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ENDING-LIFE DECISIONS: SOME DISABILITY PERSPECTIVES

Mary Crossley*

INTRODUCTION

My contribution to this symposium on “*Quinlan* at 40: Exploring the Right to Die in the U.S.” considers the challenges to end-of-life decision-making that disability poses. I am perhaps an odd choice to offer the disability perspective on this or any topic, as I am able bodied and of sound mind, at least for the moment. For the past thirty years, however, I have puzzled over how people with disabilities experience the health care system in this country and how the health care system experiences people with disabilities.¹ Either I am not very good at puzzles of this sort, or it is a really tough puzzle, or perhaps both. In any event, I am still struggling with it. The topic continues to engage me, because, to my mind, understanding what it means to be disabled is an inextricable part of understanding what it means to be human. In offering these perspectives, I do not speak for people with disabilities. Instead, this essay simply offers my understanding of views commonly expressed by members of the disability community.

My starting premise is that disability lies at the heart of questions about making ending-life decisions² simply because most people whose lives end as the result of a decision to withhold or terminate

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1. Beginning with Mary A. Crossley, *Selective Nontreatment of Handicapped Newborns: An Analysis*, 6 MED. & L. 499 (1987).

2. The choice of how to refer to decisions about medical interventions that sustain or end life is itself disputed. See Tom Koch, *The Ethicist as Language Czar, or Cop: “End of Life” v. “Ending Life,”* 25 HEC Forum 345, 346 (2013) (suggesting that language used in bioethical arguments is itself prejudicial). Although the more common usage is “end-of-life” decisions, in this essay I prefer to use “ending-life” decisions. Particularly in cases involving persons whose disabilities do not pose an imminent threat to their lives, a decision to refuse life-sustaining medical interventions is better understood as a decision that ends life, rather than as a decision that occurs proximate to an already imminent end to life.

medical treatment or to seek active medical assistance in dying are disabled.³ Many persons whose lives end through such a conscious choice may have become disabled only near the end of their life, although some may have been disabled for many years or their entire lives. By and large, discussions of the right to die have *not* been about able-bodied, mentally competent people choosing to die.⁴ Our society remains profoundly uncomfortable with the idea that an able-bodied, healthy person would voluntarily direct her own death. But something about infirmity, and the loss of function and independence, sometimes *but not always* coupled with the conviction that death is imminent anyway, make the decision to go ahead and die—or let die—acceptable. I do not argue that this judgment—whether intuitive or the product of moral reasoning—is necessarily wrong. I am convinced, however, that disability, or fear of disability, is nearly always part of the ending-life calculus, whether acknowledged or not.

In the forty years since *Quinlan*,⁵ disability has occasionally been present in the conversation within medicine, bioethics, and law about the acceptability of death-hastening medical decisions, but it has at times been viewed as an interloper,⁶ an uninvited guest to the party, or perhaps the guest whom the host was obliged to invite, but whose presence was not entirely welcomed. Notwithstanding some short-term reversals and counter-currents, the steady arc of end-of-life law during the past four decades has been towards liberalization of ending-life choices by and for patients who are severely

3. The most notable exception to this generalization involves persons facing life-threatening medical circumstances whose refusal of medical care or particular interventions is religiously motivated. See, e.g., *Application of President & Dirs. of Georgetown Coll., Inc.*, 331 F.2d 1000 (D.C. Cir. 1964), *reh'g en banc denied*, 331 F.2d 1010 (D.C. Cir. 1964), *cert. denied*, 377 U.S. 978 (1964); *Pub. Health Trust v. Wons*, 541 So. 2d 96 (Fla. 1989).

4. See Ian Basnett, *Health Care Professionals and Their Attitudes Toward and Decisions Affecting Disabled People*, in *HANDBOOK OF DISABILITY STUDIES* 450, 455–56 (Gary L. Albrecht et al. eds., 2001).

5. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

6. See Carol J. Gill, *No, We Don't Think Our Doctors Are out to Get Us: Responding to the Straw Man Distortions of Disability Rights Arguments Against Assisted Suicide*, 3 *DISABILITY & HEALTH J.* 31, 36 (2010) (noting the irony of “assisted suicide proponents view[ing] disability advocates as interlopers in these matters”).

compromised or near the end of their lives.⁷ During that time, many leading thinkers and activists in the disability community have questioned that liberalization.⁸ My sense is that physicians, bioethicists, and lawyers have sometimes viewed disability advocates' questioning as marginal, if not bordering on the paranoid, or as the product of manipulation by other interest groups.⁹ Disability concerns may be perceived as distracting attention from broadly held values and interfering with progress. As a result, discussions about ending-life decisions within the bioethics, medicine, and law communities and those within the disability community too often proceed along parallel tracks, rather than directly engaging with each other. I contend that, because most ending-life decisions are made by or for disabled persons, persons with disabilities must be included at the center of conversations about the meaning of and limits on those decisions.¹⁰

This essay does two things. First, it briefly describes the nature of and basis for disability concerns about the liberalization of ending-life decisions.¹¹ This account is largely descriptive and explanatory, summarizing the reasons for the apprehension that many in the disability community experience surrounding treatment termination and physician-aided dying. I offer this account recognizing both that I am not a person with a disability and that people with disabilities have diverse views on these issues. Second, this essay considers how recent conversations about racial justice issues in policing and criminal justice, promoted by the Black Lives Matter movement, among others, might offer parallels to the concerns of disability

7. See, e.g., *Quinlan*, 355 A.2d at 663–64 (starting the arc when the court held that the guardian of a woman in a non-cognitive, vegetative state could assert the woman's right of privacy and thereby end her life).

8. See Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-Life Decision Making Advocates Are Not out to Get Them*, 37 *LOY. U. CHI. L.J.* 343, 345 (2006).

9. Cf. Cerminara, *supra* note 8, at 371–73 (suggesting that disability advocates may have been manipulated by right-to-life activists during the *Schiavo* case).

10. Accord Adrienne Asch, *Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?*, *HASTINGS CTR. RPT.*, (SPECIAL REPORT) S31, S36 (2005).

11. See *infra* Part I.

advocates.¹² To my mind, these parallels help explicate the concerns of disability activists and reveal them as deeply imbued with social justice commitments.

I. SUMMARIZING DISABILITY CONCERNS ABOUT ENDING-LIFE DECISIONS

To be clear, people with disabilities have diverse views about terminating life-sustaining treatment and assisted dying.¹³ As a consequence of living with impairments that limit their ability to function typically and often provoke discomfort, and even fear among members of the majority, people with disabilities have a distinctive perspective. That perspective is not monolithic, however, just as no single, all-encompassing “disability community” exists.¹⁴ Much of the experience of living with a communication disorder differs from that of living with blindness, an anxiety disorder, quadriplegia, or an intellectual disability. The experience shared by people with diverse disabilities, however, is that of being excluded, socially isolated, devalued, and dismissed by the dominant culture and the physical, social, and economic structures that culture builds.¹⁵ Those shared experiences provide the foundation on which disability studies scholars, disability rights organizations, and disability activists build their work.¹⁶

This part seeks to summarize the views commonly articulated by major disability groups, disability theorists, and disability activists for readers who may not be steeped in disability theory or accustomed to thinking from a disability viewpoint.¹⁷

12. See *infra* Part II.

13. See Cerminara, *supra* note 8, at 372; Alicia Ouellette, *Context Matters: Disability, the End of Life, and Why the Conversation Is Still So Difficult*, 58 N.Y.L. SCH. L. REV. 371, 375 (2013).

14. Cf. Rosemarie Garland-Thomson, *Becoming Disabled*, N.Y. TIMES (Aug. 19, 2016), <http://www.nytimes.com/2016/08/21/opinion/sunday/becoming-disabled.html> (noting that most people do not see people with different disabilities as having a shared social identity or political status).

15. See Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES L. & MED. 141, 141–42 (1987); W. Thomas Smith et al., *Disability in Cultural Competency Pharmacy Education*, 75 AM. J. PHARM. EDUC. 1, 2 (2011).

