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Context Matters: Disability, the End of Life, and Why the Conversation Is Still So Difficult

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Context Matters: Disability, the End of Life, and Why the Conversation Is Still So Difficult

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DISABILITY, THE END OF LIFE, AND WHY THE CONVERSATION IS STILL SO DIFFICULT

I. INTRODUCTION

In the weeks prior to the symposium on which this volume of the *New York Law School Law Review* is based,¹ the disability-rights group Not Dead Yet declared on its blog that the symposium was a “farce” that showed “just how little respect and regard [the symposium organizers] have for people with disabilities.”² The post took special issue with the third panel of the symposium, of which I was a participant.³ It claimed,

1. New York Law School Law Review Symposium, *Freedom of Choice at the End of Life: Patients' Rights in a Shifting Legal and Political Landscape* (Nov. 16, 2012). Video recordings of the symposium are available at <http://www.nylslawreview.com/freedom-of-choice-at-the-end-of-life-videos/>.
2. Stephen Drake, *NY Law School—Justice Action Center's Upcoming Annual Justice Symposium Not Fair to Disability Advocates, Let Alone "Just"*, NOT DEAD YET (Oct. 24, 2012), <http://www.notdeadyet.org/2012/10/ny-law-school-justice-action-centers-upcoming-annual-justice-symposium-not-fair-to-disability-advocates-let-alone-just.html>.
3. The post reads in part:

[T]here are multiple and major problems with the third panel of the Symposium. Here's the title and description of that section:

Panel III: Special People, Special Issues

This panel will discuss the issues of concern for people with disabilities and the conflict between organizations dedicated to protecting their rights and end-of-life advocates. The panel will discuss the views of some of the major religion (sic) and whether conservative theological values can co-exist with patient choice. Finally, the panel will conclude with a discussion of the quality of medical care provided to prisoners and how their end of life choices are treated.

The title about “special” people should alert readers immediately that there will be no disability advocates or activists describing our conflict(s) with so-called “end of life” advocates. Most of us roll our eyes, make gagging noises or give other subtle cues that we detest the “special” label when someone uses it around us. This session, btw, is moderated by yet another board member of Compassion and Choices.

I would bet that the lion's share of the load in terms of “discussing” the “issues of concern” that disability activists and advocates have will be the job of panelist Alicia Ouellette. Ouellette recently published a text on bioethics and disability—apparently becoming the newest bioethicist who wants to become known as the “disability-conscious” bioethicist—someone who can relate slanted, distorted and outright ‘straw man’ versions of disability critiques, concerns and strong objections to both bioethics and so-called ‘end of life’ advocates. (I'm not linking to her book—I hear it's not selling well and it would be nice if it continued on that path.) Suffice it to say, Ouellette gets many things wrong about disability issues in her book—especially when it comes to NDY-related issues. Small wonder—she didn't reach out to anyone we know of (in checking her preface) in disability advocacy who was actually involved in cases she talks about in her book—Elizabeth Bouvia, Larry McAfee and Terri Schiavo to name a few.

...

That's the kind of respect we “special” people can expect from this session.

What makes it all the more appalling is that this will happen under the auspices of the University's Justice Action Center. The Center describes its goals, in part, this way:

... the Center seeks to instill in students a deeper intellectual understanding of the law regardless of their final career goals, and to present opportunities to maintain their ties to the social justice community beyond law school. Recognizing that students will pursue varied careers, the Center aims to provide a framework for analyzing

among other things, that the panel demeaned people with disabilities by virtue of its title (“Special People, Special Issues”) and its composition (by including Ann Neumann⁴ and me, but no members of Not Dead Yet or similar disability-rights groups). According to the post, the symposium’s sponsors had denied disability advocates “even a modicum of respect in making sure the perspectives of disability advocates and activists are represented fairly and accurately.”⁵ “It’s a shame to see so many organizations join them in their total disdain for disability activists and advocates,” the post stated.⁶ At the event itself, a small group from Not Dead Yet protested outside the conference hall. They displayed signs and distributed handouts that repeated the charge that symposium organizers had shown contempt for persons with disabilities through the content of the presentations.⁷

Regardless of the merits of the charges made by the disability activists,⁸ the presence of disability-rights protesters during an academic conference is noteworthy. However, such protests are not new. Indeed, forty protesters from Not Dead Yet took

the pervasive questions and contradictions relating to social justice in American society, irrespective of the context in which they may arise.

The main “contradiction” attendees will see at this symposium is the Justice Action Center’s failure to show even a modicum of respect in making sure the perspectives of disability advocates and activists are represented fairly and accurately. Do I have to add that ‘justice’ [sic] would mean having disability activists themselves speaking for ourselves?

Shame on the Justice Action Center for showing everyone just how little respect and regard they have for people with disabilities.

Shame on the sponsors of this farce—the New York Law School Law Review and the Diane Abbey Law Center for Children and Families, the American Bar Association Commission on Law and Aging; the National Academy of Elder Law Attorneys; the Elder Law Section of the New York State Bar Association; and Collaborative for Palliative Care, Westchester/NYS Southern Region.

Id. (quoting description of Panel III at the New York Law School Law Review symposium *Freedom of Choice at the End of Life: Patients’ Rights in a Shifting Legal and Political Landscape*, available at <http://www.nylslawreview.com/freedom-of-choice-at-the-end-of-life/>); see also *Justice Action Center*, N.Y.L. SCH., <http://www.nyls.edu/justice-action-center/> (last visited Dec. 20, 2013).

4. Ann Neumann is a hospice volunteer, and has written for *Guernica*, the *Nation*, *AlterNet*, and other publications. She edits the *Revealer*, a publication of the Center for Religion and Media at New York University, and teaches journalism at Drew University.
5. Drake, *supra* note 2.
6. *Id.*
7. See Stephen Drake, *NDY Activists Leaflet Justice Action Center (NY Law School) Featuring Opponents Discussing “Disability Concerns” Without Including Disability Rights Activists to Speak for Ourselves*, NOT DEAD YET (Nov. 19, 2012), <http://www.notdeadyet.org/2012/11/ndy-activists-leaflet-justice-action-center-ny-law-school-featuring-opponents-discussing-disability-concerns-without-including-disability-rights-activists-to-speak-for-ourselves.html>.
8. As I understand it, New York Law School did reach out to disability-rights advocates to participate in the symposium, but those invitations were declined. In addition, the panel included two presentations on inmates and one on disability, which might explain the moniker.

