

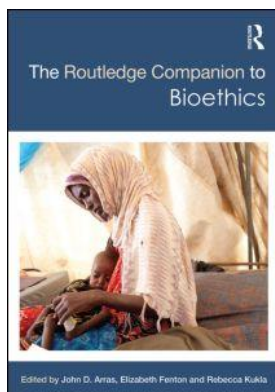
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Publisher: *Routledge*

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## **The Routledge Companion to Bioethics**

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### **Disability and Assisted Death**

Publication details

<https://test.routledgehandbooks.com/doi/10.4324/9780203804971.ch37>

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**Published online on: 12 Dec 2014**

**How to cite :-** Leslie P. Francis, Anita Silvers. 12 Dec 2014, *Disability and Assisted Death from: The Routledge Companion to Bioethics* Routledge

Accessed on: 30 Sep 2023

<https://test.routledgehandbooks.com/doi/10.4324/9780203804971.ch37>

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# DISABILITY AND ASSISTED DEATH

*Leslie P. Francis and Anita Silvers*

## Introduction

### *The Disability Critique*

For the past quarter century, disability rights organizations have joined sanctity-of-life proponents so regularly in opposing the practice of helping people to die that such advocacy has become a hallmark of the organized disability movement. These disability activists have advanced political rather than theological considerations to the forefront of the debate. They have argued that practices permitting medical professionals to assist in enabling patients' deaths unavoidably discriminate against people with disabilities, an especially vulnerable group (Coleman 2010). By advancing this argument, they give opposition to the practice of assisting dying additional weight by characterizing it as a violation of justice, and therefore as a collective political concern rather than as a violation of individual moral conscience.

A tri-partite generalization about social realities that make the practice of assisting death threatening to disabled people lies at the heart of this disability critique. First is the fear that individuals whose disabilities render them unable to articulate decisions about living and dying for themselves will be sacrificed, supposedly in the name of compassionately relieving them of the burdens of their lives. Second, permitting medical professionals to aid in dying invites the health care system to become more aggressive about reducing society's burden of care for people with disabilities by viewing at least some medical interventions as futile for them, as unlikely to succeed in addressing underlying conditions or bringing them a normal quality of life, or as unjustifiably risky and therefore not medically indicated. Third, even individuals with disabilities who can formulate and express their own decisions about living or dying may not be truly free to make such choices. Because their everyday existence unremittingly exposes them to negative assessments of their worthiness, persons marked by disability cannot help but be coerced or manipulated into devaluing their lives. Moreover, the contingencies of social and economic circumstances may deprive them of control, deepening dependency and restricting meaningful access to important human goods such as companionship or work. These generalizations—about misplaced compassion, problematic medical assessments, and thwarted autonomy—have been deployed to raise different but related disability concerns (Menzel and Steinbock 2013) about aid in dying.

### *A Pressing Paradox*

To the extent that disability activists defend disability rights, but condemn offering people with disabilities the right to obtain aid in dying, they might be expected to acknowledge a pressing paradox. On the one hand, choosing one's manner of dying seems an important exercise of autonomy. On the other hand, if for people with disabilities making this choice ineluctably and irreversibly results from their devaluing themselves, just having the choice unavoidably exposes them to manipulation and coercion that compromise their autonomy.

This paradox has not deterred disability critiques of assisting dying. A common resolution from a disability perspective is to dissolve the paradox by denying that autonomy rights hold value for people with disabilities. Denials of this sort typically take being autonomous as being incompatible with being dependent and therefore as irrelevant to the kind of individual most people with disabilities are. From this assumption it seems to follow that establishing practices of assisting dying to allow self-determination for persons at the end of life endanger rather than emancipate people with disabilities because autonomy is not a possibility for them. This rejoinder, however, divorces disability from autonomy in a manner that is potentially deeply problematic and undoubtedly paternalistic.

The paradox has not gone unnoticed by political theorists. For example, Katharina Heyer (2011; see also Bagenstos 2006) examines potential legal and political consequences of the disability opposition's rejection of a right framed by its proponents as a fundamental liberty interest or a right to privacy. Heyer posits an inherent conflict between such anti-rights rhetoric and a global disability civil rights movement energized by an emphasis on the autonomy of people with disabilities (Degener 2013) and by aspirations for self-determination in regard to where and how people with disabilities live their lives (Harnacke and Graumann 2012).

