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**John B. Kelly
Not Dead Yet
Communications Director
Boston, Massachusetts**

**HB0403
End of Life Option Act
Position: Unfavorable**

My name is John B. Kelly. I am Communications Director for [Not Dead Yet](#), the leading national disability rights group opposing assisted suicide, futility judgments, and “better dead than disabled” policies. We organized in 1996 to help stop Kevorkian, whose client victims were presented in the media as terminally ill. Two thirds of them were later found by [the New England Journal of Medicine](#) to be NOT terminally ill but disabled.

I keep thinking about Canada, where people like me – I’m a quadriplegic paralyzed below my shoulders, but I am not terminally ill – have become eligible for its version of an “aid in dying” program – and by aid in dying Canada means euthanasia 99% of the time.

At first, Canada legalized euthanasia/assisted suicide for people diagnosed as terminally ill, which it defined as people whose deaths were “reasonably foreseeable.” The courts soon stretched that definition to include non-dying disabled people. Now, anyone with a “grievous irremediable medical condition” can qualify for euthanasia. Disabled people have “chosen” euthanasia when denied services ([Sean Tagert](#)) or accessible housing (“[Sophia](#)”).

In Maryland and other states, proponents insist that “aid in dying” hinges on a definition of terminal illness that limits the population to people expected, “within reasonable medical certainty,” to die within the following six months. There have already been calls to expand eligibility beyond six months and beyond people diagnosed terminally ill. For example, [New Mexico’s HB 90](#), the Elizabeth Whitefield End Of Life Options Act, was first submitted in 2019 with a definition of terminal illness encompassing all incurable and irreversible conditions that “will result in death within the foreseeable future.” The bill passed in 2021 after switching back to the six-month standard used in other states. When proponents testify before committees such as yours, they often emphasize “safeguards.” When bills get passed, they return in following sessions to complain about these same safeguards as “barriers” to care.

From the first Oregon report in 1998 regarding its “Death with Dignity Act,” it’s been clear that use of assisted suicide has been most associated with perceptions of individual control and autonomy, not the experience or fear of physical pain. The reported ["end of life concerns" in Oregon](#) largely reflect people's “existential distress,” [as one study](#) termed it, in reaction to the disabling features of their illness: “losing autonomy” (over all years, 90%), “less able to engage

in activities” (90%), “loss of dignity” (72%), “burden on others” (48%) and “losing control of bodily functions” (44%). These are all disability-related concerns.

The best article on this issue is by Washington Post reporter [Liz Szabo](#). In 2016, she reported that where assisted suicide has been legalized, proponents have succeeded in “convincing voters, lawmakers and courts that terminally ill patients have the right to die without suffering intractable pain in their final days or week.”

Yet the latest research shows that terminally ill patients who seek aid in dying aren’t primarily concerned about pain. Those who have actually used these laws have been far more concerned about controlling the way they exit the world than about controlling pain.

No less an authority than Lonny Shavelson, now the Chair of the [American Clinicians Academy on Medical Aid In Dying](#), told Szabo, “It’s almost never about pain, it’s about dignity and control.”

Szabo also quotes ethicist Ezekiel Emanuel on the social factors that motivate usage of the suicide drugs.

“The dominant reasons for wanting euthanasia or assisted suicide are psychological and involve control factors,” said Ezekiel Emanuel, chair of medical ethics and health policy at the University of Pennsylvania’s medical school. He noted that most of those who have used aid-in-dying laws are white, well insured and college-educated. “These are people who are used to controlling every aspect of their lives, and they want to control this aspect of their lives.”

Szabo reports on a [2009 study](#) on 56 Oregon patients, who were found not to be concerned about pain, but “quality-of-life” issues such as loss of autonomy and dependence on others.

Then she talked to leading opponent Dr. Ira Byock:

“It’s a bait-and-switch. We’re actually helping people hasten their deaths because of existential suffering. That’s chilling to me.”

Although right-to-die campaigns suggest that excruciating pain is often unavoidable, Byock said that “we can relieve the suffering of almost everyone that we care for if we have the time to prepare.”

Szabo interviewed Barbara Coombs Lee, co-author of the Oregon bill and former director of Compassion & Choices, who admitted that there are many kinds of suffering. In her book, Lee describes one person with incontinence saying that “I like doing things for myself, and the idea of having somebody take care of me like I am a little 2-month-old baby is just absolutely repulsive. It’s more painful than any of the pain from the cancer.”

