

**NEW YORK
LAW SCHOOL**

NYLS Law Review

Vols. 22-63 (1976-2019)

Volume 58

Issue 2 *Freedom of Choice at the End of Life:
Patients' Rights in a Shifting Legal and Political
Landscape*

Article 1

January 2013

Introduction

PETER J. STRAUSS

Distinguished Adjunct Professor of Law and Co-Director of the Elder Law Clinic at New York Law School

Follow this and additional works at: https://digitalcommons.nyls.edu/nyls_law_review



Part of the [Bioethics and Medical Ethics Commons](#), [Elder Law Commons](#), and the [Health Law and Policy Commons](#)

Recommended Citation

PETER J. STRAUSS, *Introduction*, 58 N.Y.L. SCH. L. REV. (2013-2014).

This Article is brought to you for free and open access by DigitalCommons@NYLS. It has been accepted for inclusion in NYLS Law Review by an authorized editor of DigitalCommons@NYLS.

PETER J. STRAUSS

Introduction

58 N.Y.L. SCH. L. REV. 233 (2013–2014)

ABOUT THE AUTHOR: Peter J. Strauss is a Distinguished Adjunct Professor of Law and Co-Director of the Elder Law Clinic at New York Law School. He is also a partner at Epstein Becker & Green, P.C.

INTRODUCTION

In the autumn of 1979, my mother killed the cats. We had seven; one morning, she grabbed four, took them to the vet and had them put to sleep. She said she didn't want to feed them anymore. It occurred to me that she might be going mad.¹

So Marion Roach began her powerful and provocative article, *Another Name for Madness*, in the Sunday magazine section of the *New York Times* on January 16, 1983.² The article detailed Ms. Roach's mother's struggles with Alzheimer's disease, and how her mother's illness had affected the Roach family.³

I first met Ms. Roach in 1981, a few years after I had changed the direction of my law practice from traditional estate planning to dealing primarily with the legal problems of aging and later life—an area of law that became known as “elder law” in the mid-1980s.⁴ I provided advice to the members of the Roach family as the Roaches began the difficult process of making legal arrangements for the care and support of Ms. Roach's Alzheimer's-afflicted mother.⁵

-
1. See Marion Roach, *Another Name for Madness*, N.Y. TIMES MAG. (Jan. 16, 1983), <http://www.nytimes.com/1983/01/16/magazine/another-name-for-madness.html>.
 2. Ms. Roach later published a similarly titled book that expanded on her January 1983 article. See MARION ROACH, *ANOTHER NAME FOR MADNESS* 195 (1985) (discussing the author's professional interactions with the Roach family).
 3. In 1980, the over-sixty-five population in the United States was approximately twenty-five million (11%), compared to today's over-sixty-five population, which is roughly forty million (13%). CARRIE A. WERNER, U.S. CENSUS BUREAU, *THE OLDER POPULATION: 2010* 3 (2011), available at <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>. Between 2000 and 2010, the eighty-five to ninety-four age group saw the fastest growth of any age group in that decade. *Id.* at 4. Alzheimer's disease most frequently affects older persons; younger persons such as Ms. Roach's mother, who was fifty-four years old when the disease struck her, do suffer from Alzheimer's disease, but the under-sixty-five cohort comprises roughly 4% of sufferers, while approximately one-third of persons aged eighty-five or older have the disease. ALZHEIMER'S ASS'N, *2013 ALZHEIMER'S DISEASE FACTS AND FIGURES* 15 (2013), available at http://www.alz.org/downloads/facts_figures_2013.pdf. Perhaps it is because the over-sixty-five population in the United States was significantly lower in the early 1980s than in the years that followed that the incidence of the disease was not as noticeable then as it has been in more recent years. From my perspective, in 1980 Alzheimer's disease was an “orphan” illness and individuals who had significant cognitive loss were often misdiagnosed as suffering from “hardening of the arteries” or multi-infarct dementia. Little money was being spent on understanding or researching Alzheimer's disease.
 4. Ms. Roach visited me to discuss how to manage her mother's financial affairs, how to ensure her mother would receive proper medical care, and how to pay for the significant long-term care expenses (which included determining whether the Medicaid program might be an available resource). Other major concerns of Ms. Roach's related to decisionmaking for her mother at the end of her life were: How would her mother's wishes be implemented? Would the health care providers honor those wishes? What did the law say about Marion's rights to enforce those wishes? In my experience, the issues raised in the Roach case are typical of the problems that elder law attorneys face.
 5. The threshold question in many cases presented to the elder law practitioner is “Who is the client?” This is particularly true when the older person has diminished cognitive capacity. Is the client the spouse? The children? The older person with the medical issues? All of them? For an overview of various differing opinions and suggested best practices concerning this issue, see generally MODEL RULES OF PROF'L CONDUCT R. 1.6, R 1.7, R 1.14 (1983); PROFESSIONALISM & ETHICS COMM. OF THE NAT'L ACAD. OF ELDER LAW ATTORNEYS, *ASPIRATIONAL STANDARDS FOR THE PRACTICE OF ELDER LAW WITH COMMENTARIES* (2005), available at http://www.naela.org/App_Themes/Public/PDF/

