

Good afternoon, my name is Sarah Launderville and I'm the Executive Director of the VT Center for Independent Living. I'm writing regarding S.74 which we understand you are discussing in committee today.

VCIL is a statewide nonprofit organization of people with disabilities working together for dignity and independence.

Over the years VCIL has testified on bills related to "patient choice at the end of life laws" and we've expressed concerns that have not been addressed in the laws that have passed. We are hoping that as we raise these concerns S.74 might help remedy them and create a law that adds additional protections to individuals seeking end of life supports. All people eligible for accessing the prescription are people with disabilities as defined in federal law.

The healthcare system is not equitable. This is especially true regarding people who have disabilities, and have chronic conditions including the conditions that may lead to seeking medical support at the end of life.

We know that there is bias in the medical profession and society as it relates to disability. This begins at the beginning of life when medical professionals offer amniocentesis as a normal procedure during pregnancy. The process of amniocentesis is to screen for developmental abnormalities in the fetus. And studies have shown that this common practice has led to a demonstrable decrease in births of people with Down Syndrome. While this bill is not about the decisions that people make around birth, it's important to highlight that our society places less value, consciously or not, on a life lived with disability.

This continues when a child is born. In the state of Vermont if a child is born Deaf, the state sends a packet to parents informing them of every medical intervention possible to help the child hear but that packet doesn't include details on the Deaf community

and the broad range of supports and culture that the family could access.

Biases come across in every day life as people wish for “healthy babies”. The biases turn into discrimination within our systems when doctors’ offices purchase scales that are not wheelchair accessible, when a person with a disability can’t get a mammogram, or when information about vaccines are not in plain language for everyone to understand. Biases are evident when providers advise against life-sustaining treatment for people with disabilities whose conditions would be treated were they not living with a disability.

While systems are changing, they are not where they should be. The disability community asked for more robust data to be collected and reported on regarding those requesting end of life prescriptions, but only some of that data made it into the law. Data is important as it relates to determining if something is working, where money and attention should be allocated and helps us make sound decisions regarding policy.

Considering the bias and equity issues surrounding health care, we believe that additional demographic data at the very least should be collected and reported in the biannual report. Our suggestions include

- More robust demographic data: race, gender identity, county, type of health insurance
- The reason for the request is important to be noted and the cause of deaths should be accurately reported
- Duration of the prescribing doctor and patient relationship
- Whether the prescribing doctor conducted an in-person examination
- Type of setting where the patient lived at the time of the prescription
- Reasons for requesting the lethal prescription
- Time between writing of prescription and death
- Whether the patient took the prescription

In terms of the bill itself, we know that telemedicine is a positive accommodation for many, but it is gravely concerning to us that a doctor prescribing medication that will kill a person would potentially not have direct contact with that individual. It could be much more difficult to really judge a person's condition and the forces at play in them making their life and death decisions in a remote setting.

S.74 implies that there is an implicit trust of doctors. This is extremely concerning. S.74 creates a mechanism geared towards protecting providers with immunity and it assumes that providers will protect individuals. Experience has shown us that there is some prejudice in the health care profession that affects individuals with disabilities and it comes across in ways from implicit bias all the way to outright discrimination.

In addition to inequity in services to individuals with disabilities, we are concerned that not having in-person meetings with a doctor can increase the possibility of not knowing of actual abuse or coercion.

We are concerned about the definition in the bill of health care services. "Health care services" means services for the diagnosis, prevention, treatment, cure, or relief of a health condition, illness, injury, or disease."

We would prefer this language call out exactly what is hoped for which is the assistance of ending life. That should include all the specifics to end of life care instead of creating a brand-new definition of health care services which demands a much broader discussion if it is to include the ending of life.

VCIL is also opposed to the language "No physician, nurse, pharmacist, or other person licensed, certified, or otherwise authorized by law to deliver health care services in this State shall be subject to civil or criminal liability or professional disciplinary action for acting in good faith compliance with the provisions of this chapter."

We are concerned this law gives implicit trust to doctors, then allows for anyone connected to that end of life care to be relieved from liability if they are acting in good faith. There is not a specific, strong mechanism for individuals and families to make complaints, thus setting up a system that can fail individuals and offers no consequences.

We owe it to people at the end of their lives to have significant access to true choice. To true connection to supports, services, palliative care and a process in which a person chooses to talk about a prescription to end their life. A process that we can feel comfortable knowing that they've been treated equitably and fair. This bill does not create that equitable system. While on the appearance the bill seeks to offer support and choice, it's stripped away of protections that can support the people who may seek to utilize it.

VCIL has been participating on the newly formed Health Equity Advisory Commission. This commission was set up by the legislature because it has been shown that there are inequities in the healthcare system. On the Vermont Department of Health's website you can find what Health Equity is:

*Health equity exists when all people have a fair and just opportunity to be healthy, especially those who have experienced socioeconomic disadvantage, historical injustice, and other avoidable systemic inequalities that are often associated with social categories of race, gender, ethnicity, social position, sexual orientation and disability.*

*Health is shaped by where we live, learn, work and play. Some people in Vermont have more opportunities than others to enjoy good health and a high quality of life. Vermonters who identify as white and heterosexual, who are able-bodied, live in urban or suburban areas, or are middle or upper class generally have better health compared to*

*other Vermonters. These are health inequities and together with our partners we are committed to addressing them.*

We are asking that the VT Legislature take a hard look at the underlying issues that continue to be concerning to the disability community regarding end of life laws and hold this law to the same standards in equity as other laws.