REJECTING RIGHTS: THE DISABILITY CRITIQUE OF PHYSICIAN ASSISTED SUICIDE

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ABSTRACT

This chapter examines disability rights movement’s rejection of a right to physician-assisted suicide (PAS). Supporters of PAS frame the right to enlist a physician’s help in determining the nature and timing of one’s death as a fundamental liberty interest and as a right to privacy. The disability opposition counters this with disparate impact and slippery slope arguments and stories of disability pride as a rhetorical rejection of a right it deems dangerous and discriminatory. In examining this clash of rights talk, this chapter analyzes the legal and political consequences of anti-rights rhetoric by a movement that is grounded in notions of autonomy and self-determination.
INTRODUCTION: BETTER DEAD THAN DISABLED?

I began to notice that when assisted suicide advocates really wanted to scare their audience, they did not use unremitting pain to do it. They use disability. The need for help to go to the toilet was the big stick. Wouldn’t you rather die than have someone else wipe your butt? It never seemed to cross those advocates’ mind that thousands of people in the United States get help to wipe their butts every day. Many of them are my friends. The blunt disdain that the assisted suicide advocates showed for people with real disabilities disgusted me. I began to see the smug slogan, "Death with Dignity" in a new light: it hid the assumption that dignity was forever out of reach of people who were disabled: “Better Dead than Disabled” (Amundson & Taira, 2005).

Philosopher and disability rights activist Ron Amundson issues a formidable challenge to supporters of physician-assisted suicide (henceforth PAS).1 Advocates for legalization of PAS frame the right to determine the nature and timing of one’s death as a progressive realization and extension of a right to autonomy and self determination, both of which are considered cornerstones in the contemporary disability rights movement. Both movements share a concern over paternalism in the medical care of patients and emphasize the importance of autonomy in decision making. And yet, the disability rights community has rejected this claim to a “right” to die. Moreover, as we see in Amundson’s caustic critique, disability activists criticize the rhetorical strategies of PAS activists as fundamentally ignorant if not contemptuous of disability identity. They interpret the rhetorical strategies arguing for a right to assisted dying as evidence of pervasive fear of the disabled and non-functioning body.

Amundson elaborates his opposition to PAS on the basis of his experiences as a person with a disability. His essay is part of a special issue of the Journal of Disability Policy Studies that focused on the disability opposition to legalizing PAS. With his former student Gayle Taira, Amundson explains his frustration with the use of disability as a rhetorical tool to garner support for PAS as public policy. Disabling conditions that require personal assistance, such as the infamous “butt wiping” that is described in almost every article in the journal, are commonly used as horror stories that would convince anybody that PAS is the proper, if not inevitable solution to terminal illness. As Amundson and others explain in this journal, living with disabilities that require personal assistance in the most private aspects of everyday life is taken as a matter of course by many people with disabilities and does not suggest a reduced quality of life.

The disability rejection of a right to PAS has not been well theorized outside of the disability studies literature. Clearly, the rejection of a right holds powerful implications both for disability activism (Bickenbach, 1998) and for our understanding of the role of rights in social movements more generally. Scholars within disability studies need to investigate the reasons for the disability rights movement’s rejection of that right to autonomy and self-determination and contemplate the implications for the way disability activism posits itself vis-à-vis other progressive movements. Societal scholarship, in turn, can examine the disability rejection of PAS as a productive site for examining the role of rights in social movements.

The sociological literature examining the role of rights (McCann, 1994) and legal mobilization (Barclay, 2009a; Goldberg-Hiller, 2002; Marshall, 2005a) has provided a wealth of insights to the way that rights matter for the politics of social movements. Especially in the politics of identity-based social movements, much attention has been paid to the work of expanding the role of rights in the lives of those denied of legal equality. As such a movement, the disability rights movement has worked to secure the rights of people with disabilities in various contexts where their legal status had denied them equal opportunities to participate in education, employment, housing, voting, and public transportation (Barnatt, 2001; Colker, 2005; Fleischer, 2001). A central organizing principle of disability activism has been the emphasis on autonomy, choice, and independence, as well as a critique of a healthcare system that promotes patients’ rights, choices, and empowerment vis-à-vis their healthcare providers. Self-determination is another foundational principle in disability activism: “nothing about us without us” was the rallying cry of international disability activism at its very foundation at the 1981 Singapore meeting (Driedger, 1989; Charlton, 2000). Similarly, Ed Roberts, now considered the father of the U.S. disability rights movement, gave a speech at a 1983 rally entitled, “when others speak for you, you lose” that came to define a movement and catapulted Roberts into the national spotlight (Roberts, 1983).

Viewed from within that emphasis on advocacy, self-determination, and rights expansion, the disability rejection of a right that shares a common
background in progressive politics seems counter-intuitive and merits closer analysis. PAS advocates locate the right to hasten one’s death in the patients’ rights movement, which echoes the disability rights critique of paternalistic healthcare provisions, as well as in the reproductive rights movement, which also shares basic principles of self-determination with the disability rights project. And yet, opponents of PAS – most prominently religious groups, the American Medical Association, and, of course, disability groups – also invoke rights and use similar civil rights arguments.

This chapter examines the clash of rights discourse between the proponents and opponents of PAS. Proponents of PAS argue that the right to enlist a physician’s help to determine the nature and timing of one’s death is an integral part of a person’s autonomy and self-determination. They posit PAS as a struggle for patients’ rights against a paternalistic and oppressive medical establishment; one that will not honor patients needs when these needs conflict with a doctor’s commitment to preserving life at all costs. PAS is framed as a privacy right and liberty interest and likened to the struggle women had to wage for reproductive rights. Opponents of PAS also use civil rights argument, claiming that the legalization of PAS will have a disparate impact on vulnerable groups, such as the poor, minorities, and people with disabilities. These groups are in positions of powerlessness and are thus likely to choose PAS not by “rational” choice but due to social pressures and financial constraints. The right to PAS, opponents argue, should not extend to these vulnerable groups since they might feel compelled to elect PAS to relieve emotional and financial burdens to their families, that they cannot afford alternatives in palliative care, and that their physicians will be too quick to judge their conditions as not worth living.

For both supporters and opponents, what is at stake in this struggle is nothing less than a question of life and death. To that end, both groups speak the language of rights, self-determination, and autonomy and yet invoke very different meanings of these terms. Underlying the passion of this struggle are larger questions of human dignity, equal treatment, and equal citizenship. When supporters speak of a right to a death with dignity, they link autonomy over end-of-life decisions with Constitutional privacy rights of bodily integrity and human dignity and the struggle for patient autonomy over medical decisions. When disability rights opponents speak of autonomy and self determination they also summon up a history of distrust over medical paternalism, but in this case it is a distrust over a medical system that has historically denied them “the right to live in the world” (tenBroek, 1966), as well as a legal system that has denied them the rights to equal citizenship. For the disability rights project, citizenship can only be meaningfully equal when our understanding of the liberal subject includes the disabled body; a body that is not terminally ill and close to death, but rather fully living with the aid of assistive technologies.

The goal of this chapter is to examine both uses and implications of rights talk surrounding the contested issue of physician assisted suicide. I begin by tracing the development of rights talk in the movement to legalize PAS and examining the way these arguments have fared in the courts. My analysis focuses on use of rights talk as well as personal stories as mobilizing strategies for the legalization of PAS, using examples from the two only successful legalization initiatives in Oregon (1994) and Washington (2008), as well as the first statewide initiative in Washington in 1991. Next, I examine the civil rights opposition to the legalization of assisted suicide. This opposition uses slippery slope and social justice arguments in its critique of the legalization of PAS. Within this opposition, disability rights activists counter the personal stories used by PAS proponents with stories of their own. They criticize the ways that disability has become a rhetorical tool to garner support for PAS as policy. Proponents of PAS point to the loss of bodily autonomy that accompanies terminal illness that needs to be recovered by the assertion of autonomy over death. Yet, this loss of bodily autonomy is a commonplace experience for people with disabilities, many of whom require daily personal assistance with the most private aspects of everyday living which are not automatic grounds for suicide. Disability activists publicly break ranks with fellow progressives in their support for Terri Schiavo’s right to have her feeding tubes left in place. Progressives just “don’t get it” they claim (M. Johnson, 2004) and uncritically apply libertarian notions of autonomy to a discriminatory healthcare system. The disability alignment with the conservative movement to protect Schiavo’s “right to life” is a compelling illustration of Amudsen’s claim made earlier: in the end, it is the lived experience of disability, rather than a commitment to progressive politics, that will powerfully shape one’s view of this right to die. In that sense, disability activists posit that disability identity is a necessary tool to resist the decriminalization of PAS, even if it embodies a new form of paternalism. In their critique of PAS people with disabilities assume once again the mantle of a vulnerable group that must be protected by the state.

