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Michael A. Refolo

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THE PATIENT SELF-DETERMINATION ACT OF 1990: HEALTH CARE'S OWN MIRANDA

Birth and death are the most singular events we experience and, therefore, the contemplation of death should be a thing of beauty and not of ignobility.¹

By 1985, only fifteen percent of the population had written advance directives² pertaining to future health care decision-making.³ These advance directives take several forms, with the most limited being the living will.⁴ Living wills allow individuals, prior to incompetency, to dictate the specific treatments they would accept under certain situations and conditions.⁵ Living will statutes, however, are often limited to situations when death is imminent, and therefore, the statutes do not protect patients from all unwanted treatment.⁶ Living wills may be used to request treatment as well as refuse

1. HOUSE SELECT COMM. ON AGING, 99TH CONG., 1ST SESS., *DYING WITH DIGNITY: DIFFICULT TIMES, DIFFICULT CHOICES* 5-6 (Comm. Print 1985) (statement of former Senator Jacob Javits (R-N.Y.)).

2. Advance directives may be broadly defined as "any statement made by an individual, while competent, of the individual's preferences for any treatment decision, or for the process of decision-making, in the event the person loses the ability to make decisions." AMERICAN BAR ASS'N, COMM'N ON LEGAL PROBLEMS OF THE ELDERLY, *PATIENT SELF-DETERMINATION ACT STATE LAW GUIDE* 16 (1991) [hereinafter A.B.A. COMMISSION]. The Patient Self-Determination Act (PSDA), however, narrows this general definition to any "written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of . . . [health] care when the individual is incapacitated." Pub. L. No. 101-508, §§ 4206(a), 4751(m), 104 Stat. 1388-116, 1388-205 (1990) (to be codified at 42 U.S.C. §§ 1395, 1396). Accordingly, informal instructions made orally by individuals to doctors, family, or friends are not promoted by PSDA.

3. See *Fiscal Year 1991 Reconciliation Issues Relating to Durable Medical Equipment, Clinical Laboratory Services, and Other Issues Under the Medicare Program: Hearing Before the Subcomm. On Health of the Comm. on Ways and Means*, 101st Cong., 2nd Sess. 81-82 (1990) [hereinafter *Reconciliation Issues Hearing*] (statement of Ezekiel J. Emanuel, M.D., Ph.D., Harvard University Medical School). Dr. Emanuel based his estimate on a study conducted in 1985. The study found that despite the fact that 90% of patients and the general public desire advance directives, only 15% actively completed a document, appointed a proxy, or had a formal discussion of terminal care decisions with their physician. *Id.* Another study found that between 4% and 17.5% of adults have completed an advance directive. John La Puma et. al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402, 402 (1991).

4. See generally, David Orentlicher, *Advance Medical Directives*, 263 JAMA 2365, 2365-66 (1990).

5. *Id.* at 2365.

6. *Id.* See, e.g., ILL. ANN. STAT. ch. 110 1/2, para. 702 (Smith-Hurd Supp. 1991) (stat-

it,⁷ but state law dictates the terms of the document,⁸ thereby limiting its scope.⁹ The documents' primary deficiency is that in many instances the living will fails to guide families or medical providers, who wish to consider the patient's interests regarding treatment.¹⁰

Another form of advance directive allows individuals to designate a proxy who may be authorized to make health care decisions when events occur that are outside the specific conditions stated in the living will document or in a health care durable power of attorney.¹¹ A health care power of attorney is a relatively new variation of the traditional durable power of attorney forms, used solely to appoint proxies for property management and transactions.¹² Due to the existence of traditional power of attorneys, there is much debate among courts as to whether separate health care power of attorney forms are necessary.¹³ Those opposed to their use are concerned that the forms may be too ambiguous and therefore inadequate absent the expressed statutory language delegating medical decision-making powers.¹⁴

Although legislators and scholars acknowledge the increasing usefulness and benefits of advance directives, the majority of the general public fails to

ing that nutrition and hydration shall not be withdrawn if the withdrawal would result in death solely from dehydration or starvation rather than from the existing terminal condition).

7. Tamar Lewin, *Led By Court, Hospitals Take New Interest in Living Wills*, N.Y. TIMES, July 23, 1990, at A1.

8. See A.B.A. COMMISSION, *supra* note 2, at 17.

9. *Living Wills: Hearings on S.1766 Before the Subcomm. On Medicare and Long Term Care of the Committee on Finance, United States Senate*, 101st Cong., 2d Sess. 161 (1990) [hereinafter *Living Wills Hearings*] (statement of the National Legal Center for the Medically Dependent & Disabled, Inc.).

10. See, e.g., Elisabeth Rosenthal, *Filling the Gap Where a Living Will Won't Do*, N.Y. TIMES, Jan. 17, 1991, at B9.

11. *Living Wills Hearings*, *supra* note 9, at 41 (statement of Charles Sabatino, Assistant Director, ABA Commission on Legal Problems of the Elderly of the ABA). *But see The Choice of Not Living a Vegetative Life: Power of Attorney*, N.Y. TIMES, Dec. 23, 1990, at E10 (letter to the editor by Mary K. Goldstein discussing the pitfalls of the durable power of attorney laws). In addition to generally worded power of attorney forms, some commentators advocate a checklist type form or a "values history" type form to determine a declarant's view on quality of life. See, e.g., Linda L. Emanuel & Ezekiel J. Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 261 JAMA 3288 (1989). For a list of the state statutes, see *infra* note 57.

12. See A.B.A. COMMISSION, *supra* note 2, at 19.

13. See, e.g., *In re Peter*, 529 A.2d 419, 426 (N.J. 1987) (stating that New Jersey's general power of attorney statute specifically authorizes conveyance of durable authority to make medical decisions). Additionally, in *Cruzan v. Director, Mo. Dep't of Health*, Justice Sandra Day O'Connor argued that use of the state's general power of attorney as a "procedure[] for surrogate decisionmaking . . . may be a valuable additional safeguard of the patient's interest in directing his medical care." 110 S. Ct. 2841, 2857 (1990) (O'Connor, J., concurring).

