

Good Afternoon Representative Hennessey,

Thank you for taking the time yesterday to take my request to schedule an informal informational meeting or formal hearing with you and some of your colleagues to discuss Pennsylvania's restrictive practices governing how individuals with severe disabilities may choose to use state and federal funding to support their needs in where they live, who they spend time with or how they integrate into the community or workforce. I defer to you to identify who you think best attend, but it would seem effective to begin with Representative Frank Ferry in his role as Chair of the Human Services Committee. Personally, I believe it imperative to ensure that Deputy Secretary Kristin Ahern is in attendance. I am hopeful for a two-hour length of time to adequately outline our concerns and receive responses from the Deputy Secretary.

More specifically, we are concerned about the size and number limitations imposed by 55 Pa. Code Secs. 6100.444 and 6100.445 in order for a setting to qualify for Medicaid waiver funding. Sec. 6100.444 - Size of Service Location, limits residential settings funded prior to February 1, 2020, to eight individuals and residential settings newly funded on or after February 1, 2020, to four individuals. Day service locations newly funded on or after March 17, 2019, may not provide services to more than 25 individuals.

Sec. 6100.445 – Locality of Service Location, prohibits a residential setting from being located adjacent to another residential location or a day service location. It also requires that no more than 25% of the units in an apartment building, condominium, or townhouse building be occupied by individuals with disabilities.

The numerical and location restriction in these two Pennsylvania regulations exceed the requirements of the federal Settings Rule. This was made clear in the recent exchange of letters between Rep. Fitzpatrick and the Centers for Medicare and Medicaid Services (CMS). Rep. Fitzpatrick's April 28, 2021 letter to CMS asked whether the federal Settings Rule limits the number of individuals served in a residential or day service setting or the percentage of units in a multi-unit building that may be occupied by individuals with disabilities.

CMS's response was clear; the Settings Rule contains no such limitations. CMS's June 11, 2021 letter to Rep. Fitzpatrick states:

The settings criteria contained in the regulation require that individuals receiving Medicaid-funded HCBS have the same degree of access to the community as individuals not receiving Medicaid-funded HCBS; **there is no numerical threshold defining this requirement.** The degree of interaction with the community should be determined by each individual, as outlined in his or her person-centered service place.

Lastly, CMS does not believe that there is a threshold number of individuals receiving services beneath which it can be presumed that a setting would meet the HCBS settings criteria, or above which it can be presumed that a setting would not meet the criteria. **Therefore, there is no cap as mentioned in your letter on the number of individuals who can receive services in a setting.** In determining a setting's compliance with the regulatory criteria, the focus should be on the experience of the individuals in the setting. This applies to both residential and non-residential settings in which individuals receive Medicaid-funded HCBS. (Emphasis added).

Among the settings that the restrictive Pennsylvania regulations prohibit are farmsteads, campus settings, and intentional communities. Such settings typically exceed the numerical limits in 6100.444 and the density limits in 6100.445. Yet, CMS's recent letter to Rep. Fitzpatrick makes it clear that the federal Settings Rule does not prohibit farmsteads, campus settings or intentional communities: "the HCBS settings rule **does not prohibit** HCBS funding in farmsteads, intentional communities, and campus settings, nor does the settings rule require that individuals receive services in other setting types prior to choosing to receive services in a compliant farmstead, intentional community, or campus setting." (Emphasis added.)

These alternative settings offer environments that are more suitable for certain individuals with I/DD, particularly those with significant behavioral challenges, such as men and women with severe autism. Many of these men and women cannot live in small group homes, the only setting that meets the requirements of Pennsylvania's regulations. These small group homes often trigger destructive and violent behavior that endangers the individual, the other residents in the home, and the staff who serve them. Such behaviors are often better managed in the calm and communal environments offered by farmsteads, campus settings, and intentional communities.