As I soon learned from working with the Roach family and other clients who sought my counsel after I began focusing on elder law, “later life” often meant “end of life,” with these clients in desperate need of advice about the legal and practical issues they were facing as they made health care decisions for family members who had diminished quality of life or were at the end of life.

Elder law attorneys like to say that this new area of the law has turned the focus of legal services from planning for the disposition of a person’s assets at death to the problems attendant to disposing of assets during one’s life. How should the financial affairs of a person who is incapacitated be managed? Is a guardianship necessary? Who decides where an incapacitated person will reside? How is incapacity to be determined? How is the cost of chronic care to be financed? Is this cost to be an individual responsibility or should taxpayer-funded public health care initiatives be expanded to cover long-term care expenses?

Articles like Ms. Roach’s helped make the nation aware that a large segment of the population was alive but with diminished physical and mental capacity—a group with significantly diminished quality of life who could no longer care for themselves nor express their wishes, particularly about the kind of medical care and treatment they would want, or would wish to forgo, at the end of life. Recent census figures show that 50% of persons over the age of eighty-five have limited functioning and need assistance with performing the activities of daily living.⁶ How to make end-of-life decisions for such persons is no longer a purely theoretical exercise.

As I became more involved in end-of-life and “right-to-die” issues (I joined the Board of Directors of the Society for the Right to Die, later known as Choice in Dying after a merger with Concern for Dying), society too began to discuss and debate issues about death, dying, and individual rights at the end of life. Meanwhile, the courts began to deal with more cases that touched on these issues.⁷

The legal debate over individual rights to control one’s life and death can be traced back to Justice Benjamin Cardozo’s statement in the *Schloendorff v. Society of the New York Hospital* opinion, written in 1914 when he sat on the New York Court of Appeals, that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body”⁸ However, U.S. courts then took a long vacation from dealing with end-of-life issues—a vacation that ended with the 1976 New Jersey Supreme Court decision in *In re Quinlan*.⁹

Essentially, the *Quinlan* court held that a person’s right to refuse unwanted medical treatment—a constitutionally protected interest—was not surrendered as a

Media/AspirationalStandards.pdf; Stuart D. Zimring, *Ethical Issues in Representing Seniors, Persons with Disabilities and Their Families*, 4 NAT’L ACAD. ELDER L. ATT’YS J. 125 (2008).

6. U.S. CENSUS BUREAU, SIXTY-FIVE PLUS IN THE UNITED STATES (1995), available at http://www.census.gov/prod/1/statbrief/sb95_8.pdf.

7. See *Washington v. Glucksberg*, 521 U.S. 702, 719 (1997).

8. 211 N.Y. 125, 129 (1914). The phrase “of . . . sound mind” is relevant to a number of the ideas and concerns discussed in the various articles in this publication.

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

INTRODUCTION

result of a person's incapacity, but rather, that a person's wishes could be expressed and enforced by another person in appropriate circumstances.¹⁰ This concept—that a close family member may make a “substituted judgment”¹¹ decision about treatment to be provided or not—was vigorously debated over the succeeding years and, in time, many states came to accept some form of substituted judgment.¹²

New York's jurisprudence, however, initially took a different track, rejecting the substituted judgment approach for a strict test requiring *clear and convincing evidence* of a patient's wishes. As discussed in his luncheon presentation at the symposium that gave rise to this publication, former New York Court of Appeals Chief Judge Sol Wachtler, whose paper is published in this issue, wrote the 1980 opinion in the companion cases *In re Storar*¹³ and *Eichner v. Dillon*,¹⁴ which rejected the concept of substituted judgment and instead imposed the clear and convincing evidence rule.

