



Services for Individuals with Complex Challenging Profiles: A Population Overlooked

Background: Raising and caring for an individual with autism and/or other developmental disabilities presents challenges across the lifespan for impacted families. For some, though, when a loved one presents with dangerous maladaptive behaviors, including those that are self-injurious and/or aggressive, each day brings risk and fear. Across NYS families live day-to-day in unimaginable circumstances - at home with adult children who may explode, hit themselves or others, exhibit severe head-banging, bite (self or others), and/or constantly attempt to escape their homes. During their education years, students who exhibit such complex profiles receive services in school (or sometimes a highly structured and protective residential placement away from home) which are specially designed to mitigate or eliminate behaviors and/or associated dangers. In these instances, research-based interventions, provided by trained and certified professionals, are proven to reduce maladaptive behaviors, improve communication, reduce or eliminate the need for 911 calls, hospitalizations, and psychiatric stays, and increase independence and functioning in all areas of daily living – *and are mandated by education law.*

Unfortunately, when a student's right to education ends at age 21, so too, does the assurance of access to the specialized supports and services that previously ensured safety and functioning. In the world of adult Medicaid and OPWDD services, there are no guarantees - and few options - for this vulnerable minority. While effective models do exist for such populations, they remain almost non-existent in the adult world. Residential options structured with appropriate behavioral supports run at a significantly higher cost than OPWDD reimbursement rates support, and thus, are only made possible through philanthropy. As such, many adults with the most significant needs are forced to remain in their school residential programs years after graduation, taking up beds intended for younger students whose families are in their own dire circumstances. Others end up in psychiatric hospitals, or sedated to the point of inertia, or homeless, or in prison. Still others remain at home, supervised by a family member forced to forgo career, endangering themselves and other family members, and experiencing severe regression as the services that were their lifeline - and their families' hope - end. There is nowhere else to go.

Systemic Issues:

While a wide range of research-based supports and interventions have been proven to be effective with individuals with complex profiles, the adult system in NYS has not built capacity to implement best practice:

Clinical Services: A holistic model which incorporates psychiatric counseling and research-based interventions is not currently utilized in the OPWDD system. This results in part from a reimbursement structure that does not support or encourage the advanced training of certified staffing and the more labor-intensive processes to create and monitor appropriate behavior plans and teaching programs.

Staff to Resident Ratios: Current ratio requirements in Day Habilitation and Residential Services are not sufficient to implement complex behavior plans, safely implement strategies for crisis intervention and protection, accompany individuals into the community to support independence, and develop daily living skills.

WIHD's Community Task Force on Disability Complex Profile Priorities:

Funding:

A tiered reimbursement structure must be developed to assure skilled direct service providers are available and labor-intensive services required to support adults with complex profiles are developed and maintained.

Infrastructure:

OPWDD must complete a comprehensive needs assessment, identify models that are successful in and out of NYS, and develop both its fiscal and procedural infrastructure across the state to support its most vulnerable population.

Training:

Funding must be allocated to support advanced training in techniques of ABA and other proven intervention methodologies, and the appropriate supervision of staff implementing in order to assure service delivery with fidelity specified by research.



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*This Policy paper was developed by the **WIHD's Community Task Force on Disability**. Comprised of individuals with autism and other developmental disabilities, their families, and the professionals that support them, the Community Task Force on Disability represents the collective voice of its members, while promoting their education and full participation in the dialogue on critical issues impacting people with disabilities in our cities and towns, the Hudson Valley, New York State, and the nation.*

About WIHD:

Westchester Institute for Human Development is a leader in addressing major social and health issues affecting people with disabilities and vulnerable children. WIHD addresses major social and health issues by developing and delivering medical, clinical and support services to individuals, their families and caregivers. As one of only 67 University Centers for Excellence in Developmental Disabilities, WIHD creates better futures for these individuals through the creation and dissemination of innovative research, professional leadership education and best practices trainings. WIHD provides nearly 50 programs and services to families and professionals throughout Westchester County and the Lower Hudson Valley. At WIHD, everything we do is guided by our vision of a future in which all people, including people with disabilities and vulnerable children, live healthy and productive lives as full members of society.

MISSION: WIHD creates better futures for people with disabilities, for vulnerable children, and for their families and caregivers. WIHD accomplishes its mission through professional education, comprehensive services and supports, community training and technical assistance, and innovative research and information dissemination.

