

2005

Optional or Optimal?: The Medicaid Hospice Benefit at Twenty

Lainie Rutkow

Follow this and additional works at: <https://scholarship.law.edu/jchlp>

Recommended Citation

Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. Contemp. Health L. & Pol'y 107 (2006).

Available at: <https://scholarship.law.edu/jchlp/vol22/iss1/5>

This Article is brought to you for free and open access by CUA Law Scholarship Repository. It has been accepted for inclusion in Journal of Contemporary Health Law & Policy (1985-2015) by an authorized editor of CUA Law Scholarship Repository. For more information, please contact edinger@law.edu.

OPTIONAL OR OPTIMAL?: THE MEDICAID HOSPICE BENEFIT AT TWENTY

*Lainie Rutkow**

After a two-year battle, Jane's doctors believed that breast cancer had left her with months—possibly only weeks—to live.¹ Her body was weak, and she was in constant pain. Jane felt fortunate that her health insurer, Medicaid, covered her time in the hospital.² She knew she was dying and she wanted to spend her final weeks at home, with her family. When Jane asked if Medicaid would allow her to relocate to her home and cover a nurse to administer palliative treatments, she was told no. Jane didn't know what to do. Her pain-relieving medications were too complicated for her friends or relatives to administer at home, and Jane was afraid to forego a doctor's supervision during her final months. Jane chose to stay in the hospital, where she shared a room with another patient and had little privacy during her final days. When she died, her friends and relatives were not present; the hospital notified Jane's daughter of her death an hour after it occurred. Jane lived in Connecticut, where there is no Medicaid Hospice Benefit.

Jane's friend Marsha lived about 100 miles away in New York. Marsha suffered from a congenital heart defect that slowly sapped her strength and energy. Doctors told Marsha that she had less than six months to live. Like

* Candidate for Ph.D., Department of Health Policy & Management, Johns Hopkins Bloomberg School of Public Health; M.P.H., Johns Hopkins Bloomberg School of Public Health, 2005; J.D., New York University School of Law, 2004; B.A., Yale University, 1999. The author would like to thank Stephen Teret, Jon Vernick, James Hodge, and the staff of *The Journal of Contemporary Health Law & Policy*.

1. Jane's story is fictional and is used for illustrative purposes only.

2. Jane's hypothetical assumes that she qualified for Medicaid because her family met the "income and asset eligibility criteria in effect for Aid to Families with Dependent Children (AFDC) on July 16, 1996." CONN. DEP'T OF SOC. SERVS., MEDICAID (2005), available at <http://www.dss.state.ct.us/svcs/medical/> (last visited Aug. 20, 2005); 42 U.S.C. § 1396a(a)(10)(A)(i) (2000). For qualified individuals, Medicaid covers inpatient hospital stays. 42 U.S.C. § 1396d(a)(1) (2000).

Jane, Marsha was grateful that her insurer, Medicaid,³ covered her time in the hospital.⁴ When Marsha asked a hospital social worker if she could spend her final months at home, the social worker asked if she was interested in hospice care. Marsha lived in New York, where qualified Medicaid beneficiaries can elect hospice care.⁵ Marsha returned home and a nurse visited everyday to administer her pain-relieving medication. A social worker also stopped by the house regularly. Marsha died at home, in her sleep, a few months later. Afterwards, her family received bereavement counseling through the Medicaid Hospice Benefit.⁶

As these anecdotes demonstrate, Medicaid coverage varies significantly among the states. Because the federal Medicaid program requires states to cover some health care services and allows states to choose whether or not to cover other services,⁷ the scope of Medicaid coverage a person receives depends on the state in which he or she lives. As Jane and Marsha discovered, states are allowed to choose whether or not they will cover hospice care under Medicaid.⁸ When states do offer a Medicaid Hospice Benefit, a beneficiary can choose to receive palliative care, or comfort measures, exclusively during his or her final six months of life.⁹ Because hospice care is frequently provided at home and invasive hospital-based treatments are forsaken, hospice care can be less expensive than conventional hospital-based care.¹⁰ Although nearly every state has elected to provide a Medicaid Hospice Benefit,¹¹ budget crises are forcing many states to consider cutting this benefit.¹²

This article will argue that the federal Medicaid program should require states to offer a Medicaid Hospice Benefit. Part I chronicles the rise of the American hospice movement and explains the theories behind hospice care. It also discusses the codification of the Medicare Hospice Benefit, which

3. Marsha's story is also fictional and is used for illustrative purposes only. Marsha's hypothetical, like Jane's, assumes that she qualified for Medicaid because her family met the AFDC income criteria in effect on July 16, 1996. 42 U.S.C. § 1396a(a)(10)(A)(i) (2000).

4. For qualified individuals, Medicaid covers inpatient hospital stays. 42 U.S.C. § 1396d(a)(1) (2000).

5. N.Y. SOC. SERV. LAW § 365-a(2)(m) (McKinney 2003).

6. Dianne Rosen, *A Hospice Primer*, N.J. LAW., Mar.-Apr. 1998, at 12 (explaining that hospice care includes bereavement counseling for family members after the patient dies).

7. See *infra* Part I.C.1.

8. See *infra* Part I.C.2.

9. 42 U.S.C. 1396d(o)(1)(A) (2000).

10. See *infra* Part III.A.

11. See *infra* note 102 and accompanying text.

12. See *infra* Part II.A.

served as the model for the Medicaid Hospice Benefit, and examines the codification of the Medicaid Hospice Benefit. Part II explains why states' Medicaid Hospice Benefits are at risk and proposes mandating coverage of hospice care under Medicaid. Part III considers reasons to implement the proposal, including hospice care's potential for cost savings. Part IV addresses reasons to maintain the status quo, such as respecting states' autonomy to cut programs that could lessen their budget shortfalls. Finally, this paper will conclude that fiscal considerations, public opinion, and ethical arguments all suggest that Congress should require coverage of hospice care by state Medicaid programs.

I. MEDICARE, MEDICAID, AND THE AMERICAN HOSPICE MOVEMENT

A. *Hospice Care in America: Theory and Practice*

In 1963, British physician Dame Cicely Saunders was invited to give a lecture at Yale-New Haven Hospital.¹³ Saunders spoke about St. Christopher's Hospice in England, a "free-standing, inpatient facility for the dying,"¹⁴ which she helped to found. The hospice operated with the understanding that "the terminally ill should have pain control, family involvement, and honest dialogue about their condition."¹⁵ During her visit to New Haven, Saunders invited like-minded individuals from the United States to visit St. Christopher's and to study the philosophies behind hospice

13. Helen Butterfield-Picard & Josefina B. Magno, *Hospice the Adjective, Not the Noun*, 37 AM. PSYCHOLOGIST 1254, 1254 (1982); Pamela J. Miller & Paula B. Mike, *The Medicare Hospice Benefit: Ten Years of Federal Policy for the Terminally Ill*, 19 DEATH STUD. 531, 532 (1995); Lenora Finn Paradis & Scott B. Cummings, *The Evolution of Hospice in America Toward Organizational Homogeneity*, 27 J. HEALTH & SOC. BEHAV. 370, 373 (1986).

14. Butterfield-Picard & Magno, *supra* note 13, at 1254.

15. Miller & Mike, *supra* note 13, at 532; see also Dame Cicely Saunders, *The Hospice: Its Meaning to Patients and Their Physicians*, HOSP. PRAC., June 1981, at 93, 93 (discussing Saunders's conception of hospice care's role at end of life); cf. Wolfgang Saxon, *Cicely Saunders Dies at 87; Reshaped End-of-Life Care*, N.Y. TIMES, Aug. 4, 2005, at A17 ("Dame Cicely, a medical doctor, played a major role in reinventing [hospices] as last way stations for the terminally ill, offering palliative care and, if possible, peace of mind before a death without needless pain.").

care.¹⁶ Contemporary scholars trace the origins of the American hospice movement to Saunders's speech.¹⁷

Six years later, in 1969, Elisabeth Kübler-Ross published *On Death and Dying*, which further introduced hospice philosophy into Americans' minds.¹⁸ Kübler-Ross spent years interviewing dying patients, and her observations "ripped apart the traditional medical model [of dying]."¹⁹ She outlined five "stages" of dying, and her model continues to be taught in medical schools today.²⁰ *On Death and Dying* highlighted how little physicians actually knew about the process of death.

Within a decade, Saunders, Kübler-Ross, and other hospice advocates permanently changed perceptions of dying in America. In response to growing concerns about neglect or overzealous treatment of dying patients in hospitals,²¹ the first American hospice opened in New Haven, Connecticut

16. See Finn Paradis & Cummings, *supra* note 13, at 373 (explaining that Saunders wanted St. Christopher's Hospice to serve as model for hospices in United States).

17. See, e.g., Butterfield-Picard & Magno, *supra* note 13, at 1254 (suggesting that Saunders's speech ignited American hospice movement); Miller & Mike, *supra* note 13, at 532 (noting that Saunders is founder of modern hospice movement). The contemporary use of the term "hospice" stems from a medieval practice. Originally hospice denoted a stopping place for pilgrims on their way to the holy land. For a brief history of this practice, see SANDOL STODDARD, *THE HOSPICE MOVEMENT* 24-36 (1978). See also Rosen, *supra* note 6, at 12 ("Dr. Saunders adopted the term 'hospice,' which earlier, was a way-station where travelers making a pilgrimage to the Holy Land could stop and be cared for en route to their ultimate destination. In the same way . . . hospice cared for travelers nearing the end of their journey through life.").

18. ELISABETH KÜBLER-ROSS, *ON DEATH AND DYING* (1969); see Finn Paradis & Cummings, *supra* note 13, at 373 (suggesting that Kübler-Ross's book had significant impact on general public's understanding of death and dying); Miller & Mike, *supra* note 13, at 532 ("[A] book published in 1969, *On Death and Dying* by Dr. Elizabeth [sic] Kübler-Ross, also served an important historical role in the establishment of the hospice philosophy in the minds of Americans.").

19. Miller & Mike, *supra* note 13, at 532.

20. *Id.* (noting that Kübler-Ross's five stages of dying became "the academic hallmark for the death and dying classroom").

21. See Finn Paradis & Cummings, *supra* note 13, at 370 ("The American [hospice] movement emerged as a reaction to the depersonalized care the dying received from the established medical system which failed to relieve patient pain and discomfort The movement provided a basis for challenging traditional medicine and examining the quality of care given the dying."); William G. Bartholome, *Physician-Assisted Suicide, Hospice, and Rituals of Withdrawal*, 24 J.L. MED. & ETHICS 233, 234 (1996) ("[T]he emergence of hospice was a response to a systematic failure by mainstream health care professionals to deal with the problems of the dying. American physicians had taken on themselves the so-called 'duty to prolong life,' and they were equally insistent that disease was to be conquered in every encounter and that it was to be prevented for as

in 1974.²² The achievements of the Connecticut hospice, such as the innovation of providing hospice care at home, along with the success of three other hospices funded by the National Cancer Institute,²³ led to the 1978 incorporation of the National Hospice Organization.²⁴ This group sought to develop standards for hospice care and also lobbied for legislation that would provide Medicare reimbursement for hospice care.²⁵

By the early 1980s, hospice care had become quite appealing to terminally ill patients and their families because of its philosophy and accompanying practice: “[H]ospice philosophy emphasizes palliative care, treatment of symptoms rather than disease, to allow patients with a terminal prognosis (generally 6 months or less) the highest quality of life in the time which remains.”²⁶ The hospice team included physicians, nurses, social workers,

long as possible through increasingly aggressive medical intervention.”); cf. Robin Marantz Henig, *Will We Ever Arrive at the Good Death?*, N.Y. TIMES MAG., Aug. 7, 2005, at 28 (“[Hospice] began in the 1960’s as an antiestablishment, largely volunteer movement advocating a gentle death as an alternative to the medicalized death many people had come to dread.”).

22. Butterfield-Picard & Magno, *supra* note 13, at 1254 (“In 1974, the first operational hospice program of care began in Connecticut.”).

23. See Ann C. Petrisek & Vincent Mor, *Hospice in Nursing Homes: A Facility-Level Analysis of the Distribution of Hospice Beneficiaries*, 39 GERONTOLOGIST 279, 280 (1999) (“In 1974, the National Cancer Institute funded the first demonstration project to promote the establishment of hospice programs and facilities.”).

