



# THE RIGHT-TO-DIE EXCEPTION:

## HOW THE DISCOURSE OF INDIVIDUAL RIGHTS IMPOVERISHES BIOETHICAL DISCUSSIONS OF DISABILITY AND WHAT WE CAN DO ABOUT IT

MARGARET P. WARDLAW

### Abstract

Major considerations of disability studies—such as provision of care, accommodation for disabled people, and issues surrounding institutionalization—have been consistently marginalized in American bioethical discourse. The right to die, however, stands out as a paradigmatic bioethical debate. Why do advocates for expanding the volition and self-direction of disabled people emerge from the periphery only to help those disabled people who choose death? And why do the majority of people assume an unrealistically low quality of life for those with disabilities? This paper will argue that the dominance of the Western liberal tradition in American culture motivates both these phenomena: by emphasizing individual rights over duties and responsibilities, assuming the isolated and independent rights-bearer as the prototypical person, and evoking an unrealistically atomistic view of human interaction. As an alternative, I offer a framework rooted in feminist ethics that emphasizes context, gives moral weight to human relationships, abandons the problematic ideal of a lone rights-bearer, and emphasizes the mutual vulnerability of embodied individuals.

*“Tell the health professionals why people with disabilities get depressed and suicidal. Tell them about institutions. Let them know the real reasons people with disabilities give up.”*

—ANONYMOUS DISABILITY-RIGHTS ACTIVIST WITH  
CEREBRAL PALSY (GILL 2004, 171)

The disability studies perspective has been consistently marginalized in twentieth-century American bioethical discourse. Like Ralph Ellison’s nameless protagonist who is “invisible . . . simply because people refuse to see me” (Ellison 1995, 3), both disabled people and disability studies perspectives have been conspicuously absent from mainstream contemporary bioethical inquiries. Considerations of provision, accommodation, and institutionalization have been pushed to the periphery of discourse. The lament of Ellison’s invisible man—“I have . . . been called one thing and then another while no one really wished to hear what I called myself” (ibid., 573)—remains relevant. In contrast to this general marginalization, debate surrounding the right to die stands out as a major exception. Assisted suicide, refusal of life-saving medical care, and euthanasia have led to paradigmatic bioethical debates garnering substantial attention for disabled people. Underpinning this “right-to-die exception” is a consistent underestimation of the quality of life with disability by nondisabled people.

The dominance of the Western liberal tradition in American culture and the ideal of the person as an independent rights-bearer somewhat paradoxically motivate both passionate advocacy for the individual right to die, as well as generalized indifference to disabled persons who have become symbols of dependence. I suggest that a framework rooted in feminist ethics that emphasizes the mutual vulnerability inherent in embodiment, attends to context, and gives moral weight to human relationships is a more useful paradigm for motivating and engaging issues of disability in bioethics and medical humanities.

### **The dominance of individual rights in discourse about disability**

In his 2001 clarion call to the bioethics community to take on the issue of disability,<sup>1</sup> Mark Kuczewski pointed out the unique treatment of issues surrounding the right to die in bioethics literature. He stated: “What attention has been

given to disability [in bioethics] has largely focused on requests to terminate potentially life-sustaining treatment or requests for assistance in dying such as those of Dax Cowart, Elizabeth Bouvia, and Larry McAfee” (Kuczewski 2001, 36). Arguing in this same vein, Ron Amundson asserts that a great deal of bioethical discussion inappropriately assumes a low quality of life for people with disabilities. Amundson describes the reduced appropriation of health care to disabled people as a consequence of this misconception (Amundson 2005). Despite a great deal of work in the area of disability from some prominent bioethicists, the disability studies perspective continues to be marginalized. This is particularly troubling in educational settings where the right-to-die exception is apparent in a tight focus around end-of-life issues in the context of disability in popular bioethics textbooks. When and if disability is discussed, it is often in the context of issues at the beginning and end of life; as examples, consider euthanasia, physician-assisted suicide, and selective abortion. Compounding the problem is a lack of attention to the perspectives of people with disabilities. This marginalization of disability studies perspectives is similarly apparent in resources aimed at the education of medical professionals.<sup>2</sup> For example, in a search of Ovid MEDLINE, which is one of the two primary publication databases for medical professionals, the terms *euthanasia*, *assisted suicide*, and *treatment refusal* are associated with six separate keywords that house more than 22,000 articles, while *disability* is not even a searchable keyword in terms of bioethics.

