

Senate Intergovernmental Operations Committee Public Hearing: SB 657

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Department of Human Services

Senate Intergovernmental Operations Committee

Public Hearing

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Pennsylvania  
**Department of Human Services**

Chairman Coleman, Chairwoman Tartaglione, and members of the Senate Intergovernmental Operations Committee, thank you for inviting the Department of Human Services (Department) to submit testimony on the topic of SB 657.

The Department appreciates the Committee's interest in addressing the issue of residential and vocational services for people with intellectual disabilities and autism and is committed to working with stakeholders and the General Assembly to find solutions. Abrogating regulations under 55 Pa. Code §§ 6100.444 (relating to size of service location) and 6100.445 (relating to locality of service location) does not result in increasing residential and vocational services. Instead, increased funding and additional affordable and accessible housing, along with an increase in workforce, would result in an increase in these services.

The Department is committed to and actively working with individuals, families and the regulated community to find solutions and innovative approaches to increase access to services. Examples of ODP's actions are:

- Meeting with family groups to identify solutions for their loved ones. Meetings have resulted in connections with providers willing to explore residential arrangements with these families.
- Providing technical assistance to the consultant supporting the Love Ran Red organization prior to the organization's community planning meetings.
- Targeted discussions with providers that spun-off from Camphill Soltane to better understand their unique service delivery approaches and to encourage expansion to address the needs of individuals and families in the region.
- Re-convening a stakeholder workgroup to advise on policy changes for Community Participation Supports services which includes adult training and prevocational facilities.

Regulations governing home and community-based services have a complex set of statutory, regulatory, historical, practical and financial considerations. Efforts to amend regulations must address the extraordinary complexities of providing home and community-based services to individuals of all ages with ID/A who represent a vast continuum of need, including adults with arguably the most complex needs presenting for services in Pennsylvania's Medicaid system.

Any amendments to the current framework must balance ensuring the protection of individual rights, health and safety of Pennsylvania's most vulnerable adults and practical and financial constraints faced by the regulated community. The necessity of undertaking amendments should also be balanced against the available regulatory waiver process ([55 Pa. Code § 6100.43. Regulatory waiver](#)) and service options available through ODP's funded intermediate care facilities.

### ***Need Outpacing Funding for Residential Services, Workforce Shortages, and Lack of Affordable Housing***

For the past decade, the need for Consolidated Waivers has outpaced the availability for enrollment of adults with ID/A. Program expansion for ID/A services has been in the Person/Family Directed Support and Community Living Waivers, which have annual financial caps, and largely do not accommodate residential services. This on-going need for increased residential service solutions for adults with ID/A is a primary contributor to the residential access issue. Additionally, the availability of affordable accessible housing is a persistent barrier for people with ID/A who, by and large, rely on public benefits for income (18% of working age adults registered for ID/A services are employed and typically part-time).

Workforce shortages hamper provider expansion of residential services. Over the past ten years the vacancy rate for Direct Support Professionals (DSP) has hovered around 20% or above. past ten years the vacancy rate for Direct Support Professionals (DSP) has hovered around 20% or above.

During the Shapiro administration, the General Assembly has supported major actions that are beginning to address these root causes. First, through an increase in funding and change in approach, progress is being made on ending the emergency waiting list for adults and addressing workforce issues. Governor Shapiro proposed an increase of \$480M for the Fiscal Year 2024-25 budget to raise rates for ID/A providers and make a historic investment in ending the adult emergency waiting list. The General Assembly ultimately appropriated a \$354M increase which funded a 7% average increase in payment rates and capacity to enroll more than 1,500 adults into services. This major investment in waiver capacity has put the commonwealth on a path to end the adult emergency waiting list. The most current survey on workforce shows a Direct Support Professional vacancy rate of 14% which is the lowest since 2015. There has also been a dramatic decrease of 24% in the emergency waiting list for adults since February of 2024. Further, the Fiscal Year 2024-25 appropriation for community services for people with ID/A included funding for performance-based contracting which will improve the responsiveness of providers to individual and family needs.

