

**SAY WHAT? HOW THE PATIENT SELF-
DETERMINATION ACT LEAVES THE
ELDERLY WITH LIMITED ENGLISH
PROFICIENCY OUT IN THE COLD**

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The Patient Self-Determination Act requires all health care facilities that receive state funds to provide patients with written information regarding advance directives. The legislation, however, fails to address the provision of such materials for patients with limited English proficiency. In this note, Catherine Jones examines how federal and state legislation has failed to protect end-of-life care rights for elderly patients with limited English proficiency. Ms. Jones considers the impact of case law and Title VI on advance directive policy. She ultimately finds that a large segment of society is unable to enjoy the benefits conferred by the Patient Self-Determination Act. She concludes that Congress should amend the Act to require the provision of translated written information on advance directives and that states should create online databases to store translations.

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I. Introduction

Medicalese, an often incomprehensible form of quasi-English, confronts Americans every time they walk in the door of a health care facility. Even for native English speakers, medicalese has proven to be so complicated that it has become the subject of internet sites,¹ “dictionaries,”² journal articles,³ and translating tools.⁴ But what about those individuals who do *not* speak English well? In addition to aggravating factors such as the stress of an illness or other medical situation, cultural constraints on communication, and advanced age, communicating medical concepts to an individual seeking medical treatment can become impossible, especially if medical professionals are unaided by appropriately translated material.

Current law sets the stage for this frustrating scene to play out repeatedly between older patients with limited English proficiency (LEP) and a medical document known as an advance directive. Federal legislation passed over fourteen years ago stipulates that all health care facilities receiving funds from state programs must provide patients with written information regarding advance directives.⁵ That legislation, now known as the Patient Self-Determination Act (PSDA),⁶ provides that some form of written information be provided, but *not* that the patient receiving the written materials be able to effectively understand it.⁷ In a nation that has always been multicultural and multilingual, such legislation is woefully inadequate.

The advance directive is a relatively recent innovation,⁸ addressing the ever-increasing public awareness of end-of-life self-determi-

1. A Google search on Oct. 10, 2005, revealed nearly 12,000 websites containing the word “medicalese.”

2. See, e.g., PETER MEYER, *MEDICALESE: A HUMOROUS MEDICAL DICTIONARY* (1994).

3. See, e.g., Lora M. McGlade et al., *Eliminating Jargon, or Medicalese, from Scientific Writing*, 64 AM. J. CLINICAL NUTRITION 256 (1996).

4. See, e.g., Medicalese, <http://www.medicalese.org> (last visited Oct. 10, 2005) (allowing users to obtain simplified definitions of medical words in non-medical terms).

5. Richard L. Kaplan, *Crowding Out: Estate Tax Reform and the Elder Law Policy Agenda*, 10 ELDER L.J. 15, 36 (2002).

6. *Id.*

7. See *infra* Part I and note 11.

8. See Meta Calder, *Chapter 765 Revisited: Florida's New Advance Directives Law*, 20 FLA. ST. U. L. REV. 291, 294-95 (1992) (stating that advance directive legislation first appeared less than fifty years ago).

nation.⁹ At the same time, a growing number of America's elderly population can be classified as LEP.¹⁰ For this segment of society, the PSDA fails to protect their right to self-determination of end-of-life care because its mandate does not ensure that written materials are translated, either orally or on paper.¹¹ If the Act is to fulfill its promise to all American residents, Congress must change the PSDA to require translation of advance directive materials. Changes to the Act need only to be general because implementation falls better to individual state law and agencies who have better information regarding the linguistic capabilities of their citizens.

This note will address the critical need for amendment to the PSDA for the sake of the LEP elderly population's terminal care rights. Part II will explain the history of the PSDA, and describe the situation of the growing LEP elderly population. Part III will analyze both the practical problems with English-only advance directives and the failure of the PSDA to fulfill its purpose of providing information for the senior LEP population in the United States. Finally, Part IV will suggest a resolution that calls for action by both federal and state legislatures and will provide a viable model for implementing PSDA and state law amendments so that all Americans can enjoy their right to self-determination.

II. Background

A. Advance Directives and the Patient Self-Determination Act of 1990

The development of the advance directive and its subsequent codification in the PSDA is a surprisingly recent occurrence, coming within the past forty years.¹² It began as a tool used by cautious doctors, and, as the result of a few forward-thinking legislators and well-

9. See *infra* Part II.A.

10. See WAN HE, U.S. CENSUS BUREAU, THE OLDER FOREIGN-BORN POPULATION IN THE UNITED STATES: 2000 3 (Sept. 2002), available at <http://www.census.gov/prod/2002pubs/p23-211.pdf> (predicting that the number of immigrants from non-English-speaking countries in Asia and Latin America will comprise a majority of individuals immigrating to the United States in coming years).

11. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204 (mandating only that information about state laws on advance directives be provided without further qualification regarding language, translation, or understandability).

12. See Calder, *supra* note 8, at 293-322 (detailing the brief history of advance directive legislation in states starting in the 1960s).

timed judicial decisions, grew into an issue of public education in patient autonomy.¹³

Advance directives allow a patient to specify in writing his or her end-of-life medical care preferences in the event that mental or physical incapacitation renders the patient incapable of making such wishes known.¹⁴ Forms of the advance directive include: living wills, the health care proxy (also known as the durable power of attorney for health care), or even “simple declarations that the maker of the instrument does not want life-extending medical procedures performed” in the case of imminent death.¹⁵ Depending on which type of instrument the patient employs, he or she effectively either makes clear his or her decision regarding medical treatment or designates an agent to authorize treatment according to the patient’s stated desires.¹⁶

Advance directives first emerged as an issue for state legislation in the late 1960s.¹⁷ At that time, medical professionals began encouraging patients to use advance directives for two purposes: first, so that the patient need not endure unwanted treatment, and second, to protect medical personnel from liability after carrying out the patient’s wishes.¹⁸ However, efforts to codify policy regarding advance directives remained unsuccessful until September 1976, when California passed a bill proposed by State Senator Barry Keene which advocated the use of living wills.¹⁹ The bill passed in large part because of a decision delivered by the New Jersey Supreme Court that steered the nation’s attention towards a patient’s right to die.²⁰ That decision, *In re*

13. Maude B. Hecht & William C. Shiel, Jr., *Advance Medical Directives (Living Will, Power of Attorney, and HealthCare Proxy)*, http://www.medicinenet.com/advance_medical_directives/article.htm (last visited Oct. 10, 2005).

14. Lainie Rutkow, *Dying to Live: The Effect of the Patient Self-Determination Act on Hospice Care*, 7 N.Y.U. J. LEGIS. & PUB. POL’Y 393, 406 (2003).

15. Kaplan, *supra* note 5, at 35.

16. Rutkow, *supra* note 14, at 406.

17. See Calder, *supra* note 8, at 294–95 (discussing the budding of state legislation on advance directives in Florida); Thane Josef Messinger, *The Gentle and Easy Death: From Ancient Greece to Beyond Cruzan Toward a Reasoned Legal Response to the Societal Dilemma of Euthanasia*, 71 DENV. U. L. REV. 175, 200 (1993) (noting the proposal and subsequent failure of “death with dignity” statutes in several states in the late 1960s).

18. Rutkow, *supra* note 14, at 407.

19. Hecht & Shiel, Jr., *supra* note 13; see also Judith F. Daar, *Direct Democracy and Bioethical Choices: Voting Life and Death at the Ballot Box*, 28 U. MICH. J.L. REFORM 799, 811–12 (1995).

20. See Daar, *supra* note 19 (referencing *In re Quinlan*, 355 A.2d 647 (N.J. 1976)).

Quinlan,²¹ gave the parents of a comatose woman the authority to remove their daughter from life support without liability.²² *In re Quinlan* and California's subsequent legislation ignited public interest in the issue, and by the end of 1988, forty-two states had enacted advance directive legislation.²³ Nevertheless, despite the efforts of state legislatures, by the late 1980s "very few Americans had executed advance directives for themselves."²⁴

Shortly thereafter, members of Congress began showing their concern for the implementation of advance directives in 1989, when Senator John C. Danforth introduced the PSDA to the Senate.²⁵ Senator Danforth stated that the bill intended to "ensure that a patient's right to self-determination in health care decisions be communicated and protected."²⁶ Furthermore, the bill espoused the idea that "increased knowledge" would promote the use of advance directives and in turn "enhance patient participation in health care decisions."²⁷ Senator Danforth's initial bill contained three mandates: (1) all health care facilities receiving Medicare or Medicaid funds, including hospitals and nursing homes, must inform incoming patients of their right to predetermine end-of-life medical treatment (including their option to refuse treatment), and then review and enforce those preferences;²⁸ (2) states must enact legislation that allows the use of advance directives;²⁹ and (3) the federal Department of Health and Human Services

21. 355 A.2d 647 (N.J. 1976).

