

Pennsylvania Waiting List Campaign

WAITING LIST WATCH



Volume 2, Issue 1
January 2002

CHANGE, HELPING EACH OTHER & UNITY IN THE DAYS AHEAD

Features

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The Pennsylvania Waiting List Campaign is struggling with the dramatic life changes we have all experienced since the September 11 attack on the World Trade Center. We share our nation's sorrow. We support our people and our Nation's strength and courage in these most difficult times. We urge the disability community to strengthen, support and unite in the upcoming months or years that might lie ahead. As people and families who share a common goal of addressing the waiting list for supports and services it is an even more stressful time.

We lost Governor Ridge to a newly created federal post, Director of Homeland Security. Governor Ridge is a compassionate and visionary leader who saw and understood what people on the waiting list were experiencing. Within less than a year, he addressed the issue by ordering the Department of Public Welfare to develop a plan, and had created a Five Year Initiative of \$853 Million dollars.

Special points of interest:

- Paper trail doesn't give answers to how many people came off the Waiting List.
- 8 recommendations in PA Waiting List Plan under scrutiny.
- Transformation Project Concerns over lack of Consumer involvement and individual budgets.
- Time to STAND UP! And become part of developing our future.

We feel strongly that Governor Schweiker will continue to honor Governor Ridge's commitment. Very shortly we will begin to see political advertisements as 2002 elections draw near. This is always an anxious time for the disability community. We need to find out who is running for what office, and how they feel about disability initiatives and we also need to spend time educating legislators about current practice. We need YOU to become more politically active in helping people get off waiting lists.

We have made great progress in drawing attention to the issue and funding. We cannot allow ourselves to return to the lack of funding that existed three years ago. We can not afford to sit back and let go without speaking up. We need your support. Please contact Governor Schweiker and the Appropriation Committee. Take the time to make a phone call, send a fax or email with the simple message, "Keep the Waiting List and Direct Care



Maureen Devaney, Chairperson,
Waiting List Campaign

Sheila Stasko, Editor,
State/Community Organizer

Worker's Recruitment and Retention Initiative in the budget." You can make an appointment with your legislators and take along friends, or invite your legislator to your home and have other people attend. You can check your local papers and go to committee meetings, or if they are televised, call in. Make the disability agenda positive and visible. There are 16,000 Pennsylvanian's registered and waiting for services and supports who need your help.

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Newsletter Publisher:
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Cast Iron Building
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Phone: 215-923-3349

Funding for the Campaign is provided by Pennsylvania protection and Advocacy, Inc. through Vision for Equality, Inc.

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WAITING LIST NUMBERS -- WE HAVE WORK TO DO

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Considering that it took nearly ten years of work to get the waiting list noticed, it is not unexpected that addressing the waiting list would be a monumental task. As part of the state Plan, a subcommittee of the Planning and Advisory Committee to the Office of Mental Retardation designated an Oversight Committee to just look at the implementation of the Waiting List Plan.

As of this January, the Oversight Committee continued to be frustrated by not being able to obtain clear information. We are presenting you with the information given to us by the Office of Mental Retardation for the year 00-01:

- 748 people were to receive Residential Services. The Counties have served 543 people.
- 2,117 people were to receive Person/Family Directed Support Waivers. The Counties have served 1,779.

We are disturbed by the fact that many more people were to have been served last year. Our question is--why haven't more people been served? Contact your local MH/MR Office to find out the numbers are in your county.



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SERIOUS ISSUES AFFECTING THE WAITING LIST

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State and Community Organizer, Sheila Stasko, for the Waiting List Campaign, is a Co-Chair of the Planning and Advisory Council and also co-chairs the Oversight Committee of the Waiting List to the Office of Mental Retardation with Maureen Devaney, from Vision for Equality. This past Fall was devoted to a review of the eight recommendations that were developed as part of the state plan to address Waiting Lists.

Perhaps the most serious question presented is: Did the 411 people originally cited as being in the Emergency Category on PUNS by the Office of Mental Retardation receive services? The answer --The Office of Mental Retardation has no way of knowing. Temple University, Center for Excellence, will work with the Office to see if they can find an answer.

ISSUES

Capacity issues. More OMR staff were hired and many counties saw an increase in staff. Remaining problem -- Many counties are experiencing serious provider and staff salary issues.

PUNS -- It is difficult for people to move out of the critical category to services. There is a dilemma as to who should be served first, children who need supports, or adults whose caregivers are medically fragile who have been waiting decades.

Technical training for State, County and Consumers is needed. Should there be an interagency agreement with the Department of Corrections? The cost for services and supports for a person with mental retardation in the Criminal Justice System could be astronomical.