The right-to-die exception arises in part from a debate that has been largely framed in the context of the American liberal tradition. Kuczewski writes, “Of course, appeals to law will generally be appeals to rights claims, especially within a liberal democratic society. As a result, questions concerning the disabled are usually seen as a question of rights” (Kuczewski 2001, 36). The dominance of rights-based thinking in issues of disability can be attributed to two factors: the importance of legal decisions in framing bioethical discourse about disability, and the related appeal of rights-based discourse in the American liberal tradition.

The intersection of bioethics and the law has profoundly influenced the way discussions of disability have been framed in bioethical discourse. Bioethical debates often follow legal events, and the treatment of disability in bioethics has been no exception. Bernard Lo describes the important influence of legal decisions on clinical practice: “Dramatic legal cases regarding life-sustaining interventions have received prominent coverage in the news media. Such landmark court rulings have shaped clinical practice and stimulated people to discuss their preferences for such interventions” (Lo 2000, 147). Legal thinking permeates both lay and bioethics

discourse on disability issues. Additionally, disability-rights advocates have used the legal system successfully to garner advances for disabled people. As Kuczewski points out, “The disabled have used the legislative process and the courts to try and regain entry to society” (Kuczewski 2001, 36). Many significant strides have been made for the disabled through an appeal to the legal system, most significantly (in the United States) with the passage of the Americans with Disabilities Act of 1990.

Because appeals to the legal system tend to take the form of rights claims, civil rights advocacy that uses a framework of individual rights has certain advantages. Appeals to individual rights in a democratic society have the important benefit of being able to secure changes that favor disadvantaged minority groups before a massive shift in public opinion occurs. These rights-based claims have been useful in many major political movements of the last half-century, including the civil rights and women’s rights movements.

The downside of applying this traditional avenue of rights-based thinking to a discussion of Americans with disabilities is that successful rights-based claims, especially on the federal level, tend to take the form of what have been termed “negative rights”—rights that require only negative action on the part of others. Examples include freedom of religion and freedom of speech. These rights are traditionally distinguished from positive rights, which require definitive action on the part of others for fulfillment (Donner 1992, 161; Ho 2008). Examples of positive rights include the right to education and the right to health care.

The focus on negative rights in American legal discourse at a federal level limits the usefulness of rights-based thinking for discussions about people with disabilities. While various United Nations bills of rights and the constitutions of many European countries (Sunstein 1993) and American states (Hershkoff 1999) include positive rights, the U.S. Supreme Court has generally upheld the idea that the federal constitution is “a charter of negative rights rather than positive liberties” (*Jackson v. City of Joliet*, 715 F.2d 1200, 1203 [7th Cir. 1983]). This idea has played out on the national stage in a successive denial of American constitutional rights to housing (*Lindsey v. Normet*, 405 U.S. 56, 74 [1972]), public education (*San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 35 [1973]), and medical care (*Harris v. McRae*, 448 U.S. 297, 318 & n.20 [1980]).

Despite their pervasiveness globally and locally, the very existence of positive rights has been called into question. The United Nations Universal Declaration of Human Rights, for example, received strident criticism in the 1960s from legal theorists and political philosophers who questioned the legitimacy of positive

rights and argued that only rights defined in terms of freedom from interference by others exist (Goodin 1988, 184–85). Although a line of reasoning that questions the existence of positive rights has largely been abandoned, the standard interpretation of the American federal constitution continues to focus nearly exclusively on negative rights.

Despite the heuristic appeal of rights-based thinking, it is limited for discussions about people with disabilities, because so often disability rights are positive rights. This is particularly problematic in American liberal society where, as political scientist Mary Ann Glendon writes, “‘liberty’ and ‘equality,’ did not rub shoulders with ‘fraternity’” (Glendon 1993, 47–48). Consistent with the American tradition of rugged individualism, in American discussions of individual rights, negative rights tend to dominate. Because of this focus, American debate about disability rights tends to be a particularly limited way of advocating for the kinds of positive accommodation that disabled people often need to function in society. Furthermore, by focusing on rights to the exclusion of their corresponding duties and responsibilities, a discussion of the potential responsibilities that nondisabled members of society have toward those who are disabled is often curtailed.