16. See Longmore, *supra* note 15, at 147–48.

17. I view my role in writing this essay as that of a guide or teacher, not an advocate. The essay

At its core, much of the concern that the disability community expresses regarding ending-life decisions flows from a lack of trust and confidence that all persons and institutions involved in those decisions will respect the experiences, values, and welfare of people with disabilities.¹⁸ The apprehension that their lives may be devalued extends to physicians, courts, society, and even family members.¹⁹ In the experience of many people with disabilities, the strands of concern that I describe below are woven tightly into a fabric of unease, but I will present them strand by strand, starting with concerns about physicians and the health care system.

A. A History of Discrimination by Medicine and Public Health

Historical examples abound of instances where physicians, public health officials, and government programs have discriminated against, abused, or isolated people with disabilities, often with society's sanction. Pictures from this hall of shame are familiar: the photo of Virginian Carrie Buck, who—like more than 60,000 other Americans believed to be feebleminded, disabled, or otherwise unfit to reproduce—was sterilized without her consent, all in the name of a eugenic vision of public health that endured from the 1920s until well after the end of World War II.²⁰ The Supreme Court upheld Virginia's eugenic sterilization law with Justice Holmes' ringing endorsement: "Three generations of imbeciles are enough."²¹

The images from the 1970s of disabled youth in wretched conditions at Willowbrook State School in New York also come to mind. For many years, physicians were complicit in the mistreatment of people with disabilities, including involuntary institutionalization

seeks to enlarge the readers' understanding, not to convince them that the views described are "right" in an absolute sense or that contrary views are "wrong." That said, I personally believe that the views described are rational, well founded, and deserving of greater heed.

18. For two legal scholars' accounting of the experiences of patients with disabilities and these concerns, see Ouellette, *supra* note 13, at 379–85; Elizabeth Pendo, *What Patients with Disabilities Teach Us About the Everyday Ethics of Health Care*, 50 WAKE FOREST L. REV. 287, 292–93 (2015).

19. See *infra* Sections I.A, I.B, I.C.

20. See generally PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND *BUCK V. BELL* (2008).

21. *Buck v. Bell*, 274 U.S. 200, 207 (1927).

and forced medical procedures.²² Willowbrook State School, with its history of inhumane treatment of and experimentation on children with intellectual disabilities, is symbolic of physician mistreatment of disabled people, much as the Tuskegee Syphilis Study is for black people.²³

In the 1980s, the public became aware of another example of physicians supporting death-dealing decisions for vulnerable persons with disabilities.²⁴ Significant media attention focused on the story of Baby Doe, an infant born with Down Syndrome, whose parents chose not to authorize routine surgery to correct an esophageal blockage and instead permitted their infant to die of starvation.²⁵ Baby Doe was not an isolated case. So-called “selective nontreatment” for disabled newborns was described in one medical journal as the “highest form of medical ethic,”²⁶ and surveys showed significant physician support for the practice.²⁷

For decades, systemic, government-sanctioned practices isolated people with disabilities in institutions where they had little or no opportunity to participate in community life or to pursue educational or economic opportunities.²⁸ The societal stigma attached to disability contributed to and reinforced Medicaid’s preference for institution-based long-term care services, which required people with disabilities to live in institutions to receive needed supportive and

22. See *Remembering an Infamous New York Institution*, NPR (Mar. 7, 2008, 7:00 AM), <http://www.npr.org/templates/story/story.php?storyId=87975196>.

23. Residents of Willowbrook reportedly were intentionally exposed to the hepatitis virus as part of an experiment. See *id.*; David J. Rothman, *Were Tuskegee & Willowbrook ‘Studies in Nature’?*, in HASTINGS CTR. REP., Apr. 1982, at 5–6 (comparing the two experiments); see generally DAVID GOODE ET AL., *A HISTORY AND SOCIOLOGY OF THE WILLOWBROOK STATE SCHOOL* (2013).

24. See, e.g., *Down’s Syndrome Baby Barred from Food Dies*, WASH. POST, Apr. 16, 1982, 1982 WLNR 58354.

25. *Id.* The case of Baby Doe was also the impetus for several efforts at the federal level to regulate medical decisions regarding life-sustaining treatment for disabled newborns, ultimately resulting in Child Abuse Amendments of 1984. Pub. L. No. 98-457, 98 Stat. 1749 (codified at 42 U.S.C. §§ 5102-5106 (2016)). The Child Abuse Amendments required states to pass laws requiring the reporting of and responding to instances of withholding of medically indicated treatment for disabled infants with life-threatening conditions. See generally Steven R. Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 HASTINGS L.J. 765 (1986).

26. John M. Freeman, *Is There a Right to Die—Quickly?*, 80 J. PEDIATRICS 904, 905 (1972).

27. I. David Todres et al., *Pediatricians’ Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197, 201 (1977).

28. See, e.g., Rothman, *supra* note 23.

medical services.²⁹ The emergence of the independent living movement in the 1970s challenged the concept of institutions as the presumptive setting for disabled life and medical care and contributed to Medicaid revisions permitting increased coverage of more home- and community-based services.³⁰ It was not until 1999, however, that the Supreme Court's decision in *Olmstead* recognized that, in cases where institutional care is unnecessary and undesired, a state's failure to provide services in a community setting constitutes disability discrimination in violation of the Americans with Disabilities Act.³¹ Despite *Olmstead*, Medicaid's historic structural bias in favor of institutional care persists.³² Although allocation of Medicaid funding varies from state to state, in 2013 more than thirty states devoted less than half of their long-term care spending to home- and community-based services.³³

Even today, many physicians' offices remain largely inaccessible to people with disabilities.³⁴ The *New York Times* recently described a study in which a physician called more than 250 specialists, seeking to refer a hypothetical patient who was partially paralyzed, used a wheelchair, and weighed 200 pounds.³⁵ The specialists' responses to

29. See Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 955, 958 (2010).

30. See Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 987 (2003); Watson, *supra* note 29, at 958–59; see also Chava Willig Levy, *A People's History of the Independent Living Movement*, INDEP. LIVING INST. (1998), <http://www.independentliving.org/docs5/ILhistory.html>.

31. *Olmstead v. L.C.*, 527 U.S. 581, 600–01 (1999).

32. Watson, *supra* note 29, at 968.

33. ERICA L. REAVES & MARYBETH MUSUMECI, KAISER FAMILY FOUND., *MEDICAID AND LONG-TERM SERVICES AND SUPPORTS: A PRIMER* (2015), http://kff.org/report-section/medicaid-and-long-term-services-and-supports-a-primer-report-dec-2015/#endnote_link_172646-27. For historical background regarding the coverage of home and community-based services (HCBS) under the Medicaid program, see Laura D. Hermer, *Rationalizing Home and Community-Based Services Under Medicaid*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 61, 63–72 (2014).

34. See Michelle A. Meade et al., *The Intersection of Disability and Healthcare Disparities: A Conceptual Framework*, 35 DISABILITY & REHAB. 632, 637 (2015) (citing studies that show “a significant number of healthcare offices remain both inaccessible . . . with regard to physical barriers as well as the training provided to office staff” and that “the majority of primary care physicians, dentists and psychologists continue to work out of offices that are minimally accessible . . .”).

35. Pauline W. Chen, *Disability and Discrimination at the Doctor's Office*, N.Y. TIMES: WELL BLOG (May 23, 2013, 3:56 PM), https://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/?_r=0. The results of the research were published in Tara Lagu et al., *Access to Subspecialty Care for Patients with Mobility Impairment: A Survey*, 158 ANNALS INTERNAL MED. 441,

the referral request were disturbing. Fewer than ten percent of the specialists had appropriate equipment, eighteen percent reported not having trained staff to provide care for the patient, and twenty percent refused to even schedule an appointment.³⁶ Other sources confirm that people with disabilities continue to face pervasive problems of access when they seek medical care.³⁷

These examples illustrate how biases against people with disabilities have colored the history of, and still persist within, the health and medical systems in the United States. Despite advances in cultural attitudes toward disability, the health care system often remains a space that many people with disabilities perceive as neither welcoming nor supportive. They attribute that perception at least in part to both anecdotal and empirical evidence that many doctors hold negative views of disabled life, as described below.