22. *Id.* at 671-72; see also Rutkow, *supra* note 14, at 407 n.67.

23. See ALAN MEISEL, THE RIGHT TO DIE 333 tbl.10-1, 359 tbl.11-1 (1989) (listing the following states and the District of Columbia as having enacted advanced directive legislation by the end of 1988: Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Mexico, North Carolina, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming).

24. Rutkow, *supra* note 14, at 408.

25. Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 251 (1997).

26. Rutkow, *supra* note 14, at 408 (quoting *Living Wills: Hearing on S. 1766 Before the Subcomm. on Medicare & Long-Term Care of the S. Comm. on Fin.*, 101st Cong. 4 (1990) (statement of Sen. John C. Danforth)).

27. S. 1766, 101st Cong. § 2(b)(6) (1989).

28. Larson & Eaton, *supra* note 25, at 251.

29. *Id.* at 251-52 ("[As of 1989], forty states had living will statutes and twenty-five states had laws authorizing durable powers of attorney for health care.").

must initiate a national campaign to educate the public about advance directives and conduct a study to gauge the impact of the PSDA.³⁰

Senator Danforth found an ally in Representative Sander M. Levin.³¹ Representative Levin's goal in proposing the bill was to empower individuals with knowledge about their terminal treatment rights.³² He stated that "[w]ithout knowledge there is no power. And what this bill . . . attempts to do is capacitate people . . . by providing them knowledge, informing them, and making certain their wishes are noted in a useful way on the record."³³

Representative Levin introduced his version of the bill in the House of Representatives in April 1990,³⁴ but not before making a number of modifications to placate the concerns of health care providers and agencies regarding the burden of monitoring the mandate.³⁵ The modifications, with one exception, were in fact deletions: the cuts included the mandatory state authorization of advance directives as well as the mandatory hospital ethics committees.³⁶ Representative Levin's proposed bill also replaced the obligation to inform a patient of his or her advance directive rights and periodic review of a patient's choice with respect to those rights with a mandate that health care facilities simply supply *written* information about advance directives only at the time of a patient's admission into the facility.³⁷

While these modifications may have removed some of the bite from the PSDA, they also helped pave the way for its passage.³⁸ By reducing the administrative burden on health care facilities, agencies, and providers, Representative Levin mollified groups like the American Medical Association, the American Hospital Association, and the nursing home lobby.³⁹ Additionally, the U.S. Catholic Conference and the National Right to Life Committee relaxed their opposition once

30. *Id.* at 252.

31. *See* Rutkow, *supra* note 14, at 409 (describing the history of the PSDA as it passed through the House of Representatives).

32. Larson & Eaton, *supra* note 25, at 256.

33. *Id.* at 256–57 (quoting *Living Wills: Hearing on S. 1766 Before the Subcomm. on Medicare & Long-Term Care of the S. Comm. on Fin.*, 101st Cong., 6 (statement of Rep. Sander M. Levin)).

34. Rutkow, *supra* note 14, at 409.

35. Larson & Eaton, *supra* note 25, at 252.

36. *Id.* at 252–53.

37. *Id.* at 253.

38. *See id.* at 254–55.

39. *See id.* at 254 (describing various interest groups and how Representative Levin's changes to the PSDA won their support).

the mandatory state authorization of advance directives was omitted.⁴⁰ Objections from the Health Care Financing Administration led to further modifications by the committee, resulting in the elimination of the proposed study by the Department of Health and Human Services on the PSDA's national impact.⁴¹

The U.S. Supreme Court's decision in *Cruzan v. Director, Missouri Department of Health*⁴² further greased the wheels of enactment of the PSDA.⁴³ The *Cruzan* Court made two major points: (1) it assumed that the "Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition;"⁴⁴ and (2) the Court acknowledged that states were authorized to require an advance directive or other clear and convincing evidence of an incapacitated individual's wishes regarding refusal of medical treatment.⁴⁵ *Cruzan* not only advanced the issue of advance directives in the political and judicial arenas; it also helped to bring the issue into the consciousness of the general public.⁴⁶ Patient-doctor dialogue regarding end-of-life treatment became more frequent,⁴⁷ and within a day of the *Cruzan* decision, the *New York Times* had published an editorial promoting the advantages of executing living wills.⁴⁸

With the apparent blessings of the Court and the public, both the Senate and the House of Representatives passed the PSDA as part of the Omnibus Budget Reconciliation Act,⁴⁹ and the President then signed the Act into law in November 1990.⁵⁰ The enacted and current PSDA provides that:

[E]ach hospital, nursing facility, provider of home health care or personal care services, hospice program, or health maintenance organization . . . receiving funds under [state plans for medical assistance] shall . . . maintain written policies and procedures with respect to all adult individu-

40. *Id.* at 255.

41. *Id.*

42. 497 U.S. 261 (1990).

43. Larson & Eaton, *supra* note 25, at 255.

44. *Cruzan*, 497 U.S. at 279.

45. *Id.* at 280 ("Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be proved by clear and convincing evidence. The question, then, is whether the United States Constitution forbids the establishment of this procedural requirement by the State. We hold that it does not.")

46. Rutkow, *supra* note 14, at 407-08.

47. *Id.* at 408.

48. Editorial, *Doing Justice to Life*, N.Y. TIMES, June 27, 1990, at A22.

49. See Larson & Eaton, *supra* note 25, at 255-56.

50. Rutkow, *supra* note 14, at 409.

als receiving medical care by or through the provider or organization

(A) to provide written information to each such individual concerning—(i) an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives . . . (ii) the provider's or organization's written policies respecting the implementation of such rights;

(B) to document in the individual's medical record whether or not the individual has executed an advance directive;

(C) not to condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive;

(D) to ensure compliance with requirements of State law (whether statutory or as recognized by the courts of the State) respecting advance directives; and

(E) to provide (individually or with others) for education for staff and the community on issues concerning advance directives.⁵¹

The PSDA further stipulates that the *states* must “develop [the] written description of the law of the State (whether statutory or as recognized by the courts of the State) concerning advance directives that would be distributed by providers or organizations.”⁵² In essence, rather than preempt state laws regarding advance directives, the PSDA mandates that “health care facilities receiving federal funds through Medicare and Medicaid comply with their state's laws about patient's rights.”⁵³ Since the enactment of the PSDA in 1990, all fifty state legislatures and the District of Columbia have implemented some form of law regarding advance directives.⁵⁴

51. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204.

52. *Id.*

53. Rutkow, *supra* note 14, at 409.

54. *Id.* at 409-10. These state statutes include: ALA. CODE §§ 22-8A-1 to -13 (LexisNexis 1997 & Supp. 2004); ALASKA STAT. §§ 18.12.010-100 (2002); ARIZ. REV. STAT. ANN. §§ 36-3201 to -3287 (2003 & Supp. 2004); ARK. CODE ANN. §§ 20-17-201 to -218 (2000 & Supp. 2005); CAL. HEALTH & SAFETY CODE § 1569.156 (West 2000), CAL. PROB. CODE § 4605 (West Supp. 2005); COLO. REV. STAT. ANN. §§ 15-18-101 to -113, 15-18.5-101 to -103, 15-18.6-101 to -108 (West 2005); CONN. GEN. STAT. ANN. §§ 19a-570 to -580d (West 2003); DEL. CODE ANN. tit. 16, §§ 2501-2518 (2003); D.C. CODE ANN. §§ 7-601 to -630 (LexisNexis 2001); FLA. STAT. ANN. §§ 765.101-404

B. The Growing Population of Limited English Proficiency Senior Citizens

Meanwhile, senior citizens who do not speak English well constitute a large number of people living in the United States.⁵⁵ As both the immigrant population and the elderly population continue to grow, the correlating number of LEP seniors will expand as well.⁵⁶ Accordingly, making information about advance directives understandable is increasingly important.

