
A MATTER OF LIFE, DEATH, AND
CHILDREN: THE PATIENT PROTECTION
AND AFFORDABLE CARE ACT
SECTION 2302 AND A SHIFTING LEGAL
PARADIGM

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I. INTRODUCTION

Don't give up the fight, life is your right.

—Bob Marley (mantra adopted by Nick Snow, former pediatric hospice patient)

Nick Snow was diagnosed with neuroblastoma, a rare and deadly form of cancer, at the age of six.¹ After undergoing “chemotherapies, surgeries, four types of radiation, a bone marrow transplant and many experimental therapies,” Nick saw his cancer finally go into remission six years after diagnosis.² Twice during this grueling ordeal, doctors told Nick that he would soon die and enrolled him in a hospice program.³ Unexpectedly, Nick’s general health improved during hospice treatment, enabling him to resume the fight against his cancer.⁴ Under then-existing federal laws, Nick’s improved health and decision to seek a long-term cure simultaneously rendered him ineligible for hospice services. As this Note discusses and as Nick Snow explained in his own words, this legally mandated result is unsatisfactory:

It seems kind of strange that [hospice] would only come when I was dying and not when my family and I really needed it most, like when I was going through all the hard (chemotherapy) treatment But when I decided that I felt better enough to try a new treatment, hospice couldn’t come anymore. That was hard on all of us—to lose support just because I wanted to try to live.⁵

Motivated by his personal experience, Nick Snow lobbied the United States Congress and the California State Assembly to change the law so that children could access hospice services at an earlier point in their illnesses.⁶ Nearly three years after Nick first advocated reform of the laws governing hospice, California passed a statute and received a Medicaid waiver authorizing a program designed to expand pediatric end-of-life services.⁷ Another four years passed before Congress adopted a similar

1. Liz Kellar, *Teen’s Medical Fight Comes to Fruition*, UNION (Grass Valley), Oct. 1, 2009, <http://www.theunion.com/article/20091002/NEWS/910019958?layout=320>.

2. *Id.*

3. Dave Moller, “*Don’t Give Up the Fight, Life is Your Right: After Losing Battle with Cancer, Student’s Push for Law Rages On*,” UNION (Grass Valley), May 26, 2006, at C1.

4. *Id.*

5. *Id.* (internal quotation marks omitted).

6. *Id.*

7. Kellar, *supra* note 1.

proposal at the federal level—the subject of this Note.⁸ Sadly, Nick Snow passed away before either of these measures took effect.⁹

Nick Snow's tragic story is, unfortunately, not the only one of its kind. However, the recent extensive and sometimes rancorous debate over the Patient Protection and Affordable Care Act of 2010 ("ACA") has largely ignored a section of the Act that could greatly alter the care of an important, yet invisible, population—terminally ill children, like Nick Snow. Section 2302 of the ACA dramatically revises the structure in which end-of-life care and hospice services are delivered to Medicaid-eligible children.¹⁰ Although other portions of the ACA received much publicity for their incidental effects on end-of-life issues, Section 2302, which actually alters medical services for seriously ill children, received little attention, especially within the legal community.¹¹ Section 2302 generally expands hospice services for Medicaid-eligible children,¹² yet leaves untouched much of the complex legal and regulatory environment governing pediatric end-of-life care. Understanding the tension between that which the ACA changes and that which it ignores is of critical importance to developing a legal framework that better cares for society's seriously ill children.

This Note carefully studies the ACA-driven shift in the legal landscape governing pediatric hospice care, projects the likely effects of the new law, and recommends a modified approach. Part II introduces and explains the legal paradigm which has traditionally governed federally funded care at the end of life. That section also explicates the hospice concept as well as the related Medicaid statutory provisions. Part III explores the history of Section 2302, argues that it represents a substantial shift in the end-of-life legal paradigm, and predicts the effects of the new

8. See *infra* Part III.A.

9. Kellar, *supra* note 1. For a detailed discussion of the program implemented pursuant to the Nick Snow Act, see *infra* Part IV.B.

10. The United States Supreme Court's landmark opinion on the ACA leaves untouched Section 2302. See *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566, 2608 (2012) (concluding that, even though the ACA unconstitutionally threatened to withdraw existing Medicaid funding if states did not comply with the Act's Medicaid expansion, the remaining provisions of the Act remain in force). To clarify, the ACA provides Medicaid coverage for "all individuals under the age of 65 with incomes below 133 percent of the federal poverty line." *Id.* at 2601. This is a tremendous expansion from the program's traditional purview, which, as the Court describes it, consists of "certain discrete categories of needy individuals—pregnant women, children, needy families, the blind, the elderly, and the disabled." *Id.* In essence, Congress must give states the choice to opt out of this expansion. See *id.* at 2608 ("Congress may offer the States grants and require the States to comply with accompanying conditions, but the States must have a genuine choice whether to accept the offer.").

11. Michelle Andrews, *New Healthcare Law Will Expand Hospice Option*, L.A. TIMES, Sept. 20, 2010, <http://articles.latimes.com/2010/sep/20/health/la-he-palliative-care-20100920>.

12. *Id.*

law. Part IV presents a critique of this new law, identifies several states' efforts in addressing the failure, and offers a new model for the Medicaid legal landscape governing pediatric end-of-life care. Part V concludes that Section 2302, while a substantial change in the legal framework for children's Medicaid, leaves untouched an important barrier to palliative care for children, namely the six-month prognosis-of-death requirement; this requirement will need to be reshaped if terminally ill children are to enjoy timely access to hospice services.

II. HOSPICE, MEDICINE, AND MEDICAID

A. THE LONGITUDINAL VIEW

To glance briefly back at the origins and development of modern medicine is to understand the genesis of the laws governing today's end-of-life care. Attributed, in part, to the historic philosopher Rene Descartes, the "reductionism" of modern medicine has been both a cog in the wheel of scientific understanding and an enabler of the system's chronic undertreatment of pain and suffering.¹³ As Milton Lewis notes, while medical reductionism pushed for a greater comprehension of the physical causes of illness, it simultaneously turned a blind eye to the patients' more immediate manifestations of disease, such as pain and discomfort.¹⁴ This hyperfocus on the physical causes of illness bore much fruit in the quest to conquer disease. A broadened knowledge of the human anatomy, augmented further by advances in technology, led to a dramatic increase in medicine's ability to cure the body,¹⁵ and with it came the "objectification of the doctor / patient relationship."¹⁶ Emboldened by these tremendous advances in science, members of the medical community viewed death as a failure of their profession.¹⁷

Perhaps equal in effect, or at least complementary, to modern medicine's early rejection of death were the general social attitudes on the subject. For many years, death was an event that western society denied.¹⁸

13. MILTON J. LEWIS, *MEDICINE AND CARE OF THE DYING* 49–51 (2007).

14. *Id.* at 51.

15. *Id.* at 79; CATHY SIEBOLD, *THE HOSPICE MOVEMENT: EASING DEATH'S PAINS* 18–19 (1992).

16. SIEBOLD, *supra* note 15, at 19.

17. *See id.* ("Physicians not only perceived care of the dying as being outside the scope of medical work, they viewed death as a threat to their professional advancement."); David A. Simpson, *Hospice at the Crossroads: Can It Survive?*, 2 J. HEALTH CARE L. & POL'Y 310, 311 (1999) ("It is also not surprising that armed with such sophisticated technology, the most appropriate paradigm for death is that it is really a failure of medicine and technology eluding our control only because we haven't yet found the right elixir.").

18. SIEBOLD, *supra* note 15, at 30–31. *But cf.* KENNETH P. COHEN, *HOSPICE: PRESCRIPTION FOR*

Labeled, at its worst, as a “conspiracy of silence,” society’s unease with the subject of death may be related to self-reflective fear of the event,¹⁹ secularization,²⁰ or even a growing concern with maintaining youthful appearances.²¹ Regardless of its source, society’s longstanding hesitancy when dealing with death has had a nonnegligible impact on the administration of medical care at the end of life.

Hospice developed largely in response to the “belief that death in American culture was denied.”²² As a philosophy of care, hospice embraces a comfort-based approach to death for both patients and their families.²³ Put simply, hospice care accepts the premise that “death is easier when pain and other symptoms are well controlled, and when the patient’s family and friends can surround him—care for him, love him—throughout the dying process.”²⁴ As an institution, hospice “provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care.”²⁵ Furthermore, hospice shifts the focus from curative treatment in hospitals to pain management and interdisciplinary support in the patient’s home.²⁶ Typical hospice services include “nursing care, medical social services, physical therapy, counseling, and short-term inpatient care”²⁷ and are often provided by an interdisciplinary team

TERMINAL CARE 38 (1979) (noting that death was often a shared family event in American farm society during the early twentieth century).

19. COHEN, *supra* note 18, at 31–32.

20. SIEBOLD, *supra* note 15, at 32.

21. See LEWIS, *supra* note 13, at 74 (“[I]n a culture that encouraged the avoidance of dirt and unpleasant odors, the preservation of appearances with cosmetics, and a turning to plastic surgery to help people feel young, . . . it [is] difficult to confront the reality of death and senile decay.” (citing James J. Farrell, *The Dying of Death: Historical Perspectives*, 6 DEATH EDUCATION 105, 120–21 (1982))).

22. SIEBOLD, *supra* note 15, at 54.

23. Kathleen Tschantz Unroe & Diane E. Meier, *Palliative Care and Hospice: Opportunities to Improve Care for the Sickest Patients*, 25 NOTRE DAME J.L. ETHICS & PUB. POL’Y 413, 418 (2011) (“[T]he hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness . . .” (quoting Diane E. Meier, *The Development, Status, and Future of Palliative Care*, in PALLIATIVE CARE: TRANSFORMING THE CARE OF SERIOUS ILLNESS 3, 18 (Diane E. Meier et al. eds., 2010)) (internal quotation marks omitted)).

24. MARILYN WEBB, *THE GOOD DEATH* 64 (1997).

25. Jack M. Zimmerman, *General Features of Hospice Care*, in HOSPICE: COMPLETE CARE FOR THE TERMINALLY ILL 17, 17 (2d ed. 1986).

26. Unroe & Meier, *supra* note 23, at 415. See also WEBB, *supra* note 24, at 64 (“Most hospice patients in America are cared for in their homes . . .”).

27. Kelly Noe, Pamela C. Smith & Mustafa Younis, *Calls for Reform to the U.S. Hospice System*, 37 AGEING INT’L. 228, 229 (2012). It is important to distinguish between hospice care and nonhospice palliative care. While hospice care, under Medicare, has strict eligibility requirements,

consisting of “physicians, nurses, and social workers as well as . . . chaplains, psychologists, and physical therapists.”²⁸ Given the well-documented, deleterious effects of terminal illness on the family unit,²⁹ hospice focuses on providing care and support for both the ill patient and his or her family.³⁰

Although hospice began as a resting place for weary European travelers in the Middle Ages, its modern-day focus on caring for the terminally ill has taken hold in America only within the last half century.³¹ American hospice programs arose largely amidst the backdrop of the very large proportion of deaths that occurred in hospitals, where “the feelings of the dying person and the family tended to come second.”³² By focusing on the hitherto invisible dying process, the hospice movement cast light onto an otherwise dark corner of medical care, garnering attention and, ultimately, popularity for the concept.³³ Despite this initial recognition and a concomitant uptick in physicians’ interest in learning pain management techniques, the hospice movement had difficulty convincing doctors to refer eligible patients to the program.³⁴ A number of justifications have been hypothesized to explain the significant gap between hospice-eligible and hospice-enrolled patients: physicians feared hospice would interfere with the patient-doctor relationship; “physicians had difficulty acknowledging death;” and medical schools did not provide sufficient

nonhospice palliative care focuses largely on pain management and may be provided at any time during the course of an illness. Unroe & Meier, *supra* note 23, at 415.

28. Unroe & Meier, *supra* note 23, at 415.

29. Ezekiel J. Emanuel et al., *Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers*, 132 ANNALS INTERNAL MED. 451, 457 (2000) (“[C]aregivers of patients with substantial care needs were significantly more likely than caregivers with low care needs to have depressive symptoms . . . and [more likely] to report that their role as caregiver was ‘interfering with [their] family or personal life.’”); WEBB, *supra* note 24, at 207–08 (“[R]esearchers found that the consequence of serious illness and its medical treatment . . . can have a major, and sometimes catastrophic, impact on the patient’s entire family, even putting other family members dangerously at risk.”). See generally Amy R. Williams, *Beyond Physical: The Wave Effect of Terminal Illness* (July 6, 2008) (unpublished manuscript), available at <http://www.thriveboston.com/counseling/beyond-physical-the-wave-effect-of-terminal-illness/> (discussing the particular challenges a family unit will face when either a parent or child is diagnosed with a terminal illness).

30. See WEBB, *supra* note 24, at 64 (noting that hospices provide “psychological and spiritual counseling for patients and family members”); Zimmerman, *supra* note 25, at 21 (“In hospice care programs, the unit of care is not just the patient, but the patient and his or her family.”).

31. See *Introduction to HOSPICE CARE FOR CHILDREN* 3, 3 (Ann Armstrong-Dailey & Sarah Zarbock Goltzer eds., 1993) (discussing the historical origins of hospice); Unroe & Meier, *supra* note 23, at 416–18 (noting that the U.S. Department of Health, Education, and Welfare recognized the viability of the hospice model of care in 1978 and created the hospice Medicare benefit in 1982).

32. LEWIS, *supra* note 13, at 74–75.

33. See *id.* at 136 (discussing the growth of hospice’s popularity in the 1970s and 1980s).

34. *Id.* at 138.

instruction on hospice care.³⁵ Of particular importance to this Note is the theory that the federal laws and regulations governing hospice depressed the rate at which physicians referred patients to the programs because, in part, such laws required “that a patient must be informed of his or her terminal status before being referred to a hospice program.”³⁶ Studies have shown, however, that physicians are often uncomfortable discussing terminal diagnoses with their patients.³⁷ In an effort to avoid being “the bearers of bad tidings,” physicians merely place the duty of inquiry upon their patients, expecting that they will take the initiative of asking for the “bad news.”³⁸ This presumption is faulty, though, because it is often the patients who expect their doctors to keep them informed.³⁹ What results is something of an awkward construct in which the most critical information—that the patient has a terminal condition—is never verbalized. This failure of communication leads to, at worst, no hospice referral and, at best, a later-than-ideal one.

