



<http://www.growny.org/>

email: info@grow-ny.org

Phone: 914-493-1318

POSITION PAPER ON SELF DIRECTION

Based upon the experience of families represented by GROW, the current OPWDD guidelines for Self-Direction (SD) fail to take into account the needs and special accommodations required for individuals with developmental disabilities who have moderate to high needs, thus preventing them from accessing this funding source.

For example, the guidelines for community classes require that they are open to, and attended by, the broader community in a non-OPWDD setting. However, the vast majority of individuals with developmental disabilities are incapable of participating in 'typical' classes. After all, if an individual requires the services provided by OPWDD, it is likely that they are not able to access community services provided in non-regulated settings due to their disabilities. In these same guidelines, these 'typical' classes are allowed to "focus on specialized content at a slower pace that may be of greater interest to people with disabilities." Hence the "Catch-22." No 'typical' person is going to participate in a class that is modified enough to accommodate individuals with greater needs. Essentially the regulations encourage classes with content directed towards those with developmental disabilities while at the same time requiring that most of those attending the class not have developmental disabilities. Huh?

Problems in the creation and maintenance of self-directed housing are such that only families with means are able to do so. This is discriminatory. A person seeking self-directed housing has a budget of only 70-80% of what is received for Certified Housing. If a self-directed person has roommates, his or her individual housing supplement goes down, furthering the impossibility of creating a home. And it gets worse: individuals are not allowed to use their Personal Resource Allowance (PRA) to help cover the cost of housing. Simply put, even if individuals utilizing self-direction are able to find residential options that are cheaper than alternative certified settings, the lack of sufficient reimbursement denies them the opportunity to pursue such housing, which not only deprives them of choice, but also represents a loss to the State.

Beyond the inadequacy of the rates for self-directed residences is the lack of funding for paid overnight staff. The live-in caregiver of the SD residence is not paid for this service except in the case of active service (i.e. assisting a person during sleep hours). Furthermore, other funding sources from outside OPWDD are difficult to access or, are not designed for individuals with developmental disabilities. For example, the

applications for HEAP (Heating Assistance) and SNAP (food stamps) must currently be accessed separately and are not permanent. A suggestion would be to have food allocations with a separate budget line instead of SNAP. The allowance for OTPS (Other Than Personal Services), which is only \$3000 a year and must cover staff activity fees, phone, cable, clothing, and utility bills, also remains inadequate.

Beginning in March, 2016, OPWDD ceded its review and approval authority to the Fiscal Intermediaries (FIs), which approve and pay for self-directed services without clear and precise guidelines or standards. In turn, each has created its own set of rules regarding the quality of and breadth of services it will approve. OPWDD should promulgate standardized guidelines and software.

OPWDD also should offer more co-training for brokers and Medicaid Service Coordinators (MSCs) who handle self-direction and compensate them appropriately as self-direction requires much more work on their part to manage.

Self-Direction is a funding source without any supportive services (legal, medical, or social). OPWDD needs to create a new profession to support the system.

Self-direction must be greatly reformed if it is to achieve its vast potential of providing an alternative choice of accessing services and supports for OPWDD certified individuals.

GROW recommends:

- Appropriate Community-Based Classes
- OPWDD to Rectify Problems With Funding For Self-Directed Housing
- Fiscal Intermediaries Need Uniform Guidelines and Standards
- More Co-Training For MSCs And Brokers With Just Compensation