Kuczewski points to this problem in his insightful understatement, “Of course right-based thinking also has its inherent limitations” (Kuczewski 2001, 38–39). Kuczewski is pointing to rights that prohibit discrimination, not the right to refuse care even when it results in death. But it is the distinctive limitations of rights-based thinking that can help explain why the right to refuse medical treatment has gained so much support so quickly in bioethics discourse about disability. Carol Gill points out how traditional conceptions of personal privacy and freedom of choice can form an inappropriate paradigm for understanding what constitutes freedom for those with disabilities. She writes:

The struggle for equal citizenship, for basic self-determination, and even for survival is ongoing for Americans with disabilities. That struggle provides an illuminating context for examining “right to die” issues for people with disabilities. Although arguments to legalize assisted suicide, for example, often center on issues of personal privacy and freedom of choice over one’s body, many disability advocates assert that assisted suicide is a political issue as much as a personal one. They believe its legalization would jeopardize, not advance, the freedom of persons with disabilities to direct the lives they choose. (Gill 2004, 172)

It seems counterintuitive that a right could jeopardize freedom. But Gill and

others argue that the right to die might jeopardize the freedom of persons with disabilities, because for a severely disabled person, things like equal citizenship, basic self-determination, and freedom might necessitate positive provisions. Unlike the right to pursue a meaningful life (a positive right for which some disability-rights groups advocate), the right to refuse care is a negative right, the type of right generally legally protected in Western liberal tradition. A focus on negative rights such as refusal of care can sideline the discussion. From this perspective, the traditional division between negative and positive rights breaks down somewhat. Even Mill's right to the pursuit of property, or Jefferson's reformulation "the pursuit of happiness," may require some positive accommodation for those with disabilities. And with an eye toward disability as a social construction, even rights like "equal citizenship" that are traditionally conceived as negative rights in the American political tradition might necessitate many positive provisions for a disabled person. Gill writes:

The sources of disabled people's despair are often misattributed to their bodies rather than to their social circumstances. [Disability-rights advocates] denounce society's willingness to facilitate dying in persons with disabilities and other irreversible conditions rather than . . . addressing the remediable social problems underlying the death wish, such as poverty, institutionalization, isolation, and lack of meaningful social roles. (Gill 2004, 172)

Gill's criticism that society focuses on helping disabled people to die rather than helping them to live cannot be adequately addressed in the language of negative rights that dominates American political discourse and consequently a substantial amount of bioethical debate. Those with disabilities need positive accommodation by society to address "remediable social problems . . . such as poverty, institutionalization, isolation, and lack of meaningful social roles" (ibid., 172), but these accommodations do not fit nicely within the American paradigm that emphasizes negative rights to an extreme degree.

Take the example of Larry McAfee, a Georgia man who developed quadriplegia after a motorcycle accident. The right to have his ventilator removed, a negative right, was granted by the court. But the provisioning of resources he needed to live a meaningful life was never guaranteed (Quill and Battin 2004). Gill writes:

Like Bouvia, Larry McAfee, a resident of Georgia, said his disability rendered life intolerable. The court affirmed that the diminished quality of his life justified his right to die. Disability rights activists and their allies publicly

denounced state policies that supported institutional living while withholding funds for assisted independent living. . . . Advocates managed to break through to McAfee and offer emotional support as well as options for living and working that he had not known were possible. Instead of acting on his option to escape disability through dying, McAfee escaped institutional life, found assistance to live in the community, and learned how he could resume his past work as an engineer through computer adaptations. (Gill 2004, 172)

Of course, what the court affirmed was McAfee's right to refuse unwanted care. But the idea of a "right to refuse care" was arguably less meaningful to McAfee than the provisioning of the things he needed to live a fulfilling life. The very idea that the medical care was "unwanted" was contextually dependent on his life in an institution. McAfee's case represents the limitations of rights discourse to secure many meaningful advances for disabled people. The kind of support that eventually allowed him to live meaningfully after disability cannot be considered using the traditional language of negative rights.

The primacy of negative rights in American political discourse can provide some insight into the strict focus on the right to refuse care in discussions of disability, but it does not entirely explain the right-to-die exclusion in bioethical discourse. While the legal consensus stops short of positing a right to die and instead focuses on the right to refuse care, bioethicists have paid a great deal of attention to discussing a possible right to die in the form of advocating for access to physician-assisted suicide and voluntary euthanasia. Unlike the right to refuse care, which is generally recognized as a part of the common-law doctrine of informed consent (Weisbard 1986), no legal right to die has been recognized. The failure of the Supreme Court to establish a right to die in the *Cruzan* case<sup>3</sup> points to the reticence of the American legal system to recognize positive rights. But despite the nonexistence of such a right according to the Supreme Court, the legitimacy of the right to die is hotly debated in the bioethics literature while substantial discussions of issues such as institutionalization or provisioning of care for the disabled remain at the periphery of discourse.