24. See, e.g., Finn Paradis & Cummings, *supra* note 13, at 376 (“The Connecticut Hospice . . . received money from [the National Cancer Institute] to expand their program The Connecticut organizers used the funds to experiment with providing hospice care in the home. . . . Using the demonstration sites. . . to gain legitimation and credibility for hospice, the director of the Connecticut Hospice. . . and colleagues from other programs, met in February 1977 to form the [National Hospice Organization.]”); Miller & Mike, *supra* note 13, at 533 (discussing expansion of hospice programs during 1970s). The National Hospice Organization is now called the National Hospice & Palliative Care Organization.

25. See Petrisek & Mor, *supra* note 23, at 280 (“[The hospice guidelines] were ultimately transformed into legislation as part of the Tax Equity and Fiscal Responsibility Act of 1982, which made hospice a federal program reimbursable under Medicare.”); Finn Paradis & Cummings, *supra* note 13, at 377 (“Two accomplishments of the [National Hospice Organization] were (a) lobbying for passage of Medicare reimbursement for hospice care. . . and (b) working . . . to develop hospice standards.”).

26. Mark A. Mesler, *The Philosophy and Practice of Patient Control in Hospice: The Dynamics of Autonomy Versus Paternalism*, 30 OMEGA 173, 173 (1995); see also Rosen, *supra* note 6, at 12:

Since its inception, the focus of hospice care has been on patient comfort. Emotional comfort comes from care at home or in a home-like setting that welcomes families and friends. Spiritual and psychological support is provided

and volunteers.²⁷ In a medical culture dominated by the desire to cure disease and prolong life, hospice provided an alternative for patients who wished to spend their final months receiving comfort measures only.²⁸

In 1980, the Health Care Financing Administration funded twenty-six hospice demonstration projects.²⁹ These projects served as the foundation of the National Hospice Study, which was commissioned “to evaluate the feasibility of introducing hospice as an option for Medicare reimbursement

for the patient and the family, including bereavement counseling for the family when the patient dies. The patient’s physical comfort is maximized through state-of-the-art pain and symptom management.

Id.; Butterfield-Picard & Magno, *supra* note 13, at 1255 (“[H]ospice. . . describes a conceptual framework based on the premise that when the quantity of life is limited, the quality of that life must be optimal.”); *Coverage of Hospice Care Under the Medicare Program: Hearing on H.R. 5180 Before the Subcomm. on Health of the H. Comm. on Ways and Means*, 97th Cong. 29 (1982) (statement of National Hospice Organization) (“Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortable [sic] as possible Hospice neither hastens nor postpones death.”).

27. Butterfield-Picard & Magno, *supra* note 13, at 1255 (describing standard elements of hospice care). A typical hospice team consists of the patient’s family, the patient’s personal physician, a hospice physician, nurses, home health aides, social workers, clergy, and trained volunteers. CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, ISSUE BRIEF 2 (2001), available at [http://www.futureofaging.org/publicationsfiles/V2N9%20\(revised\).pdf](http://www.futureofaging.org/publicationsfiles/V2N9%20(revised).pdf).

28. See David A. Simpson, *Hospice at the Crossroads: Can It Survive?*, 2 J. HEALTH CARE L. & POL’Y 310, 311 (1999) (explaining that scientific advances lead physicians to feel that death “is really a failure of medicine and technology”); Frank K. Abou-Sayf et al., *Study: Hospice Care Can Yield Savings to HMOs, Patients*, HEALTHCARE FIN. MGMT., Aug. 1991, at 85 (“The philosophy behind hospice care is to provide a low-cost setting in which a patient can be comfortable, family members can be involved in a patient’s care, and caregivers can provide palliative treatment without attempting a cure.”); *but cf.* Bartholome, *supra* note 21, at 234 (“[Hospice] stands ready to help *both* those who want to continue as best they can ‘living in the light of death’ and those who are anxious to seek relief in the ‘valley of the shadow of death.’”); Debra Parker-Oliver, *The Social Construction of the “Dying Role” and the Hospice Drama*, 40 OMEGA 493, 494 (2000) (“[T]he hospice community symbolically and in real time renegotiates a ‘sick role’ into a ‘dying role,’ and in the process replaces a loss of meaning and purpose, fear and suffering, with a peace of mind . . .”).

29. Karen Matherlee, National Health Policy Forum, *Managing Advanced Illness: A Quality and Cost Challenge to Medicare, Medicaid, and Private Insurers*, 779 NHPF ISSUE BRIEF 1, 4 (June 20, 2002) (“In 1980, under Medicare and Medicaid waivers, HCFA began paying 26 hospice providers for home health services, as well as for bereavement counseling and pain-control drugs.”).

of terminal care.”³⁰ The study’s results were not available until 1985.³¹ But, in December 1981, Rep. Leon Panetta introduced a bill in the House of Representatives that proposed covering hospice care under Medicare for terminally ill patients.³² Sen. Robert Dole subsequently introduced the bill in the Senate; it went to committee in early 1982.³³

B. *The Medicare Hospice Benefit*

1. *The Medicare Program*

With the creation of Medicare in 1965, Congress took “direct responsibility for health insurance for the aged and seriously disabled.”³⁴ Medicare is a federal health insurance program, and the Centers for Medicare and Medicaid Services administers it.³⁵ Medicare provides health insurance to eligible persons who are sixty-five years or older, persons under age sixty-five with certain disabilities, and people with end-stage renal disease.³⁶ Medicare is divided into Part A and Part B. Part A covers medically necessary inpatient hospital care, skilled nursing facility care,

30. Petrisek & Mor, *supra* note 23, at 280.

31. Vincent Mor & David Kidder, *Cost Savings in Hospice: Final Results of the National Hospice Study*, 20 HEALTH SERVICES RES. 407 (1985).

32. H.R. 5180, 97th Cong. (1981); see Miller & Mike, *supra* note 13, at 534 (discussing congressional origins of Medicare Hospice Benefit).

33. S. 1958, 97th Cong. (1981).

34. Eleanor D. Kinney, *The Future of Medicare, Post Great Society and Post Plus-Choice: Legal and Policy Issues*, 60 WASH. & LEE L. REV. 1461, 1464 (2003).

35. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE INFORMATION RESOURCE: ORIGINS OF MEDICARE, (last visited Sept. 9, 2005) <http://www.cms.hhs.gov/medicare/>

In 1977, the Health Care Financing Administration (HCFA) was created under [the Department of Health, Education, and Welfare (HEW)] to effectively coordinate Medicare and Medicaid. In 1980 HEW was divided into the Department of Education and the Department of Health and Human Services (HHS). In 2001, HCFA was renamed the Centers for Medicare & Medicaid Services (CMS).

Id.

36. 42 U.S.C. §§ 1395c, 1395i-2, 1395o (2000). The following people are eligible for Medicare: “Individuals entitled to Social Security retirement insurance who are sixty-five or older and individuals entitled to Social Security disability benefits for not less than twenty-four months . . . [as well as] individuals suffering from end stage renal disease and individuals entitled to Railroad Retirement benefits or Railroad Retirement disability benefits. . . .” Judith Stein & Alfred J. Chiplin, Jr., *A Practical Guide to Medicare Hearings and Appeals*, 34 REAL PROP. PROB. & TR. J. 403, 405 (1999).

hospice care, and some home health care services.³⁷ Part A is funded by the Social Security payroll tax.³⁸ Medicare Part B covers medically necessary doctors' services and outpatient care.³⁹ Beneficiaries pay a monthly premium for Part B.⁴⁰

2. Codification of the Medicare Hospice Benefit

The Medicare Hospice Benefit was enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982.⁴¹ Its passage can be attributed to two factors: hospice's humanitarian appeal and its potential for cutting health care costs. According to Panetta, the new benefit received broad bipartisan support because it "allow[ed] people to make the choice that if they want to receive hospice care, if they want to receive the counseling services, the family services that are available through this kind of care, they can choose to receive it."⁴² In addition, as Dole explained, "[e]nactment of the [Medicare] hospice provision was possible because many believe, as I do, that it is less costly to care for a patient at home, foregoing expensive hospital treatment."⁴³

Congress envisioned a comprehensive benefit that would require hospices to offer certain core services, including "nursing care provided by or under the supervision of a registered professional nurse, medical social services

37. 42 U.S.C. §§ 1395c–1395i (2000).

38. 42 U.S.C. § 1395i (2000).

39. 42 U.S.C. §§ 1395j–1395w-4 (2000).

40. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE & YOU 2005 20 (2005) ("You pay the Medicare Part B premium each month . . ."); cf. 42 U.S.C. § 1395t (2000) (listing congressional appropriations as contributing to funding for Medicare Part B).

41. Pub. L. No. 97-248, § 122, 96 Stat. 324, 356–63 (codified as amended at 42 U.S.C. § 1395c (2000)).

42. *Administration's Proposed Payment System for Hospice Care: Hearing Before the H. Select Comm. on Aging*, 98th Cong. 46 (1983) (statement of Rep. Leon E. Panetta).

43. *Implementation of the Medicare Hospice Benefit: Hearing Before the Subcomm. on Health of the S. Comm. on Fin.*, 98th Cong. 2 (1984) (statement of Sen. Robert Dole, Member, S. Comm. on Fin.). Much of the Medicare Hospice Benefit's appeal stemmed from its cost-saving potential:

[T]he new hospice benefit has the potential of providing many patients with health care which is less costly and more satisfactory to the patient than institution-based care.

The hospice benefit also has the potential of saving the Medicare program significant amounts of money. Costs per day for hospice patients, whether cared for at home or in hospital-based hospices, are significantly less than for the same patients as conventional hospital inpatients.

Id. at 3 (statement of Sen. Max Baucus, Member, S. Comm. on Fin.).

under the direction of a physician, physician services and counseling services.”⁴⁴ The passage of the Medicare Hospice Benefit meant that Medicare beneficiaries could only enact the benefit for Medicare-approved hospice programs. To become Medicare-approved, a hospice had to comply with statutorily enumerated federal guidelines.⁴⁵

To receive the Medicare Hospice Benefit, a person must be eligible for Medicare Part A,⁴⁶ receive a prognosis of six months or less to live from his or her doctor and the hospice medical director, sign a statement electing the Medicare Hospice Benefit, and enroll in a Medicare-certified hospice program.⁴⁷ By electing the Medicare Hospice Benefit, a person waives the standard Medicare benefits for treatment of an illness and chooses to receive only palliative care.⁴⁸ If a beneficiary lives longer than six months after entering hospice, he or she can continue to receive the Medicare Hospice Benefit as long as the physician and hospice medical director re-certify the prognosis of six months or less to live.⁴⁹ If, on the other hand, a person wants to opt out of the Medicare Hospice Benefit and return to receiving curative treatment, this can be done at any time, for any reason.⁵⁰ If a beneficiary revokes the benefit, he or she can reenter hospice care at a later

44. H.R. REP. NO. 97-760, at 428 (1982), *reprinted in* 1982 U.S.C.C.A.N. 1190, 1208.

45. 42 U.S.C. § 1395(x)(dd)(2) (2000).

46. *See supra* Part I.B.1 for a discussion of who is eligible for Medicare.

47. Medicare Hospice Benefit, 42 C.F.R. §§ 418.20, 418.22(b), 418.24 (2002); *see, e.g.*, CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE HOSPICE BENEFITS 1 (2002) (explaining who is eligible for Medicare Hospice Benefit); CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, *supra* note 27, at 2–3.

48. 42 C.F.R. § 418.202 (2004); *see, e.g.*, CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, *supra* note 27, at 2 (“Under the Medicare Hospice Benefit, people with Medicare who enroll in hospice elect to receive non-curative treatment and services for their terminal illness by waiving the standard Medicare benefits for treatment of a terminal illness.”); MEDICARE PAYMENT ADVISORY COMM’N, MEDICARE BENEFICIARIES’ ACCESS TO HOSPICE 3 (2002) (“To be eligible for the rich package of hospice services, beneficiaries must give up other Medicare services related to curative treatment of their terminal illness.”); CTRS. FOR MEDICARE & MEDICAID SERVICES, HOSPICE SERVICES: WHAT IS COVERED, <http://www.cms.hhs.gov/medicaid/services/hospice.asp> (“In general, the [hospice] services must be related to the palliation or management of the patient’s terminal illness, symptom control, or to enable the individual to maintain activities of daily living and basic functional skills.”).

49. 42 C.F.R. §§ 418.21(a), 418.22 (2004); *see also* Rosen, *supra* note 6, at 42 (“Re-certification is necessary because prognoses cannot be exact.”).