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over a plenary session of one of the first national conferences I helped to organize.⁹ The Not Dead Yet blog was also deeply critical of a conference that I organized to engage disability activists in a conversation about a range of bioethical issues.¹⁰ Disability activists are not alone in contesting discussions favoring choice in dying—some disability scholars also contend that arguments favoring choice in dying are necessarily harmful to persons with disabilities.¹¹ The protests are noteworthy nonetheless because they reveal a deep-seated disconnect between two groups: advocates for choice in dying and disability-rights activists. Both groups purport to share a commitment to respect for all individuals, but disability-rights activists argue that advocates for choice in dying threaten the rights of people with disabilities as individuals.¹²

This essay seeks to explain the context that gives rise to this disconnect. My point here is not to debate the merits of the arguments made in opposition to choice-in-dying laws. Others have done that.¹³ My objective is to share what I have learned

9. See *Not Dead Yet!*, CTR. FOR DISABILITY RTS. (July 13, 2006), <http://cdrnys.org/images/oldcdr/20060714ndy.html>.

10. The post stated:

Give me a break. First of all, there have been several single-shot events by different entities over the years that accomplished nothing—except perhaps for the bioethicists who sponsored the events to pat themselves on the back for their one-time exercise in inclusion. And, having done that, return to exclusion as a matter of standard operating procedure.

.....
The reality is that this “discourse” around bioethics is more than just an exchange of philosophies, ideas, and experiences. 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, [sic]

And no one knows it better than the bioethicists who are hosting this event.

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

11. See generally JOHN B. MITCHELL, UNDERSTANDING ASSISTED SUICIDE: NINE ISSUES TO CONSIDER 57–104 (2007) (discussing the complex issues of assisted suicide through nine contexts). See, e.g., Christopher Newell, *Disability, Bioethics, and Rejected Knowledge*, 31 J. MED. & PHIL. 269, 275 (2006) (charging that bioethics is a disabling project); DIANE COLEMAN & TOM NERNEY, GUARDIANSHIP AND THE DISABILITY RIGHTS MOVEMENT 1, available at <http://www.centerforself-determination.com/docs/guard/GuardianshipDisabilityRightsColemanNerney1.pdf> (last visited Dec. 20, 2013) (“[The] powerful field of bioethics represents the single greatest threat to the welfare of those with significant disabilities in this country. Under the rubric of utilitarian ethics and the language of rights, discrimination against people with disabilities has become enshrined in law and popular imagination.”).

12. The claim is that “legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not.” TOM SHAKESPEARE, DISABILITY RIGHTS AND WRONGS 122 (Routledge 2006) (quoting *About Us*, NOT DEAD YET (Nov. 30, 2006), <http://web.archive.org/web/20061130080647/http://www.notdeadyet.org/docs/about.html>).

13. See, e.g., SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT (2009); 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 (2006); Lois Shepherd, *In Respect of People Living in a Permanent Vegetative State—And Allowing*

in a decade of research about why the two groups appear to remain mired in a permanent conflict that prevents constructive work on achieving the shared goal of ensuring respect for all persons at the end of life. I will explain why seemingly strong claims by advocates for choice in dying that procedural rules and precise definitions (such as those used in Oregon's Death with Dignity Act)¹⁴ protect against discriminatory applications of laws allowing choice in dying nonetheless fail to reassure disability activists who worry that the laws will be used to kill people with disabilities against their will. The short answer: disability activists have good reason to distrust the health care system in the United States, and until the system is perceived as more fair and trustworthy they will continue to find inadequate the argument that procedures safeguard against abuse. To the extent advocates for choice in dying want to defuse the tension that marks interactions with disability-rights activists, they must begin to understand and address the marginalizing, stigmatizing, and discriminatory aspects of the health care system experienced by people with disabilities throughout their lives. That understanding will go a long way toward facilitating better and more effective communication between the groups.

Part II of this essay explains how I became involved in the dispute over disability rights at the end of life, and why I believe that understanding the broader context of life with disability helps to explain the deep conflict between advocates for choice in dying and advocates for disability rights. Part III explores the experience of people with disabilities in the U.S. health care system, including the troubling disparities in care. Finally, Part IV suggests that by better attending to the systemic disparities faced by people with disabilities in the health care system, advocates for choice in dying might begin to break through the distrust and anger that characterize disability-rights activists' protests of discussions about choice in dying. Building trust with members of the disability-rights community is, in my view, an important element of promoting strong doctor-patient relationships, sound medical policy, and, most importantly, increased access to physician aid in dying.¹⁵ When trust in physicians and policies that affect the lives of persons with disabilities is eroded, the

Them to Die, 16 HEALTH MATRIX 631 (2006); Lois Shepherd, *Terri Schiavo and the Disability Rights Community: A Cause for Concern*, 2006 U. CHI. LEGAL F. 253.

14. See Oregon Death with Dignity Act, OR. REV. STAT. ANN. §§ 127.800–897 (West 2013); Washington Death with Dignity Act, WASH. REV. CODE ANN. §§ 70.245.010–904 (West 2013); see also OR. HEALTH AUTH., DEATH WITH DIGNITY ACT REQUIREMENTS, available at <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/requirements.pdf> (last visited Dec. 20, 2013) (explaining that under Oregon's Death with Dignity Act, a request for lethal medications can be granted only when the patient is an adult (eighteen years of age or older); is a resident of Oregon; is capable (defined as able to make and communicate health care decisions); is diagnosed with a terminal illness that will lead to death within six months; has made two oral requests of his or her physician separated by at least fifteen days; has provided a written request to his or her physician, signed in the presence of two witnesses; and the prescribing physician and a consulting physician have confirmed the diagnosis and prognosis, and determined that the patient is capable).
15. I present this argument in more depth in my book, *BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS* (Cambridge Univ. Press 2011).

prospects for collaboration and consensus around expanded options for all people at the end of life remain poor.

II. AN ACCIDENTAL INTERLOPER

My interest in the disability-rights community began after I wrote a law review article¹⁶ that discussed the case of Sheila Pouliot.¹⁷ I became involved in the Pouliot case when I was an assistant solicitor general in the Office of the New York Attorney General. My office represented a state agency that sought to enjoin Pouliot's family and doctors from discontinuing the medical provision of nutrition and hydration that was sustaining her life.¹⁸ Pouliot was an adult with profound cognitive and physical disabilities. At the time, she was terminally ill and unable to digest any food or water administered orally.¹⁹ Pouliot was also being kept alive through intravenous administration of fluids.²⁰ When her case went to court, New York state law did not allow family members or doctors to withhold nutrition or hydration from a person who never had the capacity to make her own decisions.²¹ Pouliot's family and doctors contested the application of New York law, arguing that they should have the right to terminate Pouliot's treatment because, although the intravenous fluids were keeping her alive, they were also causing her intractable pain, bloating, and the deterioration of her organs.²² The family was ultimately unsuccessful.²³ As a result, Pouliot's death was agonizingly slow and painful, stretching over the course of months.²⁴ My article was a criticism of New York's end-of-life laws, which kept people like Sheila Pouliot alive no matter the cost.²⁵ I argued specifically that New York law was especially harmful to people with cognitive disabilities because it deprived them of the right to palliative care, and exposed them to the risk of the horrific death experienced by Pouliot.²⁶ In my view, the law's barrier to medically appropriate comfort care—including cessation of the provision of medically administered nutrition and hydration—was a form of disability

16. See Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1 (2004).

17. *Blouin ex rel. Estate of Pouliot v. Spitzer*, 356 F.3d 348 (2d Cir. 2004).