14. See A.B.A. COMMISSION, *supra* note 2, at 19.

benefit from these statutes. The Patient Self-Determination Act of 1990¹⁵ (PSDA) attempts to promote the use of advance directives by increasing public awareness about them. The critics argue that the PSDA's goals cannot be achieved by such a simple measure,¹⁶ while the statute's supporters find merit in the PSDA's unique ability to compel states to work for increased awareness of their various advance directive statutes by threatening them with the loss of Medicare and Medicaid funding.¹⁷ This Commentary briefly discusses the PSDA's historical setting and essential components. Next, it explains and responds to the arguments of the statute's critics and discusses the reasons why the PSDA should be endorsed. Finally, this Commentary concludes by suggesting that, in time, the PSDA will be a significant and effective initial piece of legislation promoting the use of advance directives and allowing individuals to control health care decision-making.

I. ACTIONS LEADING UP TO THE PSDA'S PASSAGE

In the time between the PSDA's enactment¹⁸ and its effective date,¹⁹ a book called *Final Exit*,²⁰ which discusses various methods of suicide, became a bestseller.²¹ The book reflects the public's ever-increasing interest in self-determination.²² This interest results from the advances in medical technology which make it possible to keep patients alive by artificial and technological means.²³ It also stems from highly publicized cases over the past fifteen years involving incompetent patients such as Karen Ann Quinlan²⁴ and Nancy Beth Cruzan.²⁵

Medical technology has advanced so dramatically that eighty percent of the reported daily deaths in America are individuals who have been depen-

15. §§ 4206, 4751, 104 Stat. at 1388-115, 1388-205.

16. See *infra* notes 74-113 and accompanying text.

17. See *infra* notes 114-130 and accompanying text.

18. President Bush signed the PSDA into law on November 5, 1990. § 4206, 104 Stat. at 1388-115.

19. The PSDA went into effect on Dec. 1, 1991. § 4206, 104 Stat. at 1388-117.

20. DEREK HUMPHRY, *FINAL EXIT* (1991).

21. *Best Sellers*, WASH. POST, Oct. 27, 1991, (Book World), at 13.

22. For other examples of the public's interest, see Joyce Price, *Suicide Initiative Vote Shows Changing Mood*, WASH. TIMES, Nov. 7, 1991, at A3 (referring to Washington State's failed referendum legalizing euthanasia); Isabel Wilkerson, *Opponents Weigh Action Against Doctor Who Aided Suicides*, N.Y. TIMES, Oct. 25, 1991, at A10 (referring to use of a "suicide machine" by Dr. Jack Kevorkian on critically ill patients).

23. See *infra* notes 26-29 and accompanying text.

24. See *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976).

25. *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841, 2841 (1990). See John K. Gisleson, Commentary, *Right To Die, Forced To Live: Cruzan v. Director, Missouri Department of Health*, 7 J. CONTEMP. HEALTH L. & POL'Y 401 (1991).

dent on respiratory ventilation or artificial tube feeding and hydration.²⁶ Indeed, bodily functions may now be sustained long after many believe the patient is dead.²⁷ This statistic represents a dramatic change from 1939, when just over one-third of the population died in institutional settings such as hospitals and nursing homes.²⁸ Additionally, about eighty percent of the deaths in American institutions occur subsequent to decisions by the patient, family, or medical staff, either individually or collectively, to apply, withhold, or withdraw a medical procedure.²⁹

In 1976, as developments in medical technology forced new interpretations of the definitions of death, the case of Karen Ann Quinlan demonstrated the inadequacy of laws that failed to respond to rapid technological advancement.³⁰ Karen Ann Quinlan was a twenty-two-year-old comatose patient completely dependent upon a respirator which maintained her in a "chronic persistent vegetative state" for an entire year prior to litigation.³¹ Her family urged the court to order the withdrawal of the life support apparatus. The New Jersey Supreme Court ultimately granted the family's request upon the concurrence of her guardian, her attending physicians, and the hospital's ethics committee.³² Recognizing that the parents believed that their daughter would have refused treatment if capable, the court determined that the right to privacy in choosing medical treatment—and the extent of bodily intrusion—should not be discarded merely because the patient is incapable of exercising her rights.³³

Quinlan put New Jersey at the forefront of an ethical and legal dilemma concerning incompetent patients who do not have advance directives or the

26. Andrew H. Malcolm, *A.M.A. Rule: Step Toward A Social Policy on Dying*, N.Y. TIMES, Mar. 17, 1986, at B7. See 136 CONG. REC. E943 (daily ed. Apr. 3, 1990) (statement of Rep. Sander Levin (D-Mich)). See also George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?*, 22 U.C. DAVIS L. REV. 275, 367 (1989); George P. Smith, II, *Death Be Not Proud: Medical, Ethical and Legal Dilemmas in Resource Allocation*, 3 J. CONTEMP. HEALTH L. & POL'Y 47, 51 (1987).

27. 135 CONG. REC. S13,573 (daily ed. Oct. 17, 1989) (statement of Myra J. Christopher, Midwest Bioethics Center).

28. 136 CONG. REC., *supra* note 26, at E943 (statement of Rep. Levin).

29. *Id.* For a general discussion of the removal of nutrient feeding tubes, see Scott E. Squillace, Comment, *Removal of a Nutrient Feeding Tube and the Need for a Living Will*, 3 J. CONTEMP. HEALTH L. & POL'Y 253 (1987).

30. *In re Quinlan*, 355 A.2d 647, 656 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976).

31. *Id.* at 654.

32. *Id.* at 671. The court found that "there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state." *Id.* at 671.

