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Thank you for the opportunity to share my perspective on the protections in Act 39 and the sunset in the law.

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."

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 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 at least five proposed laws that attempt to address the shortcomings and inability of Adult Protective Services to protect our most vulnerable citizens.

Act 39 as passed possesses a bare minimum of protections for vulnerable elders and people with disabilities. The historical opposition of the disability community to assisted suicide comes from a very real and ongoing history of prejudice and abuse from society at large. We grapple with that prejudice and abuse despite laws that offer supposed protections, despite a system of jurisprudence designed to provide relief. Despite these so called protections, the abuse is real and pervasive. I have experienced the prejudice that leads to abuse many times over the course of my son's life, the most horrific instance being when my son was eight years old and had developed pneumonia. My son's pediatrician took me into the hallway and gave me two treatment options: he could prescribe antibiotics or we could "let nature take its course". When his second option elicited a quizzical look from me, my son's pediatrician went on to explain that perhaps "letting Conor go" was the better choice in order to spare me the "lifetime work" of raising a child with autism and cerebral palsy. Would that second option have been offered to me if my son had been a typical eight year old? I think you and I both know it

wouldn't have been. It was only offered because Conor was a child with disabilities. With antibiotics, Conor recovered quite easily from his pneumonia and is now a hale and hearty 32 year old man. 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 potential "terminal" condition⁴. It is not. Many people with disabilities have been pronounced terminal a laughably large number of times in their lives. In VEN's "Start the Conversation" toolkit there is a worksheet to help people clarify under which situations they would not want medical treatment to keep them alive. The worksheet is titled "Are some conditions worse than death?" and the first item on the list is "no longer can walk but get around in a wheelchair". To have that as the first item under "conditions worse than death" is just plain insulting to the disability community and indicative of the prejudiced culture we face every day. Consider my colleague Diane. Diane Coleman is the president and CEO of Not Dead Yet a national disability rights group which she founded in 1996 to give voice to disability rights opposition to the legalization of assisted suicide and euthanasia. She is a lawyer with an MBA and a long history of civil rights work. She is also a person with a neuromuscular disability and she has used a motorized wheelchair since she was eleven. Almost every time she needs hospitalization for lung issues related to her disabilities, she is questioned or, even more insidiously, her husband is questioned about whether she has or "needs" a DNR order. She is fifty-eight years old. Do you think typical 58 year old women are routinely asked if they have a DNR? Do you know how she gets the doctors to back off? She looks them in the eye and says " I have a full-time job." That seems to do the trick - " look, I actually have worth as measured by our society, I'm not just a tiny frail-looking woman in a power wheelchair." She can't count the number of times she has been told she is "terminal".

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, 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 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, as written, without the sunset, works under the following circumstances: The law works if every family situation is mentally healthy and functional. The law works if every family is financially secure and no one in the family 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. What makes us think they will be safe under this law when to date we have been unable to protect them under any other? The abuse, neglect and sheer violation of their civil and human rights just keeps on happening. 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.

It should be noted that while lacking even the most rudimentary protections, Act 39 goes far beyond Oregon's law in one very dangerous way. In Oregon, the patient must be the one to raise the topic of assisted suicide. In Vermont, once a terminal diagnosis is determined or, in the case of people with disabilities "assumed" - doctors have an affirmative obligation to tell their patient that assisted suicide is an option. The doctor has to tell them even if the doctor does not believe that it is best practice for that particular situation. The doctor has to tell them even if he or she has doubts about the safety of the patient's home situation. The doctor must disclose the availability of assisted suicide no matter what the doctor personally believes in or what the patient may truly need.

The bottom line? After 32 years of personal and professional experience working alongside people with disabilities, as a liberal, pro-choice Democrat, as a former House member I fight assisted suicide laws on behalf of the Vermont Center for Independent Living for one very simple reason. Under this law people will die who did not want to die or who did not truly choose to die. And I can't live with that eventuality. The question is: can you?

Notes:

1. <http://www.healthline.com/health-news/senior-elder-abuse-more-common-than-you-think-012714>
2. <http://www.disabilityscoop.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>