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**Testimony in strong opposition to HB 7015**

**An Act Concerning Aid in Dying for Terminally Ill Patients**

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Senator Coleman, Rep. Tong, and members of the Judiciary Committee:

I am an adult on the autism spectrum and one of the leaders of Second Thoughts Connecticut, a coalition of people with disabilities opposed to the legalization of assisted suicide.

Legislation nearly identical to this bill has been rejected by the Public Health Committee in the last two years, as have over 140 attempts to pass such legislation. So far this year, Colorado, Wyoming, Montana, and Utah have all rejected “aid in dying” or “death with dignity” legislation. When legislators look at the details of these bills, they understand that legalizing doctor-prescribed suicide diminishes rather than enhances choice. It also poses unacceptable risks to people who have no intention of dying, or who could have lived productive lives with treatment. They have second thoughts and oppose such legislation.

The ostensible safeguards in HB 7015 are actually hollow. The witnesses to the requests for the lethal prescription can be close friends of an heir seeking to pressure someone into ending his or her life. There is no requirement that either of the two requests be made in the presence of the physician who will prescribe the lethal dose. The heir could pressure the victim to sign the two requests at home and mail them to the physician, who may have no clue that the requests were coerced. Moreover, the bill does not require any witnesses at the time the lethal prescription is consumed. Did Grandpa take the 100 Seconal pills voluntarily, or did he change his mind only to have his heir compel him to do it? HB 7015 has no investigational authority and gives legal immunity to prescribing doctors who act in “good faith.” Furthermore, in Section 9 (6) (b), doctors are **required** to falsify death certificates, listing the cause of death as the underlying illness and not the lethal prescription, further covering up potential foul play. The possibilities for elder abuse are enormous.

For people with communication disabilities, there an additional concern. HB 7015 defines “competent” in a manner that allows someone else to claim to communicate for the patient, referring to “communicating through a person familiar with a patient's manner of communicating.” This is in direct conflict with Section 2 (b), which would forbid such third-party representation. It is not at all clear which section prevails.

Three months ago, I testified in opposition to an assisted suicide bill in New Jersey. Dawn Parkot, who has multiple disabilities including a severe speech disability, testified that a similar provision in that bill endangered her life and would allow someone else to murder her. Subsequently she wrote a letter to the New Jersey Senate, published on the website of Second Thoughts Massachusetts, detailing this danger: <http://www.second-thoughts.org/main.legislative_efforts.dawn_parkot_letter_to_nj_senate>

At the time the patient makes a second oral request, the attending physician shall offer the patient an opportunity to rescind the request. However, the bill defines "capable" as having the capacity to make health care decisions and to communicate them to a health care professional, including communication through persons familiar with the patient’s manner of communicating if those persons are available.

Simply, legislation makes it possible for someone to speak for the person if they are familiar with the person's manner of communicating. As someone who is disabled and unable to speak without communication aids, this makes this bill extremely frightening to somebody with a significant speech disability. Legalizing this bill raises the potential for a profoundly dangerous situation.

Abuse of the elderly and disabled is a growing problem, making coercion virtually impossible to prove or stop. Who can confirm that the assisted suicide choice was freely made when the only witness is dead? With the lack of witnesses present, someone else can administer the lethal drug without the patient’s consent. Someone could use an alternate method, such as suffocation. Who would know? The mere presence of a lethal drug request would provide an alibi. Without witnesses, the patient’s control over the “time, place and manner” of his or her death, isn’t guaranteed.

Contrary to claims of proponents, there have been a number of documented abuses in Oregon, in addition to all the ones we will never know about because of the lack of investigational authority. The case of Tami Saywer and Thomas Middleton is instructive. Middleton had ALS and moved into Sawyer’s home, where he died a month later under Oregon’s assisted suicide law. Two days after the death, Sawyer sold Middleton's house and deposited the proceeds into her account. Sawyer pleaded guilty to fraud and money laundering in a Ponzi scheme. A second case involving Middleton’s estate was dropped only because she was already serving jail time. We will never know whether this was merely fraud or murder for profit. Indeed, this story came to light only because of suspicious real estate transactions and in spite of the concealment entailed by Oregon’s assisted suicide law.

Oregon also demonstrates the deadly mix between assisted suicide and medical cost-containment. Barbara Wagner and Randy Stroup were denied chemotherapy for their cancers under the Oregon Health Plan (Medicaid) yet offered suicide drugs instead. Chillingly the president of Compassion & Choices, former HMO executive Barbara Coombs Lee, wrote an op-ed in *The Oregonian* defending Oregon’s denial of Tarceva to Barbara Wagner, suggesting that government steer people away from curative care and toward less aggressive treatment or suicide.

Indeed, it is worth noting that no one from Compassion & Choices offered testimony on HB 6709, An Act Concerning the Right to Try Experimental Drugs. I testified in favor of HB 6709 on behalf of Second Thoughts Connecticut. The bill, which has passed the Public Health Committee, would give people diagnosed with terminal illnesses and have run out of other options the right to try drugs that have passed phase 1 clinical trials so they might have hope to live. Why do those who claim to support “end-of-life choice” fail to support the choices of people like Debra Gove, a woman with ALS who is fighting to try an experimental drug so she can live? Are they really for end-of-life choice, or only one choice?