The second action by the General Assembly was that Act 54 of 2022 created the *Home and Community-Based Services for Individuals with Intellectual Disabilities Augmentation Account*. The creation of this restricted account ensures that any savings from state center closures are directed to the ID/A community program. One of the allowable uses of this fund is for housing for people with ID/A. ODP's advisory body, the Information Sharing and Advisory Committee's (ISAC) Housing subcommittee developed a model for housing subsidies for people with ID/A using these funds and recommended the Department pilot this model. The Department implemented a 10-county pilot (Bradford/Sullivan, Centre, Chester, Delaware, Erie, Greene, Lancaster, Lehigh, Westmoreland) providing a supportive housing model for people with ID/A who do not live in licensed community homes. A year into the pilot, the supportive housing model is proving to foster greater independence and is showing great potential to reduce costs for the Department over time by transitioning or diverting people from licensed residential services.

***SB675 Does Not Provide for Necessary Stakeholder Engagement***

SB675 proposes the Department undertake stakeholder engagement, promulgation of regulations and corresponding amendments to four 1915(c) agreements within 180 days of bill passage. History of the development of the current regulations is important as it illustrates the level of challenge in arriving at rules that the regulated community largely supports and people with disabilities and families feel protect their rights, health and safety needs. This bill as written would negate the possibility of meaningful stakeholder engagement in regulatory reform by imposing an aggressive and unachievable timeframe that does not account for stakeholder engagement or the regulatory promulgation process as outlined in the Regulatory Review Act.

SB657 has the potential to significantly re-shape the landscape for services for people with intellectual disabilities and autism in ways that pose significant risk to this group without regard for the decades of intensive stakeholder engagement that shaped the current service system, which was intentionally designed to combat the persistent segregation of the population, a top priority of stakeholders.

Pennsylvania's rules about home sizes and locations were **crafted by stakeholders and well preceded the federal rules governing HCBS settings** but had not been codified in regulation until the promulgation of the Chapter 6100 regulations.

***HCBS Settings Rule Establishes Characteristics, States were Required to Develop Measurable Standards***

The federal HCBS Settings Rule requires Medicaid HCBS delivered to people with disabilities living in the community – outside of institutions – meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections.

What SB657 fails to contemplate in the provisions: “(3) Shall not impose any requirements on the types of settings that may be funded through a home- and community-based waiver beyond those imposed by Federal law under 42 U.S.C. § 1396n (relating to compliance with State plan and payment provisions).” And “(4) Shall not preclude settings from receiving funding through a home- and community-based waiver due to location, service type, size or type or number of individuals served except as required by Federal law under 42 U.S.C. § 1396n” is that the HCBS Settings rule does not establish specific measurable requirements. The rule established *characteristics*, not measurable standards, for eligible HCBS. The Centers for Medicare and Medicaid Services (CMS) left it to states to establish measurable standards by which states would report compliance. CMS required all states to submit extensive State Transition Plans detailing how each state evaluates and assures compliance.

In order to establish measurable standards by which to determine compliance with the HCBS Settings Rule, ODP worked with stakeholders to include requirements in [55 PA Code Chapter 6100](#), which was adopted in October 2019. To develop Chapter 6100 regulations, the Department engaged in a five-year process with extensive stakeholder involvement, including:

- Establishing a process for extensive stakeholder engagement – more than 15 full days of meetings, and more than 60 meetings with stakeholder groups;
- Bringing the stakeholder group back together to review changes made in response to public comment; and,
- Establishing a separate workgroup to address fiscal issues – 10 meetings

Stakeholder engagement was so extensive that that the Independent Regulatory Review Commission (IRRC) commended the Department on the efforts and extent of the engagement.