B. Physicians' Negative Views of Disabled Life

What does it mean to say that many physicians have negative views of disabled life? Reading the work of disability scholars, advocates, and activists suggests several aspects of an encounter between a physician and a patient with a disability that can help unpack that statement. This work describes evidence that physicians view disabled persons' quality of life as lower than the quality that persons with disabilities actually experience. It also suggests that physicians are often inadequately trained to understand the experience of disability and that the incurability of many disabilities may challenge physicians' self-conceptions as effective healers.

443 (2013).

36. Lagu, *supra* note 35, at 443.

37. Nancy R. Mudrick et al., *Physical Accessibility in Primary Health Care Settings: Results from California On-Site Reviews*, 5 *DISABILITY & HEALTH J.* 159, 159, 165 (2012) (reporting significant access barriers from survey of facilities serving Medicaid patients in California); *see also* Winnie Hu, *Lawsuit Says Bronx Health Center Turns Away Patients with Physical Disabilities*, *N.Y. TIMES* (July 30, 2015), <https://www.nytimes.com/2015/07/30/nyregion/lawsuit-says-bronx-health-center-turns-away-patients-with-physical-disabilities.html> (reporting on allegations that a health center was "riddled with physical access barriers" and failed to provide sign language interpreters for deaf patients or modify written materials for visually-impaired patients).

Several studies reveal that physicians' estimates of the negative impact disabilities have on the quality of a person's life diverge from the self-reported experience of people with disabilities.³⁸ Doctors asked about the quality of life that disabled patients can be expected to enjoy tend to estimate the quality as low, even though many people with disabilities report a quality of life that rivals that of non-disabled people.³⁹ As a result, doctors may underestimate the value that a disabled patient obtains from receiving treatment that addresses a medical need without "fixing" their underlying impairment. Moreover, physicians' judgments that incorporate negative assumptions about disability's impact on a person's life—for example, that disabled persons are not sexually active—may endanger a patient's health.⁴⁰

Physicians' incomplete and skewed understanding of the lived experience of disability results in part from a lack of education. Medical training has not traditionally devoted attention to providing trainees with balanced information about the experience of life with disability.⁴¹ As a result, societal biases—rather than accurate and balanced information—are permitted to supply the basis for many doctors' understanding of disability.⁴² In addition, a lack of disability-oriented training may leave physicians ill-equipped to meet the full range of disabled patients' health-related needs.⁴³ This lack of

38. See, e.g., John R. Bach, *Threats to "Informed" Advance Directives for the Severely Physically Challenged?*, 84 ARCHIVES PHYS. MED. & REHAB. S23, S23 (2003) (study of ventilator users with neuromuscular conditions); Kenneth A. Gerhart et al., *Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers*, 23 ANNALS EMERGENCY MED. 807 (1994) (study of spinal-cord injury victims with quadriplegia); cf. Saroj Saigai et al., *Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low-Birth-Weight Infants at Adolescence*, 276 J. AM. MED. ASS'N 453 (1996); Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48 SOC. SCI. & MED. 977 (1999).

39. See Alison Davis, *A Disabled Person's Perspective on Euthanasia*, 24 DISABILITY STUD. Q. 1, 2–3 (2004); *A Point of View: Happiness and Disability*, BBC NEWS (June 1, 2014), <http://www.bbc.com/news/magazine-27554754>.

40. Tom Shakespeare, Lisa I. Iezzoni, & Nora E. Groce, *The Art of Medicine: Disability and the Training of Health Professionals*, 374 LANCET 1815, 1816 (2009).

41. Lisa I. Iezzoni & Linda M. Long-Bellil, *Training Physicians About Caring for Persons with Disabilities: "Nothing About Us Without Us!"*, 5 DISABILITY AND HEALTH J. 136, 136 (2012).

42. See *id.*

43. See *id.*

knowledge prevents effective health care for people with disabilities, and disabled patients frequently perceive that inadequacy.⁴⁴

Disability studies scholars suggest another explanation for the medical profession's lack of careful attention to the full spectrum of health needs presented by people with disabilities.⁴⁵ Those scholars offer medicine's "myth of control" to help explain what they view as medicine's devaluation of disabled life.⁴⁶ The idea is that doctors historically have viewed their role as curing or fixing dysfunctional and defective bodies,⁴⁷ and that "unfixable" bodies challenge that role.⁴⁸ According to this explanation, caring for people with incurable, disabling conditions may prove demoralizing to physicians, who may seek to avoid patients with disabilities as a result.⁴⁹ Or, lacking familiarity with disabled people and their lives, doctors simply may feel social discomfort and thus avoid addressing how a patient's disability relates to other health concerns.⁵⁰ Or, perhaps viewing a patient's prospect of "success" as bleak when disabilities cannot be remedied, physicians may even too readily suggest an ending-life choice.⁵¹

44. Gloria L. Krahn, Deborah Klein Walker, & Rosaly Correa-De-Araujo, *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S204 (2015).

45. See SUSAN WENDELL, *THE REJECTED BODY: FEMINIST PHILOSOPHICAL REFLECTIONS ON DISABILITY* 94–96 (1996).

46. *Id.*

47. Cf. Stephanie M. Vertrees, *Medical Humanities, Ethics, and Disability*, 21 CAMBRIDGE Q. HEALTHCARE ETHICS 260, 263 (2012) ("[I]t is the abolition of illness that motivates physicians . . . and . . . the concept of beneficence fundamentally assumes that there is 'badness' on which 'goodness' must be affected.").

48. Cf. Lisa I. Iezzoni, *Going Beyond Disease to Address Disability*, 355 NEW ENG. J. MED. 976, 977 (2006) ("Chronic disability can thwart physicians' motivation to cure diseases."); Shakespeare, *supra* note 40, at 1815 ("Disabling conditions that cannot be cured or 'normalised', according to standard societal norms, can be especially challenging for trainee health professionals.").

49. Cf. Asch, *supra* note 10, at S33 (noting "the common discomfort of health care professionals in the presence of patients with very significant impairments").

50. Iezzoni, *supra* note 48, at 977 ("Disability becomes the elephant in the room—present, but unmentioned.").

51. Anita Silvers, *Disability Discrimination: Risky Business for "Consenting" Adults*, HASTINGS CTR. (July 16, 2012, 10:33 AM), <http://www.thehastingscenter.org/disability-discrimination-risky-business-for-consenting-adults/> (suggesting that a doctor presenting forgoing care as an option to a patient with paralysis who was suffering from a life-threatening infection may have reflected the doctor's "compulsion to relieve his own discomfort about the dubiousness of success").

C. A View that Disabled Life is Burdensome on Families and State Resources

Although members of the medical profession, like the general public, may not know much about living with a disability, many in the disability community believe physicians are keenly aware of financial costs associated with providing support and care for people with disabilities. A concern commonly voiced by members of the disability community is that decisions about their medical care, and particularly decisions about continuing or discontinuing treatment, are made in the shadow of resource constraints and may be influenced by a felt need to ration care.⁵²

American society generally has been unwilling to embrace overt systems of rationing medical care to bring rising medical costs under control.⁵³ Oregon's effort in the early 1990s to devise a rationing scheme as part of its Medicaid program is a notable exception.⁵⁴ Oregon's original rationing scheme, however, was rejected by the federal Department of Health and Human Services (HHS) on the grounds that it conflicted with the Americans with Disabilities Act.⁵⁵ The proposed scheme's central criterion for covering medical services was the comparative benefit that treatments for different conditions would provide to Oregon's population.⁵⁶ Oregonians'

52. Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 70–72 (2000).