The centrality of the right-to-die debate in bioethics, in the absence of an equally vigorous discussion of issues that will enable disabled people to live meaningful lives, lends support to a second reason for the excessive focus on death in the bioethics discussions of disability. Not only do such discussions affirm our preferences for rights discourse and particularly negative rights, but they also simultaneously affirm our preconceived prejudices about what constitutes a life

worth living. Kuczewski writes, “It is probably only in recent years that the names Dax Cowart and Elizabeth Bouvia would suggest disability issues to bioethicists having for years simply been discussed as right-to-die cases.<sup>4</sup> This tendency to reduce all questions to those of life and death has sometimes . . . been interpreted as advocating death over life with disability” (Kuczewski 2001, 36). Coupled with this charge is the documented misjudgment of quality of life with disability by physicians and laypeople alike. I will argue that these prejudices are related to rights discourse in discussions of disability, by invoking the ideal of what Glendon calls “the lone rights-bearer” (Glendon 1993, 48) as the prototypical and ideal human in American society.

### **The “lone rights-bearer” as the prototypical/ideal American**

Because of the traditional American liberal emphasis on negative over positive rights, a tight focus on individual rights curtails discussions about fraternity and mutual vulnerability that might better facilitate changes to improve the lives of disabled people. Such a focus also contributes to the marginalization of disability studies perspectives in bioethics in a second way: the negative rights emphasized in the American liberal tradition necessitate an equally problematic rights-bearer. Glendon has called this ideal person “the lone rights-bearer” who is “a self-determining, unencumbered individual, a being connected to others only by choice” (Glendon 1993, 38). Glendon sees this uniquely American image as connected to the ideals of “independence and self-sufficiency” (ibid., 38). Kuczewski writes similarly, “This kind of thinking accords nicely with the high premium placed on individualism in the self-understanding of Americans. Americans are quick to tout the virtues of self-reliance and hard work; artificial and discriminatory barriers that impede individual initiative are seen as unfair” (Kuczewski 2001, 38–39). True to its resonance with many traditional American ideals, the image of the lone rights-bearer appears as the prototypical or ideal human in many legal and bioethical discussions. Indeed, one major focus of feminist bioethics, expressed in the work of both Eva Kittay and Margaret Urban Walker, has been to identify the inadequacy of any system of morality that neglects human relationships.

While a paradigm of ethical thinking that posits the lone rights-bearer as the prototypical human is problematic for explaining any kind of human interaction, and, as several feminist thinkers have suggested, even more so for many women, the limitations of such a paradigm for a discussion of disability are particularly profound. Glendon puts it succinctly: “The lone rights-bearer is an ad-



mirable figure in many ways. Yet he possesses little resemblance to any living man, and even less to most women” (Glendon 1993, 38). The narrative that evokes the lone rights-bearer is even more limited for a discussion of disabled people who, because of their physical limitations, are often particularly socially dependent. The image of the lone rights-bearer leaves little room for a discussion of the right to curb cuts, the right to a personal attendant, the right to a meaningful social role, or the right to a government-funded, wheelchair-equipped van. Phrased in the context of the lone rights-bearer, these “rights” seem ridiculous. But they are essential to the day-to-day functioning of many disabled people. The American ideal of rugged individualism that manifests itself in our enduring attachment to the image of the lone rights-bearer is also helpful in explaining the enduring American federal emphasis on negative rights to the exclusion of the positive rights elaborated in many European constitutions and human bills of rights. The lone rights-bearer would not need positive rights because this fictionalized abstraction functions in perfect independence—not just from government intervention, but from social entanglement as well.

The American idealization of the lone rights-bearer contributes to a persistent misjudgment of the quality of life with disability. Sunil Kothari points out that “like most of the able-bodied, healthcare professionals significantly underestimate the quality of life of people with disabilities” (Kothari 2004, 300). As Kothari also points out, these (mis)perceptions among health-care professionals can have particularly far-reaching consequences, “given our positions of power in the healthcare system” (*ibid.*, 300). Kothari’s call for a rethinking of quadriplegia and traumatic brain injury by physicians easily extends to bioethicists who deal with questions of disability. By framing the debate about disability, ethicists and medical humanists also wield a great deal of power over the lives of those living with disability. The persistent undervaluing of the quality and worth of the lives of disabled people by judges, lawyers, and bioethicists probably contributes a great deal to the focus on the right to refuse care and the right to die in the bioethics literature.

