

Testimony of
Consumer Directed Personal Assistance Association of New York State
to:
Joint Assembly Committee Hearing on Employment Opportunities for
People with Disabilities

Bryan O'Malley
Executive Director

October 20, 2021

Good afternoon to Chairs Abinanti, Joyner, and Burdick, and to all of the Legislators here today. I appreciate the opportunity to provide testimony on behalf of the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) about employment opportunities for people with disabilities.

By providing consumers with the ability to take control of the employer duties related to their services, including the recruitment, hiring, training, scheduling, supervising, and if necessary, termination of their PAs, consumer directed personal assistance (CDPA) is ideal for younger disabled folks who are working or looking for meaningful work. As the only statewide organization focused solely on this program, CDPAANYS approaches today's hearing with an understanding of two key systemic issues that prevent those with disabilities from accessing employment.

Chiefly, today's hearing notice is exploring "...what programs and services are available to *prepare* people with disabilities to obtain gainful employment..." This assumes that folks with disabilities need more programs and services than other New Yorkers to help prepare for employment. In some cases, this is true. But, in many cases, disabled New Yorkers do not need new or different programs. They need access to affordable and accessible college. They need stable housing. They need transportation.

But there are real issues that need to be addressed to successfully integrate disabled folks into the workforce. Unfortunately, by focusing on preparation for employment, we miss the forest for the trees. For many disabled folks, there are two issues so fundamental to employment that they surpass every other issue - ableism and access to home and community-based services.

Addressing ableism is work that must continue at the highest levels. Much like systemic racism or sexism, systemic ableism is ingrained within our culture, and dismantling is a critical process that must be multi-pronged. It will take time and dedication; but it is a problem we must confront head on, and to do so we first have to name it. CDPAANYS encourages these committees to actively engage with the disability community to identify the forms of ableism that prevent them from obtaining work. However, some include requirements that individuals be able to lift at least 25 pounds in order to take an office job, a lack of flexibility for remote work when the entire world suddenly shifted to remote last year, and even failures of government to achieve basic measures promised by the Americans with Disabilities Act, such as accessible train stops, curb cuts, and more.

At CDPAANYS, we are particularly qualified to discuss the impact that access to home and community based services has on the ability of people with disabilities to gain, and retain, meaningful employment. For thousands of people, a lack of access to these services remains the largest obstacle to employment.

CDPA empowers consumers to control their services in ways most suited to their lifestyles and needs. Because they control scheduling, consumers can schedule their workers in ways that allow them to get ready for work. Tasks that often are taken for granted, such as getting out of bed, morning hygiene routines, getting dressed and looking professional, and transportation, are anything but for disabled individuals. In giving consumers control over when and how these tasks are performed, CDPA has an unmatched ability to provide the flexibility and consistency needed for that individual to abide by the schedule needed to work.

However, the flexibility and consistency that CDPA offers is meaningless if there are no workers for someone to hire, or those workers suddenly - and routinely - quit. As the state continues to grapple with its 'worst in the nation'¹ home care workforce crisis, this is the reality faced by many. In 2016, a report by Mercer Consulting projected a shortfall of 50,000 home care workers in the state by 2023². A 2018 update predicted that shortage would grow to 83,000 by 2025³. These workers comprise the infrastructure of the state's Medicaid-funded home and community-based (HCBS) services. The problem is growing in scope so rapidly that the entire long-term care system has effectively collapsed.

A consumer who does not have enough workers, whose workers are unreliable, or whose workers routinely quit unexpectedly, faces a host of issues related to the uncertainty of their service provision. For those in the workforce, or seeking entry to the workforce, these issues impact their ability to work and cause unexpected absences leading to instability and potential consequences with employers. They are the difference between employment and unemployment.

Any conversation about the ability of New Yorkers with disabilities to obtain gainful employment that does not address this fundamental issue misses the point. Further, it contributes to the systemic ableism that drives so much of the inequity the disability community faces. To ensure those in the disability community can fully participate in the workforce, the state must take action to ensure that we address this crisis - one borne from wages that are far and away some of the lowest in the state.

For the last decade, cuts to Medicaid reimbursement rates and a rapidly increasing private industry wage base has led the state to the situation it finds itself in today. In 2006, the average home care worker earned 168% of the minimum wage. In 2011, that worker earned 138% of the minimum wage. That same worker would today be earning at or slightly above the minimum wage, and substantially less than those low-wage workers in private sector industries - workers they used to eclipse in terms of salary. In a survey conducted by CDPAANYS in the spring of 2021, nearly two-thirds of upstate respondents reported that their PA earns the minimum wage, and 70% cited low wages as the reason their workers have quit.

