

# Assisted suicide laws create discriminatory double standard for who gets suicide prevention and who gets suicide assistance: Not Dead Yet Responds to Autonomy, Inc.

Diane Coleman

*Not Dead Yet, Rochester, NY 14608, USA*

## Abstract

Not Dead Yet is a national disability rights organization formed in 1996 to articulate and organize the disability rights opposition to legalization of assisted suicide. In the first half of 2009, Not Dead Yet and four other national disability organizations joined in an amicus brief filed in *Baxter v. State of Montana*, an assisted suicide case on appeal to the state Supreme Court. Autonomy, Inc., another disability organization, filed an amicus brief in favor of a constitutional right to assisted suicide. The author reviews the lower court opinion and the key arguments in these amicus briefs from the perspective of Not Dead Yet. The Montana District Court concluded that the privacy and dignity provisions of the Montana Constitution establish a constitutional right to physician assisted suicide for terminally ill people, and that potential abuses of that right could be regulated by state statute. The author addresses the question, “What does disability have to do with it?” The author uses a combination of clinical research, legal analysis and the Oregon Reports on assisted suicide to examine the claim that abuses can be prevented by restricting assisted suicide to competent people who are terminally ill and choose it voluntarily. Autonomy, Inc.’s arguments explicitly depend on the medical profession’s ability to reliably predict terminal status, and the capacity of society and the law to implement a double standard of suicide prevention and suicide assistance based on terminal status. Not Dead Yet’s central argument is that such a double standard based on health status constitutes unlawful discrimination under the Americans With Disabilities Act. The author highlights data from the Oregon Reports demonstrating that lethal prescriptions were issued to people who were not terminally ill under the law’s definition, and examines various problems of implementation and enforcement under the Oregon and Washington assisted suicide statutes. Particular attention is given to the problems associated with the role of physicians as gatekeepers under the statutes, providing examples of physicians pressuring people to forego life-sustaining treatment and involuntarily withholding life-sustaining treatment. © 2010 Elsevier Inc. All rights reserved.

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Not Dead Yet is a national disability rights organization formed in 1996 to articulate and organize the disability

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Corresponding author: 497 State Street. Tel.: (585) 697-1640.

E-mail address: [dcoleman@cdnys.org](mailto:dcoleman@cdnys.org) (D. Coleman).

rights opposition to legalization of assisted suicide. The majority of the original Not Dead Yet activists were also activists in ADAPT, the grassroots national group that includes civil disobedience in its tactics to advance the civil rights of older and disabled people to choose to receive long-term care services in home and community-based settings rather than being forced into nursing facilities and institutions.

Prior to the formation of Not Dead Yet, ADAPT was active in opposing a number of so-called “right to die” cases involving ventilator users who sought freedom from nursing homes, cases in which these disabled men essentially argued “give me liberty or give me death.”<sup>1</sup> Society refused to provide them in-home services to free them from nursing facilities, while pro-assisted suicide advocates urgently called for “liberating” them by pulling the plug. This spoke volumes to disability activists who follow the

traditions of Martin Luther King, Jr. in pushing for the choice to live in the community.

Not Dead Yet announced its formation “ADAPT style,” gaining media attention in connection with nonviolent protests against Jack Kevorkian covered by the Associated Press and a Supreme Court rally covered nationwide, including a front-page photograph in *USA Today*. Within the next 2 years, a number of established national disability rights groups joined ADAPT in adopting formal positions against assisted suicide, including the National Council on Independent Living, the National Spinal Cord Injury Association, the Disability Rights Education and Defense Fund, the National Council on Disability, and others.<sup>2</sup>

Shortly after Not Dead Yet began to muscle its way into the public discourse on assisted suicide, the leading pro-assisted suicide organizations each added a white male professional wheelchair user to its board of directors as a spokesperson. The Hemlock Society got Paul Spiers, Death With Dignity National Center got Andrew Batavia, and Compassion in Dying got Hugh Gallagher.<sup>3</sup> These individuals debated Not Dead Yet before the media and in other venues. In 2002, they formed a national disability organization called Autonomy, Inc.<sup>4</sup>

In the first half of 2009, Not Dead Yet and Autonomy, Inc. each filed amicus briefs in *Baxter v. State of Montana*, an assisted suicide case on appeal to the state supreme court. This article will review the key arguments in these briefs from the perspective of Not Dead Yet. Since briefs in support of appellants are filed before briefs in support of the lower court opinion, Not Dead Yet and its co-amicus<sup>5</sup> filed their brief first, and Autonomy’s brief included responses to Not Dead Yet’s arguments. In part, this article is Not Dead Yet’s reply to Autonomy, Inc.

### **A summary of the Montana District Court opinion to which Not Dead Yet and Autonomy, Inc. responded in amicus briefs**

In *Baxter v. State of Montana*, the Montana District Court first considered whether the Montana Constitution includes a right to choose to end one’s life. The Court’s analysis rested primarily on “the right of every individual to the possession and control of his own person,”<sup>6</sup> so it is difficult to see how such a right to end one’s life could be confined to terminally ill people. Nevertheless, suicide is not illegal in any state, and this conclusion is only a step along the way to the central issue, articulated by the Court as follows:

. . . [W]hether this includes the right to obtain assistance from a medical care provider in the form of obtaining a prescription for lethal drugs to be taken at a time of the patient’s choosing . . .<sup>7</sup>

The Montana District Court concluded that a physician’s assistance is essential to the right to choose to end one’s life:

. . . The physician-patient relationship would enable the terminal patient to consult with his doctor as to the progress of the disease and the expected suffering and discomfort, and would enable the doctor to prescribe the most appropriate drug for life termination, leaving the ultimate decision and timing up to the patient.

