

THE CAMPAIGN TRAIL

NEWSLETTER OF THE PENNSYLVANIA WAITING LIST CAMPAIGN
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www.pawaitinglistcampaign.org

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The Blog is Here!

www.pawaitinglistcampaign.org website



<http://wlissues.blogspot.com>

A Blog to End the Wait for Mental Retardation Services

How do you really feel?

Here's your chance to talk back to us and share your ideas with readers.

Each week we will give you something to talk about. Our topics will be important and timely. We need you to read and respond.

Here's what the Blog will do for us and you:

1. It will allow everyone to respond to issues almost instantly.
2. It will allow you to share important thoughts and questions with people from across Pennsylvania and they can reply to your ideas.
3. It will allow us to collectively seek answers and find direction.
4. It will keep us all on our toes.

There is no topic that is off topic.

Announcing Dear Wanda

The Waiting List Campaigns equivalent of Dear Abby. Wanda will answer your burning questions with concise and factual information. Wanda welcomes a challenge and loves to search for answers. You can look for Wanda on our ISSUES blog and submit your queries to her.

TIRED OF URGENT HELP NEEDED MESSAGES?

Then let's get the waiting list funded.

We have the support of Secretary Estelle Richman from the Department of Public Welfare and Office of Developmental Programs, Deputy Secretary, Kevin Casey. We need the support of the Governor and Budget Secretary Mary Soderberg and most importantly from your legislator. Your legislator needs to hear from YOU. Your voice in his or her district means more than any other call. Legislators have told us that email is fine. So please call, write or email the Governor, Budget Secretary and your legislator. Tell them to end the waiting list for people with mental retardation. You can find important information by going to the www.pawaitinglistcampaign.org website.

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Waiting List Update from the Office of Developmental Programs

By Patty McCool, ODP

We are pleased to tell you that the waiting list initiative for 2007-2008 served 96% of the 3007 people who were targeted to receive services by the end of June, 2008. These people were recent graduates and people on the emergency and critical PUNS list, who needed non-residential services. Since funds were allocated for the last six months of the year, the bulk of the work to accomplish this occurred within those six months. That timetable put pressure on families to make decisions, file paperwork and begin services quickly.

As you may have heard, we did not use all the budgeted money in the initiative last year. The time needed to get people enrolled in the waiver, to work with families on Individual Support Plans and to get commitments from providers for the appropriate services contributed to a slow start for many services. However, be assured that we have had our regional program managers checking to see that the annualized funds allocated for this year are encumbered and being spent.

In administering the waiting list initiative last year, we learned a lot about the ability of our various data systems to provide the information

we needed to monitor progress. We learned, for example, that it was difficult to track progress via PUNS data, because the process for removing someone from PUNS was not clear enough. We are now working on modifications to the PUNS process to address how it is to be used in the future.

During last year, we made great progress toward transitioning our payment system to direct payment of providers by the state. As we complete the transition this year, we know that we will be able to access data about payments for service. This data will allow us to track whether people are getting the services that are in their Individual Support Plans. Until this transition is complete, we can only assess this on an individual basis.

In addition to the people we tracked in the portion of the initiative that targeted graduates and non-residential services, we served additional people who needed group home placement and people aging out of residential services. This represents additional people served via last year's waiting list initiative.

The waiting list continued to add people, even as we moved people

into services. The PUNS is very fluid. People come on and leave on a daily basis. But, in spite of additions and keeping in mind that people served by the initiative may not have left the PUNS, but moved from emergency to planning or may not have left the list because some service was late to start, the PUNS list has declined from its June 30, 2007 of 21,847 by 689 to its October 31, 2008 of 21,158.

At this time, the waiting list initiative for FY 2008-2009 has not been finalized due to the unfortunate economic situation across the country and PA in particular. We remain hopeful that the initiatives will be released soon. When that occurs, ODP will move quickly with the Administrative Entities to ensure that individuals are enrolled in the appropriate waiver and begin to receive services and supports as soon as possible

Thank you for all the hard work of the PAWL to support individuals in need in PA!