This chapter explores tensions between end-of-life liberty and life course safety in regard to people with disabilities. We address the dilemma by demonstrating that its drivers are contextually nuanced and therefore conditional on contingencies about economic dependency and the lack of meaningful options for health care and social services, as well as on biased assessments about quality of life, suffering, and the likely efficacy of medical interventions. In this regard, we consider the potential for improving such circumstances, as well as whether doing so would help secure people with disabilities against any special dangers that practices of assisting dying may pose for them. We hope that dissolving the paradox in the ways we propose will provide an enlightening guide to a fair and safe approach for end-of-life practices.

### **People with Disabilities and Life-Ending Medical Practice: Compassion Misplaced?**

#### *Life-Ending Decision-Making*

More than people in most other walks of life, medical professionals are positioned to influence or decide when others shall die. They can exercise this capacity in several ways: By not presenting options to patients or their decision makers because they are judged not medically indicated, by not initiating essential treatment or other life-sustaining support, by withdrawing previously provided treatment or life support, by arranging for patients' self-administration of lethal substances, or by actively undertaking

fatal pharmaceutical or surgical interventions (Robinson et al. 2006). It is commonly supposed that there are circumstances in which death at a doctor's hands, through at least one of these means, is allowable and perhaps even advisable. But assisting dying in any of these ways is not free of moral or legal concerns.

The standard position about the legitimacy of end-of-life decisions is that they must be based on the patient's choices and values, so far as these are known, or the patient's best interests, when information is incomplete or completely missing about what the patient would have chosen. Concerning patients' interests, a core question is whether inhumane suffering will be the prevailing result of the intervention that extends the patient's life, so that the person himself would escape from further life if he could. Other questions may lurk in the background, less acknowledged but playing important roles in the decisions made. Is a decision not to intervene in such a circumstance motivated solely by what the patient would decide if she herself could act or refrain from acting, or by the patient's interests as perceived by the patient to the extent this is possible, rather than by someone else's judgment of what would be good for the patient? And, are decisions about what would be good for the patient influenced by physicians' interests, by reference to benefitting other individuals, or by considerations of the collective good?

When these further questions elicit a positive response, or even a hesitant moment of recognition, confidence that the patient's choices or best interests are the paramount incentives for ending life is clouded. Disability critiques of life-ending medical practice are especially trenchant because they contend that, at least in medical contexts, people with disabilities are systematically subjected to judgments that deny their own points of view. Life-ending action intended for the sake of someone else provokes suspicions that third-party judgments are being substituted for the patient's own choices and thus is especially challenging—perhaps impossible—to legitimize. If accurate, this complaint illustrates the challenges of securing autonomous life-ending decision-making for people with disabilities, and perhaps for others as well.

Euthanasia in the broadest sense includes intervening in dying and withdrawing or withholding care in order to intentionally and mercifully hasten death. Although distinctions between actions and omissions, or intention and foresight, are often drawn in this context,<sup>1</sup> the issues discussed below are similarly implicated across the spectrum of euthanasia broadly construed. Euthanasia is defined as benefitting individuals by offering them death. Euthanasia also may be thought to benefit whoever is burdened by, or otherwise disadvantageously implicated in, the lives of the aforementioned sufferers. Thus, euthanasia divides populations into two classes of people: Those who are supposed to benefit from their own quick deaths and those who are supposed to benefit from others' quick deaths. These benefits may be portrayed as aligned, with the relief of suffering of the patient also relieving burdens on others. History cautions, however, that such supposed alignment of interests may be self-serving on the part of the latter group and therefore spurious.

### *Euthanasia and Disability: Warnings from History*

The history of euthanasia programs targeting people with disabilities stands as a warning about the threats life-ending practices pose to these individuals. While some such practices have been open, others have been carried on at the periphery of public scrutiny. For example, allowing neonates with Down syndrome or other congenital anomalies to die from lack of hydration/nutrition or basic therapeutic intervention was assumed to be

good medical practice by some U.S. and U.K. physicians up until the last decade of the twentieth century (Wilkinson 2011; Wilkinson et al. 2006; Duff and Campbell 1973).

