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October 7, 2019

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

Dear Governor Wolf:

The National Council on Severe Autism (NCSA) is strongly opposed to your plan to close the Polk and White Haven State Developmental Centers.

The autism spectrum is broad, and we represent the growing number of families whose loved ones are significantly intellectually disabled, with minimal or no language. They often suffer from medical comorbidities, most commonly seizures, sleep disorders, and gastrointestinal problems. And, most importantly, many of them exhibit extraordinarily dangerous behaviors that pose grave risks to themselves and/or their caregivers, including aggression, self-injury, elopement, screaming, property destruction, and pica (a compulsion to eat inedible objects).

We understand the Commonwealth's need to be prudent in its allocation of limited resources, and why the Developmental Centers seem like obvious targets. But quite simply, closing DCs only provides the illusion of savings: supporting a population that requires intensive, round-the-clock care will impose costs no matter where they are placed. In closing DCs, prohibiting the building of new congregate settings, and drastically reducing the number of Consolidated Waivers (the only Waiver that pays for residential services) – the Commonwealth is placing a stranglehold on viable options for this very challenging population.

The Office of Developmental Programs may report savings, temporarily. But in reality all it is doing is shifting those costs: to aging parents unqualified to provide the necessary level of care; to siblings, who must give up their work; to law enforcement, whose officers may be called multiple times a week to respond to violent outbursts; to hospitals, where it's become common for severely autistic adults to languish in emergency rooms because of a lack of safe and appropriate placements. Even if that shift is sustainable in the short term, what happens when those placements can no longer manage, or when parents die? With no Developmental Centers to provide the level of care required, our most vulnerable citizens will be forced into grossly inappropriate (yet just as costly, or more so) settings, such as nursing homes or psychiatric wards.

Perhaps you've been told that the law requires the intellectually and developmentally disabled to receive services in their communities. In fact, the Supreme Court's *Olmstead* decision – touted as an "inclusion mandate" by some disability advocates – explicitly affirms the need for a wide

range of residential options to reflect the diverse needs of this population: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” In his concurring opinion, Justice Anthony Kennedy warned, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” This is exactly what is happening in Pennsylvania right now.

Mindful of such unintended consequences, the Centers for Medicare and Medicaid Services (CMS) issued new guidance in March that removed language focusing on the physical characteristics of settings (such as size) in favor of an emphasis on client outcomes. In short, both legal precedent and federal regulations reject a “one-size-fits-all” model of service provision for the intellectually and developmentally disabled.

The National Council on Severe Autism urges you to reconsider your proposal and preserve State Developmental Centers for those individuals with intellectual and developmental disabilities who require acute and lifelong care.

We would be happy to meet with you or your staff to discuss this further.

Very truly yours,



Jill Escher
President