**As you may have heard,
we did not use all the budgeted
money in the initiative last year.**

Our Story Could Be Yours

By Sigrid & Bill Hirschhorn

The story that I will be sharing with you is truly only the tip of the iceberg because what lies underneath the surface is that which so many of us must struggle with every day of our lives, yet still learn to survive.

I want you to know also that, even after all of these years having dealt with our daughter, we still get emotional over the many issues we face, mainly because of the future she will never realize.

Our story began 24 -1/2 years ago with the birth of our second daughter, Samantha, who was born healthy and developed normally (even following in her older sister Jessica's footsteps - Jessica had been identified early on as developmentally advanced and was later confirmed as being gifted). That is until a flu-like illness required Samantha to be hospitalized around the age of 2 and dealt us all another deck of cards.

Over a span of several years we very gradually became aware of an alarming and ever increasing delay between Samantha's developmental age and her chronological age. She talked less and less and eventually just stopped talking, her walk became stiff and ataxic and she often fell. She seemed quite frustrated, unable to explain what was going on with her, often breaking down in tears. During this time period numerous medical tests and consultations were conducted, but they only provided us with more questions. She was labeled as having a degenerative neurological condition of unknown origin. In other words - no one had a clue.

By the age of 9 Samantha could no longer stand or walk on her own and required a wheelchair. Being non-ambulatory further compromised her condition and eventually resulted in severe kyphosis, scoliosis, hip displasia, and muscle atrophy.

Over time Samantha's spasticity has increased in her extremities and she still continues to decline in that area. Doctors have added spastic quadriplegia to her diagnosis. Her swallowing muscles have likewise been affected and she presently eats only pureed food by mouth and takes her liquids via a syringe - like device. Feeding her usually takes around 45 minutes to an hour, as she eats very slowly and we need to be careful to avoid reflux. Samantha is considered to be medically fragile.

We started out almost 25 years ago harboring all of the dreams and hopes one has with a healthy baby and now we have a young adult who is non-verbal, non-ambulatory, in diapers, needs to be fed, and requires total care for all daily living skills. How can I possibly convey the psychological, emotional, physical, social, and financial toll this situation takes on a family?

I have sacrificed my teaching career for almost a quarter century now in order to care for and advocate for our daughter, meaning that I could not contribute financially to my family nor earn a pension to follow me into my senior years. I know for certain that, unfortunately, I am not alone in this circumstance. Many parents have given up their careers to do the same and the cost is exponential in countless ways.

Samantha spent 13 wonderful, productive years at Elwyn, an approved private school in Media, PA which serves the special-needs community. Here a committed team of professionals arranged programming to best meet all of Samantha's social, physical, and emotional needs providing such things as aquatic therapy, physical therapy, field trips, musical presentations and best of all, friends.

At age 21 in 2005 Samantha aged out of Elwyn and overnight, to our dismay and disbelief, her quality of life changed dramatically. For about 4-5 years prior to graduation, while Samantha was still in school I did my research, continued to attend yearly IEP meetings, initiated modifications when necessary, and met with prospective placement personnel while making arrangements for her transition after Elwyn. This was all documented at the IEP meetings. I was consistently reassured by my then supports coordinator at MHMR that I had all of my ducks in a row and that with Samantha's consolidated waiver, she should be set to go. I even enrolled at Villanova full-time and became a certified paralegal in order to better understand the legislative infrastructure and governmental rhetoric involved in the special-needs arena.

Imagine my surprise and frustration when I found out in June 2005 that someone, somewhere along the line, had dropped the ball and no one had noticed - not even with all of the documentation that had taken place. Samantha did not have a consolidated waiver after all! Not only could I not accept the 5 days per week day -program that had been meticulously arranged previously, but without this funding the most I could expect was 2 days a month, and that came with restrictions. Samantha has remained at home with us since graduation.

Adding to this unfortunate news was the development of serious health issues for my husband, Bill (age 66), also in 2005. My husband had 2 cataract surgeries that resulted in severe eye infections, which happens rarely, and ultimately was rendered legally blind. This was followed by 2 strokes that same year, which, along with his visual limitations cause balance and general mobility difficulties. Because of his health issues, Bill, the breadwinner of the family, was downsized to half- time. He works from home with my assistance and the help of various adaptive technologies on his computer and still his performance reviews note that he exceeds expectations.