But for such a relationship, the patient would increasingly become physically unable to terminate his life, thus defeating his constitutional right to die with dignity. If the patient were to have no assistance from his doctor, he may be forced to kill himself sooner rather than later because of the anticipated increased disability with the progress of his disease, and the manner of the patient’s death would more likely occur in a manner that violates his dignity and peace of mind, such as by gunshot or by an otherwise unpleasant method . . .<sup>8</sup>

Thus, the Court found that some people have a constitutional right to a less “unpleasant method” of suicide, and that the State could only restrict this fundamental right based on a compelling state interest. The Court then analyzed the compelling interests alleged by the State for disallowing assisted suicide.

It is easy to acknowledge the State’s interest in preserving human life in general, but it is difficult to imagine a compelling interest in preserving the life of an individual who is suffering pain and the indignity of his disease; whose life is going to end within a relatively short period of time; and for whom palliative care is inadequate to satisfy his personal desire to die with dignity.<sup>9</sup>

We are asked to disregard the fact that physician predictions of terminal status are unreliable.<sup>10</sup> We are asked to disregard the fact that pain has rarely been the reason given for requesting assisted suicide.<sup>11</sup> We are asked to disregard the fact that the Court’s reference to “the indignity of his disease” conveys an agreement with the prevalent but insulting societal judgment that people who deal with incontinence and other losses in bodily function are lacking dignity. According to the Court, the State’s interest in preserving life is not the same for everyone and, in particular, people who experience “the indignity of . . . disease.”

Then the Court addressed the State interest in preventing abuses, such as, “[t]he difficulty in defining terminal illness and the risk that a dying patient’s request for assistance in ending his or her life might not be truly voluntary . . . .” The District Court simply concluded that the legislature could address those risks “with limitations narrowly tailored to effectuate the State’s interest without unduly interfering with the individual’s constitutional rights.”<sup>12</sup> The Court listed the purported protections against abuses contained in the Oregon assisted suicide law. Since Not Dead Yet and

Autonomy, Inc. disagree about the ability of the Oregon law to prevent abuses, this topic will be addressed further later.

Finally, the Court dismissed the State interest in preserving the “integrity and ethics of the medical profession.” The Court asserted that a substantial number of physicians agree with assisted suicide and that others are free to opt out of providing it as a matter of conscience. The fact that many physicians want legal immunity for providing assisted suicides is neither surprising nor reassuring for many people with disabilities.

The Court also expressed faith in the ability of physicians to assess an individual’s terminal status and competency. People with disabilities appreciate a good physician as much as anyone, but we are somewhat less inclined than average to have unquestioning faith in the profession overall. This is a central issue, since the so-called individual right to assisted suicide is, in actual fact, a civil and criminal immunity conferred upon the physicians who serve as the gatekeepers of the practice.

The following discussion will focus on two essential claims made by pro-assisted suicide advocacy groups to convince legislators and the public to confer immunity on physicians for assisted suicide:

- Assisted suicide is only for the terminally ill, and
- Assisted suicide is only for competent people who choose it voluntarily.

The remainder of this essay will examine these two claims.

### Examining the claim that assisted suicide is only for the terminally ill

#### *What’s disability got to do with it?*

The Oregon and Washington assisted suicide statutes explicitly pertain to people with terminal illness, not mere disability, so many question the legitimacy of disability groups “meddling” and trying to “take away” what they see as the general public’s right to choose assisted suicide. For discussion purposes, assume that physicians were able to accurately predict that someone will die within 6 months and that the statute is capable of limiting assisted suicide to that group.

The disability experience is that people who are labeled “terminal,” predicted to die within 6 months, are—or will become—disabled (Figure 1).

People with terminal conditions are a subset of people with disabilities. The real issue is the reasons people ask for assisted suicide. Although intractable pain has been emphasized as the primary reason for enacting assisted suicide laws, the reasons Oregon physicians actually report for issuing lethal prescriptions are the patient’s “loss of autonomy” (89.9%), “less able to engage in activities” (87.4%), “loss of dignity” (83.8%), and “feelings of being a burden” (38.3%).<sup>13</sup> People with disabilities are concerned

that these psychosocial factors have become widely accepted as sufficient justification for assisted suicide, with most physicians not requesting a psychological consultation (only 3.3% in 2008)<sup>14</sup> or the intervention of a social worker familiar with home- and community-based services that might alleviate these feelings. The societal message is “so what?”

The primary underlying practical basis for the physician’s determination that the individual is eligible for assisted suicide is the individual’s disabilities and physical dependence on others for everyday needs, which is viewed as depriving them of what nondisabled people often associate with “autonomy” and “dignity,” and may also lead them to feel like a “burden.” This establishes grounds for physicians to treat these individuals completely differently than they would treat a physically able-bodied suicidal person.

Those feelings often arise when a person acquires physical impairments that necessitate relying on other people for help in activities formerly carried out alone. In a society that prizes physical ability and stigmatizes impairments, it’s no surprise that previously able-bodied people may tend to equate disability with loss of dignity.