Advocate Dan Diaz, widower of Brittany Maynard, stressed as a point of pride the ableist prejudice fuels the movement.

Diaz said people shouldn't underestimate how devastating it can be to lose one's autonomy.

"If I find myself in a situation where I can't go to the bathroom on my own, where someone has to change my diapers, where I can't feed myself, where I can't care for the people around me, where other people have to move me around to keep me from having bedsores, I would then submit, 'Is that really living?' " Diaz said.

We disability rights advocates view the assisted suicide movement as a reaction to disability, especially dependence on other people. In September 2020, I debated bioethicist [Thaddeus Pope](#), who conceded that "Everybody who's using medical aid in dying is disabled. And probably you could go to the next step and say the reason they want medical aid in dying is because of their disability."

In February 2021, [Pope said](#) that the US is alone in limiting eligibility for assisted suicide to people diagnosed as terminal. He predicted that eligibility will be extended to non-terminal disabled people. Last October, [Pope published](#) "Top 10 New and Needed Expansions of US Medical Aid In Dying Laws." in which he called for the elimination of any time frame for predicted death. He wrote that "many seriously and irreversibly ill individuals not within six months of dying may still suffer greatly every day from their disease."

There is no way to contain eligibility to a narrow set of people. Especially when thousands of disabled Americans now live with conditions that in some states are seen as "worse than death." Anorexia nervosa and diabetes can now qualify as terminal conditions. Once death is accepted as a positive outcome of medical care, it inevitably gets offered to more and more people.

The problem for us disabled people is that we are already treated badly in the medical system. As medicine has focused increasingly on patient "quality-of-life" as a barometer of life-worthiness, death has been recharacterized as a benefit to an ill or disabled individual. Most physicians (82%, [a 2020 Harvard study found](#)) view our "quality-of-life" as worse than nondisabled people.

Disability advocates have raised concerns about the fate of disabled people like nonverbal Oregonian [Sarah McSweeney](#) and Black Texan quadriplegic [Michael Hickson](#). Both wanted to live, both were loved by family and caregivers, but they died after hospital personnel denied them treatment based on their supposed low quality-of-life.

The 2012 Massachusetts ballot results and the patient demographics in states like California show there is a social class, race, and ethnicity component in the use of and support for assisted suicide. [A 2013 Pew Research Center study](#) showed that Blacks oppose assisted suicide by 65%-29%, and Latinos by 65%-32%. Majority Latino [Lawrence, Massachusetts, voted 69%](#) against the 2012 ballot question, while white working class towns like Taunton and Gardner

also opposed. Wealthier Massachusetts towns voted heavily in favor. In [California, 88%](#) of reported assisted suicides have been by non-Hispanic whites, more than twice the group's share of the state population. Virtually no Black people have used the program.

Black patients under legalized assisted suicide will be more likely to be "written off" as better off dead, just as has happened with medical responses to COVID-19.

Meanwhile, terminal diagnoses are often wrong. [Jeanette Hall](#) wrote the Boston Globe in 2011 that she voted for Oregon's Death with Dignity bill, and when she received a terminal diagnosis, sought assisted suicide from her doctor. He persuaded her to try more treatment, and she is still alive more than 20 years later! The late actor Valerie Harper reported in 2013 that she had been given three months to live. She lived *six years*, and in that time appeared in a movie and starred in a play.

A few years ago, Oregon revealed that 4% of people who entered the assisted suicide program were still alive after six months. But [NPR reported in 2017](#) that nearly 20% of people who enter hospice outlive their six month prognosis. The difference between 4% and nearly 20% is the percentage of people and their families who may have lost months, years, and in some cases decades of meaningful life.

That 4% survival rate in Oregon happens to match the percentage of people sentenced to death row [who are estimated to be innocent](#). Many people, especially progressives, base their opposition to capital punishment at least in part on this unavoidable fact. We believe that people with serious illnesses and disabilities deserve the same level of concern.

In this and other ways, we are making social justice arguments against systemic discrimination against vulnerable communities. Indeed, Not Dead Yet joined a [federal lawsuit](#) against the state of California, arguing that its assisted suicide program violates the Americans with Disabilities Act and the Constitution by discriminating against disabled people. While younger, more able people receive suicide prevention services, old, ill, and disabled people all too often experience support for our deaths over support for our lives.

Maryland must not sponsor people's suicides because other people consider them a burden, because they believe they are dying when they are not, and because they have been denied the treatment and support services that would keep them alive.

Please protect disability rights, reject this bill and the discrimination it promotes.