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Testimony on S.108 4/15/15, speaking on behalf of the Vermont Center for Independent Living

Thank you for the opportunity to share my perspective on whether Act 39 is “working” and the sunset in the law.

I’ve had to extrapolate what this committee might mean by the term “working”. Typically when a law is passed, legislators want to know: is the law, as currently enacted, doing exactly what it was intended to do, no more and no less? With that assumption in mind, I’m surmising that this committee is interested in hearing whether people who are using the law are:

1. “qualified” under the law to make the request ie have a diagnosis of 6 months or less to live, and do not have impaired judgment
2. requesting a prescription to end their life freely and of their own will, without being coerced, cajoled, or forced in any way to make the request
3. truly making the request as a choice and not because they have been denied access to other treatments and options
4. able to obtain those prescriptions
5. capable of self-administering the dose at the time of death, as assumed but not actually required by the law
6. successful in their use of the medication to achieve their death or if the prescription was not used to hasten death, the medication been disposed of safely as required by Department of Health Rules, Chapter 2, Subchapter 6

These are all reasonable and responsible questions to be asking to determine whether or not the law is working as intended. The problem is that under the current law we just don’t know and cannot ascertain the answers to these questions. The only thing we know for sure is how many prescriptions have been written. That is the only data point collected (of the few that are collected) that is shared with legislators and the public.

It would also make sense to be able to evaluate how the law is being used over time, with some sort of annual report given to the legislature that answers some of the questions I just posed but there is no requirement for that in the law as currently written. There is also a need to ascertain whether the law has unintended consequences, such as being a catalyst for rising suicide rates, as has happened in Oregon and Washington or if inequality of access to healthcare forces Vermonters to the point of choosing PAS because they didn’t get quality care soon enough. These are also important measures in determining if the law is “working” as intended.

So when asking if the law is working, other than knowing how many prescriptions have been written, there's a lot we just don't know.

But here is what we do know and have known for a very long time: national statistics tell us that one out of every ten elders will be physically or emotionally abused¹. 4 out of every 100 elders will be financially exploited. These figures come from the National Center on Elder Abuse which is part of the federal Administration on Aging. U.S. Assistant Secretary for Aging Kathy Greenlee was quoted in January 2014 as saying "People think abuse is isolated and only in nursing homes. In fact it is broad and widespread and it is often family members."

We know that the statistics for people with disabilities are even more disturbing. According to the Disability and Abuse Project, a federally funded project of the Spectrum Institute, 7 out of every ten people with disabilities will be physically, emotionally or financially abused in their lifetime². Of that 70% of the total disability population who WILL be abused, 57% of them will be abused more than 20 times over the course of their life. In 2014 Vermont's Adult Protective Services investigated 1,366 allegations of abuse and neglect of elders and people with disabilities. That was how many they investigated. They continually face challenges working through the backlog of allegations and were in fact successfully sued in 2013 (the year Act 39 was passed) by Disability Rights Vermont³ and others for failing to fulfill their obligation to protect Vermont's elders and people with disabilities. If you look at the bills introduced in this session, there are several proposed laws that attempt to address the shortcomings and inability of Adult Protective Services to protect our most vulnerable citizens.

If we haven't been able to protect Vermont's elders and people with disabilities under any other law, how do we believe, with so little accountability, that we are protecting them under Act 39? If our faith is entirely in doctors treating all patients equally in diagnosis, prognosis and treatment, that faith is misplaced.

The minimal protections in Act 39 give doctors legal cover for offering death as a solution to vulnerable adults and we in the disability community know from experience that the word "terminal", for an adult with disabilities, is a term bandied about very carelessly. In fact in an article in the current newsletter of the Vermont Ethics Network, quadriplegia is listed as a "terminal" condition⁴. It is not, people with quadriplegia can live a great many years but are often told they have mere months to live. Many people with disabilities have been pronounced terminal multiple times over the course of their lives, partly because society (which includes doctors) is entirely too willing to perceive their lives as being not viable.

I've heard it argued that Act 39 does not apply to people with disabilities, that the law is about the terminally ill. As I've just stated the term "terminal" is often misapplied to disability. But here's another consideration: by the time an individual reaches the true terminal stage of his or her illness, they are, by definition, likely to be a person living with a disability by virtue of the fact they are probably no longer able to perform the standard activities of daily living (called ADL's) or by virtue of needing assistive devices

such as wheelchairs, walkers or portable oxygen, or by virtue of needing caregiving in order to get through their day. One in five of us will live with disability at some point in our life. This law clearly applies to people with disabilities.

Act 39, with the sunset removed, but without more data collection and without greatly enhanced protections, works under the following circumstances: The law works if every family situation is mentally healthy and functional. The law works if every patient is financially secure and no one around the patient has any hidden agendas. The law works if every person who becomes ill has had unfettered access to high quality health care throughout the entire course of their illness. The law works if every person who is ill has a trusting, functional relationship with their physician and that relationship is built on mutual respect. But we know that these things are not true for every Vermonter. If they were, we wouldn't need this committee, or this legislature or the Agency of Human Services or the court system. We know that there are bad actors out there, we know that there are people who abuse and neglect others, we know that not all doctors come to their patients fully informed about aging, disability or mental health issues. We know that some vulnerable adults put their trust in people unworthy of that trust. This law, written with the few in mind, is a pathway to homicide for the vulnerable among us. Think about the statistics: 1.4 of every ten elders, 7 of every ten adults with disabilities. The abuse, neglect and sheer violation of their civil and human rights just keeps on happening. The question that needs to be asked is: even if there are some who might benefit under this law, does the potential for abuse outweigh the benefits? There is a point of law that is drilled into every law student in this country: a law can't just be for the benefit of a few when it endangers or harms others. We proudly defend freedom of speech but that doesn't mean you can yell "fire" in a crowded theater. We defend individual property rights but a person can't fill his swimming pool if by doing so he drains all his neighbors' wells. This law that allows one person to willfully cause the death of another, if abused creates a tragedy that can never be undone. The most important question is: are we willing to live with that?

Notes:

1. <http://www.healthline.com/health-news/senior-elder-abuse-more-common-than-you-think-012714>
2. <http://www.disabilitycoop.com/2013/09/04/survey-abuse-widespread/18652/>
3. http://www.disabilityrightsvt.org/pdfs/Press_releases/aps%20press%20release%20final.pdf
4. <http://www.vtethicsnetwork.org/newsletters/ven-newsletter-winter-2015.pdf>