Advocates of Dignity Can Do Better than Death

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Taking Care of John, it’s what I did our entire 21 years together. . . . I had the great privilege of doing that full time as he was dying. . . . Th[e] case was another way to take care of him and to respect him and to respect our relationship. —Jim Obergefell

“In the end, I was left to reflect on what I would want in the face of my own death,” Brown wrote in a signing message. “I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others.” —California Governor Jerry Brown, on signing his state’s assisted suicide bill

Looking back, my problem was never my spinal cord injury. My problem was clinical depression and that can be treated. It’s the situation thousands of Americans with disabilities find themselves in—but all too often, these people

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only hear that “I can understand; I wouldn’t want to live in your situation, either.” —Joni Eareckson Tada

To teach my students to think critically about whether political alignments represent ideological consistency, I engage in the following exercise: I tell them I support marriage equality and reproductive choice. Then I ask them to guess whether I believe human beings contribute to climate change. Most raise their hands. I ask them to guess whether they believe I support a ban on high-capacity ammunition magazines. They raise their hands. Do I oppose the death penalty in most circumstances? Hands up. I nod conspiratorially, then smirk, sharing their budding insight.

Sometimes I take it a step further: do I support physician-assisted suicide? By this point, the nerve pattern is established, and the hands fly up. And then I say, “Well, actually . . .”

At this point allow me to stop and make my position crystal clear: when I say “physician-assisted suicide,” I am not talking about the “right to die.” You and I and every competent adult in this nation already have the right to die.

By the way, if you have not written an advance directive and have not told your loved ones and health providers what your wishes are, set this Article aside and get that done now.¹ I am not going anywhere (that I know of—and that is the point).

Welcome back.

Many good and earnest progressives defend choice above all and see a natural alignment between state-approved medically assisted death (as distinct from our established “right to die”) and the liberties our Court has embraced in recent decades.² In fact, after the Court’s decision in Obergefell v. Hodges,³ which struck down laws excluding same-sex couples from civil marriage,⁴ some prominent LGBT activists set their sights on assisted-suicide laws.⁵

Considering Jim Obergefell’s story, this is passing strange to me, to say the least. It is the story of a successful battle to combat the indignity of

⁴ Id. at 2607–08.
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discrimination. It is also the story of a man with a long-term illness; of a spouse who had the privilege to care for him as he died; and of the power we all have to imbue our whole lives—even the end of our lives—with meaning.

I do not know Jim Obergefell or whether he supported the California law or similar legislation now under consideration. I do know that the indignity he fought and conquered was not his husband’s ALS and the progressive disability it brought; it was Ohio’s shameful marriage ban. If we are to draw anything from the Obergefell decision, it is that the state must never brand some loves not worth having, some lives less worth living, and some destinies less dignified than others.

In Part I of this Article, I assert that the concept of “death with dignity” stands in opposition to those principles. It is a concept that places value on some ways of being (ambulatory, verbal, capable of performing daily functions without assistance), and declares other lives—disabled lives—as “undignified.” It is also a simplistic, inadequate, and not particularly progressive approach to an issue—end-of-life needs of individuals and their families—that demands a comprehensive, progressive solution.

In Part II, I will argue that because they carve certain people out of the state’s definition of “dignity,” they are not the progeny of the Obergefell decision; that assisted suicide laws are inconsistent with a progressive conception of liberty because they do not offer meaningful choice; and that neither the history of the LGBT rights movement nor progressive values dictate that state-approved physician-assisted death is our next civil rights battle.

In Part III, I propose that those of us who value autonomy, comfort, self-determination, and justice in end-of-life care and decisions dedicate ourselves to address the stigma and misunderstanding that cause so many Americans to define dignity to be inconsistent with disability; de-link equality from sameness; enhance autonomy by providing education and supporting individuals and families in considering their options and communicating their wishes; and ensure access to high-quality care, services, and supports so that people have meaningful opportunities to exercise choice, not hypothetical rights.

I. Medically Assisted Death Is Inconsistent with the Progressive Vision of Liberty Because It Does Not Guarantee Choice

A typical progressive interpretation of “liberty” is as follows: If the guarantee of liberty in our Constitution means anything, surely it means that the government cannot control our bodies. Cases such as Griswold v. Connecticut (striking down criminal bans on dispensing contraception),4 Roe v. Wade (striking


5 Obergefell, 135 S. Ct. at 2594–95.

4 381 U.S. 479 (1965).
down criminal bans on abortion), and *Lawrence v. Texas* (striking down criminal bans on certain adult, private, consensual sex acts) demonstrate the Court’s increasing commitment to this principle:

Liberty protects the person from unwarranted government intrusions into a dwelling or other private places. In our tradition the State is not omnipresent in the home. And there are other spheres of our lives and existence, outside the home, where the State should not be a dominant presence. Freedom extends beyond spatial bounds. Liberty presumes an autonomy of self that includes freedom of thought, belief, expression, and certain intimate conduct.

Liberty as the absence of government regulation lends itself to full-throated support for allowing physicians to administer life-ending drugs to their patients who request them. This is particularly true when it comes to medical matters, where a more expert authority—a physician—is guiding the individual in exploring options and making decisions. Indeed, Justice Blackmun’s *Roe* opinion focuses on the physician-patient relationship and draws upon his work with the Mayo Clinic to use the trimester framework to balance the competing interests of the woman’s autonomy and the potential human life.