50. 42 C.F.R. § 418.28 (2004); *see, e.g.*, MEDICARE PAYMENT ADVISORY COMM’N, *supra* note 48, at 3 (“Beneficiaries can disenroll from hospice at any time.”).

date, as long as he or she still meets the qualifications for electing the Medicare Hospice Benefit.⁵¹

Once the Medicare Hospice Benefit is elected, the beneficiary will work with his or her doctor and the hospice staff to create a plan of care.⁵² The plan will designate a primary caregiver, typically a family member,⁵³ and the hospice team will be available twenty-four hours a day, seven days a week, to provide support and care.⁵⁴ If the beneficiary does not or cannot stay in a private home, the Medicare Hospice Benefit will cover hospice services that are provided at freestanding hospice facilities, hospitals, nursing homes, and long-term care facilities.⁵⁵

Since the inception of the benefit, hospice use has been increasing among Medicare beneficiaries. In 2000, twenty-three percent of Medicare decedents used the Medicare Hospice Benefit.⁵⁶

51. 42 C.F.R. § 418.28(c)(3) (2004); see Rosen, *supra* note 6, at 42 (“A patient who has revoked a hospice election may still elect hospice care at a later date.”).

52. See CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE HOSPICE BENEFITS, *supra* note 47, at 4 (explaining that services that may be incorporated into plan of care include doctor services, nursing care, medical equipment, medical supplies, drugs for symptom control, home health aide services, social worker services, and bereavement counseling); CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, *supra* note 27, at 2 (“[T]he hospice team develops a care plan that focuses on the patient’s well-being and the need for pain management and symptom control.”).

53. To receive in-home hospice care, a patient must have a primary caregiver. Carol Levine & Connie Zuckerman, *Hands On/Hands Off: Why Health Care Professionals Depend on Families But Keep Them at Arm’s Length*, 28 J.L. MED. & ETHICS 5, 10 (2000) (“[T]o receive in-home hospice services. . . there must be an available and willing primary informal caregiver. . . . In-patient hospice care is less dependent on a primary caregiver, but it is extremely limited in time and availability.”); CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, *supra* note 27, at 2 (“Typically, a family member or friend serves as the primary caregiver.”); but cf. Linda E. Moody et al., *Caring for the Dying: Reexamining Our Approach*, 2 J. HEALTH CARE L. & POL’Y 243, 254 (1999) (“Since many patients in hospice are over 65 years of age, as are their caregivers, there is a need for models of communication and decision-making that consider the special needs of elders receiving end-of-life care. Many women outlive men and face terminal illness alone.”).

54. Butterfield-Picard & Magno, *supra* note 13, at 1255 (“The authentic hospice setting offers. . . care on a 24-hour basis, seven days per week.”).

55. See, e.g., CTR. FOR MEDICARE EDUC., THE MEDICARE HOSPICE BENEFIT, *supra* note 27, at 3 (describing Medicare reimbursement for hospice care provided outside of private home); Rosen, *supra* note 6, at 42 (explaining different types of facilities that can provide hospice care).

56. MEDICARE PAYMENT ADVISORY COMM’N, *supra* note 48, at 3; see Haiden A. Huskamp et al., *Providing Care at the End of Life: Do Medicare Rules Impede Good Care?*, 20 HEALTH AFF. 204, 204 (2001) (finding that nineteen percent of Medicare

C. The Medicaid Hospice Benefit

1. The Medicaid Program

Congress created the Medicaid program in 1965 to “enabl[e] each State. . . to furnish. . . medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical expenses.”⁵⁷ The program, which is funded by the federal and state governments,⁵⁸ “provid[es] states with considerable flexibility in program design so long as they offer a basic set of medical services to those categories of low-income people deemed by Congress to be the most deserving of assistance.”⁵⁹

Each state is required to provide Medicaid coverage to certain mandatory, or “categorically needy” eligibility groups, including: low income families with children; Supplemental Security Income (SSI) recipients; children under age six; and pregnant women whose family income is at or below 133 percent of the federal poverty level.⁶⁰ States may also choose to provide Medicaid coverage to “medically needy” groups.⁶¹ Medically needy persons have too much income to qualify for Medicaid as categorically needy

decedents used the Medicare Hospice Benefit in 1998). The number of beneficiaries who use the Medicare Hospice Benefit has steadily increased. For example, in 1991, 108413 beneficiaries used the benefit. This number jumped to 338273 beneficiaries in 1996. And, in 2001, 579801 beneficiaries used the Medicare Hospice Benefit. CTRS. FOR MEDICARE & MEDICAID SERVS., HOSPICE DATA—FY 1991 THROUGH FY 2001 (2005), <http://www.cms.hhs.gov/providers/hospiceps/default.asp> (follow hyperlink under Research and Statistics subheading).

57. 42 U.S.C. § 1396 (2000).

58. CTRS. FOR MEDICARE & MEDICAID SERVS., WELCOME TO MEDICAID, <http://www.cms.hhs.gov/medicaid/> (last visited Feb. 18, 2006).

59. Jonathan R. Bolton, Note, *The Case of the Disappearing Statute: A Legal and Policy Critique of the Use of Section 1115 Waivers to Restructure the Medicaid Program*, 37 COLUM. J.L. & SOC. PROBS. 91, 96 (2003); see CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID-AT-A-GLANCE 1 (2003) (“Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each State.”).

60. 42 U.S.C. § 1396a(a)(10)(A)(i) (2000); 42 C.F.R. § 435.100 (2002). Each state also has the option to provide Medicaid coverage to other categorically needy groups, including infants up to age one, pregnant women whose family income is below 185 percent of the federal poverty level, and aged, blind, or disabled adults with incomes too high for mandatory coverage but below the federal poverty level. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID ELIGIBILITY, <http://www.cms.hhs.gov/medicaid/eligibility/criteria.asp> (last visited Sept. 9, 2005).

61. 42 U.S.C. § 1396a(a)(10)(C) (2000).

individuals.⁶² They can “‘spend down’ to Medicaid eligibility by incurring medical and/or remedial care expenses to offset their excess income, thereby reducing it to a level below the maximum allowed by that State’s Medicaid plan.”⁶³ If a state chooses to offer a medically needy program, it must include “pregnant women through a 60-day postpartum period, children under age 18, certain newborns for one year, [and] certain protected blind persons.”⁶⁴

States are required to provide a variety of health care services to categorically needy persons.⁶⁵ If states elect to cover medically needy individuals, the states are only required to offer them selected services: prenatal and delivery services, postpartum pregnancy related services (for beneficiaries under age 18), and home health services (for beneficiaries entitled to receive nursing facility services under the state’s Medicaid plan).⁶⁶ In addition to the mandatory services for categorically needy and medically needy groups, states can elect to offer optional health care services to these groups.⁶⁷

2. Codification of the Optional Medicaid Hospice Benefit

The legislation enacting the Medicare Hospice Benefit required Congress to revisit the benefit in 1986 to assess its implementation and effectiveness.⁶⁸

62. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID-AT-A-GLANCE, *supra* note 59, at 1.

63. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID ELIGIBILITY, *supra* note 60.

64. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID-AT-A-GLANCE, *supra* note 59, at 1. If states offer a medically needy program, they may also choose to cover certain aged, blind, and disabled persons. *Id.* at 2.

65. *Id.* These services include: inpatient hospital, outpatient hospital, laboratory and x-ray, certified pediatric and family nurse practitioners, nursing facility services (for beneficiaries 21 and over), early and periodic screening, diagnosis, and treatment for children under age 21, family planning services and supplies, physicians’ services, medical and surgical services of a dentist, home health services (for beneficiaries entitled to nursing facility services), nurse midwife services, and pregnancy related services. *Id.* at 4; 42 U.S.C. §§ 1396d(a)(1)–(5), (17), (21) (2000).

66. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID-AT-A-GLANCE, *supra* note 59, at 5.

67. Optional services include licensed practitioners’ services, private duty nursing, nurse practitioner, clinic services, dental services, physical therapy, occupational therapy, speech, hearing, and language therapy, prosthetic devices, eyeglasses, diagnostic services, screening services, preventive services, rehabilitative services, transportation, optometric services, respiratory care services, and hospice care services. 42 U.S.C. §§ 1396d(a)(6)–(16), (18)–(20), (22)–(25) (2000).

68. The legislation contained the following sunset provision:

During that Congress, which eliminated the sunset provision on the Medicare Hospice Benefit,⁶⁹ bills calling for a Medicaid Hospice Benefit appeared in the House and the Senate. In April 1985, Sen. William Roth introduced S. 867,⁷⁰ which proposed the addition of hospice care as an optional Medicaid-covered benefit. Upon introducing the bill, Roth explained that the addition of hospice care would lead to cost savings for Medicaid:

A number of studies have substantiated the cost effectiveness of hospice care, particularly in light of its emphasis on home versus inpatient care. . . . Cost savings will likely result [from this bill], since many of the hospice services which are not otherwise covered by Medicare. . . are already covered by the Medicaid Programs in many States.⁷¹

Three months later, in July 1985, Rep. Panetta introduced Roth's bill to the House.⁷² Within days, the proposed optional Medicaid Hospice Benefit had been incorporated into a larger bill entitled Medicare and Medicaid Budget Reconciliation Amendments of 1985.⁷³ The report accompanying the bill described the impetus for adding a Medicaid Hospice Benefit: "Since 1983, terminally ill Medicare beneficiaries have had the option of electing hospice services in lieu of most other Medicare benefits. . . . [T]he

[T]he amendments made by this apply to hospice care provided on or after November 1, 1983, and before October 1, 1986. . . . The Secretary of Health and Human Services shall conduct a study and, prior to January 1, 1986, report to the Congress on whether or not the reimbursement method and benefit structure (including copayments) for hospice care under title XVIII of the Social Security Act are fair and equitable and promote the most efficient provision of hospice care. Such report shall include the feasibility and advisability of providing for prospective reimbursement for hospice care, an evaluation of the inclusion of payment for outpatient drugs, an evaluation of the need to alter the method of reimbursement for nutritional, dietary, and bereavement counseling as hospice care, and any recommendations for legislative changes in the hospice care reimbursement structure.

Pub. L. No. 97-248, §§ 122(h)(1)(A), (i)(1), 96 Stat. 324, 362–63 (codified as amended at 42 U.S.C. §§ 1395c, 1395f (2000)).

69. Pub. L. No. 99-272, § 9123, 100 Stat. 82, 168 (codified as amended at § 1395c (2000)).

70. S. 867, 99th Cong. (1985).

71. 131 CONG. REC. S4, 000-02 (daily ed. Apr. 3, 1985) (statement of Sen. Roth).

72. H.R. 3027, 99th Cong. (1985).

73. H.R. 3101, 99th Cong. § 203 (1985).

terminally ill poor who are eligible for Medicaid should have the same basic choice."⁷⁴

In September 1985, Sen. John Heinz introduced S. 1648,⁷⁵ which incorporated the optional Medicaid Hospice Benefit originally proposed by Roth.⁷⁶ Heinz, too, pointed out hospice's ability to cut costs, saying:

Hospice care. . . costs much less than does hospital care for the same patients. If we continue to pinch pennies for these services, we will only have to pay more for hospital care, since hospice will not be available for all those who need it. . . . [W]e need to fully utilize the most cost-effective ways of meeting the health care needs of those in the last few months of life.⁷⁷

The Senate endorsed the proposed benefit,⁷⁸ and it was formally approved two months later in the conference report.⁷⁹ The report explained that the optional Medicaid Hospice Benefit would be similar to the Medicare Hospice Benefit: the benefit was limited to the terminally ill (individuals with a prognosis of six months or less to live),⁸⁰ election of the benefit could be revoked at any time,⁸¹ and reimbursement rates would be based on those used by Medicare.⁸² On April 7, 1986, the bill containing the optional

74. H.R. REP. NO. 99-265, at 64 (1985). The report went on to explain the mechanics of the proposed benefit:

The Committee bill allows States, at their option, to offer hospice care, delivered by public or private nonprofit hospice programs, to terminally ill individuals who have voluntarily elected to receive hospice care in lieu of certain other benefits. . . . The Committee bill allows the States to limit the amount, duration, or scope of the hospice care they choose to cover, but the limitations may not be more restrictive than those under Medicare. States choosing to offer hospice coverage would be required to use Medicare payment rates and methods.

Id.

75. S. 1648, 99th Cong. (1985).

76. Roth's bill, S. 867, only proposed an optional Medicaid Hospice Benefit. Heinz's bill included this proposal as well as proposals to eliminate the sunset provision for the Medicare Hospice benefit and to increase the Medicare reimbursement rates for hospice.