Chapter 6100 establishes regulations for governing the size and proximity of service locations. Without these rules the Department risks establishing segregated service locations that would be ineligible for Federal financial participation (see 42 CFR 441.300—441.310), which poses a financial threat to the commonwealth. Other states also include very specific measurable standards, including number of people per home and minimum distances between homes (i.e. 300 feet between homes, max of four or five people). Research on service location size demonstrates that size does impact multiple quality of life dimensions and outcomes, which supports the regulations as promulgated.<sup>1</sup> Historical practice demonstrates that the larger the setting, the more challenging it is to meet standards like those established in the federal HCBS Settings rule for privacy, controlling one's schedule, allowance for visitors at any time, choice of individualized activities, and access to the broader community that are all required elements of the federal rule. There are also very practical reasons to limit number of residents in provider-operated home like zoning rules.

The Commonwealth's current 1915(c) waivers and State Transition Plan that include measurable standards were approved by CMS. At CMS' request, ODP presented to other states on Pennsylvania's

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<sup>1</sup> The National Council on Disability's 2015 report "Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community" concluded that: "Small, personalized, settings increase opportunities for personal satisfaction, choice, self-determination, community participation and feelings of well-being. Small settings are similarly associated with decreases in (1) the use of services, (2) feelings of loneliness and (3) service-related personnel and other costs." This conclusion was echoed in a 2014 policy research brief by Nord, et al., "Residential Size and Individual Outcomes: An Assessment of Existing National Core Indicators Research." Nord reviewed National Core Indicator (NCI) studies published over the last decade, examining numerous outcomes for people with an intellectual disability living in different residential settings. The review found that, across all outcome areas, smaller settings, on average, produce better quality of life outcomes for people with an intellectual disability and concluded that "people living in their own homes, family homes, host family homes or in small agency residences (six or fewer residents) ranked consistently better in achieving positive outcomes than moderate size (7-15 residents) and large agency residences and institutions (more than 15 residents). Also, people living in their own homes, small agency residences, and host family homes reported more independence and more satisfaction with their lives."

implementation of the HCBS Settings Rule in relation to day services. CMS's site visit in February 2024 did not result in state corrective action. CMS raised no concerns about ODP's rules and noted the evidence of person-centered practices.

### ***Intermediate Care Facilities (ICF)***

ODP's HCBS waivers are not the only option for receiving residential services for Pennsylvanians with ID/A. Unlike a number of states, Pennsylvania has continued to invest in privately operated intermediate care facilities. Intermediate care facilities are Medicaid-funded and are specifically designed to furnish health and rehabilitative services to persons with intellectual disabilities or related conditions.

The Governor's Fiscal Year 2025-26 executive budget includes \$510MB for services in intermediate care facilities. There are 126 privately operated intermediate care facilities in Pennsylvania, with a broad range in sizes and some operating on campus settings.

SB657 contemplates the possibility of very large settings for people with ID/A funded as HCBS, which will raise concerns about "warehousing" or providing minimal custodial care for people with ID/A.

Intermediate Care Facility rules specifically include requirements for active treatment intended to combat facilities from warehousing. The provision of active treatment is routinely surveyed by the Department of Health during their ICF inspections.

### ***55. Pa Code 6100 Contains Provisions Allowing for Waiving of Regulations***



The committee should be aware that the 6100 regulations contain provisions for waivers of regulations providing that:

- (1) There is no jeopardy to an individual's health, safety and well-being.
- (2) An individual or group of individuals benefit from the granting of the waiver through increased person-centered practices, integration, independence, choice or community opportunities for individuals.

Upon demonstration that a provider has taken sufficient steps to overcome potential isolation and no health and safety issues are posed by exceeding regulatory limitations, ODP has approved numerous waivers of setting location and sizes of adult day programs and residential homes using this authority.

#### ***Residential Options Available in PA Medicaid Funded Programs for ID/A***

The committee should also be aware that ODP's approach to residential services is not 'one-size fits all.' Within ODP's existing home and community-based services and intermediate care facility programs, there is a continuum of residential options from 24/7 support in an individual's privately rented apartment to a licensed 2–4-person home to a campus setting with on-site day and medical services. The below chart describes available options.