Proponents of the “right to die” leverage the principle of corporeal autonomy and integrity in promoting so-called “death with dignity” laws, which give physicians latitude to offer lethal doses of medication to patients who request them. But whether “death with dignity” laws are the rational outgrowth—either constitutionally or logically—of the Court’s and the public’s embrace of corporeal autonomy from government intrusion is by no means clear.

In one sense, physician-assisted death could be seen as a right similar to access to abortion: a safeguard against unexpected and life-changing events. Unlike abortion, however, the power to secure life-ending medicine is not associated with one gender, and denial of it does not disproportionately burden a protected class of people. Also unlike reproductive choice, access to life-ending medication is not central to economic and employment opportunity. The finality of death also distinguishes the two: the woman who has an abortion may get pregnant again.

However, if we conceive of liberty as choice—a term embraced by those who offer reproductive health services and work to defend *Roe*—instead of freedom

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11 Id. at 562.
12 *Roe*, 410 U.S. at 162–66; LINDA GREENHOUSE, BECOMING JUSTICE BLACKMUN: HARRY BLACKMUN’S SUPREME COURT JOURNEY 18, 82 (2006) (noting that Justice Blackmun had represented the Mayo Clinic in private practice and called on his experience while drafting the *Roe* opinion).
13 Reproductive Health Is Part of the Economic Health of Women and Their Families, NAT’L WOMEN’S L. CTR. (May 29, 2015), http://www.nwlc.org/resource/reproductive-health-part-economic-health-women-and-their-families. As noted above, however, chronically or terminally ill people are not guaranteed the services and supports they need, and providing them can create a large financial burden on the family.
from regulation, then physician-assisted death does not deliver liberty. Merriam-Webster defines choice as:

[T]he act of choosing: the act of picking or deciding between two or more possibilities: the opportunity or power to choose between two or more possibilities: the opportunity or power to make a decision: a range of things that can be chosen.14

While death is not attractive for most voters (to say nothing of progressives, who support death penalty repeal),15 we treasure choice. The title of California’s newly-passed assisted-death law—the “End of Life Option Act”16—reflects this value.

To the drafters’ credit, the Act is drafted to respect choice. For example, the Act requires physicians to inform their patients of, among other things:

(D) The possibility that he or she may choose to obtain the aid-in-dying drug but not take it.

(E) The feasible alternatives or additional treatment options, including, but not limited to, comfort care, hospice care, palliative care, and pain control.17

The problem is, although the bill’s text honors choice, the real world in which we live does not. First, although a person may choose not to take a life-ending dose of drugs once she has secured them, this occurs in only a minority of cases. In fact, thirty-five percent of patients who have sought life-ending medication in Oregon have declined to exercise their option.18 However, the law contains no safeguards to ensure that once a person secures the drugs, her decision not to take them will be honored.19 A caregiver—who might be exhausted from months of care; whose resources could be dwindling because family and medical leave in this country is unpaid and our government offers scant support for caregivers; who stands to inherit when the patient dies; who

17 Id. § 443.5.
18 Or. Pub. Health Div., Oregon’s Death with Dignity Act—2014, at 2 (2015), https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf (“Since the law was passed in 1997, a total of 1,327 people have had [Death with Dignity Act (DWDA)] prescriptions written and 859 patients have died from ingesting medications prescribed under the DWDA.”).
earnestly and in good faith believes she has a duty to help her loved one honor an earlier wish to die; and whom the dying person wishes to spare any more pain and burden—may facilitate death unsupervised, unregulated, and out of the public eye.\footnote{20}

Second, the Act does not provide any of the alternatives or treatment options it requires physicians to prescribe. This is a problem because California does not guarantee all people access to comfort care, palliative care, hospice care, and/or pain control. Middle-class people with private insurance might not have coverage for home-based hospice services that permit a person to die in the presence of family rather than in an institution. For them, paying for such care out of pocket or providing it themselves might be the only feasible alternative to death. Poor and undocumented people fare even worse, finding that they might be provided cheap life-ending medications but not long-term care.

The Autistic Self Advocacy network highlighted this problem in its testimony opposing similar legislation in the District of Columbia:

When people are offered the option of suicide but not the option of affordable home care, they do not have any meaningful choice. People with significant disabilities due to illness should not have to die in order to have dignity. Instead, they need access to the things that help them make the most of their remaining time: quality palliative care, respectful in-home supports, counseling, and assistive technology to maximize autonomy.\footnote{22}

Conspicuously absent from this options bill is any form of support for any option apart from death—which so happens to be the cheapest, fastest, most budget neutral option. It is telling that the Act did not provide money for home and community-based services, expand insurance coverage for hospice care, or make the choice to live any easier for any Californian.