According to the most recent census data, there are over thirty-four million individuals in the United States aged sixty-five years or

(West 2005); GA. CODE ANN. §§ 31-32-1 to -12, 31-36-1 to -13, 31-39-1 to -9 (2001); HAW. REV. STAT. ANN. §§ 327E-1 to -16 (LexisNexis 2004); IDAHO CODE ANN. §§ 39-4501 to -4509 (2002); 210 ILL. COMP. STAT. ANN. 45/2-104.2, 85/6.19 (West 2000 & Supp. 2005), 755 ILL. COMP. STAT. ANN. 40/1-55 (West 2000 & Supp. 2005); IND. CODE ANN. §§ 16-36-4-1 to -21 (LexisNexis 1993 & Supp. 2004); IOWA CODE ANN. §§ 144A.1-.12 (West 1997 & Supp. 2005); KAN. STAT. ANN. §§ 65-28.101 to -28.109 (2002); KY. REV. STAT. ANN. §§ 311.621-.643 (LexisNexis 2001); LA. REV. STAT. ANN. §§ 40:1299.58.1-.58.10 (2001); ME. REV. STAT. ANN. tit. 18-A, §§ 5-801 to -817 (1998 & Supp. 2004); MD. CODE ANN., HEALTH-GEN. §§ 5-601 to -618 (West 2005); MASS. ANN. LAWS ch. 201D, §§ 1-17 (LexisNexis 2003); MICH. COMP. LAWS ANN. §§ 700.5506-.5520 (West 2002 & Supp. 2005); MINN. STAT. ANN. §§ 145B.01-.17, 145C.01-.15 (West 2005); MISS. CODE ANN. §§ 41-41-205, -209, -211 (1999 & Supp. 2002); MO. ANN. STAT. §§ 459.010-.055 (West 1992); MONT. CODE ANN. §§ 50-9-101 to -206 (2003); NEB. REV. STAT. §§ 20-401 to -416 (1997); NEB. REV. STAT. §§ 30-3401 to -3432 (1995); NEV. REV. STAT. ANN. §§ 449.535-.690, 450B.400-.590 (LexisNexis 2001); N.H. REV. STAT. ANN. §§ 137-H:1-.16 (1996); N.J. STAT. ANN. §§ 26:2H-53 to -77 (West 1996); N.M. Stat. Ann. §§ 24-7A-1 to -16 (LexisNexis 2000); N.Y. PUB. HEALTH LAW §§ 2960-2983 (McKinney 2005); N.C. GEN. STAT. §§ 32A-8 to -14 (2003); N.D. CENT. CODE §§ 23-06.4-01 to -14, 23-06.5-01 to -18 (2002); OHIO REV. CODE ANN. §§ 2133.01-.26 (LexisNexis 2002 & Supp. 2005); OKLA. STAT. ANN. tit. 63, §§ 3101.1-.16 (West 2004 & Supp. 2005); OR. REV. STAT. §§ 127.005-.995 (2001); 20 PA. CONS. STAT. ANN. §§ 5401-5416 (West Supp. 2005); R.I. GEN. LAWS §§ 23-4.10-1 to -12, 23-4.11-1 to -15 (2001 & Supp. 2004); S.C. CODE ANN. §§ 44-77-10 to -160 (2002 & Supp. 2004); S.D. CODIFIED LAWS §§ 34-12D-1 to -22 (1994); TENN. CODE ANN. §§ 32-11-101 to -112 (2001 & Supp. 2004); TEX. HEALTH & SAFETY CODE ANN. §§ 166.001-.166 (Vernon 2001 & Supp. 2004-2005); UTAH CODE ANN. §§ 75-2-1101 to -1119 (1993 & Supp. 2005); VT. STAT. ANN. tit. 18, §§ 5251-5262 (Supp. 2004); VA. CODE ANN. §§ 54.1-2981 to -2993 (2005); WASH. REV. CODE ANN. §§ 70.122.010-.920 (West 2002 & Supp. 2005); W. VA. CODE ANN. §§ 16-30-1 to -24, 16-30C-1 to -16 (LexisNexis 2001 & Supp. 2004); WIS. STAT. ANN. §§ 154.01-.29 (West 1997 & Supp. 2004); WYO. STAT. ANN. §§ 35-22-101 to -416 (2005).

55. U.S. CENSUS BUREAU, ABILITY TO SPEAK ENGLISH: 2000, http://factfinder.census.gov/servlet/SAFFPeople?_sse=on (follow "Ability to Speak English" hyperlink) (last visited Nov. 26, 2005) (showing that, according to the 2000 U.S. Census, 4,414,840 people over age 65 do not speak English at home, and 2,340,868 of that segment speak English less than "very well"); see, e.g., Jane Adler, *Try Finding a Home When You Can't Speak English*, CHI. TRIB., Apr. 4, 2004, at 3A (estimating that 40,000 LEP elderly individuals live in the Chicago area).

56. See Erin Hoover Barnett, *Study Depicts More Diverse Older America*, THE OREGONIAN, Aug. 10, 2000, at A01.

older.⁵⁷ Of those, 3.1 million are foreign-born.⁵⁸ Further census data shows that while one-third of the current foreign-born elder population came from Europe, by 2020, most of the foreign-born elder population will probably be from non-English-speaking countries in Latin America and Asia.⁵⁹ Since 1965, the United States has experienced a sharp influx of Latin American and Asian immigrants of all ages.⁶⁰ Assuming that the current immigration patterns do not change drastically, the number of older Latin American and Asian individuals in this country will continue to grow rapidly.⁶¹

In its Special Tabulation on Aging report, the U.S. Census Bureau reports that over 1.8 million individuals over the age of sixty indicated that their ability to speak English was either “not well” or “not at all.”⁶² With the increase in foreign-born older individuals residing in the United States from non-English-speaking countries, the number of LEP individuals is very likely to increase.⁶³ For example, in New York City, 49% of senior citizens, in general, would be considered LEP.⁶⁴ In comparison, 73% of Korean senior citizens⁶⁵ and 85% of Chinese senior citizens in New York fall into the census category of LEP.⁶⁶ These groups represent a mere snapshot of national urban demographics.

LEP senior citizens, like their English-speaking peers, have a substantial interest in the application of advance directive legislation. While the PSDA applies to all adults, “senior citizens have a signifi-

57. U.S. CENSUS BUREAU, AGE GROUPS AND SEX: 2000, http://factfinder.census.gov/servlet/SAFFPeople?_sse=on (follow “Age and Sex” hyperlink) (last visited Oct. 10, 2005).

58. See He, *supra* note 10, at 1.

59. *Id.* at 3.

60. See Elizabeth Llorente, *Half of U.S. Will Be ‘Minority’ in 2050, Census Estimate Says; Hispanics, Asians Expected to Triple*, THE RECORD (Bergen County, N.J.), Mar. 18, 2004, at A.

61. *Id.*

62. U.S. CENSUS BUREAU, CENSUS 2000: SPECIAL TABULATION ON AGING tbl.0017, available at http://www.aoa.gov/prof/statistics/tab/NV/P017_NV.XLS.

63. See He, *supra* note 10, at tbl.1.

64. Press Release, Asian Am. Fed’n, Recent Immigration, Limited English Skills and Elderly Poverty Common Among Korean American New Yorkers, Census Analysis Shows (Apr. 21, 2004), <http://www.aafny.org/proom/pr/pr20040421.asp> (stating information about Asian American senior citizens obtained from the 2000 U.S. Census report).

65. *Id.*

66. Press Release, Asian Am. Fed’n, Chinese Americans—Largest Asian American Group in New York City—Have Lower Incomes, Education Levels and English Skills than City’s Overall Population, Census Analysis Reveals (Oct. 14, 2004), <http://www.aafny.org/proom/pr/pr20041014.asp>.

cantly greater awareness of, and interest in, advance health care directives.”⁶⁷ For example, senior citizens are far more likely to have executed an advance directive than their younger counterparts.⁶⁸ Thus, as the elderly population grows more diverse, the importance of understandable advance directives will likewise increase.

III. Analysis

A. The Practical Problems with English-Only Advance Directives

Because the PSDA does not stipulate that written information about advance directives be available in an elderly patient’s native language, it is unlikely that all hospitals, nursing homes, and other home health care providers will implement their own translation programs to serve all of their patients’ needs.⁶⁹ This situation creates a number of problems for both the patient and the health care facility. First, LEP patients who do not understand what they have or have not agreed to cannot be said to have given “informed consent” because linguistic barriers would have prevented any true acquisition of knowledge.⁷⁰ Second, health care facilities that do not have translated written materials may relinquish the duty of translating the information about end-of-life treatment decisions to an untrained translator (usually a friend or family member), which could lead to distorted or omitted information.⁷¹ Third, without properly translated information, health care facilities are not only treating a growing number of patients unfairly, but they are also flirting with a violation of Title VI of the Civil Rights Act of 1964.⁷² Without some further stipulation of linguistic accommodation to elderly LEP patients, the PSDA fails to provide any service to its elderly non-English-speaking patrons.