18. See *id.* at 352–53.

19. See *id.* at 352.

20. See *id.* at 348, 353–54.

21. See *id.* at 351.

22. See *id.* at 355 & n.4.

23. See *id.* at 365 (holding that the decision to discontinue medical treatment must be grounded clearly in the patient's expressed intent—"not the desires of surrogates or family members"—and that the state was within its authority to order the continuation of treatment for as long as possible).

24. See *id.* at 351–52.

25. See Ouellette, *supra* note 16, at 21–22.

26. See *id.* at 23–24, 38.

discrimination.²⁷ In short, I thought that by advocating for expanded choices for persons with disabilities at the end of life, I had written a pro-disability article.

I soon learned that some disability-rights activists disagreed. I was surprised (and upset) to receive angry emails from disability-rights activists, and even angrier responses in person after I presented the paper at conferences and public talks. The charge was that, by advocating for a change in New York law to allow for the discontinuation of medically administered nutrition and hydration in cases involving persons with cognitive disabilities, I was promoting a new form of eugenics and the discriminatory notion that lives with disability are not worth living. Eventually, I became something of a target for disability-rights activists, who appear to take particular issue with my work and participation in discussions that touch on end-of-life issues.²⁸

The responses from disability-rights activists to my work, and that of other advocates for choice in dying in cases involving the removal of life-sustaining

27. *See id.* at 22–25.

28. *See Drake, supra* note 2. The Not Dead Yet website states:

Another prominent participant in this event is Alicia Ouellette. If you check out the link, her publications and presentations show she had developed an aggressive “interest” in disability and “end of life”—the latter a term she uses frequently without ever really defining. I first noticed Ouellette when she seemed to show precognitive ability when she wrote an entry on the bioethics blog titled “Important End-of-Life Case in Massachusetts Reaches Critical Point.” The entry was about Haleigh Poutre, an abused 11-year-old girl who was beaten so badly she went into a deep coma. At the time of Ouellette’s blog entry, the MA Supreme Court hadn’t rendered a verdict to the challenge of treatment removal on the part of her adoptive stepfather, who no doubt sought to beat a murder rap. Nevertheless, her situation was referred to as an “end of life” case by Ouellette. And Ouellette didn’t find it worth revisiting the subject two months later—after the judge had sanctioned Haleigh’s right to die a “dignified” death, she began to come out of the coma and is alert and doing well at last report.

Writing in the *Oregon Law Review* in 2006, Ouellette wrote out her analysis on “Disability and the End of Life.” In the paper, she accuses activists of conflating disability and terminal illness. Leaving a debunking of this aside, I think it’s worth noting that neither Ouellette nor other mainstream bioethicists have attacked the Final Exit Network or Compassion & Choices for their very blatant—and successful—maneuvers to conflate terminal illness and disability (and voluntary vs. involuntary, for that matter). This article is a goldmine of ad hominem attacks and selective storytelling. She makes sure to tie disability activists to religious political groups in relation to Schiavo, but also fails to mention the twenty or so national disability groups that expressed concerns over Schiavo’s situation and what it meant about dismantled protections for people under guardianship. She “tells the story” of Elizabeth Bouvia, but without relating the personal events in her life that might have led any young woman into a downward slump. She talks briefly about Larry McAfee but fails to credit disability advocates as the ones who got him what he wanted in order to live—a place to live outside of an institution. (CORRECTION: I have reread the article in question and Ouellette does indeed relate several personal losses and setbacks in Bouvia’s life cited by disability activists. Later, though, she apparently gives them short shrift by referring to the “power of choice”—implying giving Bouvia an opportunity to die with medical assistance empowered her to live.)

Drake, *supra* note 10.

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treatment and physician aid in dying,²⁹ persuaded me to learn more about the experiences of people with disabilities in and out of the health care system. Thus began a decade-long immersion in disability studies and activism that left me with many new friends and colleagues, as well as a much deeper understanding of the history and experiences that have convinced some disability-rights activists that laws that allow for choice in dying will necessarily work against people with disabilities—no matter how narrowly or carefully drafted they are.

I also came to understand that where some people perceive both choice in dying and access to choice in dying as options that respect individual autonomy, others perceive discrimination based on disability status. This position is not, as is sometimes claimed, an idea planted by right-wing, right-to-life groups, but rather one based on a real concern that the health care system does not value life with disability and would, if possible, simply eliminate people with disabilities.³⁰ This view was evident in the Terry Schiavo case, about which influential disability scholar Harriet McBryde Johnson wrote:

The State of Florida would not have authorized a man to have his non-disabled wife deprived of food and hydration, and would not have caused her death that way. It was because of her disability that her death was thought to be appropriate.³¹

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29. *See, e.g.*, Brief for Not Dead Yet et al. as Amici Curiae Supporting Petitioners, *Gonzales v. Oregon*, 546 U.S. 243 (2006) (No. 04-623); Brief for Not Dead Yet et al. as Amici Curiae Supporting Appellants, *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2005) (No. SC04-925); Brief for Not Dead Yet et al. as Amici Curiae Supporting Appellants, *Oregon v. Ashcroft*, 368 F.3d 1118 (9th Cir. 2004) (No. 02-35587); Brief for Not Dead Yet et al. as Amici Curiae Supporting Respondents, *Wendland v. Wendland*, 28 P.3d 151 (Cal. 2001) (No. S087265).
30. *See* Adrienne Asch, *Disability, Bioethics, and Human Rights*, in *HANDBOOK OF DISABILITY STUDIES* 297, 301 (Gary L. Albrecht et al. eds., 2001) (“[T]he first right of people with disabilities is a claim to life itself, along with the social recognition of the value and validity of the life of someone with a disability.”); *see also* *THE CASE AGAINST ASSISTED SUICIDE: FOR THE RIGHT TO END-OF-LIFE CARE* (Kathleen Foley & Herbert Hendin eds., 2002); *AMA CODE OF MED. ETHICS, OPINION 2.211—PHYSICIAN ASSISTED SUICIDE* (June 1996), available at <http://ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page> (“[A]llowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”); *AMA CODE OF MED. ETHICS, OPINION 2.21—EUTHANASIA* (June 1996), available at <http://ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page> (“Euthanasia could also readily be extended to incompetent patients and other vulnerable populations.”).
31. *Harriet McBryde Johnson: Civil Rights Activist*, *ABILITY MAG.*, available at http://abilitymagazine.com/harriet_mcbryde.html (last visited Dec. 20, 2013); *see also* *Schindler v. Schiavo* (*In re* Guardianship of Schiavo), 916 So. 2d 814 (Fla. Dist. Ct. App. 2005); Harriet Johnson, *Not Dead at All: Why Congress Was Right to Stick Up for Terri Schiavo*, *SLATE* (Mar. 23, 2005, 7:50 AM), http://www.slate.com/articles/news_and_politics/hey_wait_a_minute/2005/03/not_dead_at_all.html, reprinted in Harriet McBryde Johnson, *Overlooked in the Shadows*, *WASH. POST*, Mar. 25, 2005, at A19, available at <http://www.washingtonpost.com/wp-dyn/articles/A64571-2005Mar24.html>. Of course, not all disability-rights advocates oppose choice in dying. *See, e.g.*, Paul K. Longmore, *The Disability Rights Opposition to Assisted Suicide Explained and Critiqued*, in *END-OF-LIFE ISSUES AND PERSONS WITH DISABILITIES* 144, 151 (Timothy Lillie & James L. Werth eds., 2007); PAUL K. LONGMORE, *Elizabeth Bouvia, Assisted Suicide, and Social Prejudice*, in *WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY* 149 (2003); *see*