As I explain more fully below, the problem of scarce resources is particularly troubling when it intersects with disability. The Disability Rights Defense and Education Fund has explained this problem: profit-driven providers, particularly managed care systems, will be faced with the choice between life-ending medications generally costing about $300, and expensive, life-saving treatment.\footnote{23}

People with disabilities often require long-term services and supports such as medical treatment, home health aides, and adaptive equipment. When there is no guarantee that such services will be provided, the fact that death is a cheaper, quicker alternative—branded by the state as an acceptable alternative to

\footnotesize{\begin{itemize}
\item \footnote{20} In fact, forty percent of Oregon patients list being a “[b]urden on family, friends/caregivers” as a reason they want to take life-ending drugs. Or. Pub. Health Div., \textit{supra} note 18, at 5.
\item \footnote{22} 2015 ABX2 15, \textit{supra} note 19, at 1–3.
\item \footnote{23} \textit{ASAN Testimony on Assisted Suicide, Autistic Self Advocacy Network} (July 16, 2015) http://autisticadvocacy.org/2015/07/asan-testimony-on-assisted-suicide/.
\item Marilyn Golden & Tyler Zoanni, \textit{Killing Us Softly: The Dangers of Legalizing Assisted Suicide}, 3 Disability & Health J. 16, 18 (2010).
\end{itemize}}
disability—puts people with disabilities at odds with their public and private insurance providers.

At the same time, the California law—which, if history is any judge, will be a model for future states—does not provide as expansive a “right to die” as supporters of corporeal autonomy would like. Only people who have been diagnosed with a terminal illness and a life expectancy of six months or less are eligible. Setting aside the challenges of determining life expectancy (Stephen Hawking was given two years to live in 1963), the law excludes many realistic scenarios that drive the demand for access to physician-assisted death.

For example, Law Professor Norman Cantor has written poignantly about his plan to avoid the perceived loss of self that would accompany dementia should he ever be diagnosed with Alzheimer’s or a similar condition. Explaining his plan to commit suicide before losing his cognitive function, he wrote: “My aversion is grounded rather in my abhorrence of reduced mental function to a degree I deem intolerably demeaning.”

His frank calculation will resonate with some and repulse others, as discussions of death invariably do. But one thing is for sure: California’s law does not cover the situation he wishes to avoid. Nor does it offer respite to people in chronic, excruciating pain that results from a non-terminal condition.

Nor can the law guarantee that all physicians—much less the best physicians—agree to provide life-ending medication to the patients who request it. We can reasonably expect to see many physicians refuse to participate, in light of the fact that the American Medical Association describes physician-assisted suicide as “fundamentally incompatible with the physician’s role as healer.” Religiously affiliated medical networks could also prohibit member physicians from engaging in the practice.

The fight for a truly dignified and humane policy on end-of-life, then, must include services for the living.

II. Death with Dignity Is Not the Progeny of Obergefell v. Hodges

A. Obergefell v. Hodges Denying Equality = Indignity

Jim Obergefell’s late husband, John Arthur, was diagnosed with ALS in 2011, and grew progressively disabled in the next two years. The couple married...
just three months before Arthur’s death, traveling to Maryland to do so because their home state of Ohio denied them that right, and knowing that Ohio would discriminate against their union when they returned.\(^{29}\)

It was difficult for Arthur to move, and so the couple were wed inside a medical transport plane as it remained on the tarmac in Baltimore. Three months later, Arthur died. Ohio law does not permit Obergefell to be listed as the surviving spouse on Arthur’s death certificate. By statute, they must remain strangers even in death, a state imposed separation Obergefell deems “hurtful for the rest of time.” He brought suit to be shown as the surviving spouse on Arthur’s death certificate.\(^{30}\)

Obergefell committed himself to ensuring that he and his husband would not remain legal strangers. He fought for the dignity that rightly belonged to these men and that Ohio was denying them. Obergefell recounted:

> John and I started our fight for a simple reason: We wanted the State of Ohio to recognize our lawful Maryland marriage on John’s impending death certificate. We wanted respect and dignity for our 20-year relationship, and as he lay dying of ALS, John had the right to know his last official record as a person would be accurate. We wanted to live up to the promises we made to love, honor, and protect each other as a committed and lawfully married couple.\(^{31}\)

Indeed, Jim Obergefell and John Arthur’s story illustrates marriage bans at their most brutal: branding loved ones as strangers even in death.

In spring 2015, the Court considered Obergefell’s case (and several companion cases), and recognized a right to dignity grounded in the Fourteenth Amendment that includes marriage rights for same-sex couples.\(^{32}\) In his majority opinion in Obergefell, Justice Anthony Kennedy used the term “dignity” nine times, clarifying that dignity is an essential component of liberty and equality, and declaring that marriage bans, both in purpose in effect, robbed thousands of Americans of the dignity that is their birthright.\(^{33}\)

The decision, a victory both for personal autonomy and restraint on government judgments about intimate relationships, can rightly be seen as the progeny of earlier decisions on corporeal autonomy and control over family composition: Griswold\(^{34}\) and Roe.\(^{35}\) But Kennedy cited neither Roe nor Griswold,\(^{36}\)


\(^{32}\) Obergefell, 135 S. Ct. at 2597–99.

\(^{33}\) Obergefell, 135 S. Ct. at 2594–97, 2599, 2603, 2606, 2608.

\(^{34}\) Griswold v. Connecticut, 381 U.S. 479 (1965).
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choosing instead to cite his own opinion in Lawrence v. Texas36 (a decision that itself relied heavily upon Roe and Griswold).37

Lawrence forms a bridge between the reproductive choice cases and the marriage decision by linking the denial of corporeal autonomy to a stigmatizing denial of dignity:

The stigma this criminal statute imposes, moreover, is not trivial. The offense, to be sure, is but a class C misdemeanor, a minor offense in the Texas legal system. Still, it remains a criminal offense with all that imports for the dignity of the persons charged.38

By relying on Lawrence, Kennedy could hang his argument on dignity rather than solely on corporeal autonomy. Although in Lawrence, Kennedy had declined to strike down sodomy laws based on Equal Protection39 (as Justice O'Connor’s concurring opinion would have done),40 his soaring, lofty Lawrence opinion was a shot across the bow for a new vision of personal liberty grounded in equality and deep suspicion of laws that serve to stigmatize one group of people.