The disability rejection of PAS is part of a larger critique of liberal citizenship by pointing to the fundamental tension between liberty and economic inequality. In this process, it also challenges the notion of the autonomous rights holder, able to exercise rights without regard to economic or familiar concerns. Finally, the disability critique of PAS serves
as a powerful reminder that the traditional disability project of acquiring rights – those rights of equal citizenship traditionally denied to people with disabilities – necessarily contained a rejection of rights as well.

THE LEGAL LANDSCAPE: FRAMING A RIGHT TO PAS

The first prominent case regarding the right to die (rather than the right to PAS) was the case surrounding Karen Quinlan who had lapsed into a coma in 1975. Living in what we would now call a “persistent vegetative state,” she required artificial nutrition, hydration, and a respirator. Karen Quinlan’s father sought court appointment as guardian of her person for the express purpose of authorizing removal of her respirator, whether or not she died as a consequence. He was opposed not only by Karen’s physicians but also by the local prosecutor and the state attorney general. The New Jersey trial court denied Mr. Quinlan’s request to terminate the use of the respirator, holding that the decision was solely that of the attending physicians acting in accordance with prevailing medical standards. The New Jersey Supreme Court reversed the decision. Karen’s physicians gradually weaned her from the respirator, and she continued to breathe on her own. Her family did not want artificial nutrition and hydration stopped, even though the Supreme Court gave permission for all life support to be withdrawn. Karen lived another 10 years.

In its Quinlan opinion, the New Jersey Supreme Court recognized that the right to privacy is “broad enough to encompass a patient’s decision to decline medical treatment under certain circumstances.” Moreover, the court emphasized that people do not forgo this constitutional right to refuse unwanted medical care if they are incapacitated, and that mechanisms are needed for these rights to be exercised by others. Thus came the first articulation of self-determination as a privacy right, albeit limited in this case as the right to refuse life-saving medical treatment.

Another important legacy of the Quinlan decision was its mandate for hospitals to establish ethics committees, which were largely nonexistent at the time. These committees were to review decisions to forgo life-sustaining treatment when the patient lacked decision-making capacity and was being treated in a hospital. As a result of this case, ethics committees grew in number and debate arose regarding their appropriate role and authority. Patients were given a larger say in how they were going to be medically treated during the end of their lives, and courts began to recognize that patients possess an inherent right to consent to any and all medical treatment, including the right to reject unwanted treatment. States began enacting statutes allowing living wills. Quinlan also gave impetus to right to die movement. Oregon’s Death with Dignity Act can be traced to the decision stating that Karen wanted to die “with grace and dignity.”

The U.S. Supreme Court first addressed the issue of a right to die in the 1990 Cruzan case, concerning Nancy Cruzan who lived in a persistent vegetative state after a 1983 auto accident. Cruzan’s family waged a legal battle to have her feeding tube removed, but the state of Missouri maintained that it had a legitimate interest in protecting and preserving life and that this interest overrode any individual right Nancy might have to refuse unwanted medical care. The Cruzans challenged the Missouri requirement for “clear and convincing evidence” that Nancy would wish for the removal of life support, but the Supreme Court ruled 5-4 in favor of Missouri, finding it was constitutionally permissible to require such evidence and not a hindrance to Nancy Cruzan’s due process rights. The Court did conclude, however, that despite a state’s right to require clear and convincing evidence, a patient’s right to refuse medical treatment was a liberty interest protected by the due process clause. The Cruzans later presented such evidence to the Missouri courts, which ruled in their favor and issued a court order to have the feeding tubes removed. Nancy died eleven days later.

The dissenters in Cruzan saw the right to die as “fundamental” and emerging from a long line of privacy interests protected by the due process clause. The majority, however, only went as far as protecting the right to refuse unwanted medical treatment. The difference between notions of “active” and “passive” death is instructive here – patients can hold autonomy in refusing lifesaving treatment, but they cannot transfer that choice into the hand of a physician. This distinction is often blurred in the ways physicians seek to treat the experience of pain in dying patients – known as the double effect – in which physicians will justify the administration of pain medication that may have the unintended, although anticipated, consequence of hastening the patient’s death. The central argument here is the court’s notion of autonomy, which affirms a patient’s ability to refuse medical intervention as a negative right to be free from a doctor’s care, but denies a positive right to require a doctor’s medical expertise in advancing a peaceful death.

The affirmative Constitutional question – is there a fundamental right to PAS – did not reach the Court until 1997. Here the Supreme Court faced
two cases involving challenges to state laws criminalizing PAS. In the first case, the Ninth Circuit Court, sitting en banc, had ruled a Washington state law unconstitutional on due process right-to-privacy grounds (Washington v. Glucksberg). Relying on the concept of liberty in the 14th Amendment due process clause, the 9th Circuit held that competent, terminally ill patients had the right to enlist the aid of a physician to “determine the time and manner of [their] death.” The court wrote, “A competent terminally ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent.”7

In the second case, the Second Circuit had ruled a similar New York statute unconstitutional on equal protection grounds (Vacco v. Quill). The court found that state law created a distinction between the two classes of patients who were in similar circumstances: those who are legally permitted to precipitate their death by refusing or directing the withdrawal of life-prolonging interventions (such as a respirator or tube feeding), and those who are not dependent on to life-prolonging interventions and yet are not able to precipitate death by self-administering prescribed drugs.8

The Second Circuit held that withholding or withdrawing of life support of terminally ill patients amounted to the same thing as PAS. Thus, the vastly different treatment options to the two classes of patients could not serve a legitimate state interest and amounted to an equal protection violation. The court asked, “What interest can the state possibly have in requiring the prolongation of a life that is all but ended? Surely, the state’s interest lessens as the potential for life diminishes.”9

The Supreme Court unanimously reversed in both cases, upholding both state laws as constitutional. Despite several concurring opinions, all members of the court agreed that neither the equal protection clause nor the liberty interest in the 14th Amendment provided a basis for a right to physician assisted suicide. Since all the patients in the Glucksberg and Quill cases had died by the time the case reached the Supreme Court, the court addressed the broader question of the constitutionality of PAS, rather than the rights of the specific patients involved. In declining to find a constitutional right to PAS, the court noted longstanding traditions against suicide and found that states have a legitimate interest in preserving human life, protecting the integrity and ethics of the medical profession, safeguarding the vulnerable from coercion, and ensuring the value of life, even of those who are ready to die. The court reaffirmed the right to refuse medical treatment (as established in Cruzan), and left the door open to a future successful challenge, while leaving the issue to the states for the time being.10

Less than half a year after the Supreme Court’s ruling, voters in Oregon refused to repeal their Death with Dignity Act. Originally passed in 1994, the Act makes it legal for a physician to prescribe a lethal dose of medicine for a terminally ill patient. Oregon Voters had passed the Death with Dignity Act with 51 percent in favor, but implementation was delayed by a legal injunction. The Ninth Circuit Court of Appeals lifted the injunction in October 1997. In November 1997, a measure asking Oregon voters to repeal the Act was rejected by a large margin, making Oregon the first state to legalize PAS. Many observers (Battin, Rhodes, and Silvers, 1998) saw this as the first of the “state by state” experiments envisioned by the Supreme Court in Glucksberg, although it took another 10 years for another state to follow Oregon’s lead: Washington legalized physician assisted suicide in 2008. Montana legalized PAS (in this case, Aid in Dying) in 2009: not by statewide initiative as in Oregon and Washington but by a ruling of the Montana Supreme Court on issued on December 31, 2009. The lower court had ruled that the extensive privacy guarantees in the Montana Constitution – which provide broader protection that the U.S. Constitution – along with its dignity and equal protection clauses, afford a right to aid in dying to terminally ill Montanans. The Montana Supreme Court, however, chose to resolve the case on statutory grounds, ruling that the consent defense in Montana’s homicide statute does not prohibit aid in dying for terminally ill, mentally competent adult patients. The Court explained that, “A physician who aids a terminally ill patient in dying is not directly involved in the final decision or the final act. He or she only provides a means by which a terminally ill patient himself can give effect to his life-ending decision, or not, as the case may be. Each stage of the physician-patient interaction is private, civil, and compassionate. The physician and terminally ill patient work together to create a means by which the patient can be in control of his own mortality. The patient’s subsequent private decision whether to take the medicine does not breach public peace or endanger others.”11

In 2006, in Gonzales v Oregon, the U.S. Supreme Court decided another right-to-die case, although this one primarily on administrative law grounds, not as a question of constitutional privacy rights. Voting 6 to 3, the Court upheld Oregon’s Death with Dignity Act. It ruled that Attorney General Ashcroft exceeded his powers under the Controlled Substances Act when he threatened prosecution against Oregon doctors prescribing lethal drugs under that state’s Death with Dignity Act. Writing for the majority, Justice
Kennedy concluded that regulation of medical practices was primarily a job for the states and that Ashcroft failed to recognize “the background principles of our federal system.”