Additionally, the claim that laws facilitating choice in dying are a form of disability discrimination is evident in the positions taken by the group that protested the symposium at New York Law School.

After a decade of engaging in disability scholarship and listening to people with disabilities, I believe it is a mistake to dismiss the positions taken by disability advocates as fringe or radical. Underlying these positions is a deep-seated distrust of the U.S. health care system that results from historical and pervasive disparities in treatment experienced by persons with disabilities. By understanding and addressing the source of that distrust and the disparities that plague the system, advocates for choice in dying might be able to break through the conflict to foster constructive collaborative action.

III. EXPERIENCING DISABILITY IN THE U.S. HEALTH CARE SYSTEM

In May 2012, a mainstream disability-rights organization called the National Disability Rights Network published a report detailing the ways in which the U.S. health care system fails to recognize the value of life with disability.³² The report describes conversations between doctors and persons with disabilities and their families in which the disabled are “viewed as having little value as they are,” and are not considered “fully human, [and therefore not] endowed with inalienable rights of liberty, privacy and the right to be left alone—solely because they were born with a disability.”³³ The National Disability Rights Network is hardly the first group or individual to criticize the U.S. health care system for its treatment of persons with disabilities; such criticisms are widespread in disability scholarship.³⁴

Outside of the disability community, the notion that the U.S. health care system is an inhospitable place for people with disabilities might be surprising. This is, after all,

also Adrienne Asch, *Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?*, in IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT? S31 (Bruce Jennings et al. eds., 2005).

32. See DAVID CARLSON, CINDY SMITH & NACHAMA WILKER, DEVALUING PEOPLE WITH DISABILITIES: MEDICAL PROCEDURES THAT VIOLATE CIVIL RIGHTS (2012), available at http://disabilitylawva.org/wp-content/uploads/2012/10/Devaluing_People_with_Disabilities.pdf.

33. *Id.* at 5.

34. See, e.g., HARLAN LANE, THE MASK OF BENEVOLENCE: DISABLING THE DEAF COMMUNITY 212–13 (1992) (discussing the mistreatment of deaf patients in France); PAUL K. LONGMORE, *Medical Decision Making and People with Disabilities: A Clash of Cultures*, in WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY, *supra* note 31, at 204–11 (describing conflicts between disabled persons and their health care providers); ROBERT WHITAKER, MAD IN AMERICA: BAD SCIENCE, BAD MEDICINE, AND THE ENDURING MISTREATMENT OF THE MENTALLY ILL 71–72 (Basic Books 2010); Stephen Drake, *The Doctor Said It Would Be Better if I Didn't Survive*, NOT DEAD YET (Mar. 30, 2012), http://www.notdeadyet.org/2012/03/stephens_story.html; Diane Coleman & Stephen Drake, *Disability Discrimination*, HASTINGS CTR. BIOETHICS F. (July 11, 2012), <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5913&blogid=140>; Ford Vox, *'The Cyclops Child': Inhumanity in a 1960 Hospital*, THE ATLANTIC (July 14, 2012), <http://www.theatlantic.com/health/archive/2012/07/the-cyclops-child-inhumanity-in-a-1960-hospital/259810/> (recounting Dr. Fredric Neuman's cruel treatment of a child with severe birth defects).

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decades after both the passage of civil rights statutes for persons with disabilities³⁵ and the emergence of disability studies as its own field.³⁶ Nonetheless, disability-based discrimination persists. For many persons with disabilities, that discrimination is especially acute in the health care system. The long history of medical mistreatment of—and insensitivity toward—people with disabilities at the hands of the health care establishment is well documented by disability and legal scholars.³⁷ This history includes institutionalization,³⁸ eugenics,³⁹ forced sterilization,⁴⁰ and leaving newborns with correctable conditions to die.⁴¹ While these practices are now disfavored, individuals with disabilities continue to face discrimination in its modern form in medical offices and hospitals,⁴² leaving some of these individuals fearful that the health

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35. See Rehabilitation Act of 1973, 29 U.S.C. § 794 (2012); Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2012).
 36. See generally HANDBOOK OF DISABILITY STUDIES (Gary L. Albrecht et al. eds., 2001); THE DISABILITY STUDIES READER (Lennard J. Davis ed., 3d ed. 2010).
 37. See, e.g., PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK v. BELL 45 (2008); THE NEW DISABILITY HISTORY: AMERICAN PERSPECTIVES (Paul K. Longmore & Lauri Umansky eds., 2001); William J. Peace, *Comfort Care as Denial of Personhood*, 42:4 HASTINGS CTR. REP. 14 (2012); JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (Broadway Books 1994); Anita Silvers, *Formal Justice*, in DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY 13, 42 (1998); Carol J. Gill, *Becoming Visible: Personal Health Experiences of Women with Disabilities*, in WOMEN WITH PHYSICAL DISABILITIES: ACHIEVING AND MAINTAINING HEALTH AND WELL-BEING 5 (Danuta M. Krotoski et al. eds., 1996).
 38. See Richard K. Scotch, *American Disability Policy in the Twentieth Century*, in THE NEW DISABILITY HISTORY, 375, 377–78 (Paul K. Longmore & Lauri Umansky eds., 2001).
 39. See *Buck v. Bell*, 274 U.S. 200, 207 (1927). Questions existed about the heritability of conditions and whether the patients actually had the suspect conditions. For example, research indicates that Carrie Buck was not in fact mentally handicapped. See Roberta M. Berry, *From Involuntary Sterilization to Genetic Enhancement: The Unsettled Legacy of Buck v. Bell*, 12 NOTRE DAME J.L. ETHICS & PUB. POL'Y 401, 420–21 (1998); Michael G. Silver, Note, *Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History*, 72 GEO. WASH. L. REV. 862, 867 (2004).
 40. See, e.g., PHILIP R. REILLY, THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES 30–40 (1991); Silver, *supra* note 39, at 867.
 41. See *Weber v. Stony Brook Hosp.*, 467 N.Y.S.2d 685, 686 (2d Dep't 1983). The “Baby Doe” cases were explored by a presidential commission, which issued a report in 1983 that would disallow denial of surgery to “an otherwise healthy Down Syndrome child whose life is threatened by a surgically correctable complication.” Asch, *supra* note 30, at 303 (quoting PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS 6–7 (1983)). See also Dennis F. Cantrell, *Bowen v. American Hospital Association: Federal Regulation Is Powerless to Save Baby Doe*, 19 IND. L. REV. 1199 (1986) (discussing a case in which a boy, born with Down syndrome and esophageal obstruction, died because his parents refused to consent to life-saving treatment); Armand Matheny Antommara, “Who Should Survive?: One of the Choices on Our Conscience”: *Mental Retardation and the History of Contemporary Bioethics*, 16 KENNEDY INST. OF ETHICS J. 205 (2006) (discussing a film that “contains a dramatization of the death of an infant with Down syndrome as a result of the parents’ decision to not have congenital intestinal obstruction surgically corrected”).
 42. See STARING BACK: THE DISABILITY EXPERIENCE FROM THE INSIDE OUT (Kenny Fries ed., 1997); KENNY FRIES, THE HISTORY OF MY SHOES AND THE EVOLUTION OF DARWIN’S THEORY (2007);