Studies of patient attitudes toward assisted suicide confirm that “[p]atients’ interest in physician-assisted suicide appeared to be more a function of psychological distress and social factors than physical factors.”<sup>15</sup> “When patients ask for death to be hastened,” one study concluded, “the following areas should be explored: the adequacy of symptom control; difficulties in the patient’s relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety . . .”<sup>16</sup> And another study exploring psycho-social factors provided the following analysis:

The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self . . . Symptoms and loss of function can give

## What Does Disability Have to Do With Assisted Suicide?

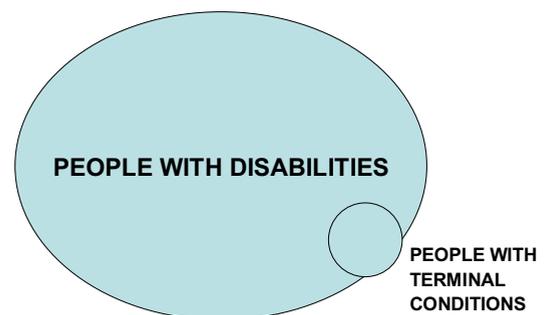


Figure 1. Disability & Terminal Illness.

rise to dependency on others, a situation that was widely perceived as intolerable for participants: “I’m inconveniencing, I’m still inconveniencing other people who look after me and stuff like that. I don’t want to be like that. I wouldn’t enjoy it, I wouldn’t, I wouldn’t. No, I’d rather die.”

Participants frequently used the notion of dignity to describe the experiences associated with disintegration: “You’ve become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors’ appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live.”

. . . Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others . . . .

Participant: “. . . I used to be somebody, but now, like I mean, you know, I’m no better than like a doll, somebody has to dress me and feed me and I guess it’s uh, I don’t know how to explain it, really.”<sup>17</sup>

These feelings are understandable for newly disabled people, whether due to a chronic or a terminal condition.

Disability groups, however, disagree that needing help in dressing, bathing, and other intimate daily tasks robs a person of dignity. Unfortunately, popular culture has done virtually nothing to educate the public about how people with severe disabilities actually live autonomous and dignified lives. Our lives are portrayed as tragedies or sensationalized as heroism, but the real-life issues and coping styles that most people will need if they live long enough are left out of the picture. No wonder people who acquire disabilities so often see death as the only viable solution.

***The political agenda of many assisted suicide organizations includes expansion of eligibility to people who are not terminally ill***

Pro-assisted suicide organizations do not express a unified position on who should be eligible for assisted suicide. The Harvard Model Statute to legalize assisted suicide, developed by Charles Baron and other Hemlock Society leaders, proposed two eligible groups for assisted suicide: (1) people with terminal illnesses and (2) people with incurable conditions who feel that their suffering is unbearable.<sup>18</sup> The recent New Hampshire assisted suicide bill applied to people with incurable conditions that would eventually shorten their life span.<sup>19</sup>

When Compassion in Dying merged with End-of-Life Choices (formerly the Hemlock Society),<sup>20</sup> members who felt

that assisted suicide should not be confined to the terminally ill formed a new organization, Final Exit Network. While the newly merged Compassion and Choices led efforts to pass an assisted suicide referendum in Washington State, providing eligibility for people predicted to die within 6 months, Final Exit Network members provided “Exit Guides” for a broader segment of people including those with nonterminal disabilities. Some Exit Guides have been arrested on charges that they have gone so far as to hold down the hands of an individual after the helium “Exit Bag” was placed over their head to ensure that they do not remove the bag.<sup>21</sup>

While expressly maintaining that assisted suicide should be limited to the terminally ill, neither Compassion and Choices nor its predecessor organizations have ever called for the prosecution of those who openly defy that limitation, e.g., Jack Kevorkian<sup>22</sup> and Final Exit Network.

Confronted with the awkward publicity that Kevorkian and now Final Exit Network have received for assisting the suicides of people with nonterminal disabilities, Compassion and Choices has simply argued that the Oregon and Washington laws provide effective safeguards to prevent abuses.<sup>23</sup>

***Autonomy, Inc.’s arguments hinge on the terminal distinction***

In its Montana brief, Autonomy, Inc., stated:

Suicide is the irrational decision of death over a life that could be lived. Those who can take advantage of the [Montana Court] Order, however, do not have that choice: they are going to die, irrespective of their wishes, and will do so soon.<sup>24</sup>

Autonomy, Inc. does not attempt to tackle the uncertainties of predicting terminal status, although the disability community has more than a passing familiarity with this reality. Many people with disabilities have outlived a prediction that they were going to die sooner than proved to be true. It is well documented that the 6-month prediction called for in the Oregon and Washington laws is not reliable.<sup>25</sup>

To further emphasize their point that assisted suicide only pertains to people who are imminently dying, Autonomy, Inc. continued at page 14 of its Montana brief:

Terminally ill individuals who choose to hasten their deaths seek to avoid a prolonged and dehumanizing process of dying. They do so because, in their view, “the quality of life during the time remaining . . . ha[s] been terribly diminished,” and because their lives “ha[ve] been physically destroyed and [their] quality, dignity and purpose gone.” *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 304-05 (Cal. Ct. App. 1986). Under these circumstances, the choice to hasten death is more akin to the legally condoned decision to refuse life-sustaining measures than what is commonly perceived as “suicide.”<sup>26</sup>

Days between 1 <sup>st</sup> request and death	2008	1998-2007	Total
Median	42	43	43
Range	15-436	15-1009	15-1009

Figure 2. Days from Request to Death.