33. *Id.* at 664.

legal option of executing them.³⁴ This dilemma plagued New Jersey and other courts throughout the country.³⁵ Later, the same New Jersey court that decided *Quinlan* faced similar issues in the case of *In re Conroy*.³⁶ Rather than removal of a respirator, *In re Conroy* involved removal of a feeding tube.³⁷ Analogizing between intravenous nourishment and respiratory assistance, the court ordered removal after applying three separate tests.³⁸ The tests allowed withdrawal of treatment if there was trustworthy evidence that the patient would have refused treatment, or if there was evidence of refusal, or if pain and suffering outweighed the benefits that the patient derived from life.³⁹

New Jersey was not alone in facing the need for advance directives. In 1988, for example, a New York court rejected the request of a stroke victim's family by ordering the insertion of a feeding tube into a seventy-seven-year-old patient and refusing to "substitute its judgment as to what would be acceptable quality of life for another."⁴⁰ That same year, a California court held that a patient's conservator could exercise a patient's constitutional and common-law rights to refuse treatment if the decision was made in good faith and if medical experts decided that treatment was necessary.⁴¹

The prevalence of cases involving incompetent patients who had either lost their right to self-determination or had that right severely scrutinized demonstrated a need to increase public awareness about advance directives and further emphasized the need for the enactment of the PSDA.⁴² Unfortunately, despite rapid technological advancement and the increasing number of controversial cases, concerns over the PSDA's potential lack of effectiveness prevented the original 1989 version of the PSDA from making

34. For a brief discussion of New Jersey's role, see Steele Chadwell, *Cruzan Ruling Settles Issues, Raises Others*, 126 N.J. L.J. 10 (1990).

35. *Id.* See *infra* notes 36-48 and accompanying text.

36. 486 A.2d 1209 (N.J. 1985).

37. *Id.*

38. *Id.* at 1231-33.

39. *Id.*

40. *In re Westchester County Medical Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988).

41. *Drabick v. Drabick*, 245 Cal. Rptr. 840, 849 (Ct. App. 1988), *cert. denied*, 488 U.S. 958 (1988).

42. See, e.g., *Gray v. Romeo*, 697 F. Supp. 580 (D. R.I. 1988); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (1986); *McConnell v. Beverly Enterprises-Conn.*, 553 A.2d 596 (Conn. 1989); *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713 (Conn. Super. Ct. 1984); *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989); *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626 (Mass. 1986); *In re Grant*, 747 P.2d 445 (Wash. 1987); *In re Hamlin*, 689 P.2d 1372 (Wash. 1984). For a discussion of one family's amazing but probably not atypical plight, see *Living Wills Hearings*, *supra* note 9, at 91-101 (statement of Julianne Delio). See generally Michael L. Daily, Administrative Comment, *Euthanasia in Maryland: The Right to Die With Dignity?*, 5 J. CONTEMP. HEALTH L. & POL'Y 297 (1989).

it out of committee before the Congress adjourned.⁴³

The Supreme Court's 1990 decision in *Cruzan v. Director, Missouri Department of Health*⁴⁴ turned the enactment of the PSDA bill into a compelling mandate.⁴⁵ Similar to earlier cases, *Cruzan* involved an incompetent patient who had not executed an advance directive.⁴⁶ In this precedential decision, the majority of the Court recognized the right to die.⁴⁷ However, the Court held that the state's interest in the protection of life absent a living will allows it to "apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state."⁴⁸ The clear and convincing evidence standard makes it more difficult for a family to refuse unwanted treatment and makes the use of advance directives all the more essential.

Following the *Cruzan* decision, Senator John Danforth (R-Mo.), a member of the Senate Finance Committee, attached the PSDA to the Omnibus Budget Reconciliation Act (OBRA).⁴⁹ The President signed the acts into law on November 5, 1990.⁵⁰

II. THE PSDA'S ESSENTIAL COMPONENTS

The PSDA is the first significant federal legislation concerning the use of advance directives to control health care treatment and decisions.⁵¹ The purpose of the PSDA is to inform the public about and increase the use of these advance directives.⁵² To achieve these objectives, the PSDA assigns specific functions to the states,⁵³ to any organization eligible for Medicare or Medicaid,⁵⁴ and to the Department of Health and Human Services.⁵⁵

43. Keith White, *Budget Bill Contains Medical Rights Measure*, Gannett News Service, Oct. 29, 1990, available in LEXIS, Nexis Library, Omni File.

44. 110 S. Ct. 2841 (1990).

45. *Living Wills Get Boost From the Lawmakers*, NAT'L L.J., Oct. 29, 1990, at 33; see also 136 CONG. REC. H4,222 (daily ed. June 27, 1990) (statement of Rep. Levin).

46. *Cruzan*, 110 S. Ct. 2841, 2846.

47. The majority agreed that, at the very least, the Due Process Clause provides a constitutional right to die by refusing life-sustaining medical treatment. *Id.* at 2853. However, Justice Sandra Day O'Connor stated more explicitly in her concurrence that "the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water." *Id.* at 2857.

48. *Id.* at 2854.

49. White, *supra* note 43.

50. A.B.A. COMMISSION, *supra* note 2, at 3.

51. *Id.* at 1; See §§ 4206, 4751, 104 Stat. at 1388-115, 1388-204.

52. 136 CONG. REC. E2,190 (daily ed. June 28, 1990) (statement of Rep. Levin).

53. § 4751(a), 104 Stat. at 1388-204.

54. § 4206(a), 104 Stat. at 1388-115.

Under the PSDA, each state must develop a written description of its statutory or judicial law concerning advance directives for dissemination and use by health care providers.⁵⁶ This type of law exists in some form in the vast majority of states.⁵⁷ In addition to developing written descriptions, states must ensure that each health care provider receiving Medicare or

55. § 4751(d), 104 Stat. at 1388-205.

56. § 4751(a), 104 Stat. at 1388-204.