53. See Leslie P. Scheunemann & Douglas B. White, *The Ethics and Reality of Rationing in Medicine*, 140 CHEST J. 1625, 1625 (2011) (describing the controversial nature of rationing due to fears regarding unfair treatment and the devaluing of human life).

54. Michael J. Garland, *Setting Health Care Priorities in Oregon*, 1 HEALTH MATRIX 139, 145–46 (1991) (describing a wide range of interest groups that support Oregon's legislation and noting its "broad public acceptability").

55. Letter from Louis W. Sullivan, Sec'y of Health & Human Servs., to Barbara Roberts, Governor of Or. (Aug. 3, 1992), in Timothy B. Flanagan, *ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 409–12 (1994) [hereinafter Sullivan Letter] (with accompanying three-page "Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration"). For more in-depth discussion of Oregon's proposal and the federal rejection of it, see Crossley, *supra* note 52, at 75–76.

56. For a detailed account of the process by which Oregon developed its rationing scheme, see generally Michael J. Garland, *Rationing in Public: Oregon's Priority-Setting Methodology*, in RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND 37–59 (Martin A. Strosberg et al. eds., 1992).

responses to survey questions about what they would count as a benefit fed into the calculation of comparative benefit.⁵⁷ In short, Oregon was prepared to ration its Medicaid population's care partly based on the perceptions of non-disabled persons about the benefit of life with disabling conditions.⁵⁸ In rejecting Oregon's application for a Medicaid waiver permitting it to implement this rationing scheme, Secretary of HHS Lewis Sullivan wrote:

The record regarding the manner in which the list of condition/treatment pairs was compiled contains considerable evidence that it was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability. This is a premise which is inconsistent with the ADA.⁵⁹

The disability community was encouraged by the federal government's recognition that a rationing scheme overtly subordinating the value of providing medical care to persons with some disabling conditions was discriminatory.⁶⁰ Ultimately, however, the government's rejection of Oregon's rationing scheme provided no reassurance that medical decisions made in individual cases would not incorporate the same sorts of judgments.⁶¹ Instead, the concern that medical choices for people with disabilities often reflect implicit biases against disabled life and covert rationing is a frequent refrain in writing by people with disabilities.⁶² Such concerns exist when doctors offer advice or make decisions to limit

57. *Id.* at 44–46.

58. Sullivan Letter, *supra* note 55, at 410.

59. *Id.*

60. Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179, 199 (1995).

61. Chen, *supra* note 35.

62. *See, e.g.*, Gill, *supra* note 6, at 34 (describing disabled people's fear of doctors "who see our lives as burdensome and who know little about options that make life with disability valuable . . . , [whose] misplaced pity and pessimism . . . is reinforced by . . . the health care funding system that rewards them for holding costs down").

care, sometimes invoking the justification of medical futility.⁶³ These concerns also extend to choices made by family members acting as surrogates for incompetent patients.⁶⁴ Indeed, persons with disabilities may themselves consider the crippling cost of their care as one reason for choosing to discontinue life-sustaining medical care.

D. Questions About the Primacy of Autonomy in the Context of Unsupportive Living Arrangements

In light of the fact that people with disabilities sometimes affirmatively choose to discontinue medical treatment, many bioethicists and some members of the disability community emphasize the importance of ensuring that people with disabilities are empowered to make autonomous decisions about their medical care.⁶⁵ Respected voices from the disability community argue that equal respect for people with disabilities demands their ability to choose for themselves, based on whatever factors they deem relevant.⁶⁶ The primacy accorded to autonomy extends to choices for patients who once had, but now have lost, decision-making capacity.⁶⁷ Those patients argue that respecting autonomy demands that their previous expressions of values and preferences regarding medical treatment and quality of life, made while competent, be

63. See generally Crossley, *supra* note 60; Philip G. Peters, *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. L. REV. 798 (1997).

64. Cf. Crossley, *supra* note 60.

65. See generally Gurit Lotan & Carolyn Ells, *Adults with Intellectual and Developmental Disabilities and Participation in Decision Making*, 48 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 112 (2010).

66. For example, attorney Andrew Batavia and historian Hugh Gallagher together published an open online letter to people with disabilities, along with “A Declaration of Disability Rights,” both expressing their views in support of people with disabilities’ ability to make private choices at the end of life, including physician-assisted suicide. Drew Batavia & Hugh G. Gallagher, *Gallagher and Batavia on Physician-Assisted Suicide—An Open Letter to People with Disabilities*, INDEP. LIVING INST., <http://www.independentliving.org/docs1/gallbat.html> (last visited Feb. 18, 2017); see also Anita Silvers, *Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups*, in PHYSICIAN ASSISTED SUICIDE: EXPANDING THE DEBATE 133 (M. Pabst Battin et al. eds., 1998).

67. See Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 615–16 (1994); Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1693, 1699 (2014).

given effect by their surrogates.⁶⁸ Courts generally accept this argument and adopt the approach that, in cases where a now-incompetent patient had previously clearly expressed treatment preferences, substituted decision-making by a surrogate is appropriate, and respect for the patient's prior autonomous wishes should be accorded primacy over attention to the patient's current welfare interests.⁶⁹

Others in the disability community, however, are less sanguine about the primacy of autonomy.⁷⁰ While not necessarily diminishing the value of autonomy in the abstract, they question whether the choices that people with disabilities face actually resemble the idealized notion of autonomous choice.⁷¹ These concerns are particularly salient for a person disabled by sudden trauma, who must abruptly transition from being able-bodied to facing severe impairments.⁷² Expressions of desire to withdraw life-sustaining treatment or technology, or even to pursue affirmatively life-ending measures, soon after the disabling event are not unusual.⁷³ Millions of Americans watched a fictionalized account of such a scenario in the closing scenes of the 2005 Academy Award-winning movie *Million Dollar Baby*.⁷⁴ In the movie, the young boxing champion Maggie suffers an injury that leaves her paralyzed and dependent on a ventilator, and she persuades her trainer to end her life.⁷⁵

Members of the disability community roundly condemned the movie as filled with inaccuracies about life with spinal cord injuries

68. See Dresser, *supra* note 67, at 615–16; Shepherd, *supra* note 67, at 1699. The situation presented by patients who never have enjoyed decision-making capacity is different. See generally Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37 (2004) (considering whether autonomy-based rights extend to never competent persons in the context of end-of-life decisions).

69. Shepherd, *supra* note 67, at 1697–1704 (describing “the lay of the land” with respect to end-of-life law).

70. See Dresser, *supra* note 67, at 622.

71. See Asch, *supra* note 10, at S34.

72. See *id.*

73. See *id.*

74. MILLION DOLLAR BABY (Warner Bros. 2004).

75. *Million Dollar Baby Built on Prejudice About People with Disabilities*, DISABILITY RIGHTS EDUC. & DEF. FUND (Feb. 2005), <https://dredf.org/2005/02/13/million-dollar-baby-built-on-prejudice-about-people-with-disabilities/>.

and as portraying Maggie's life as being of such poor quality that it was not worth living.⁷⁶ In the real world, many persons who have suffered disabling injuries have described their gradual shift in perspective, from wishing for death in the aftermath of the injury to discovering satisfaction in their life with disability.⁷⁷ This common, though not necessarily universal, adaptation to changed life circumstances and a renewed desire to live lead many in the disability community to "question how truly autonomous . . . anyone's wish to die [is] when living with changed, feared, and uncertain physical impairments"⁷⁸

Moreover, disability advocates highlight the importance of appropriate supports and accommodations in permitting adaptation and satisfaction with life with a disability.⁷⁹ By failing to provide supports allowing independent living in the community and accommodations making education, employment, and social and civic engagement possible, society shapes the context in which people with disabilities make choices about their medical care.⁸⁰ A paradigmatic case informing the disability view was David Rivlin's.⁸¹ While young, Rivlin suffered a spinal cord injury that left him quadriplegic, but for some period he tried living in the community, enrolled in college, and got engaged.⁸² An operation fifteen years after his original injury left him further disabled and unable to breathe on his own.⁸³ Rivlin continued to seek to live independently in Michigan, but the level of funding he could receive for personal attendants was not sufficient, leaving him confined to a

76. *Id.* The more recent movie *Me Before You*, which portrayed the romance between a man with quadriplegia and his aide, as the man planned to end his life, provoked similar reactions. See Emily Ladau, *Spare Me, "Me Before You": Hollywood's New Tearjerker Is Built on Tired and Damaging Disability Stereotypes*, SALON (May 24, 2016, 6:58 PM), http://www.salon.com/2016/05/24/spare_me_this_tearjerker_romance_me_before_you_is_the_latest_in_an_endless_line_of_disability_objectification/.