Accompanying this pervasive underestimation of the quality of life that is possible with disability is a concomitant devaluation of the lives of those with disabilities. Gill suggests that this underestimation has led to a double standard in the provisioning of suicide prevention, based on the idea that suicide for the disabled is a “rational choice.” When disabled people choose death, their actions affirm our misperceptions about the value and quality of their lives. The “right to die” is granted only to those who are living with disability. For others, we prohibit

suicide. If desired, death is seen as appropriate for a disabled person. It is called a “right” in part because it reaffirms our own (mis)conceptions about what qualifies as meaningful life. To see a person who we believe has no quality of life fight for his or her own death is quite compelling. As Ellison’s invisible man put it, “I’ve never been more loved than when I tried to ‘justify’ and affirm someone’s mistaken beliefs” (Ellison 1995, 537). Ellison illustrates how compelling it can be to have our own prejudices affirmed by the person we are prejudiced against. This phenomenon does help explain the appeal of right-to-die cases for bioethicists, but in addition to fulfilling existing prejudices, right-to-die cases also allow us to frame the disabled person as a lone rights-bearer in an independent and spirited legal struggle, tenaciously pursuing her own death.

### ***Bouvia v. Superior Court***

Framing a disabled individual’s death as a right is particularly persuasive in the American paradigm of individual liberty: since the disabled person is fighting for her own death, the powerful American trope of individual freedom validates preexisting social prejudices that suggest the lives of the disabled are of less value. A close reading of the famous case *Bouvia v. Superior Court* illustrates how misperceptions of quality of life with disability are facilitated by the construction of the lone rights-bearer as the paradigmatic or ideal human.

Elizabeth Bouvia’s story evinces the blurry boundaries between the right to refuse care and the right to, or even appropriateness of, physician-assisted suicide or voluntary euthanasia for people with disability. Her story begins when she “sought the right to be cared for in a public hospital in Riverside county while she intentionally ‘starved herself to death’” (*Bouvia v. Superior Court*, 179, Cal. App. 3d 1127 [Cal. Ct. App. 1986]). With this in mind, the case might be more appropriately framed in terms of assisted suicide. Furthermore, although the case is overtly about the right to refuse care, the court’s language suggests many prejudices about what qualifies as a life worth living that are latent in this and many discussions of the right to refuse care. Justice Edwin Beach’s decision for the California Court of Appeals reads as follows:

Her condition is irreversible. There is no cure for her palsy or arthritis. Petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years! Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through the physical acts of others. Her mind and spirit may be free to take great flights, but she

herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness. We do not believe it is the policy of this state that all and every life must be preserved against the will of the sufferer. It is incongruous, if not monstrous, for medical practitioners to assert their right to preserve a life that someone else must live, or more accurately, endure, for 15 to 20 years. We cannot conceive it to be the policy of this state to inflict such an ordeal upon anyone. (*Bouvia v. Superior Court*).

A close reading of this passage from the *Bouvia* decision is instructive. Justice Beach's final decision emphasized that "A person of adult years and in sound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment" (*Bouvia v. Superior Court*). But despite the stated goal, Beach's decision may hinge less on the desire to protect *Bouvia's* autonomy and more on the common tendency to label suicidal ideation as rational for people who are disabled.

Gill writes:

It frightens us to find that our basic rights to live and learn and work are increasingly questioned as socially burdensome. . . . Concurrently, we are being singled out as a group whose dying makes more sense than the dying of people who function more typically . . . after years of struggle to win equal citizenship, the labeling of our suicides as rational may be the most dangerous form of discrimination we have ever faced. (Gill 2004, 180)

Gill's description highlights the irony of advocating for the right to die without advocating for "basic rights to live and learn and work." Beach's decision can be read as the kind of rational justification for suicide that Gill describes.

First, I would like to treat Beach's use of the term *irreversible* to describe *Bouvia's* conditions. People with chronic disabilities have historically been labeled *incurables*, and this description suggests one reason we are uncomfortable with disability: disabled people are reminders of the failure of modern medicine to deliver its promise to cure. Kuczewski writes that, "Contemporary bioethics has been somewhat skewed by its focus on high-tech medicine and the resultant development of ethical frameworks based on an acute-care model of healthcare" (Kuczewski 2001, 36). Justice Beach bemoans of *Bouvia's* illness, "There is no cure." Incurable conditions are frustrating in a bioethical climate based in an acute care model, because they are reminders of the failure of our system of medicine (Gill 1999, 171).

Beach moves from describing the incurable nature of Bouvia's condition to exclaim, "Petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years!" The terms *fed*, *bedded* and *toileted*, followed by the terms *brave* and *feisty*, are infantilizing descriptions that suggest a life not worth living. His following description of the "ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness" suggests an important aspect to why physical disability seems the worst fate and why the rights rhetoric is so powerful. The thrust of Beach's argument is this: it is dehumanization to be physically dependent on another. To be disabled in a way that requires—as disability often does—physical dependence on another is to be the opposite of the lone rights-bearer, the opposite of a freely functioning citizen, and in a significant and emotionally compelling way defines one as less than human. The use of the word *dehumanizing* to describe physical dependence on another is a covert message that is made more explicit at the end of this passage. Beach makes it more overt that he considers Bouvia's current circumstance to be *lebensunwertes leben* (life unworthy of life) when he describes her life as "a life that someone else must live, or more accurately, endure for 15 to 20 years" (emphasis added). He concludes by describing her continued existence as "an ordeal," one that would be "monstrous" of the state to "inflict." Each of these descriptors implies that Bouvia's life with disability signifies something less than being alive.