USE OF RIGHTS TALK IN THE EFFORTS TO LEGALIZE PAS

While attempts to frame right to PAS as a fundamental right under the Supreme Court’s privacy jurisprudence ultimately failed, rights talk proved a powerful tool in the arguments for the legalization of PAS. As early as the case of Karen Ann Quinlan, personal choices of “living” or “dying” were cast as a conflict of rights to be played out in the courts. The New Jersey Supreme Court’s finding that Karen had a constitutional privacy right to refuse treatment and that her incompetency did not negate her right that her parents could exercise on her behalf, set the stage for a vigorous national debate on the meaning of such rights. Even the Cruzan case acknowledged the centrality of the freedom to decide when to remove one’s own life-sustaining equipment, which could be considered as at least some form of a right to die. Susan Channick (1999a) summarizes that, “since In re Quinlan, death and dying jurisprudence has followed the conflict of rights model, pitting the right of the individual to make medical decisions against the right of the state to protect those citizens unable to protect themselves.”

Central to the arguments for the right to PAS has been the expansion of the Supreme Court’s privacy jurisprudence, which protects certain consensual acts such as birth control (Griswold v Connecticut), abortion (Roe v Wade), and sodomy (Lawrence v Texas). When the Glucksberg case first went to trial in March of 1994, Chief District Court Judge Barbara Rothstein reasoning for overturning Washington’s ban on due process grounds drew heavily from the abortion precedent. In Rothstein’s opinion, the reasoning used to establish a liberty interest in granting a woman’s right to choose abortion is “highly instructive and almost prescriptive” for cases in which the liberty interest is the right to commit suicide. Citing a well-cited passage from Planned Parenthood v. Casey, she claims that, “the suffering of a terminally ill person cannot be deemed any less intimate or personal, or any less deserving of protection from unwarranted governmental interference, than that of a pregnant woman.”

Once Judge Rothstein determined suicide to be a constitutionally protected right, the court, as the Supreme Court did with abortion, determined if the statute being challenged interfered with, or served as an “undue burden,” to someone wishing to exercise this right. Using the “undue burden” standard set in Casey, the court concluded that Washington’s ban on assisted suicide placed a “substantial obstacle in the path” of someone’s right to commit suicide and Judge Rothstein ruled that Washington’s ban on assisted suicide was unconstitutional.

The District Court’s decision to lift the ban was overturned in March of 1995, by the 9th Circuit U.S. Court of Appeals but then re-instated by the 9th Circuit. Here Judge Steven Reinhardt’s majority opinion relied heavily on Judge Rothstein’s abortion analogy and concluded that, “Casey and Cruzan provide persuasive evidence that the Constitution encompasses a due process liberty interest in controlling the time and matter of one’s death – that there is, in short, a constitutionally recognized right to die.”

This assumption is echoed in a brief by a group of prominent philosophers (Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomson) as amicus curiae when Glucksberg came before the Supreme Court. The brief claims that,

Denying that opportunity to terminally ill patients who are in agonizing pain or doomed to an existence they regard as intolerable could only be regarded as justified on the basis of a religious or ethical conviction about the value or meaning of life itself. Our Constitution forbids governments to impose such convictions on its citizens.
(Dworkin, 1997)

As an established liberty interest protected by the due process clause of the 14th Amendment, then, the right to PAS is fundamental and may not be restricted by the states. Even more importantly, the brief argues that any opposition to PAS can only be justified on religious or ethical grounds, not on the basis of civil rights.

THE CENTERPIECE OF RIGHTS TALK: AUTONOMY

In death and dying jurisprudence, as well as in political struggles to legalize PAS, the centerpiece of rights talk is personal autonomy: the right of an individual to make medical treatment decisions even – or especially – when such decisions result in the accelerated death of the actor. The autonomy paradigm is most evident in the practice of medicine. Paternalism and beneficence, principles that elevated the authority of the physician over the autonomy of the patient, were the hallmarks of the traditional
physician–patient relationship. Since the early twentieth century's recognition of a competent individual's right of self-determination, however, the paradigm of the physician–patient relationship has shifted. The former paternalistic model, in which the physician commanded and the patient obeyed, has slowly given way to a shared decision-making model where the ultimate decision lies with the patient. The now well-entrenched principle of informed consent, which requires the physician to inform the patient of all information necessary for a knowing decision, is the cornerstone of this shift from paternalism to individual patient autonomy. The corollary of informed consent is the right to refuse recommended, even lifesaving, medical treatment.

Autonomy also lies at the heart of the Philosopher's Brief cited in the previous section. Dworkin and his colleagues argue that the patient petitioners in Glucksberg had a constitutional liberty interest in hastening their deaths, which flows from individuals' recognized right to make decisions about matters "involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy" (Dworkin, 1997, p. 41). The brief seeks to extend Cruzan as more than just the right to forgo unwanted medical treatment and posits it as a case about personal autonomy and the right to control the time and manner of one's death. Nancy Cruzan's extension of the right to refuse medical treatment to include the right to forgo life-sustaining nutrition and hydration was "influenced by the profound indignity that would be wrought upon an unconscious patient by the slow atrophy and disintegration of her body[and] can only be understood as a recognition of the liberty, at least in some circumstances, to physician's assistance in ending one's life" (Dworkin, 1997, p. 42). Relying on the language proposed in Casey – about dignity, autonomy, and the right to define the meaning of one's own existence – the brief proposes a logical extension of the Court's privacy rights jurisprudence to include PAS.

The Supreme Court, however, did not view Cruzan as an assisted suicide case. Indeed, Rehnquist argued in his Glucksberg opinion that "in Cruzan itself, we recognized that most States outlawed assisted suicide – and even more do today – and we certainly gave no intimation that the right to refuse unwanted medical treatment could be somehow transmuted into a right to assistance in committing suicide."14 Rehnquist spent very little time discussing autonomy and dignity arguments, but rather used the historical argument to refute a constitutional right to PAS by pointing to the fact that rights criminalizing PAS are "deeply rooted in the Nation's history and tradition."15 If the court recognized any right in this case, it clearly was not the right to autonomy, but rather the right to pain relief through palliative care.

The court's refusal to engage in a discussion about dignity and autonomy struck a blow to proponents of PAS. The PAS advocacy organization Compassion & Choices had represented the patient petitioners and prepared them well with detailed counseling to ensure that decisions to hasten their death was indeed informed, rational, and uncoerced, rooted in autonomy and choice. In that sense, the patients represented the perfect model for thoughtful and voluntary decision making that is championed by the medical community (Law, 1998). This organization has become a central force in the efforts to legalize PAS16 and centers its activism on the autonomy and dignity of the patients it represents. What follows is an analysis of this strategy.

**RHETORICAL STRATEGIES: THE POWER OF PERSONAL STORIES**

The rhetoric of autonomy and choice was at the core of the claim for the right to precipitate one's death. PAS proponents such as Compassion & Choices use two types of stories to illustrate what the presence – and absence – of this right can mean for people with terminal illness and their families. One type of story is that of a "good death." This story spells out the possibilities of a death in which competent patients are fully exercising the right to control the timing and manner of their deaths. This means time to assemble their loved ones, take that last trip, share memories, and prepare families and for what is to happen after their deaths. Exercising that degree of autonomy is universally experienced as peaceful and empowering, for both the person dying and for the family. Death is still inevitable, but there is less fear of the process of dying.