These decisions held that while a patient's common law right to refuse life-sustaining treatment was paramount to the physician's duty to provide medical care, the evidence of the patient's wishes to forgo treatment must be established by clear and convincing evidence; no “substituted judgment” or “best interests” test could

10. *See id.* at 661–64.

11. As its name suggests, “substituted judgment” means that the surrogate decisionmaker—whether a guardian, a conservator, an agent under a health care proxy, or some other person authorized to make health care decisions on behalf of a particular patient—must, when possible, make end-of-life decisions on behalf of the patient that are in accordance with the known wishes of the patient; it does not mean that the decisionmaker substitutes her or his values and beliefs for those of the patient. Under many states' laws, the surrogate decisionmaker must try to ascertain what the patient would have decided if able to communicate a decision. If the surrogate decisionmaker is unable to make such a decision, the law generally allows him or her to follow a “best interests” standard. For example, under New York's Health Care Proxy Law, the agent must make decisions “in accordance with the principal's wishes, including the principal's religious and moral beliefs, or, if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests” N.Y. PUB. HEALTH LAW § 2982(2)(a)–(b) (McKinney 2013). New York's Family Health Care Decisions Act, adopted in 2010, states that “the surrogate shall make health care decisions: (i) in accordance with the patient's wishes, including the patient's religious and moral beliefs; or (ii) if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the patient's best interests.” N.Y. PUB. HEALTH LAW § 2994-d(4) (McKinney 2013). The New York law governing guardianships permits guardians to make treatment decisions according to the decisionmaking standard set forth in section 2994-d(4). N.Y. MENTAL HYG. LAW § 81.22(a)(8) (McKinney 2013). These statutes clearly distinguish between the substituted-judgment approach and a best-interests one.

12. “Many States, for example, now permit ‘living wills,’ surrogate health-care decisionmaking, and the withdrawal or refusal of life-sustaining medical treatment.” *Glucksberg*, 521 U.S. at 716. *See also* Alan Meisel, *End-of-Life Care*, in *FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS* 51–54 (Mary Crowley ed., 2008) (“When individuals have not made manifest their decisions about medical care, the ethical and legal protocol is to implement a person's presumed wishes through a doctrine known as ‘substituted judgment.’ Under this doctrine, a surrogate must make decisions for a patient. If the patient has not appointed a surrogate in an advance directive, close family members are ethically and legally empowered to make decisions for the patient.”).

13. 52 N.Y.2d 363 (1981).

14. *See id.*

suffice.¹⁵ The court found that while the evidence of the wishes of Brother Joseph Fox (the patient in *Eichner*), had met the clear and convincing evidence test, the evidence concerning John Storar (the patient in the companion case), had not.¹⁶

I was deeply distressed by the *Storar* decision. John Storar was a fifty-two-year-old man who was profoundly mentally retarded.¹⁷ He had undergone radiation for bladder cancer that metastasized to his lungs, with probable metastasis to his liver and brain as well.¹⁸ He was receiving blood transfusions because of bladder bleeding; his mother—who was his court-appointed guardian—refused to consent to further transfusions, prompting the hospital to seek a court order allowing continuation of the transfusions.¹⁹ The Court of Appeals decided that the treatment had to be continued because, since Mr. Storar had been retarded from birth, he could never have expressed his wishes regarding the treatment; thus, the clear and convincing evidence test could not, by definition, be met.²⁰ The court failed to see that the effect of its decision was to discriminate against a “never competent” person, thus emasculating the right to refuse medical treatment at the end of life for such persons.

There was relatively little guidance from the New York courts in the first few years after the decision in *Eichner* and *Storar* as to what would constitute “clear and convincing” evidence. So when Selma Alderson retained me in 1985 to seek a court order permitting withdrawal of all medical treatment for her partner, Paxson Kimbrough—a man who had suffered a traumatic brain injury during an assault and who lay in a hospital bed in their apartment in a persistent vegetative state, sustained by a nasogastric feeding tube—I prepared for trial with few guideposts.