In his discussion of *Buck v. Bell*,<sup>5</sup> Menikoff emphasizes "two distinct themes" in the legal discourse on involuntary sterilization. These are "the government's attempt to override a person's autonomy, as by destroying the person's ability to reproduce, and the impropriety of actions based on a negative attitude toward disabled persons" (Menikoff 2002, 40). In the *Bouvia* case, we see a potential case of the latter (Beach's decision may have been based on a negative attitude toward disabled persons) being justified by an appeal to the former (he justifies the decision by suggesting that government has no right to override Bouvia's autonomy). Beach's negative rhetoric reflects a historical legacy of undervaluing the lives of the chronically disabled, rooted in eugenic thinking. It is not entirely dissimilar to the discourse of *Buck v. Bell*, a case that "has never been formally repudiated by the court" (Menikoff 2002, 39). It was argued that Carrie Buck would "benefit" from her own sterilization. Oliver Wendell Holmes's infamous logic, that, "It would be strange if we could not call upon those who already sap the resources of the state for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence" (*Buck v. Bell*, 247 U.S. 200, 207 [1927]) is dissimilar to Beach's

in that was couched in terms of benefit to the state. Still, Beach's argument in the *Bouvia* case uses the rhetoric of individual rights to arrive at a similar conclusion to the one Holmes gets to by utilitarian appeals: that the lives of disabled people are worth less than those of the nondisabled. In another ironic twist, Beach advocates passionately for Elizabeth Bouvia's right to starve to death, just as Holmes advocated the forcible sterilization of people like Carrie Buck, rather than letting them "starve for their imbecility."

### From rights talk to mutual vulnerability

By teasing out the ideal of the lone rights-bearer as the prototypical American, it becomes easier to understand our sympathy for Elizabeth Bouvia's claim that she did not "want to be a burden." When disabled people like Elizabeth Bouvia advocate for a negative right, like the right to refuse care, they more easily evoke the image of the lone rights-bearer.

An excessive focus on the individual's right to refuse care or even to have the right to die also plays a more subtle function. This discourse can be a way for us to avert our eyes from suffering. William May makes this point in his treatment of the case of Dax Cowart, a man who was severely burned and attempted unsuccessfully to refuse life-sustaining treatment. May writes, "The editors of a book on the Dax case sent me the audiovisual tape of the interview with Donald (Dax) Cowart but five months passed before I could force myself to watch it" (May 1994, 15). May's reason was that he felt, "a troubling aversion." He states, "After the surgeons have done their best and built a face they consider a technical success, the scarred patient must cope with the averted eyes of others" (*ibid.*, 15). Sidelining difficult conversations about how to improve the lives of the vast majority of severely disabled people who don't want to die is doing just that. Moving the discussion to the right to refuse care or the right to die can be a coping mechanism by which we shift our eyes away from the horror of the sufferer, reconstituting her as a perfectly autonomous individual whose rights are being infringed because she is being forced to live. Gill's description of Elizabeth Bouvia is an example of this type of characterization. She writes, "Right-to-die' proponents lauded her quest as a model of autonomous rational decision-making. She was adult, bright, and persistent. She said she knew her options, had reflected on her circumstances" (Gill 1999, 172). By constructing Bouvia as a perfectly rational lone rights-bearer, onlookers could construct an image of her that removed the complexities and social entanglements that attend

disability, and they could avert their eyes from the reality of her suffering: a suffering that we as a society might be responsible for alleviating.

The appeal of the narrative is enhanced by the disabled person's successful use of the legal system. In this narrative, the disabled person is lifted from social entanglement and dependence and is reconstructed as a lone hero using the legal system to fight for what is right. Thus, instead of engaging in the difficult moral act of witnessing suffering, this narrative allows legal-rights discourse to reconstruct the disabled person as a perfectly rational lone rights-bearer engaged in an individual struggle for negative rights.

By reconstituting the disabled person within the context of an individual struggle for negative rights, we transform her from the helpless sufferer who is *lebensunwertes leben* into an autonomous advocate for her own rights. While institutionalized, the disabled person is a humiliated and dehumanized sufferer, but while she is a citizen fighting out a courtroom battle she fits well into the radically constricted notion of what it means to be human in the context of a highly individualistic society.