Compassion & Choices advocates collect these stories as evidence for the need to make PAS, or Aid in Dying, an available end of life option. In "Michael's Story," for example, Michael explains how his mother had made the choice to die while she was still conscious and could enjoy time with her three sons and grandchildren. He initially resisted, but "we were products of strong parents who raised us to take responsibility for our actions. We had to accept and support her choice."17 Together they planned a weekend sharing memories, playing cards, taking photos, and spending happy moments together until,
She said it was time. She chose her clothes to wear and had a few private minutes alone. When she called us she was in bed and ready. She drank the morphine we had picked up that afternoon from the pharmacy. Morphine prescribed by a wonderful doctor who really cared for her and us. Although it took much longer than we expected (12 hours) she finally fell asleep and joined her partner in the better world she believed she was entering.18

In contrast to Michael's mother's good death, Jean's story exemplifies the "bad death," in which patients lose physical or mental control over their bodies, ask their loved ones to relieve their suffering, or even end up committing suicide using extraordinary and often horrific means. Jean's daughter was in hospice, dying of brain cancer. Jean tells of her frustration watching her daughter's suffering:

When we spoke to her she screwed up her face, crying without tears. She mumbled only two intelligible sentences during those weeks: "Why does it take so long?" and, "I didn't know it would be so hard. (...) Now we are praying for her to die. (...) If we should try to help her die, we would be breaking the law and probably go to prison. June has a Living Will and a "Do Not Resuscitate" order. She expressed her wishes while she was still lucid, but that doesn't help us to help her.

Jean ends her story with a plea for legalization of aid in dying: "Don't these people who vote against the law realize that some day their loved ones - or they themselves - might welcome the release such a law can provide? No one should have to choose an end like my father's or my daughter's. Death is inevitable - let's make it easier for those who want help."19

THE 1991 WASHINGTON INITIATIVE

Personal stories such as these were used in media campaigns in many of the failed state initiatives to pass PAS legislation. In 1991 Washington became the first state to vigorously debate and ultimately reject an initiative allowing PAS in limited circumstances. This came at the time of intense media scrutiny of the issue. Cruzan had just been decided, and that summer Jack Kevorkian, an unemployed Michigan pathologist, made headlines by assisting in the suicide of Janet Adkins, who preferred death to living with Alzheimer's disease. Kevorkian had company in the media spotlight when a New York internist, Timothy Quill, published an article in the New England Journal of Medicine describing his decision to prescribe barbiturates to a terminally ill leukemia patient who preferred a peaceful death to an excruciating course of treatment which held only a twenty-five percent chance of survival (Quill, 1991). Quill posed an important challenge to the medical system by respecting a patient's rational wish to die and framing it as part of responsible health care.

The Washington state initiative is the first public debate on the question of PAS as a right and as such has tested the validity of rights and autonomy arguments by supporters (Jacobs, 1993).20 Choice became a dominant theme in the pro-PAS rhetoric. Consider this op-ed piece written by a cancer patient and right to die activist which epitomizes the use of choice rhetoric.

I do not know where I will draw the line and decide the machines and the drugs are not prolonging my life, but are prolonging my death. However, I am determined that it will be me who draws the line, it will be me who has the choice, who has control over what happens to me at the end of my life. No one has the right to deny me that choice.21

The image of an autonomous rights-bearer making free, unfettered choices is the central argument for the passage of the PAS Initiative. The issue of choice in this piece echoes arguments made by reproductive rights activists: intimate choice over one's body, especially choices as central as life and death, is to be made by the individual and not the state. In the ultimately successful initiative that legalized PAS in Oregon, for example, connections between a woman's reproductive choices and the right to determine the nature and timing of one's death were made explicit. In a television ad a woman's voice intoned, "this is my body. I don't need you, I don't need government, I don't need any church playing politics with my choices, with my life" (Hillyard, 2001). These words could have just as easily been spoken in support of a woman's right to choose.

Jacobs (1993, p.19) describe another strategy used to fortify the autonomy and choice-based argument: the attempt to show that deep suffering necessitated a turn to choice. By offering horrific images of death and dying, supporters created the prerequisite for a right to die. Lee Shipley, a hospice volunteer, wrote:

No legal amount of morphine is going to stop the agony of someone who is slowly suffocating to death, as the tumor in their throat gets larger and larger daily. It is not unusual for a dying person to fill with fluid. What this means is that the person drowns, slowly ... Choice is the key word here ... There need to be legal options, and the choice given to each and every individual.22

Shipley's appeal to choice was echoed by a Seattle art gallery manager, who spoke of a friend's agonizing death of AIDS and how she regretted his lack of choice: "He literally went without water and food for three weeks trying to end his life ... There was no outlet for him to enable it to end faster. He asked me to help him but I didn't feel I could. It was pretty grim." The power of these images of dying invited the public to consider the choices
they would make – die in agony or chose assisted suicide. Whatever the choice may be, the advertisement clearly suggests that this choice must be made autonomously and that, by extension, dying patients should have a right to a peaceful death.

A related strategy was an appeal to family members. The public was invited to not only think of themselves as the person faced with a choice but also think of themselves as having to make that choice with (or, in some cases, for) terminally ill family members. Here the appeal was primarily to those thinking about their aging parents. A television commercial aired during the Washington Initiative captures this strategy. In the commercial viewers see themselves as Nancy Cruzan, kept alive by machines against their expressed wishes. The advertisement begins with a long shot of a frail, elderly man, lying in a hospital bed, hooked to an array of life support machines and monitors. Over the grim picture, a woman’s voice states: “This isn’t what Dad wanted – these machines. That’s why he made a living will.” An announcer intones: “Most people don’t know, but in Washington, living wills are often ignored or overturned and patients are kept alive by machines against their will. . . .”

The audience, experiencing both dad’s plight, as well as that of the daughter as she painfully watches her father, is driven to support the Initiative, which is presented as the only solution to the violation of dad’s will and the lack of choice and autonomy represented by the scene. In the commercial, dad is already all but dead, and portraying him as such highlights the choice issue without forcing the audience to grapple with its deep unease and squeamishness about issue relating to death and dying.

One post-referendum poll suggested that the rhetorical strategy of forcing viewers to vicariously experience what the Initiative could mean in their lives succeeded. The survey showed that support for the Initiative was strongest among those who had confronted terminal illness in their own lives or the lives of a loved one, while support was weakest among those who had never experienced the issue. This finding echoes, once again, the importance of personal experience (be it terminal illness or disability) over logical arguments for or against legalization, that will shape attitudes toward aid in dying. Carol Gill, a psychologist and disability rights activist, confirms this statement empirically: she conducted a study on attitudes by people with disabilities towards PAS before and after informational presentations, outlining equally arguments “pro” and “con” (Gill, 2005). Results showed that participants who expressed neutrality before the presentation were more likely than participants who had a predetermined position (either supporting or opposing PAS) to change their responses. Changes in views tended toward opposition to legalize assisted suicide. Moreover, while participants were equally divided on their views regarding PAS for people with terminal illness, they overwhelmingly opposed legalization of PAS for people with incurable disabilities. Gill’s study confirms that individual experiences with disability as well as contact with disability rights information will make a person less likely to support legalization of assisted suicide. This insight is important as we consider the arguments of PAS opponents and ponder Amundsen’s assertion that common ground between progressive supporters of PAS and disability rights may not be possible after all (Amundson & Taira, 2005, p. 53).

THE CIVIL RIGHTS OPPOSITION TO PAS:
DISPARATE IMPACT, VULNERABLE GROUPS,
AND SLIPPERY SLOPES

The opposition to legalization of PAS also uses rights in its strategies, primarily to counter the heavy reliance on rights talk used by supporters. The most prominent civil rights critique of PAS points to its disproportionate or “disparate impact” on various “vulnerable populations” such as the elderly, the poor, people with disabilities, and minorities (King & Wolf, 1998). The most influential and heavily quoted statement of this argument comes from the New York State Task Force on Life and the Law’s report entitled When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context (New York State Task Force on Life and the Law, 1994). This report was well cited in Rehnquist’s Glucksberg opinion and has found its way into most academic writings that examine arguments critical of PAS. Patricia King and Leslie Wolf (1998) argue that society does not yet sufficiently understand of “how and why competent individuals are rendered vulnerable near the end of life” (p. 1016). Echoing Glucksberg they argue that states have an interest in protecting vulnerable groups from abuse, neglect, and mistakes. The risk is greatest for these groups, because their autonomy and well-being are already “compromised by poverty, lack of access to good medical care, advanced age or membership in stigmatized groups.” King and Wolf caution that “if we do not fully appreciate the multiple ways in which an individual’s autonomy and well being can be compromised, we cannot modify existing institutional arrangements and practices in the health care system in ways that will empower and protect all patients. It is important to empower patients so that their decisions will
be respected, while at the same time protecting them from abuse and exploitation” (1998, p. 1916).

