

Testimony in support of LD 1883: An Act to Enact the All Maine Health Plan

Senator Bailey, Representative Mathieson and members of the Health Coverage, Insurance and Financial Services Committee,

My name is Marie Follayttar, and I live in South Portland.

I've experienced nearly every kind of health coverage available in this country: private insurance, Medicare, Medigap, Medicaid, concierge care, ACA marketplace plans, and even medical crowdfunding through GoFundMe. I'm grateful for illness-specific grants and nonprofit foundations with donations from Big Pharma that help with co-pays and deductibles.

I use nine different patient portals to manage my care across providers. I have an energy deficiency disorder, and at times, the only energy I've had has gone toward coordinating my medical care. Managing multi-system disorders is incredibly complex. While care coordinators exist, I have yet to find one with the skills, medical knowledge, and independence from the system(insurance, medical umbrella & providers) to coordinate patient care effectively with no new medical errors.

I've spent countless hours handling prior authorizations—because one denial from an insurer was enough for my doctor to give up and put me without treatment. I call the insurance company, the doctor's office, the vendor. I find out what's missing and fix it. I'm on over a dozen medications and have five active prior authorizations. My doctor isn't compensated for the time this takes—and 47.7%<sup>1</sup> of providers report that lack of time is a moderate or large barrier to caring for patients with disabilities.

Disability is the fastest-growing demographic group, comprising 27%<sup>2</sup> of the U.S. population in 2019, with exponential growth expected in the coming decade. To be clear: we are not just in a healthcare emergency—we are bracing for a wave of complex, chronic illness, intensified by COVID-19 and aging."The existing treatment and coverage options for people with Long COVID are insufficient to address the immense and growing needs. ..nearly half rely on high-deductible health plans and may still delay or forgo necessary medical care, therapy, and prescriptions due to cost. With management of Long COVID left to the private sector, individuals from low-income communities, those with high out-of-pocket costs, and marginalized populations are often excluded from access to proper care.<sup>3</sup>"

In our current system, my doctor simply doesn't have enough time to manage my care. I've had to take on the administrative burden just to survive. I chose a primary care provider who is kind and compassionate—and I do everything I can to shield them from burnout, because I know what moral injury<sup>4</sup> can do to a provider. It can cause harm to patients like me. I spoke at the 9th

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<sup>1</sup> [US Physicians' Knowledge About The Americans With Disabilities Act And Accommodation Of Patients With Disability | Health Affairs](#)

<sup>2</sup> [Disability Impacts All of Us Infographic | Disability and Health | CDC](#)

<sup>3</sup> [Addressing The Long COVID Quandary | Health Affairs](#)

<sup>4</sup> [Moral injury in healthcare professionals: A scoping review and discussion - PMC](#)

Annual Interprofessional Preventive Health Medicine Conference at MaineHealth and I asked a medical ethicist whether a burnt-out provider should continue treating the patient they feel overwhelmed by. The answer was no. And yet, the system forces both patients and providers into these unsustainable and harmful dynamics every day.

I live with the constant awareness that I take up "too much time." That my doctors don't understand many of my conditions. And that the system doesn't allow them the time or resources to try.

It's isolating. When a spinal tap or IV is a normal part of your week, it can be frightening to your community. Going to the ER is a calculated risk—will the emergency be taken seriously, or will the harm of medical errors outweigh the benefit? Will they follow my illness-specific treatment manual <sup>5</sup> accommodations that are in my chart, or will I have to fight for them to listen to me—again? Will I be believed when I bring up my ammonia levels? Will I be treated with dignity, or dismissed because I am complex, chronically ill, and therefore assumed to be "psychological"? Will my friends and family be able to handle it when a doctor or provider is cruel to me or says they are torturing me?

As long as healthcare remains a privilege, people with disabilities—who depend on care to stay alive—will remain on the margins of society. We do not have a right to life, liberty and pursuit of happiness.

Universal healthcare treats health as a **human right**, not a commodity. That's not just a slogan—it's something patients experience. It separates healthcare from being something you seek only when you're sick, and reframes it as something essential to maintaining your body and quality of life.

Barriers to care, mistrust in the system, and the constant need to prove one's worthiness for treatment allow bias to flourish. They prevent accountability, continuity, and healing. Only by shifting to a universal model can we begin to repair the deep harm caused by othering people who rely on medical care to survive.

No one chooses to juggle dozens of doctors, conditions, medications, IV fluids, and a growing list of diagnostic tests. It's messy, scary, and exhausting. When I post a photo of myself receiving an IV, someone inevitably worries or dismisses it as 'attention seeking.' For me, that's just a normal week, and I'm trying to be authentic about my reality rather than continue to hide the mess people judge because of my disability. Special can be a slur.

There is a pathology in our culture that judges and distances itself from illness. I started to understand the stigma of mental health at age 13, when my father struggled to access care in a system without mental health parity.

We are not just facing a healthcare crisis today—we are hurtling toward a cataclysm, as post-COVID conditions and an aging population strain an already broken system in our state.

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<sup>5</sup> [Medical-Care-Considerations-Letter-V5.pdf](#)

We cannot continue to disable our people and leave them with no healthcare. The emergency may have stopped for the state but it's only begun for the individual and their family left behind.

We live in a world where we poison the air, the water, and the soil we grow our food in. Our food and products are recalled for long-term health risks. Our indoor air quality harms us. We are poisoning people—and then refusing to care for them.

Today, we have a chance to build a system of care. A system where no one has to fight like hell just to stay alive.

I urge you to vote "ought to pass on LD 1883."