care system is a dangerous place. Disability-rights scholar and cultural anthropologist William Peace explains: “Most 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?”⁴³

A variety of medical innovations make disability-rights advocates very uncomfortable. For example, controversial procedures such as genetic screening and pre-implantation genetic diagnosis can be used to prevent people with disabilities from even being born.⁴⁴ There are also growth attenuation procedures for children with disabilities that were modeled on the “Ashley X” case.⁴⁵ Ashley was a six-year-old girl from Seattle who was given high doses of estrogen in order to stunt her growth; she underwent both a hysterectomy and a mastectomy in order to keep her small, so that she could be treated at home.⁴⁶ There are cases in which health providers unilaterally decide to withdraw treatment from children and adults with disabilities.⁴⁷ There have been attempts at rationing health care resources based in part on disability status, such as in Oregon, where the federal government eventually found that the proposed scheme would unlawfully discriminate against people with disabilities.⁴⁸ And there are reports that fertility clinics routinely deny their services to people with disabilities.⁴⁹

HARRIET MCBRYDE JOHNSON, *TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE* (2005); Peace, *supra* note 37, at 14.

43. William J. Peace, *Disability Discrimination: The Author Responds*, HASTINGS CTR. BIOETHICS F. (July 27, 2012), <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=5935&blogid=140#ixzz22VbDNxiW>.
44. See Bonnie Steinbeck, *Disability Prenatal Testing and Selective Abortion*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 108 (Erik Parens & Adrienne Asch eds., 2000); Deborah Kaplan & Marsha Saxton, *Disability Community and Identity: Perceptions of Prenatal Screening*, *OUR BODIES OURSELVES*, <http://www.ourbodiesourselves.org/book/companion.asp?id=31&compID=43&page=2> (last visited Dec. 20, 2013).
45. See CARLSON, SMITH & WILKER, *supra* note 32.
46. See Alicia Ouellette, *Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case*, 8 *HOUS. J. HEALTH L. & POL'Y* 207, 211–12 (2008), available at http://www.law.uh.edu/hjhlp/Issues/Vol_82/Ouellette.pdf.
47. See OUELLETTE, *supra* note 15, at 105–08 (describing the case of Emilio Gonzalez, a child with Leigh’s disease whose doctors terminated medical care and provided only comfort care, despite the wishes of Emilio’s mother).
48. See Dan Brock, *Health Care Resource Prioritization and Discrimination Against Persons with Disabilities*, in *AMERICANS WITH DISABILITIES: IMPLICATIONS FOR INDIVIDUALS AND INSTITUTIONS* 1, 3–4 (Leslie Francis & Anita Silvers eds., 2000); Lisa L. Dahm, *Medical Futility and the Texas Medical Futility Statute: A Model to Follow or One to Avoid?*, 6 *HEALTH LAW* 25, 28 (2008).
49. See NAT’L COUNCIL ON DISABILITY, *ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN* 205 (2012), available at <http://www.ncd.gov/publications/2012/Sep272012/>; see also Barbara Faye Waxman, *Up Against Eugenics: Disabled Women’s Challenge to Receive Reproductive Health Services*, 12 *SEXUALITY & DISABILITY* 155 (1994).

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Beyond controversial medical innovations, disability-rights advocates are even more troubled by the day-to-day experience of persons with disabilities in the health care system. A report published in 2009 by the National Council on Disabilities found that people with disabilities experience significant health care disparities and barriers to care.⁵⁰ People with disabilities are more likely to go without needed care; they make more preventable emergency room visits and hospitalizations; they experience a significantly higher prevalence of secondary conditions; they get less preventive care—fewer pelvic exams, fewer pap smears, fewer prostate exams, less prenatal care; they are not as likely to be weighed when they go to the doctor; and they have poor health outcomes.⁵¹ The statistics reveal a disparity similar to the disparity that is well recognized with respect to race and health care.⁵² Researchers are just beginning to recognize and document the depth of disability-based disparities in health care.⁵³

Many factors contribute to disability-based disparities in health care, including the cost of care.⁵⁴ In addition, there are also communication barriers,⁵⁵ architectural barriers, problems with accessible medical equipment, and stereotypes about disabilities.⁵⁶ Understanding how these barriers affect the day-to-day experience of people with disabilities in the health care setting will help to explain the reluctance

50. See NAT'L COUNCIL ON DISABILITY, *supra* note 49.

51. See *id.*; Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 2010 UTAH L. REV. 1057, 1059–60; Karen Hwang et al., *Access and Coordination of Health Care Service for People with Disabilities*, 20 J. DISABILITY POL'Y STUD. 28, 29–30 (2009) (collecting results of population-based surveys); U.S. DEP'T OF HEALTH & HUMAN SERVS., THE SURGEON GENERAL'S CALL TO ACTION TO IMPROVE THE HEALTH AND WELLNESS OF PERSONS WITH DISABILITIES (2005), available at <http://www.surgeongeneral.gov/library/calls/disabilities/calltoaction.pdf>; Ctr. for Research on Women with Disabilities, *Health Disparities Between Women with Physical Disabilities and Women in the General Population*, BAYLOR C. MED. (May 2005), <https://www.bcm.edu/research/centers/research-on-women-with-disabilities/?PMID=1331> (discussing the first national survey of women with disabilities on their experiences with women's health care conducted in the years immediately following the passage of the ADA).

52. See INST. OF MED. OF THE NAT'L ACADS., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* (Brian D. Smedley et al. eds., 2003), available at <http://www.nap.edu/openbook.php?isbn=030908265X>.

53. See, e.g., U.S. DEP'T OF JUSTICE & U.S. DEP'T OF HEALTH & HUMAN SERVS., *ACCESS TO MEDICAL CARE FOR INDIVIDUALS WITH MOBILITY DISABILITIES* 8–19 (2010), available at http://www.ada.gov/medicare_mobility_ta/medicare_ta.pdf.