The Nazis conducted the most often cited and clearest example of euthanizing people because they were physically or mentally anomalous and deemed thereby to be disabled and unfit (Florida Center for Instructional Technology 2012). The formal program was presented as prompted by the best medical judgment, and the process included review of cases by committees of physicians (Gallagher 2001). Authorized by this program, physicians ordered people who were diagnosed with incurable illnesses, including those with impairments who were far from dying of natural causes, to be put to involuntary, but supposedly merciful, deaths. On October 6, 1939, Hitler issued an order to “relieve through death” those mentally ill individuals who could not “take any conscious part in life” (Schmidt 2007: ch. 5)

The Nazi program put people with disabilities to death against their interests and without their consent, under the guise of relieving their suffering but actually to relieve and thereby benefit non-disabled people who otherwise would have had to care for them. Other benefits were realized as well; for example, institutionalized individuals with psychiatric illnesses were euthanized to enable transition of mental hospitals into acute trauma facilities for wounded troops. At the Nuremberg trials, however, the physician who administered the Nazi program for euthanizing people with disabilities claimed explicitly that the standard of practice among medical professionals in all nations understood people with disabilities to be burdensome to themselves, their families, and society in general (Morris 1992).

Knowledge of this historical practice of euthanizing people with disabilities, by no means unique to the Nazis, fuels the disability critique of life-ending medical practice by evoking fear of medical professionals’ self-serving or paternalistic assessments of the value of the lives of people with disabilities and the supposed benefits for them of relieving their suffering. Among the theoretically benevolent, but practically malignant, ideas that have been applied to people with disabilities, euthanasia probably is the most prominent. However, problematic judgments about the supposed unhappiness and poor quality of life of people with disabilities, as well as about the limited benefits of treatment for them, have generated support for decisions to withhold or to withdraw treatment that go far beyond practices of involuntary active euthanasia.

## Judgments of Suffering and Quality of Life

### *Suffering*

The Nazi contentions that people with disabilities would welcome relief from suffering were chillingly disingenuous. But from the point of view of the disability critique of end-of-life practices, they echo eerily in contemporary practices. Euthanasia in the Netherlands is premised on the justifiability of compassionate relief of intolerable suffering, when that is the patient’s choice. The Swiss organization Dignitas announces on its web site that:

Anyone suffering from an illness which will lead inevitably to death, or anyone with an unendurable disability, who wants voluntarily to put an end to their life and suffering can, as a member of DIGNITAS, request the association to help them with accompanied suicide.

(Dignitas 2013)

Physicians in Belgium construed their euthanasia law as permitting the practice in the case of 45-year-old identical twins with deafness who judged the loss of their sight “unbearable” (Reuters 2013). An Irish High Court decision rejecting aid in dying as an autonomy right nonetheless invited prosecutors to avail themselves of the “fullest opportunity to consider . . . the special and extenuating factors arising from the harrowing experiences being endured by the plaintiff,” a woman rendered largely immobile by multiple sclerosis and seeking assistance in dying.<sup>2</sup> But the assumptions that underlie these claims—that these judgments of intolerable suffering are accurate reflections of the patient’s own experiences—are precisely what concern the disability advocates who oppose aid in dying.

In many court cases in the U.S., Canada, the U.K., and elsewhere, people with chronic or life-limiting illnesses have sought assistance in death as their autonomous choice, claiming that they would rather have their lives end than continue to endure their current suffering. In the U.S. in the 1980s, Elizabeth Bouvia, whose cerebral palsy and arthritis led her to want to cease eating, obtained a court order to prevent nutrition being forced on her.<sup>3</sup> Larry McAfee, a respirator-dependent quadriplegic, designed a device that enabled him to turn off his respirator independently; he obtained a ruling from the Georgia Supreme Court that he had the right to refuse continued ventilator support and to receive pain medication from physicians during the process of withdrawal (*New York Times* 1995).<sup>4</sup> In Quebec in 1992, a patient with paralysis from Guillain–Barré syndrome sought discontinuation of ventilator support, and the court agreed that she was a competent patient who had the right to refuse treatment.<sup>5</sup> In British Columbia in 1993, Sue Rodriguez unsuccessfully petitioned to enable a physician to provide a device permitting her to self-administer a lethal dose when she believed her motor neuron disease (MND) had reached an intolerable stage.<sup>6</sup> Also in British Columbia, in 2012 Gloria Taylor won an exemption from the principle of opposition to assisted suicide established in *Rodriguez*.<sup>7</sup> The British Columbia Supreme Court declared the equality rights of patients were infringed by treating differently patients who can refuse treatment and patients who require an active intervention to end their lives, an issue not reached in *Rodriguez*. The Court suspended its judgment for a year, granting the exception to Taylor, to allow for appeal as *Rodriguez* is binding Canadian Supreme Court precedent. Despite Taylor’s death from an acute infection, the Canadian government is continuing the appeal (Global Montreal 2012).

