

From: Richard Jennings <rjen@ptd.net>

Sent: Tuesday, October 15, 2019 3:22 PM

To: Erin Raub <Eraub@pahousegop.com>

Subject: Written Testimony - Susan Jennings White Haven Center Health and Human Services Hearing Oct 21

I am the mother of a severely autistic intellectually disabled young man with Co-morbid psychiatric disorders who resides at White Haven Center. He was previously served in the "Community" service system where he was discharged in and out of 6 different group homes, and Section 302'd into 5 different psychiatric wards in the short space of 4 years before he was finally admitted to White Haven Center where he lives, works and thrives today. I am writing to implore you to sponsor and support House Bill 1918 and stop the proposed closures of White Haven and Polk Center until such time as the issue, the future ramifications and consequences and all of the questions can be thoroughly investigated and evaluated.

I am expressing the need for our loved one's choices and needs to be valued and respected. Unfortunately because of systemic shortcomings in the "Community" service system which has been well documented by the media and by an intergovernmental report the 2018 joint report by the Office of Inspector General, the Office of Civil Rights, the Administration for Community Living and the Department of Health and Human Services entitled "**Group Home Beneficiaries at Risk of Serious Harm**" my son and thousands of other disabled adults need to be able to access the intensive care and assistance that can only be provided by the Intermediate Care Facilities (ICF) of White Haven and Polk Center. There simply is no equivalent services in the "Community".

ICF's must provide Active Treatment, group homes do not. ICF's have on-site daily monitoring by a multi-disciplinary team of doctors, nurses, supervisors, trained staff, behaviorists, psychologists, and therapists, group homes do not. ICF's must comply with CMS federal regulations (the 257 page Appendix J of the State Operating Manual), group homes do not have any federal regulations. ICFs must report all critical incidents, group homes are not reporting all critical incidents.

In 1998 before the Centers were closed to voluntary admissions, there were less than 1000 individuals that were on the Waiting List, today there are 13,000 and 5,000 need emergency services. Presently there are over 900 certified beds available at all of the remaining 4 Centers. I know you are being told that no one on the Waiting List wants these beds but I can personally testify that we were never told about the Centers by the frontline social service workers and when we discovered the existence of the State Centers accidentally, we were told the Centers were closed to admissions. We had to hire a personal attorney, assemble an army of expert witnesses and battle the Office of Developmental Programs all the way through Commonwealth Court, which our son won at every level, to gain admittance to White Haven Center. It is a terrible injustice to put desperate and beleaguered families through such a costly and traumatizing legal battle with ODP.

The disability landscape has changed. In 1960 when Deinstitutionalization began only 1 in 10,000 births was autism, today it is 1 in 59. Most autistic children on the DHS caseload are under the age of 18 but will reach adulthood in the next 10 years and there will be a catastrophic need for residential services as between 10-50% of these children will be severely impaired. If the State Centers are closed, where will they go? Retro-fitted Emergency Rooms? psychiatric wards?, jails? the streets? See [Nowhere to go, Young People with Severe Autism Languish in Hospitals](#) . See also from [Because We Care - A Hospital is Not a Home](#)

How many dually diagnosed individuals in Pennsylvania are presently languishing in hospitals, psychiatric wards and Jail and at what cost to the Commonwealth? See the Cost of Deinstitutionalization

You are told that the State Centers are unsustainable. What are they talking about? Polk Center has been sustainable for 120 years. Although all the State Centers take up a mere 7% of the ODP budget, they deliver superior services and higher wages to their stable workforce more efficiently than the "Community" which eats up 93% of the ODP budget. It is the "Community" which is unsustainable. Community group homes cannot keep their residences staffed - there is a shortage of 55,000 Direct Staff Personnel every year in Pennsylvania and they are scrambling to fill 11,000 positions for every shift every day. Group homes come and go out of business continuously. Part of the high cost per resident at the Centers is due to the harmful policy of closed admissions resulting in less residents to share the fixed costs. Open the Centers to voluntary admissions and the Economy of Scale employed by Universities, Hospitals and Corporations can be applied. Fewer professionals are needed to treat more patients and the cost per resident drops precipitously.

You are told that the Hamburg closure was a great success. 15 out of 80 Hamburg residents died, nearly one in five. That is simply not acceptable and it means that as many as 60 Polk and White Haven residents could likewise die from transfer trauma. Multiple wrongful deaths suits against the Commonwealth are not a way for the State to save money either. Money Follows the Person will become Liability Follows the Person.

Please support HB 1918 - Moratorium Bill until all these questions can be studied and answered.

Sincerely,
Susan Jennings
Mother/Co-guardian of Joey, White Haven State Center
KIIDS - Keeping Individuals with Intellectual Disabilities Safe
VOR - Pennsylvania State Coordinator and Board Member
Email: rjen@ptd.net
Websites: www.thekiids.org
www.vor.net