I tried the case before then-Justice C. Beauchamp Ciparick, a judge of the New York State Supreme Court (New York’s trial court of general jurisdiction) for New York County. Justice Ciparick²¹ found that the evidence I had introduced regarding Mr. Kimbrough’s wishes failed to meet the clear and convincing evidence standard; she denied the application to withdraw the feeding tube and to cease other treatment.²² A reading of the decision will demonstrate how difficult it was at this time for residents of New York to make reasonable and rational decisions about life-sustaining treatment, such as artificial nutrition and hydration, at the end of life. Justice Ciparick, in denying Ms. Alderson’s application, wrote that “[i]t is . . . inappropriate for the court to allow the family, guardian, conservator, or other third

15. *Id.* at 378–79.

16. *See id.* at 380.

17. *See id.* at 373.

18. *See id.* at 373–74; *In re Storar*, 433 N.Y.S.2d 388, 391 (Sup. Ct. Monroe Cnty. 1980) (describing medical experts’ testimony on the extent of metastasis), *rev’d*, 52 N.Y.2d 363 (1981).

19. *See In re Storar*, 52 N.Y.2d at 373–74.

20. *See id.* at 380–82.

21. Justice Ciparick became Judge Ciparick in 1993, when she was appointed to the New York Court of Appeals, New York’s highest appellate court. *See Honorable Carmen Beauchamp Ciparick*, N.Y. CT. OF APPEALS, <http://www.nycourts.gov/ctapps/JCiparick.htm> (last visited Dec. 30, 2013).

22. *See In re Alderson*, No. 90193/86, slip op. at 23–25 (Sup. Ct. N.Y. Cnty. Aug. 19, 1988).

INTRODUCTION

party to make such a decision [to withdraw treatment] for the patient or for the court to make the decision itself.”²³

In effect, the New York clear and convincing evidence rule perpetuated the authority of the state over the patient and the patient’s surrogate decisionmakers to make end-of-life decisions. In the struggle between autonomy and paternalism, the state was the victor. Even in the absence of bad faith,²⁴ a rule of evidence prevailed over well-meaning and caring persons who knew the wishes of the patient far better than the judges who crafted the rule.

In other states, the pendulum had swung to placing decisionmaking power in the hands of the patient or the patient’s representative. This shift in the nature of end-of-life decisionmaking worked well, except in cases in which conservative voices would rouse the media and politicians to intervene, as occurred in the case of Terry Schiavo, which captured news headlines in 2005.²⁵

The clear and convincing evidence rule remained the law in New York until 2010, when, after seventeen years of debate, the New York legislature passed the Family Health Care Decisions Act, thereby bringing New York in line with states that had accepted some form of substituted judgment. There had already been some movement to soften the rigid effects of the New York rule. The New York legislature had authorized limited substituted judgment with respect to do-not-resuscitate orders in 1987,²⁶ and, by enacting the Health Care Proxy Law in 1990, gave a health care agent the right to make substituted-judgment and best-interests decisions.²⁷

New York’s legislature allowed substituted-judgment and best-interests decisions to be made for mentally retarded persons in 2003,²⁸ thus specifically overturning the *Storar* decision. Fortunately, New York (for the most part) has joined the mainstream as a result of the passage of the Family Health Care Decisions Act in 2010, which allowed a surrogate to make end-of-life decisions.

I began teaching the elder law course at New York Law School in 1992. Health care decisionmaking and end-of-life issues have been a major part of the course curriculum. While my students recognize that American jurisprudence has accepted

23. *Id.* at 24.

24. Justice Ciparick also wrote in *Alderson* that “[t]he court truly sympathizes with the plight of Paxson Kimbrough and his loved ones. They have shown him nothing but intense devotion by bringing him back home and lavishing care upon him.” *Id.* at 25.

25. Sherrie Dulworth’s article in this publication examines the media reporting on the Schiavo case. See Sherrie Dulworth, *From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion*, 58 N.Y.L. SCH. L. REV. 391 (2013–2014).