54. See generally Kirsten L. Kirschner, Mary Lou Breslin & Lisa I. Iezzoni, *Structural Impairments that Limit Access to Health Care for Patients with Disabilities*, 297:10 JAMA 1121 (2007).

55. See Michael A. Schwartz, *Deaf Patients, Doctors, and the Law: Compelling a Conversation About Communication*, 35 FLA. ST. U. L. REV. 947 (2008) (describing the difficulties experienced by deaf patients who are not provided sign language interpreters by their doctors).

56. See Elizabeth Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 15, 17–18 (2008) (describing barriers posed by inaccessible buildings and medical equipment); Elizabeth Pendo, *Shifting the Conversation: Disability, Disparities and Health Care Reform*, 6 FLA. INT'L U. L. REV. 87, 92 (2010) (noting that “twenty years after passage of the [ADA], many people with mobility impairments cannot get on examination tables and chairs, cannot be weighed, and cannot use x-ray and other imaging equipment”).

of some disability advocates to trust the system to prevent the abuse of choice-in-dying laws at the end of life.

Consider, for example, “equipment barriers.” Medical equipment—examination tables, weight scales, x-ray and mammography equipment—is often not accessible to people with mobility disabilities.⁵⁷ Mammography equipment, for instance, is designed so that women must stand up to position their breasts in the machine for scanning.⁵⁸ As a result, women with mobility disabilities cannot get screening mammograms, except when they happen to have access to an adjustable machine.⁵⁹ Consequently, the data shows that women with mobility disabilities are being diagnosed with breast cancer at a more advanced stage than people who can stand up and make use of the more common inaccessible screeners.⁶⁰ Similarly, women with mobility disabilities face equipment-based challenges getting pap smears; because the tables are not accessible, they are not screened.⁶¹ Imagine the frustration that people with mobility disabilities must feel when they are told—more than two decades after the Americans with Disabilities Act (ADA) was passed—that certain screening tests are not available because medical equipment remains inaccessible.

If the problem was only inaccessible medical equipment, the barriers to care for people with disabilities would be eminently fixable. Unfortunately, attitudinal barriers are also affecting care. People with disabilities face negative stereotypes and assumptions about the tragedy and limitations of life with a disability.⁶² These negative

57. See June Isaacson Kailes, *The Patient's Perspective on Access to Medical Equipment*, in *MEDICAL INSTRUMENTATION: ACCESSIBILITY AND USABILITY CONSIDERATIONS* 3, 6 (Jack M. Winters & Molly Follette Story eds., 2007); Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, *supra* note 56, at 17–18.

58. See U.S. DEP'T OF JUSTICE & U.S. DEP'T OF HEALTH & HUMAN SERVS., *supra* note 53, at 17; Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, *supra* note 56, at 17–18.

59. See Nancy Mele, Jeanne Archer, & Burton D. Pusch, *Access to Breast Cancer Screening Services for Women with Disabilities*, 34 *J. OBSTETRIC, GYNECOLOGICAL & NEONATAL NURSING* 4, 453–64 (2005), available at <http://www.memphis.edu/nursing/Suha/Mele.pdf>; see also *Women with Disabilities and Breast Cancer: Know Your Rights*, INDEP. CARE Sys., http://www.icsny.org/sitemanagement/wp-content/uploads/2013/03/Beast-Cancer-Flyer_FINAL.pdf (last visited Dec. 20, 2013).

60. See NAT'L COUNCIL ON DISABILITY, *supra* note 49, at 57–58; Ellen P. McCarthy et al., *Disparities in Breast Cancer Treatment and Survival for Women with Disabilities*, 145 *ANNALS INTERNAL MED.* 637 (2006).

61. The problem of inaccessible medical equipment has not gone unnoticed by lawmakers. Because the ADA did not solve the problem as intended, the Department of Justice (DOJ) issued a 2010 guidance document about accessibility to health care that mentioned equipment. U.S. DEP'T OF JUSTICE & U.S. DEP'T OF HEALTH & HUMAN SERVS., *supra* note 53, at 8–19. In 2012, the DOJ issued a notice of proposed rulemaking “to ensure that medical diagnostic equipment, including examination tables, examination chairs, weight scales, mammography equipment, and other imaging equipment used by healthcare providers for diagnostic purposes are accessible to and usable by individuals with disabilities.” *Medical Diagnostic Equipment Accessibility Standards*, 77 *Fed. Reg.* 6916, 6917 (proposed Feb. 9, 2012) (to be codified at 36 C.F.R. pt. 1195).

62. See Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, *supra* note 56, at 44, 55.

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assumptions affect their health care in ways that are far more intractable than inaccessible examination tables. Descriptions of dehumanizing experiences in health care settings are all too frequent in disability scholarship.⁶³ People with mobility disabilities describe their experiences in doctors' offices as dehumanizing. Despite their interest in living full lives, having children, and enjoying sexual relationships, people with disabilities report that providers focus so intently on their impairment that they disregard the possibility that their patients have more global needs.⁶⁴ Women with mobility disabilities report that they must be trailblazers in order to get the kind of reproductive health care that they want. As scholar Carol Gill explains:

[W]omen with disabilities are stripped of our roles. We are not expected to be workers, romantic partners, caregivers, or mothers. Socially, we are in limbo—not quite children, but not adults; not men, but not real women either. It is difficult to get your bearings and struggle out from under that kind of unremitting yet subtle oppression, because it steals from you the very sense of self you need in order to fight.⁶⁵

Disability scholarship also demonstrates that doctors consistently underestimate the quality of life one can have with disabilities.⁶⁶ When asked to evaluate the quality of life of disabled patients, doctors are significantly more negative than the individuals who live with impairment; they make negative assumptions about the possible quality of life with disability that are simply inaccurate.⁶⁷ This misperception about how people experience their own lives plays out in painful ways. William Peace offers an example. Peace is well published,⁶⁸ writing a powerful blog advocating for social justice for persons with disabilities.⁶⁹ He kayaks, skis, and drives. He also uses a wheelchair to get around. One day, Peace's middle school-aged son lacerated his arm, and Peace brought him to the emergency room to get stitches. Although Peace was sitting next to his son when the health provider came in, the provider looked right past him to the young boy and asked who should be called about the boy's medical

63. See, e.g., NAT'L COUNCIL ON DISABILITY, *supra* note 49; FRIES, *supra* note 42, at 1–2; MCBRYDE JOHNSON, *supra* note 42, at 1; Kailes, *supra* note 57, at 5; Waxman, *supra* note 49, at 155–56, 159, 165; STARING BACK: THE DISABILITY EXPERIENCE FROM THE INSIDE OUT, *supra* note 42, at 2, 4.

