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Testimony of Sherri Landis The Arc of Pennsylvania Before the Senate Intergovernmental Affairs Committee – Senate Bill 657 June 9, 2025

Good morning Chairman Coleman and members of the Intergovernmental Affairs Committee. Thank you for the opportunity to testify today on Senate Bill 657.

My name is Sherri Landis, and I serve as Executive Director of The Arc of Pennsylvania, a statewide nonprofit organization that advocates with and for individuals with intellectual and developmental disabilities (IDD) and their families. Founded in 1949, The Arc of Pennsylvania works in partnership with 29 local chapters across 52 counties and is affiliated with The Arc of the United States. We are a grassroots, member-driven organization with more than 9,300 members, all dedicated to ensuring that individuals with IDD receive the supports they need, are included in their communities, and have control over their own lives.

The Arc of Pennsylvania was created by families who envisioned something better for their loved ones at a time when institutionalization was the default. While institutions once appeared to offer safety, structure, and community, the reality was very different. Underfunding and understaffing often led to neglect, isolation, and abuse. Decades of research confirm that these were not exceptions, but systemic failures of large congregate care settings.

In 1970, The Arc of Pennsylvania took a landmark step by securing educational rights for children with disabilities. The lawsuit we filed resulted in the PARC Consent Decree, which later became the foundation for the federal Individuals with Disabilities Education Act (IDEA). This was a pivotal moment—affirming that integration and inclusion are civil rights.

Over the years, policy and practice continued to shift away from institutional care and toward community-based living. As people with disabilities moved into smaller, more integrated homes, true community inclusion became possible.

The Americans with Disabilities Act (ADA) and the U.S. Supreme Court's Olmstead v. L.C. decision (1999) reaffirm the right of individuals with disabilities to receive services in the most integrated setting appropriate. Pennsylvania's regulations under 55 Pa. Code §6100 were developed to uphold this mandate. These rules are not about limiting choice—they are about preventing a return to segregation and ensuring that public funds support true community inclusion.

History has shown that clustered housing models—such as campus-style or farmstead settings—can replicate many of the same harms found in institutions. Regulations that limit proximity and density are grounded in evidence and civil rights law. They help ensure that "home and community-based" services remain genuinely community-based—not institutions by another name. Even well-intentioned, family-designed "intentional communities" can result in social isolation, limited autonomy, and minimal contact with nondisabled peers. The HCBS Rule and Pennsylvania's regulations do not prohibit these settings—but they do ensure that Medicaid dollars are used only to support models that are integrated.

## The HCBS System Is Complex and Underfunded

The home and community-based services (HCBS) system is both complex and deeply underfunded. It serves a wide continuum of people—from children with complex medical needs to older adults with dementia who require specialized care. The intent of the current regulations is sound, but their impact is limited by a lack of resources. With greater investment, individuals and families would have access to more meaningful options, and direct care professionals could be better supported. The challenge lies not in the rules themselves, but in the chronic underfunding of the systems intended to uphold them.

## Removing Regulations Won't Fix Systemic Barriers

Eliminating the regulations will not solve the HCBS system's most pressing challenges—particularly in the face of ongoing threats to Medicaid funding, a persistent workforce crisis, and the increasing involvement of private equity firms purchasing provider agencies. Recent news stories have highlighted how profit motives can compromise the quality of care for individuals with disabilities and impact their safety.

The Arc of Pennsylvania is concerned about the bill's requirement to repeal and replace the regulations within 180 days. It is neither practical nor responsible to complete such a process in that timeframe. Regulatory revision—when done with proper stakeholder engagement and deliberation—requires time to produce thoughtful, workable changes. Our current regulations are the result of a five-year process that involved robust input from individuals with disabilities, families, providers, and other key stakeholders. You can read the feedback from the stakeholder community on the IRRC website that shows appreciation for the meaningful stakeholder process that resulted in the final form regulations. Attempting to rewrite these regulations in six months risks bypassing that essential engagement and undermining the progress that's been made. If Senate Bill 657 is truly about finding real solutions, we should begin by reconvening a diverse group of stakeholders—including families—to evaluate the current system and make informed recommendations. At the same time, we must

prioritize funding initiatives like the Office of Developmental Programs' (ODP) Subsidized Housing Pilot. This program helps individuals find and maintain homes in their communities through rental assistance supported by the Augmentation Fund. It was created in response to what individuals and families have consistently requested: the opportunity to live independently with the right support.

## In Conclusion

Senate Bill 657 proposes to eliminate regulations that were designed to protect the civil rights of people with disabilities. These rules do not limit freedom—they safeguard it. They ensure that people with disabilities are not relegated to separate and unequal lives simply because they rely on publicly funded services. Individuals and families deserve residential options. While the current options may not always be ideal, they often reflect the limitations of an underfunded system of care. The reality is that all residential options—and the supports needed to sustain them—are critically underfunded. Regardless of the discussion here today, the most pressing and consistent issue facing individuals and families is the longstanding underfunding of the Home and Community-Based Services (HCBS) system.

The Arc of Pennsylvania urges the Committee to pursue real solutions rather than endorsing legislation that carries the risk of re-segregation and risking the health and safety of people receiving HCBS. Simply repealing regulations will not solve the system's problems. Instead, we must commit to reinvesting in the system, re-engaging stakeholders, and upholding the rights and dignity of people with disabilities.

Thank you for the opportunity to speak today. I would be happy to answer any questions.