In its entirety, the Obergefell opinion seamlessly conflates equality and liberty.41 Dignity, the Court concludes, is under assault when a group of people who are similarly qualified to enjoy a right so basic as marriage are denied it out of animus. This is not Griswold’s nor Roe’s medicalized approach to the body, nor even the right to be left alone that libertarians articulated in their briefs opposing sodomy laws: “The right of same-sex couples to marry that is part of the liberty promised by the Fourteenth Amendment is derived, too, from that Amendment’s guarantee of the equal protection of the laws.”42

In Obergefell the Court described the denial of marriage as:

[A]n exclusion that soon demeans or stigmatizes those whose own liberty is then denied. Under the Constitution, same-sex couples seek in marriage the same legal treatment as opposite-sex couples, and it would disparage their choices and diminish their personhood to deny them this right.43

Unlike the miscegenation statutes struck down in Loving v. Virginia,44 or the Defense of Marriage Act, which the Court struck down in 2013,45 bans on

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37 Obergefell, 135 S. Ct. at 2598–2604.
38 Lawrence, 539 U.S. at 575.
39 Id. at 574–75.
40 Id. at 578 (O’Connor, J., concurring).
41 Admittedly, Kennedy acknowledged the importance of autonomy in Obergefell, noting that “[a] first premise of the Court’s relevant precedents is that the right to personal choice regarding marriage is inherent in the concept of individual autonomy. This abiding connection between marriage and liberty is why Loving invalidated interracial marriage bans under the Due Process Clause.” Obergefell, 135 S. Ct. at 2599.
42 Id. at 2602.
43 Id.
44 388 U.S. 1 (1967).
assisted suicide were not enacted out of animus toward a disfavored group. Nor is there evidence that opponents of “death with dignity” laws harbor animus toward people who earnestly believe they would wish to hasten their deaths if they had a terminal illness. Thus, to the extent that such laws constitute a denial of liberty, a challenge based on Obergefell is unlikely to succeed.

B. Obergefell’s Rationale Should Not Be Divorced from the Right It Considered—Marriage

Far from being a victory for individualism, freedom from regulation, or autonomy unfettered by responsibility, the Obergefell decision is a paean to marriage, with its purported civilizing influence and centrality to building a society. “In Maynard v. Hill, the Court echoed de Tocqueville, explaining that marriage is ‘the foundation of the family and of society, without which there would be neither civilization nor progress.'” 46 “No union is more profound than marriage, for it embodies the highest ideals of love, fidelity, devotion, sacrifice, and family.” 47

Because Kennedy is so insistent that marriage represents the zenith of human aspiration and experience, some commentators have criticized the decision as degrading to single people and those who choose intimate relationships other than marriage. 48

In spite of this, some see in Obergefell an opportunity for a more expansive vision of liberty to take hold—including in the area of end-of-life decisions. 49 Some have said that the decision undermines the Court’s 1997 ruling in Washington v. Glucksberg, 50 holding that Washington State’s criminal ban on causing or aiding a suicide did not violate the Fourteenth Amendment’s Due Process Clause. 51

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46 Obergefell, 135 S. Ct. at 2601 (citation omitted).
47 Id. at 2608.
48 Bella DePaulo, Gay Marriage Ruling Is Matrimaniacal, Shames Single People, Psychology Today (June 26, 2015), https://www.psychologytoday.com/blog/living-single/201506/gay-marriage-ruling-is-matrimaniacal-shames-single-people (“What all these people are swooning over is all-out matrimania (the over-the-top hyping of marriage and weddings and coupling). The message is that marriage is magical, transforming unremarkable unmarried people into ‘something greater.’ It is an unapologetic declaration of the superiority of the marital bond over every other bond and every other relationship that humans hold dear. And it is a crass degrading of single people as ‘condemned to live in loneliness.’”).
51 Id. at 705.
In *Glucksberg*, the Court justified Washington’s criminal law on the longstanding history of suicide bans in this country. In rejecting the Due Process challenge, the Court concluded that the Due Process Clause protects rights that are “deeply rooted” in the nation’s legal tradition. The *Glucksberg* approach to Due Process is about judicial modesty:

But we “ha[ve] always been reluctant to expand the concept of substantive due process because guideposts for responsible decisionmaking in this unchartered area are scarce and open-ended.” By extending constitutional protection to an asserted right or liberty interest, we, to a great extent, place the matter outside the arena of public debate and legislative action. We must therefore “exercise the utmost care whenever we are asked to break new ground in this field,” lest the liberty protected by the Due Process Clause be subtly transformed into the policy preferences of the Members of this Court.

Chief Justice Roberts’s dissent in *Obergefell* relies heavily on *Glucksberg*, appealing to the sense that courts must “proceed with caution” in order to avoid disrupting our legal and political systems. Justice Alito’s dissent cites *Glucksberg* while raising the specter of “five unelected Justices from imposing their personal vision of liberty upon the American people.”