Ultimately, the foregoing history suggests that hospice care and traditional medical care evolved in two different spheres, a separation reinforced by Medicare and Medicaid laws.⁴⁰ As will be discussed later, recent legislative events may signal a shift in this paradigm.

B. EMPIRICAL GROWTH IN HOSPICE

With the goal of comprehensive care, hospice and palliative programs produce beneficial outcomes for both patients and their families.⁴¹ As the philosophy of hospice has gained cultural acceptance in America, the overall use of hospice services has predictably increased. Twenty-three

35. SIEBOLD, *supra* note 15, at 152 (citing various studies).

36. *Id.* at 153. Note that federal hospice regulations require something similar, if not more onerous for the patient. In order for a patient to qualify for hospice under Medicare, a doctor must certify that the patient is “terminal” and the patient must, essentially, accept that diagnosis by agreeing to forego any curative treatment. *See infra* text accompanying notes 106–07.

37. *See, e.g.*, Betsy T. Friedman, M. Kay Harwood & Matthew Shields, *Barriers and Enablers to Hospice Referrals: An Expert Overview*, 5 J. PALLIATIVE MED. 73, 78 (2002) (presenting results of interviews with hospice experts indicating that physicians are reluctant to discuss a terminal diagnosis with their patients). It should be noted that because the Friedman study is qualitative, the scientific rigor of its evidence is somewhat lessened.

38. *Id.* (italics omitted).

39. *Id.*

40. *See* Deborah Witt Sherman, Editorial, *Access to Hospice Care*, 3 J. PALLIATIVE MED. 407, 407 (2000) (“Medicare regulations reinforce late enrollment [into hospice] by specifying a limit of 6 months survival.”).

41. *See* Unroe & Meier, *supra* note 23, at 418–20 (citing studies demonstrating that hospice and palliative care programs improve the patient’s pain management, aid the caregiver, improve family satisfaction, and reduce health care costs).

years after the first American hospice was founded in 1974, hospice programs numbered nearly three thousand⁴² and, in 2006, cared for 1.3 million people.⁴³ This figure represented 36 percent of all American deaths.⁴⁴ By comparison, in 1997, hospices cared for only 400,000 Americans.⁴⁵ In terms of cost, between the years 2000 and 2007, federal Medicare spending on hospice services increased by \$7.1 billion.⁴⁶

Although the overall consumption of hospice services has dramatically increased in the last decade, a closer look at use among pediatric patients tells a different story. Child death comprises a very small proportion of the total number of deaths within the United States—approximately 2.2 percent in 2005.⁴⁷ Moreover, the National Hospice and Palliative Care Organization (“NHPCO”) reports that “the percentage of younger hospice patients has been decreasing.”⁴⁸ This is true “despite increases both in the number of hospice programs nationwide . . . and in the number of patients who received hospice care.”⁴⁹ However, aggregate data on the use of pediatric hospice services is somewhat misleading. It is more important to compare the volume of hospice services consumed with the number of children who are hospice eligible. With this as the appropriate metric, there is evidence to suggest that “less than 20 [percent] of children eligible (i.e., qualify for hospice) are actually receiving services nationwide.”⁵⁰

42. WEBB, *supra* note 24, at 63.

43. SARAH FRIEBERT, NAT’L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES: PEDIATRIC PALLIATIVE AND HOSPICE CARE IN AMERICA 3 (2009), available at http://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf.

44. *Id.*

45. WEBB, *supra* note 24, at 63–64.

46. Noe, Smith & Younis, *supra* note 27, at 229.

47. FRIEBERT, *supra* note 43, at 3. For this statistic, a “child” is any individual between zero and nineteen years of age. Note that approximately half of all child deaths are among “infants” (those less than one year of age). *Id.* Also note that, among those children ages one to nineteen, the majority of deaths occur between fifteen and nineteen years of age. *Id.* at 4. Interestingly, the death rate among those between the ages of twenty and twenty-four—which are not considered “children”—has increased over time. *Id.* This result is due, in part, to medical advances, which help to postpone deaths that would have occurred to individuals between the ages of zero and nineteen. *Id.*

48. *Id.* at 8. It should be noted that, in 2006, the number of hospice patients less than 35 years old was still small—approximately 11,700. *Id.* In 2005, the number of hospice patients less than 35 years old was only marginally larger—approximately 13,200. *Id.* Due to such small fluctuations in the number of patients between years, great care should be taken before declaring any broad trend.

49. *Id.*

50. See Kathryn E. Artnak, Richard M. McGraw & Vayden F. Stanley, *Health Care Accessibility for Chronic Illness Management and End-of-Life Care: A View from Rural America*, 39 J.L. MED. & ETHICS 140, 149 (2011).

Moreover, the location of most pediatric deaths is concerning. Although the number of child deaths occurring in the hospital has decreased with time, it still remains true that most children who die do so in a hospital bed.⁵¹ This result holds despite the overwhelming preference, among families, that their terminally ill child dies at home.⁵²

The statistical growth in the popularity of hospice is undeniable, yet it still remains true that death sometimes carries with it the stigma of failure⁵³ and, as such, encourages individuals to pursue ex ante every conceivable tool of curative treatment.⁵⁴ Though this cure-at-all-costs approach is intuitively desirable and has received tacit support from Medicaid laws governing end-of-life care, it cannot be doubted that the same approach is, in part, why most American deaths occur in institutions, such as hospitals and nursing homes.⁵⁵

C. MEDICAID AS A LEGAL ENTITLEMENT

Unheralded in its 1965 enactment,⁵⁶ Medicaid has grown into a behemoth entitlement program. In 2008, for example, Medicaid had an estimated fifty-five million enrollees and received federal and state outlays nearing \$300 billion.⁵⁷ The growth in Medicaid funding has been particularly dramatic in the last ten years.⁵⁸ Although it began as merely an “add-on” to other welfare programs,⁵⁹ Medicaid is now America’s largest means-tested entitlement law.⁶⁰ Individual states may opt into the Medicaid program and, if so, are largely responsible for administering its benefits.⁶¹ States are not without help, though. In return for providing their citizens with Medicaid benefits, participating states have a legally enforceable right to receive federal financial assistance in covering the costs of both the

51. FRIEBERT, *supra* note 43, at 6.

52. *Id.*

53. Unroe & Meier, *supra* note 23, at 416.

54. *Id.*

55. *Id.*

56. DAVID G. SMITH & JUDITH D. MOORE, *MEDICAID POLITICS AND POLICY: 1965–2007*, at 21 (2008).

57. *Id.* at 370.

58. *Compare id.* (noting that the 2007 estimated federal and state spending on Medicaid approached \$300 billion), with Sara Rosenbaum & David Rousseau, *Medicaid at Thirty-Five*, 45 ST. LOUIS U. L.J. 7, 17 (2001) (“In [Fiscal Year] 1997 . . . total federal and state Medicaid spending stood at \$161.2 billion.”).

59. SMITH & MOORE, *supra* note 56, at 1.

60. Rosenbaum & Rousseau, *supra* note 58, at 16.

61. *Id.* at 17. Note that, currently, all states are Medicaid providers. MaryBeth Musumeci, *Modernizing Medicaid Eligibility Criteria for Children with Significant Disabilities: Moving from a Disabling to an Enabling Paradigm*, 37 AM. J.L. & MED. 81, 93 (2011).

benefits and the program's administration.⁶²

In order to receive assistance under Medicaid, an individual must meet eligibility criteria including categorical, financial, residency, and citizenship.⁶³ States are required to provide services to "categorically needy" individuals and may elect to provide benefits to the "medically needy."⁶⁴ Without becoming mired in the "notoriously complex" eligibility rules of Medicaid, it suffices to classify the program as one designed to benefit low-income populations of children, the disabled, the elderly, and some nondisabled, nonelderly adults.⁶⁵

A Medicaid-eligible individual is entitled to a set of mandatory benefits,⁶⁶ and states may elect to provide any or all of the wide-ranging optional services enumerated in the Medicaid statute.⁶⁷ Although a state may establish criteria further limiting its services,⁶⁸ it still must provide each service "sufficient in amount, duration, and scope to reasonably achieve its purpose."⁶⁹

Medicaid benefits of particular interest to this Note are those of the Early and Periodic Screening, Diagnosis and Treatment ("EPSDT") program. Created in 1967, the EPSDT provisions focus on improving child health.⁷⁰ Initially faced with many challenges, the EPSDT statute was

62. Rosenbaum & Rousseau, *supra* note 58, at 25.

63. *Id.* at 17–18.

64. Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL'Y 107, 117–18 (2005). "[C]ategorically needy" groups include "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." *Id.* at 117. "Medically needy" are those with incomes that do not qualify as "categorically needy." *Id.*

65. Rosenbaum & Rousseau, *supra* note 58, at 17, 26. The Patient Protection and Affordable Care Act of 2010 ("ACA") generally expands Medicaid coverage and will, by 2014, cover "nearly all uninsured individuals with incomes up to 133 percent of the federal poverty level." Musumeci, *supra* note 61, at 93.

66. See 42 U.S.C. § 1396a(a)(10)(A) (2006 & Supp. V. 2011) (noting that states must provide "at least the care and services listed in paragraphs (1) through (5), (17), (21), and (28) of section 1396d(a)"). The services required by the Medicaid statute include hospital services, both inpatient and outpatient, laboratory tests, nursing services, early and periodic screening, diagnostic, and treatment services, family planning services, physician and dentist services, midwife services, services of a pediatric nurse practitioner or family nurse practitioner, and services provided by freestanding birth centers. 42 U.S.C. § 1396d(a)(1)–(28) (2006 & Supp. V 2011). It is important to note that some of these services have additional limiting criteria. See, e.g., *id.* § (4)(C) (noting that family planning services are provided only "to individuals of child-bearing age"). States electing to cover medically needy individuals are required to provide a comparatively small selection of services. Rutkow, *supra* note 64, at 118.

67. Rosenbaum & Rousseau, *supra* note 58, at 21.

68. 42 C.F.R. § 440.230(d) (2012).

69. *Id.* § 440.230(b).

70. SMITH & MOORE, *supra* note 56, at 77.

amended in 1989 to more concretely define and support the program.⁷¹ Most relevant to this Note, Congress has expanded the EPSDT treatment provisions to encompass “any medically necessary treatment for conditions identified through screening and/or diagnosis, even though such services were not covered in the Medicaid state plan.”⁷² In other words, the EPSDT program requires states to provide all traditional Medicaid services to children under the age of twenty-one, regardless of whether those services are also available to Medicaid-eligible adults.⁷³ In the context of the Medicaid statute, the available services within the EPSDT program include screening, vision, dental, hearing, and the crucial, expansive catch-all “such other necessary health care, diagnostic services, treatment, and other measures . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services.”⁷⁴ Although the EPSDT provisions have given rise to a spate of legal disputes,⁷⁵ it remains true that the program represents unquestionably broad coverage of medical care for children.⁷⁶

In addition to reinforcing Medicaid’s EPSDT requirements, Congress sought to expand coverage of uninsured children through the State Children’s Health Insurance Program (“SCHIP”). Enacted in 1997 and codified in Title XXI of the Social Security Act, SCHIP is a block grant program designed to aid states in providing medical services to those

71. See *id.* at 181–82 (“The EPSDT amendments . . . attacked these issues comprehensively and expansively, defining terms, spelling out obligations, and coming down hard on anticipatory diagnosis and treatment of at risk children, including obstacles to their growth and development, not just existing pathologies or diseases.”). The amendments also created more stringent reporting requirements and provided that states not meeting their EPSDT obligations “would be out of compliance with the Medicaid program.” *Id.* at 182.

72. *Id.* at 182. It should be noted that, prior to the statutory amendments in 1989, interest groups persuaded the Health Care Financing Administration “to change its EPSDT regulations from their historical orientation favoring screening toward one that encourages comprehensive and continuing care.” Margaret A. McManus & Stephen M. Davidson, *Medicaid as Public Health Insurance for Children*, in CHILDREN IN A CHANGING HEALTH SYSTEM: ASSESSMENTS AND PROPOSALS FOR REFORM 131, 142–43 (Mark J. Schlesinger & Leon Eisenberg eds., 1990).

73. Rosenbaum & Rousseau, *supra* note 58, at 22.

74. 42 U.S.C. § 1396d(r)(1)–(5) (2006). Note that the Medicaid statute delineates these other services at 42 U.S.C. § 1396d(a) (2006 & Supp. V 2011).

75. See, e.g., S.D. *ex rel.* Dickson v. Hood, 391 F.3d 581 (5th Cir. 2004) (dispute concerning whether incontinence underwear are covered under EPSDT); Pediatric Specialty Care, Inc. v. Ark. Dept. of Human Servs., 293 F.3d 472 (8th Cir. 2002) (dispute concerning the availability of early intervention day treatment under EPSDT).

76. See SMITH & MOORE, *supra* note 56, at 78 (“EPSDT eventually became one of the most flexible and bounteous sources of funding of health care for children in poverty and almost, by itself, a separate entitlement.”); Rosenbaum & Rousseau, *supra* note 58, at 22 (“In the case of children under age twenty-one, Medicaid coverage is the broadest of any public or private health coverage arrangement in the U.S.”).

children whose parents' incomes are too high to qualify for traditional Medicaid.⁷⁷ Under SCHIP, states have discretion in structuring the program⁷⁸ and in defining its eligibility and benefits.⁷⁹ However, this discretion is limited by the various benefits "benchmarks" set forth in the statute. Moreover, unlike traditional Medicaid, SCHIP does not establish an individual legal entitlement to benefits.⁸⁰

Congress first recognized the Medicaid Hospice Benefit in 1986, four years after it enacted the same benefit for Medicare.⁸¹ Encouraged by the medical cost savings of hospice care, members of Congress spent over one year lobbying for the inclusion of a hospice benefit in Medicaid.⁸² Largely modeled after Medicare's approach, the Medicaid Hospice Benefit was available only to terminally ill individuals, could be revoked at will, and would be reimbursed using the same formulae as applied to Medicare.⁸³ However, unlike the Medicare Hospice Benefit, Medicaid's hospice provision is not a service that states are required to provide.⁸⁴ Despite a number of legislative attempts to codify a mandatory hospice benefit for Medicaid,⁸⁵ it still remains an optional service.⁸⁶

Set forth in Title XIX of the Social Security Act, the Medicaid Hospice Benefit incorporates, by reference, the definitions of hospice care used in Title XVIII, the Medicare portion of the Act.⁸⁷ More specifically, the Medicaid Hospice Benefit includes nursing care, physical or occupational therapy, medical social services, home health services, medical supplies, physicians' services, occasional inpatient care,

77. Robert F. Rich & Cinthia L. Deye with Elizabeth Mazur, *The State Children's Health Insurance Program: An Administrative Experiment in Federalism*, 2004 U. ILL. L. REV. 107, 107, 112 (2004).