64. See Gill, *supra* note 37, at 6; see also Waxman, *supra* note 49.

65. Gill, *supra* note 37, at 6.

66. See G.L. Albrecht & P.J. Deulieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48:8 SOC. SCI. & MED. 977 (1999); J.R. Bach & M.C. Tilton, *Life Satisfaction and Well-Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia*, 75:6 ARCH. PHYS. MED. REHABILITATION 626 (1994); S. Saigal et. al., *Self-Perceived Health Status and Health Related Quality of Life of Extremely Low-Birth-Weight Infants at Adolescence*, 276:6 JAMA 453 (1996).

67. See NAT'L COUNCIL ON DISABILITY, *supra* note 49, at 57, 304; Kailes, *supra* note 57, at 5; Albrecht & Deulieger, *supra* note 66; Bach & Tilton, *supra* note 66; Saigal et. al., *supra* note 66.

68. See, e.g., Peace, *supra* notes 37, 43.

69. William J. Peace, BAD CRIPPLE, <http://badcripple.blogspot.com/> (last visited Dec. 21, 2013).

care. The provider did not even consider the possibility that the man in the wheelchair might have been a parent, which left Peace feeling less than fully human.⁷⁰

The kind of dismissive attitude experienced by Peace in that emergency room is representative of the day-to-day experiences in the health care setting reported by people with disabilities. Individuals cannot get on examination tables for necessary exams and cannot be weighed.⁷¹ They have to convince surprised doctors that they need reproductive health care because they are sexually active.⁷² They have to go to court to enforce their right to a sign language interpreter for communication with doctors.⁷³ These situations illustrate a pattern of barriers that leaves some people with disabilities feeling marginalized, stigmatized, and viewed as tragically flawed. Such experiences erode their trust in the health care system, and such eroded trust affects discussions about choice in dying.

IV. UNDERSTANDING THE CONTEXT OF LIFE WITH DISABILITY TO ADVANCE DISCUSSIONS ABOUT CHOICE AT THE END OF LIFE

Advocates for choice-in-dying laws often counter the concern that such laws will be abused to kill persons with disabilities with assurances that procedural safeguards will prevent this type of abuse.⁷⁴ For example, choice-in-dying advocates ask people to trust that the procedures that limit access to physician aid in dying (e.g., firm diagnosis of terminal condition, confirmed assessment by multiple providers, etc.),⁷⁵ will ensure that no one would be forced to accept unwanted aid in dying. Procedural rules are carefully designed and enshrined in law so that aid-in-dying laws are not used to eliminate vulnerable populations (including people with disabilities)⁷⁶ who have not met the diagnostic criteria or made a clear, unequivocal choice to control the time and manner of death.⁷⁷ It thus seems reasonable to reassure disability advocates that physician aid-in-dying laws are not targeted at them. In Oregon, for example, aid in dying is available for only competent, terminally ill adults who have a confirmed diagnosis of less than six months to live and have made multiple requests (including a witnessed written request) for the lethal prescription.⁷⁸

70. I relate this story in my book. See OUELLETTE, *supra* note 15, at 200.

71. See NAT'L COUNCIL ON DISABILITY, *supra* note 49.

72. See *id.* at 59.

73. See, e.g., Schwartz, *supra* note 55, at 981.

74. See Margaret Battin, *Physician-Assisted Dying and the Slippery Slope: The Challenge of Empirical Evidence*, 45 WILLAMETTE L. REV. 91, 99 (2008). Choice-in-dying advocates also point to statistics demonstrating the effectiveness of the safeguards. See Anne Marie Su, Note, *Physician Assisted Suicide: Debunking the Myths Surrounding the Elderly, Poor, and Disabled*, 10 HASTINGS RACE & POVERTY L.J. 145, 157 (2013).

75. See OR. REV. STAT. ANN. § 127.897 (West 2013).

76. See *id.* § 127.805(2).

77. See *id.* § 127.897.

78. See *id.*

Such assurances provide little comfort in the context of an untrustworthy health care system. As discussed above, assurances of screening tests and preventive care in the current system have not been realized for people with mobility disabilities. Assurances of equal access to care have not been met for disabled women seeking reproductive health care. Assurances of respect for individuals have not been met by providers who dismiss the notion that a disabled person can be a parent. The breach of trust experienced at other points in the health care system affects conversations about end-of-life decisionmaking.

Conversations initiated in this context, especially conversations about terminating treatment or facilitating death, can raise primal fears in patients with disabilities.⁷⁹ Persons with disabilities and their allies may question whether conversations about terminating treatment mean that the doctor thinks that a disabled life is no longer worth living. These individuals may wonder whether a conversation is really about a current condition or whether it is based on the same misassumptions that led other providers to believe that the person with a disability could not be a parent or was not worthy of screening tests.⁸⁰ The larger context of a lifetime of experience in the medical setting helps to explain the skeptical response of people with disabilities to well-meaning discussions about choices for death. Discussions that look perfectly reasonable and non-threatening to advocates for choice in dying can feel very threatening to someone who comes from a context in which the system cannot be trusted.

For this reason, advocates for choice in dying might better serve their cause by listening to—and learning from—people with disabilities about their experiences in the health care system, and then advocating for systemic change. In order to break the impasse between advocates for choice in dying and disability advocates (an impasse that has played a role in stalling the adoption of choice-in-dying laws around the country), advocates for choice in dying would be well served by working to reshape the legal and health care system more broadly to ensure that it respects people with disabilities while they are living. Committing to a system that respects people of all abilities throughout their lives will help those of us who are committed to building a system that respects all of our choices at the time of our deaths. Part of this task involves questioning assumptions about the quality of life experienced by people with disabilities—and making changes to the way we discuss disability-related cases.

For example, consider the classic California case *Bowvia v. Superior Court*,⁸¹ which is included in most textbooks on bioethics, health law, and end-of-life issues. It is the seminal case used to teach the principle that individuals have the right to refuse treatment—even life-saving, medically administered nutrition and hydration. *Bowvia* involved a twenty-eight-year-old woman who had cerebral palsy and arthritis, was in a wheelchair and incontinent, and used a nasogastric (NG) tube for feeding.⁸² During a hospitalization, she requested that the NG tube be removed and that she

79. See Peace, *supra* note 43.

80. See *id.*

81. 225 Cal. Rptr. 297 (Ct. App. 1986).