The U.K. has also decided significant cases involving the decision to die by competent people with disabilities. In 2000, 19-year-old “AK,” a patient with degenerative MND, won the right to have his ventilator removed when he became “locked in” and no longer able to communicate even by blinking (BBC News 2000). Another patient with MND, Diane Pretty, sought a legal shield against her husband’s prosecution, should he help her to kill herself, but was not granted the shield in the U.K. courts or the European Court of Human Rights.<sup>8</sup> More recently, the British courts denied stroke patients Tony Nicklinson and “AM” assistance in dying (BBC News 2012).

The arguments pressed in court by many of those seeking aid in dying rest heavily on the intolerability of their circumstances. For example, the recent *Taylor* decision in British Columbia quotes expert witnesses on the moral importance of choosing relief from suffering:

“[N]eedless suffering” should be avoided (Wayne Sumner).

“[N]o one should be deprived of liberty or forced to suffer, without adequate cause” (Margaret Battin).



“Nor do I think it is right to allow grievously and irremediably ill patients to suffer against their wishes if they are far from death but their suffering is protracted over time and life is no longer bearable to them as may be the case for bedridden individuals or those facing major loss of autonomy” (Dr Cohen).<sup>9</sup>

What, from the standpoint of observers, does suffering that makes life itself unbearable consist of? And from the standpoint of the suffering parties themselves, does such suffering make death appear the best choice? As we shall argue, inappropriate epistemic privileging of an observer standpoint over a sufferer standpoint, along with normative biases and contingencies of social injustice, shape these judgments of the nature and profundity of suffering (Silvers 1997). Attention is required to guard against special dangers assisted dying may pose for people with disabilities.

### *Quality of Life*

A number of studies indicate the frequency with which the able-bodied project judgments concerning the poor quality of life of persons with disabilities (NCD 2009: 47; Adelman 2004; Boslaugh et al. 2009; Bryant and Fernandes 2010; McPhail and Haines 2011; Sandel 2011; White-Koning et al. 2008). Correlations between chronic conditions causing disability and perceived low quality of life are imperfect at best and may reflect remediable circumstances or depression (Patrick et al. 2000). Studies also document the increasingly positive or accepting views that many persons acquiring disabilities during their lives have to their circumstances (Patrick et al. 1997). But, particularly when held by physicians, disparaging views about the quality of life of people with disabilities may significantly influence life-ending decisions about continuing to receive treatment or withdrawing it.

In a recent essay in the *Hastings Center Review*, anthropologist William Peace, who has been paraplegic since 1978, reports how a physician approached him about consent to receive aggressive antibiotic treatment:

What transpired after the nurse exited the room has haunted me. Paralyzed me with fear. The hospitalist . . . grimly told me I would be bedbound . . . most likely a year or more. . . there was a good chance the wound would never heal . . . I would never sit in my wheelchair . . . I would never be able to work again . . . I was looking at a life of complete and utter dependence. My medical expenses would be staggering. Bankruptcy was . . . likely. Insurance would stop covering wound care well before I was healed. Most people with the type of wound I had ended up in a nursing home.

This litany of disaster is all too familiar to me and others with a disability. The scenario laid out happens with shocking regularity to paralyzed people. The hospitalist went on to tell me I was on powerful antibiotics that could cause significant organ damage . . . Many paralyzed people die from such a wound.

(Peace 2012: 14)

It's no accident that Peace chooses the word “litany”—a prolonged or tedious account—to characterize the “consenting” to which he was subjected. What he had to listen to while being “consented” are words prompted by a health care professional's compulsion to

relieve his own discomfort about the dubiousness of success. The two have profoundly different perspectives on the risks involved. The physician measures the risk of a bad outcome, and the degree of badness this potential outcome bears, against his experience of patients generally. But Peace's attitude and assessment differ from the usual patient's. His life's history is one of overcoming intimidating odds, often painfully. He is expert at picking up and functioning even if treatment outcomes fall far short of optimal. To succeed, he knows, calls not only for determination, but also for the kind of hope the physician's litany seems aimed to destroy.

