

## **At a Crossroads: Unlocking Potential or Losing Hope? The Urgent Need for Equity and Sustainability in Self-Direction**

**Written Testimony Submitted to the Joint Legislative Budget Hearing on Mental Hygiene  
February 5, 2025, Presented by Heather M. Burroughs**

### **Introduction**

My name is **Heather M. Burroughs**, and I am the mother of four children with varying levels of disability, including my daughter Devyn, who has a rare genetic condition requiring 24/7 care. I am also the sister of an adult with intellectual and developmental disabilities (IDD). My life has been defined by advocacy—not just for my own family, but for countless others navigating a system that too often fails the very people it was designed to support.

Nearly 50 years ago, when my sister was growing up, autism was barely understood. She struggled in school, placed in classrooms for children with behavioral issues—not because she belonged there, but because **there were no better options**. Watching her struggle, I followed in my father's footsteps and became a psychologist, determined to make a difference.

I began my career in schools, then transitioned to healthcare, working in a 500-bed long-term care facility. There, I had my first real wake-up call. Some of the very individuals I had supported in the community had ended up **stuck** in this nursing home—not because they needed to be there, but because **there were no other options**. At first, I was able to help many of them return to their communities by weaving together **self-direction and consumer-directed home care (CDPAP)**. It wasn't easy, but it was possible.

Then the pandemic happened. The cracks in the system split wide open. Traditional home care collapsed. Certified settings began closing faster than they opened. Suddenly, the pathways out of institutions were **fewer and far between**.

**Today, families like mine—those supporting loved ones with complex needs—remain in crisis.** We have money in our self-direction budgets that we **cannot spend**, staff we **cannot retain**, and programs that **cannot accommodate** the growing need.

**Self-direction has incredible potential, but it cannot remain a solution only for those with the time, knowledge, and bandwidth to sustain it. It must be a viable option for all.**

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### **Devyn's Story: Potential Trapped in a Broken System**

Devyn is my soon-to-be 18-year-old daughter. She has a rare genetic disorder that requires round-the-clock care, making her one of many individuals classified as "hard to place." But **she is so much more than that**.

Devyn is an **intelligent, determined young woman** with a mind that outpaces her "uncooperative" body. Like any teenager, she longs for independence, new experiences, and a future beyond our four walls. With the right supports, she **is not just capable of growth—she is thriving**.

Yet, instead of **helping us build a pathway toward that future, the system keeps families like mine in survival mode**, forcing us to tread water indefinitely.

Devyn's care is complex but **not impossible**. She has life-threatening seizures that **can often be avoided** with the right supports. Through self-direction, we have been able to carefully structure her care team, resulting in **fewer medical emergencies, better health outcomes, and lower costs to the system**.

And yet, **the very framework that allows this progress is under constant threat**.

- The looming **overhaul of CDPAP** will drive even more workers out of an already depleted workforce.
- Self-direction is **treated as an "alternative program" rather than an essential path forward**.
- Group homes and institutional settings are **unable or unwilling** to accept individuals with complex needs.

If a multi-billion-dollar system **cannot** accommodate someone like Devyn, why are **families expected to do it alone?**

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### **The Impossible Roles Families Must Take On**

Families in this system are not just caregivers. **We are case managers, HR representatives, crisis responders, and full-time problem solvers**.

The stress is more than emotional—it is **physical**. Research confirms what we already know: **the chronic strain of caregiving shortens lifespans**. We are expected to endure this for decades, without relief, without retirement, and without the ability to punch out at the end of a shift.

And yet, we are being **forced to do more with less**.

**If any other group were treated this way, it would be considered targeted discrimination.**

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### **A Future That is Possible—If We Choose It**

Devyn **wants** to move out of our family home someday. Right now, that dream is out of reach—**not because she isn't capable, but because New York has not built a system that makes it possible**.

I refuse to accept that as her fate. If I have to **move mountains** to create a better system, I will. **Not just for Devyn, but for every person who deserves the right to direct their own life.**

### **Key Recommendations**

**Equitable Funding** – Self-direction budgets must be **aligned with the costs of certified settings**. If self-direction saves the state money while improving outcomes, why is it underfunded?

- ✓ **Professional Support Options** – A **separate budget line for house managers** should be established to ensure the long-term sustainability of self-directed homes.
  - ✓ **Funding Parity** – Property tax exemptions and increased SSI rates must be **extended to self-direction participants**, just as they are for certified settings.
  - ✓ **Clear Appeal Process** – Families **must** have a transparent and accessible way to **appeal self-direction budgets**. The current system is arbitrary and fails to recognize individual needs.
  - ✓ **Oversight** – The newly established **IDD Ombuds Program must be independent of OPWDD** and empowered to expose systemic failures **without interference**.
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### The Cost of Inaction

Families like mine do not have the luxury of waiting. **We are losing staff, losing options, and losing hope.** If we fail to act:

- More individuals will be **forced into institutions**, stripping them of dignity and independence.
- The cost of institutional care—**significantly higher** than self-directed homes—will **burden taxpayers even further**.
- The workforce crisis will **worsen**, driving more caregivers out of the field.

New York has the opportunity to lead the way in disability services. But that requires **bold action**, not just incremental change. **We must stop treating self-direction as a privilege and recognize it as a fundamental right.**

My family—and thousands of others—**cannot wait another year**. We must build a system that:

- ✓ **Prioritizes choice**
- ✓ **Values sustainability**
- ✓ **Respects the dignity of every person with a disability**

**Let's get to work.**

**Respectfully submitted,**  
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