57. At least forty states have living will statutes: ALA. CODE §§ 22-8A-1 to -10 (1975); ALASKA STAT. §§ 18.12.010-12.100 (1991); ARIZ. REV. STAT. ANN. §§ 36-3201 to -3211 (1986 & Supp. 1991); ARK. CODE ANN. §§ 20-17-201 to -218 (Michie 1991); CAL. HEALTH & SAFETY CODE §§ 7185-7194 (West Supp. 1992); COLO. REV. STAT. §§ 15-18-101 to -113 (1987 & Supp. 1991); CONN. GEN. STAT. ANN. §§ 19a-570 to -575 (West Supp. 1990); DEL. CODE ANN. tit. 16, §§ 2501-2508 (1983); D.C. CODE ANN. §§ 6-2421 to -2430 (1989); FLA. STAT. ANN. §§ 765.01-.15 (West 1986 & Supp. 1992); GA. CODE ANN. §§ 31-32-1 to -12 (Michie 1991); HAW. REV. STAT. §§ 327D-1 to -27 (1991); IDAHO CODE §§ 39-4501 to -4508 (1985 & Supp. 1991); ILL. ANN. STAT. ch. 110 1/2, para. 701-710 (Smith-Hurd Supp. 1991); IND. CODE ANN. § 16-8-11-1 (Burns 1990); IOWA CODE ANN. §§ 144A.1-.11 (West 1989); KY. REV. STAT. ANN. §§ 311.622-.644 (Michie/Bobbs-Merrill Supp. 1990); LA. REV. STAT. ANN. §§ 40:1299:58.1-.10 (West Supp. 1991); ME. REV. STAT. ANN. tit. 18A, §§ 5-701 to -714 (West Supp. 1991); MD. HEALTH-GEN. CODE ANN. §§ 5-601 to -614 (1990); MINN. STAT. ANN. §§ 145B-.01-.17 (West Supp. 1992); MISS. CODE ANN. §§ 41-41-101 to -121 (Supp. 1991); MO. ANN. STAT. §§ 459.010-.055 (Vernon Supp. 1992); MONT. CODE ANN. §§ 50-9-101 to -206 (1991); NEV. REV. STAT. ANN. §§ 449.535-.760 (Michie 1991); N.H. REV. STAT. ANN. §§ 137-H:1 to -H:16 (Supp. 1991); N.M. STAT. ANN. §§ 24-7-1 to -11 (Michie 1991); N.C. GEN. STAT. §§ 90-320 to -323 (1990 & Supp. 1991); N.D. CENT. CODE §§ 23-06.4 to -.4-14 (1991); OR. REV. STAT. §§ 127.605-650 (1991); R.I. GEN. LAWS §§ 23-4.11 to -9 (Supp. 1991); S.C. CODE ANN. §§ 44-77-10 to -160 (Law. Co-op. Supp. 1991); TENN. CODE ANN. §§ 32-11-101 to -112 (Supp. 1991); TEX. HEALTH & SAFETY CODE ANN. §§ 672.001-.021 (West Supp. 1991); UTAH CODE ANN. § 75-2-1101-75 to -1118 (Supp. 1991); VT. STAT. ANN. tit. 18, §§ 5251-5262 (1987); VA. CODE ANN. §§ 54.1-2981 to -2992 (Michie 1991); W. VA. CODE §§ 16-30-1 to -10 (1985 & Supp. 1991); WIS. STAT. ANN. §§ 154.01-.15 (West 1989); WYO. STAT. §§ 35-22-101 to -108 (1988).

At least thirty states provide for health care powers of attorney: ARK. CODE ANN. § 20-17-202 (Michie 1991); CAL. CIV. CODE §§ 2430-2438 (West Supp. 1992); DEL. CODE ANN. tit. 16, § 2502 (1983); D.C. CODE ANN. §§ 21-2201 to -2213 (1989); FLA. STAT. ANN. §§ 745.41.52 (West Supp. 1992); GA. CODE ANN. §§ 31-36-1 to -13 (Michie 1991); IDAHO CODE § 39-4505 (1991); ILL. ANN. STAT. ch. 110 1/2, para. 804-1 to -12 (Smith-Hurd Supp. 1991); IND. CODE ANN. §§ 16.8-12-5 to -12-8 (Burns 1990); IOWA CODE ANN. § 144A.7(1)(a) (West 1989); KAN. STAT. ANN. § 58-632 (Supp. 1989); KY. REV. STAT. ANN. §§ 311.970-.990 (Michie/Bobbs Merrill Supp. 1990); LA. REV. STAT. ANN. §§ 40:1299.58.1-.58.10 (West Supp. 1991); ME. REV. STAT. ANN. tit. 18-A, § 5-501 (West Supp. 1991); MINN. STAT. ANN. § 145B.03 (West Supp. 1992); MISS. CODE ANN. § 41-41-151 (Supp. 1990); MONT. CODE ANN. § 50-9-103 (1991); N.H. REV. STAT. ANN. §§ 137-J:1 to -J:16 (Supp. 1991); NEV. REV. STAT. ANN. §§ 449.613-.860 (Michie 1991); OHIO REV. CODE ANN. §§ 1337.11-.17 (Anderson Supp. 1990); OR. REV. STAT. § 127.505-.585 (1991); R.I. GEN. LAWS § 23-4.10-1 (1989); S.D. CODIFIED LAWS ANN. § 59-7-2.5 (Supp. 1990); TENN. CODE ANN. §§ 34-6-202-215 (Supp. 1991); UTAH CODE ANN. § 75-2-1106 (Supp. 1991); VT. STAT. ANN. tit. 14, §§ 3453-3467 (1989 & Supp. 1991); VA. CODE ANN. § 54.1-2984 (1991); WASH. REV. CODE ANN. § 11.94.046 (West Supp. 1990); W.VA. CODE §§ 16-30A-3 to -20 (Supp. 1991); WYO. STAT. § 35-22-102 (1988).

Medicaid funds complies with the duties imposed on them by the PSDA.⁵⁸

Health care organizations, including hospitals, skilled nursing facilities, home health agencies, and hospice programs, where approximately eighty percent of all individuals die, have more extensive duties under the PSDA.⁵⁹ First, any organization receiving Medicare or Medicaid funding must provide the advance directive descriptions to adult individuals admitted as patients, residents,⁶⁰ or those receiving hospice care.⁶¹ Second, these health care providers must formulate written policies to implement the state's

58. § 4751(a), 104 Stat. at 1388-204.