Opponents of PAS cite health research that documents the marginalized position of the poor and minorities vis-à-vis their health care providers. The Task Force has reported tendencies by patients who come from low education and income levels to underemphasize and underreport levels of pain to their doctors, and as a result often receive inadequate pain treatment, primarily because they feel compelled to act like “good patients.” This can make PAS in terms of terminal illness too inviting of an alternative even when potentially better forms of pain management are available (NY Task Force 1994, p. 46). Additionally, the Task Force reported that patients in health centers providing low income care were three times as likely to suffer from inadequate pain treatment as patients elsewhere (NY Task Force 1994, p. 44). Finally, due to the high percentage of uninsured and underinsured patients in this country, there is a concern that poor patients cannot afford adequate levels and amounts of pain medication. Even insured patients often have not enough coverage to pay for expensive and extensive hospice stays or in-home care as alternatives to PAS (NY Task Force 1994, p. 46). For these reasons, the Task Force concluded that the poor would be too likely to feel coerced to elect PAS as a solution to their terminal illness. A move towards legalizing PAS, according to this view, would surely start society on a dangerous path down a “slippery slope.”

**SLIPPERY SLOPES TO INVOLUNTARY EUTHANASIA**

This slippery slope argument claims that, “whatever criteria for justifiable PAS and active euthanasia ultimately are chosen, abuse of the system is likely to follow.” In other words, the slippery slope is to be seen as an “empirical prediction” of what is likely to happen once we insert a particular social practice into our existing social system (Arras, 1997). Thus, as soon as we accept the “killing of chronically ill patients...we will inevitably accept the killing of depressed patients, and ultimately, children” (Smith, 1997). Indeed, in both *Washington v. Glucksberg* and *Vacco v. Quill*, the Supreme Court relied on the Taskforce’s slippery slope argument and recognized a desire to prevent a slide down a slippery slope as a legitimate state interest that is rationally related to a ban on assisted suicide.25

University of Michigan Law professor and prominent critic of legalizing assisted suicide Yale Kamisar argues that assisted suicide “will be practiced through the prism of social inequality and prejudice that characterizes the delivery of services in all segments of society, including health care” (Kamisar, 1993). Thus, the problem lies within social inequalities reinforced by the healthcare system, rather than individual physicians misdiagnosing or delivering sub-standard care to their marginalized patients. Kamisar writes, “this risk does not reflect a judgment that physicians are more prejudiced or influenced by race and class than the rest of society – only that they are not exempt from the prejudices manifested in other arenas of our collective life” (Kamisar, 1995).

Indeed, opponents point to structural problems within the entire healthcare system that render this right to PAS so dangerous. For example, contemporary medical practice tends to allow for only limited relationships between physicians and patients and makes alternatives to assisted suicide prohibitively expensive for uninsured or underinsured patients. Thus, when placed in the context of poverty, the slippery slope argument gains additional weight: owing to the cost-based system of managed health care, many theorists predict that “the right to die will turn out to be much more valuable to the poor than the rich” (Hickey, 1999). In a society that legalizes PAS, the rich will still have access to hospice care, to palliative care and private doctors who have long-term relationships with their patients and who can correctly diagnose and treat reversible depression. The poor, however, will feel pressured to select a quick death not only because it appears the only financially feasible solution to pain or misdiagnosed depression but also because it will reduce financial burdens on survivors. This is the kind of indirect pressure that is impossible to erect safeguards against, argue opponents.

Nancy Mairs (1996, pp. 120–21) describes this indirect pressure as an obligation to die from the perspective of a person with a disability, another “vulnerable population.”

Behind the view of death as a “right” to be seized and defended lurks the hidden assumption that some lives are not worth living and that damaged creatures may be put out of their misery. True, all kinds of safeguards would be put into place to ensure that only the person doing the dying could make the ultimate decision; but no amount of regulation can eliminate the subtle pressure to end a life perceived by others to be insufferable. If, ideally, I ought never to have been born, and if my dependent existence creates a burden on those who must care for me, then don’t I have not merely the right but the obligation to die? How can I honorably choose otherwise?
CLASH OF RIGHTS DISCOURSE

The slippery slope argument leaves supporters and opponents of assisted suicide in a theoretical and rhetorical standoff. Until the entire health care system is reformed, opponents say, PAS cannot be defended, or, in some cases, even debated. Supporters counter that if the slippery slope truly is an "empirical prediction" of what might happen with PAS as public policy then the burden of proof is on opponents to show that horrible consequences will truly come to pass and that safeguards are ineffective (Frey, 1998). And in fact, studies on the implementation of Oregon's Death with Dignity Act – posted every year on Oregon's Department of Human Services website – have shown that the slippery slope arguments have not come to bear; that the safeguards are working, and that the patients who make use of the law are predominantly white, well educated, had either private health insurance, Medicare, or Medicaid, and were enrolled in hospice care. Only about two-thirds of the patients who receive lethal medications under the law actually use them: in 2008, 88 prescriptions were written under provisions of the Death with Dignity Act, and only 54 patients took the medication. Since its implementation in 1997 only 401 patients have died under the terms of the law (Oregon DHS, 2009). This leads Seth Kreimer to conclude that "the current prohibitions against assisted suicide and euthanasia sacrifice the autonomy and dignity of some citizens for the safety and support of others. Its elimination would reverse the terms of the sacrifice but would not avert the tragic choice" (Kreimer, 1995).

Critics of the slippery slope thus counter the argument with rights arguments of their own: the rights of the majority of Americans who support assisted suicide are sacrificed for the rights of a vulnerable minority that might be differentially affected by the policy. It becomes a question of minority rights trumping those of the majority. To this end, Alicia Ouellette warns that, "in seeking to protect members of the disability community from perceived and real threats, the activists could limit options for all of us by declaring how we must, or more correctly, how we must not die" (Ouellette, 2006). Philosopher Jerome Bickenbach counters this view with an assertion of minority rights: "it is commonplace in political theory that an institutional constraint on autonomy may well be justified if, in general and in the long run, it protects people who are vulnerable, though on occasion it produces undesirable, even right-infringing, results for the exceptional few" (Bickenbach, 1998). As proponents and opponents find themselves in this clash of rights it becomes even more important to consider the arguments by the disability rights critique of PAS.

THE DISABILITY RIGHTS CRITIQUE:
FOCUS ON DIGNITY

The disability rights critique is a logical extension of the slippery slope and disparate impact arguments, but it also brings with it new strategies. As members of a "vulnerable population" disability rights activists counter the progressive agenda of right to die activists with their own version of rights talk and counter the use of personal narratives with stories of their own. Perhaps the most prominent opposition to PAS has been launched by Not Dead Yet, a national disability rights organization that was founded in 1996 shortly after Jack Kevorkian was acquitted in the assisted suicides of two women with non-terminal disabilities. The disability rejection of the right to PAS reframes the issue from a rights and autonomy-based issue to one of "disability discrimination, a profit-oriented health care system, and a legal system that does not guarantee the equal protection of the law" (Coleman, 2000).