Within the current regulatory and funding structure ODP providers have created and operate some innovative and unique service models to meet the expansive continuum of needs and preferences of enrolled individuals including individuals with very high acuity needs.

<b>24/7 Residential Service Options Available through Consolidated and Community Living Home and Community Based Services Waivers</b>			
<b>Service</b>	<b>Size</b>	<b>Ownership/Licensure</b>	<b>Notes</b>

Supported Living	1-3 people	Private homes/apartments of individuals (not licensed)  Provider Managed	<ul style="list-style-type: none"> <li>• May include technology including use of remote supports</li> <li>• Payment rates are adjusted for acuity of support needs</li> </ul>
Lifesharing	1-2 people	Individual typically lives in home of lifesharer but lifesharing can also be provided in private home of individual. (may be licensed or unlicensed)  Provider Managed	<ul style="list-style-type: none"> <li>• Includes an option for specialty provider type for individuals who are medically complex</li> <li>• Includes providers that specialize in behavioral/mental health</li> <li>• Option available to be provided by a relative</li> <li>• Payment rates adjusted for acuity of support needs</li> </ul>
Residential Habilitation <sup>2</sup>	1-4 people (5-8 bed homes grandfathered)	Licensed community home owned/leased and operated by a provider	<ul style="list-style-type: none"> <li>• Providers/homes specializing for individuals who are medically complex or have dual diagnosis</li> <li>• Licensed under 55 Pa Code Chapter 6400</li> <li>• Payment rates adjusted for acuity of support needs</li> <li>• 5,800 licensed homes (available in every county in the commonwealth)</li> </ul>
Unlicensed Residential Habilitation	1-3 people	Owned/leased and operated by a provider	<ul style="list-style-type: none"> <li>• Individuals who need less than 30 hours direct support/week</li> </ul>
<b>Intermediate Care Facilities</b>			
Intermediate Care Facilities	Minimum of 4, no upper limitation	Owned/leased and operated by a provider. Certified and licensed.	<ul style="list-style-type: none"> <li>• Numerous campus settings in the commonwealth</li> <li>• Some specialty providers (medically complex, dual diagnosis, single gender only etc.)</li> <li>• Most facilities 4-8 beds and dispersed in community settings</li> <li>• Some large facilities (75-125 people)</li> </ul>
<b>Non-residential Services Available through Consolidated, Community Living and Person/Family Directed Support Waivers</b>			
<ul style="list-style-type: none"> <li>• ODP also has an extensive array of non-residential services that are available to support individuals including up to 24 hrs/day</li> <li>• Many of these services may be self-directed</li> </ul>			

<sup>2</sup> Consolidated Waiver Only

### ***Day Service and Vocational Options Available in PA Medicaid Funded Programs for ID/A***

ODP HCBS waivers fund both facility-based and community-based day and prevocational services as a service referred to as “Community Participation Support” (CPS). Services can be provided ranging from 2:1 (staff to individual) for people with high acuity needs in community or facility settings to 1:11-1:15 staffing ratio in a licensed 55 Pa. Code Chapter 2390 facility. Licensed facility sizes range from 10 people to over 150 individuals. Many providers have elected to provide this service only in community-based settings and do not operate out of a licensed facility. In 2023, with funding made available through the American Rescue Plan Act (ARPA), ODP funded Administrative Entities (AEs)/Counties for innovative strategies to provide alternatives to CPS services. ODP does not yet have results from any projects.

ODP HCBS waivers also fund supported employment including small group employment (ex: mobile work crews), career assessment, job development and job coaching.

Post-pandemic, the CPS service has lagged in recovery in spite of tremendous investment by the Commonwealth (federal CARES Act funding and funding made available through ARPA) to support recovery. The Department is hopeful that AE/County experience with innovative approaches can be replicated to improve access to these much-needed services. ODP’s CPS stakeholder workgroup is re-convening and will address the need for innovations to expand capacity for service delivery.

