



Written Testimony for Legislative Hearing on OPWDD Budget
February 16, 2023

We are the Care Management Alliance of New York (CMANY), representing the seven specialized care coordination organizations (CCOs) who provide care management services to approximately 115,000 New Yorkers with intellectual and/or developmental disabilities (I/DD) and their families. One of our primary roles is to ensure that individuals with I/DD get and maintain access to supports and services that will help them live a quality life. In doing so, we engage and collaborate with service providers across multiple service sectors including, but not limited to, I/DD, medical, dental, and behavioral health.

We want to thank Senator Kreuger, Assembly Member Weinstein, and all the Committee members for the opportunity to share our views on the proposed budget for the Office of People with Developmental Disabilities (OPWDD).

DSP Wages and the workforce challenge:

As part of her Executive Budget, Governor Hochul has put forward several increases for OPWDD, most notably, a cost-of-living adjustment (COLA) for all OPWDD funded supports and services; funding to support expansion of services; and increased housing funding to support people who live in their own apartments. While we need the legislature to support increases for this workforce and for these services, more must be done than what has been proposed in the Executive Budget.

Governor Hochul's budget does not address, in any meaningful way, the number one issue confronting the provider agencies, and one that is being felt daily by individuals with I/DD and their families, which is the lack of a direct support professional (DSP) workforce. The proposed budget increase is not sufficient to attract or retain DSPs, given the need to recognize and reward the responsibilities and unique skills required of this workforce.

The current DSP workforce crisis continues to negatively impact the I/DD population, which has only exacerbated our efforts to address years of segregation, congregation and significant, existing healthcare disparities. The DSP vacancy rate has ballooned by an average 25%, or nearly three times higher than 5 years ago. Despite last year's COLA and one-time funding through ARPA, the DSP crisis remains acute and significantly impacts the quality of life for New Yorkers with I/DD and their families. This population needs to be supported by a well-trained, stable workforce that can successfully support a population with unique developmental, medical, and behavioral needs.

The impact of the DSP workforce challenge

Both turnover and staff vacancies affect the quality of care by disrupting social support networks, jeopardizing program continuity, and ultimately, increasing the costs of providing services both within OPWDD and in other service systems (i.e., hospitalizations). The ongoing systemic and pervasive failures in the I/DD service system have created heavy consequences for DSPs, individuals with I/DD, families, and service providers, including the following:

- **Direct Support Professionals**

DSPs work with the most vulnerable New Yorkers. Given that the workforce is predominantly comprised of women and a majority of whom are minorities, this workforce challenge should also be considered an equity issue. High turnover and vacancy rates result in many DSPs being overworked, tired, and more prone to making mistakes. That coupled with the economic stresses of their employment can undermine the willingness of DSPs to remain



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in their jobs. Many DSPs can stay in the direct support workforce because they are willing to work two or three jobs and 80 hours a week to have enough income to support their families while others, because of their low wages, are receiving government subsidies such as SNAP benefits. Low wages often correlate with low value, respect, and status. DSP wages are so low, and their accountability so high, that far too often good people leave a highly skilled profession they love. The work of a DSP is not minimum wage work and shouldn't be paid as such.

- **Individuals with I/DD**

Those currently supported:

Collectively, our seven CCOs work with over 700 voluntary provider agencies who provide direct services and supports to our members. All are reporting significant challenges in maintaining safe staffing levels to support people both in their residences and in the community.

The health, safety, and well-being of individuals with I/DD is at risk daily because of the workforce problems. A revolving door of strangers coming in and out of a person's life, often required to support in the most intimate personal care routines, means that far too often the people being supported may not trust or develop a meaningful professional relationship with the DSP. Signs and symptoms of illness are missed, opportunities for community participation are lost, and individuals with I/DD have few choices because staffing is so unstable. Additionally, service providers have been forced to make the unfathomable decision to close or consolidate group homes and day service programs forcing many individuals to relocate from their homes and day services, often leaving behind friends and familiar staff who they may have known for years. Some group home relocations have resulted in individuals moving to other counties or further away from access to their family members.

Those in need of supports (now and in the future):

The current DSP workforce crisis has made it very difficult for individuals who are new to the system and those currently supported and in need of other or additional services to gain access to those services. To put this in perspective, minimally, there are approximately 3,000-5,000 new eligible individuals in need of I/DD services every year, many of whom are struggling to gain access to services that they have been approved to receive through OPWDD.

Having skilled, committed, and known DSPs is critical for family members to maintain employment and engage in their own community life. As evidenced by this workforce shortage and exacerbated by the pandemic, caregivers have had to make major career concessions (e.g., not taking a job, working fewer hours, dropping out of the workforce, turning down a promotion) related to having a child with I/DD (Anderson, Larson, Lakin, & Kwak, 2002). This results in caregivers being challenged to get any respite which causes stress, health issues, burnout and, ultimately, added societal costs.

- **Service Providers**



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The costs and wasted resources associated with high DSP turnover over decades have resulted in serious consequences for providers. This sustained turnover rate alone is debilitating and organizations simply cannot find enough qualified individuals to fill positions. The limited candidate pool, and greater competition from other businesses and industries that pay better wages, have resulted in organizations being forced to consider applicants they would not have previously hired. This "lowering of the bar" results in less dependability among DSPs, and an increase in unacceptable workplace behavior among some employees.

What is needed?