The irony of Autonomy, Inc. quoting from the *Bouvia* case is that Ms. Bouvia was a woman with cerebral palsy in her late 20s, in no way terminally ill, but suicidal following several major life setbacks, including a miscarriage and marriage breakup, among others.<sup>27</sup> This was well documented in the court proceedings and media, yet the *Bouvia* Court had no difficulty equating her situation to that of a terminally ill person. The simple truth that Autonomy, Inc. highlighted by citing the *Bouvia* case is that terminally ill people are not separated from other disabled people by a bright line, either in reality or in the minds of courts, media, or most of the public.

**Oregon assisted suicide not limited to terminally ill**

The Oregon Reports demonstrate that some people who received prescriptions were not terminal (i.e., lived longer than 6 months). The 2008 Death with Dignity Act Annual Report summarizes the “Duration (days) between 1st request [for assisted suicide] and death” as given in Figure 2.<sup>28</sup>

In the first 2 years, the Reports also include the number of days between the receipt of a lethal prescription and death (range 0-66 days in 1998 and 0-247 days in 1999), but these data are not included in subsequent reports. Inexplicably, the number of people who did not die within 180 days of their first request for assisted suicide is not in the Oregon Reports. From the Oregon state web site, the range of days between the first request for assisted suicide and death for each reporting year except the ninth (not included on the web site) is given in Figure 3.

Therefore, for every reported year from 1999 to 2008, at least one person per year lived from 109 to 829 days longer than 6 months before their death.<sup>29</sup> By definition under the Oregon law, these individuals were not terminally ill. There is no indication that the dispensing of lethal prescriptions to people who proved not to be “terminal” under the law’s 6-month criteria was the subject of discussion, investigation, or remedial action in any form.

Rather than being “easily regulated,” as Autonomy, Inc. asserts at page 1 of their brief, so that lethal prescriptions are only provided to people who are imminently dying, the Oregon law appears to operate about as well as highway speed limits. The Oregon Reports clearly document that the “terminal” limit in the assisted suicide law was exceeded every year after the first without consequence, much like highway speed limits.

Year	1	2	3	4	5	6	7	8	9	10
Range	15-83	15-289	15-377	15-466	16-329	16-737	15-593	15-1009	NA	15-436

Figure 3. Days from Request to Death, multi-year.

The Oregon Reports also consistently admit that the state has no way to assess the extent of nonreporting or the extent of noncompliance with the law’s criteria.<sup>30</sup>

It seems at best naïve and at worst dishonest to claim that a terminal limitation has been observed or will be observed or that consequences will be imposed for violating that limitation. Even under the spotlight that the Oregon law has generated, no prosecutions have been brought regarding the nonterminal cases. After all, the Oregon law provides an unassailable “good faith” defense that effectively shields negligent, reckless, and potentially even intentional acts outside its parameters.

Because apparently only the most extreme violations of the “speed limit” might be addressed by law enforcement, the “speed limit” should not have been raised in Oregon or Washington. Illegality of assisted suicide offers two, albeit limited, sources of protection:

- The most serious violations have at least a chance of being investigated and prosecuted, rather than enjoying the safe harbor of blanket immunity; and
- Physicians may feel some pressure from the fear of prosecution, however rare that may be.

**Assisted suicide discriminates in violation of the Americans With Disabilities Act**

Not Dead Yet’s central argument is that legalized assisted suicide sets up a double standard for how health care providers, government authorities, and others respond to an individual’s stated wish to die. Some people get suicide prevention while others get suicide assistance, and the difference between the two groups is the health status of the individual. As explained in the brief submitted by Not Dead Yet, et al. in the Montana case, this is a clear cut violation of the Americans With Disabilities Act (ADA). Quoting at length from the Not Dead Yet brief:

*Assisted suicide singles out some people with disabilities, those labeled “terminal” or very severely impaired, for different treatment than other suicidal people receive . . . .*

*The lower court’s decision, immunizing physicians for assisting the suicides of persons with “terminal” disabilities or conditions, turns on its head the general assumption that suicide is irrational and is a “cry for help.” For certain people who are disabled, suicide will be viewed as understandable and acceptable. According to assisted suicide advocates, an incurable disability is sufficient for*

eligibility, while others require a “terminal” label, however unreliable and slippery such predictions may be. The ruling permits doctors to affirmatively facilitate suicide, an act that would be a crime but for the person’s disability. Persons with severe health impairments will be denied the benefit of Montana’s suicide prevention laws and programs. *Mo. Rev. Stat. §630.900*. Indeed, the lower court’s holding guarantees these suicide attempts will succeed—unlike those of the majority of other persons with suicidal ideation who are not disabled. A practice that the State would otherwise expend public health resources to prevent is instead actively facilitated as long as the person has a “terminal” or disability label.