77. 131 CONG. REC. S11, 543-01 (daily ed. Sept. 16, 1985) (statement of Sen. Heinz).

78. S. REP. NO. 99-146, at 311-12 (1985).

79. H.R. REP. NO. 99-453, at 145-47 (1985) (Conf. Rep.). At this point, the optional Medicaid Hospice Benefit had been incorporated into H.R. 3128, 99th Cong. § 163 (1985), which was the bill that the Conference Report accompanied.

80. H.R. REP. NO. 99-453, at 146.

81. *Id.*

82. *Id.*

Medicaid Hospice Benefit was signed into law by President Ronald Reagan.⁸³

3. Attempts to Codify a Mandatory Medicaid Hospice Benefit

During each of his final four years in Congress, Rep. Panetta introduced bills to mandate Medicaid hospice care coverage. None of his attempts were successful. In 1988, Panetta introduced H.R. 3913,⁸⁴ which required hospice coverage under Medicaid. He stressed hospice's ability to save states money and explained his growing concern that "[i]n spite of the growing number of persons who could benefit from hospice care under the Medicaid Program, especially with the AIDS crisis, only five States. . . have so far created a Medicaid hospice benefit"⁸⁵ The bill had thirty-five co-sponsors and died in committee.⁸⁶

During the next Congress, in March 1989, Panetta reintroduced his hospice legislation along with forty-nine co-sponsors.⁸⁷ He reemphasized his concern about the country's growing AIDS crisis and reminded Congress that "[h]ospice, with its combination of in-patient and out-patient care, provides the most appropriate means of care for many who are dying of AIDS. . . . [T]he current need is great enough to warrant making the hospice Medicaid benefit mandatory."⁸⁸ In July 1989, Rep. Henry Waxman introduced H.R. 2924,⁸⁹ which included Panetta's proposed mandatory Medicaid Hospice Benefit. The House Subcommittee on Health and the Environment issued a Committee Print that endorsed the mandatory benefit, stating:

[H]ospice care is a benefit available to all terminally ill Medicare beneficiaries, regardless of the State in which they reside. In the view of the committee, the hospice care benefit should also be available to low-income, terminally ill individuals who are not elderly or disabled Medicare beneficiaries, regardless of the State in which they reside. The committee recognizes that hospice services may frequently be sought by low-income persons with

83. Comprehensive Omnibus Budget Reconciliation Act of 1986, Pub. L. No. 99-272, § 9505, 100 Stat. 82, 208-09 (codified as amended at 42 U.S.C. §§ 1396a, 1396d (2000)).

84. H.R. 3913, 100th Cong. (1988).

85. 134 CONG. REC. H262-01 (daily ed. Feb. 4, 1988) (statement of Rep. Panetta).

86. H.R. 3913: Bill Summary & Status for the 100th Congress, <http://thomas.loc.gov> (last visited Oct. 13, 2005).

87. H.R. 1259, 101st Cong. (1989).

88. 135 CONG. REC. E623-01 (daily ed. Mar. 2, 1989) (statement of Rep. Panetta).

89. H.R. 2924, 101st Cong. (1989).

AIDS, few of whom are eligible for Medicare. The committee bill would therefore require all States to offer hospice coverage under their Medicaid programs.⁹⁰

One month later the House issued a report that formally endorsed the mandatory Medicaid Hospice Benefit.⁹¹ Despite this, the House conference report rejected the proposed mandatory benefit.⁹²

A few months after this defeat, Panetta, with eighty-two co-sponsors, again introduced a bill to make hospice coverage mandatory under Medicaid.⁹³ He restated his distress about the treatment of AIDS patients: "Expanding the hospice Medicaid benefit . . . will enable many more AIDS patients to receive the care they need in hospice programs. Otherwise, they will be forced into expensive acute care settings or, worse, into the streets."⁹⁴ Sen. John Danforth echoed Panetta's concern, saying, "Almost half of all AIDS patients—44 percent are Medicaid recipients. [By not mandating hospice coverage], [w]e are denying AIDS patients. . . the option of choosing to spend the last months of their lives in a supportive and nontechnological setting."⁹⁵ This bill, too, died in committee.⁹⁶

In February 1991, Panetta again introduced a bill to mandate hospice coverage under Medicaid.⁹⁷ Like its predecessors, this bill, which had 115

90. STAFF OF H. COMM. ON ENERGY & COMM., 101ST CONG., MEDICARE AND MEDICAID HEALTH BUDGET RECONCILIATION AMENDMENTS OF 1989 125 (Comm. Print 1989).

91. H.R. REP. NO. 101-247, at 454–56 (1989), *as reprinted in* 1989 U.S.C.C.A.N. 1906, 2180–82.

92. H.R. REP. NO. 101-386, at 472–73 (1989) (Conf. Rep.), *as reprinted in* 1989 U.S.C.C.A.N. 3018, 3075–76. At this time, Congress did clarify the reimbursement system for terminally ill Medicaid beneficiaries who received hospice care while in skilled nursing facilities (SNF) or intermediate care facilities (ICF). The conference report required:

States, in paying for hospice care [under Medicaid], to pay amounts no lower than the amounts paid under Medicare, and to use the same methodology as Medicare's. For terminally ill SNF and ICF residents electing hospice, require[d] States to pay the hospice an additional amount equal to or at least 95 percent of the rate that would have been paid by the State to that facility for the Medicaid beneficiary.

Id. at 473–74, *as reprinted in* 1989 U.S.C.C.A.N. at 3076–77.

93. H.R. 3935, 101st Cong. (1990).

94. 136 CONG. REC. E163-01 (daily ed. Feb. 1, 1990) (statement of Rep. Panetta).

95. 136 CONG. REC. S6307-01, S6328 (daily ed. May 16, 1990) (statement of Sen. Danforth).

96. H.R. 3935, 101st Cong. (1990); H.R. 3935: Bill Summary & Status for the 101st Congress, <http://thomas.loc.gov> (last visited Oct. 13, 2005).

97. H.R. 860, 102d Cong. (1991).

co-sponsors, died in committee. Finally, during his last year in Congress, Panetta made one more attempt to create a mandatory Medicaid Hospice Benefit.⁹⁸ Again, this bill died in committee.⁹⁹

II. THE CURRENT SITUATION AND A PROPOSAL

A. Hospice Programs at Risk

The federal government requires each state to cover certain mandatory services under Medicaid.¹⁰⁰ In addition, states can choose to cover optional services, such as hospice care, that are enumerated in the Medicaid statute.¹⁰¹ Currently, forty-seven states and the District of Columbia cover hospice services under Medicaid.¹⁰² Each state has limited autonomy in

98. H.R. 474, 103d Cong. (1993).

99. *Id.*; H.R. 474: Bill Summary & Status for the 103rd Congress, <http://thomas.loc.gov> (last visited Oct. 13, 2005).

100. See *supra* note 65 and accompanying text.

101. See *supra* note 67 and accompanying text.

102. Connecticut, New Hampshire, and Oklahoma do not offer a Medicaid Hospice Benefit. The following list summarizes the Medicaid Hospice Benefit rules and regulations for the forty-seven states that offer the benefit as well as the District of Columbia: ALA. ADMIN. CODE r. 560-X-51.01 (2003); ALASKA ADMIN. CODE tit. 7, § 43.938 (2003); ARIZ. REV. STAT. §§ 36-2932(C), 36-2939(A)(3) (Lexis-Nexis 2003); 016-06-027 ARK. CODE R. §§ 200.000-280.000 (Weil 2004); CAL. WELF. & INST. CODE § 14132(w) (West 2001); COLO. REV. STAT. § 26-4-302(1)(q) (2004); 16-5000-5100 DEL. CODE REGS. § 13310 (Weil 2003); D.C. CODE § 4-601(3) (2001); FLA. STAT. § 409.906(14) (West 2005); FLA. ADMIN. CODE ANN. r. 10C-7.0533, 59G-4.140 (2004); GA. DEP'T COMMUNITY HEALTH, PART II POLICIES AND PROCEDURES FOR HOSPICE SERVICES §§ 901-902 (2005); HAW. CODE R. § 17-1737-101, -103 (Weil 2005); IDAHO ADMIN. CODE r. 16.03.09.104 (2005); ILL. ADMIN. CODE tit. 89, §§ 140.3(19), 140.469 (2005); IND. CODE ANN. §§ 12-15-40-1, 12-15-40-71 (West 2002); 407 IND. ADMIN. CODE 3-3-1(a)(11) (2004); IOWA ADMIN. CODE r. 441-78.36(249A), -86.14(514I)(j) (2003); KAN. ADMIN. REGS. § 30-5-115 (2004); 907 KY. ADMIN. REGS. 1:330 (2004); LA. REV. STAT. ANN. § 46:159.1 (Supp. 2005); 10-144-101 ME. CODE R. § 43 (Weil 2004); MD. CODE ANN., HEALTH-GEN. § 15-128 (2000); 130 MASS. CODE REGS. § 437.403 (2004); MICH. COMP. LAWS ANN. §§ 333.21401-21421 (West 2005); OUTLINE OF STATE OF MICH. HEALTH PROGRAMS 85 (2001); MINN. STAT. ANN. § 256B.0625(22) (West 2003 & Supp. 2005); MISS. CODE ANN. § 43-13-117(26) (West 1999 & Supp. 2004); MO. CODE REGS. ANN. tit. 13, § 70-50.010 (2004); MONT. ADMIN. R. 37.85.206(1)(z) (2003); 471 NEB. ADMIN. CODE § 36-002 (2004); NEV. REV. STAT. § 422.304 (2003); N.J. STAT. ANN. § 30:4D-6(a)(20) (West 1997 & Supp. 2003); N.M. ADMIN. CODE R. § 8.325.4.1-.18 (Weil 2004); N.Y. SOC. SERV. LAW § 365-a(2)(m) (McKinney 2003); 10A N.C. ADMIN. CODE 13K.0100-.1200 (March 2004); N.C. DIV. OF MED. ASSISTANCE,

enacting the benefit.¹⁰³ For example, in Alabama, only categorically needy individuals can receive hospice care under Medicaid.¹⁰⁴ Yet, in neighboring Georgia, both categorically needy and medically needy individuals are covered for hospice care.¹⁰⁵

While nearly 100 percent coverage of hospice care by state Medicaid programs sounds heartening, the statistic masks imminent threats: "In many states the Medicaid Hospice Benefit. . . is facing immediate jeopardy."¹⁰⁶ Medicaid is the second-largest item in most state budgets,¹⁰⁷ and

COMMUNITY CARE MANUAL, § 8 Hospice (2001); N.D. ADMIN. CODE § 75-02-02-08(1)(j) (2004); OHIO ADMIN. CODE 5101:1-39-83 (2004); OR. ADMIN. R. 410-142-0100 (2004); 55 PA. CODE § 1130.1 (2004); 15-020-007 R.I. CODE R. § 300-20 (Weil 2003); S.C. CODE ANN. REGS. 44-71 (2002); S.C. PARTNERS FOR HEALTH, HEALTH CARE BENEFITS 6 (2002); S.D. ADMIN. R. 44:04:06:13 (2004); S.D. MEDICAID PROGRAM, HOSPICE PROVIDER MANUAL (2002); TENN. COMP. R. & REGS. 1200-13-10-.02-.04 (2004); 40 TEX. ADMIN. CODE §§ 30.10, 30.2 (2004); UTAH ADMIN. CODE r. 414-1-6(y) (2003); 13-170-008 VT. CODE R. §§ 103.2 (A)(1), 105.1 (2003); 12 VA. ADMIN. CODE §§ 30-50-270, 30-60-130 (2004); WASH. REV. CODE ANN. § 74.09.520(1), (5) (West 2001 & Supp. 2004); W. VA. CODE § 9-4A-2b(a)(2) (2003); WIS. STAT. § 49.46(2) (2003); WIS. ADMIN. CODE HFS §§ 105.50, 107.31 (2004); WYO. STAT. ANN. § 42-4-103(a)(xxv) (2003); *see also* Nat'l Hospice and Palliative Care Org., *NHPCO and State Hospice Organizations Fight Medicaid Hospice Benefit Cuts*, NEWSLINE, Apr. 2003, at 5 ("The state of Louisiana is in the [second] year of a two-year pilot project to test the impact of providing hospice under Medicaid. The program began serving patients in July of 2002 and upon its completion could lead to hospice being a permanent part of Louisiana's optional services.").