67. Kaplan, *supra* note 5, at 36.

68. *Id.*

69. Thaddeus Mason Pope, *The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act*, 9 HEALTH MATRIX 139, 184 (1999).

70. *Id.* at 181.

71. See Barbara Plantiko, *Not-So-Equal Protection: Securing Individuals of Limited English Proficiency with Meaningful Access to Medical Services*, 32 GOLDEN GATE U. L. REV. 239, 240 (2002).

72. See ASS’N OF WASH. PUB. HOSP. DIST., WASH. STATE HOSP. ASSOC., END OF LIFE CARE MANUAL § 1 (2001), <http://www.awphd.org/EndOfLife/manual/1.asp> [hereinafter AWPHE].

1. A LACK OF UNDERSTANDING MEANS A LACK OF CONSENT

Executing an advance directive not only expresses a patient's wishes for end-of-life treatment, it also exercises the patient's right to consent to the performance or nonperformance of certain medical procedures.⁷³ This raises a question: if an LEP senior citizen chooses to sign a form for an advance directive without fully understanding the ramifications of his or her signature, has he or she given consent to the document's stipulations? Scholars are at odds with the current health care system⁷⁴ and each other⁷⁵ over the requisite amount of information a patient must have in order to give consent when executing an advance directive. One thing, however, is clear—unassisted LEP patients are not receiving sufficiently understandable information to give consent in an advance directive.

Advance directives and consent are closely entwined concepts. In fact, advance directives grew out of the right to consent to medical treatment.⁷⁶ In *Cruzan*, the Court avowed the sacred "right of every individual to the possession and control of his own person"⁷⁷ and went further to affirm the "right *not* to consent, that is, to refuse [medical] treatment."⁷⁸ The Court subsequently upheld and clarified its emphasis on the filial relationship between advance directives and informed consent in *Washington v. Glucksberg*⁷⁹ by stating that "[t]he right assumed in *Cruzan*, however, was not simply deduced from abstract concepts of personal autonomy,"⁸⁰ but rather from "the common-law rule that forced medication was a battery, and the long legal tradition protecting the decision to refuse unwanted medical treatment."⁸¹ The courts have since uniformly upheld "the prerogative of competent patients to reject life-sustaining medical intervention," and "[i]n so doing, they look to the doctrine of informed consent, a doc-

73. Pope, *supra* note 69, at 184.

74. *Id.* at 180–81.

75. *See id.* at 167–80 (summarizing at least three opposing positions regarding advance directives and informed consent).

76. *Id.* at 184.

77. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 269 (1990).

78. *Id.* at 270 (emphasis added).

79. 521 U.S. 702, 725 (1997) (analyzing the *Cruzan* decision and reaching the conclusion that while the right to refuse treatment enjoys constitutional protection, the right to assisted suicide does not).

80. *Id.*

81. *Id.*

trine based on notions of bodily integrity.”⁸² If the right of autonomy espoused by advance directives and codified in the PSDA hinges on the doctrine of informed consent, then the right of LEP elderly patients is severely threatened if health care providers do not supply properly translated information.

On a practical level, the requirement for informed consent is often overlooked because hospitals and health care providers have assumed that a patient need only be *competent* when he or she executes an advance directive to show the requisite amount of consent to anything stated in the document.⁸³ The concept of consent as it applies to the advance directive is intertwined with the concept of mental capacity.⁸⁴ Informed consent laws state that competency hinges on the patient’s ability to understand his or her options.⁸⁵ This is a critical issue because “an individual needs to possess adequate competency . . . to complete written advance directives.”⁸⁶ While adequate legal competency generally includes the ability to understand the “diagnosis, prognoses, and options,”⁸⁷ the question still remains whether LEP senior citizens are competent and therefore informed if they are capable of understanding the information but not in the language in which it is presented.

One response is that while current “[l]egal doctrine governing end-of-life medical care starts with the competent patient,”⁸⁸ it should not end there as well.⁸⁹ Mere competence and a signed advance directive are not enough.⁹⁰ Patients must fully understand the ramifications of the document in order for it to have effect.⁹¹ While some courts have recognized that a patient’s inability to communicate with a health care professional due to language barriers “obstruct[s] a pa-

82. Norman L. Cantor, *The Real Ethic of Death and Dying*, 94 MICH. L. REV. 1718, 1729 (1996).

83. Pope, *supra* note 69, at 184.

84. James H. Pietsch & Kathryn L. Braun, *Autonomy, Advance Directives, and the Patient Self-Determination Act*, in CULTURAL ISSUES IN END-OF-LIFE DECISION MAKING 37, 45 (Kathryn Braun et al. eds., 2000) (discussing the issue of competency and advance directives for adults in general).

85. *Id.*

86. *Id.*

87. *Id.*

88. Cantor, *supra* note 82, at 1729.

89. See Pope, *supra* note 69, at 141, 157 (explaining that hospitals merely apply the black letter of the law and do little or nothing to ensure that patients receiving PSDA-mandated information actually understand it).

90. *Id.* at 183.

91. *Id.* at 160–61.

tient's ability to give informed consent" in general medical settings,⁹² no precedent exists regarding LEP elderly patients and advance directives. Still, it seems that because the Supreme Court has already stated that the right to consent to treatment and the right to refuse treatment are logical corollaries,⁹³ the same factors used to determine the former ought to be used to determine the latter. In other words, if language barriers obstruct the ability of an LEP patient to consent to treatment, then those barriers logically obstruct the ability of an LEP patient to *refuse* treatment via an advance directive because the patient would not be properly informed about the document's ramifications.

Moreover, the uninformed advance directive raises the frightening specter of medical treatment ceasing against a patient's wishes. "[A]dvance directives can . . . be hazardous if written without understanding,"⁹⁴ given that many courts place substantial weight on signed advance directives as evidence of an individual's terminal treatment preferences.⁹⁵ Such judicial interpretations could result in disastrous situations in which courts presume consent from a signed directive, despite a lack of understanding on the part of LEP seniors at the time of signing. Unfortunately, this scenario may be frighteningly common, especially because the PSDA requires that advance directive information be delivered at the time of hospital admission.⁹⁶ Patients are often overwhelmed at admission and suffering from illness or trauma.⁹⁷ In addition, patients are dealing with an onslaught of paperwork, including medical histories and health insurance docu-

92. Plantiko, *supra* note 71, at 242; *see, e.g.*, *Powers v. United States*, 589 F. Supp. 1084, 1098 (D. Conn. 1984) (where a doctor's inability to speak understandable English left a patient too uninformed to have given consent to a medial procedure); *Dandashi v. Fine*, 397 So. 2d 442, 446 n.5 (Fla. Dist. Ct. App. 1981) ("a 'language barrier' . . . lends additional credence to [a patient's] claimed lack of informed consent").

93. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 270 (1990) ("The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment.").

94. Pope, *supra* note 69, at 167 (quoting Joanne Lynn & Joan M. Teno, *Advance Directives*, in *ENCYCLOPEDIA OF BIOETHICS* 572, 575 (Warren T. Reich ed., 1995)).

95. *See, e.g.*, *In re Martin*, 538 N.W.2d 399, 410 (Mich. 1995) ("Among the factors identified as important in defining clear and convincing evidence . . . the predominant factor is 'a prior directive in which the patient addresses the situations in which the patient would prefer that medical intervention cease.'" (citations omitted)).

96. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204 to -205.

97. Pope, *supra* note 69, at 156.

ments.⁹⁸ Advance directive information could easily appear to be nothing more than another line to sign and date, especially Do Not Resuscitate Orders, which are often brief, full of medical terms, and look like any other form urging the reader to fill in the blanks.⁹⁹

Without proper translation of advance directive documents, the right of LEP patients to determine their own end-of-life care is in jeopardy. Currently, the health care system's minimal threshold for determining advance directive¹⁰⁰ consent exposes LEP senior citizens to further danger because language capacity may not be taken into consideration as a matter of competence.¹⁰¹ Based on the historical application of the PSDA's distribution of materials requirement in health care facilities,¹⁰² it seems unlikely that this precarious situation will improve unless legislative changes compel it to do so.