. . . Central to the civil rights of people with disabilities is the idea that a disabling condition does not inherently diminish one’s life; rather, surrounding barriers and prejudices do so. In contrast, assisted suicide gives official sanction to the idea that life with a disabling condition is not worth living.<sup>31</sup> As the U.S. Supreme Court has recognized:

*The State’s interest here [in prohibiting assisted suicide] goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and “societal indifference. . . .” The State’s assisted-suicide ban reflects and reinforces its policy that the lives of terminally ill, disabled and elderly people must be no less valued than the lives of the young and healthy, and that a seriously disabled person’s suicidal impulses should be interpreted and treated the same as everyone else’s.*<sup>32</sup>

. . . Providing assisted suicide only for people with disabilities and denying them suicide prevention services, based on a doctor’s prediction of terminal status or other justification, violates the ADA because the presence or absence of disability determines whether state and local governments:

- Enforce laws requiring health professionals to protect individuals who pose a danger to themselves;
- Respond to expressions of suicidal intent in people with disabilities with the application of lethal measures that are never applied to people without disabilities;
- Investigate and enforce abuse and neglect and homicide statutes in cases reported as assisted suicides.

*The doctor’s determination of someone’s eligibility for assisted suicide confers absolute legal immunity on the doctor, and all normal suicide-related procedures are set aside. The existence of a disability should never be the basis for these distinctions.*

The ADA violation inherent in assisted suicide laws has neither been discussed nor refuted by assisted suicide proponents. Autonomy, Inc.’s Montana brief does not even attempt to provide a counterargument on the ADA violation issue, and mentions the ADA only once as follows: “The entire point behind the Americans with Disabilities Act was to give disabled individuals equal access to the world, and the choice of what to do within it.”<sup>33</sup> Actually, the purpose of the ADA is to prohibit discrimination based on disability. The silence of a self-identified disability rights group on this issue suggests that it is unable to formulate a disability rights response and is left to simply adopt the arguments of its nondisabled allies.

Paradoxically, the only ADA issue that some assisted suicide advocates ever mention is the law’s purported requirement that the lethal drugs be “self-administered.” They argue that this is discriminatory because some people will be too physically impaired to place the lethal drugs in their mouth and swallow them. The issue of self-administration of the lethal drugs is an appropriate segway to a discussion of the risk of “assisted suicide” abuses in terms of “voluntariness,” ranging from coercion to outright homicide.

### **Examining the claim that assisted suicide is only for competent people who choose it voluntarily**

Autonomy, Inc.’s opening summary asserts:

The Appellants and the amici who support them have alleged that a parade of horrors will befall the citizens of Montana should the right to physician-assisted dying be upheld. But. . . : Physician-assisted dying is rarely used and is easily regulated, and in actual practice there is no evidence of undue influence or coercion. Indeed, their fears are not borne out in jurisdictions where physician-assisted dying is legal, but instead where it is illegal and thus unregulated.<sup>34</sup>

As Autonomy, Inc. pointed out, there is evidence in the form of anonymous surveys indicating that illegal assisted suicides are already provided by physicians throughout the country.<sup>35</sup> Yet we rarely if ever hear of prosecutions of such illegal actions. Moreover, there is no evidence that illegal assisted suicides have discontinued in Oregon despite the enactment of the assisted suicide law. As noted earlier, the Oregon Reports consistently acknowledge that they cannot assess the extent of nonreporting or actions taken outside the scope of the law.<sup>36</sup>

The Montana District Court agreed that there is a compelling state interest in preventing abuses of a right to voluntary assisted suicide for the terminally ill, but asserted that such abuses could be prevented by the legislature through a statute like those in Oregon and Washington.

***The Oregon and Washington laws: insights from an attorney specializing in elder abuse issues***

The prevalence of elder abuse has been one factor that raises concerns about the risk that older people with health impairments may be coerced into choosing assisted suicide. Disability abuse is similarly prevalent but less well known.<sup>37</sup>

Recently, an attorney who specializes in elder law has lent her expertise to an analysis of the statutes in Oregon and Washington. As Margaret Dore clarified in her amicus brief filed in the Montana case, the Washington State law defines “self-administration” of the lethal drug as “ingesting,” with no requirement for the more commonly understood meaning of the term.

Oregon’s law implies that patients administer the lethal dose to themselves. The law does not, however, require this. Oregon’s law does not state that “only” the patient can administer the lethal dose.

Oregon’s law instead refers to patient administration as the “act of ingesting medication to end his or her life.” Oregon’s official forms also refer to administration as “ingestion,” “ingesting” and other forms of the word “ingest.”

With administration described as the “act of ingesting medication to end his or her life,” someone else putting the lethal dose in the patient’s mouth qualifies as proper administration; someone else putting the lethal dose in a feeding tube or IV nutrition bag would also qualify.<sup>38</sup>

While finding the meaning of “self-administration” under the Oregon law requires some search and analysis that might raise doubts, the clear definition in the Washington law puts any doubt to rest:

In Washington’s law, the phrase “act of ingesting medication to end his or her life” is the statutory definition of “self-administer.”<sup>39</sup>

Thus, if the safeguards under the assisted suicide statutes were carefully crafted as claimed by assisted suicide advocates, they were carefully crafted to preclude liability for any third party who administers a lethal drug prescribed under the statute. After reviewing other statutory provisions, Ms. Dore summarizes the fact that the Oregon “safeguards” expressly apply at the time the lethal prescription is requested, but not when it is administered:

In summary, Oregon’s law contains no requirement that the patient be competent, capable or even aware when the lethal dose is administered. There is no requirement that the patient consent when the lethal dose is administered. Someone other than the patient is allowed to administer the lethal dose.