103. Earl Dirk Hoffman et al., *Overview of the Medicare and Medicaid Programs*, 22 HEALTH CARE FIN. REV. 175, 185 (Fall 2000) ("Within broad national guidelines established by Federal statutes, regulations, and policies, each State [participating in the Medicaid program] (1) establishes its own eligibility standards; (2) determines the type, amount, duration, and scope of services; (3) sets the rate of payment for services; and (4) administers its own program.").

104. ALA. ADMIN. CODE r. 560-X-51.01 (2005). For an explanation of "categorically needy" Medicaid beneficiary groups, *see* CTRS. FOR MEDICARE & MEDICAID SERVS., *MEDICAID-AT-A-GLANCE*, *supra* note 59, at 1.

105. GA. DEP'T MED. ASSISTANCE, *supra* note 102. For an explanation of "medically needy" Medicaid beneficiary groups, *see* CTRS. FOR MEDICARE & MEDICAID SERVS., *MEDICAID-AT-A-GLANCE* *supra* note 59, at 1-2.

106. Nat'l Hospice and Palliative Care Org., *NHPCO and State Hospice Organizations Fight Medicaid Hospice Benefit Cuts*, *supra* note 102, at 5.

107. KAISER FAMILY FOUND., *MEDICAID/SCHIP: SPENDING & BUDGETS*, <http://www.kff.org/medicaid/spending.cfm> (last visited Jun. 7, 2005) ("States play a major role in the delivery and financing of health care in the United States, primarily through the Medicaid program, which is the second-largest program in state budgets."). The largest item in most state budgets is education. Vernon K. Smith, *Making Medicaid Better: Options to Allow States to Participate and to Bring the Program Up to Date in*

“[e]xpanding Medicaid to cover. . . optional services, such as hospice care, proved politically popular. . . when times were flush.”¹⁰⁸ Unfortunately, many states currently face budget shortfalls, and the Medicaid program, with its large budget and optional services, is an easy target.¹⁰⁹ Several states are considering eliminating their Medicaid Hospice Benefit as a way to save money.¹¹⁰

Today’s Health Care Marketplace 3 (2002) (unpublished manuscript, on file with author) (“Medicaid is now one of the largest categories of state spending, second only to education.”).

108. Stephanie Simon, *The Nation Medicaid Ax is Falling as Recession Saps States*, L.A. TIMES, Mar. 5, 2002, at A1.

109. See, e.g., Sarah Lueck, *States’ Spending on Medicaid Slows*, WALL ST. J., Sept. 23, 2003, at A2 (“State spending on the Medicaid program for the poor slowed for the first time in seven years as state governments continued to cut coverage, tighten eligibility and reduce payments to physicians and hospitals.”); Elizabeth Shogren, *Cash-Strapped States Plan to Cut Medicaid*, L.A. TIMES, Jan. 14, 2003, at A10 (“Every state except Alabama has cut or plans to cut Medicaid health-care benefits for the poor this fiscal year as part of efforts to balance state budgets as revenue plummets.”).

110. See, e.g., Russell King, Editorial, *Governor Shows His Priorities Aren’t In Sync With Rest of “Family,”* WIS. ST. J., May 21, 2001, at A6 (“Our elderly and disabled [Wisconsin residents] have recently lost a great deal of access to [Medicaid-funded] home, hospice and personal care, but the governor’s budget offers no meaningful help.”); Kevin Corcoran, *O’Bannon Will Lobby to Spare Medicaid*, INDIANAPOLIS STAR, Apr. 2, 2003, at B1 (explaining that, in face of budget crisis, “[a] Medicaid freeze [in Indiana] would mean. . . [t]erminally ill patients won’t get hospice care in their homes.”); Alan Johnson et al., *More Cuts, Tax Hikes on Horizon*, COLUMBUS DISPATCH, Jan. 19, 2003, at 1A (“Other cuts to Ohio’s Medicaid program that may be considered are. . . [e]liminating optional Medicaid services, including coverage for. . . hospice.”); Laura B. Benko, *Medicaid Cuts Could Endanger Patients*, MOD. HEALTHCARE, Jan. 20, 2003, at 26 (“[California Governor Gray Davis] has proposed scrapping 18 of the 34 optional benefits now available to [Medicaid] enrollees, including. . . hospice care.”); Rachel Brand, *Uninsured are “Everybody’s Problem,”* ROCKY MOUNTAIN NEWS, Mar. 11, 2003, at 2B (“The Colorado legislature. . . now is considering axing Medicaid. . . [coverage for] hospice care.”); Dan Carter, *Hospice Care on the Increase*, BILLINGS GAZETTE, Nov. 19, 2003, at A1 (“During the last Legislature, a cost-cutting proposal would have eliminated Medicaid-funded hospice care for those Montanans who didn’t have insurance or Medicare support. . . .”); Kathy Barks Hoffman, *Tax No Quick Fix for Medicaid*, GRAND RAPIDS PRESS, Feb. 16, 2004, at A1 (listing hospice care as one of the Medicaid-covered services that Michigan residents could lose to budget cuts); Clark Kauffman, *Human Services Budget Envisions Cuts for Ill, Aged*, DES MOINES REG., Nov. 20, 2003, at 1A (“Almost 1,800 Medicaid-dependent Iowans are expected to need hospice care next year. Unless \$3.1 million can be found for this program, those terminally ill people would lose some hospice care services. . . .”); Press Release, State Medicaid Eligibility Cutbacks & Exclusions—Proposed & Recently-Enacted, 2001–04, Title II Community AIDS National Network (Jan. 12, 2004) (on file with author) (“[In Nevada], the state Human

B. A Proposal for Mandatory Coverage of Hospice by Medicaid

Congress has not faced a proposal to mandate hospice coverage under Medicaid in over ten years.¹¹¹ Today, after twenty years of success with the optional Medicaid Hospice Benefit,¹¹² it is time for Congress to reconsider creating a mandatory Medicaid Hospice Benefit.

When Rep. Panetta proposed that hospice care become a mandatory Medicaid benefit, the country was in a very different place than it is now. In 1989, the year that Panetta's proposal received the most serious consideration by Congress,¹¹³ less than half of the states had chosen to cover hospice under Medicaid.¹¹⁴ In addition, during the early years of the AIDS epidemic, legislators could only begin to estimate the costs that would accompany medical care for persons with HIV/AIDS.¹¹⁵ By citing AIDS as a reason to mandate hospice care under Medicaid,¹¹⁶ Panetta may have

Resources Director told the legislature that, if the new funds aren't voted and cuts are needed, Medicaid . . . hospice coverage would be likely first target[.].")

111. H.R. 474, 103d Cong. (1993). The last bill was proposed by Representative Leon Panetta, during the 103d Congress.

112. Comprehensive Omnibus Budget Reconciliation Act of 1986, Pub. L. No. 99-272, § 9505, 100 Stat. 82, 208-09 (codified as amended at 42 U.S.C. §§ 1396a, 1396d (2000)). The optional Medicaid Hospice Benefit was enacted in 1985.

113. *See supra* Part I.C.

114. H.R. REP. NO. 101-3.386, at 473 (1989) (Conf. Rep.), *as reprinted in* 1989 U.S.C.C.A.N. 3018, 3076 (reporting that National Governor's Association conducted survey in March 1989 and found that twenty states offered hospice coverage under Medicaid).

115. *See, e.g.,* Michael Specter, *Early AIDS Treatment Would Cost Billions*, HOUS. CHRON., Sept. 17, 1989, at 30 ("Providing effective early treatment to the more than 1 million Americans now infected with the AIDS virus would cost at least \$5 billion a year and have profound effects on nearly every aspect of the nation's health-care system."); Editorial, *Cost Implications of AIDS Aid*, L.A. TIMES, Sept. 16, 1989, at 8 ("At the federal level, there are no precise cost estimates of extending AZT to asymptomatic persons with HIV infection, but experts have spoken of an annual cost of \$2.5 billion to cover basic treatments, including aerosol pentamidine, AZT and the immune system tests required to monitor the treatment program for the infected population."); Victor F. Zonana, *Staggering Costs AIDS Care: Who Will Pick Up the Bill?*, L.A. TIMES, Aug. 7, 1989, at 1 ("The estimated costs of a national program to medically monitor and treat those infected with HIV before they develop full-blown AIDS are staggering. The total annual bill could range from \$2.5 billion to \$10 billion.").

116. 135 CONG. REC. E623-01 (daily ed. Mar. 2, 1989) (statement of Rep. Panetta) ("Hospice, with its combination of in-patient and out-patient care, provides the most appropriate means of care for many who are dying of AIDS. . . . [T]he current need is great enough to warrant making the hospice Medicaid benefit mandatory.").

frightened legislators who were witnessing the exponentially rising costs of caring for AIDS patients.¹¹⁷

In 2005, with nearly every state already electing to cover hospice care under Medicaid,¹¹⁸ mandating hospice coverage would ensure that states could not regress by cutting a successful program.¹¹⁹ In the next section, this article will examine reasons to support a mandatory Medicaid Hospice Benefit. It will then consider reasons to maintain the status quo.

III. SHOULD CONGRESS REQUIRE STATES TO OFFER A MEDICAID HOSPICE BENEFIT?

A. Hospice Care Has the Potential to Save States Money

Legislators who promoted the Medicare and Medicaid Hospice Benefits repeatedly listed cost savings as a benefit of hospice care.¹²⁰ These anticipated savings were grounded in the knowledge that “[h]ospice involves less invasive technological intervention and, with timely referral, less staff

117. See, e.g., Ruth Sorelle, *By '91, AIDS Care Costs May Reach \$8.5 Billion*, HOUSTON CHRON., May 13, 1989, at 27 (“By 1991, medical care for an estimated 250,000 U.S. AIDS patients will cost \$8.5 billion and the indirect costs—lost wages and revenues—will top \$55 billion . . .”).

118. See *supra* note 102 and accompanying text.

119. The initial fears about thousands of AIDS patients overrunning hospice programs have subsided. This is due, in large part, to the development of drugs that can suppress the virus and extend people’s lives by decades. See, e.g., David Brown, *Batch of New HIV Drugs Looks Promising*, WASH. POST, Feb. 15, 2004, at A14 (“The pipeline of new AIDS drugs looks more promising than it has in years.”); Martha Irvine, *As Teens, AIDS “Babies” Have a Secret to Share; New Drugs are Enabling Children Born HIV-Positive to Live Almost-Normal Lives*, L.A. TIMES, Dec. 21, 2003, at A13 (“[For ‘AIDS babies’], [e]arly on, the diagnosis was a death sentence, with few children living long enough to attend kindergarten. Eventually, new drugs emerged and the prognosis brightened for a population of young survivors who have quietly but tenaciously outlived life-expectancy predictions.”).

120. See, e.g., 131 CONG. REC. S11, 543-01 (daily ed. Sept. 16, 1985) (statement of Sen. Heinz) (“We must continue to seek creative, cost-effective ways of delivering needed health care to Medicare beneficiaries. Hospice care works for the Federal Government because it costs less than hospital care for the same patients.”); 131 CONG. REC. H5, 837-01 (daily ed. July 17, 1985) (statement of Rep. Panetta) (“[A]s expected, cost savings have been achieved as a result of Medicare beneficiaries utilizing the hospice benefit rather than receiving regular Medicare benefits. As we seek to reduce the cost of Health Care Programs, we must recognize the benefits of a greater utilization of hospice care.”).

time than acute care or skilled nursing care. . . Hospice saves significant money by preventing the medical crises that send patients to more costly hospitals and nursing homes.”¹²¹ In 1980, shortly before the Medicare Hospice Benefit was proposed to Congress by Leon Panetta and Robert Dole, the Health Care Financing Administration commissioned twenty-six hospice demonstration projects to serve as the basis of the National Hospice Study.¹²² The National Hospice Study evaluated the financial ramifications of covering hospice care under Medicare. The study limited itself to Medicare beneficiaries with terminal cancer diagnoses who were receiving hospice care.¹²³ The study’s final report concluded that

[H]ospice patients . . . are less costly than their [conventional care] counterparts, particularly in the last months of life and overall in the last year of life. The ostensible mechanism for this difference in costs is via the substitution of home care services for inpatient care and . . . a relative reduction in the intensity of ancillary service use when in an inpatient setting.¹²⁴

The National Hospice Study’s results helped to convince Congress to reauthorize the Medicare Hospice Benefit when the legislation’s sunset provision came up in 1985.¹²⁵

In the twenty years since the National Hospice Study was conducted, other studies have continued to evaluate whether the Medicare Hospice Benefit truly provides the cost savings that were originally anticipated. In 1996, the *Journal of the American Medical Association* published an article that synthesized the results of these studies.¹²⁶ The article seconded the

121. HEALTH COUNCIL OF S. FLA., INC., HOSPICE MEDICAID EDUCATION PROJECT FINAL REPORT 6 (2002); see also *Implementation of the Medicare Hospice Benefit*, *supra* note 43, at 2 (statement of Sen. Lloyd Bentson) (“In 1982, when Congress opened the Medicare Program to hospice, it was estimated by the Congressional Budget Office that millions of dollars in savings could accrue to the Medicare trust fund if only some individuals with a need for care chose hospice rather than traditional hospital services.”).