59. 136 CONG. REC., *supra* note 26, at E943 (statement of Rep. Levin). *But see* 135 CONG. REC., *supra* note 27, at S13,566 (statement of Sen. John Danforth (R-Mo.)) (estimating that 75% of all deaths occur in hospitals and medical centers). Rep. Levin probably bases his 80% figure on a study conducted by the President's Commission for the Study of Ethical Problems in Medicine. *See* PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 16-18 (1983).

60. § 4206(a), 104 Stat. at 1388-116.

61. *Id.* Eligible organizations must also follow these procedures. The term "Eligible organization" is defined in 42 U.S.C. § 1395mm(b) as:

[A] public or private entity (which may be a health maintenance organization or a competitive medical plan), organized under the laws of any State, which—

(1) is a qualified health maintenance organization (as defined in section 1310(d) of the Public Health Service Act [42 U.S.C.S. § 300e-9(d)], or

(2) meets the following requirements:

(A) The entity provides to enrolled members at least the following health care services:

(i) Physicians' services performed by physicians (as defined in section 1861(r)(1) [42 U.S.C.S. § 1395x(r)(1)]).

(ii) Inpatient hospital services.

(iii) Laboratory, X-ray, emergency, and preventive services.

(iv) Out-of-area coverage.

(B) The entity is compensated (except for deductibles, coinsurance, and copayments) for the provision of health care services to enrolled members by a payment which is paid on a periodic basis without regard to the date the health care services are provided and which is fixed without regard to the frequency, extent, or kind of health care service actually provided to a member.

(C) The entity provides physicians' services primarily (i) directly through physicians who are either employees or partners of such organization, or (ii) through contracts with individual physicians or one or more groups of physicians (organized on a group practice or individual practice basis).

(D) The entity assumes full financial risk on a prospective basis for the provision of the health care services listed in subparagraph (A), except that such entity may—

(i) obtain insurance or make other arrangements for the cost of providing to any enrolled member health care services listed in subparagraph (A) the aggregate value of which exceed \$5,000 in any year,

(ii) obtain insurance or make other arrangement for the cost of health care service listed in subparagraph (A) provided to its enrolled members other than

guidelines concerning advance directives⁶² and inform patients about these policies.⁶³ Health care organizations must document in each individual's medical record whether an advance directive has been executed,⁶⁴ and, if so, ensure that it complies with the state developed description.⁶⁵

In addition, health care providers must develop educational programs for the organizations' staff and the community it serves on issues concerning advance directives.⁶⁶ Finally, these organizations are prohibited from placing conditions on the provision of care or otherwise discriminating against patients based on whether they have executed an advance directive.⁶⁷ Failure by any organization to follow the PSDA's mandates may result in the loss of federal Medicare and Medicaid funding.⁶⁸

Complementing the mandates of the state and provider organizations, the Department of Health and Human Services (DHHS) is required to undertake a national educational campaign by June 1, 1992.⁶⁹ The campaign is designed "to inform the public of the option to execute advance directives and of a patient's right to participate and direct health care decisions."⁷⁰ The DHHS is also responsible for developing materials to be distributed by

through the entity because medical necessity required their provision before they could be secured through the entity,

(iii) obtain insurance or make other arrangements for not more than 90 percent of the amount by which its costs for any of its fiscal years exceed 115 percent of its income for such fiscal year, and

(iv) make arrangements with physicians or other health professionals, health care institutions, or any combination of such individuals or institutions to assume all or part of the financial risk on a prospective basis for the provision of basic health services by the physicians or other health professionals or through the institutions.

(E) The entity has made adequate provision against the risk of insolvency, which provision is satisfactory to the Secretary.

Paragraph (2)(A)(ii) shall not apply to an entity which had contracted with a single State agency administering a State plan approved under title XIX [42 U.S.C.S. § 1396 et seq.] for the provision of services (other than inpatient hospital services) to individuals eligible for such services under such State plan on a prepaid risk basis prior to 1970.

But see § 4751(a), 104 Stat. at 1388-205, which does not require the states to supervise "eligible organizations."

62. § 4206(a), 104 Stat. at 1388-115.

63. *Id.*

64. *Id.*

65. *Id.* at 1388-115 to -116.

66. *Id.* at 1388-116.

67. *Id.* at 1388-115.

68. § 4206(b), 104 Stat. at 1388-116. In reality, "providers need to be 'substantially out of compliance' with the conditions of participation before action to exclude them will be taken." *Living Wills Hearings*, *supra* note 9, at 116 (statement of Rep. Levin).

69. § 4751(d)(1), 104 Stat. 1388-205; § 4206, 104 Stat. 1388-115.

70. *Id.*

health care organizations,⁷¹ aiding in the development of state law descriptions,⁷² and assisting states in ensuring that health care providers receive copies.⁷³

III. OPPOSITION TO THE PSDA

The PSDA fails to address all the potential problems that might arise through its mandates. For instance, critics argue that the PSDA cannot effectively achieve its goals of increasing the public's use and awareness of advance directives.⁷⁴ The PSDA is criticized as being too weak;⁷⁵ some argue that state law summaries cannot be written in a coherent and complete manner⁷⁶ and that health care providers are not the optimal disseminators of information about advance directives.⁷⁷

One of the PSDA's principal weaknesses stems from the fact that it was enacted in abbreviated form with many of its original mandates either intentionally or involuntarily deleted. For instance, the PSDA does not require health care providers to create ethics committees; however, the original version of the PSDA contained this requirement.⁷⁸ Ethics committees serve to diffuse professional responsibility in health care decision-making.⁷⁹ These committees have been the subject of debate,⁸⁰ including the question of whether they are actually effective and if mandating their use would be appropriate.⁸¹ To facilitate passage, there are indications that the ethics com-

71. § 4751(d)(2), 104 Stat. 1388-205.

72. § 4751(d)(3), 104 Stat. 1388-205.

73. *Id.* at 1388-205 to -206.

74. *See infra* notes 78-113 and accompanying text.

75. *See infra* notes 78-89 and accompanying text.

76. *See infra* notes 90-95 and accompanying text.

77. *See infra* notes 98-113 and accompanying text.

