



<http://www.grownny.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 the diverse universe developmentally disabled individuals who have moderate to high needs, thus preventing them from accessing this funding source.

As we have previously stated, the guidelines for the services that can be accessed with SD funding remain too restrictive not allowing for the person-centered tailoring that is the *raison d'être* for self-direction.

While we acknowledge OPWDD's attempts to improve various processes, it is still the case that problems in the creation and maintenance of self-directed housing are such, that only families with means, are able to make the program work. Those individuals utilizing self-direction who are able to find residential options that are cheaper than alternative certified settings, but do not have independent financial resources, still find that the lack of sufficient reimbursement denies them the opportunity to pursue such housing.

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 developmentally disabled individuals. 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 allowances for OTPS (Other Than Personal Services), which is only \$3000 a year, which must cover staff activity fees, phone, cable, clothing, and utility bills also remain inadequate.

The continued lack of guidelines for and lack of choice in Fiscal Intermediaries (FIs), which approve and pay for self-directed services has frustrated families who have to contend with different policies and procedures whenever changes are made. We seek more standardization and transparency in how the FIs operate.

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

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, Care And Brokers With Adequate Compensation

March 2018