The ethical question is which view of Peace's future should prevail. It's hard to see why the prognosis should not be Peace's hopeful one, as it is epistemologically superior; his intentions not only best serve his interest but are better informed about achievable gain as the actual outcome—his recovery—shows. Peace and other people with disabilities like him (not all people with disabilities are like him, of course) are knowledgeable about themselves, are responsive to their specific physiological situation rather than to that of the typical patient, and are well informed about health dangers that might befall them as well as medical services they might need.

Individuals with chronic illness or disability often are experienced at functioning under adverse health conditions and thus have developed not only knowledge, but also adaptive skills, capacity to maintain morale, and endurance that surpass those of the "normal" patient. These are strengths that equally often health care professionals do not fully understand or appreciate. Consequently, these biased approaches to risk, and to restrictions on activity as well, can gnaw at patients' confidence in pursuing treatment and become further barriers to overcome.

### Misplaced Judgments of Futility

Problematic judgments about quality of life are entangled with problematic judgments about medical futility. It is a principle of medical ethics that medically futile interventions need not be provided, absent strong countervailing reasons. Understanding this principle demands recognition that "futility" is a slippery concept. "Medical futility" in the strictest (and, we believe, most appropriate) sense should be reserved for interventions that simply will not work: An antimicrobial against an organism that is resistant to it, a blood transfusion for a person with an unrepaired aortic aneurism, or ventilator support for a patient whose lungs can no longer exchange oxygen at all. For purely physiological reasons, these interventions will not achieve their intended purpose. But medical futility in this sense is often blurred with concepts such as low probability, inability to alter underlying conditions that are judged to affect quality of life, or high cost (Schneiderman et al. 1990; Jecker 1995). Each of these latter conceptions involves a value judgment: How high a probability of success is needed to offset the risks of an intervention? Must goals of treatment address the patient's underlying condition in addition to the problem to which the intervention at hand is directed? Should costs be considered in treatment decisions, by whom, and in what ways? The American Medical Association's (2012) ethics opinion on futility in end-of-life care judges that "there are necessary value judgments involved in coming to the assessment of futility" and recommends a "due process" approach to futility judgments.

Conceptualized as physiological claims, judgments of medical futility must rely on the best scientific evidence. Unfortunately, disability rights advocacy may at times become entangled with problematic attitudes toward scientific evidence. For example, some advocates



in the case of Teresa Marie Schiavo advanced questionable beliefs about the potential efficacy of hyperbaric therapy as well as refusals to believe the findings in autopsy reports about Schiavo's capacity for cognitive functioning (Francis and Silvers 2007).

This said, people with disabilities all too often find themselves subjected to harm from bias masquerading as scientific fact or from supposedly objective claims that are infected by conflicts of interest (NCD 2009: 10). Moreover, judgments of medical futility prompted by medical professionals' personal values and attitudes are especially problematic when decisions involve patients with disabilities. Patients or their personal representatives may be told by health care providers that interventions would be "futile," without disaggregation of whether this is a judgment of medical futility in the strict sense or some kind of additional value judgment that the intervention has a small probability of success, that it will not reach to an underlying disabling condition, or that it may be very costly in comparison to the likely benefits in overall quality of life to be achieved. But if patients or their representatives are to weigh what is at stake in recommendations about futility, these distinctions are exactly what they need to understand.

### Autonomy and Loss of Self-Determination

In Oregon where physician-assisted suicide is permitted, most of those who seek it are not economically disadvantaged. For the most part, the same is true of euthanasia in the Netherlands. One recent study interviewed patients seeking aid in dying about their reasons for the request. Loss of independence and the desire for control over circumstances of dying (especially the ability to die at home) were paramount reasons (Pearlman et al. 2005). Also important were perception of self as a burden, the prospect of worsening pain or quality of life, and the inability to care for self. Physical symptoms such as pain or loss of bladder or bowel control were rated as much less important (Ganzini et al. 2009a, 2009b).

From the demography of choice in Oregon and the Netherlands, some scholars have concluded that, as practiced at present, assisted death presents little risk to the vulnerable in these jurisdictions (Battin 2008; Battin et al. 2007). The data about patients who seek active intervention in dying indeed do not indicate over-representation of patients who fall into selected "vulnerable" groups: The elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. People with HIV/AIDS are over-represented, the only potentially vulnerable group identified. This research strategy, of searching for over-representation of members of vulnerable groups among those seeking active intervention, has limits, however. It does not identify ways in which problematic judgments such as those that underestimate quality of life, or those that exaggerate profundity of suffering, might be affecting non-treatment decisions more generally, including those of persons both within and outside of the groups identified as vulnerable.