The disabilities community is very diverse, with widely varying needs and preferences. To meet the needs of this diverse community, Pennsylvania must fund a wide variety of residential and vocational settings. This will permit the individual and her family to choose the setting that is most appropriate. As the above-quoted CMS letter states, "the focus should be on the experience of the individual in the setting," not the size, location, or type of setting.

It should also be noted that 6100.444 and 445 are discriminatory and violate the Americans with Disabilities Act. Last year, the federal court in the Central District of Illinois ruled that a local ordinance that prohibited group homes for individuals with disabilities from being within 600 feet of each other unlawfully discriminated against individuals on the basis of their disability. The court stated:

[T]he spacing rule treats group homes for up to five unrelated individuals with disabilities less favorably than it does a similarly situated living arrangement consisting of up to five unrelated non-disabled people. By maintaining the discriminatory spacing rule and enforcing it against the 2328 S. Noble group home, the City has denied housing and made it unavailable on the basis of disability, in violation of 42 U.S.C. § 3604(f)(1)(B). The spacing rule renders certain housing "unavailable" to persons with disabilities that would otherwise be available. The 600-foot spacing rule on group homes for individuals with disabilities that do not apply to comparable housing for non-disabled individuals plainly imposes discriminatory "terms" and "conditions" on housing on the basis of disability, in violation of 42 U.S.C. § 3604(f)(2).

Valencia v. City of Springfield, 2020 WL 1035229, pp. 6-7 (C.D. IL, March 3, 2020)

Pennsylvania would not think of prohibiting persons of color from living adjacent to each other or from occupying more than 25% of the units in a multiunit building. It cannot apply these restrictions to individuals with disabilities.

Additionally, Pennsylvania places restrictions on the number of individuals with disabilities who would be permitted to be in any one place in the community using state and federal funds to pay for staff to support them. In other words, if two individuals with disabilities and their support staff went to Starbucks for a coffee and three additional individuals with disabilities and their support staff came in for their coffee, someone would have to leave. Ms. Ahern denies this prohibition stating "...there is no regulation prohibiting people with disabilities from gathering in groups..." but later reveals "billing rules specify that a provider may not serve more than three people at a time". (Philadelphia Inquirer OpEd September 6, 2020). Commonwealth funding is in place to support people with disabilities. If you cannot use your funding if you are with more than three of your friends – then the state is prohibiting individuals with disabilities from "gathering in groups". Ms. Aherns further states "No one is required to use these services". I would suggest to you that these services are in place because those individuals with these services **must** use these services to survive much less thrive. If not, why has the Commonwealth granted the services in the first place?

We would appreciate ODP's explanation for imposing restrictions on residential, vocational, and community settings and experiences for individuals with disabilities that go beyond the requirements of federal law and that treat individuals with disabilities differently from those of

other groups. We believe Pennsylvania's regulations should be revised so that they are consistent with, and no more restrictive than, the federal Settings Rule.

To assist in further understanding the extent and vital importance of this crisis, I have attached several documents:

- [Testimony from several constituents from across the Commonwealth outlining the real-life challenges suffered at the hands of PA's overreaching regulations.](#)
- [Correspondence between Congressman Brian Fitzpatrick and Melissa Harris, Deputy Director, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services](#)
- [Pa Regulation 6100.44/6100.445 outlining restrictions on the number of individuals with disabilities who may be served together](#)
- [Proposed Amendment to the 6100 regulations which would afford individuals with disabilities the right to choose how, where, and when their support services are provided.](#)
- [Reprint of the Op-Ed article: ***How Pa. Strips People Living with Autism and Intellectual Disabilities of Personal Choice*** and the reply by Kristin Aherns, Deputy Secretary, Office of Developmental Programming](#)

I look forward to the opportunity to share my perspectives and suggestions to improve the quality of life for Pennsylvania's most vulnerable citizens with you and your colleagues. Thank you for your time, support, and investment in our lives.

Respectfully Submitted,

Gloria Martino Satriale

Gloria Martino Satriale