77. See Asch, *supra* note 10, at S32–33.

78. See *id.* at S33.

79. See *id.* at S35; Paul K. Longmore, *The Strange Death of David Rivlin*, 154 W. J. MED. 615, 616 (1991).

80. Longmore, *supra* note 79, at 615.

81. See *id.*

82. *Id.*

83. *Id.*

nursing home—for which the state paid.⁸⁴ Believing he had no prospect of any other life, Rivlin sought and received approval from a court in Michigan to have his ventilator disconnected, eighteen years after his original injury.⁸⁵

From the disability perspective, Rivlin’s decision to disconnect his ventilator was not the predictable product of a spinal cord injury and ventilator dependence.⁸⁶ Instead, it was the product of the societal devaluation of life with disability that underpins social policies that segregate and isolate disabled people in institutions rather than support their independent living.⁸⁷ His “choice” to disconnect his ventilator and die, they suggest, should not be seen as an exercise of the kind of idealized autonomy that bioethicists extol.⁸⁸

Even aside from inadequate supports for community living, negative and ill-informed medical and societal assumptions about the quality and burdensomeness of disabled life can influence the decisions of disabled persons.⁸⁹ Author Harriet McBryde Johnson emphasizes that the expectations of others—whether voiced or unspoken—provide part of the context in which disabled persons make end-of-life decisions:

You know how easy it is to internalize other people’s expectations, how exhausting it can be to oppose them, especially when you’re sick. What we confront usually isn’t homicidal hate, it’s that pervasive assumption that our lives are inherently bad. That attitude can wear us down to the point where we want to be killed.⁹⁰

84. *Id.*

85. *Id.*

86. *See* Longmore, *supra* note 79, at 615.

87. *Id.* at 615–16.

88. *Id.* Longmore also describes Rivlin’s inability to live outside the nursing home as leaving him “despondent and despairing,” but points out that he received no psychological counseling in the two years before he chose to die. *Id.* at 616.

89. *See id.*

90. *See* Mary Johnson, *Liberals and Disability Rights: Why Don’t They “Get It?”*, RAGGED EDGE ONLINE (Jan. 26, 2004), <http://www.raggededgemagazine.com/focus/liberals0104.html> (quoting statement made by McBryde to Barry Corbet).

To be sure, not all people with disabilities express such concerns. Some leading scholars in the disability community reject portrayals of people with disabilities that emphasize their vulnerability rather than their agency, arguing that such a portrait reinforces stereotypes of people with disabilities as weak and in need of protection.⁹¹ Other advocates and scholars argue that respect for autonomy requires that people with disabilities enjoy a full range of choices involving end-of-life care, even including physician-assisted suicide,⁹² and that narrowing the range of treatment options for patients may sometime harm people with disabilities.⁹³

E. Concerns About the Adequacy of Legal Protections

In addition, proponents of liberalized rights to discontinue life-sustaining medical treatment and to physician-assisted suicide often downplay the types of concerns previously described by emphasizing the existence of legal and procedural safeguards protecting persons with disabilities, whether competent or incompetent, from being the victims of discriminatory decisions to end their lives.⁹⁴ These legal safeguards, they may assert, can be trusted to prevent a slide down a potentially slippery slope towards a regime of permissive euthanasia where the lives of disabled people are ended without their request or consent.⁹⁵ But members of the disability community may not be willing to trust the legal system much more than they trust the health care system. As people with disabilities know, able-bodied judges and lawyers—like their medical counterparts—often fail to

91. See Silvers, *supra* note 66, at 408.

92. See, e.g., *End of Life Liberty Project Moves to CascadiaNow*, GEORGETOWN UNIV.: BIOETHICS RESEARCH LIBRARY (Oct. 31, 2016), <https://bioethics.georgetown.edu/2016/10/end-of-life-liberty-project-moves-to-cascadianow/>. For example, under the leadership of Kathryn Tucker, a leading advocate for legalization of the practice variously known as physician aid-in-dying and physician-assisted suicide, in January 2015, the Disability Rights Legal Center launched the End of Life Liberty Project (ELLP). *Id.* Both Tucker and the ELLP have since moved from the Disability Rights Legal Center to the nonprofit organization CascadiaNow! *Id.*

93. See Lois Shepherd, *Terri Schiavo and the Disability Rights Community: A Cause for Concern*, 2006 U. CHI. LEGAL F. 253, 267–272 (arguing that disability groups' support of proposed legislation that would prohibit withholding artificial nutrition and hydration from patients who have never been competent could in some cases cause suffering for profoundly disabled patients).

94. See Ouellette, *supra* note 13, at 385.

95. *Id.* at 385.

appreciate the value of life with disability and the impact of social context on choices made by disabled persons.⁹⁶ After all, a court sanctioned David Rivlin's decision to end his life, even though the surrounding circumstances suggested a decision borne out of remediable despondency rather than an enduring objection to the use of a ventilator.⁹⁷

Others have noted how the language used by some judges deciding treatment termination cases involving people with disabilities exhibits devaluation, sometimes bordering on disgust, for the material conditions of life with disability.⁹⁸ The poster child for this judicial depreciation of disabled life is the opinion of the court in *Bouvia v. Superior Court*, a case in which a woman with cerebral palsy and arthritis sought the removal of a nasogastric feeding tube while she was hospitalized.⁹⁹ The court upheld Elizabeth Bouvia's right to make the autonomous choice to discontinue artificial nutrition, but only after referring to her as "imprisoned" in her body and "subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness."¹⁰⁰ Moreover, the judge implicated that Bouvia's physical condition had robbed her life of "quality, dignity and purpose" and that she could not be faulted if she found her existence "meaningless."¹⁰¹ Reading the opinion in *Bouvia*,¹⁰² it is not hard to understand why some people with disabilities may not view the legal system as protecting their lives with the same vigor as it does the lives of able-bodied people who exhibit a wish to end their lives.

96. *Id.* at 388.

97. *See supra* text accompanying notes 83–87.

98. *See* Asch, *supra* note 10, at S32; Ouellette, *supra* note 13, at 387.

99. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1986). For background on Elizabeth Bouvia's life and the social context of her request, see Longmore, *supra* note 15.

100. *Bouvia*, 225 Cal. Rptr., at 305.

101. *Id.* at 304–05.

102. *See id.* As Ouellette points out, *Bouvia* is not the only judicial opinion in which judges have exhibited a remarkable equating of a disabled person's need for assistance with breathing, eating, toileting or other bodily functions with "a childlike state" and indignity. Ouellette, *supra* note 13, at 387 n.89 (quoting *Compassion in Dying v. Washington*, 79 F.3d 790, 814 (9th Cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 521 U.S. 702 (1997)). Such a view is apparently ignorant of the numerous persons with disabilities who work, parent, enjoy recreational activities, and participate in civic life, and who also need assistance with their bodily needs. *See id.* at 388.

In summary, this part highlights several aspects of concerns often expressed by members of the disability community regarding the liberalization of laws regarding the termination of life-sustaining treatment or physician-assisted dying. As noted, a diversity of views exists among people with disabilities, some of which the previous part described.¹⁰³ Nonetheless, the concerns described can fairly be said to encapsulate views articulated by many leading disability rights organizations, disability studies scholars, and disability rights activists.