By default, I am now the designated driver and caregiver for both my husband and our adult daughter.

The frightening truth for us is that if something happens to me, then our entire family structure will fall apart. Because of his continuing health issues, my husband will be retiring in December of this year after 40 years in the pharmaceutical industry and in academia. That means I lose my health insurance. He will then go on Medicare and Samantha already has Medicaid, but I, the person who needs to stay healthy in order to keep the family together, will lose my insurance coverage. There seems to be no safety net for me, nor for the many others in similar circumstances. Neither of us could have imagined the challenges the future held.

I would like to share a saying that seems to fit the occasion and also reflects what all families who face special challenges in their lives feel. "Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says I'll try again tomorrow."

What we would like for you to take away from our message is the recognition that there needs to be a better understanding and a more compassionate approach to addressing the problems that we and so many others like us face in life, because except for the Grace of God...OUR STORY COULD BE YOURS!

SIS™ UPDATE

SIS and PA PLUS Background

The implementation of the Supports Intensity Scale continues. The SIS is the standard assessment tool that ODP is using to evaluate the needs of Waiver participants. The Office of Developmental Programs reported more than 1300 assessments either completed or scheduled through September of this year. Thirty two assessors are working for Ascend to administer the test in all geographic areas in Pennsylvania. Over the next five years, everyone in the Person Family Directed Support and the Consolidated Waivers will be required to have a SIS. When you are notified to receive an assessment, you will choose at least two people to participate in an interview process to respond to the questions on the test. Your Supports Coordinator is also expected to be there. After the meeting, you and the ISP team will get a copy of the Summary Report. Results of the assessment will be used during the ISP planning process. For more information, you can ask your supports coordinator, visit www.odpconsulting.org, www.siswebsite.org, and

www.ascendami.com, or request a training through the Training Partnership at 1-866-865-6170.

Ascend has completed about 2,000 assessments since March, 2008, and approximately 600 per month are now being scheduled. Ascend anticipates completing 760 assessments per month by Spring, 2009. With your help, ODP and Ascend continue to resolve problems as they occur, and I'm happy to say that they are decreasing. We've had many good experiences and have received lots good feedback from you, as people see the difference between the SIS™ and other assessment tools.

Assessments are currently being conducted statewide on all Waiver participants. We're seeing a reduction in the length of time for the actual assessment process with the average hovering around 2.5 hours. As soon as the 09/09 Initiatives Wait List is available, those individuals will be identified to receive Sis™ Assessments.

The PA Plus was developed by stakeholders to be used concurrently with the SIS™. It consists of a set of nine questions to provide additional planning information not covered in the SIS™ assessment. Topics include supports needed for mobility, transfers, vision, hearing, communication, and safety, as well as assistive technology, treatments, medications, and behavioral health. These additional questions are designed to support the planning process and better serve individuals' needs. We anticipate implementation in late January or February, 2009, depending on HCSIS functionality.

For further information, please go the following websites:

ODP/SIS:
www.odpconsulting.net

SIS:
www.siswebsite.org

Ascend:
www.ascendami.com

Employment Update

Written by: Dana Olsen, Director of Quality Improvement Initiatives
Office of Developmental Programs

The Office of Developmental Programs (ODP) tracking reports that the FY 2007-08 Waiting List Initiative to provide home and community services for young adults transitioning to adult served 750 of the 800 individuals budgeted for the program as of June 30, 2008. These young adults generally received at least 5 hours of employment or community inclusive support or held a part time job. Based on the approval of additional growth in this program in the FY 2008-09 authorization bill, we expect this initiative to continue in FY 2008-09 although the number of young adults to be funded has still not been finalized.