2. THE NEGATIVE IMPACT OF ILL-QUALIFIED TRANSLATORS

Because state programs are not required by the PSDA to provide translated advance directive literature or forms, health care facilities find themselves in the unenviable position of either translating the material themselves or providing them in English, the latter of which proves to be of very little use to the patient. No matter how thorough and appropriate the information in the materials, it cannot inform a patient if he or she cannot understand the content.¹⁰³ Health care providers will sometimes leave the responsibility of translation to family members and friends,¹⁰⁴ this is a situation with its own host of problems and dangers.¹⁰⁵ Untrained translators often translate incorrectly;¹⁰⁶ other times they are unavailable entirely.¹⁰⁷ Using family

98. See Emedicine, Hospital Admission, <http://www.emedicinehealth.com/articles/11983-2.asp> (last visited Oct. 10, 2005) (advising potential patients on what kinds of documents and information they should bring to the hospital for admission).

99. See, e.g., Univ. of Mich. Health Sys., Do-Not-Resuscitate Order, available at <http://www.michbar.org/elderlaw/pdfs/dnr.pdf> (last visited Oct. 10, 2005).

100. See Pope, *supra* note 69, at 164.

101. Pietsch & Braun, *supra* note 84, at 45 (noting that, under current law, determining competence is a matter of mental capacity).

102. See Pope, *supra* note 69, at 157 (noting that hospitals merely follow the black letter of the law).

103. *Id.* at 190 (referring to all patients regardless of English proficiency).

104. Plantiko, *supra* note 71, at 240.

105. See Jane E. Allen, *Worlds and Words Apart*, L.A. TIMES, Nov. 6, 2000, Part S (Health), at 1 (commenting that untrained interpreters often inaccurately translate or editorialize doctors' instructions or diagnoses, which can lead to misunderstanding of the problem and/or the treatment).

106. Plantiko, *supra* note 71, at 240.

members or friends may also present a conflict with cultural norms.¹⁰⁸ This problem could be substantially eliminated if patients were provided with appropriate written information in their native language.

Often in the medical context, doctors and other health care providers rely on family members or even any available person to translate to LEP patients.¹⁰⁹ Such arrangements create numerous difficulties that hinder effective communication of both the content of written information contained in the advance directive and the true wishes of the patient.¹¹⁰ As stated, without effective communication and information, the legitimacy of an elder LEP patient's advance directive, or lack thereof, may be questionable.

On a technical level, allowing family members or friends to interpret "has been associated with omissions, additions, substitutions, volunteered opinions, and semantic errors that can seriously distort translation."¹¹¹ In particular, patients' children or grandchildren, who likely learned English in school, tend to be "prone to omissions, additions and guessing."¹¹² Also, friends and family members, who themselves may lack proficiency, often fall into the translator role by default because they happen to have a better handle on the English language than the LEP patient.¹¹³

An even more frightening prospect arises from the possibility that a translator might understand the information provided by the hospital and purposefully deliver inaccurate information to the elderly LEP patient. For example, an elderly LEP Japanese woman suffering from an obstructing bronchial squamous cell carcinoma was

107. See Lisa C. Ikemoto, *Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS U. L.J. 75, 84 (2003) (discussing, in general, the inability of LEP patients to access medical care due to language barriers and lack of translation).

108. See, e.g., *id.* at 87 (noting that issues of women's health in Korean culture are extremely private and rarely discussed, even to physicians, and are never discussed with outsiders of the opposite sex).

109. JANE PERKINS, KAISER COMM'N ON MEDICAID & THE UNINSURED, ENSURING LINGUISTIC ACCESS IN HEALTH CARE SETTINGS: AN OVERVIEW OF CURRENT LEGAL RIGHTS AND RESPONSIBILITIES 4 (Aug. 2003), available at <http://www.kff.org/uninsured/upload/Ensuring-Linguistic-Access-in-Health-Care-Settings-An-Overview-of-Current-Legal-Rights-and-Responsibility-PDF.pdf>.

110. See Ikemoto, *supra* note 107, at 84 (referring to patient participation in his or her own medical treatment in general).

111. PERKINS, *supra* note 109, at 4.

112. Plantiko, *supra* note 71, at 240.

113. See Stuart D. Zimring, *Multi-Cultural Issues in Advance Directives*, NAT'L ACAD. ELDER L. ATT'YS Q., Summer 2000, at 14 (noting that the "spokesperson" of the family in medical settings is sometimes the individual who speaks English better than the other members of the family).

admitted to her local hospital for treatment.¹¹⁴ Her family designated her youngest son, who spoke the best English, to be the spokesperson, but the son refused to discuss the condition with his mother, who was subsequently discharged without appropriate treatment.¹¹⁵ Following discharge, the patient's condition drastically deteriorated until her family finally insisted on aggressive treatment during the last stages of the illness.¹¹⁶ Unfortunately, by that time it was too late and doctors could do nothing for her.¹¹⁷ In similar situations, family and friend translators realistically could horde this kind of power over elderly LEP patients in the context of executing an advance directive by refusing to translate the information. Worse yet, the translator could instruct the patient to sign forms that he or she otherwise would not have signed or unknowingly designate the translator as the durable power of attorney for health care. Advance directive documents executed in these contexts are completely contrary to the purpose of the PSDA because the purpose of an advance directive is defeated if it does not reflect what the patient actually wants.¹¹⁸

Furthermore, proper translation of advance directive information is extremely difficult for cultures that do not observe or place significant value on an individual's right to make end-of-life choices.¹¹⁹ In fact, "not every culture . . . places as much emphasis on the right of self-determination . . . as the mainstream American culture does" and "some [cultures] do not consider it a value at all."¹²⁰ Consequently, translation may prove even more nettlesome for untrained translators who are unfamiliar with advance directive terminology.

In addition, family members or friends are not always available to translate. Moreover, health care professionals may find that bilingual family members or friends have personal or social objections to translating between the doctor and the elder patient.¹²¹ If professional translators are not available, hospitals are left in an unfortunate position. In rare instances, hospitals have been known to ask complete strangers with no medical expertise to translate when a more appro-

114. *Id.* at 13–14 (citing Gwen Yeo, *Ethical Considerations in Asian and Pacific Island Elders*, 11 *CLINICS IN GERIATRIC MED.* 141 (1995)).

115. *Id.*

116. *Id.*

117. *Id.*

118. Pope, *supra* note 69, at 156–57.

119. See Zimring, *supra* note 113, at 14.

120. *Id.* at 12.

121. Ikemoto, *supra* note 107, at 85.

priate option was unavailable.¹²² If even this inappropriate form of translation is unavailable, then the only option that health care facilities have is to deliver the information about advance directives to the patient in English.¹²³ Of course, this amounts to not providing the information at all and consequently renders the PSDA toothless as a safeguard for the rights of the LEP elderly.

The use of untrained translators can also run afoul of cultural norms. Admittedly, not all members of certain cultures living in the United States speak limited English, but demographic trends suggest that an increasing number of immigrants will come from non-English-speaking countries, likely increasing the number of LEP individuals among those groups.¹²⁴ Many individuals of non-English-speaking cultures, in particular some Asian cultures, observe stricter social rules on communication between individuals and nonfamily members,¹²⁵ as well as between individuals who are of two different ages, than mainstream American culture.¹²⁶ For example, Mexican Americans often consider medical decisions to be a family affair,¹²⁷ and thus translation through a family member may be well received and even preferred.

When cultural norms dictate end-of-life decisions, understanding and execution of the appropriate advance directive documentation is critical for LEP seniors. Elderly individuals may *want* to surrender medical decisions to a family member, and they may, in fact, feel that "the exercise of . . . autonomy means being able to relinquish it."¹²⁸ Advance directives offer a means for ensuring that those wishes are honored.¹²⁹ Either through designation of durable power of attorney

122. See, e.g., *id.* at 87.

123. See generally *id.* at 83–86 (discussing the existence of an English-only monoculture in the U.S. health care system).

124. He, *supra* note 10, at 3 (predicting most foreign-born elderly will be Asian and Latin American immigrants in the coming years).