Another problem in Oregon is suicide contagion. According to the Centers for Disease Control, Oregon’s already high suicide rate has increased much more than the national average; from 1999 (shortly after the Oregon Death with Dignity Act took effect) until 2010, the rate of increase for people age 35-64 was 49% in Oregon versus 28% nationally. Given the motto of Compassion & Choices and other “right-to-die” organizations is “My Life. My Death. My Choice.” this should come as no surprise.

Mercilessly bullied autistic and LGBT youth can pick up this message that “my death” is “my choice”—a message which Compassion & Choices has displayed in the Capitol concourse for two weeks—and act on it. Those of us on the autism spectrum can take messages like this quite literally. Nikki Bacharach, the autistic daughter of Burt Bacharach and Angie Dickinson, committed suicide eight years ago. Her parents issued the following statement, according to Lisa Jo Rudy of About.com: "She quietly and peacefully committed suicide to escape the ravages to her brain brought on by Asperger's." This strange and creepy announcement is the logical product of Compassion & Choices’ assisted suicide advocacy, where “peaceful suicide” is glorified and disability is viewed as “ravaging” our minds and bodies. This is disability discrimination and is unacceptable.

Misdiagnosis and incorrect prognosis are also serious concerns. HB 7015 allows for a prognosis of six months to live, but does not take into account the effects of treatment. Many people with severe disabilities who need breathing support, or people with diabetes controlled by insulin, would be eligible for suicide under this bill. Even if the bill were to include the effects of treatment, many people have dramatically outlived doctors’ expectations. Senator Ted Kennedy was diagnosed with brain cancer and given 2-4 months to live, yet lived 15 very productive months. Actress Valerie Harper was diagnosed with a different form of brain cancer and given 3 months to live; she is alive and fighting her disease 27 months later.  Jeanette Hall, diagnosed with cancer and given six months to a year to live, sought to die under Oregon’s assisted suicide law.  Her doctor persuaded her to accept treatment, and she is alive and well nearly 15 years later. John Norton was diagnosed with ALS at age 18 and given 3-5 years to live. Six years later, the progression of his disease suddenly stopped and he is alive at age 77, with a wife, children, and retired from a successful career.  He writes that if assisted suicide had been legal at the time, “I would have taken that opportunity.”

Rahamim Melamed-Cohen, sometimes called “Israel’s most famous terminally ill patient,” was diagnosed with ALS over 20 years ago and was also given 3-5 years to live. In spite of the fact that he can only think and blink his eyes, he has said that “if they [the doctors] had let me die, I would have missed out on the best, most beautiful years of my life.” He has written 12 books and created beautiful artwork using Microsoft’s eye-tracking technology. What makes Dr. Melamed-Cohen a role model for the rest of us is his attitude, which is the complete opposite of the “death with dignity” movement: “Don't despair. Be optimistic and work on joy in your heart. No matter what you're lacking think of what's possible to do in your present situation.”

Dr. Melamed-Cohen’s attitude reminds us of the importance of our social interconnectedness, that “my death” is not a private, individualistic choice, but affects all around us. In the immortal words of Reverend Dr. Martin Luther King, Jr., “We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.” Yet under HB 7015, family notification is merely recommended, not required. What if one of your relatives took the lethal prescription and you had no idea this was coming? Death is too important to be reduced to six word slogans claiming it is merely a matter of “my choice.”

Finally, there is the issue of expansion. Leaders of Compassion & Choices and other “right-to-die” organizations have publicly stated their intent to come back later to expand beyond “six months,” “terminally ill,” and “mentally competent.” When Compassion & Choices president Barbara Coombs Lee came to Hartford last October, she declared her support for assisted suicide for people with dementia and cognitive disabilities unable to consent.  *CT News Junkie* quoted her saying, “It is an issue for another day but is no less compelling.”  Dr. Marcia Angell, leading proponent of the defeated Massachusetts’ assisted suicide ballot question, recently wrote in *The New York Review of Books* that she now favors euthanasia as well as assisted suicide. Oregon is currently debating legislation (HB 3337) that would extend eligibility for assisted suicide from a six month prognosis to one year. And our state’s Attorney General, George Jepsen, testified last year in favor of expanding beyond six months terminal.

If the General Assembly enacts HB 7015, expansion will move into the hands of judges. It would likely be a violation of the Americans with Disabilities Act and Article XII of the Connecticut Constitution not to extend the “benefit” of “aid in dying” to people with other disabilities. What about the person with ALS who has a six month prognosis, but has lost the ability to self-administer—the justification behind Oregon HB 3337? What about the person with Parkinson’s disease, who will have tremors for years before dying? What about people with communication disabilities who may not be able to make the request on their own? What about Grandma with dementia, or the person with a severe psychiatric disability? Once the door to assisted suicide is pried open in enough states, Compassion & Choices will seek to open it further through the courts, going from six months terminal to one year, to perhaps five years; from assisted suicide to euthanasia; and from euthanasia for terminal illness, to chronic illness, to mental suffering. This is how we go down the same road as Belgium and the Netherlands, where we see euthanasia for deaf twins who fear going blind, or for someone unhappy with gender reassignment surgery, and where euthanasia is the cause of 1 out of every 50 deaths. For Compassion & Choices, these are merely issues for another day, and for them, no less compelling.

For those of us in the disability community, opposition to assisted suicide is an issue of justice and civil rights. Reject HB 7015, which enshrines lethal disability discrimination into our law. Instead, let us recall Dr. King’s dream, in which we all—regardless of race, religion, gender, sexual orientation, or disability—have inherent dignity, and we do not have to die to get it.

We Shall Overcome!

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