122. Matherlee, *supra* note 29, at 4.

123. Mor & Kidder, *supra* note 31, at 409.

124. *Id.* at 418–19.

125. Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, § 9123, 100 Stat. 82, 168 (codified as amended at 42 U.S.C. § 1395c (2000)).

126. Ezekiel J. Emanuel, *Cost Savings at the End of Life*, 275 JAMA 1907 (1996). The studies examined in the article are: NAT’L HOSPICE ORG., AN ANALYSIS OF THE COST SAVINGS OF THE MEDICARE HOSPICE BENEFIT (1995); David Kidder, *The Effects of Hospice Coverage on Medicare Expenditures*, 27 HEALTH SERV. RES. 195 (1992); Charles H. Brooks & Kathleen Smyth-Staruch, *Hospice Home Care Cost Savings to Third-Party Insurers*, 22 MED. CARE 691 (1984); William D. Spector & Vincent Mor, *Utilization and Charges for Terminal Cancer Patients in Rhode Island*, 21 INQUIRY 328

National Hospice Study's finding that "savings from hospice are predominantly the result of the reduced use of hospital care. . . in the last month of life."¹²⁷ However, the article pointed out an important shortcoming of the earlier studies, which mostly enrolled cancer patients: "[C]ompared with decedents with other diagnoses, cancer patients incur significantly higher per capita costs at the end of life and therefore have more room for savings. . . . [C]ost savings are likely to be smaller for patients who die of stroke, myocardial infarction, chronic obstructive pulmonary disease, or other illnesses."¹²⁸

In 2004, the *Annals of Internal Medicine* published a study that reinforced this observation.¹²⁹ The study, which included Medicare beneficiaries with terminal cancer diagnoses and beneficiaries with terminal conditions other than cancer,¹³⁰ concluded that "[h]ospice is cost-neutral to cost-saving for persons who die of cancer and generally yields added costs for those who do not die of cancer."¹³¹ This finding was largely attributed to "differences in service needs and certainty of prognosis that are associated with 3 major trajectories to death."¹³² Whereas cancer patients have relatively short periods of decline at the end of life, other patients, such as those suffering from chronic organ system failure, face long-term disability with unpredictable timing of death.¹³³ When death is difficult to predict, physicians may be reluctant to refer patients to hospice care.¹³⁴ This often means that by the time non-cancer patients enter hospice care, their conditions have reached a crisis state and they require more and higher cost

(1984); Mor & Kidder, *supra* note 31; Robert L. Kane et al., *A Randomised Controlled Trial of Hospice Care*, 323 LANCET 890 (1984).

127. Emanuel, *supra* note 126, at 1912.

128. *Id.* at 1911.

129. Diane E. Campbell et al., *Medicare Program Expenditures Associated With Hospice Use*, 140 ANNALS INTERNAL MED. 269 (2004).

130. *Id.* at 269 ("We estimated the effects of hospice enrollment on national Medicare expenditures during the last year of life among persons who died of conditions other than cancer and made more recent estimates of effects for persons who died of cancer.").

131. *Id.* at 275.

132. *Id.*

133. *Id.*

134. See MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 48, at 6 ("[M]ore important causes of late referrals [to hospice] appear to be the difficulty of making prognoses of death within six months. . . ."); Ben A. Rich, *Prognostication in Clinical Medicine*, 23 J. LEGAL MED. 297, 356 (2002) ("[T]he disinclination to prognosticate [by physicians] and the lack of physician training and enculturation in breaking bad news would be plausible explanations for why so many dying patients come too late. . . to hospice care.").

palliative treatments.¹³⁵ The study concluded that “[e]arlier entry to hospice in the non-cancer cohort may appear to be a way to reduce added costs associated with hospice care.”¹³⁶ Thus, while hospice care always saves Medicare money for cancer patients, it may not produce equivalent savings for non-cancer patients.

Only one report has specifically examined the ramifications of hospice care for the Medicaid program.¹³⁷ This report estimated what the costs to Medicaid would be if states discontinued their Medicaid Hospice Benefits. Commissioned by the National Hospice and Palliative Care Organization and released in 2003, the report estimated that “[i]f all states discontinued [Medicaid] hospice coverage, national Medicaid spending would increase by about \$282 million or approximately \$7,000 per beneficiary that would have enrolled in hospice.”¹³⁸ This spending increase was attributed to three findings. First, “[w]ithout hospice, more patients would continue to receive end of life care in a hospital.”¹³⁹ Second, “[w]ithout hospice, Medicaid would continue to pay for expensive pharmaceutical treatments.”¹⁴⁰ Third,

135. See *Barriers to Hospice Care: Are We Shortchanging Dying Patients: Hearing on Hospice Care Before the S. Spec. Comm. on Aging*, 106th Cong. (2000) (statement of Sen. Charles Grassley, Chairman, S. Spec. Comm. on Aging), 2000 WL 1349514 (“[Medicare beneficiaries] are receiving [hospice care] for shorter and shorter periods of time. . . . [I]t is a problem for hospices, because patients in their final week of life have very high costs. . . .”); Miller & Mike, *supra* note 13, at 539 (“The course of cancer is supposedly easier to predict than those of other major or chronic diseases. . . . This limitation. . . excludes other diseases that are generally terminal but more difficult to predict, including many chronic heart and lung conditions and also progressive dementia.”).

136. Campbell et al., *supra* note 129, at 275.

137. KATE FITCH & BRUCE PYENSON, VALUE OF HOSPICE BENEFIT TO MEDICAID PROGRAMS (2003). The *Annals of Internal Medicine* study explicitly stated that its findings were not directly applicable to Medicaid. Campbell et al., *supra* note 129, at 275.

138. FITCH & PYENSON, *supra* note 137, at 1.

139. The study estimated this component would save \$282 million. *Id.* at 1. This finding was based on a comparison of costs for Medicaid-eligible patients who die in hospitals versus costs for Medicaid-eligible patients who die in hospice care. *Id.* at 5; see Nat’l Hospice and Palliative Care Org., *NHPCO and State Hospice Organizations Fight Medicaid Hospice Benefit Cuts*, *supra* note 102, at 6 (“[I]f the Medicaid [hospice] benefit is not available and since the hospice benefit recipients are already eligible for Medicaid services and know how to access the health care system, they will receive their necessary services in the emergency room and intensive care units at a much higher rate.”).

140. The study estimated this component to save \$41 million. FITCH & PYENSON, *supra* note 137, at 1. In addition, “[h]ospice provides all medications related to terminal illness. . . . [W]ithout hospice, Medicaid’s drug costs would increase for people otherwise on hospice.” *Id.* at 6.

“[w]ithout hospice, states will pay about 5% more per day for hospice eligible Medicaid patients in nursing homes, due to technicalities in federal rules.”¹⁴¹ Since its release, this report has been cited in many states as a reason to preserve the Medicaid Hospice Benefit.¹⁴²

Analyses of hospice’s cost saving potential for Medicare and Medicaid are far from comprehensive. With only one report focusing on the Medicaid Hospice Benefit and several reports that only consider the Medicare Hospice Benefit in the context of cancer,¹⁴³ it would be premature to make a definitive statement about cost savings and hospice care. However, it would also be foolhardy to ignore the studies and reports that have considered Medicare, Medicaid, and hospice care and concluded that hospice care cuts medical expenses for cancer patients and, when timely referrals are made, potentially cuts costs for patients with non-cancer terminal diagnoses.¹⁴⁴

141. The study estimated this component would save \$13 million. *Id.* at 1. Also: [W]hen a Medicaid-only or dually eligible Nursing Facility beneficiary with a Medicaid hospice benefit enrolls in hospice, Medicaid pays hospice 95% of room and board allowable rather than the 100% Medicaid typically pays directly to the Nursing Facility. Hospice in turn reimburses the Nursing Facility 95% of room and board. For Nursing Facility eligibles without a Medicaid hospice benefit, Medicaid would pay 100% of the room and board charges to the Nursing Facility.

Id. at 7; see also *supra* note 92.

142. See, e.g., Kim Underwood, *Caring Place Project Will Expand Winston-Salem's Hospice and Better Organize Services for Terminally Ill*, WINSTON-SALEM J., July 15, 2003, at 1 (“Some states have considered eliminating the Medicaid hospice benefit as a way to reduce spending. But a study commissioned by the National Hospice and Palliative Care Organization shows that hospice services actually save a state money. . . .”); Michele McMahon, *Hospice Actually Saves Ohio, Families Money*, NEWARK ADV., Aug. 12, 2003, at A6 (citing study and stating that “[t]his cost-savings for the state of Ohio makes it easy to see that eliminating hospice as a benefit would quickly add costs to the state budget.”); see also Marsha Austin, *Colorado, Other States Make Deep Cuts to Medicaid Programs*, DENV. POST, Sept. 23, 2003, at C1 (“Colorado will continue to fund innovative programs that give patients what they want while saving the state money Hospice care for dying patients is a good example. . . . Thirty-days of hospice care costs Medicaid about the same as three days in a hospital. . . .”).

143. See HEALTH COUNCIL OF S. FLA., INC., *supra* note 121, at 7 (“There is no data on the cost of providing hospice care to non-cancer patients, but anecdotal evidence indicates the cost may be higher than for cancer patients.”).

144. See, e.g., Campbell et al., *supra* note 129, at 275 (“Hospice-related savings are often realized among patients with cancer. . . . Earlier entry to hospice in the noncancer cohort may appear to be a way to reduce added costs associated with hospice care.”); Emanuel, *supra* note 126, at 1911 (“[C]ancer patients and those who complete advance directives probably represent the most favorable groups of patients for demonstrating significant cost savings. . . .”); FITCH & PYENSON, *supra* note 137, at 1 (“[I]n 2003, if all

The extant literature overwhelmingly suggests that hospice care, under the Medicare and Medicaid programs, saves states money.

B. The Medicare Hospice Benefit Ensures That Hospice is Already Part of States' Health Care Infrastructures

1. Medicaid Hospice Certification Mirrors Medicare Hospice Certification

By law, qualifying Medicare beneficiaries may access the Medicare Hospice Benefit.¹⁴⁵ The Medicare Hospice Benefit plays a huge role in end-of-life care in the United States—80.9 percent of all decedents who used hospice in 2002 were covered by the Medicare Hospice Benefit.¹⁴⁶ Hospices can only receive reimbursement for the Medicare beneficiaries they serve if they become Medicare-certified.¹⁴⁷ To become certified, the hospice must comply with certain guidelines listed in the Medicare statute.¹⁴⁸ As of 2002, there were 2322 Medicare-certified hospices in the United States,¹⁴⁹ and every state contained at least two Medicare-certified hospices.¹⁵⁰ Due to the

states discontinued hospice coverage, national Medicaid spending would increase by about \$282 million or approximately \$7,000 per beneficiary that would have enrolled in hospice.”); Mor & Kidder, *supra* note 31, at 418–19 (“[H]ospice patients. . . are less costly than their [conventional care] counterparts, particularly in the last months of life and overall in the last year of life.”).

145. For a discussion of how a person qualifies for the Medicare Hospice Benefit, see *supra* Part I.B.2.

146. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES (2004), <http://www.nhpco.org/files/public/Facts%20Figures%20Feb%2004.pdf> (last visited Jun. 7, 2005).

147. 42 U.S.C. § 1395(x)(dd)(2) (2000).