It also looks only at the patterns with which intervention is obtained—the conclusions—and not at counter pressures that might, for a time, be functioning protectively for certain of these groups. Notably, the authors' discussion distinguishes between pre-existing disability (e.g., paralysis or chronic illness) and terminal illness (which surely also is a source of disability or vulnerability), arguing that there is no over-representation in the first group among those choosing aid in dying.

The core to the disability critique is that end-of-life practices only apparently reflect autonomous patient choice. If people with disabilities are subject to frequent negative judgments by others about their supposed quality of life, they may be coerced or deluded into embracing the view that their lives should not be prolonged. Compounding the assault of quality-of-life judgments on autonomy are the problematic social and economic circumstances in which many people with disabilities must lead their lives.

It is far from clear, however, whether such oppressive societal disregard prevents people from autonomously forming ideas of their good and thereupon exercising, attempting to exercise, or wishing they could exercise self-determination.

Recall the case of Larry McAfee, described in detail by Alicia Ouellette (2010). McAfee was a person with quadriplegia who required ventilator support. For almost a year after his accident, McAfee was able to live in an apartment near friends and family; round-the-clock nursing care was paid for by his Blue Cross insurance policy, his Social Security disability check, and his parents. When the private insurance ran out, McAfee became eligible for Medicare, which with Social Security disability payments and contributions from the hospital that cared for him in Georgia, paid for \$650-a-day nursing home care. However, as there were no nursing homes in Georgia that would accept patients on ventilators (Applebome 1990), all McAfee could find for his care was an institution in Ohio. Eventually the Ohio nursing home decided that he should be discharged and he was sent to Grady Memorial Hospital in Atlanta, where he was placed in the ICU. Then the *Medicare Catastrophic Coverage Act*, which had been paying for McAfee's nursing home care, was repealed, and McAfee was faced with a shift to Medicaid, the health insurance plan for the poor, with payments substantially less than Medicare. Moreover, neither government program would pay for care in the community, outside an institution, even though the cost was substantially less than hospital care.

At this point, McAfee decided that he had had enough and sought the installation of a device that would enable him to turn off his own ventilator. "I've been moved from place to place with no say-so on why or where or how," he said. "I'm just tired of it. I'm fed up. I have no control over what's done to me, how it's done or by whom." A Georgia Superior Court judge decided in his favor and the Georgia Supreme Court affirmed.<sup>10</sup>

McAfee did not avail himself of the right to die he had won, however. As a result of the attention he gained by going to court, he was able to move to a nursing home in Birmingham, Alabama, where the director of the Injury Prevention Research Center at the University of Alabama assisted him in learning to operate adapted computer equipment. Subsequently, he moved again, this time to a personal care home in Augusta, where he lived until hospitalized with pneumonia, from which he died in 1995.

McAfee's story was made into a television drama in 1993. The theme was his conversion from choosing death to choosing life; the insight was the crucial role gaining some control over his living conditions played. By no means was McAfee's autonomy compromised by his socially devalued situation. His own idea of his good drove his campaign to regain self-determination over the details of his daily life. Absence of control is well known to be correlated with and to create anxiety, frustration, and despair (WomenWorld 2012). But whether an individual who is disabled experiences such hopelessness depends in part upon the person's social circumstances, and especially on whether the individual can command respectful living conditions or whether instead demeaning conditions are imposed either deliberately or through the impact of social policies and circumstances. McAfee's gaining more secure governance of his living conditions clearly shifted his choice from dying to living. The key to his choice to live

was a change of circumstance that expanded his opportunity to self-determine his daily life (California Advocates for Nursing Home Reform 2010). But how to facilitate the requisite social responsiveness for disabled people generally remains a stubborn dilemma, as we explain more fully below.

Commanding funding for support services will alleviate despair in some circumstances, but not in all. For example, a reason frequently given by members of eligible populations for seeking physician-assisted suicide is the loss of dignity occasioned by not being able to perform intimate functions of ingestion and excretion in privacy by one's self. In this case, it is the presence of assistants rather than their absence due to lack of funding that is experienced by the person with a disability as powerlessness. So there are different ways of altering context to reduce the anxiety of dependence. In some cases, changing an individual's economic situation may do the trick but in others changing psychological or cultural attitudes will be more important.