78. *See* Diane E. Hoffmann, *Regulating Ethics Committees in Health Care Institutions—Is It Time?*, 50 MD. L. REV. 746, 749-754 (1991) (discussing the historical role of ethics committees in the PSDA). *See generally* Symposium, *Hospital Ethics Committees and the Law*, 50 MD. L. REV. 742 (1991) (discussing the functions and usefulness of ethics committees and ethics committee legislation).

79. *In re Quinlan*, 355 A.2d 647, 668-69 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976). Relying on an article by Dr. Karen Teel, the New Jersey Supreme Court found that ethics committees help screen out cases "which might be contaminated by less than worthy motivations of family or physician." *Id.* at 669; *See* Dr. Karen Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 BAYLOR L. REV. 6, 8-9 (1975).

80. *Compare* John C. Fletcher, *The Patient Self-Determination Act: Yes*, HASTINGS CENTER REP., Sept.-Oct. 1990, at 33, 33-35 (endorsing the PSDA for upholding advance directive legislation) *with* Alexander M. Capron, *The Patient Self-Determination Act: Not Now*, HASTINGS CENTER REP., Sept.-Oct. 1990, at 35, 35 (1990) (discussing how the PSDA fails to reduce barriers to the use of advance directives).

81. *Living Wills Hearings*, *supra* note 9, at 122-23 (statement of Paul C. Rettig, Executive Vice President, American Hospital Association). *See generally* George P. Smith, II, *The Eth-*

mittee provision was replaced during "mark-up" sessions with the national educational campaign mandate.⁸² However, many medical institutions have created committees to protect the interests of patients, especially those who are incapacitated.⁸³

Further, critics argue that the PSDA's designated means of enforcement (loss of Medicare and Medicaid funding) has proven to be ineffective.⁸⁴ One commentator notes that the only likely consequence of this penalty is "a great deal of resentment on the part of physicians and hospital personnel, along with more trips to the courthouse induced by fear of liability."⁸⁵ The penalty's effectiveness is further stymied by the fact that additional funding has not been provided to the DHHS or the states to monitor compliance with the PSDA.⁸⁶ While problems like these cannot be readily dismissed, and admittedly weaken the PSDA, a stronger bill that allocated specific funds may not have received the necessary support to pass congressional scrutiny.⁸⁷ However, if criticism increases, supplemental bills can be introduced to Congress.⁸⁸ Furthermore, if an evaluation determines that the law is not adequately furthering its stated objectives, the PSDA can be amended.⁸⁹

In addition to complaints about the PSDA's inherent inability to address all issues and its failure to create effective methods of enforcement, critics also charge that states are incapable of writing adequate summaries of their

ics of Ethics Committees, 6 J. CONTEMP. HEALTH L. & POL'Y 157, 162-67 (1990) (discussing the models for ethical decision-making that have been suggested as operational frameworks through which ethics committees may act).

82. Cynthia B. Cohen, 1990 and Beyond: *The Genie Out of the Bottle?*, HASTINGS CENTER REP., Sept.-Oct. 1990, at 33 (1990). For a discussion of the educational requirement, see *supra* notes 69-73 and accompanying text.

83. Hoffmann, *supra* note 78, at 747.

84. See, e.g., Capron, *supra* note 80, at 35 (stating that the three sets of "Baby Doe" Regulations have had no beneficial effect despite threats to cut off aid). See also *Living Wills Hearings*, *supra* note 9, at 10-16 (statement of Hon. Gail R. Wilensky, Ph.D.). Dr. Wilensky, Administrator of the Health Care Financing Administration, argues that Medicare and Medicaid restrictions should only be placed on conditions that are immediately and directly related to the quality of health care because the effects of termination are so severe. *Id.* at 13.

85. Capron, *supra* note 80, at 35.

86. A.B.A. COMMISSION, *supra* note 2, at 3.

87. In fact, a more compelling bill did not get the necessary support to pass. See, e.g., H.R. CONF. REP. NO. 1037, 101st Cong., 2nd Sess. 774-78 (1990), reprinted in 6 U.S.C.C.A.N., 194 Stat. 2479, 2479-83 (1990).

88. For a description of legislative procedure, see generally AMERICAN SOC'Y OF LEGISLATIVE CLERKS & SECRETARIES, MASON'S MANUAL OF LEGISLATIVE PROCEDURE 263 (1989).

89. *Id.*

laws.⁹⁰ Many critics claim that the language of the state laws is often too ambiguous to provide clear guidelines.⁹¹ States have also failed to establish clear judicial opinions or statutes concerning the important issue of self-determination.⁹² Still other states have neither legislation nor judicial opinions addressing advance directives.⁹³ Further, states cannot predict the impact of *Cruzan* on their laws until judicial action or legislative initiative clarifies the issues.⁹⁴ Additionally, a conflict of laws issue may arise because states rarely address the concerns of patients who have executed advance directives outside the health care provider's home state.⁹⁵

These problems are not insurmountable, and the state law guidelines can always be revised to correct deficiencies. Furthermore, enactment of advance directive legislation significantly increased in the past five years, and these laws have been refined.⁹⁶ Thus, it is expected that the state guidelines will become more clear and therefore more effective. However, the threat of removing Medicare and Medicaid funding will prove ineffective if the states or federal government fail to authorize funding for monitoring compliance.⁹⁷

Generally, critics also argue that health care providers are improper and ineffective disseminators of advance directive information for several reasons. First, the PSDA might reassign the role of advocating advance directives from doctors to other health care providers.⁹⁸ In truth, physicians still

90. William Booth, *U.S. "Living Will" Rule Creates Confusion*, WASH. POST, July 17, 1991, at A1.

91. *Id.*; see, A.B.A. COMMISSION, *supra* note 2, at 2; see also Kelly C. Mulholland, Recent Developments, *Protecting the Right To Die: The Patient Self-Determination Act of 1990*, 28 HARV. J. ON LEGIS. 609, 627-628 (1991) (discussing several procedural shortcomings of PSDA).

