

Below is a sample letter you can use to write your own, individualized letter to the Governor, The Secretary of Human Services, Secretary Arkoosh, and your state Representative and Senator. It is CRITICAL that you include your own story of how the system is failing your child and family. Use your own words. Letters MUST be different.

The Blood is on their hands.....let them know it.

Good afternoon, (Governor Shapiro, Secretary Arkoosh, Senator XXX, Representative XXX or whomever you want to write to).

Allow me to start with my deep gratitude to you for taking the time to read this letter. Your personal attention is a testament to your interest and dedication to quality in your (representation/administration) and respect for your constituencies.

My purpose in writing is to impress upon you the urgency of the crisis facing individuals with disabilities, most specifically those individuals who are most severely impacted, the providers of support services to them and our families. Truly, the system is collapsing: there are over 13,000 individuals with disabilities who were receiving services prior to the pandemic who are no longer receiving services. These individuals and our families are languishing. An additional 5,000 individuals are in emergency status. Thousands more are on "shadow waiting lists" in that services are approved for them, but there are no providers to provide the services. Many providers have gone out of business completely or were forced to "choose" some service lines over others in discontinuing many services. Their choice is a no-brainer – they are choosing to serve higher-functioning individuals because ODP is paying more to serve them than the more profoundly disabled.

These changes in the system which are driven by a singular inclusive ideology regardless of the intensity of need or preference of the family have essentially moved all of the great sins of the Pennhurst era into the community: overcrowding; underfunding; over-regulation and administrative oversight that does not target or positively impact the quality of care or elevate the quality of life for the individual served; public policy that does not support choice and quality of life; and the overall lack of equity and failure to provide a continuum of care including options from the most inclusive to the most intentional disability specific necessary to achieve positive individual outcomes. For some, individuals with disabilities in Pennsylvania are suffering just as much as during the tragedies of Pennhurst, except they are suffering silently because no one can see them. They are disbursed throughout the community, existing without appropriate levels of support or no support at all. Seventy-five percent (75%) of all individuals served by ODP are in private homes.

This may all sound overwhelming, but all of the issues negatively impacting our ability to provide appropriate services can be repaired – some more easily than others, some more quickly than others.

Immediately and without legislation or other administrative processes, Secretary Arkoosh has the authority to:

1. Rescind the Rounding Rule
2. Eliminate Prudent Pay
3. Alter implementation of CPS and Revive IHCS

4. Initiate an Authentic and Transparent Rate REview and resetting process to take effect 7/1/23.
5. Convene a Blue Ribbon Advisory Panel to the Secretary

With the help of the Governor, the Secretary can immediately request funding sufficient to:

1. increase rates of reimbursement to allow for greater base salaries to DSP's thereby addressing the staffing crisis
2. Increase the investment in IHCS services

Longer-term critical changes center on equity including eliminating PA's restrictive practices and allowing for the development of a clinically competent continuum of care.

My goal here today is for you to see me and those I represent as a resource to bring to you a certain perspective. I and my constituency base are here to assist you in any way to make meaningful and lasting change. Change that is frankly overdue. It would be my privilege to engage further with you for a deeper dive into these issues. I would like to schedule a personal appointment with you. I have several recommendations and strongly encourage your consideration to convene a Blue-Ribbon Advisory Panel to assist you in serving us. I need my voice to be heard.

I look forward to hearing from you soon.

Respectfully,