



## Center for Disability Rights, Inc.

Testimony Presented to the  
NYS Assembly Standing Committee on Health  
Opposing AB2383 and Physician Assisted Suicide Generally  
April 23, 2018

## Introduction

The Center for Disability Rights thanks the Committee for extending an invitation to provide testimony on AB2383 at this critical time.

The Center for Disability Rights (CDR) is a disability led, not-for-profit organization headquartered in Rochester, New York, with satellite offices in Geneva, Corning, and Albany. CDR advocates for the full integration, independence, and civil rights of people with disabilities. CDR provides services to people with disabilities and seniors within the framework of an Independent Living Model, which promotes independence of people with all types of disabilities, enabling choice in living setting, full access to the community, and control of their life. CDR works for national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education. As an organization that both employs and serves many New Yorkers with various disabilities, and advocates for all disabled New Yorkers, CDR can ably comment on the experience of living with a disability and how proposed laws and policies such as this would impact us.

**AB2383 and bills like it are dangerous for many reasons and should not be permitted to proceed.** Proponents of AB2383 frame their arguments around increasing individual choice, but the disability community is concerned with losing our choice to live, which is why organizations like the Autistic Self-Advocacy Network, the New York Association on Independent Living, the American Association of People with Disabilities, ADAPT, the Arc of the United States, TASH, the Disability Rights Education and Defense Fund, the National Council on Disability, the National Council on Independent Living, the National Spinal Cord Injury Association, Not Dead Yet, and United Spinal all oppose assisted suicide. This bill allows opportunities for mistake, coercion, and abuse. Disabled people are at greater risk of coercion and abuse, and if even one person died of assisted suicide under these circumstances, it would be one person too many. The Committee should regard this possibility as unacceptable and AB2383 as inherently flawed.

CDR would like to bring the Committee's attention to three concerns. First, the reasons given for seeking assisted suicide are typically related to disability going unaddressed by

services or supports. Second, the requirement that a candidate for assisted suicide be “terminal” cannot be narrowly applied. Third, an individual’s economic situation will undoubtedly influence their end-of-life decisions.

While this testimony focuses on these points, they are far from the only reasons CDR opposes assisted suicide. A summary of CDR’s arguments is available as a position paper.<sup>1</sup> CDR also urges the Committee to refer to the *Primer on Assisted Suicide Laws*.<sup>2</sup>

## **AB2383 Contemplates Assisted Suicide**

Some people refer to the practice contemplated by AB2383 by the euphemism “aid in dying.” The Center for Disability Rights chooses accuracy of terminology based on a dictionary definition. This is also consistent with the ruling of the New York Court of Appeals in *Myers v. Schneiderman*, which declined to accept the assertion that “aid in dying” is not “assisted suicide” under the statute which bans it.<sup>3</sup>

## **Physician-Assisted Suicide Only Kills People with Disabilities**

Although intractable pain has been emphasized as the primary reason for enacting assisted suicide laws, the top five reasons Oregon doctors actually report for issuing lethal prescriptions are the “loss of autonomy” (92%), “less able to engage in activities” (90%), “loss of dignity” (79%), “loss of control of bodily functions” (48%) and “feelings of being a burden” (41%).<sup>4</sup> These are disability issues. The way to address these issues is not to offer a way out, but to provide adequate supports and services. Having adequate attendant services, for instance, would alleviate feelings of being a burden, and give someone the personal care assistance and support they need to live independently. In this way, proper services and supports for disabled people are an effective form of suicide prevention because they provide aid in living. We should be focused on dignifying peoples’ lives, rather than trying to dignify their deaths.

Proponents claim that AB2383 is not targeting people with disabilities, but only makes assisted suicide available to the “terminally ill.” While not every person with a disability is terminally ill, every person who is terminally ill is, or will eventually become, a person with a

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<sup>1</sup> Center for Disability Rights. *CDR Position Paper: Suicide Prevention and Assisted Suicide*. <http://cdmns.org/wp-content/uploads/2015/12/Assisted-Suicide-Position-Paper.pdf>.

<sup>2</sup> Patients Rights Action Fund, DREDF. *A Primer on Assisted Suicide Laws*. Available at <https://dredf.org/wp-content/uploads/2017/04/a-primer-on-assisted-suicide-laws.pdf>.

<sup>3</sup> *Myers v. Schneiderman*. 28 N.Y.3d 1131 (2017)

<sup>4</sup> (Death With Dignity Act Annual Reports, 2016).

disability. The suggestion that disability acquired as the result of illness is cause enough to end one's life is a devaluation of disabled peoples' lives and is offensive.

## **Hospice and Palliative Care Exist for End of Life**

When it comes to actual pain, hospice and palliative care exist for end of life. These services should also be expanded. Anyone dying in discomfort that is otherwise not relievable may legally today, in all 50 states, receive palliative sedation, wherein the patient is sedated to the point where discomfort is relieved while the dying process takes place. Thus we have a legal solution to any remaining painful and uncomfortable deaths.

## **“Terminal” Requirement Will be Applied Broadly**

Again, proponents of assisted suicide argue that it is only available to people who are “terminally ill,” implying that this population is extremely small. However, a dialogue between a man named Fabian Stahle and the Oregon Health Authority indicates that many more people than we are led to believe may be considered terminal and therefore candidates for assisted suicide. Mr. Stahle queried,

“If the doctor suggests, to an eligible patient, a treatment that possibly could a) prolong life, or b) transform a terminal illness to a chronic illness, or c) even cure the disease—and if the patient doesn't give his/her consent to the proposed treatment is he/she still eligible to take use of the Act?