Indeed, *Obergefell* casts doubt on the reasoning in *Glucksberg* that Due Process analysis is a backward-looking affair, defining what must be by what has been. However, Justice Kennedy took great pains not to frame marriage equality as a new right that would be foreclosed by a *Glucksberg* approach. He stated that the Petitioners were not asking the Court to recognize a new right to same-sex marriage; they were challenging their exclusion from a right that is deeply rooted in our nation’s history and legal tradition:

*Loving* did not ask about a “right to interracial marriage”; *Turner* did not ask about a “right of inmates to marry”; and *Zablocki* did not ask about a “right of fathers with unpaid child support duties to marry.” Rather, each case inquired about the right to marry in its comprehensive sense, asking if there was a sufficient justification for excluding the relevant class from the right.

Although Kennedy also indicates that rights do not always arise from ancient sources and may in fact come “from a better informed understanding of how constitutional imperatives define a liberty that remains urgent in our own
era,” this statement leads to the discussion of the liberty-equality hybrid, not a wholesale abandonment of a modest approach to recognizing new rights.

Even assuming Justice Kennedy jettisoned the deeply rooted approach of Glucksberg, as Justice Roberts claimed in dissent, Kennedy explicitly denied that his new approach necessarily extended to assisted suicide:

Glucksberg did insist that liberty under the Due Process Clause must be defined in a most circumscribed manner, with central reference to specific historical practices. Yet while that approach may have been appropriate for the asserted right there involved (physician-assisted suicide), it is inconsistent with the approach this Court has used in discussing other fundamental rights, including marriage and intimacy.

Therefore, even if Glucksberg’s reasoning is on shaky ground, its rejection of a right to assisted suicide probably is not.

C. The Death with Dignity Movement Creates a Special Exception to Generally Applicable Laws on Suicide, Making Disability the Only Valid Reason to End One’s Life Rather than Seek Psychological Help

*Why should a quadriplegic get help to commit suicide when most people get suicide intervention, unless there is an underlying belief that our lives are worth less than that of an able bodied person*?—Kelly Buckland, National Council on Independent Living

*Get used to the new person who is growing inside you. Look for support near and far. The Internet is full of people telling their stories on blogs and discussion threads. You are not alone. You will be amazed by how many people are like you.*—A Letter to Any Teen Who’s Thinking About Suicide

Although proponents of physician-assisted suicide are not motivated by animus, in practice so-called “death with dignity” laws single out certain people—those with disabilities. Such people are carved out from generally applicable criminal laws against suicide. Increasing public acceptance of assisted suicide demonstrates a double standard; when a person expresses the desire to die because of homophobia or transphobia, either because she believes her family

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59 Id.
60 Id. at 2620–21 (Roberts, C.J., dissenting).
61 Id. at 2602.
will not accept her, or because her sexuality conflicts with her religious faith and community beliefs, then we direct her toward psychological and psychiatric services.

By contrast, “[t]hree of the 105 [Oregon Death with Dignity Act] patients who died during 2014 were referred for formal psychiatric or psychological evaluation.” As Autistic Self Advocacy Network Director of Public Policy Samantha Crane explained to me, “Nothing other than disability, which includes illness-related disability, is seen as an actual basis for wanting to die.” Kelly Buckland of the National Council on Independent Living has seen this double standard affect the care that people with disabilities receive:

I have seen far too many of my brothers and sisters with disabilities treated differently than their non-disabled peers when they are depressed and feeling suicidal, and die as a result! I have personal experience with this and tried suicide shortly after my injury. Just think what would have happened if I had succeeded! My life would have been cut short by over forty years, and my son would not have been born.

By calling themselves “death with dignity” laws, these measures also equate disability with indignity and indicate that in the eyes of the state, some lives are less worth living than others (or that it would be reasonable to conclude that certain lives are not worth living). And although these laws are often promoted as a means of escaping unavoidable pain, in fact the prospect of disability, not pain, drives both political support and individual decisions to choose assisted suicide where available.

Experience with Oregon’s physician-assisted suicide law demonstrates this. Since 1998, only twenty-five percent of Oregon patients who ingested life-ending medications cited pain as a motivation for choosing assisted suicide. By contrast, in 2014, the “three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%).” Forty percent of patients also cited being a burden on family, friends, and caregivers as a motivation.

As Marilyn Golden and Tyler Zoanni of the Disability Rights Defense and Education Fund explain:

This fear of disability typically underlies assisted suicide. Janet Good, an assisted suicide advocate who worked with Jack Kevorkian, was clear

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66 Telephone interview with Samantha Crane, Legal Director and Director of Public Policy, Autistic Self Advocacy Network (Aug. 5, 2015).
68 Or. Pub. HEALTH Div., supra note 18, at 5 (211 out of 859 individuals who took the drug).
69 Id. at 2.
70 Id. at 5.
about this: “Pain is not the main reason we want to die. It’s the indignity. It’s the inability to get out of bed or get onto the toilet. . . . [People] . . . say, ‘I can’t stand my mother—my husband—wiping my butt.’” But as many thousands of people with disabilities who rely on personal assistance have learned, needing help is not undignified, and death is not better than reliance on assistance. Have we gotten to the point that we will abet suicides because people need help using the toilet?\textsuperscript{71}