78. *Id.* at 112. "States can implement SCHIP by choosing one of three options: creating their own separate programs (the stand-alone option), expansion of their existing Medicaid programs, or a combination of Medicaid and creation of a separate program." *Id.*

79. *Id.* at 114.

80. *Id.*

81. Rutkow, *supra* note 64, at 114, 118–21.

82. *See id.* at 119–21 (cataloging the Medicaid Hospice Benefit's movement through Congressional political channels from April 1985 through April 1986).

83. *Id.* at 120.

84. *Id.* at 123. Note, though, that as of 2005, forty-seven states provided a Medicaid Hospice Benefit. *Id.* at 138.

85. *See id.* at 121–23 (describing the attempts by various United States representatives to codify a mandatory Medicaid hospice benefit).

86. *Id.* Lainie Rutkow argues that Congress should consider creating a mandatory Medicaid hospice benefit for three primary reasons: (1) hospice care reduces overall health costs; (2) having already implemented the Medicare hospice benefit, states have the proper infrastructure for implementing a mandatory Medicaid benefit; and (3) hospice is a humane form of care. *Id.* at 127–37.

87. 42 U.S.C. § 1396d(o)(1)(A) (2006 & Supp. V 2011).

counseling, and any other service specified in the state plan.⁸⁸ Although not discussed in this Note, federal law establishes numerous requirements for an organization to be certified as a “hospice program.”⁸⁹

III. PATIENT PROTECTION AND AFFORDABLE CARE ACT SECTION 2302: A SHIFT IN THE LEGAL PARADIGM

A. LANGUAGE AND ORIGINS

Buried deep within the 906 pages of the Affordable Care Act is Section 2302, titled “Concurrent Care for Children.” Relatively short in length, Section 2302 amends several subsections of the Medicaid Act and inserts the following language:

A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the treatment of the child’s condition for which a diagnosis of terminal illness has been made.⁹⁰

Section 2302 also adds a similar provision to the State Children’s Health Insurance Program (“SCHIP”) statutory code.⁹¹ In a sentence, Section 2302 eliminates one of the major legal barriers standing in the way of pediatric hospice care and permits those children electing the Medicaid hospice benefit to simultaneously pursue curative treatment; this approach is known as “concurrent care.”⁹² Although such change is surely a positive step forward, Section 2302 simultaneously overlooks a different legal rule, which has long-served as an additional obstacle to children’s hospice services.⁹³

88. *Id.* § 1395x(dd)(1)(A)–(I) (2006).

89. *Id.* § 1395x(dd)(2).

90. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2302(a)(2), 124 Stat. 119, 293 (2010) (amending 42 U.S.C. § 1396d(o)(1)).

91. *Id.* § 2302(b). The ACA amended the SCHIP statute to define “child health assistance” as, among other things, “[h]ospice care (concurrent, in the case of an individual who is a child, with care related to the treatment of the child’s condition with respect to which a diagnosis of terminal illness has been made[]).” 42 U.S.C. § 1397jj(a)(23) (2006 & Supp. V 2011).

92. It is worth noting that Congress also established demonstration programs to gauge the effectiveness of the concurrent care approach for Medicare-eligible patients. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3140, 124 Stat. 119, 440 (2010).

93. See NAT’L HOSPICE AND PALLIATIVE CARE ORG., PEDIATRIC CONCURRENT CARE 3 (2012), available at http://www.nhpco.org/sites/default/files/public/ChiPPS/Continuum_Briefing.pdf (“Physicians must still certify that the child is within the last six months of life, if the disease runs its normal course.”).

Those lawmakers who supported Section 2302 were motivated, in part, by the desire that “fewer children . . . and families will have to make the heart-rending choice between coverage that fights an illness and coverage that provides needed comfort.”⁹⁴ Buttressed by such compassionate goals, Section 2302 has garnered wide-acclaim from hospice and palliative care organizations.⁹⁵

In actuality, though, impetus for the change ushered in by Section 2302 did not originate with the ACA. In 2008, Congressmen James Moran and Thomas Davis introduced a bill that proposed to amend the Medicaid Act to cover a plan of service modeled after the Children’s Program of All-Inclusive Coordinated Care (“ChiPACC”).⁹⁶ Although the proposed legislation has numerous provisions, the most germane is that defining the scope of services available to a child meeting the prescribed eligibility criteria.⁹⁷ More specifically, the ChiPACC Act of 2008 mandated an “interdisciplinary and multidisciplinary health and social service delivery system which integrates . . . acute and long-term care services, palliative, respite and curative treatment, [and] counseling and support for family members who are caretakers or otherwise relevant to appropriate care and treatment of the individual.”⁹⁸ In removing the traditional legal barrier between hospice services⁹⁹ and curative treatment, the proposed ChiPACC Act sought the same result that was adopted in the ACA two years later. The ChiPACC Act of 2008 was never enacted.¹⁰⁰ Congressman Moran reintroduced the ChiPACC legislation in 2009,¹⁰¹ and again it failed to emerge from committee.¹⁰²

94. Proclamation No. 8594, 75 Fed. Reg. 67905 (Oct. 29, 2010).

95. See, e.g., Press Release, Nat’l Hospice and Palliative Care Org., Concurrent Care for Children: Implementation Toolkit Released by NHPCO and DCPACC (Apr. 15, 2011), available at <http://www.nhpc.org/i4a/pages/index.cfm?pageid=6485> (quoting Dr. Sarah Friebert’s observation that Section 2302 has been a long-term goal of the pediatric hospice community).

96. ChiPACC Act of 2008, H.R. 6931, 110th Cong. (2008). For a brief overview of the ChiPACC guidelines for pediatric palliative and hospice care, see *Children’s Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC)*, CHILDREN’S HOSPICE INT’L, <http://www.chionline.org/programs/> (last visited Aug. 8, 2013).

97. H.R. 6931, 110th Cong. § 2(b)(1)(B)(ii) (2008).

98. *Id.* § 2(c)(1)(B).

99. For an overview of “hospice services” under the Medicaid statute, see *supra* text accompanying notes 87–89.

100. See 154 CONG. REC. H8396 (daily ed. Sept. 17, 2008) (referring H.R. 6931 to the Committee on Energy and Commerce).

101. ChiPACC Act of 2009, H.R. 722, 111th Cong. (2009). See also Press Release, Congressman Jim Moran, Coordinated Hospice Care for Seriously Ill Children Reintroduced (Jan. 28, 2009), available at <http://moran.house.gov/press-release/coordinated-hospice-care-seriously-ill-children-reintroduced>.

102. See 155 CONG. REC. H602 (daily ed. Jan. 27, 2009) (referring H.R. 722 to the Committee on

Prior to the passage of the ACA, the most recent legislative attempt to remove the legal barrier between hospice and curative services came on May 21, 2009, with the introduction of the Advance Planning and Compassionate Care Act of 2009. The bill aimed to achieve three noteworthy goals: (1) to allow hospice-eligible children to receive curative treatments concurrent with hospice care; (2) to establish hospice as a required benefit under Medicaid; and (3) to authorize demonstration projects aimed at evaluating how best to care for long-term Medicare beneficiaries who could benefit from hospice services for which, under existing federal law, they would not otherwise qualify.¹⁰³ Similar to the ChiPACC bills, the Advance Planning and Compassionate Care Act did not emerge from the legislative committee to which it was referred.¹⁰⁴ Given these recent efforts at reforming the laws governing pediatric hospice care, it is perhaps unsurprising that a small, but meaningful, provision was included in the ACA.

B. A SHIFT IN THE LAW

An examination of the specific legal and regulatory context in which Section 2302 emerged and in which it will operate in the future should elucidate the very real way in which it alters the legal landscape governing Medicaid and the Medicaid Hospice Benefit. The latter was framed, in many ways, on the basis of the already existing Medicare Hospice Benefit, which was first adopted in 1982.¹⁰⁵ In order to receive hospice services under Medicare, recipients are legally required to sign a certification form indicating that they understand “the palliative rather than curative nature of hospice care” and that they are willing to waive Medicare coverage of “services that are related to the treatment of the terminal condition for which hospice care was elected.”¹⁰⁶ Furthermore, a physician must certify that the hospice-eligible patient has “a life expectancy of [six] months or less if the terminal illness runs its normal course” and must support this conclusion using “[c]linical information and other documentation.”¹⁰⁷

Energy and Commerce).

103. Advance Planning and Compassionate Care Act of 2009, S. 1150, 111th Cong. §§ 226–28 (2009). For the (seemingly identical) version of the bill introduced in the House of Representatives, see Advance Planning and Compassionate Care Act of 2009, H.R. 2911, 111th Cong. (2009).

104. See 155 CONG. REC. S5819 (daily ed. May 21, 2009) (referring S. 1150 to the Committee on Finance).

105. See Rutkow, *supra* note 64, at 114–20 (noting that the Hospice Benefit for Medicaid arose during Congressional reconsideration of the Medicare Hospice Benefit).

106. 42 C.F.R. § 418.24(a)(2), (d)(2) (2012).

107. *Id.* § 418.22.

The Medicaid Hospice Benefit has similar eligibility criteria. Notwithstanding the passage of Section 2302, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions of the Medicaid Statute have long required states to provide any one of twenty-nine enumerated services, including hospice care, to an eligible child.¹⁰⁸ However, prior to Section 2302, an eligible child's election of the Medicaid hospice benefit was, simultaneously, a forfeiture of coverage for any other service that was directed at treating or curing that child's terminal illness.¹⁰⁹ This presented seriously (and terminally) ill, Medicaid-eligible children and their families with an impossible choice: continue to pursue treatment that places a premium on curing over comfort or elect to maximize comfort while simultaneously giving up all practical hope for a cure. Asking parents to make this choice draws into conflict the innate parental desires to protect their child's life and mitigate their child's suffering. It seems likely that the Medicaid statute's previous acceptance of this choice contributed to the long-standing chronic underutilization of hospice services among pediatric patients.¹¹⁰

Section 2302 of the ACA dramatically alters the prior constraining legal framework governing pediatric hospice care under Medicaid. As a result, states are now required to provide curative services¹¹¹ to a Medicaid-eligible child, even after that child qualifies for and elects hospice coverage under the statute.¹¹² The same requirement applies for those states

108. 42 U.S.C. § 1396d(r)(5) (2006). *See also* Rosenbaum & Rousseau, *supra* note 58, at 22 (“[I]n the case of children and as part of the EPSDT program, [states must] cover all federally recognized categories of benefits and services that are determined to be medically necessary.”).

109. Letter from Cindy Mann, Dir., Dep't Health & Social Servs., to State Health Official (Sept. 9, 2010), available at <https://www.cms.gov/smdl/downloads/SMD10018.pdf>.

110. For a discussion of the statistics delineating this trend of underutilization, see *supra* text accompanying notes 47–50. Bruce Himmelstein recognizes that there may be some credence to this hypothesis because “[t]he philosophy of palliative care is often in direct conflict with physicians and patients / families who continue to clamor for life at any cost until the last breath.” Bruce Himmelstein, *Palliative Care for Infants, Children, Adolescents, and Their Families*, 9 J. PALLIATIVE MED. 163, 174 (2006). Dr. Himmelstein notes that other barriers to proper palliative care include “[c]are fragmentation,” federal financial reimbursement policies, and physician education. *Id.* It also seems likely that requiring patients to choose between curative and hospice care contributes to underutilization of hospice among adults. *See* Kathy L. Cerminara, *Hospice and Health Care Reform: Improving Care at the End of Life*, 17 WIDENER L. REV. 443, 450 (2011) (“[H]aving to renounce all curative efforts before Medicare will pay for hospice care may result in patient delay in accessing hospice care even if healthcare professionals have discussed that option in a timely fashion.”).

111. The Center for Medicare and Medicaid Services, which is the government administrator of the federal health benefit program, refers to the services both as “curative” and as those “for treatment of the terminal condition.” Letter from Cindy Mann to State Health Official, *supra* note 109. This Note will use the “curative” label.

112. *Id.*

operating a Medicaid-expansion Children's Health Insurance Program (CHIP).¹¹³ States with an independent CHIP program may elect to cover hospice services for children and, if so, must comply with Section 2302.¹¹⁴ Although the procedures by which states must implement Section 2302 are somewhat technical,¹¹⁵ it remains true that states will pay providers of curative services "using the payment methodology approved for those services" and will reimburse hospice care providers using the state's Medicaid Hospice Benefit.¹¹⁶ Under Section 2302, states do have flexibility in defining the parameters of "medical necessity;" this is the only permissible criteria which might limit the provision of an otherwise "curative" service provided by the Medicaid statute.¹¹⁷

By ending the traditional legal dichotomy between curative treatment and end-of-life care,¹¹⁸ Section 2302 represents a tangible shift in children's Medicaid law. It improves the quality of care and health outcomes for pediatric patients,¹¹⁹ as well as extends yet another bridge across the long-standing gap (both social and medical)¹²⁰ between the worlds of the living and the dying.

C. IMPLICATIONS OF THE LEGAL SHIFT

Although many in the hospice advocacy community have heralded ACA Section 2302 as an achievement,¹²¹ its adoption has remained largely unnoticed by the general public. Despite this relative invisibility, Section 2302 is likely to have a significant, practical impact on the care of very sick children.¹²²

113. *Id.* For a discussion of the State Children's Health Insurance Program, see *supra* text accompanying notes 77–80.

