

Direct Support Professionals need and deserve better pay

Well, here we are again.

Despite Gov. Kathy Hochul touting the Empire State as a leader in the fight for equity, and her vision of the “New York Dream” that promises opportunity and dignity for all citizens, New Yorkers with intellectual and developmental disabilities (IDD) — and those who care for them — remain forgotten.

The system of supports and services New Yorkers with IDD rely on is rapidly eroding. New York’s leaders are accountable for this system. Our elected officials must face the crisis they have allowed to perpetuate, and they must correct it.

For well over a decade, inflation has far outpaced the state’s investment in services for New Yorkers with IDD. The state has made no investment in our system for 10 years. Last year’s increase was announced as a “historic investment” for the field. Realistically, that 4 percent increase did not even cover half the cost of inflation. Year after year, providers have been forced to make do with less than they needed as the state underfunded and disinvested in this system.

Today, providers are doing less than is needed.

Our workforce is faltering. More than 20,000 direct care positions are vacant across the state. Essential shifts go unfilled. We cycle through a revolving door of support staff in a field where continuity of care is critical. Programs are shuttered. Facilities are degrading. People with disabilities are being displaced from their homes, while others are living in isolation with no opportunity for engagement or connection to their community. An already-long wait list for care is growing.

As a parent, I live the reality of a system in crisis every day. My daughter has IDD, and as often is the case with such individuals,

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other disabilities including autism and cerebral palsy. She receives residential, clinical, therapeutic and habilitative services from The Arc of Monroe. She is completely dependent, 24 hours a day, seven days a week, on support for all her activities of daily living, her continued safety, health, and quality of life. This level of support for her, and to a greater or lesser



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the average DSP starting wage is just over \$16 an hour. These complex and critical roles have become minimum wage jobs.

Imagine you have a child who needs support with the most basic tasks of daily living. Imagine that, over time, your child came to trust their support staff with intimate care. Imagine that staff have come to understand the nuances of your child’s nonverbal communication, their medical needs, their food preferences, their emotional triggers, how to soothe them in stress, how to make them smile.

Now imagine that staff leaves. Imagine they leave because they are not earning enough to put food on their table.

The skill, complexity and responsibility of direct care work is deeply devalued.

In turn, the people they support are devalued.

That is not equity.

That needs to change. This underfunded system is unsustainable. Why do providers have to plead with Albany every year for funding and investment to enable the system to be sustainable?

The NYS budget deals with numbers and statistics, as it must. It also reflects priorities. What is the priority of this most vulnerable population of New Yorkers, like my daughter?

Advocates for New Yorkers with disabilities are calling for a 3.2% Cost of Living Adjustment (COLA) and a Direct Support Wage Enhancement in the 2024-25 budget.

This COLA would compensate for one year’s inflation. It would merely meet current rising costs and keep our system from slipping further. The Direct Support Wage Enhancement would invest an

degree for all the 130,000 New Yorkers with IDD, requires trained and dedicated staff. It goes beyond just meeting the requirements in an individual's documentation. To know and understand a person — their likes and dislikes, what works and what does not work — requires familiarity with them and their trust in the staff person. That requires continuity of caregivers. It requires staff that are competent and attentive when on duty and who genuinely are interested in and invested in this type of challenging work.

Across New York, 100,000 dedicated Direct Support Professionals (DSPs) deliver essential supports and services to people with IDD around the clock, every day. While the cost of living skyrocketed, DSP pay stagnated. Today,

additional \$4,000 in each of our dedicated DSPs — raising their pay about \$2 an hour.

It is a minimal investment, but it is a needed investment.

If New York is truly committed to equity and dignity for all her citizens, it is an investment that must be made.

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