II. RECOGNIZING PARALLELS AND “GETTING IT”

The ideas described so far in this essay are not novel; members of the disability community have been raising them in one form or another for decades.¹⁰⁴ Yet, too often discussions of ending-life decisions fail to engage these concerns seriously and in a sustained fashion.¹⁰⁵ As noted earlier, most decisions to discontinue life-sustaining medical treatment involve patients who are in some way disabled, a fact that suggests disability concerns should be at the center of these discussions rather than a peripheral concern to be addressed and moved beyond.¹⁰⁶

Why have disability concerns not achieved greater traction in these discussions? Do they not make sense to the physicians, bioethicists, and lawyers who tend to dominate these discussions? Or, do the concerns seem overwrought, failing to acknowledge the strength of the legal protections formally accorded to persons with disabilities?

From the perspective of the disability community, these folks simply don't “get it” when it comes to disability concerns about ending-life decisions.¹⁰⁷ This part describes two parallels between the concerns of the disability community around care-terminating

103. *See supra* Section I.D.

104. *See, e.g.*, Johnson, *supra* note 90.

105. *See*, Ouellette, *supra* note 13, at 372–73 n.3; Johnson, *supra* note 90.

106. *See, e.g.*, Longmore, *supra* note 79, at 616; Ouellette, *supra* note 13, at 372–75, 372 n.3; Johnson, *supra* note 90.

107. *See* Johnson, *supra* note 90.

decisions and the concerns of the African-American community around policing, in hopes that drawing attention to these parallels might bring home disability concerns in a different way. The parallels are admittedly not exact, and fully fleshing them out is beyond the scope of this essay. Perhaps, however, they might make the disability perspective more accessible to some readers.

Over the past few years, Americans have watched media coverage of repeated instances of African-American men and boys, many of them unarmed, being shot and killed by police.¹⁰⁸ They have also seen the growth of the Black Lives Matter movement and other responses shining a light on systemic racism in the criminal justice system.¹⁰⁹ As a result, many Americans have become familiar with concepts like implicit bias and white privilege, and have come to appreciate the justifiable fear of police harassment and violence that is second nature for many African Americans.¹¹⁰ Compared to five years ago, I would wager that today many more white Americans at least have begun to “get it” when it comes to issues of race in criminal justice. My hope is that suggesting parallels between the experiences of African Americans and those of people with disabilities might provide a path towards greater appreciation of disability community concerns.

A. *Legal Protections and Lethal Threats*

My inspiration for looking for parallels between the points that Black Lives Matter makes and the disability perspective on ending-life decisions came from William Peace. Peace is an anthropologist

108. Adrienne LaFrance, *Death by Police*, ATLANTIC (July 7, 2016), <http://www.theatlantic.com/technology/archive/2016/07/monitorial-citizenship-technology/490286/>.

109. For example, two books on the topic, *Just Mercy* by Bryan Stevenson (describing the author’s work combatting racial and economic injustice in the criminal justice system) and *The New Jim Crow: Mass Incarceration in the Age of Colorblindness* by Michelle Alexander (describing the mass incarceration of African-American males) were both New York Times Bestsellers. *Bestsellers in Paperback Nonfiction*, N.Y. TIMES (Jan. 29, 2017), <http://www.nytimes.com/books/bestsellers/paperback-nonfiction/>.

110. See LaFrance, *supra* note 108; Shannon Richmond, *Becoming Consciously White*, M.K. GANDHI INST. FOR NONVIOLENCE, <http://www.gandhiinstitute.org/2015/10/26/becoming-consciously-white/> (last visited Jan. 23, 2017).

and disability rights advocate who uses a wheelchair.¹¹¹ In his extensive writing about disability and bioethics, he uses his own experiences with the health care system and medical profession, as well the experiences of other people with disabilities.¹¹² He writes of the suspicion and fear with which many people with disabilities view the health care system: “[M]ost people with a disability fear even the most routine hospitalization. We do not fear any of the commonplace indignities those without a disability worry about when hospitalized. Our fear is primal—will our lives be considered devoid of value?”¹¹³

Peace’s fear of the health care system is not unique. Many scholars, disability advocates, and activists relay some version of it.¹¹⁴ Not all of them experience health care providers as a threat to continued existence, as Peace did.¹¹⁵ Anita Silvers, responding to Peace, writes: “I’ve not yet believed myself to be fighting for my life against professional health-care providers. . . . But from childhood I’ve had to battle healthcare providers to retain effective functionality despite my physical impairment.”¹¹⁶ The refrain of distrust of health care providers pervades the literature on disability concerns about ending-life decisions, and particularly discussions of physician-assisted suicide.¹¹⁷

Peace’s description immediately made me think of similar statements about fears of police violence against men of color. A news account of the July 2016 shooting of an unarmed black man, who was lying on the ground with his hands in the air, explained that the shooting “illustrates the longstanding fear among black men that almost any encounter with police can go awry with potentially deadly results, even when a person follows every law enforcement command.”¹¹⁸ Scholars have recognized this fear as well: “Based on

111. William J. Peace, *Disability Discrimination: The Author Responds*, HASTINGS CTR. (July 27, 2012), <http://www.thehastingscenter.org/disability-discrimination-the-author-responds>.

112. *Id.*

113. *Id.*

114. Ouellette, *supra* note 13, at 386.

115. *See* Silvers, *supra* note 51.

116. *Id.*

117. *See* Ouellette, *supra* note 13, at 379, 386.

118. Jesse J. Holland, *Why Black Men Fear That Any Police Encounter Could Go Awry*, SAN JOSE MERCURY NEWS (July 21, 2016), <http://www.mercurynews.com/2016/07/21/why-black-men-fear-that->

personal and shared experiences, blacks believe that the police are constantly watching them and treat them as if they don't belong; blacks fear that every small offense will result in a stop and that every encounter with the police can escalate and turn ugly."¹¹⁹ The existence—and justifiability—of a fear of indignity and harm from disproportionate policing has even been recognized by the Massachusetts Supreme Court, which ruled in 2016 that a black man's running from approaching police does not necessarily give police reason to suspect his guilt.¹²⁰ The disproportionate policing of African American men does not abide only in crime-infested urban neighborhoods.¹²¹ It also affects men in professional roles, even a U.S. Senator.¹²²

The parallels between blacks' fears of being physically harmed or killed by police violence and disabled people's fears of being physically harmed or killed by physicians' treatment choices are striking to me. In each case, members of a profession charged with advancing safety or health are feared by a subset of the population.¹²³ Although data on the frequency of and explanation for harmful actions is woefully limited in each case,¹²⁴ commentators have posited that those actions often flow from misperceptions and implicit bias rather than from overt racism or ableism.¹²⁵ The suggestions are that police may be more likely to use lethal force

any-police-encounter-could-go-awry/.

119. CHARLES R. EPP ET AL., PULLED OVER: HOW POLICE STOPS DEFINE RACE AND CITIZENSHIP 47 (2014).

120. *Commonwealth v. Warren*, 58 N.E.3d 333, 342 (Mass. 2016). Citing data showing that Boston police disproportionately stopped black males, the court reasoned, "[s]uch an individual, when approached by the police, might just as easily be motivated by the desire to avoid the recurring indignity of being racially profiled as by the desire to hide criminal activity." *Id.*

121. See Laura Barron-Lopez, *Black GOP Senator Talks About Being Pulled over by Police 7 Times in One Year*, HUFFINGTON POST (July 15, 2016), http://www.huffingtonpost.com/entry/tim-scott-pulled-over_us_5786bfff4b08608d332eaa0 (describing personal accounts of racial profiling experienced by black GOP Senator Tim Scott of South Carolina).

122. See *id.*

123. See Ouellette, *supra* note 13, at 386; Holland, *supra* note 118.

124. Cf. Alex E. Crosby & Bridget Lyons, *Assessing Homicides by and of U.S. Law-Enforcement Officers*, 375 NEW ENG. J. MED. 1509 (2016) (considering the value of using public health surveillance tools to assess the number of killings by law-enforcement).