Fair Pay for Home Care would guarantee that home care workers earn 150% of the highest minimum wage, or \$22.50/hour. The bill has enjoyed bipartisan support since its introduction, and we note and appreciate the support of the all of the Chairs here today. However, if we want to address the workforce crisis and allow those with disabilities to enter the workforce, action must be taken in the upcoming session. One report by the CUNY School of Urban and Labor Studies found that the bill would address the crisis immediately and in the long-term by adding 10,000 home care workers to the workforce per year for the next decade⁴.

¹ Stevenson, M. (2018). Demand for Healthcare Workers Will Outpace Supply by 2025: An Analysis of the US Healthcare Labor Market (Rep.). Mercer.

² Narlock, J., PhD, & Stevenson, M., PhD. (2016). Healthcare Workforce 2025 Part II (Rep.). Mercer.

³ Stevenson, M. (2018). Demand for Healthcare Workers Will Outpace Supply by 2025: An Analysis of the US Healthcare Labor Market (Rep.). Mercer.

⁴ Jabola-Carolus, I., Luce, S., & Milkman, R. (2021). (rep.). *The Case for Public Investment in Higher Pay for New York State Home Care Workers: Estimated Costs and Savings*.

Reforms like Fair Pay for Home Care will solve part of the problem to getting folks with disabilities more into our workforce; but, it does not address another fundamental problem in the system. The failure of commercial, employer-sponsored health plans to include long-term supports and services in their benefit package means that those with disabilities must rely on Medicaid to receive their services. For most, this is a system that requires forced impoverishment.

For some, one way to earn at least some money while still accessing the services that allow them the ability to work is to enroll in the Medicaid Buy-In for Working People with Disabilities; but, this is far from an ideal choice. The Medicaid buy-in caps the amount an individual may earn annually at \$65,436. Further, they may have no more than \$20,000 in savings, regardless of their position at work or education, meaning that even though they may earn some money while working, they may not engage in the singular activity that every working age individual is encouraged to do - save for retirement.

Further, the requirement that individuals earn no more than \$65,436 itself places limits on disabled individuals in the workforce. For instance, the minimum threshold for salaried workers in New York City is \$58,500/yr. This means that an individual with disabilities supervising that individual has less than a \$6,000/yr window in which they can make more than the person they supervise.

It should not come as a surprise then that this system in fact results in many with disabilities earning less than those they supervise. These are individuals with student debt. Who have multiple degrees. They have housing needs. Yet, they are individuals who are forced by government to accept less than their worth for employment because they are disabled. In some cases, this is to the tune of hundreds of thousands of dollars per year.

Further, the increase in the earning limit to \$88,140 for married couples creates yet one more marriage penalty for those with disabilities. Two people with disabilities earning up to the individual limit will gain more cumulatively than if they were married. In the event that someone with a disability marries a spouse who is not disabled, that individual will have their income artificially capped.

The only way to solve these problems is to decouple health insurance from employment and create a single, state-funded option for all. The New York Health Act (NYHA) provides a single-payer system with a long-term care option that would be more cost-efficient for almost all workers in New York.⁵ It would eliminate the systemic ableism built into the current system - ableism that forces those with disabilities to live in poverty and go without marriage equality.

Put simply, New York Health would go a long way toward levelling the playing field for those with disabilities seeking to enter the workforce by eliminating multiple obstacles to employment simultaneously.

By pooling all nineteen million New Yorkers into one actuarial pool, the increased costs that private insurance would see as a result of the addition of a long-term care benefit would be minimized in New

⁵ Liu, Jodi L., Chapin White, Sarah A. Nowak, Asa Wilks, Jamie Ryan, and Christine Eibner, An Assessment of the New York Health Act: A Single-Payer Option for New York State. Santa Monica, CA: RAND Corporation, 2018. https://www.rand.org/pubs/research_reports/RR2424.html.

York Health. According to Rand Corporation, any additional costs due to incorporating long-term care are more than offset by the savings realized by eliminating the administrative bloat of the managed care companies.

People with disabilities are employed at far lower rates than people who are not, and when unemployment rises, they are more impacted. Acknowledging this fact and identifying barriers to employment is important, but closing the gap requires acknowledging and addressing the fundamental, systemic issues that underlie them and harm all efforts to address smaller points. The two pieces of legislation I have discussed, Fair Pay for Home Care and the New York Health Act, would increase disability representation in the workforce by ending the home care workforce, ensuring that New Yorkers have comprehensive health coverage no matter their health conditions, and building a stronger economy for all. It is past time we stop penalizing people with disabilities who wish to participate in the labor market and instead embrace reform - doing so will benefit us all.