ODP joined the State Employment Leadership Network, or SELN, in FY 2007-08, and continues its affiliation with the network in FY 2008-09. Funding for ODP participation in the SELN comes from a Medicaid Infrastructure Grant (MIG) that helps states develop the necessary administrative support structures to improve employment outcomes. The SELN has been ac-

tive in providing training opportunities, information on best practices, meetings with other states. SELN staff from the Institute on Community Inclusion and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) has provided ODP with an assessment of its progress and is assisting in a multi-year employment plan that is underway.

ODP continues to issue monthly Employment Updates to its network of interested stakeholders, including provider agencies, employment point persons at State Centers, County Programs and Regional personnel. Families and individuals interested in receiving Employment Updates at no charge can contact Carmen Donegan at 717-705-7986 or cdonegan@state.pa.us.

ODP is continuing to fund employment pilots in 19 County MH/MR Programs during fiscal year 2008/9. These pilots have allowed County Programs to fund follow-along supported employment services for hundreds of youth and

young adults when OVR funding is no longer available.

The State Center Quality Council has identified employment as a quality improvement action for the last few years, resulting in increased and more diversified employment opportunities for people in State Centers.

ODP recently issued two studies relating to community services and employment for adults in the service system. The studies titled: Report on ODP Survey of Employment and Adult Non-Residential Services for State Fiscal Year 2007-08, and Habilitation Survey, FY 2005-06 Survey Cycle, Independent Monitoring for Quality, provide information on individual and family satisfaction and outcomes, as well as program characteristics or employment and other adult community programs. Copies are available on request by contacting Carmen Donegan.

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

ODP is continuing to fund employment pilots in 9 County MH/MR programs during fiscal year 2008/9.

I am Very Excited About My Life!

By Matthew DeWeese

October 28, 2008

Hi my name is Matt DeWeese. I have always lived at home with my mom and dad. When they became very sick and went into a nursing home, for 19 months I had nowhere to live.

My county had no money for services.

June 1, 2008 everything changed. NOW I have a family to live with. NOW I have a hab aide to take me into the community.

NOW I am living an Everyday Life.

Thank you Sheila and the Pennsylvania Waiting List for caring about people that wait for services.

Many people worked together to help individuals like myself get the supports needed for a life in the community. Thank you Department of Public Welfare Secretary, Estelle Richmond for understanding how desperate and scared I was.

Thanks to Deputy Secretary Kevin Casey, and Sandy Schalcoski at the Western Region Office of Developmental Programs for taking the steps necessary to make funding available for me.

I am very excited about my life. I have two jobs! I am a trainer in the Partnership for Self Advocates United as One. I have also been hired to water, feed horses, and clean their stalls at the Shaffer farm.

I volunteer at Good Shepherd and for the Salvation Army.

I know I am a very lucky young man. I know that there are many more people waiting for services just like I waited. We need to help them too.

It is a big job. I don't know how to get money for supports for the people that wait. I'll trust you to help the others that are still waiting.

Thank you for listening.

Matt DeWeese

Mercer County, PA

We can. We will. We must.

**END THE
WAIT!**

<http://www.pawaitinglistcampaign.org>

Latest PUNS Figures from the
Office of Developmental Programs
November 30, 2008

TOTAL: 21,209

Planning: 6,919
Critical: 9,746
Emergency: 4,544

Pennsylvania Waiting List Campaign

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Slatington PA 18080

Phone/Fax 610.767.2437

email sstasko@pawaitinglistcampaign.org

Website: www.pawaitinglistcampaign.org

Dear Representative :

The Pennsylvania Waiting List Campaign looks to you for help in retaining and securing funds for the most vulnerable people in our commonwealth. The proposed waiting list budget for this year was already decreased by \$6 million dollars, meaning 400 people with mental retardation will be denied community services and supports they need. More so, that \$6 million state dollars would have been matched by federal dollars, therefore the state has lost \$24 million dollars in federal funds. Please help us to find a solution and continue funding to help people.

The waiting list for people needing community mental retardation services and supports is 4,500 in the emergency category alone. Pennsylvania has the third highest number of elderly parent caregivers in the United States. Our caregivers are also aging and there is no relief for them. We have 80 and 90 year old moms and dad's taking care of their 60 and 70 year old son's and daughters. Without families, institutions would be filled to the brim and institutional costs (at \$200K a person) would skyrocket. Strong families are and have been the backbone of our system. We believe in taking care of our own, but need support when our family or body's start breaking down. That's where we turn to the system for help.