114. Letter from Cindy Mann to State Health Official, *supra* note 109.

115. See D.C. PEDIATRIC PALLIATIVE CARE COLLABORATION & NAT'L HOSPICE & PALLIATIVE CARE ORG., CONCURRENT CARE FOR CHILDREN IMPLEMENTATION TOOLKIT 3 [hereinafter TOOLKIT], available at http://www.nhpco.org/sites/default/files/public/ChiPPS/CCCR_Toolkit.pdf ("[I]mplementation of this provision could be accomplished by the state Medicaid agency eliminating any provider claims that deny or pend concurrent curative/life prolonging and hospice claims States are also required to submit a Medicaid state plan amendment when CMS releases a template for this submission.")

116. NAT'L HOSPICE & PALLIATIVE CARE ORG., PROVIDER QUESTIONS AND ANSWERS FROM CMS 4 (2011), available at http://www.nhpco.org/sites/default/files/public/ChiPPS/Children_QA_%20CMS_Feb2011.pdf.

117. *Id.* at 3.

118. This dichotomy is a simple legal construct discussed at *supra* note 137 and accompanying text.

119. See *infra* Part III.C.2.

120. For a discussion of the development of this "gap," see *supra* Part II.A.

121. See *supra* text accompanying note 95.

122. Although Section 2302 of the ACA marks an explicit change in the Medicaid hospice law, it

1. Increased Cost and Increased Access to Hospice Services

It seems an obvious point that Section 2302, in eliminating what David Casarett calls the “terrible choice between treatment and hospice services”¹²³ that the prior law required patients to make, will generally increase the utilization of the Medicaid Hospice Benefit among children.¹²⁴ Because Section 2302 now permits patients to elect “a blended package of curative and palliative services,”¹²⁵ the Center for Medicare and Medicaid Services estimates that the legal change will increase the yearly cost of Medicaid between fifteen and twenty-five million dollars; in the ten-year period between 2010 and 2019, Section 2302 is projected to cost \$195 million.¹²⁶

Despite this increase in short-term cost, there is evidence suggesting that a concurrent care model similar to Section 2302 could actually decrease the health care budget in the long run.¹²⁷ In fact, Kathy L. Cerminara, a hospice law scholar, argues that “Congress’s authorization of payment for concurrent care for children and establishment of a study of concurrent care coverage for adults are not likely to increase Medicaid and Medicare care costs overall.”¹²⁸ Although the debate about cost is a robust one more fully discussed in Part IV.C, what seems indisputable is that the shift in the legal paradigm ushered in by Section 2302 makes it more likely that children in need of hospice care are able to gain access to treatment.

The traditional legal separation between hospice care and curative treatment has been both a tangible regulatory barrier as well as a factor

is worth noting that another section of the Act suggests Congress is seriously considering making a permanent, corresponding change in the Medicare law. Section 3140 of the ACA authorizes the establishment of a three-year demonstration program in which Medicare beneficiaries may receive concurrent curative and hospice care. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3140(a)(1)–(2), 124 Stat. 119, 440 (2010). At the conclusion of this program, the Secretary of Health and Human Services is required to report on measures of its general effectiveness, including measures of “patient care, quality of life, and cost-effectiveness.” *Id.* § 3140(b)(1), 124 Stat. 119, 440–41. Thus, the shift in the legal paradigm ushered in by Section 2302 is not cabined to the Medicaid Hospice Benefit, though only time will tell whether Congress chooses to make a similar change in the Medicare laws.

123. David J. Casarett et al., *The Terrible Choice: Re-Evaluating Hospice Eligibility Criteria for Cancer*, 27 J. CLINICAL ONCOLOGY 953, 953 (2008).

124. Letter from Cindy Mann to State Health Official, *supra* note 109.

125. *Id.*

126. RICHARD S. FOSTER, DEP’T. HEALTH & HUMAN SERVS., ESTIMATED FINANCIAL EFFECTS OF THE “PATIENT PROTECTION AND AFFORDABLE CARE ACT,” AS AMENDED tbl.4 (2010), available at <http://graphics8.nytimes.com/packages/pdf/health/oactmemo1.pdf>.

127. See Cerminara, *supra* note 110, at 457–58 (discussing several studies demonstrating that earlier access to hospice services leads to decreased health care expenditures).

128. *Id.* at 458.

contributing to the psychological barrier that has prevented children from gaining timely access to hospice services. In a comprehensive survey of hospice and medical professionals, Betsy Friedman identified the connotation of “hospice” as “giving up” as a barrier to time-appropriate hospice referrals.¹²⁹ Friedman notes that “[s]tanding in juxtaposition to this negative connotation of hospice, are the many potential medical breakthroughs that the media serve up daily—sometimes giving patients false hope for a cure.”¹³⁰ Thus, even though in many cases there was no reasonable prospect for a cure, the prior Medicaid laws forced doctors and patients to accept this outcome before hospice care could be accessed. The results were predictable: patients would only opt for hospice care when death was imminent and would accordingly only spend a short time receiving this form of palliative treatment.¹³¹

In a related study, Joanne Wolfe compared the end-of-life care received by children with terminal cancer diagnoses to the comprehension and communication of those diagnoses by both the children’s doctors and parents.¹³² Among other things, Dr. Wolfe concluded “that parents of children with advanced cancer can maintain dual goals of care concurrently.”¹³³ In other words, parents are willing to pursue, for their very ill children, treatment that is directed both at curing the child’s illness or extending the child’s life, and at providing comfort (hospice-style) care to the child.¹³⁴ However, as Dr. Wolfe correctly notes, the American health care system has long-disallowed such combined treatment goals,¹³⁵ and as discussed previously, the Medicare and Medicaid laws have, for many decades, endorsed this separation. Section 2302 closes the legal divide between curative and hospice care. By expanding the availability of hospice care for those patients who might also benefit from life-prolonging treatment, Section 2302 recognizes, in part, the “growing consensus that in

129. Friedman, Harwood & Shields, *supra* note 37, at 79.

130. *Id.*

131. Sherman, *supra* note 40, at 407.

132. Joanne Wolfe et al., *Understanding of Prognosis Among Parents of Children Who Died of Cancer*, 284 J. AM. MED. ASS’N 2469 (2000).

133. *Id.* at 2474. The Wolfe study is further noteworthy in its conclusion that the presence of a social worker in the child’s plan of care resulted in “greater concordance in the timing of physicians’ and parents’ understanding that the child had no realistic chance for cure.” *Id.* Note that both the Medicaid and Medicare statutes require hospices to maintain an interdisciplinary team that includes a social worker. 42 U.S.C. § 1395x(dd)(2)(B)(i)(III) (2006).

134. See Robert F. Tamburro et al., *Care Goals and Decisions for Children Referred to a Pediatric Palliative Care Program*, 14 J. PALLIATIVE MED. 607, 609 (2011) (describing a study in which children and families receiving palliative care still wished to receive “therapies to maintain or regain health”).

135. *Id.*

patients with life-threatening illness, palliative care should be integrated early and concurrent with treatment of the underlying disease.”¹³⁶

A host of scholars have argued that the law’s traditional, but artificial, partitioning of curative treatment and hospice care, and its refusal to fund both concurrently, has led to relative underconsumption of palliative services among eligible patients.¹³⁷ Given the intuitive assumption that doctors and families of terminally ill children are likely to be even more resistant than average to accept death as inevitable,¹³⁸ it stands to reason that the Medicaid law’s former barrier between curative and hospice care resulted in a vast underutilization of pediatric hospice programs.¹³⁹ Accordingly, Section 2302’s elimination of this “false dichotomy”¹⁴⁰ promises to expand pediatric access to hospice services and, in turn, make more widely available all of the many tangible benefits of pediatric palliative care.¹⁴¹

This conclusion, however, must be somewhat qualified, for the magnitude by which Section 2302 expands access to pediatric hospice services depends, in large part, on both the willingness of physicians to refer their patients to such programs and the willingness for minor patients’ parents to agree with such referrals.¹⁴² Although Section 2302 eliminates the legal barrier traditionally preventing concurrent care, it does nothing to ensure that medical professionals will alter their behavior. Given that

136. Wolfe et al., *supra* note 132, at 2474. Note that there is a difference between hospice care and palliative care. See *infra* Part III.C.2.

137. See, e.g., David J. Casarett, Commentary, *Rethinking Hospice Eligibility Criteria*, 305 J. AM. MED. ASS’N 1031 (2011) (noting that hospice eligibility criteria contribute to delayed enrollment, with over “one-third of patients . . . referred for hospice care in the last week of life”); Cerminara, *supra* note 110, at 449–51 (arguing that, in the Medicare context, the “false dichotomy” between curative and palliative treatment results in physicians underreferring patients to hospice and patients becoming unwilling to acknowledge that a cure is unlikely).

138. Scholars provide support for this assumption. Caprice Knapp & Lindsay Thompson, *Factors Associated With Perceived Barriers to Pediatric Palliative Care: A Survey of Pediatricians in Florida and California*, 26 PALLIATIVE MED. 268, 270 (2012) (demonstrating that, in a survey of 303 pediatricians in two states, “the two greatest barriers as perceived by pediatricians were related to family reluctance to accept palliative care (95 [percent]) and families viewing palliative care as giving up (94 [percent])”); Elaine R. Morgan & Sharon B. Murphy, Editorial, *Care of Children Who Are Dying of Cancer*, 342 NEW ENG. J. MED. 347, 348 (2000) (“More profound barriers to effective palliation reflect the overall perception of physicians, other care givers, and families that discontinuing aggressive care means that they are giving up and, in effect, represents failure.”).

139. For the supporting data, see *supra* Part II.B.

140. Cerminara, *supra* note 110, at 449.

141. For a discussion of the typical benefits of hospice care, see *supra* text accompanying notes 22–30.

142. See Morgan & Murphy, *supra* note 138, at 347 (noting that, in the treatment of childhood cancer, both caregivers and parents are “reluctant to abandon a curative approach”).

physicians have historically underreferred their patients to hospice,¹⁴³ it is unsurprising that authors often mention improved physician education on the benefits of pediatric hospice and palliative care as a requirement for increasing children's access to such services.¹⁴⁴ Accordingly, the extent to which Section 2302 increases children's use of hospice will likely vary directly both with physicians' awareness of the provision and their general understanding (and acceptance) of the benefits of hospice and palliative care.

2. Improved Health Outcomes by a Sharpened Focus on Palliative Care

Although perhaps counterintuitive, expanding patients' access to hospice (and palliative) services might simultaneously improve both their health and well-being. Section 2302, by increasing the availability of hospice services, will primarily help patients utilize the comparative advantage offered by hospices, over traditional hospitals, in the treatment of pain and management of symptoms. Furthermore, Section 2302 marks one more step along the road of increasing society's cognizance of the many health benefits offered by general palliative care.

The first and most concrete health-related effect of Section 2302 is improvement in the pain and symptom management of Medicaid-eligible children who face a very critical illness but nevertheless continue to pursue curative treatment.¹⁴⁵ While hospice-like services may lead to increased patient survival,¹⁴⁶ it has been firmly established that standard hospice care generally improves the symptoms of its patients.¹⁴⁷ In the particular context

143. See SIEBOLD, *supra* note 15, at 152 (noting the various explanations for physicians' historical hesitancy to make hospice referrals).

144. See, e.g., Himmelstein, *supra* note 110, at 174 (identifying "[l]ack of provider education" as a barrier to effective pediatric palliative care); Joan Stephenson, *Palliative and Hospice Care Needed for Children with Life-Threatening Conditions*, 284 J. AM. MED. ASS'N 2437, 2438 (2000) (same). Although likely to offer improvement, better physician education might not be a complete solution to the problem. Some scholars note that the care received by seriously ill patients may be dictated by "systems" as opposed to individual physicians. Ben A. Rich, *Prognostication in Clinical Medicine: Prophecy or Professional Responsibility?*, 23 J. LEGAL MED. 297, 315 (2002). Thus, "[c]hanging the way critically ill patients are cared for requires systemic reform." *Id.*

145. See Lisa C. Lindley, *Healthcare Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis*, 13 J. HOSPICE & PALLIATIVE NURSING 81, 83 (2011) (mentioning, briefly, that hospice care can improve symptom management of its patients and, thus, concluding that Section 2302 "may provide effective [end-of-life care] for terminally ill children").

146. See *infra* text accompanying notes 158–59.

147. See, e.g., Susan C. Miller et al., *Does Receipt of Hospice Care in Nursing Homes Improve the Management of Pain at the End of Life?*, 50 J. AM. GERIATRICS SOC'Y 507, 512 (2002) (presenting a study that hospice care in nursing homes "is associated with superior pain management"); Ryan M. Tierney et al., *Relationships Between Symptom Relief, Quality of Life, and Satisfaction with Hospice Care*, 12 PALLIATIVE MED. 333, 342 (1998) (noting that a study of hospice care in Australia confirmed

of children, the results hold equally true. A study comparing pediatric end-of-life care using hospice services to the same care without hospice services indicated that the pediatric patients receiving hospice experienced not only better symptom control but also improved “psychosocial and emotional support.”¹⁴⁸ A similar study examined, among generally older patients, the difference in satisfaction rates between families of those patients who died in a hospital or nursing home and those who died under home hospice care.¹⁴⁹ Perhaps predictably, the families of loved ones receiving end-of-life care in the hospital or nursing home experienced high rates of concern about their loved one’s symptom management relative to those families with loved ones receiving hospice care.¹⁵⁰ By expanding access to hospice benefits among Medicaid-eligible pediatric patients, Section 2302 operates to exploit the comparative advantage in advanced pain and symptom management that hospices maintain over more traditional loci of end-of-life care, such as hospitals and nursing homes.

The second health-related impact of Section 2302 is ostensibly less direct than that previously discussed. Despite not mentioning “palliative care,” the new law places a greater focus on its benefits, especially when given to a patient both as a cure is being aggressively pursued and as death becomes imminent. Provision of palliative care during the former stage of an illness is known as “nonhospice palliative,” while provision during the latter is simply “hospice palliative.” Although both the general public and skilled commentators often conflate nonhospice palliative care with hospice palliative care,¹⁵¹ there are practical differences between the two.