Disability rights advocates, who overwhelmingly oppose physician-assisted suicide,\textsuperscript{72} recognize that the concerns motivating those who choose assisted suicide are often features of everyday life for people with disabilities.\textsuperscript{73} For example, many people with disabilities utilize home- and community-based services such as aides for personal care and to maximize independence. People who acquire a disability later in life, such as through spinal cord injury, will lose access to some of the activities they once enjoyed. And particularly due to scant (and decreasing) government support for the services that benefit people with disabilities, family and caregivers shoulder additional responsibilities.\textsuperscript{74} These features of disability are defined in opposition to dignity, and then they are used to carve out an exception to generally applicable laws.\textsuperscript{75}


\textsuperscript{74} See e.g., John B. Mitchell, supra note 27, at 1087 (“‘Death with dignity’ is, as the phrase states, about the manner of one’s death. People react to the narrative—tubes, soiled adult diapers, complete dependence—and become upset beyond comprehension.”); Susan M. Behuniak, \textit{Death with “Dignity”: The Wedge That Divides the Disability Rights Movement from the Right to Die Movement}, 30 POL. & LIFE SCI. 17 (2011) (reviewing how differing concepts of dignity between the disability rights and the right-to-die movements causes a divide, and asserting that the value of dignity is the key to productive discourse between these movements); Robin Marantz Henig, \textit{A Life-or-Death Situation}, N.Y. TIMES MAG. (July 17, 2013), http://www.nytimes.com/2013/
Testifying in opposition to the District of Columbia’s Death with Dignity Act, Crane explained, “[t]his mindset perpetuates stigma, isolation, and depression among people with disabilities, including disabilities related to illness. It also increases already heightened vulnerability to medical discrimination, abuse, isolation, and discrimination.” Others have argued:

Because of public images that disability is “a fate worse than death,” legalized assisted suicide threatens to create a “two-tiered system”: nondisabled individuals who express suicidal wishes will receive suicide prevention services, while individuals with disabilities will receive lethal prescriptions, resulting “in death to the socially devalued group.”

As troubling as physician-assisted suicide is to the disability community, the public increasingly has sympathy with this position. While only nineteen percent of Americans consider suicide morally acceptable (polygamy came in at sixteen percent), over sixty percent of Americans say that doctors should be able to assist terminally ill patients in ending their lives, and fifty-six percent say physician-assisted suicide is morally acceptable.

D. Thinking Big(ger Even than Obergefell)

For some of us, marriage will be a ticket out of the margins. But it would be a tragedy if, vindicated by the Supreme Court, many of us proclaim a premature victory, overlooking those of us who are still left out, and many more people around the world for whom the quest for basic recognition is much in doubt. Betraying our history—forgetting what it has meant to be gay—would be a price too high to pay.

The central, transformative value of Obergefell is that “[w]hen new insight reveals discord between the Constitution’s central protections and a received
legal stricture, a claim to liberty must be addressed.” Though it is a great leap forward for families seeking access to civil marriage (and not a stepping stone to strike down laws not linked to animus or unequal treatment) it does not offer much to those who do not, or cannot, claim to be the same as everyone else.

The hard-fought, important movement that led to Obergefell depended upon a narrative of sameness: this family is like yours. We are your neighbors and relatives and friends. We do the same things you do, yet we are treated differently. Amicus briefs filed in Obergefell supported the argument that families headed by same-sex couples are similar to those headed by different-sex couples. For example, the American Psychological Association’s amicus brief argued that same-sex relationships are “equivalent to heterosexual relationships in essential respects.” In support of their argument, they wrote that “[e]mpirical research demonstrates that the psychological and social dimensions of committed relationships between same-sex partners largely resemble those of heterosexual partnerships.”

The amicus brief of the American Sociological Association described how children raised by same-sex couples fare no differently than those raised other families. The Human Rights Campaign’s brief stated: “gay couples have been supporting each other, raising children together, and facing the same quotidian joys and burdens (‘in sickness and in health’) faced by other married couples for many years."

If we accept the implication that equality is the reward for sameness, then our societal conceptions of sameness and otherness control other people’s destinies. This is particularly insidious when it comes to disability. At this point in time, many straight Americans see the lesbians next door, who use reproductive technology to build their families, as the same and therefore entitled to the same privileges afforded everyone. However, the autistic person who uses assistive technology to speak is seen as other. The person who uses an ostomy for bodily wastes is other (and, according to the death-with-dignity narrative, that person is not dignified). And even for many people who have come to support marriage equality, the transgender woman who uses hormone therapy to maintain her physical and mental health is also seen as other.

The distinction between the above-mentioned people and needs is an artificial one—as artificial as the purported distinctions between same-sex and different-sex couples. However, in a world where sameness is the ticket to civil

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84 Id. at 12.
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rights, these distinctions matter. If one may only secure equal justice when they are acknowledged as the same, then the very prejudice and mistrust that marginalizes people with disabilities justifies their exclusion from constitutional rights and liberties.

It is not surprising that Obergefell, a case about access to a conservative institution, articulates a fairly conventional idea of human dignity: being allowed into the same club as other respectable people. But its reasoning is inadequate to tackle the challenge of providing resources to people who do not purport to be the same, and for whom symbolic opportunity is meaningless without tangible supports. We must therefore see Obergefell’s promise as a floor, not a ceiling—and fight for the progressive priorities (health care, economic security, acceptance of diversity).

III. Universal Design for End-of-Life Decisions: The Disability Rights Model

So, what is a good progressive to do? Short answer: aim higher. Aspire to something more than an escape hatch from a life deemed not worth living; invest in improving lives and creating a landscape of meaningful, realistic, and accessible choices for every person.

