

PA STATE CENTERS ARE A LIFE LINE AND A SAFETY NET FOR PENNSYLVANIA FAMILIES

My name is Susan Jennings and I am the mother of a severely autistic young man with intellectual disabilities and co-morbid psychiatric disorders named Joey.

We could not manage his difficult and challenging behaviors at home. He would fly into unpredictable and violent meltdowns. I was busy scrubbing feces off the carpet, treating the bite marks he gave me with hydrogen peroxide, sweeping up shattered glass when he broke light fixtures and running down the highway when he would elope into traffic. And he almost never slept.

So my son entered the "Community" who could not manage him safely either in their service system. In 4 years time, he was discharged from 6 different group homes, Section 302's into 5 different psychiatric wards for as long as 6 months at a time, his eye socket broken, exposed to pornography, toxically overmedicated and left with Parkinsonian tremors, Serotonin syndrome and disfiguring female breasts. He was isolated and segregated in one-person group homes and apartments, so lonely he would call us up to 18X per day.

He was rescued by the professional, and therapeutic environment of White Haven Center with it's skilled, caring staff and on-site multi-disciplinary team of nurses, doctors, behaviorists, psychologists, therapists, dieticians and supervisors. White Haven also gives him many opportunities to socialize at dances, parties, barbecues, and trips to restaurants, movies and amusement parks.

The Department will tell you that none of the 13,000 people on the Waiting List want services in the Intermediate Care Facilities of the State Centers. We know we were kept in the dark as to the very existence of the State Centers by the frontline social workers and when we found out accidentally, we were told that the Centers were closed to admissions. Our son only gained admittance after a costly court battle with ODP.

The assertion that the money taken from the State Centers can be used to substantially reduce or eliminate the Waiting List is demonstrably untrue. In 2016, when Governor Wolf poured an extra \$196 million dollars into "Community" services, which is \$58 million more dollars than the State Centers cost altogether, only 39 people were removed from the Waiting List for community services.

I know that you are told by the Department that the State Centers are not sustainable. But what do they mean by sustainable? Polk Center has sustained itself for 120 years and White Haven has sustained itself for more than half a century. All four State Centers account for only 7% of the Office of Developmental Programs budget and yet they are more efficient, provide superior comprehensive services, and can pay higher wages and benefits to their stable professional staff than the "Community" can. All of this fiscal efficiency is achieved, in spite of the harmful policy of closed voluntary admissions adopted in 1998 by ODP which led to the State Centers' declining census. ODP's own policy, adopted without legislative or public input, caused the cost per resident to go up with the declining census as there were fewer residents to share the fixed costs. ODP uses this predictable result caused by their own policy, to complain that the costs are too high. If the Centers were open to voluntary admissions, the cost per resident would precipitously decline.

It is the "Community" service system which is unsustainable. They eat up 93% of the ODP budget and yet they cannot staff their waiver homes, lacking 11,000 Direct Support Personnel for each shift, they go in and out of business, and they neglect to report critical incidents to State authorities resulting in multi-million dollar lawsuits against the States, such as the 4.5 million dollar lawsuit in Oregon, where DHS Teresa Miller presided over ICF closures 10 years ago. See [\\$4.5 Million lawsuit alleges abuse of developmentally disabled man at state-licensed group home](#). How efficient can managed care companies who oversee privatized care for the Commonwealth be when they must take 15-20% from actual healthcare dollars for their expected profits?

Deinstitutionalization is a national disgrace – a failed social experiment that has left 40 years of chaos, suffering, homelessness, abuse and neglect in its wake. We must let go of the delusion that the sickest among us should be expected to manage their own care and that all institutions are inhumane. Without the institutional care of the PA State Centers, beleaguered families of dually diagnosed loved ones will have nowhere to turn but to the inappropriate and costly institutions of psychiatric wards, jails and emergency rooms.

With over 900 certified empty beds at the State Centers, why close them when they have the experience and skill to provide needed services for the 13,000 on the Waiting List and for the coming tsunami of autistic adults coming of age in the next 10 years. Why evict the 300 residents who love and appreciate the State Center services? Open the doors of the State Centers to voluntary admissions to bring down the costs and utilize the services and facilities for the short and long term.

I implore you to sponsor and support House Bill 1918 – the Moratorium on the closure of White Haven and Polk Centers until a thorough study and investigation of all the consequences of such a grave and short-sighted decision can be evaluated.

Sincerely,

Susan Jennings
Mother/ Co-guardian of Joey, White Haven Center
KIIDS – Keeping Individuals with Intellectual Disabilities Safe
VOR- Pennsylvania State Coordinator and Board Member

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