125. See Cynthia Lee, *'But I Thought He Had a Gun'—Race and Police Use of Deadly Force*, 2 HASTINGS RACE & POVERTY L. J. 1, 9–10 (2004).

against black men because of culturally prevalent perceptions of dangerousness and criminality,¹²⁶ and that doctors may be more likely to advise against life-sustaining treatments for people with disabilities because of culturally prevalent perceptions of burdensomeness and hopelessness.¹²⁷ The contexts of the professionals' decisions are quite different, but both police officers and physicians must often make decisions quickly and while relying on ambiguous or incomplete information,¹²⁸ circumstances that increase the risk of biases infecting decisions.¹²⁹

The law does not formally sanction biased treatment in either case, but neither does it effectively constrain bias-tainted behavior or provide a reliable remedy to those harmed.¹³⁰ In short, the law carried out on the streets—and, in the case of medical choices for disabled people, the law in the wards—differs from the formal law on the books.¹³¹ Laws that are supposed to protect against biased treatment are rarely applied to address the harm that is feared.¹³²

Indeed, fears of harm at the hands of police and physicians—the fears this essay presents to illustrate parallels between the experiences of African Americans and people with disabilities—actually overlap substantially. African American patients also express a fear that doctors will too readily suspend life-sustaining treatment for them in order to conserve resources.¹³³ And on the flip side of the

126. *See id.* at 12.

127. *See Gill, supra* note 6, at 33–34.

128. Julian N. Marewski & Gerd Gigerenzer, *Heuristic Decision Making in Medicine*, 14 *DIALOGUES IN CLINICAL NEUROSCIENCE* 77, 80 (2012); Michael T. Uttaro, *Naturalistic Decision-Making in Law Enforcement Practice—Exploring the Process 2* (Mar. 26, 2002) (unpublished Ph.D. dissertation, Virginia Polytechnic Institute and State University), https://theses.lib.vt.edu/theses/available/etd-04102002-114630/unrestricted/Chapters_1-5.pdf. For additional comparisons between medicine and policing, see Evan D. Anderson & Scott Burris, *Policing and Public Health: Not Quite the Right Analogy*, 27 *J. POLICING & SOC'Y* (2017), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2835461.

129. *See* Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 *VILL. L. REV.* 195, 236–38 (2003).

130. *Id.* at 276; Crossley, *supra* note 52, at 55 n.23.

131. *See* Crossley, *supra* note 129, at 276–77.

132. Crossley, *supra* note 52, at 55 n.23.

133. *See* Fenit Nirappil, *Right-to-Die Law Faces Skepticism in Nation's Capital: 'It's Really Aimed at Old Black People'*, *WASH. POST* (Oct. 17, 2016), https://www.washingtonpost.com/local/dc-politics/right-to-die-law-faces-skepticism-in-us-capital-its-really-aimed-at-old-black-people/2016/10/17/8abf6334-8ff6-11e6-a6a3-d50061aa9fae_story.html?utm_term=.16cdfa9b116e.

coin, advocates for people with disabilities have decried how a lack of police training on how to interact and communicate with persons who have mental illness or impairments can lead to police violence.¹³⁴

To be clear, people with disabilities do not generally assert that doctors are out to “get [them].”¹³⁵ Disability Studies scholar Carol Gill refutes such a claim as a “straw man fallac[y]” that obscures the true nature of disabled people’s concerns.¹³⁶ Instead, the problem lies not in physician animus, but in attitudes that are widespread among medical professionals and that underestimate the quality of life with a disability, fail to appreciate the options available for increasing functionality and independence, and reflect heightened sensitivity to health care costs.¹³⁷ Gill writes:

We are, in fact, much more frightened by the doctors who are out to help us but who see our lives as burdensome and who know little about options that make life with disability valuable. We know that the misplaced pity and pessimism of such doctors is reinforced by the medical institutions surrounding them, the policies that guide them, and the health care funding system that rewards them for holding costs down, and the prevailing culture that influences their thinking about disability.¹³⁸

Certainly, some members of the disability community might not accept the parallels this essay identifies and might honestly disclaim any distrust or fear of their doctors. The fact that this distrust is not

134. A 2016 report estimates that a third to half of all people killed by police have disabilities. DAVID M. PERRY & LAWRENCE CARTER-LONG, RUDERMAN FAM. FOUND., THE RUDERMAN WHITE PAPER ON MEDIA COVERAGE OF LAW ENFORCEMENT USE OF FORCE AND DISABILITY I (2016), http://www.rudermanfoundation.org/wp-content/uploads/2016/03/MediaStudy-PoliceDisability_final-final1.pdf; see also Conor Friedersdorf, *Methods That Police Use on the Mentally Ill Are Madness*, ATLANTIC (March 25, 2015), <http://www.theatlantic.com/politics/archive/2015/03/methods-that-cops-use-with-the-mentally-ill-are-madness/388610/>.

135. See Gill, *supra* note 6, at 33.

136. See *id.*

137. *Id.* at 34.

138. *Id.*

universal, however, does not undermine the authenticity and validity of the widely expressed concern. Moreover, recognizing that people with disabilities as a group may experience harms flowing from cultural stereotypes devaluing their quality of life need not equate to a dismissal of their agency, as some disabled proponents of liberalized choice fear.¹³⁹

B. Privileged Perspectives and Political Power

The importance of privilege is a second parallel between the literature presenting disabled people's concerns about ending-life decisions and points made by racial justice advocates. In the latter context, "white privilege" refers to a set of unearned advantages that white persons benefit from, often unconsciously, simply by virtue of their skin tone and that function to perpetuate racial hierarchy.¹⁴⁰ The concept is by no means universally accepted, but conversations about white privilege have become common over the past several years in settings ranging from higher education to religious congregations.¹⁴¹ Openness to recognizing the existence of white privilege seems to have increased as media coverage of police shootings and the Black Lives Matter movement have exposed people across the racial spectrum to compelling evidence of racial disproportionality in the criminal justice system.¹⁴²

Just as the unearned advantages conferred by skin tone may be invisible to white people until they make an effort to become aware of those advantages, so too the unearned advantages conferred by an

139. Cf. Martha T. McCluskey, *Thinking with Wolves: Left Legal Theory After the Right's Rise*, 54 BUFF. L. REV. 1191, 1201–02 (2007) (discussing how critical scholarship has sought "to both engage and transcend the problematic choices offered by liberal jurisprudence . . . [including] the costs on both sides of the conventional liberal choice between equal treatment or different treatment, integration or separation, autonomy or dependence, victimhood or agency").

140. See Joshua Rothman, *The Origins of "Privilege"*, NEW YORKER (May 12, 2014), <http://www.newyorker.com/books/page-turner/the-origins-of-privilege>.

141. See, e.g., Thomas Columbus, *University Offers Class on 'The Problem of Whiteness'*, COLLEGE FIX (Dec. 19, 2016), <http://www.thecollegefix.com/post/30434/>; Eric Smith, *The Sin of David: A Sermon on Power and (White) Privilege*, PATHEOS: LECTIO (July 26, 2015), <http://www.patheos.com/blogs/lectio/2015/07/the-sin-of-david-a-sermon-on-power-and-white-privilege/>.