148. *Id.*

149. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES., *supra* note 146, at 1. Of the total number of hospices in the United States, 96.7 percent were Medicare-certified in 2002. *Id.*

150. In 1999, Medicare-certified hospices were distributed as follows: Alabama: 66; Alaska: 2; Arizona: 37; Arkansas: 55; California: 186; Colorado: 39; Connecticut: 28; Delaware: 5; District of Columbia: 4; Florida: 41; Georgia: 94; Hawaii: 7; Idaho: 26; Illinois: 98; Indiana: 60; Iowa: 59; Kansas: 35; Kentucky: 29; Louisiana: 38; Maine: 16; Maryland: 31; Massachusetts: 42; Michigan: 80; Minnesota: 63; Mississippi: 41; Missouri: 66; Montana: 18; Nebraska: 29; Nevada: 7; New Hampshire: 20; New Jersey: 42; New Mexico: 26; New York: 54; North Carolina: 71; North Dakota: 15; Ohio: 93; Oklahoma: 66; Oregon: 41; Pennsylvania: 117; Rhode Island: 7; South Carolina: 32; South Dakota: 14; Tennessee: 62; Texas: 140; Utah: 21; Vermont: 9; Virginia: 46;

Medicare Hospice Benefit, hospices are well-entrenched in the states' health care infrastructures.

In states that offer the Medicaid Hospice Benefit, hospices can only receive reimbursement for the services they provide to Medicaid beneficiaries if they are Medicaid-certified.¹⁵¹ The Medicaid certification rules for hospices mirror the Medicare-certification rules for hospices.¹⁵² This means that any Medicare-certified hospice is also a Medicaid-certified hospice. In other words, any hospice that already receives federal reimbursement for Medicare beneficiaries can also receive federal reimbursement for Medicaid beneficiaries.

2. Medicare and Medicaid Hospice Beneficiaries Face Many of the Same Conditions

Medicare and Medicaid beneficiaries who qualify for hospice care suffer from many of the same illnesses.¹⁵³ Diseases such as cancer, the most

Washington: 28; West Virginia: 20; Wisconsin: 52; Wyoming: 15. HOSPICE ASS'N OF AM., HOSPICE FACTS & STATISTICS (2002), <http://www.nahc.org/Consumer/hpcstats.html> (last visited Jun. 7, 2005).

151. 42 U.S.C. § 1396d(o)(1)(A) (2000).

152. *Id.* (citing 42 U.S.C. § 1395(x)(dd)(2), the Medicare-certification rules for hospice programs, as appropriate rules for certification of Medicaid hospice programs).

153. The profiles for Medicare and Medicaid beneficiaries differ for HIV/AIDS. Medicare serves approximately nineteen percent of persons with HIV/AIDS. *Financing HIV/AIDS Care: A Quilt With Many Holes*, CAPITOL HILL BRIEFING SERIES ON HIV/AIDS (Kaiser Family Found., Wash., D.C.), Oct. 2002, at 7. Medicaid serves approximately fifty-five percent of persons living with AIDS and up to ninety percent of children living with AIDS. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID AND ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) AND HUMAN IMMUNODEFICIENCY VIRUS (HIV) INFECTION (2004), <http://www.cms.hhs.gov/hiv/hivfs.asp> (last visited Apr. 16, 2004). Yet, AIDS is not listed as one of the leading causes of death among hospice patients. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146, at 2. This can be attributed to several factors. First, one would expect hospice patients' illnesses to reflect the most common causes of death in the United States, and today AIDS is not a leading cause of death in the United States. Ali H. Mokdad et al., *Actual Causes of Death in the United States, 2000*, 291 JAMA 1238, 1239 (2004) (listing leading causes of death as heart disease, malignant neoplasm (cancer), cerebrovascular disease (stroke), chronic lower respiratory tract disease, unintentional injuries, diabetes, influenza/pneumonia, Alzheimer's disease, nephritis (kidney disease)). Second, a recent study published in the *Journal of American Medical Association* explained that "[m]ortality from sexually transmitted diseases is declining due to the availability of earlier and better treatment, especially for HIV." *Id.* at 1242. In 2002, 16,371 persons

common illness among hospice patients,¹⁵⁴ do not distinguish between Medicare and Medicaid populations. The same can be said for other conditions common to hospice patients, including end-stage heart disease,¹⁵⁵ dementia,¹⁵⁶ and lung disease.¹⁵⁷

Over eighty percent of hospice patients are Medicare beneficiaries.¹⁵⁸ This means that Medicare-certified hospices are already equipped with the technology necessary to provide palliative care to patients with these diseases. In addition, hospices already employ physicians and nurses who are familiar with the latest developments in palliative care.¹⁵⁹ The skills that

with AIDS died. CTRS. FOR DISEASE CONTROL & PREVENTION, ESTIMATED NUMBERS OF DEATHS OF PERSONS WITH AIDS (2003), <http://www.cdc.gov/hiv/stats/hasr1402/table7.htm>. In addition, "all States cover FDA-approved prescribed drugs [for Medicaid beneficiaries], including various prophylactic treatment of AIDS-related opportunistic infections, and drugs for the treatment of primary HIV disease." CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID AND ACQUIRED IMMUNODEFICIENCY SYNDROME, *supra*. Medicare covers the cost of some HIV/AIDS drugs, depending on the individual beneficiary's financial situation. GAY MEN'S HEALTH CRISIS, MEDICARE IS ESSENTIAL TO HIV/AIDS CARE (2003), http://www.gmhc.org/policy/benefits/medicare_essential.html (last visited Jun. 7, 2005). This means that Medicaid and Medicare beneficiaries living with HIV/AIDS can access prescription drugs that can significantly prolong their lives. The above discussion leads to the conclusion that while HIV/AIDS was a major issue in hospice care in the late 1980s and early 1990s, medical advances and prescription drug coverage have significantly lowered the number of people dying from AIDS each year. See *supra* note 115.

154. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146. In 2002, 50.5 percent of hospice patients were diagnosed with cancer upon admission. *Id.*

155. In 2002, 10.7 percent of hospice patients were diagnosed with end-stage heart disease upon admission. *Id.*

156. In 2002, 8.3 percent of hospice patients were diagnosed with dementia upon admission. *Id.*

157. In 2002, 6.7 percent of hospice patients were diagnosed with lung disease upon admission. *Id.* The other most common non-cancerous causes of death among hospice patients are end-stage kidney disease (three percent) and end-stage liver disease (1.6 percent). *Id.*

158. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146.

159. See HOSPICE ASS'N OF AM., HOSPICE FACTS & STATISTICS, *supra* note 150 ("Hospice care relies on the combined knowledge and skill of an interdisciplinary team of professionals—physicians, nurses, medical social workers, therapists, counselors, and volunteers—who coordinate an individualized plan of care for each patient and family."); Miller & Mike, *supra* note 13, at 536 ("[A] [hospice] plan of care is devised by an interdisciplinary team that must include a registered nurse, a medical social worker, a physician, and a pastoral or other counselor. These professionals must be employees of

hospice personnel use and the technologies they employ may vary among terminal diseases, but they do not vary between Medicare and Medicaid recipients; a Medicare beneficiary with end-stage heart disease and a Medicaid beneficiary with end-stage heart disease require the same types of palliative care.

3. Access Issues

Medicare beneficiaries are the single largest group to use hospice services.¹⁶⁰ Since the inception of the Medicare Hospice Benefit in 1982, Medicare beneficiaries have steadily increased their use of hospice care. In 2002, the Medicare Payment Advisory Commission (Medpac) was asked by Congress to examine Medicare beneficiaries' ability to access and use hospice services.¹⁶¹ Medpac found that from 1992 to 2000, hospice use tripled among Medicare beneficiaries living in rural areas.¹⁶² Hospice use more than doubled among Medicare beneficiaries living in urban areas.¹⁶³ In 2000, less than one percent of Medicare decedents nationally lived in areas where no hospice care was available.¹⁶⁴

No similar study has been conducted to examine Medicaid beneficiaries' ability to access and use hospice services. However, statistics maintained by the National Hospice and Palliative Care Organization show that although almost every state covers hospice care under its Medicaid plan, only 5.1 percent of hospice users nationally reported Medicaid as their payment source.¹⁶⁵ Members and observers of the hospice community have theorized about why so few Medicaid beneficiaries use hospice services:

the hospice. . . . [T]he staff requirements. . . for implementation of the Medicare hospice benefit are enormous.”)

160. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146. In 2002, 80.9 percent of hospice users claimed Medicare as their payment source. *Id.*

161. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 48, at 3. The study's indicators of access were beneficiaries' use of services and the supply of providers. *Id.* at 4.

162. *Id.* at 5. In 1992, six percent of Medicare beneficiaries living in rural areas used hospice care. In 2000, this number jumped to nineteen percent. *Id.*

163. *Id.* In 1992, ten percent of Medicare beneficiaries living in urban areas used hospice care. In 2000, this number jumped to twenty-five percent. *Id.*

164. *Id.* The one percent figure represents a national average. “In four states (Montana, South Dakota, Wyoming, and Nebraska) between 10 and 30 percent of rural Medicare beneficiaries lived in counties without apparent access to hospice care.” *Id.*

165. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146. Because the Medicaid hospice reimbursement rates mirror the Medicare hospice reimbursement rates, one cannot claim that reimbursement disparities contribute

[M]any hospices are still unable or unwilling to serve diverse populations. Hospice began as a white, middle-class movement, and some still view it that way today. For this reason, and because hospice organizations are often located in the “better” parts of town, their ability to serve people of color and the poor has never been questioned. . . .

Lack of cultural sensitivity in letters, brochures, fact sheets and other written materials also may be a barrier to hospice access. Information, including pictures and presentation, may be geared for whites. Reading level may also be inappropriate, for literacy in English, as well as other languages, varies among people of color and especially those of low socioeconomic status.¹⁶⁶

While this explanation reveals bias and stereotype issues that need to be overcome, it does not suggest that Medicaid beneficiaries should not have access to hospice care. If anything, it demonstrates the need for already existing hospices to broaden their outreach efforts to poorer communities that are likely to include Medicaid beneficiaries.

C. Hospice Care is Humane

The hospice movement’s underlying philosophy does not envision a system in which hospice care is available to some people and not to others.¹⁶⁷ When Dame Cicely Saunders and Elisabeth Kübler-Ross championed hospice care,¹⁶⁸ they did not claim that only dying Medicare

to access problems for Medicaid beneficiaries. Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, § 9505(c), 100 Stat. 82, 209 (1986) (codified as amended at 42 U.S.C. § 1396a(a)(13) (2000)).

166. Bruce Jennings et al., *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, HASTINGS CENTER REP., Mar.–Apr. 2003, S35, S43 (citations omitted); see also Eric L. Krakauer, *Mistrust, Racism, and End-of-Life Treatment*, HASTINGS CENTER REP., May–June 1997, at 23 (“[M]istrust related to social inequalities, racism, and cultural difference may be an important consideration in negotiating a conflict between family and physicians over end-of-life care.”); Houkje Ross, *End of Life Care Issues Need Culturally Sensitive Approaches*, CLOSING THE GAP (Office of Minority Health, Wash., D.C.), Feb.–Mar. 2001, at 13–14 (listing ways in which health care workers can be more attuned to cultural differences in terms of death and dying rituals).

167. Butterfield-Picard & Magno, *supra* note 13, at 1258 (“In explaining hospice care’s philosophical base, [Dame Cicely] Saunders has frequently phrased it this way: ‘You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you to die in peace, but also to live until you die.’”).

168. See, e.g., DeWitt C. Baldwin, Jr., *The Role of the Physician in End-of-Life Care: What More Can We Do?*, 2 J. HEALTH CARE L. & POL’Y 258, 259 (1999) (“The past several decades have seen a significant countermovement [against the denial of death]—

recipients suffered from overzealous treatment or neglect by their physicians. As Rep. Leon Panetta explained to Congress in 1985, “[e]ven though more than eighty percent of the terminally ill patients are reported to be elderly, persons eligible for Medicaid benefits should also be entitled to choose the hospice alternative.”¹⁶⁹ Since then, forty-seven states have agreed with this proposition and instituted a Medicaid Hospice Benefit.¹⁷⁰ By mandating coverage of hospice care under Medicaid, Congress would recognize and reinforce nearly every state’s commitment to choice and compassion in death.¹⁷¹

IV. DOES IT MAKE SENSE TO MAINTAIN THE STATUS QUO?

A. Many States Face Budget Crises

For the last few years, many states have faced record budget crises.¹⁷² When state legislators sit down to cut costs and balance their budgets, one obvious target is Medicaid. In fiscal year 2003, Medicaid was the third most common program to be cut by the states.¹⁷³ Medicaid cuts ranged from placing limits on eligibility to increasing co-payments and eliminating

led by persons such as Elizabeth [sic] Kübler-Ross and Dame Cicely Saunders—one that has led us back to a reconsideration of the place of death and dying in our society and in the life span.”).

