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United for Quality Care

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Testimony in Support of H-5228 – Supporting Self-Directed Care and Direct Support Professionals

Chair Corvese and Honorable Members of the House Labor Committee,

My name is Julia Cusack, and I fulfill many roles: daughter, sister, student, artist, friend, and partner. But today I am here to speak on behalf of one of my titles: caregiver. I care for my mother, who fell ill in 2017 and has been diagnosed with metastatic breast cancer.

I am here today to voice my support for bill H-5228.

Today, we stand in solidarity with family members who are dedicated full-time caregivers to their loved ones. Just as some of us—family caregivers who provide homecare through the Personal Choice Program—have recently won the right to organize and advocate for fair wages and working conditions, it's time to extend that same right to others doing the same essential work in the developmental disabilities system.

As family caregivers, we often work tirelessly, day in and day out, without the support or recognition we deserve. We give up careers, education, and opportunities to care for those we love—sacrifices we willingly make out of compassion, loyalty, and love. But those sacrifices aren't enough to sustain us. We are still human. We need compassion and support too. The weight of our responsibility often goes unspoken, the grief unaddressed, and the difficulty unseen.

We provide vital care and support, often without training, time off, or resources. We are the backbone of our families, and yet we are left to navigate these challenges alone. Being a caregiver for a loved one is a full-time job. Some of our loved ones need round-the-clock care—and doing that without a strong support system in place is exhausting and unsustainable.

It's easy to talk about our work in terms of tasks—feeding, bathing, managing medications—but harder to talk about the emotional reality. The intimacy. The grief. Caring for a dying loved one breaks your heart over and over. And sometimes, asking for help feels like failure. But it isn't. Acknowledging your own needs isn't weakness—it's human.

By giving more family caregivers the ability to organize, H-5228 helps ensure that we can advocate for the support we need—and that our loved ones receive the high-quality care they deserve. When caregivers are empowered, families are stronger, care is more stable, and everyone benefits.

That's why I urge you to pass H-5228—Supporting Self-Directed Care and Direct Support Professionals.

Thank you.
Sincerely,
Julia Cusack