92. In fact, "[a]mbiguities and uncertainties arise in virtually every state's law, even in those states with quite detailed advance directive statutes." A.B.A. COMMISSION, *supra* note 2, at 2.

93. For a list of states that have enacted legislation regarding advance directives, see *supra* note 57.

94. See A.B.A. COMMISSION, *supra* note 2, at 7-8.

95. *Living Wills Hearings*, *supra* note 9, at 125-26 (statement of Charles P. Sabatino, Associate Director of the American Bar Association's Commission on Legal Problems of the Elderly).

96. At one point, state legislatures enacted health care power of attorney acts on average of one per month. See *id.* (citing 20 health care power of attorney acts passed through state legislatures from February 1989 through July 1990).

97. U.S. DEP'T OF HEALTH AND HUMAN SERVS., STATE MEDICAID MANUAL § 2-82.36 (1991) (allowing for federal reimbursement for 50% of the administrative costs of the development and distribution of information).

98. See *Reconciliation Issues Hearing*, *supra* note 3, at 179 (statement of Concern By Dying and The Society for the Right to Die).

play an essential role in advance directive decision-making.⁹⁹ However, recent studies demonstrate that, while theoretically physicians are viewed as the most effective disseminators of information about advance directives because of the unique doctor/patient relationship, in practice, they have failed in their duty to inform patients of advance directives because they deem them to be a patient's responsibility.¹⁰⁰ In addition, physicians often lack sufficient understanding of the laws which precludes them from providing an informed opinion.¹⁰¹ In many instances, physicians are reluctant to introduce the topic because they fear the patient's reaction.¹⁰²

Second, fears exist that the advance directive information disseminated to the patients will prove confusing especially if accompanied by complicated, perhaps intimidating,¹⁰³ bureaucratic forms.¹⁰⁴ In most instances, the staff member disseminating the information may not be able to answer questions pertaining to the forms.¹⁰⁵ To prevent this problem, it is imperative that health care providers inform all their employees, not just admission clerks, about the requirements of the PSDA.¹⁰⁶ Further, the PSDA's mandate of continuing education on issues concerning advance directives can prevent this problem.¹⁰⁷

Third, health care provider liability might increase under the PSDA.¹⁰⁸ For example, hospitals have not been given guidelines on how to effectively

99. *Id.*; see also Capron, *supra* note 80, at 35. The American Bar Association Commission on Legal Problems of the Elderly notes that:

Physicians play the central role in promoting understanding of one's condition, situations that are likely to arise, and the pros and cons of options available for care and treatment. . . . If the physician does not fully understand or has moral objections to instructions given in one's advance directive, the directive's impact will be impaired or undermined altogether.

A.B.A. COMMISSION, *supra* note 2, at 25.

100. La Puma et al., *supra* note 3, at 402-03.

101. 136 CONG. REC., *supra* note 26, at E943, E944 (statement of Rep. Levin) (citing a Colorado survey which found that 23% of doctors are not familiar with living wills, and 74% are not familiar with durable powers of attorney).

102. *Id.*; see also Paul Cotton, *Providers to Advise of 'Medical Miranda'*, 265 JAMA 306, 306 (1991) (finding that physicians are unaware of how to talk to patients about the issue). One doctor noted, "I'd rather shoot myself in the foot than start a living will discussion." Lewin, *supra* note 7, at A13.

103. See Terese Hudson, *Hospitals Work To Provide Advance Directives Information*, HOSP., Feb. 5, 1990, at 26, 32 (1991).

104. See La Puma et al., *supra* note 3, at 403.

105. See Capron, *supra* note 80, at 35.

106. See Cotton, *supra* note 102, at 306.

107. See § 4206(a)(2)(E), 104 Stat. 1388-116 (1990).

108. Hudson, *supra* note 103, at 32.

convey information on advance directives to illiterate patients¹⁰⁹ or patients who enter hospitals in an emergency condition.¹¹⁰ Indeed, institutions might implement improper policies, and patients might misread or misunderstand forms.¹¹¹ Should patients and their families attempt to impose liability on health care providers who fail to follow institutional policies regarding advance directives, the PSDA might serve as the standard for determining whether the policies adequately reflect the duty of disclosure.¹¹² The potential that health care provider liability may increase may be considered a positive consequence of the PSDA if it leads to greater internal monitoring by institutions. This increased internal monitoring serves to offset the states' obligation to conduct external supervision to ensure compliance with the PSDA's requirements.¹¹³

III. AN ARGUMENT IN SUPPORT OF THE PSDA

Prior to the PSDA, the media, through informational articles and coverage of high profile cases, increased the public's awareness about advance directives.¹¹⁴ The PSDA represents a legislative effort to ensure that the disseminated information is reliable and applicable in the state in which a reader resides. By contributing to this flow of information, the federal government benefits the people both individually and collectively. In an individual capacity, it promotes a person's right to choose to end his life; in a collective capacity, it promotes the public's rights by decreasing wasted resources that result from unwanted and unnecessary medical treatment.

The PSDA attempts to return the right of self-determination to the patient.¹¹⁵ As life sustaining medical technology has increased, this right seems to have slowly moved away from the individual into the hands of third party decision-makers.¹¹⁶ These third-party-players cannot truly act on behalf of the patients' best interests if those interests are unknown. The roles

109. See La Puma et al., *supra* note 3, at 404. "Even well-educated patients may find it difficult to understand the terms and conditions of such plans." *Id.* at 403.

110. See Mulholland, *supra* note 91, at 628.

111. See Hudson, *supra* note 103, at 26.

112. See La Puma et al., *supra* note 3, at 404.

113. § 4206(a)(2), 104 Stat. 1388-115 to -116.

114. High profile media coverage of the *Cruzan* case demonstrates how the media has increased public awareness about advance directives. See, e.g., Jackie Fitzpatrick, *Volunteer Lawyers Visit the Elderly As Interest in Living Wills Grows*, N.Y. TIMES, Oct. 21, 1990, at CN12 (Conn. ed.).

115. *Living Wills Hearings*, *supra* note 9, at 6 (statement of Rep. Levin).