VISION: We envision a future in which people with disabilities and vulnerable children live healthy and productive lives as full members of society.

VALUES:

- **INCLUSION & SELF-DETERMINATION:** We believe that every person with a disability or special health care need should have the opportunity to live a healthy, meaningful, and productive life as a full member of the community, and we believe that individuals with disabilities and their families should have the tools necessary to make informed choices and decisions about their own lives.
- **SAFETY, PERMANENCY & WELL-BEING:** We believe that every child deserves a safe, loving, and permanent home that fosters healthy development.
- **FAMILY & COMMUNITY PARTNERS:** We believe that WIHD best achieves its mission when individuals, families, caregivers, advocates and community members participate as full partners.
- **CULTURAL COMPETENCY & DIVERSITY:** We believe that the needs of diverse people with disabilities and vulnerable children and families are best served by a diverse and culturally competent workforce.
- **LEADERSHIP & INNOVATION:** We believe that interdisciplinary leadership is required to generate creative solutions and positive outcomes.



Self-Directed Services for Individuals with Intellectual Disabilities and Autism in NYS:

A Crisis in Capacity

Background: Self-direction (SD) provides an alternative to the way support services have traditionally been delivered through an agency-driven model for individuals with intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD). It promotes personal choice and individual and family control over the delivery of Medicaid waiver and state-funded services a loved one may require to live and contribute safely within the community. *Self-direction gives individuals and families greater control over the services they receive; how, when, and where they receive them; and from whom.* Families are able to recruit, hire, train, supervise and schedule the individuals who provide necessary supports to their loved ones, meeting their own unique needs and circumstances. Importantly, self-direction is also cost efficient, with individual budgets that are far lower than the budgets of individuals receiving services through agencies, whose costs are higher due to the overhead, administrative and oversight costs, and compensation and benefits packages they provide. Here in the Hudson Valley, WIHD is the largest provider of self-direction brokerage services, assisting over 160 families who have chosen to self-direct services, to develop and gain OPWDD approval for their service plans and budgets.

Systemic Issues: Individuals and families in the region and across NYS are facing a crisis, unable to secure services for their family members who are stuck at home without supports, unable to work, and denied the opportunity to engage with friends and participate in their communities. This lack of capacity is driven by systemic issues, including the following:

- **Self-Direction Brokers:** There are an insufficient number of certified, trained, quality self-direction brokers in the state to support the families who choose self-direction. Brokers are trained and required to assist families to develop support plans and gain approval for budgets. In many regions, long waitlists exist for required Broker OPWDD trainings. In addition, agencies, including WIHD, are reanalyzing their commitment to providing the service due to complex billing procedures and low reimbursement rates that barely cover costs.
- **Fiscal Intermediaries (FI)** are approved by NYS to be payors of record in the self-direction process and required for reimbursement and payment to support providers and the individuals or families for funds expended on services. Their processes and quality are sporadic from one to another. Currently in the Hudson Valley region, many FI's have stopped taking new cases, so that families with approval to begin self-direction are unable to hire staff and implement the Self-Directed budget and support plan and are left without access to critical services.
- **Direct Service Providers (DSP):** Services and supports are provided by people and finding quality staff is difficult for low pay. While self-direction does enable a family to actually pay staff more than an agency employed DSP, the process for approval (including background checks, fingerprinting, and other cumbersome requirements), is both lengthy and different with each FI, creating barriers for a DSP to serve individuals from more than one. In addition, NYS previously funded exploration of the feasibility of a DSP credentialing system to promote career paths within the system. To date there is no follow up.

WIHD's Community Task Force on Disability Self-Direction Priorities:

Self-Direction Brokers:

- OPWDD should offer more required broker trainings and/or expand and fund Master Brokers to provide this training.
- Review current payment structure for self-direction brokers and align to the process used for Care Coordination (a monthly fee at tiered rates)

Fiscal Intermediaries:

- OPWDD guidance and processes for FI's must be consistent across NYS
- OPWDD needs to develop a statewide web-based infrastructure for reporting and reimbursement. In the short term, implement higher admin tiered fees for FI's and/or extend reimbursement timeframes for reimbursement from Medicaid

Direct Service Providers:

- A centralized system for DSP background checks, fingerprinting, approval, and hiring so that eligibility for one FI applies to others in the region and state
- Credentialing and tiered wage scale for DSPs with specialized training for individuals with high support needs



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