26. See Act effective Apr. 1, 1988, ch. 818, 1987 N.Y. Laws 3140, 3143–46 (codified at N.Y. PUB. HEALTH LAW §§ 2960–66 (McKinney 2013)).

27. See New York Health Care Proxy Law, ch. 752, 1990 N.Y. Laws 3547 (codified at N.Y. PUB. HEALTH LAW §§ 2980–94 (McKinney 2013)).

28. See Act effective Mar. 16, 2003, ch. 500, § 3, 2002 N.Y. Laws 3376 (codified at N.Y. SURR. CT. PROC. ACT § 1750-b (McKinney 2013)). The law was expanded to include persons with developmental disabilities two years later. See Act effective Oct. 11, 2005, ch. 744, sec. 1(2), § 1750-a(2), 2005 N.Y. Laws 3585, 3585 (codified as amended at N.Y. SURR. CT. PROC. ACT § 1750-a (McKinney 2013)).

the principle that a patient enjoys the right to refuse unwanted treatment, and that such a right is not lost when a patient loses decisional capacity, lively classroom discussions have highlighted the many areas in which the law is unclear, is in dispute, or has not addressed frequent violations of patients' rights.

The idea for the symposium held at New York Law School on November 16, 2012,²⁹ grew out of my experience as an elder law attorney, my service as a board member of not-for-profit organizations engaged in advocacy with respect to end-of-life issues, and my teaching career. I was delighted when the editors and the publisher of the *New York Law School Law Review* agreed to sponsor the symposium, and I embarked on a year-long task of developing the program for the symposium, assisting the able administrative staff, working with the *Law Review* publisher and student editors, and assembling speakers who would, in my view, be able to articulate the end-of-life issues America faces and to contribute to positive movement towards solutions.

The symposium addressed many of the critical issues of today, and, to some extent, the participants commented on these issues in their papers published in this issue of the *Law Review*.

Kathryn Tucker, Esq., Director of Legal Affairs for Compassion & Choices, presented the keynote address, in which she addressed aid in dying, a practice that the nation has not yet come to grips with, notwithstanding the widespread public acceptance of it as a fundamental right. Ms. Tucker also presented her views about the future of end-of-life decisionmaking in general, including palliative care and "voluntary stopping eating and drinking" (VSED). In her paper, *Give Me Liberty at My Death: Expanding End-of-Life Choices in Massachusetts*,³⁰ Ms. Tucker discusses these issues and focuses in particular on the 2012 legislative referendum in Massachusetts to legalize aid in dying that was narrowly defeated; she presents the position that, at least in states that do not expressly criminalize aid in dying, it might nonetheless be legal under existing common law as being consistent with best medical practices (meaning that physicians who engage in this practice would not be subject to criminal prosecution).

Other symposium speakers addressed the widespread problem of health care providers improperly extending unwanted medical treatment, thus failing to honor patient choices even when they have been clearly expressed in a "living will," by unambiguous oral statements, or through the instructions of a health care agent or surrogate. Lisa Comeau, Esq., a New York appellate attorney who represented the family in one of the leading cases holding that there is no tort of "wrongful living,"³¹ discussed the extent of this problem and what remedies for it currently exist. Professor

29. *Freedom of Choice at the End of Life: Patient's Rights in a Shifting Legal and Political Landscape*. Video recordings of the symposium are available at <http://www.nylslawreview.com/freedom-of-choice-at-the-end-of-life-videos/>.

30. Kathryn Tucker, *Give Me Liberty at My Death: Expanding End-of-Life Choices in Massachusetts*, 58 N.Y.L. SCH. L. REV. 259 (2013–2014).

31. *See Cronin v. Jamaica Hosp. Med. Ctr.*, 875 N.Y.S.2d 222, 223 (2d Dep't 2009).

INTRODUCTION

Nadia N. Sawicki³² participated in this discussion at the symposium; in her article published here, *A New Life for Wrongful Living*,³³ she argues for and offers “an ultimately optimistic view about the viability of tort claims for wrongful prolongation of life” as the remedy for failure to follow patient decisions.