We need a permanent wage increase for DSPs that differentiates it as a professional position with unique responsibilities and skillsets. Wage increases are the first and most effective way to attract workers to these jobs with the goal of getting the DSP workforce to a "living wage". To help us get there, we support an 8.5% COLA, which is tied to the consumer price index, and a permanent \$4,000 annual wage increase for DSPs. The 2.5% COLA included in the budget doesn't come close to the inflation rate and such a small COLA on a low wage still results in a low wage.

Creative solutions, such as funding to support a marketing campaign to generate interest in working in the I/DD system, development of a curriculum or pathway for people to enter I/DD professions from High School, loan forgiveness, and/or tax incentives, should also be explored to help alleviate the workforce problems.

Access to integrated healthcare:

In addition, NYS needs a plan to address the significant healthcare disparities that exist for this population. Specifically, people with I/DD do not have adequate access to primary and specialty medical, behavioral health and dental care. In New York State, People with I/DD have unique health needs that are not sufficiently addressed by the current Medicaid fee-for-service (FFS) system. As described by *Johnston, Chin, & Pollack* in their October 2022 JAMA article,ⁱ the I/DD population faces the following issues, which have all been magnified by the COVID pandemic and have resulted in the population experiencing significant health disparities and lower life expectancies compared to the broader population:

- Difficulty in accessing quality health care,
- Complicated eligibility process to access I/DD Home and Community Based (HCBS) services,
- Long waiting periods for critical HCBS services,
- Expensive, inflexible, highly regulated residential programs, with limited independent housing options,
- A complicated and administratively burdensome system to self-direct services, which makes it difficult to use for most individuals without an involved, sophisticated advocate, and
- Increasing regulation coupled with multiple years of rate reductions making it more difficult for service providers to recruit and retain a qualified direct support workforce.

People with I/DD often have complicated genetic conditions, neurodevelopmental diagnoses, and other co-occurring health conditions which require advanced training and experience. Finding providers of such services for the I/DD population is difficult, however, because of training and reimbursement challenges, including but not limited to lack of access to value-based programming for providers of waiver services to individuals with I/DD. Additionally, many people with I/DD have limitations in cognitive capabilities, limited communication skills, and sensory issues requiring



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longer office visit and procedure times than the general population; often requiring sedation for simple procedures such as dentistry, x-rays, and bloodwork. As described by *Lagu et al.* in their October 2022 Health Affairs study,ⁱⁱ also highlighted in a recent New York Times article,ⁱⁱⁱ providers are not reimbursed for the additional time to diagnose and treat, additional staff and specialized equipment needed, or the additional steps required to provide comprehensive patient care to people with disabilities. Thus, many providers feel ill-equipped to treat this population and individuals are often sent to emergency rooms out of precaution, resulting in unnecessary testing, undue stress and often hospitalization. Furthermore, as noted by *Raj et al.* and *Lonchamp et al.* in their respective studies,^{iv,v} people with I/DD often experience polypharmacy as a result of inappropriate prescribing, poor medication management and lack of monitoring of side effects – which can be subtle and lead to other medical issues and a poor quality of life.

The New York State system of long-term services and supports (LTSS) provided through the HCBS Waiver has not substantively changed since the closure of the institutions, Olmstead decision, and the creation of the HCBS Waiver. Many of NY's current services were designed over four decades ago and have retained many vestiges of the institutional past, heavily weighted towards segregated care models. Even though over 70% of the population lives in the community today, this antiquated process dedicates a significant portion of the current OPWDD budget to congregate-based care services leaving limited resources for supporting the majority of those it is meant to serve.

The current LTSS system can do far better to advance the goal of inclusion and integration. NYS regulations are laden with outdated language and processes that prevent people from living inclusive lives in the community and making it difficult for providers to hire and retain staff. If providers are given the ability and/or the incentive to develop new, innovative models of care, it can help reduce the number of people reaching a crisis and reduce unnecessary emergency department visits, hospitalizations, and more expensive permanent placements. In the current FFS system of supports and services, Care Coordination Organization (CCO) care managers do not have the ability to effectively respond to the needs of people due to a siloed system of care that has long waiting lists, unnecessarily complicated processes of approval, and a lack of direct support staff.

What is needed?

We need to embrace an integrated approach to health and long-term support services that incentivizes medical, behavioral health and dental professionals to serve the population, provides comprehensive, integrated care, and provides care managers the ability to effectively respond to the needs of people with I/DD and their families.

Thank you for your consideration, and we welcome the opportunity to provide further information to the Committees.

Respectfully submitted,

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Care Management Alliance
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ⁱ *Health Equity for Individuals With Intellectual and Developmental Disabilities*. (October 7, 2022). JAMA. Johnston, K., Chin, M., & Pollack, H.

ⁱⁱ *'I Am Not the Doctor for You:’ Physicians’ Attitudes about Caring for People with Disabilities*. (October 2022). Health Affairs. Lagu, T. et al.

ⁱⁱⁱ *These Doctors Admit They Don’t Want Patients with Disabilities*. (October 19, 2022). The New York Times. Kolata, G.

^{iv} *Polypharmacy in a Patient with Intellectual and Developmental Disabilities*. (February 8, 2022). Cureus Journal of Medical Science. Raj, R., Owen, D., Kannan, L., & Adler, J.

^v *Prevalence of Polypharmacy and Inappropriate Medication in Adults with Intellectual Disabilities in a Hospital Setting in Switzerland*. (June 25, 2021). Frontiers in Psychiatry. Lonchamp, S. et al.