The disability rights critique of PAS posits people with disabilities as a vulnerable minority precisely because of pervasive social views and assumptions that life with a severe disability (often confused with terminal illness) is unbearable and not worth living. Most legislative efforts to legalize assisted suicide will use the term "dignity," a term that is not lost on members of the disability rights community. As evidence, disability activists point to a well-cited interview by Janet Good, the founder of the Hemlock Society explaining the indignities of death:

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, let alone drive a car or go shopping with another's help. Every client I've talked to, (...) says, "I can't stand my mother - my husband - wiping my butt. That's why everybody in the movement talks about dignity. People have their pride. They want to be in charge."99

Claims such as these lead disability activists to conclude that it is a fear of disability, rather than pain, that forms the central argument for legalizing PAS. When describing the indignities that assisted suicide would help people avoid, proponents of PAS essentially describe disability, a "substantial impairment of a major life function," in the terms of the Americans with Disabilities Act. Prominent here is the life function of "self-care," most importantly, the ability to use the bathroom independently that causes the most indignity. As Diane Coleman, co-founder of Not Dead Yet argues, PAS supporters describe "the dreaded image of the indignity of disability,
a form of 'imprisonment' from which the only 'escape' is death. Disability is feared more than death" (Coleman, 2002). She goes on to explain:

This widespread public image of severe disability as a fate worse than death is not exactly a surprise for the disability community. Disability rights activists have fought these negative stereotypes of disability for decades in the effort to achieve basic civil rights protections. What has been a surprise for many advocates is the boldness with which these stereotypes are asserted as fact by proponents of assisted suicide, and the willingness of the press and the public to accept them, without even checking them against the views of people who themselves live with severe disabilities. Numerous studies have documented that people with disabilities almost universally attribute their "suffering" to societal attitudes about disability, rather than disability itself. (Coleman, 2002, p. 221)

This assertion reflects one of the central tenets of disability theory and activism grounded in what is considered a "social model" of disability (Oliver, 2009). This model claims that the true cause of a person's disability is not a person's mental or physical impairment but rather the disabling environments and social structures surrounding that person. In that sense, disability is to be seen as a social construct, rather than an individual deficit, and people with disability as a minority group deserving of civil rights protection. This emphasis on discriminatory attitudes and assumptions of what it means to live with a disability is especially pertinent when considering that legalized PAS would "take place within the context of a health care system and a society pervaded with prejudice and discrimination against people with disabilities"(Bickenbach, 1998; Longmore, 2003). In the healthcare context this prejudice often plays out in deadly ways, including "Do Not Resuscitate" forms and the general tendency of the medical establishment to interpret severe disability as a legitimate reason to elect assisted suicide. As History Professor and prominent PAS opponent Paul Longmore explains, it is "the discriminatory elements of public policy, health-care delivery and social services that made the lives of people unendurable," not their disabilities (Longmore, 2005). In retelling the story of David Rivlin, for example, Longmore claims that, it is "the discriminatory elements of public policy, health-care delivery and social services that made the lives of people unendurable," not their disabilities (Longmore, 2005). In retelling the story of David Rivlin, for example, Longmore claims that,

Henry's life must be so miserable that he should not want to live after a heart attack. Henry refused to sign the DNR. The doctor offered it again at his next visit. And his next. Henry finally changed his HMO in order to escape his doctor's "care." Who knows how many other people with disabilities were convinced to sign away their rights to medical care by doctor's bigotry against disability?

ADVOCACY AND THE POWER OF PERSONAL STORIES

As Henry's story illustrates, the use of personal stories has become a prominent tool in the disability rights critique of assisted suicide. The point here is to counter popular images of disability as tragic, shameful and undignified ("better dead than disabled") with personal stories of people who live full, happy and productive lives despite — or because of, or perhaps completely unrelated to — their disabilities. Personal stories embracing disability appear in the literature of most disability rights organizations, and more recently, also in academic writings in disability studies. As an example, consider the special issue of the Journal of Disability Policy Studies examining the impact of PAS on the disability community: almost every essay contains personal reflections by the authors regarding the nature of their disability and the quality of their lives.

If life with a disability shouldn't be seen as any less valuable or fulfilling, and especially not as an automatic death wish, then what to make of the prominent stories of those people with disabilities who have asked for assistance in hastening their deaths? Here the disability literature has engaged in a re-telling of the well-known stories of Elizabeth Bouvia, David Rivlin, and Larry McAfee. The point of this re-telling is to elucidate the "real" reasons why these people were suicidal: not because of the "indignities" of their disabilities, but rather, because of lack of proper medical and psychological care. As History Professor and prominent PAS opponent Paul Longmore explains, it is "the discriminatory elements of public policy, health-care delivery and social services that made the lives of people unendurable," not their disabilities (Longmore, 2005). In retelling the story of David Rivlin, for example, Longmore claims that,
adequate funding for independent living facilities and counseling, as well as the perpetuation of negative as well as medically incorrect images of disability in the media, that made these prominent cases so troubling for the disability rights community.

Elizabeth Bouvia’s story is especially instructive here, because her 1986 petition to a California Court to remove her nasogastric tube, so that her death could be hastened by dehydration and starvation was hailed as landmark victory for autonomy as the gold standard in medical decision making (Malloy, 1998). She was not terminally ill but still had, as all citizens do, the right to terminate her treatment. The disability community’s retelling of her story focuses on the circumstances that had brought Bouvia to want to die: she was a woman with cerebral palsy who had recently had a miscarriage, she was in severe pain from advanced arthritis, her marriage ended, her brother had drowned, she could not find work without losing her disability benefits, and she was forced to quit graduate school because her professors believed that her disability had made her an inappropriate student. The appropriate response to Bouvia’s plight, disability activists argue, were social supports to give her life meaning, rather than granting her the right to starve herself. The courts’ decision, which outlined the “humiliation and dehumanizing aspects of her helplessness,” was not a champion of her autonomy, but rather a judicial confirmation that her life with a disability was not worth living (Malloy, 1998).30

**TERRI SCHIAVO AS A DISABILITY RIGHTS CASE**

Another prominent story is that of Terri Schiavo. Disability rights activists broke rank with fellow progressives and supported the parents of Terri Schiavo in their refusal to grant her the “death with dignity” her husband Michael said she was entitled to. Disability organizations claimed Terri Schiavo as one of their own and likened the removal of her feeding tube as “death by starvation” (Ragged Edge, 2003). Not Dead Yet, along with 23 other disability organizations submitted an amicus in support of Florida’s “Terri’s Law” which gave Governor Jeb Bush the authority to re-insert her feeding tube.31 The argument goes that as a woman with a severe disability, Terri Schiavo is like “thousands of people with disabilities” who cannot articulate their views because of physical or cognitive disabilities and thus rely on surrogates. Who should speak for Terri? The brief claims that it is “those of us who live with disability, are the experts – not husbands, not parents, not doctors.”32

Prominent disability rights activists Mary Johnson and Harriet McBryde Johnson issued separate statements explaining their support for Terri Schiavo as a woman with a disability. (H. Johnson, 2005; M. Johnson, 2006) Both authors note that Schiavo was not “terminally ill” and that therefore, her situation should not be considered one of end-of-life decision making. They argue that her feeding tube is not medical equipment, but rather an accommodation to her inability to eat and drink by mouth. As a person with a disability, then, Ms. Schiavo has a statutory right under the Americans with Disabilities Act not to be treated differently because of her disability. Obviously, Florida law would not allow a husband to kill a non-disabled wife by denying her nourishment, argues Johnson. It is Ms. Schiavo’s disability that makes her killing differently in the eyes of Florida courts. Because the state is overtly drawing lines based on disability, she concludes, it has the burden under the ADA of justifying these lines (Johnson, 2006). Both authors see the public discussion of the Schiavo case as confusing or rather conflating – disability with long-term illness. They question the assumption that people with severe disabilities want to die, since many people who acquire severe disabilities change their minds about suicide once they receive the proper accommodations and personal assistance for their disabilities. Finally, Mary Johnson notes that although Terri Schiavo was a disabled woman, women’s groups did not take up her cause for fear of being seen as part of the conservative agenda.

Harriet McBride Johnson includes a personal reflection into her analysis. The power of her essay lies in her deep identification with Terri Schiavo’s physical condition. She writes,

> I watch nourishment flow into a slim tube that runs through a neat, round, surgically created orifice in Terri Schiavo’s abdomen and I’m almost envious. What effortless intake! Because of a congenital neuromuscular disease, I am having trouble swallowing, and it’s a constant struggle to get by mouth the calories my skinny body needs. For whatever reason, I’m still trying, but I know a tube is in my future. So, possibly, is speechlessness. That’s a scary thought. If I couldn’t speak for myself, would I want to die? If I become uncommunicative, a passive object of other people’s care, should I hope my brain goes soft and leaves me in peace?