Intentionally killing an incompetent person or intentionally killing some other person without his consent, is homicide. . . . Oregon’s law states:

Actions taken in accordance with [this chapter] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law. (Emphasis added.) [Citations omitted.]<sup>40</sup>

Assisted suicide proponents may argue that the Oregon law prevents involuntary killing by providing criminal liability for “undue influence.” Ms. Dore states that this “purported liability is illusory because conduct that would normally support a finding of undue influence is specifically allowed by Oregon’s law.”<sup>41</sup> Since one of the witnesses to the request for a lethal dose may be an heir of the individual’s estate, an involvement that creates a legal presumption of undue influence under estate law, proof of undue influence under the assisted suicide law is rendered difficult if not impossible by the standard legal rule of construction that the specific controls the general. Since the Oregon law does not otherwise define *improper undue influence*, criminal liability standards would be difficult or impossible to meet. Moreover, everyone present when the lethal dose is “self-administered” is also immunized from liability if they participated in “good faith,” another “standard” very difficult to legally disprove. There is no requirement that a disinterested witness be present at the time the lethal dose is ingested.

Thus, the safeguards under the Oregon law do little or nothing to prevent undue influence, coercion, or involuntary killing. The minimal reporting requirements under the law, which rely entirely on self-reporting by physicians who participate in the law’s process, ensure that abuses will not be identified. In short, the only ironclad safeguard under assisted suicide laws is the blanket civil and criminal immunity granted to physicians and other participants. Safeguards for the individual who dies are illusory.

***The risks of abuse in the form of coercion***

The Autonomy, Inc. brief specifically attacks Not Dead Yet and its co-amici national disability organizations by mischaracterizing our concerns about coercion:

*... Not Dead Yet asserts that “[t]here is no way to ensure that persons are not unduly pressured by family members, because of financial, emotional or other reasons.” Not Dead Yet at 18. However, this erroneously assumes that individuals with disabilities are incapable of making rational, voluntary and independent decisions to hasten their own imminent and inevitable deaths.*

In essence, Autonomy, Inc. accuses Not Dead Yet and other national disability organizations of being paternalistic

toward people with disabilities, a very objectionable sentiment that has too often victimized people with disabilities. Autonomy, Inc. skirts around our demand for suicide prevention equal to that offered to “healthy” people by retreating back to the already disproved assumption that assisted suicide is only for people who are otherwise imminently dying:

However, the point of this right is not to coerce disabled individuals into euthanasia and deny them suicide prevention services . . . . Quite simply, those who might take advantage of the right to physician assisted dying are, by definition, already going to die and do so in short order.<sup>42</sup>

Not Dead Yet also challenges the simplistic abandonment of suicide prevention for people who actually are terminally ill. Studies show that whether or not terminally ill, people who ask for assisted suicide or euthanasia usually change their minds.<sup>43</sup>

Autonomy, Inc. does not attempt to dispute that disability-related concerns are reported by physicians as the reasons for assisted suicide, but disputes that the state has implicitly endorsed these reasons or that this might have the impact of devaluing the lives of people with disabilities.

Some assert that the District Court’s Order will have the cumulative impact of devaluing the lives of people with disabilities . . . .

The Order’s distinction, however, between individuals with terminal conditions and those without does not manifest such judgments on behalf of the State. Quality of life is a subjective valuation that belongs to the individual.<sup>44</sup>

Again, Autonomy, Inc. must rely on the assumption that a bright line between terminal and non-terminal people with disabilities exists and will be enforced, and then asserts, “The [Montana Court] Order simply recognizes that this choice belongs neither to the State nor healthcare providers, but instead to the individual alone.”<sup>45</sup> This assertion is not consistent with the express provisions of the Oregon and Washington laws.

### Physicians as gatekeepers of assisted suicide

In fact, anyone could ask for assisted suicide, but physicians decide who gets it. Assisted suicide laws provide that two physicians determine whether a request for a lethal prescription is made by a competent terminally ill person on a voluntary basis (i.e., not based on a mental condition that causes impaired judgment). In effect, the Oregon law gives physicians the power to judge whether or not a particular suicide is rational. This judgment would involve comparing the patient’s feelings and resulting decision to those the physician believes he or she and other people

would have in similar circumstances (i.e., based on his or her evaluation of the individual’s quality of life).

The disability rights movement has a long history of healthy skepticism toward medical professionals, and there’s an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our own assessments.<sup>46</sup> Our skepticism has increased in today’s profit-driven health care system.

It should be noted that suicide, as a solitary act, is not illegal in any state. Disability concerns are focused on the systemic implications of adding *assisted* suicide to the list of “medical treatment options” available to seriously ill and disabled people. The Oregon law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of “good faith” belief that the person was terminal and acting voluntarily. This is the lowest culpability standard possible, even below that of “negligence,” which is the minimum standard theoretically governing other physician duties.

Physicians also decide what “feasible alternatives” to disclose to the individual. It must be noted, however, that these same physicians have never been required to disclose any financial conflicts of interest they might have in determining what course of treatment to recommend. We’re all supposed to take it on faith that no physician will be influenced by the financial terms of his or her health plan contracts in the information and advice they give.

