

ODP Policy Change Fact Sheet

Current policies restrict choices of service for Individuals and prioritize an ideological agenda over provision of a continuum of care that provides for individuals with more complex needs (behavioral, medical, mental health). ODP has chosen to implement CMS settings rule in a manner that exceeds the requirements and limits choices for individuals that may meet their needs and comfort level, safety concerns

- Day services have all been defined as Community Participation Supports with a bias toward every person finding competitive integrated employment. Competitive, integrated employment is not a realistic possibility for some individuals with severe disabilities. Community Participation Supports limits the number of people served at any one time
 - Facility-based Community Participation Supports, are capped to limit the number of individuals at any one site. New services are limited to 25 people.
 - The rate paid for these facility-based services is significantly lower than the rate paid for service that occurs outside of the facility which disincentivizes providers from providing these needed services. 64 Programs have closed
 - Community Participation Supports that occur outside of a facility (community activities) are limited to a maximum of three people present, together in any community setting at any one time – resulting in individuals being separated from their friends and social supports
 - Individuals are strongly encouraged to leave facility-based services, including employment, to spend time out “in the community” exploring volunteer work, recreational activities, potential employment opportunities, etc.
 - There are many challenges with finding meaningful activities that meet these expectations, particularly in rural areas, in bad weather, during winter months, that are low cost or free, and that do not overlap with the activities that individuals participate in on the weekends, and evenings with their families or friends
 - When the individual earns money working in a facility and leaves to do “community activities”, they no longer earn money
 - When staff leave the facility to support individuals in CPS, they are limited to supporting a group of three individuals or less (if they want to be paid the higher rate associated with community activities versus facility rates), resulting in the need for more staff, and providers are facing a severe staff shortage

- Pennsylvania is significantly more restrictive than most states and is more restrictive than required by CMS:
Residential settings are limited in size and can't be located in contiguous locations
 - No more than 4 people with a disability can live in the same house or in contiguous locations
 - Apartment buildings – No more than 25% of the units in an apartment, condominium or townhouse building may be newly-funded in accordance with this chapter on or after February 1, 2020. With the exception of a duplex, two bi-level units and two side-by-side apartments that serve a minimum of 8 people)
 - Life sharing – no more than 2 individuals can be served in a Life sharing home
 - Campus settings not permitted to be waiver funded

The practical impact of many of these policy decisions directly limit where and how intellectually and developmentally disabled individuals can choose to spend their lives. Policies against congregate settings are not supported by research (See [A House is not a Home, Mandell 2017](#) and [Ideology, not Data, Lutz \(2017\)](#)) are interdependent: programmatic, fiscal and systemic issues all affect key concerns that have already been identified by the new administration, including workforce shortages and waitlists for services. Meaningful change requires both immediate responses to save services and longer-term policy changes to protect the future of the system.

The current ODP system needs to be carefully reviewed. Significant changes in policy are indicated in order to align policies with those of other DHS departments, other Pa. regulations regarding business practices, and to emulate national best practice. Meaningful, authentic, transparent and responsive dialogue with stakeholders is necessary in order to effect changes that can be realistically implemented. Services must address a comprehensive continuum of care that aligns with family preferences, evidence-based practice and which prioritizes choice over any philosophical, political or ideological agendas. Rates must reflect actual costs.

Clearly there are systemic changes requiring review such as the Legislative Budget Task Force recently convened, but that is a longer-term process which cannot address the crisis at hand. Change is necessary now. Individuals with disabilities and their families cannot wait. Providers are already closing their doors leaving hundreds of vulnerable Pennsylvanians without the critical supports necessary to survive much less thrive. Programs such as CPS must be restructured immediately to support ALL individuals, including those with severe and complex disabilities and medical/ behavioral complications. The settings rule interpretation must come in line with federal guidelines.

1. **Commitment to Request of \$430 million dollars in the Governors Budget ([see Unified Budget Request from Pennsylvania's Provider Associations](#))**
2. **Commitment to appoint representation to all existing DHS/OPD stakeholder committees as appropriate in equal proportion to self and inclusion advocates**
3. **Commitment to repeal regulations 6100.444 (size of service location) and 6100.445 (locality of service location) restricting housing options (see [suggested amendment to the regulations attached to Hennessey letter](#))**
4. **Commitment to Convene Authentic Rate Reevaluation and Rate Setting Process to take effect 7/1/2023**
5. **Commitment to convene a Blue-Ribbon Advisory Panel serving the Secretary directly**
6. **Commitment to rescind burdensome administrative policies:**
 - a. ***Rounding Rule***
 - b. ***Prudent Pay***
 - c. ***60 Hour Cumulative Relative Caregiver Rule***

d. Variance Requirement

- 7. Commitment to redaction of PA restrictive interpretation of the CMS Settings Rule consistent with recommended amendments (see draft regulation on settings rule).**
- 8. Commitment to developing good public policy. Developing good public policy is rooted in the ability to solicit positions/opinions/feedback from constituencies with divergent interests (i.e. families, individuals who can self-report, providers, advocacy organizations, etc.) and shape that input into something acceptable to all to move the system forward. –**
- 9. Establish ODP Leadership who is willing to demonstrate and be accountable for increased*:**
 - a. Responsiveness**
 - b. Collaboration**
 - c. Solicitation and incorporation of feedback**
 - d. Develop a Blue-Ribbon Advisory Panel grounded in demographics of the commonwealth and constituencies of service for the purpose of consultation and collaboration with experts with applied experience. Administrators who do not have applied, boots on the ground experience are enhanced by the opinions of those who are actively providing services and those who are actively receiving services.**
 - e. Open minded**

***The current atmosphere is one where anyone who is interested in ODP data (i.e. the number of individuals receiving enhanced services) typically must file a Right To Know Request in order to receive the information.**

- 10. Integrity in performance and discharge of their fiduciary responsibilities to their constituencies and the Commonwealth.**