82. See *id.* at 297, 299–300.

be provided comfort care by the hospital while death from starvation occurred.⁸³ The case went to court and she was granted that right.⁸⁴ The court rejected the argument that withdrawing treatment was a form of suicide.⁸⁵ Finding Bouvia competent and that tube-feeding was a form of medical treatment, the court emphasized the importance of the right to self-determination:

Elizabeth Bouvia's decision to forego medical treatment or life-support through a mechanical means belongs to her. It is not a medical decision for her physicians to make. Neither is it a legal question whose soundness is to be resolved by lawyers or judges. It is not a conditional right subject to approval by ethics committees or courts of law. It is a moral and philosophical decision that, being a competent adult, is hers alone.⁸⁶

After detailing the physical elements of Bouvia's disability, the court further explained that it would be "monstrous" to extend her life.⁸⁷ The court also explained that Bouvia's decision that her life had no meaning was reasonable: "Her mind and spirit may be free to take great flights but she herself is imprisoned, and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness."⁸⁸ Thus, the judge asserted that disability had ruined Bouvia's life: "Such life has been physically destroyed and its quality, dignity and purpose [are] gone."⁸⁹

83. *See id.*

84. *See id.* at 307. Elizabeth Bouvia chose not to end her life after the court granted her wish to die. She explained her decision during a *60 Minutes* segment broadcast on September 7, 1997:

Mike Wallace: (voiceover) After several attempt[s] at starvation, Elizabeth told us, it just became physically too difficult to do. She didn't want to die a slow, agonizing death, nor to do it in the spotlight of public scrutiny. And she told us, with great regret, she quietly chose to live.

Ms. Bouvia: Starvation is not an easy way to go.

Wallace: Oh, no.

Ms. Bouvia: You can't just keep doing it and keep doing it. It really messes up your body. And my body was already messed up.

JERRY MENIKOFF, *LAW AND BIOETHICS: AN INTRODUCTION* 262 (Geo. Univ. Press 2001).

85. *See Bouvia*, 225 Cal. Rptr. at 305–06.

86. *Id.* at 305.

87. *Id.*

88. *Id.*

89. *Id.* Such language is not infrequent in legal cases. In a 1996 decision that supported physician-assisted suicide, the U.S. Court of Appeals for the Ninth Circuit portrayed life with disabilities as hopeless by referring to people with physical impairments as existing in "a childlike state of helplessness" exemplified by physical immobility or by their use of diapers to deal with incontinence. *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); *see also State v. McAfee*, 385 S.E.2d 651, 651 (Ga. 1989) (describing the plaintiff, a ventilator-dependent man who had been needlessly housed in a hospital intensive care unit for months as being "incapable of spontaneous respiration, and . . . dependent upon a ventilator to breathe" and stating that, "[a]ccording to the record, there is no hope that Mr. McAfee's condition will improve with time, nor is there any known medical treatment which can improve his condition").

What the judge did not mention was the context of the case.⁹⁰ Bouvia had been a graduate student, and she had been kicked out of school because, according to the dean, the school could not handle the difficulty of dealing with a student who had her physical conditions.⁹¹ On top of that, Bouvia's husband had left her. She had lost her house and had a miscarriage.⁹² There were many difficult things happening in Bouvia's life that made her life seem hopeless, but none of them were her disability. She lived a full and rewarding life with the disability for many years.

Thus the *Bouvia* case rests on and perpetuates faulty assumptions about disabilities. Disability scholars and activists recognized the faulty assumptions behind the case long ago.⁹³ But legal scholars and choice-in-dying activists continue to cite the case uncritically for the proposition that individuals have the right to refuse life-sustaining care. A discussion of the *Bouvia* case would be richer if it included the context in which Bouvia found herself, instead of implicitly confirming the humiliation that attends physical disability. As disability scholars point out, it is important to remember that Bouvia did not experience her life as monstrous when she was a graduate student who was married and pregnant. Perhaps a recognition of the context would give rise to a more broadly focused search for solutions—better housing, more social support—as alternatives to medically assisted death.

Recognizing the context surrounding these cases might also diffuse some of the tension between disability activists and choice-in-dying advocates. It was after *Bouvia* that disability scholars and activists started to openly question whether such cases were really about autonomy—a principle cherished by the community—or about a new eugenics.⁹⁴ They argued, “[The nondisabled public] readily concludes that the disabled person's wish to die is reasonable because it agrees with their own preconception that the primary problem for such individuals is the unbearable experience of a permanent disability. . . . If permanent disability is the problem, death is the solution.”⁹⁵ These arguments are the direct precursors to the argument used in opposition to laws that would expand choice in dying: “[W]hen the nondisabled say they want to die, they are labeled as suicidal; if they are disabled, it is treated as ‘natural’ or ‘reasonable.’”⁹⁶

Continued uncritical reliance on *Bouvia* as a seminal case perpetuates this line of argument. Based on principles of autonomy and self-determination, the judge reached the correct decision in *Bouvia* by recognizing the right of individuals to refuse unwanted medical treatment. Yet the assumptions about life with disability on which

90. See Asch, *supra* note 30, at 311.

91. See *id.*

92. See *id.*

93. See *id.*

94. See Stanley S. Herr et al., *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 ISSUES L. & MED. 3, 36 (1992).

95. Carol J. Gill, *Suicide Intervention for Persons with Disabilities: A Lesson in Inequality*, 8 ISSUES L. & MED. 37, 39 (1996).

96. *Compassion in Dying v. Washington*, 49 F.3d 586, 593 (9th Cir. 1995).

the decision rested are flawed. One step toward changing the legal and medical systems to better respect persons with disabilities would be to question such assumptions about the tragedy of life with disability. Becoming familiar with the teachings of disability experts would go a long way toward broadening our understanding of life with disability and its many possibilities. Perhaps it is also time to look for a different paradigm case.

In order to develop the skills and knowledge needed to question (mis)assumptions about life with disability that alienate disability activists, it will be necessary to better educate medical and legal professionals about disability issues and about the way that people with disabilities value their own lives (i.e., develop cultural competencies in disability).⁹⁷ There is also a need to diversify the health care workforce to increase the number of physicians with disabilities so that the population of medical providers better reflects the general population, and so that persons with disabilities see individuals like themselves as part of the health care system.⁹⁸ And, while contentious, it is likely necessary that advocates for choice in dying will need to work together with disability advocates and listen more closely to their concerns about end-of-life cases.

V. CONCLUSION

End-of-life issues take place in the broad context of people's lives. Recognizing that the lived experience of people with disabilities often includes negative encounters and discrimination in the health care system may help to explain why conversations about expanding choice-in-dying laws are so difficult for many disability advocates. The fierce opposition by disability advocates to laws that would expand choice in dying will likely continue so long as such laws depend upon a health care system that has not proven itself trustworthy. Developing an inclusive health care system in which all participants deeply understand disability-related issues and work together against disability discrimination will help engender the trust necessary for a system that provides options at the end of life. At minimum, that understanding will help make room for constructive conversation by bringing disability advocates to the table. By respecting the lives that able-bodied and disabled individuals live, choice-in-dying advocates will be better able to expand laws that allow for respectful deaths.

97. As disability scholar Lennard Davis notes, "[T]o be ignorant of disability studies is simply to be ignorant." LENNARD J. DAVIS, *THE DISABILITY STUDIES READER*, at xii (Routledge 3d ed. 2010).

98. See Alcia R. Ouellette, *Patients to Peers: Barriers and Opportunities for Doctors with Disabilities*, 13 *NEV. L.J.* 645 (2013), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2147902.