

Hello, my name is Meghan Schrader, and I am writing to express my strong opposition to Act 39, which I feel should be repealed. I am in the Women's Studies department at the University of New Hampshire, have presented several papers at the Society of Disability Studies, and I am a contributor to Oxford University Press's recently released book, *Anxiety Muted*, in which I discuss the representation of disability and assisted suicide in film music. I represent the Massachusetts chapter of the disability rights group ADAPT, and I am here to express our group's solidarity with our disabled colleagues in Vermont. In addition to my Massachusetts citizenship, I am also a part-time resident of Vermont whose family has owned a house here since the early 1980s. Hence, one might say that I've adopted it as my "second home state." My brother and his family live in Vermont, and I care deeply for the welfare of its citizens.

First I would like to note that like Brittany Maynard, I am a member of the "millennial generation." Since her story became public, bioethicist Arthur Caplan and Star-Ledger editor Tom Moran predicted that young adults would follow her in promoting legalization. But Caplan and Moran's speculation about millennials is undercut by the report of the prominent Pew Research Center, which found 54% of young adults oppose assisted suicide.

Before I continue, I feel moved to share a personal experience in regard to the conceptual intersections between the experience of living as a disabled person and right-to-die arguments concerning familial burden and suffering.

In the course of doing research for my aforementioned book chapter, I had occasion to review the writings of many utilitarian bioethicists whose arguments concerning death, disability and death with dignity are framed in regard to familial burden, which tends to be situated as a legitimate reason for choosing or being obliged to die. Such statements are similar to hate speech I experienced growing up, and I was shocked when I first saw it in bioethics literature. As a person with autism who struggles with executive functioning, I still live with my parents, who serve me in completing many daily tasks. This often makes me feel guilty. In any case, the philosophical reflection that my studies engendered means that such ideas are in my mind. During a particularly horrible bout of depression (I was on a new medication that messed with my hormones); I thought "Maybe the assisted suicide advocates are right; Maybe God is allowing this to happen because it is ok, I am a burden to my family, and so maybe it would be ok if I killed myself." I wound up hurting myself impulsively and going to the emergency room. That episode was the result of mental illness, but such research did not help. **That the State of Vermont now sanctions a method for ending one's life also does not help. It hurts. It makes me feel vulnerable and even helpless.**

I would like to return to the portion of my testimony that apply to my representation of ADAPT, Massachusetts and cite one of three instances of problematic language in this law.

As a person who has lived with major depression for seventeen years, I am very concerned that patient referral for psychiatric evaluation is not automatic, but is contingent upon whether the potential prescriber suspects clinical depression. Because major depression involves a tendency toward suicidality, patients experiencing depressive symptoms are disproportionately more likely to view death from cancer as a release from our suffering, particularly because such a death is framed as negating the intrapersonal conflict that typically precedes the decision to commit suicide. It is unjust to put such patient's lives in the hands of general practitioners who are not licensed to diagnoses clinical depression. Management of this disorder tends to require regular competent psychiatric care, and may involve several different pharmaceutical attempts to manage it, which must often be combined with

changes to nutrition and exercise. Moreover, because of the stigma surrounding this disorder, many people experiencing symptoms do not seek help. Oncologists and general practitioners are not trained to provide this standard of care. Hence, this provision leaves the door wide open for this condition to go undetected in an oncological or general medical setting. Even if such individuals did refer individuals for a psychiatric evaluation, diagnosis on the basis of a single basis sets and extremely low standard of care for those who may be experienced undiagnosed depression. Lastly, due to the likely assumption that the person's depression is due to having been diagnosed with cancer, the current provisions place people with such conditions in the position of being systemically disadvantaged by the mechanisms of this law.

A second concern involves the provision that allows a person's wishes to be communicated through a person who is, quote, "familiar with the person's manner of communicating." This provision strikes at the very heart of the disability community's objections to this law. Assisted communication involves the invariably involves a microcosm of privilege and oppression, in which the disabled person's voice is subject to more empowered, able-bodied individuals. Indeed, I witnessed this power dynamic when I testified in New Jersey. Because there were no accommodations made concerning the intersection of disabled people's medical needs and the amount of time that such individuals waited before testifying, one woman's assisted communication device ran out of power before she was called to speak. Hence, she had to have her testimony read by her father. I am not suggesting that legislators intended for this to occur, but such is the nature of systemic oppression: it results from identity-specific conditions that people from dominant people groups are not conditioned to recognize or anticipate. Such a situation could easily present itself in a medical setting, wherein accommodations to facilitate such communication were not provided and the disabled person was placed in the position of someone who may disagree, and thus miscommunicate, their actual choices. Moreover, the provision of the law that requires the mere execution of "good faith" on the part of doctors implementing the law provides little legal incentive to anticipate such situations.

In addition to the specific objections that I have cited, such laws have much broader implications. As someone who has both experienced and studied discrimination against disabled people, I view assisted suicide in light of the disabled community's cultural invisibility, which compounds social and political ignorance. To return to the example of Brittany Maynard, I am disturbed by how Brittany Maynard's image has covered over the vast social inequalities in our society. In designing the law, legislators must consider everyone, especially those people whose choices are already constrained by circumstance. The experience of autonomy that Maynard represented is simply not available to less privileged individuals.

For example, since 2008 I have served as a Special Education Surrogate Parent in the Massachusetts school system, in which volunteers make educational decisions on behalf of disabled students in foster care. All of the students I've worked with were younger members of the millennial generation; people of color who had been abused both by their families and social services. If assisted suicide were to be legalized, many However, If one of them became seriously ill, their experience of autonomy would be much different than Maynard's. Unlike the support system she had, they would navigate their choices through the auspices of over-extended social workers. They would not have loving families to stand by them during their illness; instead, they would be subject to the ministrations of volunteers like me. Because such students are not trained to expect or demand equality, they would be less likely to know about all of the treatment options available to them. This compounds the universal problem of inaccurate diagnoses that have that potential to cut patient lives' short by months, years, or even decades.

Even if these students did have this information, their choices would be constrained by whatever resources that the state is willing to put into their care. Their situations would be parallel to that of Oregon woman Barbara Wagner. They would be offered limited choices for treatment, one of which would be assisted suicide. Unlike people with a more stable background, they would not have the financial, familial or personal resources to “own,” their bodies completely. Unlike the people whose stories are being used to affirm the law, their bodies would always be partially owned by the state. Hence, any ostensive "choice" for assisted suicide on their part would be made in the context of their social subjugation.

In considering the real-world implications of this law, I urge legislators to remember the thousands of people who lack practical autonomy, and will never appear on the cover of People Magazine. In recognition of that largely invisible population, I urge you to repeal Act 39. Thank you.