Dear Vermont Legislators,

Last year I served as an Honorary Witness for the Vermont Truth and Reconciliation Commission (VTRC), hearing persons of minority status and with disabilities speak on their experiences in the Vermont Health System. To be clear, I do not represent the voice of the VTRC Commission, I am only expressing the views and lived experiences of one person, myself. But I would like to share resources from my experience serving the VTRC with the legislative Committee.
Please share with the Committee members and listen to the experiences discussed by panels of patient populations who routinely experience injustice by the Health System in Vermont:
https://vtrc.vermont.gov/educational-series-vtrc-narratives-history-present-day-extending-olive-branch-through-education
More Truth Telling of patient experiences can be heard here:
https://vtrc.vermont.gov/publictruth#HealthWellbeing

I volunteered as Honorary Witness, and prior to that as Patient Advisor at UVMMC for nine years, because I, myself, as someone who had numerous privileges and advantages as a new patient entering the system (am someone with a graduate level biomedical education, had a physician spouse, was under the care of the state's best primary care physician, was covered by the best BCBS policy) was still harmed multiple times at different system levels while struggling to receive care at Vermont's UVMMC and Fanny Allen. I realize now the prevalence of the trauma our health system is causing Vermont patients.

When I was in my most vulnerable moments, I placed my trust completely in the system to provide me the care that I needed after a complex head injury- care that included three skull fracture repair surgeries and therapy for a moderate Traumatic Brain Injury, and psychological and neurological sequelae. My trust was betrayed when they: released immediately post-op after skull fracture surgery: cleared the bone fragments, drilled screws into my skull to anchor a metal plate implant under my eye, damaged cranial nerve (trigeminal neuralgia) -causing me to vomit uncontrollably the next 48 hrs from the inhumane level of pain I felt-combined with hyper-sensory stimulation from the BI. As a result had to undergo a second surgery to reposition the implant displaced by the physical force of my dry heaves. Failed to schedule my eye exam in a timely so I received a horrific, torturous exam AFTER the two surgeries were performed on my eye socket as the site of incision was being torn apart for a better look at the complete globe, broken bones were leaned on causing my damaged cranial nerve pain to flare. My body still reacts just thinking about this experience today, 14 years later. The lack of neuropsychological evaluation until AFTER I failed (mental breakdown) after returning to work and school without any information on my neurological impairments nor any accommodations for them. No Speech Language therapy until AFTER I needed it- after I completed my college classes. Pain management therapy was never mentioned... to say I was provided a poor quality of care is an understatement; I now suffer chronic nerve pain all over my body and PTSD from their medical care, and I refuse to permit any other health professional other than my dentist and optometrist to lay hands on my body while I

live. I've been going without medical care since 2019 and am no longer interested in seeking care as I watch the state of our system has worsened.

By comparing the care I received decades ago for surgical repair of a shattered fibula, from reading the medical literature, reports from organizations such as the IHI and IOM, practice guidelines, continuing medical education materials and research articles, I can say with certainty that we Vermonters are receiving substandard patient care. From my own story and those of my Brain Injury Survivor peers, VTRC's participant Truth Tellers (whose stories I heard) and folks who I have spoken to from off the street who are medically struggling and/or have been medically harmed, I know we are not receiving Quality Patient Care that we need and deserve- care that is, as the IOM suggests in the 2001 Crossing the Quality Chasm: timely, effective, adequate, individualized, coordinated, comprehensive, and meets our whole person needs. Alfter asking nurse supervisors on the Quality Committees I served alongside, I found out we are not collecting and making public the patient safety data new patients should know when choosing which institution to seek care from. We keep patients in the dark about how frequently patients are harmed, mamed or even killed by our own health institutions. This may shock you, but I'll say with certainty this was not just a one event occurrence that these "medical errors" are prevalent and frequent; our state "health" system is killing us, just as what we observe is happening nation-wide.(1,2) From the top (CMS) to our local medical and political leaders have deviated from their original mission to provide the public safe and quality care to satiating profit-seeking entities in the health industry sector. We ration out care to some and deny care to others- especially harmful to those who are most vulnerable, who lack the financial means to fight the system, who most desperately, urgently need care and those who require long term supports and services. The system actively silences the voices of our vulnerable patients while putting lipstick on the pig- or why else would they need budgets for marketing, PR and branding? Why do we build a wing of single-occupancy rooms while our acute psych patients wait for theirs for weeks? Why don't our institutions dedicate enough of their budget to hire enough staff, health professionals, case managers, data analysts and staff enough patient advocates to meet current patient demands so their patients are not forced to wait for months?

The fact that we aren't hearing about these shortages coming from their own lips says to us: our political and medical leaders are satisfied with the poor quality care they deliver with the limited budget they receive. They control this narrative which is part of the problem: we have leaders who think they are doing good when in fact they are doing us all harm by settling for less than. They're a fiscally conservative (bootstrap) crowd who have never themselves experienced an urgent health event without a support network to assist them through. We have medical leaders who subscribe to or choose to follow policy and practices that uphold racist, paternalist, ableist, ageist, sexist, have body shape and size bias, etc. Yet they tell us we can "improve" our health care leaving this corruption untouched; until we get rid of this lack of empathy and love of profit, obsession of the ledger line, a loss of moral ethics, a devaluation of human life over patient's health and safety: we cannot fix what is rotten to its core.

Our politicians know that states, just as our own personal households, are currency users and will never generate the amount of funding through revenue required to sustainably support a health system. Our medical leaders subscribe to a fiscally-conservative, trickle-down form of economics deeply embedded in the medical field's Culture- they approve this austerity as good for serving the masses by sacrificing the few. As someone raised in a family of 3 generations of physicians: I've a lifetime of experience growing up in this culture, with folks who embrace this world view. But what none of our leaders understand and they DON'T want us to know is that the federal government that CREATES our currency is our only funding source that can sustain a health program that is universal, free and fair and just for all. There is no "limited resources" when it comes to the amount of federal funding- the only thing we lack is the **legislative will** to obtain it.

Patients with insights like mine are wary of those who work in the system and who lobby to maintain its status quo - they are fighting against the interests of Vermont's patients. My message essentially is that we, those of us with lived experience, have lost our trust in our medical institutions, the policies that harm, the health professionals, their training and their practices. We reject your version of "universal" or "improved" state health system. We demand an overhaul of the entire corrupt, unsafe patient-harming, profit-driven industry and demand inclusion of the public in the reconstruction: to get there we must to give our patients more voice, rights, power and transparency over their own care plans.

References:
1. https://www.cnbc.com/2018/02/22/medical-errors-third-leading-cause-of-death-in-america.html
2. https://www.cnn.com/2023/07/19/health/diagnosis-error-study

Sincerely,
Cheryl Van Epps
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