Transformation Information and Training. Who is the target? What is the message? Who is doing the training? Two levels of training are taking place; people and families are not included.

Self Determination is not being implemented



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Transition appears to have drawn a line in the sand.

Education and OMR do not appear to be willing to work with each other.

Institutional Closings -- each year less people are leaving institutions.

The Campaign is continuing to keep the public and government apprised of the Waiting List issues and concerns. The Campaign is constantly informing OMR about the issues you bring to our attention. We need to continue to hear from you! Our job is far from done.

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TRANSFORMATION PROJECT! DESIGNING A SYSTEM FOR US -- WITHOUT US

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One of the major areas of change is the need for the Office of Mental Retardation to develop a business model that will improve their effectiveness and efficiency. Who are the people, what do people want and have, who's waiting and how much funding is being used and available? What is being developed instead is another layer of bureaucracy.

The Provider Invitation to Qualify, the Provider Monitoring Process, Incident Management, Supports Coordination, and HCSIS Services and Supports Directory are among many other processes undergoing system design and implementation. However, only a handful of consumers and family members were involved in the process that is making major decisions for systems change.

The Transformation presentations that have been given show a system already developed and set in stone. Further, no one acts on the input or suggestions from people and family members. Counties already have Transformation Manager's in place. Supports Coordination (formerly called Case Management) is undergoing significant change and the people changing it are the state. Consumers and families will have an even more difficult time with the Individual Estimated Resources (IER) process. (See article, next page).

It appears that the system is intentionally confounding people by using such preposterous and rapidly changing jargon that nothing is concrete. Get information and ask questions. Visit the OMR Transformation web page at:
www.dpw.state.pa.us/omr/dpwmr.asp

**ALERT!!! YOUR INDIVIDUAL BUDGET -
- CURRENTLY CALLED INDIVIDUAL
ESTIMATED RESOURCES (IER) -- A
MUST READ**



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The greatest Transformation challenge facing people and families today is the proposed IER, which is a budget for funding that will be allotted for your services and supports. The proposed system is in the process of developing a needs assessment that will then determine the amount of funding you will have available BEFORE YOUR SERVICE PLAN IS DEVELOPED.

The IER appears to be focused and directed at people living at home. As a consumer or family member this can potentially take away your right to disagree with the county on what funding is being offered unless you are willing to spend the time to go through an appeal process. The information from your initial intake will be put in a central computer and will fit a profile of other people who have similar disabilities; that will drive funding for your budget. Budgets will become capped, with all similar disabilities costing the same amount. The budget will be driven by cost rather than need and flies in the face of Self Determination.

Funding for services has always been in short supply. An additional concern is that costs have always been held low and that the target funding estimated for people will be inadequate to fully fund what a person needs. We are in constant contact with people and families who tell us they are being told what they are allowed for funding before they have begun planning. The Person and Family Directed Support Waiver is capped at \$21,125 and will be the initial target for the IER.

People and families have barely begun to get adequate funding and now the state is trying to limit that amount even more. In two years the Consolidated Waiver will use the IER process and that funding will also be capped and have limits. If you are concerned with the possibility of a capped Individual Budget that falls short of meeting your needs, then you are encouraged to contact the PA Office of Mental Retardation, Department of Public Welfare and legislators to let them know how you feel before the IER becomes a destructive part of the system.

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CONTACT NEEDED NOW FOR WAITING LIST FUNDING AND DIRECT CARE WORKERS RECRUITMENT AND RETENTION

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Now is the time for you to stand up and make legislative contact! The state budget is being prepared. The Governor will make his Budget Address early in February. The PA Waiting List Campaign and the Direct Care Salary Initiative are intricately intertwined. In order for waiting lists to be reduced, we need to attract more qualified people to provide supports and services. As family members we trust and rely on dependable, caring and considerate staff people who will provide high quality services and support for our sons and daughters. There is nothing more basic or needed than quality care. The main problem plaguing the provider community is the ability to attract and retain high quality professionals because of extremely low salaries, some salaries are below the poverty level. We need your support. Please call, write or email Governor Schweiker and your state legislators. The message is very simple: Hello, my name is _____, and state that you are a person who is a self advocate or a parent/friend/advocate of a person with a disability and you are calling to ask Governor Schweiker (or your state legislator) to support funding this years Waiting List Initiative for Mental Retardation (you must be specific as there are many waiting lists) and to support the Direct Care Salary Increase Initiative." We rely on each others support to make positive change happen. Without this years funding people won't come off the waiting list and without a budget increase to support direct care staff we will not have people who can continue to work or be attracted to work with our families. Make those calls and contacts! 16,000 people are counting on you!



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--- The End ---

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