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Testimony in strong opposition to HB 5417 An Act Concerning End-of-Life Care March 20, 2018

Senators Gerratana and Somers, Representatives Steinberg and Srinivasan, and members of the Public Health Committee:

I am an autistic adult and one of the leaders of Second Thoughts Connecticut, a coalition of disabled people opposed to the legalization of assisted suicide. Our group works together with national disability rights organizations including Not Dead Yet and the Disability Rights Education and Defense Fund to oppose such legislation. Second Thoughts Connecticut is a member of the Connecticut Suicide Advisory Board. Personally, I serve on the board of directors of Euthanasia Prevention Coalition-USA and on the Connecticut MOLST Task Force.

HB 5417 is the **exact same bill** as the 2015 assisted suicide bill (HB 7015) that was resoundingly rejected by the Judiciary Committee. The only difference is the title of the bill and the effective date. Even the reference to the now defunct Office of Protection and Advocacy for Persons with Disabilities is still in Section 18 of the bill, revealing a lack of awareness of disabled people's concerns. The hundreds of opposition testimonies to the 2015 bill apply equally to the bill before us today.

There have been over 200 attempts to pass similar legislation in 36 states. The majority of states had assisted suicide bills in 2017 and not a single one became law. 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 5417 are actually hollow. The witnesses to the requests for the lethal prescription can be close friends of an heir, or representatives of a health insurer, with a fiduciary interest in that individual's earlier death, 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. Other ostensible safeguards are overcome by doctor-shopping.

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 5417 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: "The person signing the qualified patient's death certificate shall list the underlying terminal illness as the cause of death." This serves to further cover up potential foul play. The State of Connecticut Division of Criminal Justice submitted opposition testimony to the 2015 assisted suicide bill, HB 7015, noting that "the actual cause of death would be the medication taken by or given to the patient" and "[t]he practical problem for the criminal justice system and the courts will be confronting a potential Murder prosecution where the cause of death is not accurately reported on the death certificate." The possibilities for elder abuse are enormous.

For people with communication disabilities, there is an additional concern. HB 5417 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.

Dawn Parkot, who has multiple disabilities including a severe speech disability, testified last week that a similar provision in the assisted suicide bill in her state (A1504) endangered her life and would allow someone else to murder her:

"Capable" means having the capacity to make health care decisions and to communicate them to a health care provider, 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. If I am denied access to my communication device someone speaking for me could successfully end my life.

The legislation provisions refer to the patient choosing to self-administer but does not say "only" the patient may self-administer. Someone else could put the drug in a feeding tube or IV nutrition bag. Someone also could use an alternate method, such as suffocation. There is still no independent witness required at the time of ingestion, so who would know? The mere presence of a lethal drug request would provide an alibi. 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 Sawyer 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 Sawyer 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.

Both Oregon and California demonstrate 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. After passage of California's assisted suicide legislation, Stephanie Packer was told by her insurance company that it would not pay for her chemotherapy, but would pay for suicide drugs for a mere \$1.20 co-pay. Wherever assisted suicide is legal, it immediately becomes the cheapest treatment, distorting any concept of genuine patient 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" and act on it. We have seen such messages posted by assisted suicide advocates in the Capitol concourse in previous years. Autistic people can take messages like this quite literally. Nikki Bacharach, the autistic daughter of Burt Bacharach and Angie Dickinson, committed suicide 11 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 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.

Nearly three years ago, Connecticut became the first state to officially recognize the wrongfulness of this discrimination in its state suicide prevention plan. Here is the relevant excerpt from the *State of Connecticut Suicide Prevention Plan 2020*, which explicitly cites legalized assisted suicide as a contributing factor (pp. 43-44):

People with Chronic Health Conditions and Disabilities

Living with chronic or terminal physical conditions can place significant stress on individuals and families. As with all challenges, individual responses will vary. Cancer, degenerative diseases of the nervous system, traumatic injuries of the central nervous system, epilepsy, HIV/AIDS, chronic kidney disease, arthritis and asthma are known to elevate the risk of mental illness, particularly depression and anxiety disorders.

In these situations, integrated medical and behavioral approaches are critical for regularly assessing for suicidality. Disability-specific risk factors include: a new disability or change in existing disability; difficulties navigating social and financial services; stress of chronic stigma and discrimination; loss or threat of loss of independent living; and institutionalization or hospitalization.

Until recently, the CTSAB [Connecticut Suicide Advisory Board] was considering assisted suicide of the terminally ill as a separate issue from suicide prevention. The

active disability community in Connecticut, however, has been vocal on the need for suicide prevention services for people with disabilities. There may be unintended consequences of assisted suicide legislation on people with disabilities. Peace (2012) writes that “Many assume that disability is a fate worse than death. So we admire people with a disability who want to die, and we shake our collective heads in confusion when they want to live.”

People with disabilities have a right to responsive suicide prevention services. The CTSAB intends to continue to explore the needs of the disability community for such services.

Targeted Recommendations:

- Develop greater scrutiny of someone’s intentions to die.
- Identify and train practitioners to develop expertise in the work with disabled people who are suicidal.
- Do not “assume” suicide is a “rational” response to disability.
- Treat mental health conditions as aggressively as with a person without disability.

CTSAB should encourage and increase participation from the disability community and encourage educational presentations

Misdiagnosis and incorrect prognosis are also serious concerns. HB 5417 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 over 5 years 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 18 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 80, 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 nearly 25 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 5417, 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 in October 2014, 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, wrote in *The New York Review of Books* that she now favors euthanasia as well as assisted suicide. There have been several serious attempts to expand Oregon's assisted suicide law, including bills to go from six months to one year, and to allow euthanasia by advance directive. According to the *Washington Post*, an even more expansive bill targeting people with Parkinson's, Alzheimer's, and multiple sclerosis will be raised in 2019.

If HB 5417 were enacted, further expansion will move into the hands of judges. While we in the disability-rights community view legalizing assisted suicide as a violation of the Americans with Disabilities Act and the disability equal protection clause (Article XXI, amending Article V) of the Connecticut Constitution—people with certain disabilities are thus denied the benefit of suicide prevention services—judges could easily use both of these provisions to require extending the "benefit" of this "end of life option" to other disabled people. The limitations of "six months," "terminally ill," "mentally competent," and "self-administer" in HB 5417 all discriminate on the basis of disability. Indeed, back in 1999, former Deputy Attorney General of Oregon wrote this response to state senator Neil Bryant regarding the issue of self-administration:

"The Death with Dignity Act does not, on its face and in so many words, discriminate against persons who are unable to self-administer medication. Nonetheless, it would have that effect....It therefore seems logical to conclude that persons who are unable to self-medicate will be denied access to a 'death with dignity' in disproportionate numbers. Thus, the Act would be treated by courts as though it explicitly denied the 'benefit' of a 'death with dignity' to disabled people...."

Indeed, the Connecticut Supreme Court's ruling in *State v. Santiago*, striking down a prospective repeal of the death penalty in favor of full repeal, shows how our courts can expand laws beyond the intent of this legislature using equal protection grounds. The same principle is at work with HB 5417, which gives suicide assistance to some while others get suicide prevention, and the arbitrary difference is what disability they have.

So what about the person with ALS who has a six month prognosis, but has lost the ability to (literally) self-administer? 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. This is how we go down the same road as Canada, whose radical Supreme Court decision requiring the legalization of active euthanasia for mental suffering was heartily praised by Barbara Coombs Lee. 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 5417, 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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