Johnson’s questions are similar to those of the public viewing the images of a nonresponsive Terri Schiavo. And yet, Johnson concludes with a call for “legal restraints” for her possible future guardian, even if her guarding may think she’s “better off dead.”33 Decisions of life and death are “matters of more than private concern.” Here Johnson alludes to the importance to public scrutiny regarding end-of-life decisions of people with severe disabilities.
The prominence of the disability community’s opposition to Ms. Schiavo’s right to die became noted as an “unfortunate pairing” with pro-life groups and openly questioned in the legal literature (Cerminara, 2006; Ouellette, 2006; Shepherd, 2006). While disability activists opposing PAS have long refuted the charge that they are “duped by the religious right,” (Amundson, 2002) the intensity surrounding the Schiavo case has increased the stakes for the disability community. Prominent bioethicist and disability rights scholar Adrienne Ash has firmly rejected that paring, asserting that, “the disability perspective on the treatment of disabled newborns, physician-assisted suicide, and prenatal diagnosis and selective abortion shares nothing with the right-to-life analysis” (Asch, 1995). Similarly, Ron Amundson’s testimony before the Hawai’i State Senate challenges that assumption:

I am a strong advocate of civil rights, of government responsibility for social justice and welfare, and of a woman’s right to abortion. I agree with the religious right on almost nothing, except on opposing assisted suicide. Some of my friends are surprised by my opposition, and think that Not Dead Yet is being duped by religious conservatives. Not true. The ACLU works alongside the Catholic Church in opposing the death penalty, and no one questions their liberal credentials. Not Dead Yet does the same thing. (Amundson, 2002)

And yet, one of the outcomes of the Schiavo case has been the confluence of public agendas of Not Dead Yet and the National Right to Life Committee. Both groups are involved in legislative efforts to introduce bills in federal and state legislatures limiting the rights of surrogate decision makers in terminating life-sustaining treatment of people with disabilities (Cerminara, 2006, p. 381; Shepherd, 2006). A key feature of such bills is the requirement for an advance directive to authorize withholding nutrition and hydration from a patient in a PVS or who is otherwise incapable of making medical decisions. Thus, the presumptive treatment is to require continued treatment, even over the objection of the surrogate decision maker, as most people do not write their wishes down. Not Dead Yet seeks to limit the power of surrogates for the common tendency to view life with a severe disability is not worth living. And while the disability literature have powerfully documented the ways that especially medical professionals tend to assess the quality of life of disabled people as dramatically lower than people with disabilities do themselves (Coleman, 2002), there is very little evidence that people with disabilities wish to have less rights to refuse treatment than those without disabilities (Cerminara, 2006, p. 383).

In fact, the disability rights community is anything but united in its opposition to PAS. There is considerable variety in opinions, raging from a desire for autonomy in making end-of-life decisions, to the fear of PAS limiting such autonomy, to the fear of speaking out in favor of PAS in light of the vocal disability leadership opposing such legislation. (Fadem et al., 2003) As early as 1997, in response to Glucksberg and Quill, disabled attorney Andrew Batavia publicly stated his support for the policy from a disability perspective (Al Batavia, 1997). He founded the group “Autonomy, Inc” to assert the importance of autonomy for people with disabilities and to oppose the vulnerability arguments as paternalistic and detrimental to the cause of disability rights (Al Batavia, 2001).

Autonomy, Inc. submitted amicus curiae in support of the Oregon DWDA when it was challenged in the Supreme Court in Gonzales v. Oregon. The brief affirmed autonomy and self-determination as the cornerstones of the disability rights movement, but argued that these must include a variety of choices at the end of life. Just as the nondisabled, the brief argues that people with disabilities have complex and diverse attitudes towards the manner of their death, and the freedom to make critical life decisions that impact their “bodily integrity and dignity.” More importantly, the brief calls for the right of persons with disabilities to hasten their own death should they decide that their last days “deprive them of the personhood that they have worked so hard to achieve.” In that sense, the right to PAS is seen as an integral part of other articulations of disability rights, and the denial of which is seen as paternalistic. In fact, the brief strongly rejects arguments that they need to be “protected” from their own end-of-life decisions and do not “want their disabilities to be cited by others as justification for the wholesale denial of this right to all people with terminal illness.”

Batavia, since deceased, tells his own story, echoing the sentiment of many PAS supporters that the mere knowledge of having a way to end suffering would be a tremendous source of comfort and strength. Yet, as a person who cannot use his arms or hands, “I knew that I would have had to find some ingenious way by which to administer a lethal drug. I also knew there was some likelihood I would be unsuccessful, and my resulting condition could be worsened” (Al Batavia, 2000). In that sense, the right to enlist a physician’s aid in dying could be considered a reasonable accommodation under the Americans with Disabilities Act for a person with disabilities whose disability prevents them from committing suicide otherwise. While the ADA does outline the right to refuse reasonable accommodations, the Justice Department’s ADA regulations do not interpret medical treatment (including, presumably, lethal medication) as a special accommodation under that section.
Disability rights scholar Anita Silvers is similarly troubled by the inherent paternalism in the disability rejection of a right to die. She claims that the disparate impact arguments re-stereotypes people with disabilities as “weak, incompetent, easily coerced and inclined to end their lives” (AI Batavia, 2000). She views these arguments as disrespectful to people with disabilities and places them in the roles to which they have been confined by disability discrimination in the first place. The concern for the vulnerability of people with disabilities is based on paternalism, rather than a concern for disability rights. In fact, Silvers counters arguments by other disability activists that PAS is a form of disability discrimination under the ADA by claiming that, “it is not physician assisted suicide but rather the insistence that, as a class, people with disabilities need special protection from it that controverts the ADA’s strategy for liberating people with disabilities from their historical oppression” (Silvers, 1998, p. 137).

CONCLUSIONS: REJECTING RIGHTS AND QUESTIONING THE LIBERAL SUBJECT

This chapter has analyzed the use of rights rhetoric in the political and legal struggles surrounding physician assisted suicide. Both supporters and opponents ground their rights arguments in personal stories illustrating the complexities of making end-of-life decisions. The disability critique of aid in dying is a powerful example of the complicated role of rights in political discourse. It runs counter to the very foundation of disability rights discourse, which is firmly lodged in a civil rights model the rights based approach of previous identity-based social movements. A primary goal of this approach has been the transformation of people with disabilities from passive objects dependent on medicine or charity to active political subjects empowered by rights and entitlements. Disability rights, then, are posited as a natural extension of existing discourses of personal autonomy, self-determination, and independence. In rejecting the right to PAS and claiming the position of a vulnerable minority, are disability activists returning to a politics of paternalism? What does it mean to reject a “right” to die, when traditional disability activism has focused on expanding the rights of people with disabilities? We might consider the “perverse irony” as Ouellette suggests, “if the legacy of the same community that established civil rights for persons with disabilities were the imposition of an absolute limitation on the liberty rights of all of use as we experience the dying process with our family members” (Ouellette, 2006, p. 181).

The disability critique of PAS complicates the traditional trajectory of rights assertion by movements making civil rights claims. It confronts our assumptions of how rights are deployed to challenge the exclusion of people with disabilities from institutions of citizenship. It is this larger issue of citizenship, however, that is most troubled by the disability critique of PAS. The liberal subject - rights-bearing, autonomous, and not typically dependent on assistive technology to fulfill everyday needs such as eating, breathing, and the infamous butt-wiping – is implicated in significant ways in this debate. Already destabilized by feminist and queer critiques, our understanding of liberal personhood must now encompass the disability critique of the body, which asks us to distinguish between the decaying and dying body, and the disabled and living body. This distinction between life that is ending and life that is merely assisted is key to the disability critique, and invites us to contemplate ways to assert rights that reflect this difference.

An important part of this contemplation must be a challenge to the autonomous rights holder as constitutive of liberal citizenship. Here, the disability rights critique echoes a well documented critique within bioethics, pointing to the limitations of the autonomy principle that guides end-of-life decision making. Susan Channick, for example, argues that the autonomy-based “consumer choice model” was an important development in reforming paternalistic physician-patient relationships, but that the end-of-life context “does not fit the traditional autonomy paradigm” (Channick, 1999). She cites studies that demonstrate the disconnect from the abstract model to its applied consequences. For example, patients at the end of life may feel too overwhelmed, ill or weak to be the sole decision maker for choices regarding their death. Given the uncertainty of outcomes, they may lack the skill to make treatment choices. Furthermore, the lack of meaningful guidelines regarding these choices may be intellectually and emotionally traumatic for patients and their families. More importantly, perhaps, is the literature that examines the extraordinary dependence of terminal patients on their families, which questions the feasibility of the ideal autonomous decision making. Similar to situation of people with disabilities, then, autonomy might be a complicated ideal to put into reality for people at the end of their lives.