There is an absolute assumption made by the general public that the government would never turn its back on vulnerable people who rely on the help and support of others. People are stunned when they discover that there are waiting lists. People shaking their heads in disbelief and telling us that this is the role of government just doesn't do much for a family in crisis. We are in crisis. We need your help.

Respectfully,

Sheila Stasko, Statewide Coordinator

Budget Information from Kevin Casey, Deputy Secretary, ODP

As you will recall, I promised at the last PAC meeting to send out a specific list of our cuts in the second round of budget freeze. We took an additional \$11,842,000 in cuts in this round.

Our cuts came in the following areas:

07/08 carryover:	\$ 5,000,000
County administration:	\$ 917,000
Internal operating:	\$ 266,000
Waiting List Average:	\$ 5,659,000
(5 month average to 3 month average. Number of people served stays the same.)	

Total	\$11, 842,000
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The County cut is for a quality manager position that we had hoped to allow the Counties.

The waiting list number changes the average number of months of service this year from 5 to 3. We will continue to serve the same number of people planned for, and all waiting list budgets of people served this year, will be continued into next year.

I want to take this opportunity to remind the entire community, that these cuts do not require, nor allow, a cut in services to people currently receiving services. If you hear of any instances in which current Consolidated, or PFDS waiver services are being reduced, with budget cuts given as a reason, I ask that you please inform your regional program office.

If you have any questions, please e-mail them to me.

Kevin T Casey
Deputy Secretary
Office of Developmental Programs

Adult Protective Services

Written by Terry Roth, Esquire
Consultant

Let's get behind Protective Services for our adults between the ages of 18 to 59. Legislation will be reintroduced in January 2009 and we need to help get this legislation passed.

Throughout Pennsylvania, there have been **many cases of abuse and neglect** of people between the **ages of 18 and 59** with disabilities. A House hearing held in the fall of 2006 documented a number of them, including a young woman with mental retardation who spent several days locked in a basement with her dead sister and a woman with multiple sclerosis who was raped by her husband. **Current laws and policies do not protect them.**

Just as we **need protective services laws and systems for older Pennsylvanians and for children**, we need a law to protect vulnerable adults between the ages of 18 and 59. That was the **conclusion of a study** conducted by the Legislative Budget and Finance Committee in September 2003.

PA is one of **only six states** that fails to provide protective services for adults.

In the wake of the LBFC study, a **cross-disability coalition** of people with disabilities, their families and advocates

came together to develop **principles** for what an APS system should look like in PA. They agreed that the legislation must **balance individual rights with the need for protection.**

SB 1049 and HB 361 were drafted based on the principles outlined by the disability groups. They are **strongly supported by groups** representing people with disabilities and their family members. In fact, there's been **no opposition**. The Secretaries of Aging and Public Welfare have expressed support, while raising concern about where to find the money. Both bills saw some movement in the 2007-08 legislative session which ended in November, 2008. Legislation will be reintroduced with new bill numbers in the 2009-10 session which begins in January, 2009.

In addition to passing a good bill, we also need to secure funding for the system. As taxpayers, we understand that **budgets are tight**, but believe that this must be a **priority**. The good news is that the first year after legislation is passed will be taken up with start-up activities, so there would be no cost in the

next budget. After that, we estimate a cost of about \$6 million a year.

Our state's failure to provide protections for people between 18 and 59, at some point, could jeopardize our federal funding. That's one reason to act quickly to pass APS. But, more importantly, it's long past time to **fix this gaping hole in our safety net.**

It's critical that we all work together in the new legislative session to pass strong Adult Protective Services legislation. No one else should be injured or even killed while we wait.

PA is one of only 6 states that fails to provide protective services for adults.