142. Michael Nam, *New Polls: White American Views on Race and Police Starting to Change*, DIVERSITYINC (May 5, 2015), <http://www.diversityinc.com/news/new-polls-white-american-views-on-race-and-police-starting-to-change/>.

able body and intact cognitive functioning are often invisible to non-disabled people. Although less widely recognized than white privilege, feminist and disability scholars and activists have discussed the existence and effects of “ability privilege” or “able-bodied privilege.”¹⁴³ According to one commentator, “[a]ble-bodied privilege allows able-bodied people to maintain experiences of superiority, perfectability, security and comfort.”¹⁴⁴ But able-bodied people have not earned the privileges¹⁴⁵ that accompany having an able body, and most able-bodied people will not retain that status throughout their lives.¹⁴⁶

The privilege of being abled, rather than disabled, is particularly relevant to the dynamics of the debate around physician-assisted suicide. According to Carol Gill, proponents of a right to physician-assisted suicide typically stress how recognizing that right would further the ideals of autonomy, liberty, and control.¹⁴⁷ However, how their own ability privilege—which, like white privilege, is the product of social contingencies—affects which values they prioritize may be invisible to them. This lack of awareness of how privilege influences their perspective makes appreciating the validity of perspectives of un-privileged persons more difficult.¹⁴⁸ According to Gill:

Many of the key spokespersons in favor of assisted suicide . . . are familiar with ideals such as independence,

143. See BOB PEASE, UNDOING PRIVILEGE: UNEARNED ADVANTAGE IN A DIVIDED WORLD 149–58 (2010); Kristina R. Knoll, *Feminist Disability Studies Pedagogy*, 19 FEMINIST TEACHER 122, 124–36 (2009); cf. Alison Kafer, *Compulsory Bodies: Reflections on Heterosexuality and Able-bodiedness*, 15 J. WOMEN’S HISTORY 77, 79 (2003) (discussing the political institution of able-bodiedness and “compulsory able-bodiedness”).

144. PEASE, *supra* note 143, at 158.

145. These privileges include, for example, being able to “ignore the width of doors, the presence of steps and other architectural features of buildings,” not being “dependent on hiring strangers and acquaintances to assist me with my daily routines and private matters,” and “be[ing] fairly sure that when people look at me, they don’t assume that I would be better off dead or that I am a social burden because of my disabilities.” *Id.* at 159 (quoting Phyllis May-Machunda). The list of unearned advantages that able-bodied people enjoy is quite long. *Id.* at 158 (noting a non-exhaustive list of 49 privileges).

146. *Id.* at 160.

147. See Gill, *supra* note 6, at 31.

148. See PEASE, *supra* note 143, at 158.

control, and freedom because they are by and large from the dominant sector of society that has had access to those experiences. . . . They have enjoyed a good deal of control, know exactly what they have to lose, and are determined to retain it until death. Unfortunately, viewing the world from a position of privilege may limit one's insight into the consequences of a policy change whose greatest impact could fall on socially marginalized groups.¹⁴⁹

Ideally, recognizing the existence and impact of ability privilege in discussions about ending-life decisions would encourage greater openness to the validity of the perspectives that disabled people offer on the subject. Just as white people in America increasingly recognize that people of color often face a different reality in their interactions with the police,¹⁵⁰ non-disabled people could recognize that people with disabilities face a different reality in their interactions with the health care system.

Beyond matters of perspective, recognizing the existence of ability privilege also reveals how raw political power lurks in the background of discussions of ending-life decisions. Just as racial justice advocates assert that white privilege serves to reinforce racial hierarchies that are deeply rooted in our society,¹⁵¹ disability activists point to ability privilege as entrenching social, economic, and

149. Gill, *supra* note 6, at 31–32 (“What control-seekers want for their own peace of mind may work out quite well for them in the context of privilege and choice. However, they cannot determine how it will work out for their neighbors who reside outside that context.”). Gill’s recognition that “socially marginalized groups” broadly may be disproportionately affected by the legalization of physician-assisted suicide echoes the concerns that African-Americans express regarding the practice. *Id.*

150. Although a wide divide remains between blacks’ and whites’ views on how police treat minorities, surveys in recent years have shown modest increases in the percentage of whites who believe that blacks in their communities are treated less fairly by police than whites. See *Public Opinion Context: Americans, Race, and Police*, GALLUP (July 8, 2016) <http://www.gallup.com/opinion/polling-matters/193586/public-opinion-context-americans-race-police.aspx> (reporting finding that percentage increased from 34% in 2015 to 40% in 2016); see also Nam, *supra* note 142.

151. Dorothy E. Roberts, *The Social and Moral Cost of Mass Incarceration in African American Communities*, 56 STAN. L. REV. 1271, 1299–1300 (2004) (asserting, in discussing mass incarceration, that “[s]tructural racism systematically maintains racial hierarchies established in prior eras by embedding white privilege and nonwhite disadvantage in policies, institutions, and cultural representations”).

political structures that exclude people with disabilities.¹⁵² In short, when disability advocates challenge the priority that mainstream bioethicists place on choice and autonomy in medical decisions about ending life, they are attempting to wrest power from those bioethicists.¹⁵³ As Stephen Drake wrote on the *Not Dead Yet* blog, criticizing the dominance that the bioethics community has exercised over discussions of end-of-life policy: “At the core, this is a political struggle over public policy—a struggle between those who have power and seek to hold onto it and those directly affected by the policies who want to take power.”¹⁵⁴ From the perspective of disability advocates, bioethicists have for too long had the power to set the terms of discussions about practices that primarily affect people with disabilities.¹⁵⁵ This power to frame policy debates provokes disability activists to demand, once again: “Nothing About Us Without Us!”¹⁵⁶ And, while mainstream bioethicists may maintain their neutrality and objectivity in setting those terms, they rarely acknowledge how their invisible ability privilege affects how they frame discussions.¹⁵⁷

CONCLUSION

This essay described the nature of disability concerns about ending-life decisions and suggested two parallels between those disability concerns and the concerns of the African-American community regarding policing.¹⁵⁸ The essay’s purpose in identifying

152. Gregor Wolbring, *Ability Privilege: A Needed Addition to Privilege Studies*, 12 J. CRITICAL ANIMAL STUD. 118, 120 (2014).

153. Stephen Drake, *Disability and Ethics Conference This Weekend—Low Expectations Based on Past Performance*, NOT DEAD YET (May 19, 2010), <http://notdeadyet.org/2010/05/disability-and-ethics-conference-this.html>.

154. *Id.*

155. *Id.*

156. *Id.* (showing photo of disability activists protesting a bioethics conference).

157. *Cf.* PEASE, *supra* note 143, at 158.

158. *See supra* Sections II.A, II.B. Other apparent parallels may also emerge upon further examination. Earlier in the essay, I described how important social context is to understanding fully the nature of a disabled person’s choice to terminate life-sustaining medical care. *See supra* Part II. Similarly, discussions of crime rates in the African-American community stress the need to consider such data in its full social context. *See supra* Section II.A.

and beginning to tease out those parallels is to offer readers a different perspective on the concerns that leaders of the disability community often voice. My hope is that, viewed from this different perspective, the social justice character of those concerns will become more evident.

Comparing the fear or distrust that many people with disabilities experience when encountering the health care system with the fear or distrust that many African-Americans feel when encountering the law enforcement system shows a common apprehension of being subjected to biased treatment by authority figures that—while not legally sanctioned—has not to date been adequately recognized or addressed.¹⁵⁹ Similarly, recognizing that an unawareness of the unearned advantages of privilege obscures the bias inherent in culturally-prevalent assumptions about blackness and disability may also help reveal the unjust nature of decisions flowing from those assumptions. If we acknowledge that the benefits of privilege, whether based on skin tone or able body, are unearned, then how we view disability concerns may shift.

That shift highlights the social justice implications of ending-life decisions and thus should affect how we address the disability concerns this essay describes. Assessing whether autonomy—as idealized by mostly able-bodied, well-educated, and powerful bioethicists, physicians, and attorneys—should override disabled persons' concerns entails weighing the values of autonomy *and* justice. So framed, the possibility exists that disability advocates and proponents of liberalized standards for end-of-life decision-making might find points of agreement and ways to move the discussion forward. In addressing this subject more than a decade ago, Adrienne Asch wrote of the importance of drawing disability activists and scholars into discussions of end-of-life policy, deliberations regarding health care resource allocation, and the education of health professionals,¹⁶⁰ but those aspirations have not been sufficiently realized. Recognizing that the law and ethics of end-of-life decisions

159. See *supra* Part II; see also Gill, *supra* note 6, at 33; Holland, *supra* note 118.

160. See Asch, *supra* note 10, at S36.

must give equal respect to the demands of justice, as well as to the promise of autonomy, is a step in the right direction.