Rev. Dr. Martha R. Jacobs³⁴ discussed the effect of religion on public policy, practice, and legislation affecting end-of-life decisions, and offered some thoughts on how to find a fair balance between the rights and wishes of patients and religious doctrine that often causes hospitals to adopt policies that override those rights and wishes. Ann Neumann³⁵ also discussed the interplay between religion and end-of-life issues, and in her paper presented here, *The Limits of Autonomy: Force-Feedings in Catholic Hospitals and in Prisons*,³⁶ she presents her views on how individual rights are affected by religious values and sociological attitudes.

Speakers at the symposium also commented on the fairness of current laws in Oregon³⁷ and Washington,³⁸ two states whose legislatures have adopted³⁹ physician-provided aid in dying by statute, and in Montana, where the practice is now legal by virtue of a ruling by Montana’s Supreme Court that allows patients to obtain lethal medication from physicians. However, in all three states such assistance is only permitted when the patient is expected to die within several months. Assistance may not be provided to persons who suffer from long-term illnesses and are not deemed to be at risk of dying in the immediate future—for example, Alzheimer’s disease, Parkinson’s disease, or Lou Gehrig’s disease (amyotrophic lateral sclerosis (ALS)).⁴⁰

A few of the speakers weighed the propriety of laws allowing aid in dying that require the consent of a person with capacity to give informed consent in order for a physician to prescribe lethal medication, but that do not allow aid in dying for a person who is no longer able to give informed consent but had provided such consent in an advance directive executed when the person did have full capacity. Professors

32. Nadia N. Sawicki is an Assistant Professor of Law in the Beazley Institute for Health Law & Policy at Loyola University Chicago School of Law.

33. Nadia N. Sawicki, *A New Life for Wrongful Living*, 58 N.Y.L. SCH. L. REV. 279 (2013–2014).

34. Rev. Dr. Martha R. Jacobs is an Adjunct Professor at New York Theological Seminary, and a Per Diem Chaplain for New York-Presbyterian Hospital.

35. Ann Neumann is the Editor of the *Revealer*, published by the Center for Religion and Media at New York University.

36. Ann Neumann, *The Limits of Autonomy: Force-Feedings in Catholic Hospitals and in Prisons*, 58 N.Y.L. SCH. L. REV. 305 (2013–2014).

37. See Oregon Death with Dignity Act, ch. 3, 1995 Or. Laws 12 (codified at OR. REV. STAT. ANN. §§ 127.800–897 (West 2013)).

38. See Washington Death with Dignity Act, ch. 1, 2009 Wash. Sess. Laws 1 (codified at WASH. REV. CODE ANN. §§ 70.245.010–904 (West 2013)).

39. In May 2013, Vermont’s governor signed into law an end-of-life bill passed by the state’s legislature. See generally Patient Choice and Control at End of Life Act, VT. STAT. ANN. tit. 18, § 5289 (West 2013).

40. See, e.g., *Baxter v. State*, 224 P.3d 1211, 1215–25 (Mont. 2009).

Paul T. Menzel⁴¹ and Bonnie Steinbock⁴² spoke to this issue at the symposium, and Professor Menzel addresses this issue in his article, *Advance Directives, Dementia, and Eligibility for Physician-Assisted Death*,⁴³ arguing forcefully “that through clear, informed, and persistent advance directives, people should be allowed to direct their future deaths in the event of severe dementia” and that “[n]either current competency, terminal illness, nor unbearable suffering should be retained as strict qualifying conditions” for legalized aid in dying.⁴⁴

Professor Menzel also addresses the issue of whether the wishes of a now-incapacitated patient that had been clearly expressed prior to the loss of the ability to provide informed consent—as a result of advanced dementia or stroke, for example—should always be honored, even when an appropriate surrogate decisionmaker (a guardian, health care agent, or other statutory surrogate) concludes it is in the patient’s best interests not to do so. Should law and public policy require that the prior expressed wishes of the patient always prevail, or should such prior statements be discarded in favor of some current belief about what is “good” for the patient?