During the last ten years, a trend toward institutionalized, in-hospital (nonhospice) palliative care has gained momentum.¹⁵² Although the basis

the hypothesis that hospice is successful at relieving patients’ symptoms); Unroe & Meier, *supra* note 23, at 418–19 (“Multiple studies of palliative care and hospice programs have shown that they improve physical and psychological symptoms experienced by patients . . .” (footnotes omitted)).

148. David S. Dickens, *Comparing Pediatric Deaths with and Without Hospice Support*, 54 PEDIATRIC BLOOD CANCER 746, 748 (2010). Note that, among those medical responders included in the study, a full 86 percent considered the end-of-life care with hospice services to be preferable to those without such services. *Id.* at 746. The Dickens study, as its author himself notes, may be subject to respondent selection bias and, as such, should be considered illustrative merely of the conclusion that hospice care has tangible benefits for its patients. *Id.* at 749.

149. Teno et al., *Family Perspectives on End-of-Life Care at the Last Place of Care*, 291 J. AM. MED. ASS’N 88 (2004).

150. *Id.* at 92.

151. Unroe & Meier, *supra* note 23, at 415.

152. R. SEAN MORRISON & DIANE E. MEIER, CTR. TO ADVANCE PALLIATIVE CARE & NAT’L PALLIATIVE CARE RESEARCH CTR., AMERICA’S CARE OF SERIOUS ILLNESS: A STATE-BY-STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION’S HOSPITALS 3 (2011), <http://reportcard.capc.org/pdf/state-by-state-report-card.pdf>.

of hospice care is palliative care, it is important to realize that traditional palliative care can be provided outside the context of hospice.¹⁵³ While hospice eligibility under the Medicaid and Medicare laws currently requires a terminal diagnosis, nonhospice palliative care may be provided for those who have life threatening—but not necessarily terminal—conditions.¹⁵⁴ The focus of general palliative care is, by its very etymology, to palliate; in other words, it is designed to care for the “physical, psychological, and spiritual suffering of patients with life-threatening illness, and their families.”¹⁵⁵ Indeed, as is the case for hospice care, current medical research indicates that palliative treatment alone may improve measures of patient well-being, such as pain relief,¹⁵⁶ mood, and general quality of life.¹⁵⁷ Moreover, there is statistical evidence indicating that improvement in the patient’s “quality of life” may actually lead to longer survival times.¹⁵⁸ For example, a recent clinical study of patients with metastatic lung cancer demonstrated that integration of palliative care concurrent with curative treatments extended patient survival times by approximately two months.¹⁵⁹

Considering the tangible, proven benefits of nonhospice palliative care, it might reasonably be argued that the provisions of Section 2302 are merely superfluous. If simple palliative care can be obtained at any point in the treatment of a life-threatening illness, as many suggest it can,¹⁶⁰ then it seems logical to wonder how Section 2302 makes any real improvement to the provision of palliative care. The answer to this question can be found as much in the language of Section 2302 as it can in the practical limitations of nonhospice palliative care.

Although the number of in-hospital palliative care teams has increased twofold over the past ten years, there is substantial variation in the

153. Unroe & Meier, *supra* note 23, at 415.

154. *Id.*; MORRISON & MEIER, *supra* note 152, at 2.

155. Randy Hebert, Nicole Fowler & Robert Arnold, *Palliative Care in Acute Care Hospitals*, in CHOICES IN PALLIATIVE CARE: ISSUES IN HEALTH CARE DELIVERY 1, 1 (Arthur E. Blank et al. eds., 2007).

156. *Id.* at 4.

157. Marie Bakitas et al., *Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer: The Project ENABLE II Randomized Controlled Trial*, 302 J. AM. MED. ASS'N 741, 747 (2009).

158. *See id.* at 748 (noting that studies of over ten thousand cancer patients demonstrated that a higher measure of “quality of life” was associated with longer survival).

159. Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW. ENG. J. MED. 733, 739 (2010).

160. MORRISON & MEIER, *supra* note 152, at 2; Unroe & Meier, *supra* note 23, at 415.

availability of such programs across regions and states.¹⁶¹ Palliative care services delivered in an outpatient setting are similarly rare.¹⁶² Additionally, the prevalence of palliative care programs is strongly correlated with the size of the hospital. For instance, as of 2011, fully 85 percent of those hospitals with three hundred or more beds have dedicated palliative care programs.¹⁶³ This stands in stark contrast to the meager 22 percent of hospitals with fewer than fifty beds that also have a palliative care program.¹⁶⁴ These disparities are often most visible in “public and sole community provider hospitals,” which traditionally serve the uninsured and isolated cities.¹⁶⁵ Compounding the variation in hospital provision of palliative care, the American medical community has only recently recognized palliative medicine as a specialty worthy of independent educational fellowships.¹⁶⁶ Moreover, federal Medicare law does not provide financial assistance for training in the field¹⁶⁷ and Medicaid laws cover nonhospice palliative care to varying and uncertain degrees.¹⁶⁸ Finally, the number of nonhospice palliative care programs (1500) remains dwarfed by the number of traditional hospice ones (3400).¹⁶⁹

The current limitations of nonhospice palliative care are equally applicable to the pediatric population. As Unroe and Meier note, while the number of hospital inpatient palliative care services has grown over the

161. MORRISON & MEIER, *supra* note 152, at 3.

162. Kevin B. O'Reilly, *Early Palliative Care Lengthens Survival for Lung Cancer Patients*, AMEDNEWS.COM (Sept. 6, 2010), <http://www.amednews.com/article/20100906/profession/309069940/6/>.

163. MORRISON & MEIER, *supra* note 152, at 27 tbl.1.

164. *Id.*

165. *Id.* at 20–21.

166. *Id.* at 7. See also Diane E. Meier, *Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care*, 89 MILBANK Q. 343, 366 (2011) (arguing that, in order to improve the provision of palliative care in the American health system, the medical education curriculum must adapt to provide better training in the subject).

167. MORRISON & MEIER, *supra* note 152, at 6.

168. See Melissa D.A. Carlson, R. Sean Morrison & Elizabeth H. Bradley, *Improving Access to Hospice Care: Informing the Debate*, 11 J. PALLIATIVE MED. 438, 441 (2008) (“Currently, there is no Medicare reimbursement for interdisciplinary hospital-based palliative care teams.”). Compare Press Release, Nat’l Hospice and Palliative Care Org., *Guidance on New Hospice Benefits for Terminally Ill Children Hailed by Hospice and Palliative Care Cmty.* (Sept. 13, 2010), available at <http://www.prnewswire.com/news-releases/guidance-on-new-hospice-benefits-for-terminally-ill-children-hailed-by-hospice-and-palliative-care-community-102767944.html> (statement of Dr. Sarah Friebert) (“We have further work to do to secure reimbursement for services for children with chronic, complex and/or life-threatening illness who do not qualify for hospice.”), with *Frequently Asked Questions*, PALLIATIVE DOCTORS, <http://www.palliativedoctors.org/about/faq.html#14> (last visited Sept. 22, 2013) (“Medicaid coverage of hospice and palliative care for people of limited incomes varies by state.”).

169. Meier, *supra* note 166, at 366.

past decade, the growth of outpatient palliative programs has lagged.¹⁷⁰ Intuitively, this deficit results in increased hospitalizations for those children in need of comprehensive palliative care, but who are otherwise ineligible for hospice. This is problematic because not only are hospital stays expensive, but they may also be detrimental to the well-being of the child patient.¹⁷¹ Moreover, children without easy access to a hospital that provides nonhospice palliative care might find it difficult to receive proper treatment. This would be particularly true of those children in small or rural communities.¹⁷² Lastly, it is far from certain that a seriously ill child's cure-focused medical team has the requisite expertise in end-of-life care.¹⁷³

Given the many current shortcomings in palliative care delivered by nonhospice providers, Section 2302 permits terminally ill children who are still pursuing a cure to draw on the comparative advantage of hospice programs in administering palliative care. Even though Section 2302 does not explicitly increase the availability of nonhospice palliative services, its prescriptions for concurrent hospice and curative treatment embody the same principles that have fueled the expansion of palliative care throughout the last decade. To be very clear, hospice care is palliative care, but in a form traditionally limited to those who choose to forego life sustaining treatment.¹⁷⁴ Although other hospice eligibility limits remain in the Medicaid law,¹⁷⁵ Section 2302 has removed one—the requirement to end curative treatment—which was arguably the brightest line separating traditional hospice care from the newly developed nonhospice palliative care. This change represents yet another substantial shift in the legal paradigm traditionally separating hospice care from all other forms of care, whether curative or, recently, nonhospice palliative. Thus, similar to traditional nonhospice palliative care, Section 2302 is likely to result in the improvement of patients' symptoms, well-being, and overall quality of life; scholars identify these effects as hallmarks of the "early initiation" of

170. Unroe & Meier, *supra* note 23, at 421.

171. See ALICE MCDONNELL, *QUALITY HOSPICE CARE: ADMINISTRATION, ORGANIZATION, AND MODELS* 215 (1986) ("Children do fear separation from parents before death. Admission to a hospital increases this fear."). *But see* Belinda Barry Martin, *Home Care for Terminally Ill Children and Their Families*, in *HOSPICE APPROACHES TO PEDIATRIC CARE* 65, 73 (Charles A. Corr & Donna M. Corr eds., 1985) (noting that patients and members of a hospital staff may build relationships of trust over the years, but that these relationships can still be maintained even if the child receives care at home).

172. See MORRISON & MEIER, *supra* note 152, at 20–21 (noting that most hospitals serving rural communities lack sufficiently effective nonhospice palliative care programs).

173. See Morgan & Murphy, *supra* note 138, at 348 (making this observation in the context of a pediatric oncology team).

174. Meier, *supra* note 166, at 346.

175. For an in-depth discussion of one such eligibility requirement, unchanged by Section 2302, see *infra* Part IV.A.

palliative care.¹⁷⁶

3. Early, Comprehensive Care for the Family Unit

As has been previously noted, the central unit of hospice care is both the patient and the family.¹⁷⁷ The death of a child, especially in the case of a long-developing terminal illness, can have myriad adverse consequences on the child's family.¹⁷⁸ In response to what are often harried and agonizing times, the hospice method of treatment is effective at helping the family unit adjust to the terminal phase of its member's illness, reassert control over the situation, and strengthen the familial bond.¹⁷⁹ Moreover, hospice care can provide family caregivers with much-needed respite.¹⁸⁰

By allowing patients to access hospice services without forgoing curative treatment, Section 2302 eliminates what has traditionally been a legal and psychological barrier for families.¹⁸¹ Moreover, by encouraging earlier use of hospice services, Section 2302 implicitly adopts the notion that a family is more likely to experience a better postdeath outcome if it receives predeath hospice services at an earlier time. The Wolfe study, mentioned earlier, provides some empirical support for a related proposition. Specifically, the researchers examined a cohort of parents who lost children to cancer and sought to elucidate the relationship, if any, between those parents' understanding of their children's prognoses, the introduction of palliative care, and physician communication.¹⁸² Among other things, Dr. Wolfe concluded that earlier recognition, by both parents and doctors, of the child's inescapably terminal condition led to increased integration of palliative care and increased parental satisfaction with the quality of care the child received.¹⁸³ Ultimately, the Wolfe study is noteworthy for suggesting that "interventions aimed at facilitating earlier recognition by both physicians and parents that an illness may be fatal

176. Jennifer W. Mack & Joanne Wolfe, *Early Integration of Pediatric Palliative Care: For Some Children, Palliative Care Starts at Diagnosis*, 18 CURRENT OPINION PEDIATRICS 10, 12 (2006).

177. See *supra* text accompanying note 30. For an excellent discussion on the processes of end-of-life decisionmaking in a family with a terminally-ill child, see Kimberly Gordy, Note, *Adding Life to the Adolescent's Years, Not Simply Years to the Adolescent's Life: The Integration of the Individualized Care Planning & Coordination Model and a Statutory Fallback Provision*, 11 YALE J. HEALTH POL'Y L. & ETHICS 169 (2011).

178. See Andrew R. Tartler, *Family Dynamics*, in HOSPICE CARE FOR CHILDREN, *supra* note 31, at 107, 115–16 (discussing in detail the strain a child's death can cause for parents and siblings).

179. *Id.* at 110.

180. *Id.* at 117.

181. For a discussion of the changes Section 2302 makes to the decisionmaking calculus of families, see *supra* Part III.C.1.

182. Wolfe et al., *supra* note 132, at 2473.

183. *Id.*

could contribute to improving quality of life at the end of life.”¹⁸⁴

Although Section 2302 has been trumpeted as a tool allowing patients and parents to receive hospice services while holding out hope for a cure,¹⁸⁵ the Center for Medicare and Medicaid Services interprets the law as leaving untouched the requirement that, in order to access hospice services, the patient must have a physician-certified life expectancy of six months or less.¹⁸⁶ Thus, in a way, Section 2302 demands “earlier recognition by both physicians and parents that an illness may be fatal.”¹⁸⁷ According to the Wolfe study, it is precisely this type of earlier awareness that leads to increased palliative care and, ultimately, to improved parental satisfaction.¹⁸⁸

In addition to increasing parental comfort by encouraging earlier access to hospice, Section 2302 provides for the patient’s family a smoother transition from purely aggressive, cure-focused treatment to concurrent hospice care. Lisa Lindley, in a policy analysis of Section 2302, argues that concurrent treatment allows the patient’s family to experience a “continuity of care between the curative care and hospice care teams.”¹⁸⁹ In contrast, under the law prior to Section 2302, the transition between models of care was abrupt; families often felt uneasy that the strong bonds they formed with their cure-focused medical team were marginalized as the law effectively allowed parents to choose only a purely palliative approach to care.¹⁹⁰

Accordingly, Section 2302’s shift in the legal paradigm governing hospice care for children will almost assuredly provide tangible benefits to the patients’ families.

184. *Id.* at 2474.

185. *See supra* text accompanying note 94.

186. Letter from Cindy Mann to State Health Official, *supra* note 109, at 1.

187. Wolfe et al., *supra* note 132, at 2474.

188. *Id.* at 2473.

