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SB 657: Testimony to the Senate Intergovernmental Operations Committee

Good morning, Chairman Coleman and Chairwoman Tartaglione, and members of the committee. I want to thank you for the opportunity to provide my testimony today. My name is Ashley Kim Weiss, and I'm the Executive Director of Together for Choice, a national non-profit advocacy organization with members in all 50 states.

Our mission is to ensure a diverse array of high-quality residential and vocational options for individuals with developmental disabilities. I have also had the privilege of developing affordable housing for individuals with disabilities and I continue to support many family groups striving to build various housing communities for their loved ones.

Across the country, innovative, high-quality residential communities allow individuals with disabilities to thrive. Take, for example, The Arc Village in Jacksonville, Florida, which provides 97 affordable one- or two-bedroom apartment units for 121 residents.

However, Pennsylvania's current state regulations on size and locality of service location tragically prohibit the Home and Community-Based Services (HCBS) funding that makes such successful models possible. Places like The Arc Village, farmsteads, intentional communities, or other disability-specific settings are effectively banned from receiving HCBS funds in this state.

These regulations mean that a model like Bittersweet Farms—the first autism farmstead community specializing in supporting individuals with high behavioral needs, is not allowed in PA. And places like Opportunity Village, A New Leaf, Benjamin's Hope — these wonderful models that exist in other states across North America—are not allowed for HCBS funding here in Pennsylvania. This is regardless of personal choice, safety, or wellness.

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This isn't due to a lack of demand; it's because Pennsylvania's ODP operates under the false premise that such disability-specific settings are inherently isolating and non-compliant with the federal HCBS Medicaid Settings Rule.

This premise is directly contradicted by the Centers for Medicare & Medicaid Services (CMS). CMS has explicitly stated in its letter to Congressman Brian Fitzpatrick that the federal Settings Rule does *not* prohibit HCBS funding in farmsteads, intentional communities, or campus settings. Nor does it impose a limit or cap on the number of people receiving services in a setting. I want to specifically recognize and thank Senator Frank Farry for his crucial role in obtaining this clarification from CMS, and for all his work in supporting individuals with disabilities throughout Pennsylvania.

In addition, ODP falsely claims that these existing disability-specific settings are allowed in other states because they are grandfathered, but the settings rule does not have a grandfather clause.

The tragic reality is that Pennsylvanians with disabilities are paying the price for ODP's capricious policy, finding themselves isolated in their homes with a severe lack of appropriate options. In fact, all Pennsylvanians are paying the price.

Let's look at Matt and Dan Guerrisi, twins who flourished at the Camphill School, a farm-based program in Chester County. Due to ODP's policy, they were compelled to move into a group home after aging out of Camphill.

This move initiated a rapid decline, characterized by self-injurious behavior, staff injuries, property destruction, and a constant cycle of police calls and ambulance rides as they bounced among three different group homes. Their annual budget in the last group home setting soared to approximately \$550,000 per person. For Pennsylvania taxpayers, this translated to over \$1.1 million annually for care that only generated pain and suffering. They are now receiving temporary respite care at a campus-based setting, costing a little over \$230,000 per person—nearly half the group home cost. However, this is not a permanent solution. The question remains: what happens to them next?

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Pennsylvania treats no other group of its citizens this way. Pennsylvania's restrictions single out individuals with I/DD for disparate treatment, restricting their living options in a manner imposed on no other group. This is, by definition, discrimination, and it violates both the Fair Housing Act and the Americans with Disabilities Act.

Please broaden the options available to Pennsylvanians with disabilities so they can access the high-quality services and choices they truly need and deserve.

Thank you.

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