Professor Thaddeus Mason Pope,⁴⁵ among other speakers, considered the issue of “medical futility,” a term used to describe situations in which a physician believes medical treatment has no value and wishes to discontinue it, but the patient—through his or her surrogate decisionmaker—insists on continuation. Professor Pope analyzes this issue and presents some proposals for dispute resolution in his article, *Dispute Resolution Mechanisms for Intractable Medical Futility Disputes*.⁴⁶

The symposium also looked at the concerns of certain persons with disabilities who believe that end-of-life advocacy organizations merely perpetuate societal refusal to provide adequate protections and services for them. Balancing the valid concerns of persons with disabilities with end-of-life advocacy is challenging.⁴⁷ Professor Alicia Ouellette⁴⁸ addresses this tension and offers some approaches in her article, *Context Matters: Disability, the End of Life, and Why the Conversation Is Still So Difficult*.⁴⁹

41. Paul T. Menzel is a Professor of Philosophy Emeritus at Pacific Lutheran University.

42. Bonnie Steinbock is a Professor of Philosophy at University at Albany, State University of New York.

43. Paul T. Menzel, *Advance Directives, Dementia, and Eligibility for Physician-Assisted Death*, 58 N.Y.L. SCH. L. REV. 321 (2013–2014).

44. *Id.* at 323.

45. Thaddeus Mason Pope is Director of the Health Law Institute and an Associate Professor of Law at Hamline University.

46. Thaddeus Mason Pope, *Dispute Resolution Mechanisms for Intractable Medical Disputes*, 58 N.Y.L. SCH. L. REV. 347 (2013–2014).

47. Persons with disabilities from the organization Not Dead Yet picketed outside of the conference room where the symposium was being held.

48. Alicia Ouellette is Associate Dean for Faculty Research and Professional Development, and a Professor of Law, at Albany Law School.

49. In her article, Professor Ouellette references the picketing outside the symposium that was conducted by several members of Not Dead Yet. See 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 (2013–2014).

INTRODUCTION

Sherrie Dulworth, R.N.,⁵⁰ discussed media treatment of end-of-life issues and the effect of reporting on public attitudes, policy, and outcomes. In her paper presented here, *From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion*, she demonstrates how this occurs by examining three particular situations.⁵¹

David Muller, M.D.,⁵² discussed the current state of medical practice in many areas of end-of-life decisionmaking from a clinical perspective. David C. Leven⁵³ discussed the current level of public education about end-of-life decisionmaking and how to improve public awareness and education about people's rights, how to convince people to discuss end-of-life issues with their family members, and how to teach them to take steps to control their lives. Mr. Leven also addressed issues of physician education and recent legislation in New York dealing with these issues, and discussed how we should go about educating physicians and hospitals so that they better understand the needs of an aging population and accept that honoring patient's rights is encompassed in patient-centered medicine. Mr. Leven explores these questions in his article, *Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action*.⁵⁴

Another topic considered during the symposium was the question of how the rights of incarcerated persons should be treated at the end of life. Commissioner Brian Fischer of the New York State Department of Corrections and Community Supervision (DOCCS), and DOCCS Deputy Commissioner and Chief Medical Officer Carl J. Koenigsmann, addressed this issue and presented DOCCS's position that prisoners' rights at the end of life are respected in New York.

The central theme of the symposium revolved around the question of how we treat America's growing aging society, particularly the "oldest old." Our approaches to this issue illuminate our morality and ethics as a nation. Law, ethics, medicine, science, and religion all have rules and values that intersect and influence public policy. Crafting a fair and just resolution for end-of-life issues that will be consistent with our democratic values will require the participation of all of these cohorts. I am confident that, after reading the papers published here, the readers will agree that the symposium has made a meaningful contribution to the kind of debate that Chief Justice William Rehnquist referred to when he wrote, in the U.S. Supreme Court's most widely read opinion on the issue of aid in dying: "Throughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. . . . [T]his debate [will] continue, as it should in a democratic society."⁵⁵

50. Sherrie Dulworth is a registered nurse by training, a health care management consultant, and a freelance reporter.

51. See Dulworth, *supra* note 25.

52. Dr. David Muller is a Professor of Medicine and Dean for Medical Education at Mount Sinai School of Medicine. Dr. Muller co-founded his hospital's Visiting Doctors Program.

53. David C. Leven is Executive Director of Compassion & Choices of New York.

54. David C. Leven, *Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action*, 58 N.Y.L. SCH. L. REV. 403 (2013–2014).

55. *Washington v. Glucksberg*, 521 U.S. 702, 735 (1997).