This tragic irony, in which a person can only gain symbolic life in the struggle for her own death, is reflected in our current system of bioethics. The focus on negative rights like the right to refuse care, and the use of traditional rights-based discourse, fit very well into traditionally constructed bioethics because they emphasize autonomy. Early texts in bioethics placed a great deal of emphasis on patient autonomy, but as John Lantos points out, this narrow focus on autonomy presents similar problems to those presented with a narrow focus on individual negative rights. He writes:

We endorse a notion of autonomy in which the expressed desires of competent individuals are privileged to an extraordinary degree . . . while the thoughts or feelings that underlie those expressions are thought to be either unknowable or irrelevant. This approach entails a radically constricted, almost cartoonish notion of what it means for someone to "do" something. (Lantos 2002, 158)

The disability-rights critique is a useful one for combating this limited notion of autonomy because having a disability calls into question the traditional meaning of autonomy. It seems inappropriate for advocates for patient autonomy to fight for improved autonomy for disabled people only when it relates to their ability to die. For a person with a disability, something as simple as being able to live outside an institution may qualify as a meaningful extension of that person's autonomy. An examination of this critique can help bioethicists and

medical humanists reexamine their definition of autonomy and challenge the usefulness of a paradigm that privileges autonomy for discussing disabled or even sick people.

In order to expand discussions of disability beyond the traditional debates over euthanasia, physician-assisted suicide, and the right to refuse care, bioethicists and medical humanists must work toward a framework that emphasizes context and relationships and takes human interaction into account, does not assume the lone rights-bearer as the ideal human, and emphasizes the mutual vulnerability of embodied individuals. Scholarship from feminist bioethics can be particularly helpful here. Suggesting the inadequacy of traditional moral philosophy to describe human interactions has been one of the major projects in feminist bioethics. Each of these three proposals challenges the legitimacy of rights-based thinking as the basis for ethical decision making in the context of disability.

Attention to context has been an important component of feminist bioethics for some time. As Susan Sherwin points out, in addition to its usefulness surrounding issues of disability, feminist ethics' attention to context is well suited to many problems in medical ethics where, because of the individualized nature of clinical practice, context is vitally important to ethical reasoning (Sherwin 1989). A fundamental part of contextualizing all human lives is an attention to the importance of human relationships. Carol Gilligan's canonical work outlining an ethics of care points to the importance of relationships in ethical decision making (Gilligan 1984).

The ideal of the lone rights-bearer similarly makes possible ethical arguments that seem outlandish when placed in the context of human relationships. One bioethicist's recent book, which compares the moral status of congenitally severely mentally retarded people to that of animals, is an example (McMahan 2002). In her rigorous and moving rebuttal, Kittay points out that, for all his meticulous argumentation, the author pays little attention to the empirical realities of day-to-day life for those living with profound mental retardation (Kittay 2008, 137). Through her personal experience as mother to a child with profound mental retardation, Kittay has a profound realization about the relative importance of her child's cognitive capabilities and her relationship to her daughter, Sesha, as a parent:

Sesha would never live a normal life. . . . The worst fear was that her handicap involved her intellectual faculties. . . . Yet . . . it never even occurred to me to . . . think of her in any other terms than my own beloved child. She

was my daughter. I was her mother. That was fundamental. . . . We didn't yet realize how much she would teach us, but we already knew that we had learned something. That which we believed we valued, what we—I—thought was at the center of humanity, the capacity for thought, for reason, was not it, not it at all. (Ibid., 138)

Kittay's realization that the capacity for reason was not, as she previously believed "at the center of humanity," is rigorously argued in her work, and her empirical descriptions based in her relational experience as a mother are at the heart of her argument. Because many bioethical arguments privilege rational decision making above relationships, the leap to limiting moral personhood to those with the ability to behave rationally seems intuitive. By contrast, a framework in which respect for the ethical importance of relationships between people is central does not suppose the independent lone rights-bearer as a realistic norm or even as an ideal.

Finally, to adequately address issues of disability beyond right-to-die issues, bioethics must take issues of mutual vulnerability into account. In his book *The Wounded Storyteller*, Arthur Frank writes, "One of our most difficult duties as human beings is to listen to the voices of those who suffer. . . . These voices bespeak conditions of our own embodiment that most of us would rather forget our own vulnerability to" (Frank 1997, 25). Listening to that suffering with empathy, without objectification, and without turning away is a fundamental part of the human experience. As Frank sees it, it is a moral imperative that can greatly enrich both those who tell and those who listen. He calls for "a mutuality of listening," and writes, "I hope to show that in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is *for* the other" (ibid., 25). Our aversion to engaging people with disabilities lies in part in our own desire to deny our vulnerability. Margrit Shildrick has attributed the desire to deny connection with disabled people to "the threat of an other that would expose our underlying vulnerability to bodily degeneration" (Shildrick 2002, 69). Each of us, in our lives, will experience illness. Many of us will suffer from chronic disease. Disengaging from disability can be a way to try and shield ourselves from that reality. But, as Frank so eloquently describes, it is mutual vulnerability that makes the act of witnessing so powerful and so important for both listener and teller.

