania. All new waiver enrollees will be assessed prior to their planning meetings, and all those currently receiving services will be assessed over the next few years.

The assessment measures the frequency, intensity, and type of supports you need to participate in all areas of life, from home and community to employment and social activities. There are also questions about your medical and behavioral needs.

You will be contacted by your Supports Coordinator when you have been selected for assessment. Ascend, Inc., the independent vendor that conducts the evaluations, will then call you

to schedule an appointment for an interview. You will need to have at least two people at the appointment who know the person receiving services and can answer detailed questions about what kind of support a person needs on a day to day basis.

This is a new process for all of us, including the families, Supports Coordinators, counties, and the state. If you have any questions, you can get information on the Office of Developmental Programs Consulting System website [www.odpconsulting.org](http://www.odpconsulting.org), you can learn about the assessment at [www.siswebsite.org](http://www.siswebsite.org), and find out about Ascend at [www.ascendami.com](http://www.ascendami.com). Additionally, the Training Partnership has workshops on the SIS and other topics that are specifically for families and individuals with disabilities so they can understand this new requirement. Visit the website at [www.TheTrainingPartnership.org](http://www.TheTrainingPartnership.org) to find out more.

## **Remarks to Appropriations Committee**

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funding for adults with special-needs and the families who care for them.

Mr. Chairman, I end my testimony with my favorite quote by former Vice President Hubert H. Humphrey. You might be curious about why a Republican would quote what is sometimes called the liberal mantra, but the message is not about partisan politics here, and is clearly one of compassion, empathy, and concern for others. Vice President Humphrey said "The moral test of government is how that government treats those in

the dawn of life - our children; those in the twilight of life - our elderly; and those in the shadows of life - our sick, our needy and our handicapped."

Mr. Chairman, I want to be able to say that all of us passed that moral test, so I respectfully request your re-consideration of the preliminary budgeted amount for funding for our Mental Retardation Waiting List for Services.

Thank you Mr. Chairman and thank you to the members of the committee.

# APPROPRIATIONS PEOPLE TO CALL

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If you would like a copy of the "Crisis in the PA Communities" DVD, send \$5 to:

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718 Arch Street, 6N  
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## HOW MANY PEOPLE ARE WAITING IN THE UNITED STATES? SIT DOWN!

Coleman Report - State of the States in Developmental Disabilities, 2008 reports:

- 4,691,450 person with Intellectual and/or Developmental Disorders in US
- 716,821 live with family caregivers who are 60+ years in age.
- 991,144 live with family caregivers who are 41-59 years of age

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Join the PA Waiting List Campaign listserve. Send your email addresses to Sheila Stasko at [stasko@pawaitinglistcampaign.org](mailto:stasko@pawaitinglistcampaign.org) or visit our website at <http://www.pawaitinglistcampaign.org>!

# APPROPRIATIONS PEOPLE TO CALL

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We Will.  
We Must.  
End the Wait!**

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for the PA Waiting List Campaign  
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Latest PUNS Figures from the  
Office of Developmental Programs:  
February 29, 2008

**TOTAL: 21,359**

**PLANNING: 7,302**  
**CRITICAL: 9,461**  
**EMERGENCY: 4,596**

**Funded by the Disability  
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Pennsylvania**

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There is no point at which you can say, "Well, I'm successful now. I might as well take a nap."  
- Carrie Fisher -