

CRISIS IN THE COMMUNITY

Pennsylvania Waiting List Campaign

We can. We will. We must.

**END THE
WAIT!**

<http://www.pawaitinglistcampaign.org>

PA WAITING LIST CAMPAIGN

- The PA Waiting List Campaign grew out of an unmet need to address the social injustice of people with developmental disabilities and their families who had no services or supports plus a burning desire for systems change

History

- The 1960's opened up doors for the development of community services and supports
- The 1970's brought the right to a free, appropriate education for students with disabilities across the country under Public Law 94-142
- State institutions started closing in the 1980's because of Law suits like Pennhurst and Willow Brook.
- Waiting Lists for community services started to grow in the 1990's because of lack of community expansion.

Arc US “Unlock the Waiting List; Key of Our Own Campaign”

- PA joined the National Arc US Unlock the Waiting List; *Key of Our Own Campaign* in 1998
- Over 20 states participated and there was a renewed enthusiasm that we would begin to address this major problem across the country

Creating an Uproar In PA

- PA held a Waiting List Campaign Kickoff in 1998
- We talked with Policy makers
- We visited legislators
- We held letter writing campaigns
- We held rallies
- We collected accurate numbers of people waiting
- We developed a Wall of Tears with pictures of hundreds of families displayed at our state capitol
- Disability Rights Attorney's filed lawsuits
- At the end of the first year every Legislator knew about Waiting Lists

Pennsylvania

- In 1999 The PA's Office of MR Planning Advisory Committee developed a *Long Term Plan to Address the Waiting List*
- The Budget was announced by the Governor in February 2000 and called for \$853 million dollars to be allocated over the next 5 years

Long Term Plan

- We were overwhelmed and delighted. We thought we found the solution in PA. In the initial few years we received funds that took many people from the Emergency category off the list.
- Then 911 happened and our Long Term Plan dwindled
- In spite of the obstacles and with unrelenting Advocacy the PAWL Campaign was successful in obtaining funds almost every year since the start of our campaign
- In 2007 alone we received funds for 3,500 people on the Emergency Waiting List and all of the 800 students graduating from high school in our state
- This year we expect to receive funds for 1,800 people but we understand those funds may be in jeopardy– we are waiting to hear

Today in Pennsylvania

- Over 21,000 Pennsylvanians are presently waiting for services from the Office of Developmental Programs
- Of that number 5,000 are in emergency need and require services immediately

Today in Pennsylvania

- This year with the help of the PA DD Council and Disabilities Rights Network of PA we developed commercials that were shown all over the state
- We encouraged our Legislators to develop HR 159, an endeavor by the Joint State Government Commission which calls for Waiting List reform

Major Problems Contributing to Waiting Lists

- Young Adults Graduating from High School
- Aging Caregivers
- Insufficient funding for Community services

Young Adults Graduating from High School and their Parents

- Young Adults graduate from high school each year and after the age of 21 often sit at home with no services
- Special Education is an entitlement in this country up until the age of 2; after that time there are no entitlements for services
- Once their son or daughter leave school, parents are often forced to leave their job to become 24 hour caregivers causing a grave economic impact on families

Aging Caregivers and their Adult Sons and Daughters

- Many aging Parents in their 70's, 80's and even 90's care for their loved ones at home without support or assistance
- Often they need care themselves and are not even able to bring their sons or daughters to doctors or appointments, let alone take care of themselves
- Many live lives of quiet desperation not knowing where to go or where to turn for assistance

Issues

- Waiting Lists for Developmental Disability services are a concern in nearly every state
- Access to information about services and waivers is not readily available
- States do not always collect information nor classify and fund services in the same way. Consistent measures of collecting information is a key component to any state's waiting list initiative

Problems Facing Community Life

- People often need to wait until the last caregiver dies and even then services are sometimes not available
- Siblings who are unprepared often assume responsibility of care giving and give up their personal lives
- Parents in the sandwich generation are caring for both an ailing spouse or parent and an adult with disabilities
- Grandparents are caring for children and young adults
- This generation has an influx of single parents raising their children and adults with disabilities alone with little or no support
- Families are struggling just to get through each day

Waivers Impact on Waiting Lists

- Waivers are Major funding sources
- Waivers allow people to have choice where services and supports are provided in the community instead of an institution
- Difficulty in obtaining Waiver funding in most states because of limited access
- Waivers are not always provided on the basis of need

Funding Dilemma - Systems Issues

- State of economy in our country
- Budget growth does not match the demand
- Little to no long range planning
- No consistent National impact
- Competition for funding
- Recognition but little solution
- System reliant on families providing care

Positive Community Impact

- 61% of individuals live at home with their family saving taxpayers billions of dollars each year
- Last Twenty years Family Support and Self Determination Initiatives played a major role in changing the system
- People of today reject segregation and congregate living facilities and seek community supports
- People want choice and control of their own lives
- People want to live in the community
- People want to work
- They want innovative quality supports and services

Concern

- Today we have entitlements to live in large ICFMR's or state centers but no entitlement to community living
- **We MUST reverse this bias and call for entitlements to community supports and services**

How to Start a State Campaign

- Make a conscious decision to take a stand
- Become vocal and challenge the system
- Join *NOEWAIT* and The Arc US *Stop the Wait Campaign*
- Organize or join your own State Campaign
- Gather allies and develop a strategy and plan
- Network.
- Refuse to “settle”
- Find out what works in other states
- Visit the PA Waiting List Campaign Website and other state websites for ideas

- Make change happen and

NEVER, NEVER GIVE UP

What you can do in your state

- There is a budget process unique to each state – find out what it is
- Identify Legislative leaders set up visits
- Find out the numbers of people waiting in your state
- Keep your eye on the goal of ***ending the wait***
- ***MOST IMPORTANTLY TELL THE STORIES OF PEOPLE ON WAITING LISTS – DON'T KEEP THIS ISSUE QUIET ANY LONGER***

Politically Speaking

- Waiting Lists are not “sexy” issues; there is a lot of competition for funding
- Most Campaigns are run by families who have little financial support to keep the mission and cause in the forefront
- We must be more united on these issues across the country and make Waiting Lists a household name
- Legislators need to know they are sitting on a time bomb because any day the baby boomers will present for services

What Needs to Happen

- Local and National Public Awareness of the situation must occur
- National and State leaders of all disability rights organizations need to make this issue a priority
- Entitlements should be for community supports and services and not institutional care
- A New funding source, dedicated and annual, sufficient to fully serve those in need must be secured

How to Change the World

“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed it’s the only thing that ever has”

Margaret Meade

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**Visit the PA WAITING LIST CAMPAIGN
Website**

www.pawaitinglistcampaign.org

1-877-372-WAIT