

PRESS CONFERENCE

January 21 at 11 am Capitol Rotunda Steps

Filing of Civil Rights Lawsuit – Pennsylvania State Center residents and families/guardians

Who controls the Commonwealth of Pennsylvania?

Who determines the services the Commonwealth provides for its most vulnerable and needy citizens?

Why doesn't the Commonwealth allow the families and citizens to choose Intermediate Care Facilities?

I am the mother of a severely autistic young man with numerous co-morbid conditions. Community placement works for some, but in the case of my son, Joey, it was an unmitigated disaster. Joey suffered for 4 years in 6 different community waiver homes that could not manage his challenging behaviors and who discharged him into 5 different psychiatric wards. In the course of those terrible years, he suffered a broken eye socket, multiple stitches, was exposed to pornography, was toxically overmedicated with powerful psychotropics that left him with Parkinsonian tremors, disfiguring female breasts, Serotonin Syndrome, and psychotic breaks with reality.

Joey was rescued by the compassionate and professional caregivers at White Haven State Center. The "Community" service system failed Joey miserably. Joey was rejected by the "Community" over and over again. Joey was left with nowhere to go. Joey was never more isolated and never more segregated than in the lonely "Community" waiver houses and apartments. There are countless Joeyes in Pennsylvania.

When the Commonwealth eliminates outstanding services provided in State-run public Intermediate Care Facilities, such as White Haven Center and Polk Center, those rejected by the "Community," like Joey, end up in psychiatric wards, retro-fitted emergency rooms, prisons, and out on the streets.

The so-called "Community" asserts that my son, Joey, is just a rare case. I wish this were true, but it is not. The autism rate is now 1 in 59 births and steadily rising. A lot of these children will come of age in the next 10 years and 10% of them will be as severe as my son.

White Haven Center and Polk Center are public Intermediate Care Facilities which were donated to Pennsylvania by its compassionate citizens specifically to be used for long-term residential care of the most severely and profoundly disabled. These State Centers offer comprehensive care with on-site multidisciplinary teams of professionals, including doctors, nurses, behaviorists, therapists, and well-trained, justly compensated direct care staff. These therapeutically-designed facilities are equipped with specialized accommodations almost universally lacking in the "Community" waiver housing.

There are currently 13,000 individuals on Pennsylvania's waiting list for services. The includes 5,000 individuals on a critical waiting list. The Commonwealth would like you to believe that these individuals do not want to obtain care for their special needs at one of the remaining State Centers. The truth is, they were never offered the comprehensive care available at State Centers. The doors are closed to those in need.

Despite the overwhelming need for long-term care by thousands of disabled Pennsylvania citizens, as well as the strong support for the services offered at White Haven Center and Polk Center from so many people in our community, including individuals, civic groups, faith-based groups, and state and local legislators, the Wolf administration and the appointed officials in the Department of Human Services remain determined to shut them down. The Commonwealth is not only evicting the residents who have

called these centers home for decades, but it is denying future generations their right to receive comprehensive services now available.

The self-proclaimed “Disability Advocates” have a seemingly endless list of professional lobbying groups with an alphabet soup of acronyms. They forcibly advocate for us against our will and against the best interests of our loved ones. The Disability Advocates, have never even met our loved ones or inquired about their medical needs, but they use millions and millions of our own taxpayer dollars to undermine and eliminate the only type of care that works for our loved ones.

There is no appeasing the Disability Advocates.

There is no reasoning with the Disability Advocates.

There is no compromise with the Disability Advocates.

It is “Community” or Nothing.

Their sanctimonious attitude seems to be “I don’t want an ICF for my family, so you shouldn’t be able to choose an ICF for your family.”

Why can’t Pennsylvania offer both types of service systems – a range of services for a range of needs - Community and State Centers as provided for by FEDERAL LAW.

The Disability Advocates attack our family members’ viable options and offer alternatives that are worse than nothing. They offer only unworkable, anemic and unrealistic “in home supports” or a costly, isolating privatized system of segregated housing for our loved ones. The “Community” homes have chronic staff shortages and are amassing a record of abuse and neglect rivaling the decades old psychiatric asylums. Media expose’s report many instances of the profiteers at the top of the “Community” system raking in millions of dollars while their direct care staff are underpaid and impoverished. Direct care workers in the scattered, dispersed “Community” houses cannot collectively bargain – hence the low wages, no benefits, no on-the-job support, and minimal training which lead to a high staff turnover rate of 38% and a vacancy rate of over 11,000 positions per day in “Community.”

These lobbyists effectively control the Department of Human Services and the Office of Developmental Programs and set policies.

Both the Commonwealth and the Disability Advocates continue to claim they will save an enormous amount of money by destroying the State Centers and that the money saved will be used to eliminate the Waiting List. If that assertion was ever true, then why didn’t eliminating Altoona, Cresson and Hamburg Centers make a tiny dent in the Waiting list? Think about it.

Once these valuable Centers are destroyed, they cannot be replaced. Our families are fighting the good fight to prevent this tragedy for our loved ones and Pennsylvania.

On behalf of the residents of White Haven Center and Polk Center, I would like to thank the compassionate and courageous legislators who stand with us, fighting to protect our loved ones, as well as all of those who have supported us in our decision to help protect the Civil Rights of our family members with this lawsuit.

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