ASK DEAR WANDA

Dear Wanda -- I filled out all my paperwork with the County some time ago, and they told me I am on the Waiting List. How long will I wait? –Tired of Waiting

I don't know. The Waiting List for services includes about 22,000 people across the State. The most important thing for you to do is make sure you are keeping in touch with your Supports Coordinator and that your PUNS form is updated and accurate. While you are waiting for Waiver funding, ask your Supports Coordinator if there is any BASE MONEY or Family Support money. They may be able to get you some limited support, such as respite. The only way you can get Waiver services is if funding is allocated by the State for new people to enroll into the programs, or if someone in your County leaves the program, and I can't say when that may happen.

Good Luck,
Wanda

~~~~~  
**Dear Wanda -- How do I find out what number I am on the Waiting List? –Frustrated Family**

The Waiting List is not like a deli line where you take your number and wait for your turn. People are not assigned a position. When funding for services becomes available from the State, the AE/County must look at serving the folks in Emergency category first. Make sure your Supports Coordinator gets to know you and your family member and what you need. The AE/County chooses who will get the "Waiver slot". You can visit the PA Waiting List website to find out how many people in your County are waiting in each category.

Be Persistent,  
Wanda

~~~~~  
Dear Wanda -- I am new to this system, so I was wondering when I should apply for a waiver for my son? – Parent of a 13 yr. old

First you should register for Mental Retardation Services at your County MH/MR office. Then, if you don't have an MA Card (Medicaid), you should apply for one. Once you are registered and have your Medical Access Card, the AE/County **MUST** offer you the chance to fill out your Home and Community-Based or ICF/MR Application and Service Delivery Preference Form (DP 457). When you choose Home and Community, you are applying for the Waiver. Waivers are for people 3 and older, so I recommend that you apply now. If the AE/County or your Supports Coordinator tells you that you can't or shouldn't apply, you can Appeal that decision. If you have a problem or need more information contact the ODP Customer Service Line at 1-888-565-9435, the Partnership at 1-866-865-6170, or a local advocacy organization.

Great Question!
Wanda

18th out of 7,500 ideas is NOT GOOD ENOUGH to End the DD Wait Lists.

18th out of 7,500 ideas is NOT GOOD ENOUGH! The proposal to fully fund the Medicaid Waivers and end the waitlist for hundreds of thousands of individuals with DEVELOPMENTAL disabilities is now 18th.

http://www.change.org/ideas/view/fully_fund_medicaid_waivers_for_the_developmentally_disabled

BUT IT HAS TO BE IN THE TOP TEN TO BE BROUGHT TO THE ATTENTION OF THE OBAMA ADMINISTRATION AS DESCRIBED BELOW.

From MSNBC:

Change.org Opens Voting for the Top 10 Ideas for America

SAN FRANCISCO, CA - Change.org, the leading online platform for social change, today announced it has opened voting for the Top 10 Ideas for America, to be presented to the Obama Administration at an event at the National Press Club in Washington, D.C., just days before the Inauguration. Each winning idea will form the basis of a national advocacy campaign organized in [collaboration](#) with leading nonprofits to translate each idea into real policy.

The voting process comprises the second and final round of the "Ideas for Change in America" competition.

Since the launch of the competition more than 7,500 ideas have been submitted, addressing major challenges ranging from global warming to the economy to education. More than 30,000 comments have been added and 250,000 votes have been cast to discuss and identify the best among these ideas.

PLEASE GO TO THE WEB SITE BELOW, REGISTER, RETURN TO THE WEB SITE BELOW AND CAST YOUR VOTE (LEAVING A COMMENT DOES NOT CAST A VOTE). ALL WE NEED IS 1,600 MORE VOTES.

http://www.change.org/ideas/view/fully_fund_medicaid_waivers_for_the_developmentally_disabled

TO LEARN MORE ABOUT THE WAIT LIST, VIEW THE FOLLOWING SHORT VIDEO ABOUT SAMANTHA:

<http://blip.tv/file/1638780/>

To learn more about the National Organization to End the Wait List, please see:

<HTTP://WWW.NOEWAIT.NET>

VOTING ENDS ON THE 15TH OF JANUARY

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

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

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Vision for Equality, Inc.
For the PA Waiting List Campaign
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**Funded by the Disability
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Pennsylvania**

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