

SB 657: Testimony to the Senate Intergovernmental Operations Committee

June 09, 2025

Good morning and thank you to the Chairs, Senators Coleman and Tartaglione, and the entire Intergovernmental Operations Committee for having this hearing today on this important issue. I also want to express my gratitude to Senator Farry, who has worked with us on this and related issues for several years.

I am Richard Edley, President and CEO of RCPA, an association representing over 400 agencies and organizations across nine divisions of health and human services- including intellectual and developmental disabilities which we are focusing on today. I am also a clinical psychologist by background, and am the parent of a 32-year-old with intellectual disability and autism needing 24/7 care and services.

While this topic can take us in several directions, I am zeroing in on a key part of the legislation and discussion: Pennsylvania's interpretation of the CMS Settings Rule. Specifically, that which has been promulgated by the Office of Developmental Programs (ODP) under the Department of Human Services (DHS). Families, such as those who have approached legislators, are desperate for solutions and simply cannot understand why possibilities such as an intentional community or a campus setting are seen so negatively. Especially when other states, also dealing with CMS, have allowed such initiatives.

Before I get into what I believe is the crux of the issue and potential solutions, let me also state what this is not. It is not a partisan issue. This is not about political affiliation or which administration we are supporting. It is also not a personal issue, or about blame or blowing the current system up.

It is about what makes sense and what helps individuals and families in need.

Given that focus, like the families noted who want to propose and implement more flexible solutions, I admit that I struggle when I think about what many advocates have issues with:

- Farmsteads
- Gated Communities
- Campuses
- Adjacent Homes
- Intentional Communities
- Shared Staff

As a parent and someone who has worked in the field for many years- these are not my issues. Admittedly, it can be a difficult and complex issue, and certainly one with a history that cannot be ignored. But at the end of the day I will always fall on the side of listening to and helping families who want to provide quality, accessible, and affordable solutions for their loved ones. For a lifetime.

You want the best for your children. And when you are the parent of someone who has serious disabilities, you panic not only about today and providing for quality of life, but also are concerned as to what the future brings for your loved one. You also panic about what happens when you are gone.

All of us must have compassion for those who are managing every day with these significant, complex needs, and with these real life realities.

Their voice needs to be heard.

I do understand the history and the troubling concept of creating solutions that have the potential of becoming a “slippery slope”. No one wants congregate settings, warehousing, and a recreation of State Centers. It is 2025 and collectively as a society we are better than that.

So you need to set up a system with guardrails that makes sure we are achieving the best results and prevent against those negative outcomes that we all remember and fought so hard against.

But should our fear of recreating the past mean we never can listen? Never have flexibility? Never can change or grow/ evolve the system to ensure that we are meeting the needs of these families?

We know from the letter exchange between US Representative Fitzpatrick and CMS (dated 04/28/2021 and 06/11/2021) that the Pennsylvania interpretation of the Settings Rule is just that. An interpretation. Not a federal mandate or requirement. So it begs the question: what is wrong with creating a true continuum of services, including those that these families want, that meet the needs of those we are trying to help? Rather than forcing everyone into a system that may be well intentioned but does not meet everyone’s needs and choice.

Of course there have been wonderful movements in the field in helping those with disabilities, e.g., independent living, community participation, competitive integrated employment. We have to be careful, however, that in our desire to support these efforts that we have swung the pendulum too far. Specifically, that we have inadvertently created a system that is great- for those who are higher functioning and can take advantage of the opportunities now afforded. What about those with higher needs who cannot simply be placed into that square peg? Are we leaving them and their families behind?

The Department- ODP- does care and has stated that they are willing to look at solutions for these populations. And that is an important step. Further, ODP has stated that there can always be waivers and exceptions to the Settings Rule interpretation. Certainly that needs to be better understood and I can see why families are a bit hesitant to rely on the possibility of a future exception as the solution. Indeed, one can argue that a system built on waivers and exceptions is a sign that the system should change.

So what is the solution? Certainly this bill has spurred an important discussion and I am thankful for that. Legislation would certainly address the issue and go to the heart of the matter. Alternatively, perhaps it now is time to pause to create a stakeholder engagement group that is targeted, time limited, and concrete with specific recommendations for change. Then reporting back to the legislature. And that group has to be representative of all sides of this discussion. It has to be real.

Unfortunately, we all are often very good at creating groups and processes that meet, develop reports and recommendations, and then these ideas sit on a shelf until the next group convenes. With no action. We cannot allow that to happen.

I realize that the current regulations (“6100s”) in place had a lengthy, multi-year, stakeholder process. And it certainly was an improvement over the previous regulations (“5100s”). I was there. But time has passed and we have learned what works and where we have struggled. There is no harm in selecting out what needs to now change and be re-addressed.

If you step back, these families are suggesting that we create a system that is:

- Responsive to the individual and family needs
- High quality
- Accessible and can serve more people (and we have a wait list in PA) in a flexible and individualized manner
- Addressing the needs of those with complex and serious disabilities
- More efficient, and less costly.

I find it hard to be upset with those goals and outcomes.

Recently (02/24/25) there was a press release announcing that one agency, Melmark, is developing an “intentional planned community on a three-acre site” in Massachusetts. Their President and CEO, Rita Gardner, stated:

“We are creating an innovative new adult services model, centered around full community integration and resource-sharing, which will allow individuals to age in place through their lifespan with access to public transportation, banking opportunities, retail and leisure, etc. with supportive resources to ensure continued best outcomes”.

The release goes on to detail that there will be four residences housing 20 adults and a vocational and day program for 50+ individuals. It is further noted that this is a model that can be replicated nationally by other human services providers. Interestingly, Melmark provides services for intellectual and developmental disabilities and autism in PA, but this model would only be approved here by waiver or exception.

What these families are proposing does not have to be a return to the harsh historical realities of how our society so poorly addressed disabilities. In fact, if done right and with proper guardrails, it can actually be a step forward by ensuring there is a full continuum of services in place and no group is left behind.

I can hear advocates say: “We would then have to re-engage, rewrite these regs, go back to CMS...” Perhaps, but isn’t it more important that we do what is right?

Thank you for the opportunity to present on this important issue.