116. One commentator noted:

[I]n all too many other cases, the patient and the physician, the primary care giver with that patient and the patient's family have frequently been in agreement, but some other entity has been intruded. It might be a hospital employee; it might be a

played by patients and their families in deciding on medical treatment, although deeply rooted in tradition,¹¹⁷ has deteriorated over the past half century.¹¹⁸ Because of the lack of uniform communication mechanisms that identify patient values and wishes, patients have lost their ability to communicate their health care decisions.¹¹⁹

While deemed to be a buffer in these decisions, the third party in reality may make decisions which do not accurately reflect the interests of the individual patients.¹²⁰ In New Jersey, for example, the politically appointed Nursing Home Ombudsman serves as the surrogate decision-maker for all nursing home residents who have reached the age of sixty, and who have not, while competent, chosen to withdraw or withhold life-sustaining treatment.¹²¹ In limited cases in which the resident is in a persistent vegetative state, the Ombudsman, entering each case without any prior knowledge about the resident, has the authority to disregard the wishes of family members and the attending physicians and refuse to allow the withdrawal of life-sustaining treatment.¹²² By disseminating information about advance directives, the PSDA attempts to take this decision-making role away from the third party and ensure that the decisions uphold the interests of the patient, the families, and the physicians in each case.

Additionally, the PSDA attempts to minimize the costs of unwanted and unnecessary care.¹²³ Although these costs are assessed in both monetary and nonmonetary terms, the PSDA is, among other things, a cost containment measure.¹²⁴ With the expected increase in advance directives, the PSDA can help reduce federal Medicare payments to health care providers,

hospital institution itself; it might even be some person who appears to have no business in the case and it ends up in a court room.

Id. at 43 (statement of Dr. Nancy W. Dickey).

117. John Hardwig, *What About the Family?*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 5, 5 (1990) (discussing how patient autonomy ignores family interests in medical treatment decisions).

118. 135 CONG. REC. S13,566, 13,571 (daily ed. Oct. 17, 1989) (statement of Father Dennis Brodeur). Father Brodeur blames the erosion on advanced age, emotional strains and family life, as well as "the technological imperative that is a part of medicine, and . . . the fear of legal action on the part of providers and health care institutions." *Id.*

119. *Id.*

120. See generally AMERICAN JEWISH CONGRESS BIO-ETHICS TASK FORCE, SUBSTITUTE MEDICAL DECISION-MAKING FOR PATIENTS WHO LACK CAPACITY 4-8 (May 5, 1991).

121. See generally N.J. ADMIN. CODE tit. 5, § 100-2.3 to -2.5 (Supp. 1990).

122. *Id.* N.J. ADMIN. CODE tit. 5, § 100-2.4(g) gives the Nursing Home Ombudsman discretion to decide whether or not to defer to the judgment of two doctors, the attending physician, and at times, a family member.

123. La Puma et al., *supra* note 3, at 404.

124. *Id.*; see also Margot L. White & John C. Fletcher, *The Patient Self-Determination Act: On Balance, More Help Than Hindrance*, 266 JAMA 410 (1991) (discussing the historical perspective of congressional implementation of cost containment measures).

assuming that the directives stipulate a limit on providing life prolonging treatment.¹²⁵ The potential of this limitation is significant; of the six percent of Medicare enrollees who die annually, their care consumes twenty-eight percent of annual Medicare expenses.¹²⁶ This amount is expected to increase dramatically as the baby boom generation ages.¹²⁷

Yet, assuming that patients elect to limit expensive procedures to prolong life, nonmonetary costs, including the emotional strain of watching a family member or friend exist solely through the use of a feeding tube or respirator, can be avoided.¹²⁸ On a broader scale, the resources saved by federal or private insurers can be allocated to patients who can survive without machinery, and these savings might be reflected in the costs of health care insurance premiums.¹²⁹ Increasing the use of advance directives would also eliminate the need for expensive court battles over a patient's rights.¹³⁰

CONCLUSION

The effectiveness of the PSDA will be proven only with time. Presently, critics and supporters may only speculate about its potential failure or success. Indeed, even if there is a significant increase in the use of advance directives, whether that increase will be directly linked to the PSDA remains unclear. The PSDA, despite its faults, clearly states its objectives. Individuals have a right to autonomy; they have a right to choose their destiny. While it may take time to eliminate the statute's ambiguities, the PSDA rep-

125. See, for example, the facts surrounding the *Cruzan* dilemma in which the state of Missouri paid \$130,000 a year to maintain Nancy Cruzan. Susan Okie, *Medical Groups Criticize Court for Interfering in Life-or-Death Decisions*, WASH. POST, June 26, 1990, at A8.

126. La Puma et al., *supra* note 3, at 404 ("[M]any patients—especially the elderly—will opt to limit the expensive, intensive treatment that they may receive in hospitals.").

127. PETER J. STRAUSS ET AL., *AGING AND THE LAW* 488 (1990).

128. See, e.g., *Living Wills Hearings*, *supra* note 9, at 117 (statement of Richard A. McCormick, S.J.) (discussing examples of problems that arise when a patient fails to execute an advance directive).

129. See generally, Edmund D. Pellegrino, *Rationing Health Care: The Ethics of Medical Gatekeeping*, 2 J. CONTEMP. HEALTH L. & POL'Y 23 (1986) (discussing how costs can be cut by eliminating "unnecessary" medical care).

130. 135 CONG. REC. 13,566 (daily ed. Oct. 17, 1989) (statement of Sen. Danforth). "[W]ithout any clear directive from a patient, the fear of liability and malpractice suits sometimes causes doctors to refuse the termination of treatment, even when the family says the medical intervention is the last thing in the world that their loved one would have wanted." *Id.* This refusal can often lead to a lawsuit. *Id.* at 13,567. *But see* Hudson, *supra* note 103, at 32 (discussing the potential increase in courtroom battles because of increased hospital liability; the cases may involve a preemption of future challenges from the state).

resents an essential step by the federal government towards upholding this right.

Michael A. Refolo