189. Lindley, *supra* note 145, at 84.

190. *Id.* For an interesting discussion on the effect of political, economic, and legal factors on the speed with which states have implemented Section 2302, see Lisa C. Lindley, Sheri Edwards & Donald J. Brown, *Factors Influencing the Implementation of Health Care Reform: An Examination of the Concurrent Care for Children Provision*, 2013 AM. J. HOSPICE OF PALLIATIVE MEDICINE 1, available at <http://ajh.sagepub.com/content/early/2013/07/18/1049909113494460>.

IV. SOLVING THE RIDDLE OF SECTION 2302

A. THE PROBLEMATIC OMISSION IN SECTION 2302

As important as the change instituted by Section 2302 may be, the new legal framework governing pediatric hospice care still restricts the availability of coverage. As set forth under the Medicaid Hospice Benefit, “hospice care” explicitly incorporates the legal definitions applied to the Medicare Hospice Benefit.¹⁹¹ Medicare classifies “hospice care” as a set of enumerated services provided to a person who is terminally ill;¹⁹² in order to be “terminally ill,” that person must have a life expectancy of six months or less.¹⁹³

Although the text of Section 2302 is itself silent on the issue, the Center for Medicare and Medicaid Services interprets the statute as leaving in place the requirement that, to be eligible for concurrent care, the patient must have a physician-certified life expectancy of six months or less (“the six-month prognosis requirement”).¹⁹⁴ This prognosis standard has been the subject of academic debate,¹⁹⁵ although very little of it has focused particularly on the requirement within the context of Section 2302.

During the foundational period of American hospice care, most patients receiving end-of-life treatment suffered from some form of cancer—a disease with a medically predictable progression suitable to the six-month prognosis requirement.¹⁹⁶ Over time, perhaps due to improved

191. 42 U.S.C. § 1396d(o)(1)(A) (2006 & Supp. V 2011).

192. *Id.* § 1395x(dd)(1) (2006).

193. *Id.* § 1395x(dd)(3)(A).

194. Letter from Cindy Mann to State Health Official, *supra* note 109.

195. See, e.g., Amy J. Dilcher, *Damned If They Do, Damned If They Don't: The Need for a Comprehensive Public Policy to Address the Inadequate Management of Pain*, 13 ANNALS HEALTH L. 81, 142 (2004) (contending that Medicare’s six-month prognosis requirement should be changed); Amanda Jacobowski, Note, *Calculating Death: Implications of the Six-Month Prognosis Certification Requirement for the Medicare Hospice Benefit*, 19 ELDER L.J. 187, 214–16 (2011) (arguing that, in the context of Medicare, the six-month certification rule should be changed because, in part, physicians fear Medicare fraud allegations for misdiagnosing patients when applying the rule); Timothy S. Jost, *Public Financing of Pain Management: Leaky Umbrellas and Ragged Safety Nets*, 26 J.L. MED. & ETHICS 290, 296 (1998) (claiming that the six-month prognosis requirement should be discarded); Simpson, *supra* note 17, at 325 (same).

196. See TIMOTHY E. QUILL, CARING FOR PATIENTS AT THE END OF LIFE 157 (2001) (“Hospice programs were originally designed for cancer patients, and there was a common belief that all cancers followed a predictable time course.”); Michael D. Cantor, *Making Tough Choices*, 2004 U. ILL. L. REV. 183, 187 (2004) (noting that the six-month prognosis rule is more easily applied to those with cancer than to those with chronic illnesses); Jacobowski, *supra* note 195, at 194–96 (discussing the early

curative treatment, the number of hospice patients suffering from cancer has declined; as a result, in 2008, 62 percent of hospice patients had a diagnosis other than cancer.¹⁹⁷ The data for terminally ill children tell a similar story. In 2005, for example, cancer represented the cause of death for 43 percent of children under age 19, but neuromuscular conditions and cardiovascular disease followed at 23 percent and 17 percent, respectively.¹⁹⁸ Accordingly, although cancer still causes a significant number of childhood deaths, it is not the cause in a majority of cases. As has been argued in the Medicare context,¹⁹⁹ perhaps the six-month prognosis requirement is modeled on the outdated assumption that hospice treats almost exclusively cancer-related illnesses.²⁰⁰

In addition to being fashioned on old demographic data, the six-month prognosis requirement can be challenged on another front: time-specific terminal diagnoses are notoriously inaccurate and difficult to make. Exemplifying this conclusion is a study of 504 hospice patients—unfortunately, none of whom were children—and their 365 referring physicians in the Chicago area.²⁰¹ As part of the analysis, Christakis and Lamont contacted each patient’s physician at the time of hospice referral and obtained the doctor’s prognosis for the patient.²⁰² In comparing the physicians’ “survival estimates” with the patients’ actual lengths of survival on hospice care, Christakis and Lamont determined that a mere 20 percent of the doctors’ prognoses were accurate.²⁰³ Moreover, 63 percent of the prognoses were overestimates of the patient’s actual length of survival.²⁰⁴ Such “undue optimism” among physicians, according to Christakis and Lamont, may result in later-than-ideal referrals to hospice and, accordingly, adverse effects on patient care.²⁰⁵

prevalence of hospice patients with cancer diagnoses and the typical predictability of a cancer patient’s medical decline).

197. Jacobowski, *supra* note 195, at 194.

198. FRIEBERT, *supra* note 43, at 4 tbl.2.

199. Jacobowski, *supra* note 195, at 196.

200. Simpson, *supra* note 17, at 313. Joan Stephenson makes a similar argument. Stephenson, *supra* note 144, at 2437.

201. Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors’ Prognoses in Terminally Ill Patients: Prospective Cohort Study*, 320 *BRIT. MED. J.* 469, 469 (2000).

202. *Id.*

203. *Id.* at 471.

204. *Id.*

205. *Id.* Some scholars have suggested that, beyond mere inaccuracies in predicting patients’ life spans, doctors underrefer to hospice because certifying that a patient has less than six months to live is tantamount to admitting a professional defeat. See Jost, *supra* note 195, at 295 (“The ‘death sentence’ [six-month prognosis] requirement imposes an immediate barrier to hospice entry because . . . the

Difficulties in accurately determining a terminal prognosis are not unique to adult patients. Doctors similarly struggle to accurately predict the lifespan of gravely ill children.²⁰⁶ Related to the core finding of the Christakis and Lamont study—that doctors chronically overestimate patients' prognoses and, thus, make late hospice referrals²⁰⁷—it is well known that doctors are even more reluctant to classify a pediatric patient as in the “terminal state.”²⁰⁸ Given this fact, in combination with Medicaid's six-month prognosis requirement, it stands to reason that many children who would otherwise benefit from hospice care will either never receive a hospice referral or will receive one at a later-than-ideal stage in the dying process.²⁰⁹ This intuitive observation is consistent with the data.²¹⁰

In addition to ignoring difficulties in ex ante prognosis determinations, the current legal eligibility requirements for Medicaid-funded hospice care largely disregard the occasionally wide fluctuations in the health of children with life-limiting illnesses. The six-month prognosis requirement, although perhaps not draconian in its enforcement,²¹¹ seemingly allows situations in which patients might move into and out of hospice care.²¹² This could be especially problematic for children because they “can go in and out of terminal illness phases and the curative process is likely to be very long, making it unclear whether they will ultimately recover from

treating doctor must essentially admit defeat in curing the patient.”)

206. See, e.g., Neil Lobardi, *Palliative Care in an Inpatient Hospital Setting*, in HOSPICE CARE FOR CHILDREN, *supra* note 31, at 248, 250–51 (discussing the surprising unpredictability of the progression of a terminal illness in a pediatric patient); Kevin O'Reilly, *Medicare to Test Allowing More Palliative Care in Hospice*, AMEDNEWS.COM (May 24, 2010), <http://www.amednews.com/article/20100524/profession/305249952> (“In pediatrics, the prognosis for patients can be a lot harder to define.” (statement of Dr. Christian Sinclair) (internal quotation marks omitted)).

207. See Christakis & Lamont, *supra* note 201, at 471.

208. See MCDONNELL, *supra* note 171, at 21 (“[S]taff expertise in care of the geriatric patient is different from care of the child. The decision that a child has reached a terminal state is made more reluctantly.”).

209. *Id.* Note also that the procedural aspects of the six-month certification requirement may disadvantage rural communities that lack the physicians necessary to conduct proper hospice evaluation. Artnak, McGraw & Stanley, *supra* note 50, at 148–49.

210. For an empirical overview of hospice consumption among terminally ill children, see *supra* text accompanying notes 47–50.

211. See also Carolyn Cassin, *Hospice Care*, in CHOICES IN PALLIATIVE CARE: ISSUES IN HEALTH CARE DELIVERY, *supra* note 155, at 45, 57 (“The benefit itself, is remarkably forgiving if prognosis has been incorrect and over estimated.”).

212. See Tamara Vesel & Joanne Wolfe, *Children and Issues Around Palliative Care*, in CHOICES IN PALLIATIVE CARE: ISSUES IN HEALTH CARE DELIVERY, *supra* note 155, at 157, 164–65 (discussing a case in which a child with multiple congenital problems was enrolled in hospice, did not die within a year, was discharged, deteriorated, and was ultimately re-enrolled in hospice).

their illnesses.”²¹³ Among older hospice patients in the Medicare context, it is often the case that those who are removed from the program because they no longer meet the six-month prognosis requirement soon “crash” upon discharge and, later, re-enter hospice.²¹⁴

Ultimately, Section 2302 presents something of a riddle in its apparent inconsistency. In allowing children to access hospice services while simultaneously pursuing curative treatment, Section 2302 helps families avoid giving up hope when enrolling their child in hospice. However, Section 2302 leaves untouched the six-month prognosis requirement;²¹⁵ this is illogical.²¹⁶ Given that the six-month rule requires the patient, the family, and the doctor to all essentially agree that the terminal phase has arrived, it seems very unlikely that a child who enrolls in concurrent curative and hospice care will have any glimmer of hope for a cure. Thus, that which Section 2302 did not address, the six-month prognosis requirement, seems to work against the law’s otherwise very noble goal of ensuring that “fewer children . . . and families will have to make the heart-rending choice between coverage that fights an illness and coverage that provides comfort.”²¹⁷

B. STATE APPROACHES TO SOLVING THE PROBLEM

Although Section 2302 represents a broad shift in the federal legal paradigm governing Medicaid end-of-life care, several states have, in previous years, implemented programs that both anticipated and expanded upon the ideas of Section 2302. Two states—Florida and California—both crafted their programs using waiver authority under the Medicaid statute, which allows a state to escape otherwise applicable requirements for participating in the Medicaid program.²¹⁸ From a macro perspective,

213. JANE TILLY & JOSHUA WIENER, URBAN INST., MEDICAID AND END-OF-LIFE-CARE 10 (2011), available at http://www.urban.org/pdfs/410409_Medicaid.pdf.

214. Haiden A. Huskamp et al., *Providing Care at the End of Life: Do Medicare Rules Impede Good Care?*, 20 HEALTH AFFAIRS 204, 207 (2001). But see Michael Ash & Stephen Arons, *Economic Parameters of End-of-Life Care: Some Policy Implications in an Area of Health Care Reform*, 31 W. NEW ENG. L. REV. 305, 323 (2009) (“Medicare recipients may exit the hospice program at any time, and the benefit may be indefinitely extended in the case of patients who outlive the six-month prognosis. The six-month rule, then, is effective only insofar as it discourages uptake by patients who are uncomfortable with explicitly agreeing to the designation.”).

215. Letter from Cindy Mann to State Health Official, *supra* note 109, at 1.

216. See Casarett, *supra* note 137, at 1031 (“In effect, the [concurrent care] demonstration project [for Medicare] will also make the hospice prognostic eligibility criterion less stringent, because it would be illogical to require that patients have a prognosis of 6 months or less without treatment if they are receiving such treatment.”).

217. Proclamation No. 8594, 75 Fed. Reg. 67905 (Oct. 29, 2010).

218. Rosenbaum & Rousseau, *supra* note 58, at 11. For an excellent discussion of the political

waivers serve as a “policy and programmatic springboard for state-based health reform efforts.”²¹⁹ A third state, Washington, supported its program with private grants.

In 2005, Florida became the first American state, using public financing, to provide a program of palliative care to eligible children for the entire course of their illnesses.²²⁰ Titled “Partners in Care: Together for Kids” (“PIC: TFK”), Florida’s program utilized a “1915(b)” Medicaid waiver and simultaneous state plan amendment.²²¹ Based on the ChiPACC²²² model, Florida’s PIC: TFK program was implemented in eight sites across the state and provided coverage for a variety of hospice-like services, including: “pain and symptom consultation, specialized nursing, specialized personal care, respite care, support counseling for children and their families, and expressive therapies for children and their siblings.”²²³ Most notably, however, the PIC: TFK program offered its services to pediatric patients with “life limiting illnesses,” no longer restricting hospice-type care to those with a defined terminal prognosis of less than six months;²²⁴ this marked a substantial departure from the traditional six-month prognosis requirement of the Medicare and Medicaid hospice benefits under federal law.²²⁵

The PIC: TFK program has proven quite popular with pediatric patients and their families. Between January 2006, soon after the program was launched, and January 2008, total enrollment grew from 80 to 468.²²⁶ The average age of enrollees during this period was approximately nine years of age and the vast majority were enrolled in the middle stage of their

history and development of Medicaid waivers, see SMITH & MOORE, *supra* note 56, at 331–59. For an overview of states’ approaches to concurrent care, see Jessica Keim-Malpass, Terra G. Hart & Joy R. Miller, *Coverage of Palliative and Hospice Care for Pediatric Patients with a Life-Limiting Illness: A Policy Brief*, J. PEDIATRIC HEALTH CARE (Sept. 20, 2013), <http://www.jpeds.org/article/S0891-5245%2813%2900228-9/abstract>.

219. Rosenbaum & Rousseau, *supra* note 58, at 11.

220. UNIV. OF FLA. INST. FOR CHILD HEALTH POL’Y, CHILDREN’S MEDICAL SERVICE NETWORK PARTNERS IN CARE: TOGETHER FOR KIDS, ANNUAL EVALUATION FOR 2008, at 6 (2009) [hereinafter PIC:TFK 2008 REPORT], available at http://ahca.myflorida.com/medicaid/quality_management/mrp/contracts/med052/final_annual_pic_report_february_2009.pdf.