Fortunately, we do have a model for supporting people with chronic or terminal illness: the disability rights model.

A. Treat People Better than the Same

Physician-assisted suicide laws attempt to address the problems of low quality of life, pain, financial burden, and indignity associated with serious illness. However, most of these problems have more solutions than death alone (and experience in Oregon shows that many people do not prefer death). The challenge is to treat people differently so that their lives can be as unchanged as their illnesses will allow.

The Americans with Disabilities Act (ADA), the civil rights law that has opened the door to employment, education, and community participation for millions of Americans once consigned to the margins, recognizes that it is not enough to bar employers from making an adverse hiring decision based on disability—if an applicant cannot even get through the door, then protection from being denied an interview because of her disability is functionally meaningless. As a result, the ADA defines “discrimination” to include the failure to provide “reasonable accommodations.” Such accommodations could include anything from a quiet workspace for a worker with sensory processing issues or an interpreter at staff meetings for a deaf employee.

By defining failure-to-accommodate as discrimination, the ADA leveled the playing field. Previously, an employer had a free pass to exclude an otherwise qualified person by blaming her disability, saying: this is not the right job for you because you can’t hear. Now, the tables are turned. Instead, the law looks at an

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88 Id. § 102; 42 U.S.C. § 12112(b)(5)(A).
89 Id.
employer and says: you are not living up to your legal obligations because you make it impossible for a qualified deaf person to work there.

This is a solid model to craft an alternative to single-minded focus on physician-assisted death as an end-of-life option. We know the reasons people believe they will want to end their lives—pain, burden on family, reduced quality of life, fear of hospitals and nursing homes, and lack of autonomy. We also know that we are doing very little to maximize the wellbeing of many people in these end stages. We are not providing guaranteed palliative care, financial and psychological supports for caregivers, paid leave for family members, or services that enable a person to spend her final days in her community rather than receiving pain medication in an isolated hospital room. The absence of these services is not the fault of the assisted-suicide lobby; however, it is the responsibility of any proponent of end-of-life choices to fight for them.

I challenge anyone who is advocating for physician-assisted suicide to advocate for more, including accommodations that enable a terminally ill person to choose among a number of alternatives apart from simply misery and financial ruin or death. This is consistent with progressive priorities in other policy arenas: federal funding for low-income schools; affordable health care; the Earned Income Tax Credit. It is progressive to invest in the extra help that levels the playing field meaningfully.

I challenge supporters of assisted suicide to demand that every piece of legislation they support includes access to community-based palliative care, hospice care, and caregiver support.

B. Life in the Community

Many people fear spending the end of their lives in a nursing home or hospital. And rightly so. These institutionalized settings are the antithesis of autonomy. Other people make decisions that we all want to make for ourselves: what and when we eat, what our living arrangements look like, and who assists us with our personal needs. To the extent that proponents of assisted suicide want a way to avoid institutional living, they have no greater or more experienced ally than people with disabilities, who have been engaged in a battle for the right to live in the community for decades. Life in the community is a central principle to disability rights.\footnote{Community Integration for People with Disabilities: Key Principles, Judge David L. Bazelon Ctr. for Mental Health L. (2014), http://www.bazelon.org/portals/0/ADA/5-23-14%20Key%20Principles%20of%20Community%20Integration.pdf.}

The 1999 case of \textit{Olmstead v. L.C.},\footnote{Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999).} held that unjustified segregation of people with disabilities into institutions violated the ADA.\footnote{Id. at 587.} The Court concluded that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural

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Moreover, the Court ruled that where people were capable of living in the community and willing to do so, community-based services must be provided if resources permit it.\footnote{Id. at 607.}

Advocates of end-of-life options should work with disability advocates to demand resources for community-based care, including: home-based hospice care, palliative medicine, and personal assistance. All of these resources enhance autonomy and enable people to spend time with their families without causing excessive strains on caregivers. They are also far cheaper than the institutional care that many of us wish to avoid.\footnote{Costs in Detail, Nat’l Council on Disability, https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail (last visited May 31, 2016).}

C. Educate About the Existing Rights We Have and Avoid Linking Disability with Indignity

Even in states where assisted suicide is illegal, we retain the power to shape important decisions about how much care we receive and what kind, who will make decisions if we are unable to, and whether we want to continue to receive nutrition and water when we can no longer eat and drink on our own.\footnote{For information about advance directives, see Advance Directives, Am. Cancer Soc’y, http://www.cancer.org/treatment/findingandpayingfortreatment/understandingfinancialandlegalmatters/advancedirectives/advance-directives-toc (last visited May 31, 2016).}

Taking the time to create an advance directive and communicate wishes to loved ones is important (do it).