These are all contingencies, even though of different kinds. As such, they can in principle be addressed and ameliorated. Dependence in its various forms is not necessarily a trigger for wanting to die, although for some individuals it may reasonably be. Individuals with disabilities who seek assistance to die may or may not be motivated by the constraints of their biological conditions, but by features of the social context. The patients with MND who went to court stated that they found declining physical functioning intolerable, especially without any control over means of potential escape. However, Larry McAfee sought to die because, while his post-injury physical state was stable, his economic support and his living situation, and therefore the texture of his experienced life, appeared to be plummeting in an unstoppable downward spiral.

People prefer to live at home and in communities they value; data are overwhelming that people with disabilities are no different in this respect (NCD 1997; Shapiro 1994). Yet U.S. health care and social services are structured counter-productively with respect to these goals. Many states have long waiting lists for community-based services. The result in these states is that the only way people can receive personal care services is to be institutionalized (Watson 2009). Long state waiting lists have survived challenges brought in court under the *Americans with Disabilities Act*, so long as states structure their programs reasonably in light of resources available and the needs of all with disabilities (*Olmstead v. L.C.*, 527 U.S. 581 1999). Paul Longmore (1995) and other critics draw linkages between former Colorado Governor Richard Lamm's opposition to paratransit, needed by people with the most severe disabilities to travel outside their homes, and his opposition to providing for the educational needs of children with profound disabilities, to his views that constrained resources may portend recognition of a duty to die. Not surprisingly, some may find these circumstances intolerable. If state budget crises continue, the situation will be unlikely to improve and indeed may worsen as pressures on state funds continue to grow (Bird (2012) about Worcester, Massachusetts).

The U.S. is not alone in presenting challenges to those in need of home- and community-based services. The United Nations Convention on the Rights of Persons with a Disability, Article 19 (2008) provides for:

the equal right of all persons with disabilities to live in the community, with choices equal to others, and . . . effective and appropriate measures to facilitate

full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community . . .

However, many nations appear not to meet this rights-based provision. To take one example, Parker and Fisher (2010) document the inadequacies of disability housing support in Australia. In the U.K., cost concerns have generated controversial proposals to cap expenditures for care at home (Murray 2012). Despite an overall government commitment to independent living, home care is funded by local authorities and access to services varies significantly (Department of Health (U.K.) 2012).

## Conclusion

In this chapter, we have argued that the disability critique of current end-of-life practice is often exaggerated and paternalistic, but nevertheless raises issues that have not been well addressed in social policy. Epistemic problems are raised by the imposition of judgments (often in the guise of medical judgments), especially by medical professionals who are unqualified to judge the value of life with disability, or who are weighing in their own or third-party interests. In practice, the medical standpoint is given more weight than epistemic standards should permit. In addition, judgments of quality of life made about persons with disabilities may be invoked in ways that devalue the lives of such persons. Finally, the reality of lives faced by many people with disabilities—the absence of supports needed for them to have meaningful access to goods such as life in the community, the companionship of family and friends, or useful work—may lead people with disabilities to opt—apparently autonomously—for choices to forego care that are contingent on their remediable social circumstances. Dissolving the paradox embedded in the disability critique of assistance in dying thus requires changes in current epistemic, normative, and socio-economic practice, so that people with disabilities can be free of coercion and securely exercise the autonomy the medical system owes every individual alike.

## Related Topics

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Chapter 21, “Autonomy,” Catriona Mackenzie  
 Chapter 22, “Capacity and Competence,” Jessica Berg and Katherine Shaw Makielski  
 Chapter 32, “Reproductive Testing for Disability,” Adrienne Asch and David Wasserman  
 Chapter 38, “End-of-Life Decisions for Newborns,” Marian Verkerk and Hilde Lindemann

## Notes

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- 1 *Vacco v. Quill*, 521 U.S. 793 (1997).
- 2 *Fleming v. Ireland*, [2013] IEHC 2.
- 3 *Bouvia v. Superior Court*, 179 Cal.App.3d 1127, 225 Cal.Rptr. 297 (1986).
- 4 *Georgia v. McAfee*, 385 S.E. 2d 651 (Ga. 1989).
- 5 *Nancy B. v. Hotel Dieu de Quebec* (1992), 86 D.L.R. (4th) 385 (Que. S.C.).
- 6 *Rodriguez v. British Columbia*, [1993] 3 S.C.R. 519.
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