221. Caprice A. Knapp et al., *Partners in Care: Together for Kids: Florida’s Model of Pediatric Palliative Care*, 11 J. PALLIATIVE MED. 1212, 1212–13 (2008). It is worth noting that the supplemental services provided as part of Florida’s program are paid for by the money the state saves in using a general section 1915(b) waiver. TOOLKIT, *supra* note 115, at 56.

222. For a discussion of the ChiPACC model and previous legislative attempts to implement it nationwide, see *supra* text accompanying notes 96–102.

223. PIC:TFK 2008 REPORT, *supra* note 220, at 6.

224. Knapp et al., *supra* note 221, at 1212.

225. For a discussion and critique of the six-month prognosis requirement, see *supra* Part IV.A.

226. Knapp et al., *supra* note 221, at 1215 tbl.3.

diseases.²²⁷ Most patients who withdrew from the program due to ineligibility did so because they moved, died, or lost Medicaid coverage.²²⁸

The PIC: TFK program also garnered substantially positive reviews in its care of both the patient and the patient's family. In 2008—the most recent year for which data is available—89 percent of responding parents indicated that they were “very satisfied to satisfied” with the benefits their children received under the program.²²⁹ The percentage of parents indicating strong satisfaction with both the scope and frequency of each individual program service was similarly high.²³⁰

Ultimately, Florida's PIC: TFK program illustrates two important propositions: (1) that individual states can, independent of federal Medicaid law, utilize Medicaid waivers to expand their own pediatric hospice programs; and (2) that eliminating both the six-month prognosis requirement and the traditional prohibition against concurrent curative and hospice care can result in earlier-than-usual access to hospice and, perhaps equally important but often overlooked,²³¹ increased familial satisfaction. As previously noted, caring for the family unit is a central component of the hospice model.²³²

Soon after Florida established its pediatric palliative care program, the California State Legislature passed The Nick Snow Children's Hospice and Palliative Care Act.²³³ Carrying the name of a young man who “flunked hospice” when his physical conditions surprisingly improved after enrollment,²³⁴ the Nick Snow Act required California's state Medicaid agency to submit a federal Medicaid waiver so that California could expand the hospice and palliative services it offered to eligible children.²³⁵ This

227. *Id.*

228. PIC:TFK 2008 REPORT, *supra* note 220, at 33 tbl.7.

229. *Id.* at 23. In giving appropriate weight to these results, one should be cognizant of the potential selection bias inherent in a voluntary survey. That said, this Note references the survey results not to provide statistically unassailable proof of the program's benefits, but merely to indicate that the program has had a generally positive impact on those patients and families it serves.

230. *Id.* at 25 tbls.11 & 12.

231. See Caprice A. Knapp et al., *Family Support in Pediatric Palliative Care: How Are Families Impacted by Their Children's Illnesses?*, 13 J. PALLIATIVE MED. 421, 421 (2010) (presenting a study that suggests the importance of the family unit in the care of a pediatric patient).

232. See *supra* text accompanying note 30.

233. Devon Dabbs, Lori Butterworth & Elinor Hall, *Tender Mercies: Increasing Access to Hospice Services for Children with Life-Threatening Conditions*, 32 AM. J. MATERNAL/CHILD NURSING 311, 318–19 (2007).

234. *Id.* at 318. See also *supra* Part I (discussing Nick Snow's experience with pediatric hospice care).

235. Nick Snow Children's Hospice and Palliative Care Act, CAL. WELF. & INST. CODE § 14132.74(f)(1) (West 2011).

expansion of services was established as a pilot program in eleven California counties.²³⁶ Similar to Florida's program, California's pediatric palliative care initiative requires that hospice services be provided concurrent with curative treatment to those "individuals whose conditions may result in death, regardless of the estimated length of the individual's remaining period of life."²³⁷ Although the Nick Snow Act's allowance of concurrent care parallels Section 2302 of the ACA, its prognosis requirement is far more lenient than the federal definition of six-months or less.²³⁸ Indeed, the legislative history of the Nick Snow Act makes clear that, among other motivations, it was passed in direct response to the restrictive legal framework governing federal eligibility for the Medicaid Hospice Benefit.²³⁹

Moreover, California's policy-based justification for the program seems sound, especially within the overarching goals of pediatric palliative and hospice care. Specifically, when asked in its Medicaid waiver application to describe the program's purpose, the state reaffirmed its desire to provide "hospice-like" care outside the traditional six-month prognosis requirement and expressed the hope that the program's concurrent care structure will "minimize the use of institutions, especially hospitals, and improve the quality of life for the participant and [f]amily [u]nit."²⁴⁰

236. DAPHNA GANS ET AL., UCLA CTR. FOR HEALTH POLICY RESEARCH, BETTER OUTCOMES, LOWER COSTS: PALLIATIVE CARE PROGRAM REDUCES STRESS, COSTS OF CARE FOR CHILDREN WITH LIFE-THREATENING CONDITIONS 2 (2012), available at <http://healthpolicy.ucla.edu/publications/Documents/PDF/ppcpolicybriefaug2012.pdf>.

237. CAL. WELF. & INST. CODE § 14132.74(c)(1)–(2).

238. It should be noted, though, that the founders of California's pediatric palliative care program envision that it will be available only for those with "fairly severe medical conditions." Dabbs, Butterworth & Hall, *supra* note 233, at 318. This limitation is likely already present in the statute. See CAL. WELF. & INST. CODE § 14132.74(d) ("The department, in consultation with the interested stakeholders, shall determine the medical conditions and prognoses that render a beneficiary eligible for the benefit."). Also note that the Children's Hospice and Palliative Care Coalition recommended that California provide a pediatric hospice benefit restricting patient eligibility to those with a "life-threatening or potentially life-limiting medical condition so serious it is unlikely that the child will live to adulthood." THE CHILDREN'S HOSPICE & PALLIATIVE CARE COALITION, DRAFT, FINDINGS AND RECOMMENDATIONS 3 (2006), available at <http://www.dhcs.ca.gov/services/ppc/Documents/ppcfindings112906.pdf>.

239. S. B. Analysis, Assemb. B. 1745 (Cal. 2006), available at http://www.leginfo.ca.gov/pub/05-06/bill/asm/ab_1701-1750/ab_1745_cfa_20060829_231440_asm_floor.html ("This bill has been introduced to counter federal policy that unnecessarily results in denial of critical children's services There are approximately 10,000 terminal children on public programs in California.")

240. *Pediatric Palliative Care Waiver*, APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER (on file with author) [hereinafter *Care Waiver*]. Nick Snow's mother articulated a similar sentiment based on her son's personal frustrations with hospice eligibility rules. Letter from Shannon Snow to Hon. Arnold Schwarzenegger, Governor, State of Cal. (Sep. 5, 2006),

Preliminary studies of California's new program—officially titled Partners for Children (“PFC”)—demonstrate its success, especially when considered alongside the above policy goals. In its first three years of operation, PFC reduced the average length of hospital stays among program participants by 32 percent.²⁴¹ As a result, “[t]he average total medical expenditures per enrollee per month after enrollment (\$13,976) were \$1677 lower than expenditures before program participation (\$15,653).”²⁴² This reduction in inpatient hospital stays and concomitant decrease in medical expenditures are, together, concrete evidence that the PFC program is taking steps toward fulfilling California's policy goals.

In addition to achieving encouraging cost reductions, PFC has been met with high approval from program participants. In a survey of families with children in the program, respondents on average gave the PFC program a score of 9.6 out of a possible 10 points.²⁴³ A full 97 percent of the families surveyed indicated that they would recommend the PFC program to others.²⁴⁴ These results are cause for optimism that California's goal of “improv[ing] the quality of life for the participant and family unit”²⁴⁵ is being met.

All told, the PFC program has had a positive effect on its children participants—reducing the length of their hospital stays, cutting the costs of their care, and enriching their collective quality of life.²⁴⁶ However promising these results may be, the program is still in its early stages; more remains to be seen.²⁴⁷

Although not driven by state legislative support,²⁴⁸ a local pediatric palliative care project in Seattle, Washington (“the Washington program”) provides yet another important data point in the analysis. In 1998, Children's Hospital and Regional Medical Center in Seattle adopted a Pediatric Palliative Care Project (“PPCP”) that provided hospice services to children (ages zero to twenty-one) diagnosed with “potentially life-limiting

available at <http://nicksnow.com/archives.html>.

241. GANS ET AL., *supra* note 236, at 3.

242. *Id.*

243. *Id.* at 5.

244. *Id.*

245. *Care Waiver*, *supra* note 240.

246. GANS ET AL., *supra* note 236, at 5.

247. *See id.* (“[T]hese preliminary results must be interpreted with caution until a full analysis at the end of the three-year program is conducted because of the small number of participants and the wide variability of cost among children.”).

248. Seattle's program was supported by a multi-year grant from the Robert Wood Johnson Foundation. Ross M. Hays et al., *The Seattle Pediatric Palliative Care Project: Effects on Family Satisfaction and Health-Related Quality of Life*, 9 J. PALLIATIVE MED. 716, 717 (2006).

illness[es],” which were further defined as those that “might possibly conclude in death within twenty-four months.”²⁴⁹ Like ACA Section 2302, the Washington program provided its pediatric patients curative treatment concurrent with home hospice care.²⁵⁰ Similar to a bridge-to-hospice model, Washington’s program “made it possible to offer curative and comfort care, and to transition smoothly to comfort care when and if the patient’s trajectory so indicated.”²⁵¹

The results of the Washington program are encouraging. Derived from surveys of parents with children in the program, the data demonstrate increases in four meaningful measures of patient quality of life, including physical, emotional, academic, and psychosocial well-being.²⁵² Moreover, the surveys indicate statistically significant improvements in families’ satisfaction with the quality of information communicated to them about their children’s health.²⁵³ Parents were similarly pleased with the extent to which providers communicated this information directly to the child-patient.²⁵⁴ Despite these generally positive results, it should be noted that only one of the aforementioned quality of life measures, emotional well-being, increased by a statistically significant amount.²⁵⁵

Compared to current Medicaid hospice law (even post-Section 2302), the Washington program’s more lenient prognosis rule and its bridge-to-hospice model of care provide a potentially useful guide for future changes in the hospice legal paradigm.²⁵⁶

C. A PRESCRIPTION FOR CHANGE

Section 2302 of the ACA takes a significant step in changing the legal paradigm that long ago erected a distinct wall between curative and hospice care. However, as previously discussed,²⁵⁷ Section 2302 leaves unaddressed a federal Medicaid rule—the six-month prognosis

249. *Id.* at 717–20.

250. *Id.* at 717–18.

251. *Id.* at 718.

252. *Id.* at 724 tbl.3.

253. *See id.* at 725 tbl.4 (noting, for example, that families reported statistically significant increased satisfaction with measures of “how well providers told you all this information”).

254. *Id.* The specific measure used was “the quality of information your child received about his/her condition.” *Id.*

255. *Id.* at 726.

256. Note, though, that nearly half of patients died within three months of enrolling in Seattle’s PPCP program. *Id.* Because of this fact, those studying the program suggest that the prognosis requirement be relaxed even further in order to provide palliative care to patients and families at an earlier time in the illness. *Id.*

257. *See supra* Part IV.A.

requirement—that seemingly contravenes the purpose of the new law. Given the foregoing discussion and examination of successful state-level approaches to pediatric palliative care, Congress should move away from the strict six-month rule and, instead, reframe the pediatric hospice prognosis requirement in a way that reflects the objectives of both children’s Medicaid law and ACA Section 2302.

In shaping the context for further shift in the Medicaid laws and regulations, it is important to note the principles underlying children’s Medicaid benefits:

[S]o broad is Medicaid coverage for children that although its coverage is classified as “insurance” for purposes of statistical population coverage estimates, its “legal operating system” follows absolutely none of the conventions of insurance, particularly where children are concerned. Medicaid in a child health context is best thought of as a legal entitlement among eligible children to comprehensive health care financing.²⁵⁸

Given the historically broad construction of Medicaid laws as applied to children, ACA Section 2302 should be applauded for allowing concurrent coverage of curative and hospice treatment; clearly this is an expansive benefit. However, in the same light, the six-month prognosis requirement for access to such care should be redrawn in a manner that comports with the rule’s demonstrated practical difficulties,²⁵⁹ the established positive effects, for both the patient and family, of early access to hospice,²⁶⁰ and the general principles enshrined in children’s Medicaid laws.

In deciding how to change the federal hospice eligibility criteria for children, policymakers should look to the approaches that Florida, California, and Washington have taken in providing hospice and palliative care concurrent with curative treatment to those children with severe, life-limiting illnesses,²⁶¹ even if death is over six months away. Specifically, this Note proposes that Congress take the following graduated steps in

258. Sara Rosenbaum, Anne Markus & Colleen Sonosky, *Public Health Insurance Design for Children: The Evolution from Medicaid to SCHIP*, 1 J. HEALTH & BIOMEDICAL L. 1, 15 (2004) (footnote omitted).

259. See *supra* Part IV.A.

260. See *supra* Part III.C.2–3.

261. See Knapp et al., *supra* note 221, at 1212–13 (noting the eligibility rules for Florida’s pediatric palliative care program); The Nick Snow Children’s Hospice and Palliative Care Act, CAL. WELF. & INST. CODE § 14132.74(c)(1)–(2) (West 2011) (noting the eligibility rules for California’s pediatric palliative care program); Hays et al., *supra* note 248, at 720 (noting the eligibility rules for Washington’s program).

reshaping the existing six-month prognosis requirement.