169. 131 CONG. REC. H5, 837-01 (daily ed. July 17, 1985) (statement of Rep. Panetta).

170. See *supra* note 102 and accompanying text.

171. *Administration’s Proposed Payment System for Hospice Care*, *supra* note 42, at 46 (statement of Rep. Panetta) (explaining that hospice is one option terminally ill patients can choose for their end-of-life care); Mesler, *supra* note 26, at 173 (“[H]ospice philosophy emphasizes palliative care, treatment of symptoms rather than disease, to allow patients with a terminal prognosis (generally 6 months or less) the highest quality of life in the time which remains.”).

172. See, e.g., Iris J. Lav & Nicholas Johnson, *State Budget Deficits for Fiscal Year 2004 are Huge and Growing*, <http://www.cbpp.org/12-23-02sfp.htm> (“States are facing budget deficits in the range of \$70 billion to \$85 billion for state fiscal year 2004 The current state deficits are deeper than they have been any time in the last half-century.”); Press Release, Nat’l Governors Ass’n, *State Budget Outlook Remains Bleak* (Nov. 25, 2002) (on file with author) (“[S]tates face the most dire fiscal situation since World War II. . . . [M]any states have exhausted budget cuts and are drawing down rainy-day funds and. . . the most difficult decisions still lay ahead.”).

173. Randy Desonia, National Health Policy Forum, *Running on Empty: The State Budget Crisis Worsens*, 83 NHPF ISSUE BRIEF 1, 7 (Sept. 25, 2002). The first and second most common programs to be cut were education and corrections. *Id.*

optional benefits.¹⁷⁴ Because hospice care is an optional Medicaid benefit, states can choose to discontinue the benefit at any time.

Since 2002, at least nine state legislatures have seriously considered eliminating their Medicaid Hospice Benefit.¹⁷⁵ Despite these persistent threats, no state has actually eliminated its Medicaid Hospice Benefit since 1993.¹⁷⁶ Every time that a state's Medicaid Hospice Benefit has been threatened in recent years, legislators have managed to appropriate funds and patch together a temporary solution. For example, in 2002, Montana's legislature contemplated a cost-cutting proposal that would have abolished the state's Medicaid Hospice Benefit.¹⁷⁷ In a successful attempt to save the program, "[d]uring the waning days of the session, stabilization funds were allocated for Medicaid-funded hospice. . . keeping the service afloat through 2005."¹⁷⁸

Today, despite record budget crises,¹⁷⁹ forty-seven states and the District of Columbia have implemented and maintained a Medicaid Hospice Benefit.¹⁸⁰ Virtually every state has maintained its hospice benefit, and some states have even added the benefit in recent years.¹⁸¹ These facts speak to the states' commitment to provide hospice care to Medicaid beneficiaries. While mandating the Medicaid Hospice Benefit would curb states' autonomy by preventing states from cutting hospice programs to save money,¹⁸² it would also reaffirm a decision made by nearly every state to

174. *Id.* at 9.

175. The states are California, Colorado, Indiana, Iowa, Michigan, Montana, Nevada, Ohio, and Wisconsin. *See supra* note 110 and accompanying text.

176. HOSPICE ASS'N OF AM., HOSPICE FACTS & STATISTICS, *supra* note 150. The last state to eliminate its hospice benefit was Arizona. The state reimplemented the benefit in 1998. *Id.*

177. Carter, *supra* note 110, at A1.

178. *Id.*

179. For a discussion of state budget crises, *see supra* note 172 and accompanying text.

180. *See supra* note 102 and accompanying text.

181. In the last few years, Nebraska (2003), Minnesota (2002), South Dakota (2002), and Tennessee (2002) have added hospice care to their Medicaid coverage. *See* 471 NEB. ADMIN. CODE § 36-002 (2004); MINN. STAT. ANN. § 256B.0625(22) (West 2003 & Supp. 2005); S.D. ADMIN. R. 44:04:06:13 (2004); S.D. MEDICAID PROGRAM, HOSPICE PROVIDER MANUAL (2002); TENN. COMP. R. & REGS. 1200-13-10-.02 to -.04 (2004). In addition, Louisiana is in the middle of a pilot program that "could lead to hospice being a permanent part of Louisiana's optional [Medicaid] services." Nat'l Hospice and Palliative Care Org., *NHPCO and State Hospice Organizations Fight Medicaid Hospice Benefit Cuts*, *supra* note 102, at 5.

182. *But cf.* Laura D. Hermer & William J. Winslade, *Access to Health Care in Texas: A Patient-Centered Perspective*, 35 TEX. TECH. L. REV. 33, 53 (2004) ("While the federal

provide such coverage.¹⁸³ If Congress required coverage of hospice care under Medicaid, it would enforce a federal policy that all but three states decided on their own.

B. Medicaid Recipients Might Overwhelm Hospices

If Congress were to require coverage of hospice care by state Medicaid programs, a legitimate concern would be the impact this would have on established hospice programs. After all, it would be counterproductive to mandate a Medicaid Hospice Benefit if it would impair the operation of the Medicare Hospice Benefit. Statistics demonstrate, however, that it would be virtually impossible for Medicaid beneficiaries to suddenly overrun hospice programs.¹⁸⁴

In 2002, 80.9 percent of hospice patients claimed Medicare as their payment source.¹⁸⁵ That same year, even though almost every state had a Medicaid Hospice Benefit, only 5.1 percent of hospice patients upon admission claimed Medicaid as their payment source.¹⁸⁶ As these statistics show, Medicaid beneficiaries comprise a tiny fraction of hospice care recipients. This low level of participation can most likely be attributed to access issues, such as hospice location¹⁸⁷ and bias or prejudice experienced by Medicaid recipients.¹⁸⁸ While federally mandating a Medicaid Hospice Benefit could save money and heighten the quality of care, it certainly would not speak directly to issues of access or prejudice. For this reason, it is extremely unlikely that Medicaid beneficiaries would immediately overwhelm hospice programs if the Medicaid Hospice Benefit was mandatory.

government sets certain minimum eligibility criteria for those seeking Medicaid coverage, states may offer more expansive coverage if they choose.”).

183. See *supra* note 102 and accompanying text.

184. See NAT’L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146, at 4 (finding that in 2002 only 5.1 percent of hospice patients upon admission claimed Medicaid as their payment source).

185. *Id.* Due to Medicare beneficiaries’ demographic (i.e. persons over age sixty-five), one would expect the majority of hospice patients to be Medicare beneficiaries. See *supra* Part I.B.1.

186. See NAT’L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES, *supra* note 146, at 4.

187. See Jennings et al., *supra* note 161, at S35.

188. For a discussion of access issues that affect the Medicaid Hospice Benefit, see *supra* Part III.B.3.

C. Medicare Recipients Have “Earned” Their Hospice Benefit

Medicare and Medicaid operate under two very different premises. People usually qualify for Medicaid because they are poor,¹⁸⁹ whereas people usually qualify for Medicare because they worked for a certain number of years and contributed to the mandatory Social Security payroll tax.¹⁹⁰ Medicare beneficiaries have “‘earned’ [their] eligibility through their own work or the work of close relatives.”¹⁹¹ Medicaid beneficiaries have no equivalent sense of “earning” their health coverage.

One could argue that Medicare beneficiaries have “earned” the right to benefit from programs like hospice care, while Medicaid beneficiaries have not. In other words, why should states be forced to offer Medicaid beneficiaries a program like hospice, whose sole purpose is to provide comfort care to the dying? What have Medicaid beneficiaries done to “earn” this option? Taken to the extreme, these types of “worthiness” arguments could be used to undermine the entire Medicaid program.¹⁹²

One answer to this challenge is that many Medicaid beneficiaries never had the opportunity to qualify for Medicare: “The career self [(describing a person who can create and execute a life plan to be economically and socially productive)] was never an option for those who are poor, chronically ill, severely disabled, or the object of others’ domination or

189. See Hoffman et al., *supra* note 103, at 185 (“[Medicaid] is a Federal/State entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. . . . Medicaid is the largest source of funding for medical and health-related services for America’s poorest people.”).

190. 42 U.S.C. § 1395i (2002).

191. David A. Super, *Offering an Invisible Hand: The Rise of the Personal Choice Model for Rationing Public Benefits*, 113 YALE L.J. 815, 857-58 (2004); cf. Daniel N. Shaviro, *Accrual Accounting and the Fiscal Gap*, 41 HARV. J. ON LEGIS. 209, 210 (2004) (“It might seem artificial to treat people who have worked forty quarters as entitled to the full array of Medicare benefits, and those who have worked thirty-nine or fewer quarters as entitled to nothing.”).

192. The Medicaid program inherently raises issues of “worthiness”:

The question of “eligibility” for Medicaid is thus the question of who will be excused from the full risks of the market. It is a painful question, because as a society we have refused to pay for health insurance for all people who cannot afford to buy it directly or through their employment relationship. So some people will not be excused from full market risk, even though they may be, or seem, largely indistinguishable from the people who have been excused. Medicaid eligibility rules are about making these distinctions, about deciding who gets excused and who does not.

control.”¹⁹³ In other words, due to circumstances beyond their control, many people never have the chance to qualify for Medicare and its attendant benefits. Another response is:

[Society has a] responsibility to look after its most vulnerable citizens. . . . [Under this model,] the dying have a claim against society to a basic minimum of care that falls under two headings. The first is relief from pain, nausea, and other forms of physical suffering—this is the palliative care arm of hospice. The second kind of care is whatever relief from spiritual or existential suffering the dying can take from their connections to something greater than themselves, whether this be God, their loved ones, the flourishing of their community, or some combination of these.¹⁹⁴

Finally, on a pragmatic level, the most convincing retort to this challenge might be that public opinion clearly holds that Medicaid beneficiaries should have access to hospice care. If this were not the case, then ninety-four percent of the states and the District of Columbia would not likely have chosen to offer hospice care to Medicaid beneficiaries.¹⁹⁵

CONCLUSION

When Congress enacted the Medicare Hospice Benefit in 1982, legislators put a sunset provision on the legislation—they wanted to collect data and reevaluate their decision in three years.¹⁹⁶ In 1985, legislators were so pleased with the Medicare Hospice Benefit that they removed the sunset provision from the legislation and enacted an optional Medicaid Hospice Benefit.¹⁹⁷ In the twenty years since then, hospice care has become one of the optional services most frequently included in state Medicaid plans.¹⁹⁸

Today, with state budget cuts looming,¹⁹⁹ the time has come to reconsider mandating the Medicaid Hospice Benefit. Recent studies and reports demonstrate that hospice care already saves Medicare and Medicaid

193. Hilde Lindemann Nelson, *Pictures of Persons and the Good of Hospice Care*, HASTINGS CENTER REP., SPECIAL SUPPLEMENT May–June 2003, at S18.

194. *Id.* at S19.

195. *See supra* note 102 and accompanying text.

196. *See supra* note 68 and accompanying text.

197. Omnibus Reconciliation Act of 1985, Pub. L. No. 99-272, § 9123, 100 Stat. 82, 168 (1986) (codified as amended at U.S.C. § 1395c (2000)).

198. KAISER FAMILY FOUND., MEDICAID BENEFITS: HOSPICE CARE (2003), <http://207.22.102.105/medicaidbenefits/hospice.html> (“Hospice care is an optional benefit under Medicaid that most of the states. . . have elected to cover.”); CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID AT-A-GLANCE, *supra* note 59, at 11.

199. *See supra* note 172 and accompanying text.

money,²⁰⁰ and, with timely referrals, it has the potential to save both programs even greater sums.²⁰¹ In addition, because the Medicare Hospice Benefit forced every state to integrate hospice care into its health care infrastructure,²⁰² mandating the Medicaid Hospice Benefit would not require significant financial outlays—Medicare-certified hospices can already receive reimbursement for Medicaid patients. Finally, mandating a Medicaid Hospice Benefit would capitalize on a growing national consensus that hospice care provides a desirable, humane alternative for the dying, regardless of their income and personal assets. So far, despite recent budget shortfalls, the states have made their decision clear:²⁰³ as with their Medicare counterparts, Medicaid beneficiaries should have the option of choosing hospice care during their final months. After twenty years, Congress should make this sentiment official, not optional.

200. See *supra* note 144 and accompanying text.

201. Campbell et al., *supra* note 129, at 275 (“Earlier entry to hospice in the noncancer cohort may appear to be a way to reduce added costs associated with hospice care.”).

202. See *supra* Part III.B.1.

203. See *supra* note 102 and accompanying text.