It is difficult to know how our future self will feel about the life that illness and disability brings. Research shows that people change their minds over time.\footnote{Golden & Zoanni, supra note 23, at 20.}

As we age, care for loved ones at the ends of their lives, and develop new connections to the future through children, grandchildren, or community engagement, our values about end-of-life decisions are bound to shift. It is worth revisiting and communicating your wishes. A tool called “Five Wishes”\footnote{The Five Wishes Advance Directive Form, Positive Healthcare, http://positivehealthcare.net/wp-content/uploads/2014/04/Five-Wishes-for-Website_PHP.pdf (last visited May 31, 2016).} is a useful road map for considering end-of-life wishes and is a legally valid directive in some states.\footnote{Five Wishes, Friends Hospice, http://www.friendsofhospice.net/wishes.html (last visited May 31, 2016).}

I challenge advocates for physician-assisted death to: (a) educate the public on the extent to which the “right to die” is already in our hands (to its credit, assisted-suicide lobbying group Compassion and Choices provides advice on advance directives and a particularly useful “values worksheet” that encourages people to consider which options they might prefer, including home-based

\footnote{Id. at 601.}

\footnote{Id. at 607. Since then, advocates have been fighting the battle to secure those resources and enforce Olmstead.}


\footnote{Golden & Zoanni, supra note 23, at 20.}


\footnote{Five Wishes, Friends Hospice, http://www.friendsofhospice.net/wishes.html (last visited May 31, 2016).}

\footnote{Id. at 601.}
hospice care); (b) actively correct the record when their supporters or allies raise the specter of forced treatment, being hooked up to machines, and not being allowed to die; and (c) work in coalition with other interested groups, including disability organizations and mental health providers, to educate about end-of-life choices in a way that de-links disability from indignity.\footnote{Values Worksheet, Compassion & Choices, https://www.compassionandchoices.org/userfiles/Values-Worksheet.pdf (last visited May 31, 2016).}

The American Psychological Association’s policy statement on assisted suicide would serve as a model.\footnote{APA Resolution on Assisted Suicide, Am. Psychol. Ass’n, http://www.apa.org/about/policy/assisted-suicide.aspx (last visited May 31, 2016).} The organization, which is formally neutral on assisted suicide, favors advocating for more resources and more thorough care:

Let it be further resolved that the American Psychological Association will assist in preparing the profession to address the issue of assisted suicide by taking the following actions:

- Advocate for quality end-of-life care for all individuals; and
- Encourage and promote the development of research on assisted suicide; and
- Monitor legal, policy, and research developments that may require or encourage psychologists to involve themselves in assisted suicide cases; and
- Promote policies that reduce suffering that could lead to requests for assisted suicide; and
- Promote psychologists’ involvement in research on ethical dilemmas faced by clinicians and researchers dealing with issues related to assisted suicide; and
- Promote psychologists’ participation in multidisciplinary teams and ethics committees involved with reviewing end-of-life requests; and
- Encourage psychologists to obtain training in the area of ethics as it applies to end-of-life decisions and care; and
- Encourage practicing psychologists to inform themselves about criminal and civil laws that have bearing on assisted suicide in the states in which they practice; and
- Encourage practicing psychologists to recognize the powerful influence they may have with clients who are considering assisted suicide; and
- Encourage psychologists to identify factors leading to assisted suicide requests (including clinical depression, levels of pain and suffering, adequacy of comfort care, and other internal and external variables) and to fully explore alternative
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interventions (including hospice/palliative care, and other end-of-life options such as voluntarily stopping eating and drinking) for clients considering assisted suicide; and

- Encourage practicing psychologists to be aware of their own views about assisted suicide, including recognizing possible biases about entitlement to resources based on disability status, age, sex, sexual orientation, or ethnicity of the client requesting assisted suicide; and

- Encourage psychologists to be especially sensitive to the social and cultural biases which may result in some groups and individuals being perceived by others, and/or being encouraged to perceive themselves, as more expendable and less deserving of continued life (e.g., people with disabilities, women, older adults, people of color, gay men, lesbians, bisexual people, transgendered individuals, and persons who are poor).

D. Nothing About Us Without Us

Imagine if the marriage equality movement did not have LGBT leaders, if the NAACP had no black people in positions of leadership, or if congressional committees considered limitations on women’s reproductive choices without calling a single female witness. It would be preposterous.

Marriage equality resulted from brave same-sex couples and their families sharing their stories and successfully bringing the injustices they faced to light. By contrast, people with disabilities—the greatest stakeholders in the assisted suicide debate—have been assiduously ignored by legislatures and the media, and grapple with end-of-life decision-making. As a long-time civil rights advocate, and now as a professor at a progressive university, I have never encountered anyone outside of the disability community who has seriously considered the disability perspective on so-called “death with dignity” laws. In fact, colleagues and students tend to characterize the assisted suicide debate as yet another battle between virtuous progressives and “backward” right-wing religious people.

To the disability community, however, it is a battle to prove that one’s life is worth living, that life in the community—not death—is what we should be fighting for, and that access to quality health care, palliative care, and community supports—not death—is the civil rights battle we should be fighting. Until we have the conversation on these terms, recognizing that denial of basic care is a nefarious threat to corporeal autonomy and dignity, we cannot make informed judgments about end-of-life choices.

102 Id.

103 Ok, one of those things happened. Bet you didn’t like it. See e.g., George Zornick, Republican Hearing on Contraception: No Women Allowed, The Nation (Feb. 16, 2012), http://www.thenation.com/article/republican-hearing-contraception-no-women-allowed/. 
I challenge everyone who advocates for assisted suicide laws to consider why almost every disability organization in this country opposes these laws. I challenge you to ask yourself whether you would dismiss the pertinent concerns of every LGBT group, every African-American group, every Jewish group, or every woman’s group. And I challenge you to start listening. Fortunately, we are not in the midst of a right-to-die emergency, and since you already prepared your directive back at the beginning of this Article, you can take comfort in knowing that as we work together to provide real end-of-life choices, your own wishes are clear.