The Oregon law immunizes physicians from being accountable for each of these decisions.

### *Physicians sometimes pressure people with disabilities to forego life-sustaining treatment based on negative quality of life judgments*

For all those who wonder why progressive national disability rights organizations have joined Not Dead Yet in taking a public stand against the legalization of assisted suicide, and tolerated the false accusation that we have been misled or are puppets of the religious right, one need only look to the real-life experiences of people with disabilities in the health care system.

The story of one such experience was recently posted on both the Not Dead Yet blog<sup>47</sup> and a website series called “How We Die,”<sup>48</sup> but Terrie Lincoln’s story is entitled, “How I Didn’t Die.” The following excerpts demonstrate a type of unrelenting pressure to forego life-sustaining treatment that people with disabilities and their families too often experience:

*My name is Terrie Lincoln and I am a 31 year old quadriplegic. I live in Rochester, New York and work as a Systems Advocate at the Regional Center for Independent Living. I have a degree in social services and a bachelor’s degree in public administration. I am currently working on my master’s in social work.*

*At the age of 19, I had an automobile accident . . . I was air-lifted to a nearby hospital in West Virginia a few hours later . . . While I was lying in the hospital bed . . ., the doctors would come in and ask my mom if she was ready to pull the plug on me. “Why would I want to do that?” she would ask? The doctors answered, “What kind of life will she have—she won’t. She won’t be able to dance, walk, work, have a social life, or be independent.”*

*. . . The next day when the doctor came in my dad was there with my mom. The doctor informed us that I was going to be in a veggie state for the rest of my life . . . [M]y dad asked what veggie I was going to be because I hated green beans and would be mad if I was one.*

*The doctor said he didn’t find that funny and felt it was inappropriate. My mom said she felt he was being inappropriate by coming in every day and telling her to pull the plug on her daughter. The doctor responded that any good mother would pull the plug instead of seeing their baby suffer . . . [T]hey were killing me slowly with the lack of care I was receiving. Within fifteen days of being there, I had no bowel movement (they were scared to roll me), aspirated, had pneumonia, and collapsed lungs . . . I was life flighted out on the fifteenth day.*

*Once I arrived in Columbus, OH we felt I was on my way to recovery. I had a new team of doctors who specialized in spinal cord injuries. The relationships with the doctors started off more positive than the last set until the first time I died, which was about 3 weeks after I arrived. I was a code blue and they resuscitated me but didn’t offer any suggestions on how to inflate my lungs or help me breathe.*

*Over the weeks I got worse and worse. Pneumonia was causing my lungs to fill and I was constantly flat lining (electrical time sequence measurement that shows no heart activity). The team of doctors asked: do you want to pull the plug? They said you could take her off her feeding tube and we could induce her into a coma and she won’t suffer.*

*. . . [Weeks later] I was spending hours a day off the ventilator and the doctors were still asking if I wanted to live the rest of my life with this condition. If I chose no, they would keep me off the ventilator and I would die. I could get injected with Morphine so I couldn’t feel it.*

*They’d work at my parents, saying things like: “Your daughter was so active before this accident and now she’s nothing. She’s just like Christopher Reeve, she will need help with everything, she won’t be able to*

*push her own chair. She will have to use a sip and puff device.”*

*Then they’d work on me. Saying stuff like: “Are you sure this is something you can live with? Do you want to spend the rest of your life on a ventilator?”*

*These are all the things we heard every day even though my health was improving . . . One Friday we did our daily disconnecting of the ventilator—but this time we never connected it back. I ended up staying off of the ventilator for good . . . When I returned for my follow-up appointment a year later I made it a priority to see that team of doctors. When I rolled into the offices pushing my own power chair, without a ventilator, and healthy as can be, their jaws dropped to the floor and their eyes began to fill with tears.*

Unfortunately, experiences like Terrie’s are all too common in the disability community. Numerous studies have demonstrated that physicians underestimate the quality of life of people with disabilities compared to our own assessments. Over the last two decades, bioethicists have even moved from attempting to quantify quality of life in terms of “quality adjusted life years” (QALYs) to “disability adjusted life years” (DALYs).<sup>49</sup>

Nevertheless, people might hope that physician behavior in applying pressure to withhold or withdraw life-sustaining treatment would never progress to outright involuntary denial of life-sustaining treatment. Unfortunately, the majority of states already have statutes that explicitly authorize physicians to withhold treatments that in their judgment are inappropriate, even if this is against the expressed wishes of the individual, their surrogate decision maker, and/or their advance directive.

### **When physicians involuntarily withhold life-sustaining treatment: futility**

Now, increasingly, another type of medical decision threatens older and disabled people, decisions by physicians in open opposition to the patient, their surrogate, and his or her advance directive—futility. A big part of many futile care policies is an Ethics Committee that holds meetings to persuade the family that they should agree with the physician. If the persuasion process is successful, the physician avoids the potential for litigation. This was the strategy suggested in a 1999 article in the *Journal of the American Medical Association*.<sup>50</sup>

But if the physician cannot convince the individual or surrogate to forego treatment, futile care policies provide that a physician may overrule a patient or their authorized decision-maker in denying wanted life-sustaining treatment. Futile care policies do not generally require that the treatment be objectively, medically futile but allow

physicians to use subjective criteria such as quality of life judgments as grounds for denying treatment.