125. Elysa Gordon, Note, *Multiculturalism in Medical Decisionmaking: The Notion of Informed Waiver*, 23 *FORDHAM URB. L.J.* 1321, 1344–45 (1996) (remarking that in some Asian cultures, individuals do not consult with persons outside the family regarding personal medical matters); see also Zimring, *supra* note 113, at 12 (noting that health care for persons with Asian, Pacific Islander, and Mexican American backgrounds often have a strong family focus).

126. Ikemoto, *supra* note 107, at 87.

127. Gordon, *supra* note 125, at 1345–46 & n.138 (explaining that family may include extended family or special friends); see also Zimring, *supra* note 113, at 12–13.

128. Atul Gawande, *Whose Body Is It Anyway?*, *NEW YORKER*, Oct. 4, 1999, at 89.

129. See Zimring, *supra* note 113 (suggesting various amendments that could be made to advance directives to accurately reflect an LEP patient's wishes).

for health care or flexible advance directive stipulations (depending on state law), elderly LEP patients can designate someone to make their terminal care decisions for them.¹³⁰ However, LEP seniors are increasingly unlikely to sign an advance directive, even if they might have wanted to, if they have incomplete or inaccurate information about their rights.¹³¹

Without a federal or state mandate, health care facilities are likely to continue to allow unofficial translation by friends, family members, and even strangers. The problems that result from informal translation range from inaccuracy to violation of cultural customs to abuse of trust. Elderly LEP patients are consequently stripped of autonomy over their end-of-life care decisions, the very autonomy the PSDA purports to protect.

3. LACK OF UNDERSTANDING CREATES DISCRIMINATION

Failing to provide advance directive information as prescribed by the PSDA may also risk violation of Title VI of the Civil Rights Act of 1964 (Title VI). Title VI protection against discrimination has broad reach over government entities and beneficiaries,¹³² and the statute's language implies that PSDA-mandated documents fall within its shadow. Subsequent agency literature further supports Title VI application to PSDA-required documents and that the PSDA should be amended to clarify this application.

Title VI prohibits discrimination against individuals "on grounds of race, color, or national origin" by any program or activity receiving federal funding.¹³³ Subsequently, in *Lau v. Nichols*,¹³⁴ the Supreme Court broadened the coverage of Title VI by determining that language-based discrimination should be treated as national origin discrimination.¹³⁵ In that case, the Court maintained that federally

130. *Id.*

131. See Larson & Eaton, *supra* note 25, at 185.

132. "No person . . . shall, on the ground of race, color, or national origin, be excluded from participation, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." 42 U.S.C. § 2000d (2000) (emphasis added).

133. *Id.*

134. 414 U.S. 563 (1975).

135. *Id.* at 566 (concluding that provision of English-only materials in the publicly funded school setting denied meaningful access to education and therefore constituted discrimination); see also Perkins, *supra* note 109, at 5 ("The federal government has long recognized that Title VI requires language access . . . [T]he fed-

funded programs treated LEP participants unequally by providing English-only materials,¹³⁶ and such LEP participants were “effectively foreclosed from any meaningful” benefit from the program.¹³⁷

Furthermore, federal agencies also found themselves bound to the provisions of Title VI when President Clinton issued Executive Order 13,166 in 2000.¹³⁸ That order extended the standards that apply to federally funded programs to agencies¹³⁹ and required that all agencies draft Title VI guidance for any program or entity to which the agency granted federal funds.¹⁴⁰

One can conclude from *Lau* and Executive Order 13,166 that Title VI was intended to cover federally funded programs, and yet the question remains whether PSDA-mandated information falls under the provisions of Title VI. At this point, no legal authority has considered the application of the PSDA in light of Title VI. However, interpretive guidelines produced by the Centers Medicare & Medicaid Services (CMS) strongly indicate that health care providers must abide by Title VI standards when distributing PSDA-mandated information regarding advance medical directives.¹⁴¹

Regardless, failure to provide information mandated by the PSDA in languages other than English should be considered discrimination under Title VI. Title VI prohibits discrimination based on ethnic origin, and, as previously discussed, failure to adequately serve an entire group of people because they are unable to speak English constitutes ethnic origin discrimination.¹⁴² Accordingly, LEP elders who cannot obtain information regarding advance directives are effectively foreclosed from the benefits that the PSDA seeks to provide.¹⁴³

PSDA programs also fall squarely under Title VI. Title VI applies to “any program or activity receiving Federal financial assis-

eral government has repeatedly recognized the need for federal fund recipients to offer meaningful language access.” (citation omitted)).

136. *Lau*, 414 U.S. at 566.

137. *Id.*

138. Exec. Order No. 13,166, 65 Fed. Reg. 50,121 (Aug. 11, 2000).

139. *Id.*; see also Perkins, *supra* note 109, at 8.

140. Exec. Order No. 13,166, 65 Fed. Reg. at 50,121; see also Perkins, *supra* note 109, at 7.

141. See CTRS. FOR MEDICARE & MEDICAID SERVS., DEP'T OF HEALTH & HUMAN SERVS., STATE OPERATIONS MANUAL, PUBL'N NO. 7, SURVEY PROTOCOL, REGULATIONS AND INTERPRETIVE GUIDANCE FOR HOSPITALS app. A § 482.13(a) (2004), available at http://www.cms.hhs.gov/manuals/107_som/som107ap_a_hospitals.pdf (last visited Oct. 10, 2005) [hereinafter STATE OPERATIONS MANUAL].

142. See *supra* notes 133–37 and accompanying text.

143. See discussion *infra* Part III.B.

tance”¹⁴⁴ either directly or indirectly.¹⁴⁵ Moreover, it applies to state and local agencies that distribute federal funds.¹⁴⁶ This is significant because the PSDA applies to any “hospital, nursing facility, provider of home health care or personal care services, hospice program, or health maintenance organization” that receives funds from Medicare.¹⁴⁷ An entity that accepts Medicare payments is receiving federal funding and therefore qualifies as a “program or activity” under Title VI.¹⁴⁸ Further, the PSDA was passed as part of the federal Omnibus Budget Reconciliation Act of 1990 under the heading of Medicare, Medicaid, and Other Health-Related Programs.¹⁴⁹ Thus it becomes clear that *every* entity subject to the PSDA falls under Title VI standards.¹⁵⁰ It would lead to an absurd result to conclude that Congress meant for the PSDA to apply to the same federally funded medical programs as Title VI without carrying the guarantees of Title VI. Even if PSDA-mandated information does not afford nondiscrimination protection by definition, it should be noted that “Title VI protections extend to all of the operations of the organization . . . , not just that portion that received the federal funds.”¹⁵¹ Therefore, even though health care facilities do not receive Medicare funds to aid in distributing information about advance directives, Title VI protection may still apply to that function of the facility.

Moreover, interpretive guidelines produced by CMS support the proposition that information regarding advance directives is covered by Title VI’s protection against national origin discrimination.¹⁵² The guidelines require the hospital to inform “each patient of his or her rights in a language . . . that the patient understands For example, the patient must be given notice of the rights afforded to him/her . . . including the right to formulate an advance directive.”¹⁵³ Further, the guidelines state that in providing information about advance directives, the “hospital agrees to comply with Civil Rights laws

144. 42 U.S.C.A. § 2000d (2003 & Supp. 2005).

145. *Id.* § 2000d-4a.

146. *Id.* § 2000d-4a(1)(B).

147. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204.

148. See PERKINS, *supra* note 109, at 5.

149. Omnibus Budget Reconciliation Act of 1990 § 4751, 104 Stat. at 1388-204.

150. See PERKINS, *supra* note 109, at 5.

151. *Id.*

152. STATE OPERATIONS MANUAL, *supra* note 141, § 482.13(a)(1); see also AWPFD, *supra* note 72.

153. STATE OPERATIONS MANUAL, *supra* note 141, § 482.13(a)(1).

that assure that it will provide interpretation for certain individuals who speak languages other than English.”¹⁵⁴ While interpretive guidelines lack the force of law,¹⁵⁵ they provide an important insight into agency treatment of the administration of their programs.¹⁵⁶ Thus, it appears that CMS, the administrator of Medicare, recognizes a Title VI responsibility to provide translated PSDA-mandated materials to LEP elderly patients.

