



## 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.

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**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.