Studies consistently demonstrate that physicians and other health care providers rate the quality of life of people with significant disabilities and illnesses significantly below individuals' ratings of their own quality of life.<sup>51</sup> These health care providers may also be financially penalized for providing too much health care (contracts call it "over-utilization"). During the decade since the 1999 AMA futility article, it has become evident that lawyers rarely take wrongful death cases involving people with significant illnesses, because damages are generally calculated based on the person's economic value, and cause of death may be hard to prove. So there's very little protection for consumers with expensive needs.

In 2006, a Texas futility case received some media attention. Reportedly, Andrea Clark, a conscious heart surgery patient in Houston, was the involuntary subject of a physician's treatment withdrawal decision in Texas under its "Futile Care" statute.<sup>52</sup> An "ethics committee" told her family that life support would be removed 10 days after they were given notice. Both before her surgery and when not medicated into unconsciousness afterward, Ms. Clark herself made her wishes in favor of treatment very clear. She had reportedly been declared terminal 5 years earlier and repeatedly survived her predicted demise. Through massive efforts, including protests and legal wrangling, the hospital relented and Ms. Clark spent an extra week with her family, including her 23-year-old son, before she died. But why did her family have to fight for her wishes to be honored?

Back before the patient autonomy movement of the 1970s and 1980s, physicians made all the life-and-death decisions. Now, some physicians think that patients and their families have gone too far in demanding medical treatment for people who are deemed too old or have advanced chronic health impairments. Some physicians and lawyers think that health care resources need to be rationed, and that physicians know best who should receive health care.

These self-identified bioethicists seem to think of themselves as progressives, but they rarely focus on ways to cut unnecessary costs, like excessive marketing, administrative, and executive compensation costs, before cutting lives. Rather than conquering the waste and inhumanity of a profit-driven health care system, these bioethicists pushed new health care decisions laws to increase the authority of physicians and guardians to withdraw life-sustaining treatment without the consent of the person.

At the same time, for seniors and people with disabilities who depend on publicly funded health care, federal and state budget cuts pose a very large threat. Many people with significant disabilities, including seniors, are being cut from Medicaid programs that provide basic help to get out of bed, use the toilet, and bathe. By forcing people into nursing facilities, states are violating the civil rights of hundreds of thousands. Protests are erupting in many

states.<sup>53</sup> Autonomy, Inc.'s assertions about "choice" seem hollow and out of touch with reality.

Disability rights leader Bob Kafka said of the Texas law, "The essence of the futility law embraces involuntary euthanasia. The ability of a physician to overrule both the patient and their surrogate in withdrawing life-sustaining treatment is a violation of the principle of patient autonomy."<sup>54</sup> What looks to some like a choice to die begins to look more like a duty to die to many disability activists.

After all the public education about the importance of making one's health care wishes clear through the use of advance directives, most people are shocked to learn that futility policies and statutes allow health care providers to overrule the patient, their chosen surrogate, or their advance directive and withhold desired treatment. Indeed, these decisions are obscured from researchers by the fact that physicians list the cause of death as the individual's medical conditions. These practices are occurring without the data collection needed to assess their nature, scope, and impact, effectively under the public radar.

Since involuntary passive euthanasia by physicians is already permitted by law and policy in most states, it is difficult to discern any rational basis for assuming that physicians are absolutely committed to patient autonomy, which is the cornerstone for giving them legal immunity for assisted suicide.

## Conclusion

Disability is at the heart of the assisted suicide debate. Some people fear disability as a fate worse than death and wish to ensure that society will grant them a neat and easy way to escape that experience.

Despite the protestations of Autonomy, Inc. and its nondisabled allies, it cannot be seriously maintained that assisted suicide laws can or do limit assisted suicide to people who are imminently dying, and voluntarily request and consume a lethal dose, free of inappropriate pressures from family or society. Rather, assisted suicide laws ensure legal immunity for physicians who already devalue the lives of older and disabled people and have significant economic incentives to at least agree with their suicides, if not encourage them, or worse. Since these same physicians are already empowered by "futility" laws and policies to overrule patient decisions to receive life-sustaining treatment and thus impose involuntary passive euthanasia, there is no basis to assume that they will uniformly prevent involuntary active euthanasia, even if they could.

The simple conclusion is that proponents of legalized assisted suicide are willing to treat lives ended through abuses of the practice as "acceptable losses" when balanced against their wish for a pleasant way out and their unwillingness to accept disability, or responsibility for their own suicide. We disagree.

Assisted suicide proponents also hold tightly to the assertion that the inclusion of assisted suicide in the array of authorized medical treatments will not lead to an expectation on the part of health care providers, families, or society that it is time for some people to accept that “treatment” for the benefit of those around them. This understandable hope is not justified by the disability experience of societal devaluation. For those few who feel that they must hasten their deaths to escape what they feel is the indignity of disability, the law should leave them to their own devices. Any competent person, however disabled, can commit suicide by refusing food and water.

As society’s proverbial “canaries” in the health care system, disability rights advocates are sounding the alarm against granting legal immunity to physicians for assisted suicide based on our experiences in the front lines of that system. Anyone who lives long enough will one day face these same experiences and, for most, they will discover that they view themselves as no more expendable than we do and may find themselves asserting that they, too, are “not dead yet.”

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