It is this mutuality of need that we must seek to illuminate, both in our day-to-day interactions and in our intellectual work. Feminist ethics of care and responsibility are uniquely suited for this work because they emphasize the



moral importance of human relationships, the limitations of ethical analysis that posit perfect self-sufficiency as normative or ideal, and the fundamental flaw of assuming atomistic interactions between individuals. Furthermore, they bring focus to the particular, allowing the voices and narratives of individuals to carry moral weight. The reinventing of the helpless, disfigured, or paralyzed sufferer as an autonomous individual concerned about a violation of her rights moves the discussion away from her suffering as it reifies our own misperceptions about living with disability. But by listening to the voices of those who are disabled we can begin to transform the discourse for the benefit of all of us.

### Notes

1. For the most part I will adopt the definition of disability utilized in the 2001 revision of the World Health Organization's document, the International Classification of Functioning, Disability and Health: ICF (World Health Organization 2001). I will also adopt a model that recognizes disability as a social construct, drawing a distinction between the biomedical conditions of impairment, and disability defined as "the disadvantages that people with impairments experience in environments which contain barriers to their participation" (Amundson and Tresky 2008, 123). I will also adopt a broad definition of disability that is not limited to people born with impairments. Critically important to the later points in my paper is the idea that disability is not simply a minority issue. All humans must live daily with the vulnerability inherent in our own embodiment. A definition of disability that recognizes our mutual vulnerability will allow for an expanded notion of autonomy that does not presuppose a lifetime of independent physical functioning as the norm.

2. See, for example, *Bioethics: An Introduction to the History, Methods, and Practice* (Jecker, Jonsen, and Pearlman 2007; Beauchamp 2008), a popular anthology that does not list disability in the index, or *Contemporary Issues in Bioethics* (Beauchamp 2008), which comments on disability mainly in the context of euthanasia and physician-assisted suicide. At the other end of the life spectrum, see *Bioethics: An Anthology* (Kuhse and Singer 2006), which attends to disability mainly in the context of prenatal testing and selective abortion. For an example of this phenomenon in books aimed at educating health professionals, see *Resolving Ethical Dilemmas: A Guide for Clinicians* (Lo 2000), which devotes extensive discussion to issues of the right to refuse care, but neglects issues of institutionalization and provision of resources for disabled people.

3. *Cruzan v. The Director, Missouri Department of Health*, 497 U.S. 261 (1990) is a paradigmatic Supreme Court case in the bioethics literature surrounding the right to refuse care. Nancy Cruzan was a young woman in a persistent vegetative state following resuscitation after a car accident. The court determined that Cruzan's feeding tube could be withdrawn, finding a right to refuse unwanted medical treatment in the due process clause of the Fourteenth Amendment, but stopped short of establishing a right to die.

4. Dax Cowart was a young man who was severely burned in an explosion. Cowart underwent painful treatment for his burns despite his many attempts to refuse care and in spite of being declared competent by a hospital psychiatrist (May 1994). Although his injuries left him with many disabilities including blindness, Cowart later went on to become a lawyer and patient rights activist. He is currently a professor at the Institute for the Medical Humanities in Galveston. Elizabeth Bouvia was a woman in her midtwenties with cerebral palsy who sought palliative care in a public hospital but refused a feeding tube thought to be life saving. Her case will be discussed in detail later in the article (*Bouvia v. Superior Court*).

5. *Buck v. Bell*, a controversial Supreme Court decision written by Oliver Wendell Holmes during the height of the eugenics movement, upheld Virginia's program of involuntary sterilization of people with disabilities. As Holmes describes, "Carrie Buck is a feeble minded white woman who was committed to the State Colony above mentioned in due form. She is the daughter of a feeble minded mother in the same institution, and the mother of an illegitimate feeble minded child." He infamously concludes, "Three generations of imbeciles are enough" (*Buck v. Bell*, 274 U.S. 200 [1927]). Later scholarship has not only condemned the decision, but has even called into doubt whether or not Carrie Buck and her family suffered from any disability at all (Lombardo 1985).

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