Nonetheless, merely recognizing that PSDA-mandated information falls under the standards of Title VI is only the first step in securing the rights of LEP elderly patients. Knowing that individuals have rights to translated materials about advance directives does not guarantee enforcement of Title VI standards. In fact, recent developments in Title VI interpretation have drastically curbed the capacity of private persons to seek judicial remedy when their rights are violated.¹⁵⁷ Specifically, the Supreme Court determined in *Alexander v. Sandoval*¹⁵⁸ that Congress did not intend to grant a Title VI private right of action to individuals.¹⁵⁹ Additionally, Executive Order 13,166 explicitly states that no judicial remedy exists for LEP individuals suffering from agency or program disobedience of the Order.¹⁶⁰

Essentially, even if Title VI protects PSDA-related information, the only remedy for a Title VI violation is the termination of federal funding by the controlling agency or other means authorized by law.¹⁶¹ This limitation places the enormous burden of Title VI enforcement on the already underfunded and understaffed Health and

154. *Id.* (referring to information regarding all patients’ rights, including specifically the right to formulate an advance directive).

155. *Mercy Catholic Med. Ctr. v. Thompson*, 380 F.3d 142, 154 (3d Cir. 2004).

156. See CTRS. FOR MEDICARE & MEDICAID SERVS., DEP’T OF HEALTH & HUMAN SERVS., THE CMS ONLINE MANUAL SYSTEM, <http://www.cms.hhs.gov/manuals> (last visited Oct. 10, 2005) (indicating what State Operating Manuals are and how they are used).

157. See *infra* notes 158–59 and accompanying text.

158. 532 U.S. 275 (2001).

159. *Id.* at 290 (“Whatever these elaborate restrictions on agency enforcement may imply for the private enforcement of rights created *outside* of § 602, . . . they tend to contradict a congressional intent to create privately enforceable rights through § 602 itself. The express provision of one method of enforcing a substantive rule suggests that Congress intended to preclude others.”).

160. Exec. Order No. 13,166, 65 Fed. Reg. 50,121, 50,122 (Aug. 11, 2000) (stating in relevant part that “[t]his order is intended only to improve the internal management of the executive branch and does not create any right or benefit, substantive or procedural, enforceable at law or equity by a party against the United States, its agencies, its officers or employees, or any person.”).

161. See *Sandoval*, 532 U.S. at 289–90; see also PERKINS, *supra* note 109, at 6–7.

Human Services Office of Civil Rights.¹⁶² The lack of a viable remedy underscores even more the critical need for amendment to the PSDA itself, thereby providing a double warning to health care providers concerning their obligations to provide understandable end-of-life care information to LEP elderly patients.

B. The Lack of LEP Accommodation Defeats the Purpose of the Patient Self-Determination Act

The legislative history of the PSDA in both the Senate and the House of Representatives makes clear that the primary objective of mandatory written policies on advance directive rights is to empower individuals through education. Indeed, Senator Danforth and Representative Levin both stressed that the PSDA was meant to provide one thing: information. Informing people about advance directives, insisted Senator Danforth, was “[t]he first step in patient self-determination.”¹⁶³ Representative Levin asserted that the PSDA was meant to provide individuals with the necessary information to take the appropriate steps toward making their end-of-life treatment preferences known.¹⁶⁴ In an editorial published in the *Washington Post*, Representative Levin stated that the PSDA would “help all of us become more aware of ways to communicate our wishes more clearly.”¹⁶⁵

Information, however, does not lead to knowledge if it cannot be understood,¹⁶⁶ and LEP elderly patients struggle with understanding documents that are only in English.¹⁶⁷ The result is that LEP patients will know less about their terminal care rights and consequently fail to execute advance directives.¹⁶⁸ For example, studies have found that Hispanics are less likely to know about advance directives than non-Hispanic whites and African Americans.¹⁶⁹ By leaving these individu-

162. PERKINS, *supra* note 109, at 7.

163. Larson & Eaton, *supra* note 25, at 257 (quoting a press release by Sen. John C. Danforth).

164. *Id.*

165. Sander M. Levin, Editorial, *So That There Will Be No More Nancy Cruzans*, WASH. POST, July 6, 1990, at A23.

166. See Cantor, *supra* note 82, at 1729.

167. See Plantiko, *supra* note 71, at 239–40 (noting that LEP patients struggle to gain access to health care because of an “English-only” policy).

168. See Larson & Eaton, *supra* note 25, at 277 (stating in general that the rates of completion of advance directives correlate proportionately with awareness).

169. See G. Paul Eleazer et al., *The Relationship Between Ethnicity and Advance Directives in a Frail Older Population*, 44 J. AM. GERIATRICS SOC’Y 938 (1996); David

als with insufficient information sources about advance directives, the PSDA betrays its own objectives for an entire segment of the elderly population. A Government Accounting Office (GAO) report revealed that a relationship exists between “the public’s awareness of advance directives and completion rates.”¹⁷⁰ Although the percentage of adults who have completed advance directives remains relatively low, the GAO report suggests that without proper education on end-of-life care rights, almost no advance directives would be completed.¹⁷¹ When LEP adults receive information in English, it is virtually the same as not having received the information at all, and consequently, according to the GAO report rationale, LEP elders are unlikely to execute an advance directive.¹⁷²

However, there may be situations in which LEP elders do execute advance directives, albeit without properly translated information. As previously noted, elderly LEP patients may find themselves in a position where a family member or other translator is able to provide some form of translation of the information regarding terminal care rights.¹⁷³ But these informal or incompetent translators often fail to translate accurately or appropriately.¹⁷⁴ This presents a serious problem: if LEP patients complete advance directives without proper translation and understanding, “the formal requirements of the PSDA will fail to protect patient autonomy.”¹⁷⁵

IV. Resolution

Ideally, each health care provider would staff multilingual translators who could personally navigate elderly LEP patients through the process of terminal care decisions while documenting those decisions

Orentlicher, *Symposium: Trends in Health Care Decisionmaking: The Limits of Legislation*, 53 MD. L. REV. 1255, 1276 (1994) (citing Paul V. Caralis et al., *The Influence of Ethnicity and Race on Attitudes Towards Advance Directives, Life-Prolonging Treatments, and Euthanasia*, 4 J. CLINICAL ETHICS 155 (1993)); Linda J. Romero et al., *Influence of Ethnicity on Advance Directives and End-of-Life Decisions*, 277 JAMA 298, 298 (1997).

170. Larson & Eaton, *supra* note 25, at 277.

171. *Id.*

172. *See id.*

173. PERKINS, *supra* note 109 (noting that LEP patients often have friends or family members translate in medical settings in general).

174. *See id.*; Plantiko, *supra* note 71, at 240.

175. Pope, *supra* note 69, at 144 (referring to individuals in general who sign advance directives without comprehensive understanding of the content of the document).

for later access.¹⁷⁶ However, because we live in neither an ideal world, nor on an ideal budget, a more practical solution lies in the hands of federal and state legislators. Congress should amend the PSDA to include a stipulation that health care providers receiving Medicare and Medicaid funds provide translated documents or a means for translating documents about state advance directive laws. States should continue to be responsible for ensuring that the requirements of the PSDA are properly met within their borders. Working together, the federal and state governments can effect a meaningful change to ensure elderly LEP patients protection under the PSDA.

A. A Federal Change in Policy

The application and codification of advance directive forms has always been left in the hands of the states, but not all states are fulfilling their duty to protect their residents' end-of-life autonomy. Additionally, current advance directive policy, in which each state has its own statute, has already created a troublesome lack of uniformity throughout the country.¹⁷⁷ To leave the option of translating materials solely to the discretion of state legislatures would likely result in only a few, if any, initiatives to enact appropriate and needed changes. Alternatively, sole discretion in the states could result in radically different policies, leading to questions concerning the interstate validity of executed advance directives. Therefore, the best solution is for Congress to amend the PSDA to require that states ensure that information on advance directives be provided in appropriate language translations in all hospitals and health care facilities.

B. State Implementation

While Congress should instruct the states to enact legislation providing greater access to information for LEP individuals, it is best left to the states to implement such plans. Allowing states to coordinate implementation will allow for programs tailored to the needs of individual states. For example, foreign-born elderly individuals tend

176. See Gina Rollins, *Helping Hands*, HOSP. & HEALTH NETWORKS, May 2004, at 22, 24 (discussing the benefits of personal interaction and guidance between LEP patients and in-hospital translators).

177. Pietsch & Braun, *supra* note 84, at 47–48 (explaining how differing state legislation affects the validity of advance directives executed by older persons that often partake in interstate travel).

to be concentrated in coastal states,¹⁷⁸ primarily in the West,¹⁷⁹ while Texas and Florida have the fastest growing Latino populations.¹⁸⁰ These demographic variations will necessitate different plans in different states to best accommodate their respective citizens.