### ***Risks Posed by SB657***

SB657 establishes a process that does not allow for necessary stakeholder involvement and disregards the extent of prior stakeholder engagement. It also creates additional risks in its effort to re-shape the ID/A service system.

Individuals with ID/A, their families, advocates, and ID/A HCBS providers have combatted warehousing for decades and recent circumstances have raised concerns about pressures that will result in backsliding back into warehousing of people with ID/A, especially individuals with the most significant disabilities. SB657 compounds these concerns and potentially creates an environment ripe for increased congregation and segregation of people with disabilities.

First, the ID/A service system in Pennsylvania and nationally has begun to see private equity and similar types of financed entities purchase providers of ID/A services. These arrangements mean that beyond, individuals with disabilities, their families, providers, and taxpayers who fund these services, shareholders and bondholders become a stakeholder group in decisions about the health, safety and quality of services for our most vulnerable Pennsylvanians. Shareholder and bondholder interests may now influence the composition of homes, home sizes, locations and staffing patterns, and without proper guardrails, this is likely to result in larger homes and greater congregation of residents for “efficiency,” not by choice of individuals and families.

Second, in addition to recent financing changes in an industry that had historically been primarily mission-driven non-profit agencies, the workforce crisis also heightens concerns about a backslide to more congregated settings. Leading scholars in national IDD policy warn about the workforce crisis potentially leading to greater congregation of people with IDD: “All the progress toward community living that has been made in services for people with IDD over decades is now in jeopardy — because of catastrophic labor shortages and pervasive high turnover rates among the workforce that supports them, direct support professionals (DSPs).”

Finally, at a time when there is a high level of scrutiny of use of federal funds and state claims are requiring new levels of justification prior to payment, eliminating concrete and established ways of measuring compliance with federal rules is not prudent. Non-compliance with the federal HCBS Settings rule has considerable financial implication for the commonwealth as eligibility for federal match requires compliance. Pennsylvania has not yet received approval for settings that were submitted for CMS heightened scrutiny so the CMS determinations on settings that fall outside of the adopted measurable standards remain unclear.

### ***Conclusion***

In conclusion, there is a complex set of statutory, regulatory, historical and financial considerations for any change of this magnitude to be undertaken in the ID/A services system that is unaccounted for in SB657. For myriad reasons, there has been overwhelming stakeholder support for smaller dispersed settings for more than 30 years in the commonwealth. Especially in the current economic conditions, stakeholders have shared concerns about the services system backsliding into concentrations of larger congregate and segregated settings. Any amendment of ODP's current regulations must account for the following:

- The current stakeholder engagement occurring to address these issues;
- The extent of engagement necessary to arrive at a negotiated position balancing all stakeholder interests and the need for clear measurable standards to continue federal financial participation;
- Impact of establishing new standards on the current status of compliance with the federal HCBS Settings rule;
- Department, AE/County, and provider costs associated with implementing new regulatory and monitoring requirements and subsequent IT changes to meet federal assurances;
- The extensive residential and vocational options currently available to individuals enrolled in ODP services;
- The availability of regulatory waivers in 6100 regulations which have been used for variations in home and day program sizes and locations;
- The availability of intermediate care facilities as an alternative to HCBS;
- The impact of performance-based contracting on increasing and improving residential service options and capacity statewide; and,
- Outcomes from the ID/A Supportive Housing pilot and ARPA funded AE/County alternative day services projects

The barriers SB657 seeks to address are driven by the need for additional funding for residential services, workforce shortages, and the need for more supportive housing options. These barriers could be substantially addressed by the General Assembly appropriating funds as proposed in the Governor's Fiscal Year 2025-26 budget for ID/A services and establishing permanent stable funding for ID/A Supportive Housing which is currently funded with one-time funds available through the HCBS Augmentation Account.