“If a patient with a chronic disease (for instance, diabetes) by some reason decides to opt out from the life-sustaining medication/treatment and by doing so is likely to die within 6 months, thereby transforming the chronic disease to a terminal disease—does he/she then become eligible to take use of the act?”

Mr. Stahle then asked these same questions, but the reason given for not consenting to a treatment or opting out of a treatment is that the patient's insurance company would not pay for it. And the response was that all of these patients would qualify for assisted suicide. The analyst from the Oregon Health Authority replied that,

“Patients suffering from any disease (not just those that typically qualify one for the DWDA) may not be able to afford some treatments or medication, and may choose not to pursue

some treatments or take some medication for personal reasons. This is the patient's decision and the law does not compel them to do otherwise. If the patient does not receive treatment or medication (for whatever reason) and is left with a terminal illness, then s/he would qualify for the DWDA. I think you could also argue that even if the treatment/medication could actually cure the disease, and the patient cannot pay for the treatment, then the disease remains incurable.”<sup>5</sup>

The law on which AB2383 is based permits people who opt out of or cannot get coverage for treatment that would prolong their lives, turn their terminal conditions into chronic conditions, or even cure their conditions are eligible for assisted suicide. The power of insurance companies brings us to our next point.

## Economics Preclude Actual “Choice”

We need to think about assisted suicide in the context of the profit-driven health care system we all live in. Insurance companies have overruled physicians' treatment decisions. The cost of a lethal dose of drugs typically used in assisted suicide is much cheaper than the cost of most long-term medical treatment. The incentive to save money by denying treatment already poses a significant danger, and yet the Committee is considering whether we would like to make the incentive stronger. We say “No;” because if patients with limited financial means are denied other treatment options by their insurance, they are, in effect, being denied the choice of something other than assisted suicide.

The influence of a profit-driven system should be clear enough, but sadly there are examples of people being denied treatment options and simultaneously being offered the opportunity to kill themselves. Barbara Wagner's doctor prescribed Tarceva to extend her life in the face of lung cancer. The Oregon Health Plan notified Barbara that it would not cover this treatment, but it would cover, among other things, assisted suicide. Another Oregonian, Randy Stroup, was prescribed chemotherapy for his prostate cancer, which would have decreased his pain. Randy's insurance would not cover the chemotherapy, but would cover assisted suicide.<sup>6</sup> When you are denied options, where is your choice?

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<sup>5</sup>Oregon Health Authority Reveals Hidden Problems with the Oregon Assisted Suicide Model Fabian Stahle, Falkgrand 2B, 783 31 Sater, Sweden January, 2018 <https://drive.google.com/file/d/1xOZfLFrvuQcaZfFudEncp2b18NrUo/view> with summary and analysis here: <http://alexschadenberg.blogspot.com/2018/01/hidden-problems-with-oregon-assisted.html>.

<sup>6</sup> For more information about these cases, please see *Some Oregon and Washington State Assisted Suicide Abuses and Complications*.

Beyond our broken healthcare system, not all families are able and willing to financially provide the services and supports their relative needs. Whether intended or not, some patients will feel that they should request assisted suicide so they will not be a financial burden. Again, inadequate services and supports must be addressed.

You cannot argue that there is not an economic incentive – on the part of insurance companies or families and caregivers – to contemplate or even encourage someone committing assisted suicide. As long these external influences exist, the promise of a choice to end one's life is a lie.

## Assisted Suicide is the First Step on the Path to Euthanasia

Physician-assisted suicide refers to the act of taking one's own life; meanwhile, euthanasia refers to a *physician* bringing about the death of a patient out of concern for suffering or loss of dignity. One final point worth considering is the very real threat of a slide toward euthanasia should New York take this first step of permitting physician-assisted suicide.

When discussing physician-assisted suicide, thoughts of euthanasia are never far away. In fact they are quite near. In *Meyers v. Schneiderman*, Judge Fahey used his concurrence to argue that the government had a rational interest in not allowing physician-assisted suicide in order to avoid a possible slide toward euthanasia.<sup>7</sup> The slide toward euthanasia is a very real possibility, since other jurisdictions such as the Netherlands, Belgium and Canada have already authorized it.

## Conclusion

People with disabilities already contend with the stigma and ableist belief that our lives are less worthy of living. Legalizing assisted suicide would reinforce the idea that living with a disability is a perfectly good rationale for wanting to kill oneself. Furthermore, the promise of choice and control is a lie. There can be no free choice to die without a free choice in where and how we live. Discrimination, lack of access to good health and palliative care, and inadequate in-home service and supports limit the quality of life of elderly and disabled. Allowing these problems to continue creates a coercive and desperate situation for disabled people, pressuring them to choose assisted suicide. What's more, the broad applicability of the "terminal" requirement

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<sup>7</sup> The Committee should review the remarks of Judge Fahey, *available at* <https://www.youtube.com/watch?v=V5ideV--C7c> (00:14:00), at a symposium at Albany Law School (March 28, 2018).

means many people who would not otherwise be terminal but for opting out of treatment or being denied treatment qualify for assisted suicide.

CDR urges the Committee to consider the grave unintended consequences of what is being proposed, vote “No,” on AB 2383, and work to increase access to the services and supports people need to live their lives in freedom.

Respectfully submitted,

Kathryn Carroll, Esq.