Opponents may argue that LEP advance directive information policy should be left entirely to hospitals and health care providers. However, requiring individual hospitals to translate and produce multilingual materials creates a net burden across the state. Accordingly, it makes far more sense for state legislation to provide enforcement measures. Admittedly, states are already responsible for the creation of written information regarding advance directives.¹⁸¹ Hiring qualified translators could put an even greater strain on already tight state budgets. However, in light of the need to accommodate all state citizens, the state is in the best position to do so in the most cost-effective way possible.

C. One Model: Centralized Online Data Banks Initiated and Maintained by State Governments

As the world becomes more and more interconnected (especially via the Internet), the burden of providing uniform documents in multiple languages will decrease. Conceivably, states could have written information about advance directives translated once and placed in a central database accessible by all health care facilities that fall under the mandate of the PSDA. This would save the transaction costs of translation, and with a made-to-order database, the state could curb expenses on raw materials. States might also consider charging a periodic nominal fee or a onetime subscription fee to hospitals for use of the service, relieving the cost burden of the translation.

Numerous examples, both at the individual hospital and the state level, prove the viability of internet-accessible translations of advance directives. For example, Temple Community Hospital in Los

178. He, *supra* note 10, at 5.

179. *See id.*

180. Yvette Cabrera, *County Leader in Latino Growth, Business*, DAILY NEWS OF L.A., Sept. 5, 1998.

181. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204 (“[T]he State, acting through a State agency, association, or other private nonprofit entity, [shall] develop a written description of the law of the State (whether statutory or as recognized by the courts of the State) concerning advance directives that would be distributed by providers or organizations . . .”).

Angeles, California, provides an advance directive in Spanish.¹⁸² The file includes a summary,¹⁸³ instructions,¹⁸⁴ and a translated version of an advance directive¹⁸⁵ in compliance with the standards set by the California statute.¹⁸⁶ Another team of health care organizations in California, the Community Health Network of San Francisco's Primary Care Advance Directives Subcommittee and the Providers at Maxine Hall Health Center, have published written information on advance directives in Spanish,¹⁸⁷ and the California Coalition for Compassionate Care has issued an information sheet and form for advance directives in Chinese on its website.¹⁸⁸

While individual hospital and health care provider websites provide specific assistance to their communities, establishing a large-scale document translation database that serves the population of an entire metropolitan area, or better yet, an entire state, is not only theoretically feasible—it has been successfully done.¹⁸⁹ In response to a rapidly increasing number of foreign-born LEP individuals in Missouri, the Missouri Hospitals Association (MHA) launched a website to provide translated materials, including advance directive documents, for hospitals serving LEP populations.¹⁹⁰ The MHA partnered with the Language Access Metro Project (LAMP) of St. Louis to develop accurately translated materials through a grant from the Tenet Healthcare Foundation.¹⁹¹ These materials were published on a website, HealthTranslations.com, which currently lists 427 documents in

182. DIRECTIVA POR ANTICIPAD DE LA ATENCIÓN DE LA SALUD, SECCIÓN 4701 DEL CÓDIGO TESTAMENTARIO DE CALIFORNIA, available at <http://www.templecommunityhospital.com/advance2.pdf> (last visited Oct. 10, 2005).

183. *Id.* at 1.

184. *Id.* at 1–2.

185. *Id.* at 2–6.

186. CAL. PROB. CODE § 4701 (West 2004).

187. California Coalition for Compassionate Care, *Advance Directive Education*, http://www.finalchoices.calhealth.org/advance_directive.htm (last visited Oct. 10, 2005).

188. California Coalition for Compassionate Care, *Advance Health Care Directives*, http://www.finalchoices.calhealth.org/C4_textfiles/Chinese%20Advance%20Directive.pdf (last visited Oct. 10, 2005).

189. See Diana Toft Manos, *Converting Forms*, HOSP. & HEALTH NETWORKS, May 2004, at 22 (describing the launch of www.HealthTranslations.com, a website providing translated medical forms and information for hospitals all over Missouri).

190. Press Release, Mo. Hosp. Ass'n, MHA Launches Translation Web Site to Help Hospitals Serve Diverse Patient Population (Oct. 28, 2003), http://web.mhanet.com/asp/Communications/news_releases/healthtranslations.asp.

191. Manos, *supra* note 189, at 22.

over forty-five languages,¹⁹² including “Arabic, Bosnian (Serbian/Croatian), Chinese, Spanish, Vietnamese and Russian.”¹⁹³ Hospitals and health care providers can access the documents for a reasonable fee determined by the size and type of facility.¹⁹⁴ The website has proven to be a “huge relief” for health care providers and translators,¹⁹⁵ and it has been cost-effective for hospitals.¹⁹⁶ Most importantly, the service allows for greater accuracy and accessibility in document translation.¹⁹⁷ Without a centralized database, translations will vary because each translator individually put in the time and effort to translate a single document;¹⁹⁸ HealthTranslations.com, on the other hand, provides uniform documents throughout the state.¹⁹⁹

These examples prove that making translated materials available can be done without unduly burdening the state or individual hospitals. If state health care agencies tap into the nonprofit and grant-providing resources throughout the country and use HealthTranslations.com as a model, they might find translation services to be within their financial reach. Also, states may be significantly more effective at implementing translation services than individual health care providers in a number of ways. State-sponsored translated information would create a more uniform set of forms, instructions, and information sheets. A state-sponsored database might also offer a broader range of translations, such that even patients in the smallest minorities could be sufficiently informed about their end-of-life treatment rights under the PSDA.

A single website of translated documents may not educate every elderly individual on his or her terminal care rights, but it serves as a starting point. Some scholars argue that informational documents are not nearly enough to promote understanding of rights under state advance directive law,²⁰⁰ but the PSDA only requires distribution of written materials.²⁰¹ Because hospitals and health care facilities have a

192. See HealthTranslations, www.healthtranslations.com (last visited Oct. 10, 2005).

193. Manos, *supra* note 189, at 22.

194. *Id.*

195. *Id.*

196. Press Release, Mo. Hosp. Ass'n, *supra* note 190.

197. See *id.*

198. *Id.*

199. See *id.*

200. See, e.g., Pope, *supra* note 69, at 190.

201. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4751, 104 Stat. 1388, 1388-204.

propensity to meet only the minimum requirements of the law,²⁰² legislators have a duty to their constituents to ensure that their terminal care rights are protected. This can be accomplished by either legislating minimum requirements that are sufficient to protect patient autonomy or insisting that the state provide a means by which health care facilities can provide the most effective translated documents possible without extensive effort or expense. On a practical level, the latter option appears more viable. Online databases for translated documents can provide the means to accomplish the goal of protecting the patient autonomy of elderly LEP citizens.

V. Conclusion

As it stands, the PSDA ignores the right to self-determination of 1.8 million elderly LEP Americans. The PSDA has a history that strongly suggests that its purpose is to educate and empower individuals regarding end-of-life medical treatment, and yet it potentially abandons a rapidly growing part of the population who could gain great advantage from its provisions. LEP elders, like all older Americans, have an interest in advance directive legislation and policy, and because their age group more frequently faces decisions regarding end-of-life medical treatment, their interest is even greater than that of most Americans.

Without a stipulation that advance directive written information be provided in multiple languages, LEP elder patients are put at a severe disadvantage. They are left behind because the PSDA's mandate for knowledge and empowerment does not apply to them. All of the written instructions in the world amount to nothing if the patient who receives them cannot understand the language in which they are written. This oversight not only leaves LEP patients unable to fully enjoy the rights they are entitled to, it also undermines the very purpose of an act that is premised on educating the public. Furthermore, leaving health care facilities with little guidance regarding their obligations towards LEP elder individuals and their end-of-life treatment rights may expose facilities to discrimination litigation under the Civil Rights Act.

States have always had the option of adding provisions for linguistic accommodation to their advance directive statutes, and yet

202. Pope, *supra* note 69, at 141.

none have done so. Against that backdrop, Congress, to effectuate the PSDA's purpose, should amend the Act to include a provision that instructs states not only to provide written information about their statutes, but also to provide appropriate translations so that all residents of the state may enjoy the security of knowing their rights in the event of incapacitation. Modern technology provides a forum—the internet—in which information can be made accessible to large geographic areas without wasting resources.

Amending the PSDA in this way would help the Act fulfill its purpose of educating the public, no matter what language in which it communicates, on the importance of executing advance directives.