



**Community Support Network
Annual Legislative Town Hall
Westchester Institute for Human Development
Friday, Noon to 1:30 PM**

Participants:

Kerri E Neifeld, Commissioner of the NYS Office of People with Disabilities

Rebecca Seawright, Assemblymember, Chair of NYS Assembly Standing Committee on People with Disabilities

Chris Burdick, Assemblymember, Member Standing Committee on People with Disabilities

Naomi Brickel, Director, Community Support Network, WIHD

Welcome: (12:01 pm 12:12)

Topic 1: Self Direction: (12:12-12:27)

Background and Context:

Self-direction has also quickly become the option of choice in NYS. According to OPWDD data, between 2016 and 2020:

- total number of participants using SD increased over 350% from 5166 (2016) to 18,272(2020)
- Here in Region 3, the number increased by over 500%, from 636 to 3417
- individuals *under* 40 years old comprised almost 95% of those self-directing.

It's also more cost efficient, in 2020 according to OPWDD's data:

- average cost per individual utilizing OPWDD services ~ \$68,000.
- cost of group home bed was over \$128,000 (not inclusive of the additional costs for programing and services during the day),
- self-direction budgets averaged under \$25,000

However, self-direction is not actually self-directed, and parents or family members must manage most of the program logistics for their adults with disabilities. Assistance with those details, as well as the more complex budgeting and paperwork requirements of the self-direction process, certified brokers. Unfortunately, there are insufficient numbers of certified, trained, quality self-direction brokers in the state to support the families who choose self-direction. Reimbursement rates have not changed in over a decade and make it particularly prohibitive for agencies to support this service. The lack of trained brokers and the low reimbursement rate creates a situation whereby the demand for any, much less quality, brokerage services far outpaces the supply. In NYS, the network of certified brokers has been developed consisting mainly of independent brokers, and while there are examples of high-quality independent brokers here in Region 3 and across the state, independent brokerage lacks the inherent quality controls and safety net protocols that exist in an agency.

In Westchester County, WIHD has historically filled a substantial portion of the demand as the largest provider of brokerage services, assisting around 170 families, and has been recognized locally, regionally,

and on a state level for its high quality and dependability of services. Sadly, WIHD recently terminated over 80 families on our brokerage caseload. Unfortunately, the rate issues impacting the supply of brokerage across NYS state are greatly exacerbated for agencies attempting to maintain brokerage services, especially in the downstate region with its higher rates for cost of living. Maintaining a cadre of brokers in an agency requires substantial oversight and overhead costs including payroll taxes, DOL requirements for paid time off, insurance, rent, administration costs, supervision, broker time and mileage for travel, broker billing hours, training and professional development, etc. It has become unsustainable to maintain staff due to intensive billing requirements and a low hourly reimbursement rate that has not changed since its inception well over a decade ago.

Topic 2: Employment: (12:27-12:42)

Background and context:

Federal legislation and regulations included in the Medicaid Home and Community-Based Services (HCBS) and the Workforce Innovation and Opportunity Act, among others, encourage opportunities for meaningful integrated and competitive employment for individuals with disabilities, recognizing that Individuals with I/DD need support and resources to access and be successful in a job and make decisions about career options. Here in NYS, several layers of “employment” services exist including vocational rehabilitation through ACCESS-VR, Pre-Employment Training Services, OPWDD funded Prevocational training, Supported Employment (SDEMP), Employment Training Program (ETP), Day Hab, and more. And yet, a significant gap remains in the employment rates for people with and without IDD: 71.4% of adults without disabilities are employed, while only 14.7% of adults with I/DD are employed in the United States.

Topic 3: Services for high support need individuals: (12:42-12:53)

Background and Context:

Raising and caring for an individual with autism and/or other developmental disabilities is difficult in the best of circumstances. For some, however, when a loved one presents with dangerous maladaptive, self-injurious and/or aggressive behaviors, each day brings risk and fear. The system in NYS still lacks capacity to meet the demand and implement best practice. 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.

Topic 4: Housing: (12:53-1:05)

Background and Context:

The Olmstead Decision (1999) mandated that PWD should be allowed to live in the least restrictive settings in their communities. Group homes and other certified settings are expensive, restrictive, and hard to staff. Non-certified settings, using Self-Direction housing subsidies and supports, or other funding sources can offer creative solutions, and research has shown that people living in these less restrictive, community settings are happier, have better outcomes, and use less services overall. Innovative housing models are necessary to address Housing needs for PWD in NYS, yet they require layers of overall support such as property management, service management, or social management to make them fully sustainable.

In this year's State Budget, Governor Hochul secured a new \$25 billion, five-year, comprehensive housing plan that will increase the housing supply by creating or preserving 100,000 affordable homes across New York, including 10,000 with support services for vulnerable populations.

Topic 5: Supported Decision Making: (1:05-1:10)

Background and Context:

Supported decision-making (SDM) is a process in which people with intellectual and developmental disabilities build their own decision-making skills and develop a structure of support of trusted persons in their lives while retaining all their legal and civil rights. It is increasingly becoming recognized as a preferable and less-restrictive alternative to guardianship here in NYS, nationally, and even internationally.

In the spring of 2022, Governor Hochul signed New York's Supported Decision-Making Agreement Act, built upon Principles developed by SDMNY. This civil rights legislation recognizes SDM as an alternative to guardianship and prohibits discrimination against decisions made by people with Intellectual and

developmental disabilities with an agreement developed through SDMNY's facilitation process. New York Courts are increasingly deciding that as a less-restrictive alternative, SDM can be used to avoid the necessity for guardianship in the first place, or as a means to restore the rights to persons already under guardianship.

Topic 6: Medicaid Waiver Renewal update: (1:10-1:15)

Background and Context:

The Center for Medicaid Services (CMS) is moving away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The changes related to clarification of home and community-based settings will maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting and will effectuate the law's intention for Medicaid HCBS to provide alternatives to services provided in institutions. <https://www.medicaid.gov/sites/default/files/2019-12/final-rule-slides-01292014.pdf>

Topic 7: Workforce: (1:15-1:20)

Background and Context:

Direct Support Professionals (DSPs) are the backbone of the OPWDD service system, and low pay for high-stress work and long hours has led to high turnover. Agencies continue to face hurdles recruiting and keeping direct-care staff and COVID pushed even more out of the field. OPWDD reported 25% vacancies on average, with some having as high as 40% openings for employees in facilities for IDD in the state. The governor assigned \$1.5 billion of federal American Rescue Plan funding to help with retention and recruitment of DSPs which have been allocated by OPWDD Workforce Incentives and Bonuses and Workforce Development Grants.