In questioning the feasibility of autonomy, the disability critique offers another critique of liberal citizenship by pointing to the fundamental tension between liberty and economic inequality. The right to control one’s death becomes meaningless, if not dangerous when offered in a context of extreme health inequality, even if this does not apply as broadly and unilaterally as disability activists might claim. Echoing the autonomy critique, we also do
not think about death autonomously and independent of the economic reality we inhabit. Liberal democratic theory has long posited that individual liberty cannot be adequately realized in conditions of extreme inequality. In that sense, our support of this particular rights could be seen in many ways as ill-liberal when applied to situations of economic inequality, when this liberty can only be meaningfully exercised by those who are privileged (Mihic, 2008).

In that sense the disability rejection of a right to PAS serves as a powerful reminder that the disability project about acquiring rights necessarily contains a rejection of rights as well. This is perhaps where disability rights movements mobilize rights differently from the other rights movements they have emulated. The struggle to adopt the civil rights model contained a simultaneous rejection of a different kind of entitlement: of welfare, charity, of special needs, and of well meaning paternalism. The rejection of special needs arguments came at a price. Culturally, the rejection of well meaning intentions has sparked resentment and is part of a larger backlash against the ADA (Krieger, 2003). The ADA was conceived as a broad civil rights bill, modeled after Title VII, but the underlying assumption of its integration mandate was economic. It sought to transform people with disabilities from consumers of tax dollars to contributors of tax dollars. In that sense, it has forced a choice between rights and welfare, between the ability to survive in the world and the ability to compete in it.

RETHINKING DISABILITY IDENTITY: BOUNDARIES OF SUFFERING

My final point recalls the frequency with which the critique of PAS invokes the importance of personal experience with disability or terminal illness in determining one's attitude. The disability rights rejection of a right to die evokes to the constitutive relationships between rights and identity that the sociolegal literature has grappled with. Here I point to Engel and Munger’s important work on disability identity and rights consciousness (Engel & Munger, 2003). Disability identity is a posited as a necessary tool to resist the decriminalization of PAS, even if it embodies a new form of paternalism and, in the process, forces people with disabilities to assume once again the mantle of a vulnerable group that must be protected by the state.

Nancy Mairs’ analysis of “boundaries of suffering” in her experience of living with multiple sclerosis is useful here in suggesting a more nuanced view of the importance of personal experience with disability, death, and suffering. She writes:

“Everybody, well or ill, disabled or not, imagines a boundary of suffering and loss beyond which she or he is certain, life will no longer be worth living. I know that I do. I also know that my line, far from being scored in stone, has inched across the sands of my life: at various times, I could not possibly do without long walks on the beach or rambles through the woods; use a cane, a brace, a wheelchair; stop teaching; give up driving; let someone else put on and take off my underwear. One at a time, with the encouragement of others, I have taken each of these (highly figurative) steps. Now I believe my limit to lie at George’s death, but I am prepared to let it move if it will. When I reach the wall, I think I’ll know. Meanwhile, I go on being, now more than ever, the woman I once thought I could never bear to be.” (Mairs, 1996, pp. 120–121)

Nancy Mairs writes about living with multiple sclerosis, which means that she has gradually lost the ability to do things independently without which, as she used to believe, she would find her life no longer worth living. And yet, the right amount of personal and professional support, counseling, adequate medical care, a loving family, personal assistants, and a passion for life and writing have all shifted the line for her until, now, she lives the life of a woman she once thought she could never bear to be.

Mairs’ description of that shifting line at once validates our personal tendencies to imagine boundaries of suffering, while at the same time cautioning us not to make assumptions about those of others. Far from being etched in stone, she says, her lines have “inched across the sands of [her] life.” While those who do not use a wheelchair might imagine her life in a wheelchair as tragic and unbearable or even heroic, it is for her, as for many other wheelchair users, quite ordinary.

As I have argued in this article, imagining boundaries of suffering has been a powerful and problematic tool in the movement to gain public support for physician assisted suicide. In their efforts to convince voters, PAS advocates use personal stories of the “good” or “bad” death to garner public support. People with disabilities have countered these stories with positive affirmations of disability, rejecting assumptions about quality of life. In the end, however, it is Mairs’ reminder that these assumptions keep shifting with growing acceptance, as well as the appropriate accommodations, for the physical and emotional consequences of living with a disability. The disability critique of assisted suicide, then, although seemingly in conflict with the disability rights emphasis on autonomy and self-determination, returns to the importance of accommodations for and acceptance of difference.
NOTES

1. I continue to use the somewhat dated term “physician-assisted suicide” to reflect the way it is still used in the legal literature. The more contemporary term used by proponents of legalization is “Aid in Dying,” which removes the stigma of suicide from what proponents claim is a rational decision. Opponents of legalization continue to use the term PAS or euthanasia. For a discussion of language choices see Tucker (2007).

2. This chapter does not consider the arguments made by the religious opposition to PAS. For a treatment of the role of Right to Life organizations as well as the Catholic Church in the public debate on PAS see Hamil-Luker and Smith (1998), and more generally, Dyck (2002).


4. Ibid. at 664.


6. The Cruzans provided as new evidence testimony from friends that their daughter had said she would never have wanted to be kept alive by machines or feeding tubes.

7. Compassion in Dying v. Washington, 79 F.3d 790, at 814 (9th Cir. 1996).

8. Quill v. Vacco, 80 F.3d at 729 (2d Cir. 1996).

9. Ibid. at 729.

10. In Glucksberg, Rehnquist wrote for the majority, “Throughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality and practicality of physician-assisted suicide.”


13. Compassion in Dying v Washington, 79 F.3d 790 (9th Cir., 1996).


15. Ibid. at 2268.

16. www.compassionandchoices.org


18. Ibid.

19. Ibid.

20. Andrew Jacobs’ article (1993) offers the only detailed analysis of the 1991 Washington Initiative from which most of these examples are taken.


25. See Glucksberg, 521 U.S. at 732 (“The State may fear that permitting assisted suicide will start it down the path to voluntary and perhaps involuntary euthanasia.”); ibid. at 733 n.23 (“We agree that the case for a slippery slope has been made out…”).


30. After she won her court battle, Elizabeth Bouvier decided that she would keep on living. She appeared on 60 Minutes explaining that she still was in great pain but that she had experienced great pressure to keep on living and that she hoped to die of natural causes soon.

31. Terri’s Law was ruled unconstitutional by the Florida Supreme Court in Bush v. Schiavo, 885 S2nd 321 (2004).


35. This argument was brought in the 1993 Canadian Rodriguez case, which challenged the Canadian criminal code prohibiting anyone from counseling, aiding someone from committing suicide on the grounds that it violated the Canadian Charter of Rights and Freedoms. Canadian disability rights argued that denying people with disabilities the option of suicide available to the nondisabled population was a form of unequal treatment and thus disability discrimination. In their brief to the court, they wrote, “where disability results in a person’s autonomy being compromised or lost, every effort must be made to find inclusive methods of enabling the person to achieve equality...Self-determination...will not be realized when choices are restricted or non-existent” (Rodriguez v. British Columbia (Attorney General) 107 D.L.R. (4th) 1993. See also Bickenbach (1998).


37. See also Heyer (2007).

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REFERENCES


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**SOCIAL MOVEMENTS LASHING BACK: LAW, SOCIAL CHANGE AND INTRA-SOCIAL MOVEMENT BACKLASH IN CANADA**

Lisa Vanhala

**ABSTRACT**

Introducing the concept of intra-social movement backlash this chapter explores the “legacy phase” of legal action focusing on conflicts and debates within a social movement that has mobilised. Using a legal mobilization framework attuned to the recursive relationship between rights, rights-claiming activities, and collective identity, the chapter analyzes the mixed legacies of movement strategic litigation. Empirically, the chapter offers two illustrative case studies of intra-movement backlash in the women’s and the disability rights movements in Canada. The findings suggest that while this form of backlash can have negative, disempowering effects, it also offers opportunities to challenge hegemonic structures within a social movement and re-imagine collective identities.