



VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
<https://www.vor.net>

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Darrell Pickney
206 NE 2nd St.
Hoxie, AR 72433
(870) 530-6699
ddpickney@yahoo.com

October 23, 2019

Governor Tom Wolf
Office of the Governor
508 Main Capitol Building
Harrisburg, Pennsylvania 17120

Dear Governor Wolf,

We write this letter in hope that you will re-evaluate and ultimately reverse your decision to close the Polk and White Haven Developmental Centers.

VOR is a national non-profit organization comprised of families of individuals with severe or profound intellectual and developmental disabilities (I/DD) and autism. Many of our loved ones also have aggressive or self-injurious behaviors and/or complex medical conditions. Like the people who reside at the Polk, White Haven, Selinsgrove, and Ebensburg centers, our family members require higher levels of care and better-trained, experienced caregivers to achieve their best quality of life.

The I/DD population covers an incredibly diverse spectrum of individuals, each with their own distinct needs and abilities. While some individuals are eager to live in community settings, to interact with non-disabled persons, and to be judged on their abilities and achievements, that is not the case for those individuals at the other end of the spectrum. For them, safety and health are the keys to maximizing their potential. State-operated developmental centers are often the best place to meet the needs of this population.

Most of the individuals being moved out of White Haven and Polk Centers will be slated for moving into HCBS waiver settings. They, their parents and legal guardians will be forced to waive their rights to ICF level care in order to get placement near home. A few may be moved to Selinsgrove or Ebensburg. Teresa Miller and Sherri Landis of the ARC contend that these settings offer equivalent levels of care. But do they? Do they offer 24/7 on-site nursing? Doctors, psychiatrists on premises weekdays and on call nights and weekends? Are the direct support professionals well-trained and experienced? Do these homes retain staff like Polk and White Haven, or do they follow the national average of 45% annual turnover in HCBS waiver settings? The answer, of course, is that they do not. Our loved ones with severe I/DD and behaviors need continuity. They need staff that know them over the course of years, not weeks or months. They need doctors and nurses who are familiar with them as human beings, not cases or syndromes. That's what our State Centers offer that the waiver settings do not, *cannot* offer.

Additionally, State Centers offer a safe environment. While critical incidents of abuse or neglect can occur in any setting, larger staffs of career professionals and more visitors and volunteers are more likely to provide a higher, safer level of care.

Furthermore, ICFs are required by CMS to report critical incidents of abuse or neglect directly to state authorities. HCBS waiver settings are required to report incidents to the provider company, who determines whether the incident should be reported to authorities. A January, 2018 joint statement

from three divisions of the Department of Health and Human Services reported that up to 99% of all critical incidents in the community that may involve abuse or neglect go unreported. Reporting of such incidents is close to 100% at ICFs. Accurate reporting is essential for people who cannot advocate for themselves.

We are well aware that there are privately operated Intermediate Care Facilities (ICFs) in Pennsylvania and they play an important role. But there is a huge difference between what a private agency *may* choose to offer as opposed to what a state-operated ICF *must* provide.

While private companies manage to meet the needs of many individuals, a significant number of people do fall through the cracks. Private providers may not be able to afford to create facilities that meet the needs of those who are more severely impacted, more difficult to communicate with, more costly, or whose behaviors might put their staff members at risk. Operators of private ICFs are running a business and their first concern must be to protect their business' viability. They cannot be expected to lose money caring for people who require more services, nor can they be expected to risk their reputations by taking on people with severe behavioral issues. Only the public sector can provide the safety net to accommodate such individuals.

Critics of state-operated ICFs such as Polk and White Haven have asserted that state-operated ICFs are unsustainable. We disagree. In fact, public ICFs have managed to sustain themselves for the four decades since the ICF model was first created, despite the efforts of those critics to close them or to compromise their economies of scale by closing their doors to new admissions. What's more, it is the waiver system that is having the most trouble sustaining itself. The low wages mean lower-skilled workers, higher turnover rates, and failures in maintaining proper staffing levels.

Given these realities, closing White Haven and Polk means that Pennsylvania would be closing two of the most successful models of care for people with intellectual disabilities while continuing to allow less successful models to avoid accountability. Furthermore, the people who have been waiting for years to receive services would have to wait a few years longer, as the next 250 -300 available beds would be given to people forced out of Polk and White Haven. This can only be viewed as a lose/lose situation for all involved.

As governor, you have the power not only to reverse the decision to close these centers, but to reinvest in this part of the continuum of care to make it more efficient. By reopening the centers to new admissions, you can increase their economies of scale, provide more jobs for workers and improve commerce in the surrounding community. People who need this level of care and have not been able to find it in waiver settings would have the centers as an option. Private providers can focus on serving the clients that best suit their offerings.

Teresa Miller and Sherry Landis have argued that Pennsylvania should follow the 14 states that have closed their developmental centers, but closure is not the only alternative. Arkansas, for example, supports all levels of care and integrates people living in its Human Developmental Centers with people living independently or in group homes. In Connecticut, hundreds of people living in waiver settings are provided with quality dental care, tailored to the needs of people with I/DD, at the facility at the Southbury Training School. Illinois, Ohio, Texas, and other states support both public and private ICFs as part of their continuum of care.

Pennsylvania should capitalize on its assets, its four remaining developmental centers, in conjunction with its private providers and families offering “at home” care, to create a system that provides for all of its citizens with intellectual and developmental disabilities. The state must assume the responsibility of providing the safety net for its most vulnerable citizens when the private system is unable to meet their needs.

In the words of Mahatma Gandhi, *“The true measure of any society can be found in how it treats its most vulnerable members.”*

For the sake of the residents of Pennsylvania’s developmental centers and their families, we hope that you may find the wisdom, empathy, understanding, and political courage to reverse your decision to close the Polk and White Haven Developmental Centers and to reinvest in all levels of care and support for Pennsylvania’s most vulnerable citizens.

Thank you for your consideration,

A handwritten signature in black ink that reads "Hugo Dwyer". The signature is fluid and cursive, with a long, sweeping flourish extending from the end of the name.

Hugo Dwyer – Executive Director, VOR

A handwritten signature in black ink that reads "Darrell Pickney". The signature is cursive and clearly legible, with a distinct loop at the end of the last name.

Darrell Pickney – President, VOR Board of Directors