First, policymakers should substitute Medicaid's six-month prognosis requirement, as it applies to children, with the eligibility criterion used in the Washington program: that the patient have a "potentially life-limiting illness[,] . . . defined as [a] severe illness that might possibly conclude in death within 24 months."²⁶² This suggested change strikes a balance between the strictness of the current six-month rule and the very broad rule adopted by California— "conditions [that] may result in death, regardless of the estimated length of the individual's remaining period life."²⁶³

So that the government may study the impact of this rule change and, if necessary, refine its approach before implementing the rule nationwide, the change should first be introduced as part of a Medicaid demonstration project. Conducted by the Centers for Medicare and Medicaid Services, demonstration projects are meant to "test and measure the effect of potential program changes."²⁶⁴ Evaluations of such projects "help [the government] monitor the effectiveness of Medicare, Medicaid, and the Children's Health Insurance Program (CHIP)."²⁶⁵ Given the Washington program's generally positive impact on patient well-being and family satisfaction,²⁶⁶ as well as its ability to reduce medical expenditures,²⁶⁷ the federal government should continue its ongoing reform of the laws governing pediatric end-of-life care by adopting Washington's prognosis eligibility guideline.

Second, if adoption of the Washington program's eligibility rule proves incrementally effective in reducing cost and improving measures of patient and family satisfaction, Congress should build on this success and consider further broadening the conditions under which children are eligible to receive concurrent hospice and curative care. Although the Washington rule is broader than the current six-month prognosis requirement under federal Medicaid law, nearly one-half of patients died within three months of enrollment in the Washington program.²⁶⁸ This

262. Hays et al., *supra* note 248, at 720.

263. Nick Snow Children's Hospice and Palliative Care Act, CAL. WELF. & INST. CODE § 14132.74(c)(2) (West 2011).

264. Demonstration Evaluation Reports, MEDICAID.GOV, <https://www.cms.gov/DemonstrProjectsEvalRepts/> (last visited Sept. 22, 2013). More specifically, demonstration projects enable the government to "study the likely impact of new methods of service delivery, coverage of new types of service, and new payment approaches." *Id.*

265. *Id.*

266. See *supra* text accompanying notes 248–56.

267. See *infra* note 288 and accompanying text.

268. Hays et al., *supra* note 248, at 726.

outcome suggests that the eligibility rule was successful in “identifying seriously ill children,” but nevertheless limited “the time available to provide care to these patients and their families.”²⁶⁹ Ultimately, those who studied the Washington program conclude that “[i]t would be important for the development of palliative care services to broaden the definition of who can benefit from palliative care and seek to meet families earlier in the process so that patients and families can benefit from the care and support throughout the course of the illness.”²⁷⁰

To that end, after gaining experience implementing the more modest eligibility rule of the Washington program, the federal government should adopt a more expansive criterion for concurrent care. California’s approach—providing care to those with “conditions [that] may result in death, regardless of the estimated length of the individual’s remaining period of life”²⁷¹—is one possibility. An alternative, slightly more limited rule is that promoted by the Children’s Program of All-Inclusive Coordinated Care (“ChiPACC”), a model of pediatric palliative care.²⁷² Specifically, under ChiPACC, a child eligible for hospice-like palliative services is one who

suffers from a serious illness or health condition that is life threatening; . . . for whom there is a reasonable likelihood that the child’s life will be threatened by such illness or condition; . . . [and] whose health status is expected to decline because of such illness or condition before attaining full adulthood.²⁷³

This Note specifically proposes that Congress consider adopting the ChiPACC eligibility rule because, while it generally expands seriously ill children’s access to concurrent hospice and palliative care, it simultaneously sets forth several conjunctive eligibility criteria that must be met.²⁷⁴ These limits, although concededly not stringent, help tailor the provision of concurrent care to those children who most seriously need it. Moreover, the ChiPACC system served as the model for previously effective state approaches²⁷⁵ and has, in the past, garnered national political

269. *Id.*

270. *Id.*

271. Nick Snow Children’s Hospice and Palliative Care Act of 2006, CAL. WELF. & INST. CODE § 14132.74(c)(2) (West 2011).

272. For a discussion of the ChiPACC program, *see supra* text accompanying notes 96–102.

273. H.R. 6931, 110th Cong. § 2(b)(2)(B)–(D) (2008).

274. *Id.*

275. *Compare* Knapp et al., *supra* note 221, at 1213 (“Florida and four other states were chosen to receive approximately \$3.2 million in federal funding to develop a program based on the CHI model.”), *with supra* text accompanying notes 221–28 (discussing the demonstrated benefits of Florida’s CHI-based program).

support.²⁷⁶ Moving forward, legislators will hopefully augment this political enthusiasm by marshaling the tangible, positive results that this Note projects will accrue from Congress's earlier decision to enact an eligibility rule based on the Washington program.²⁷⁷ This, of course, assumes that Congress enacted such a rule, which is this Note's first recommendation. However, even if Congress does not take that first step, this Note suggests that lawmakers may still be able to pass a relaxed eligibility rule by capitalizing on the apparent, recent political will to expand pediatric hospice care—evidenced by Section 2302 of the ACA.²⁷⁸

It is important to recognize, though, that this Note's proposed solution is one of many alternatives; a host of scholars have argued for a variety of ways to reframe the federal hospice eligibility criteria.²⁷⁹

Implementing either of the suggested eligibility rules could, in effect, be useful in establishing something of a graduated approach to hospice care

276. See *supra* text accompanying notes 96–102 for a discussion of previous Congressional attempts to pass the ChiPACC concurrent care eligibility rule.

277. See *supra* text accompanying notes 252–56 (describing the benefits that resulted from the Washington program).

278. Note also that, by the time Congress seriously considers a relaxed eligibility rule, proponents may be able to argue the actual, beneficial effects that Section 2302 is projected to have on children's hospice care. See *supra* Part III.C.

279. See, e.g., INST. OF MED., COMM. ON PALLIATIVE & END-OF-LIFE CARE FOR CHILDREN & THEIR FAMILIES, WHEN CHILDREN DIE 290 (Marilyn J. Field & Richard E. Behrman eds., 2003) (recommending that eligibility criteria “based on diagnosis and severity of illness” should be favored over those based on life expectancy); Am. Acad. of Pediatrics, Comm. on Bioethics & Comm. on Hosp. Care, *Palliative Care for Children*, 106 PEDIATRICS 351, 352 (2000) (“With a broader definition that includes children living with a life-threatening condition, all children who need palliative care may benefit.”); Friedman, Harwood & Shields, *supra* note 37, at 77–78 (noting that eliminating the six-month prognosis requirement and permitting concurrent care will likely result in increased hospice referrals); Barbara Head, Christine S. Ritchie & Tonya M. Smoot, *Prognostication in Hospice Care: Can the Palliative Performance Scale Help?*, 8 J. PALLIATIVE MED. 492, 492 (2005) (suggesting that statistical tools used to measure functional performance of palliative care patients may be used in evaluating hospice eligibility); Jacobowski, *supra* note 195, at 215–16 (arguing that, in the Medicare context, the prognosis rule should be “either ‘an average survival of six months’ or ‘a 50 [percent] probability of death in three months,’” or a standard that varies with the type of illness at issue (quoting Nicholas A. Christakis & Jose J. Escarce, *Survival of Medicare Patients after Enrollment in Hospice Programs*, 335 NEW ENG. J. MED. 172 (1996))); Lindley, *supra* note 145, at 84 (“[E]xperts in the field . . . suggest that integrating hospice care at diagnosis permits families the opportunity to gradually transition to the [end-of-life] period. This transition time allows families to learn what to expect during the disease trajectory and communicate with their child about death and dying.”). Cf. Sherman, *supra* note 40, at 408 (noting that some experts argue that the six-month prognosis requirement should be changed to an average benchmark); Charles F. von Gunten et al., *Recommendations to Improve End-of-Life Care Through Regulatory Change in U.S. Health Care Financing*, 5 J. PALLIATIVE MED. 35, 38–39 (2002) (recommending that hospices bear the burden of demonstrating that the mean life span of its patients is no greater than six months plus one standard deviation). But see Carlson, Morrison & Bradley, *supra* note 168, at 440–41 (discussing the concerns with expanding the eligibility rule for the Medicare Hospice Benefit).

whereby a child diagnosed with a severe, life-limiting illness—and his or her family—would receive some hospice-like services early in the treatment of illness, with those services growing in amount if the disease continues to progress.²⁸⁰ This “graduated” approach to hospice care has been called many different names, including “bridge-to-hospice”²⁸¹ and “open access.”²⁸² The traditional starting point for a bridge-to-hospice program is a relaxed set of patient eligibility criteria relative to the federal six-month prognosis and forfeiture of curative care requirements.²⁸³ Seriously ill patients meeting this more liberal admissions standard would then receive some hospice and palliative services and could, if later necessary, enroll in a full-time hospice program.²⁸⁴ The bridge-to-hospice program thus provides its very sick patients with a “smooth transition” from aggressive curative treatment to comfort care.²⁸⁵

In the context of Medicare, Kathy Cerminara provides an excellent discussion of the merits of a bridge-to-hospice program.²⁸⁶ Specifically, Cerminara summarizes a host of recent studies on the effects of programs based on the bridge-to-hospice model.²⁸⁷ The results demonstrate not only the benefits of increased access to hospice and palliative care, but also that such programs could be “financially viable.”²⁸⁸ Accordingly, Cerminara contends that federal Medicare law could fund “hospice-like services,” including “pastoral care, counseling services, and more social work,” before the patient becomes eligible for the full hospice benefit.²⁸⁹ At the very least, “hospice services should not be regulated to the *comfort* side of

280. Cf. Tamburro et al., *supra* note 134, at 609 (“[Section 2302] is consistent with more current palliative care doctrine that suggests palliative care should begin at the time of diagnosis and continue concurrently with curative therapy, taking a more predominant role at the end of life.”). This Note’s author is not medically trained. The suggestions here are only based upon a layman’s observations made with a legally focused eye.

281. Kathy L. Cerminara, *Pandora’s Dismay: Eliminating Coverage-Related Barriers to Hospice Care*, 11 FLA. COASTAL L. REV. 107, 145 (2010) (quoting Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope—Aggressive Treatment, Hospice Care, and Open Access*, 357 NEW ENG. J. MED. 324 (2007)) (internal quotation marks omitted).

282. Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope—Aggressive Treatment, Hospice Care, and Open Access*, 357 NEW ENG. J. MED. 324, 324 (2007).

283. David Casarett & Janet L. Abrahm, *Patients with Cancer Referred to Hospice Versus a Bridge Program: Patient Characteristics, Needs for Care, and Survival*, 19 J. CLINICAL ONCOLOGY 2057, 2057 (2001).

284. *See id.* (describing the process of care in a bridge-to-hospice program).

285. *Id.*

286. Cerminara, *supra* note 281, at 145–48.

287. *Id.*

288. *Id.* at 145–46. Financial viability is, obviously, an important criteria of any new program introduced in today’s political climate.

289. *Id.* at 144.

the false dichotomy between comfort and cure.”²⁹⁰

Cost is likely the principal objection to any proposed expansion of hospice eligibility rules under the Medicaid statute. Although the Center for Medicare and Medicaid Services estimates that, as currently written, Section 2302 will cost a significant sum in the short term,²⁹¹ other authorities suggest that, generally, allowing patients earlier access to hospice care might actually reduce federal medical outlays.²⁹² Lainie Rutkow provides an excellent summary of many studies demonstrating the cost savings (or at least cost-neutrality) of hospice care.²⁹³ Based upon the premise that hospice shifts medical care away from expensive hospital stays, a 2003 study summarized by Rutkow found that federal medical spending would increase by \$282 million if all states eliminated their Medicaid Hospice Benefit.²⁹⁴

Pediatric palliative care programs have also demonstrated the potential to reduce medical costs on a large scale. Specifically, those programs focused on providing care in the patient’s home in order to reduce the number of hospital visits, in which the cost of care can increase almost nine fold.²⁹⁵ More generally, the average yearly cost of a child receiving home-based palliative and life-prolonging therapies is often a small fraction of the cost of a four or five day stay in a hospital intensive care unit.²⁹⁶ In the particular case of Colorado’s pediatric palliative care program—using the concurrent care model and a Medicaid waiver to expand services beyond the traditional six-month prognosis requirement—experts estimate that the state will save nearly \$22,000 per child, per year.²⁹⁷ Similarly, the

290. *Id.* at 148.

291. FOSTER, *supra* note 126, at tbl.4 (concluding that Section 2302 will cost approximately \$200 million for the years 2010 through 2019).

292. *See, e.g.*, Cassin, *supra* note 211, at 56 (discussing studies demonstrating hospice’s ability to reduce medical spending); Cerminara, *supra* note 110, at 455 (“[A]lthough it seems paradoxical, providing both curative and palliative care at the beginning of patients’ hospice care experiences can reduce overall health care spending near the end of life.”). *But see* Ash & Arons, *supra* note 214, at 331 (“We have been convinced by our review of the literature that substitution of palliative care for curative treatment offers little opportunity for *overall* savings in the health care system.”). Note that Cerminara also believes that Section 2302 will likely not increase overall Medicaid costs. Cerminara, *supra* note 110, at 458. *But see* Jost, *supra* note 195, at 296 (noting that relaxing the prognosis requirements for hospice care may increase costs).

293. Rutkow, *supra* note 64, at 127–32.

294. *Id.* at 130.

295. NAT’L HOSPICE AND PALLIATIVE CARE ORG., CHILDREN’S INT’L PROJECT ON PALLIATIVE/HOSPICE SERVS. ADMIN./POL’Y WORKGROUP, A CALL FOR CHANGE: RECOMMENDATIONS TO IMPROVE THE CARE OF CHILDREN LIVING WITH LIFE-THREATENING CONDITIONS 24 (2001) [hereinafter A CALL FOR CHANGE].

296. *Id.*

297. Joanne Kenen, *In Search of a Gentler End*, STATELINE (Oct. 29, 2007),

estimated savings of Seattle's Pediatric Palliative Care Project, discussed above, are \$3652 per child, per month.²⁹⁸ California's pediatric palliative care program likewise reduced the monthly medical costs of each enrollee by \$1677.²⁹⁹ Ultimately, although home-focused palliative care has its own costs,³⁰⁰ there is sufficient data to suggest that a further shift in the legal paradigm governing pediatric end-of-life care might result in additional cost savings.

Opponents of expanding hospice eligibility might level three additional criticisms against Section 2302 and this Note's recommendations. First, they may argue that the institutional philosophy of hospice is inimical to caring for patients who desire a cure for their illnesses.³⁰¹ Cerminara, in an article proposing changes to the Medicare hospice rules, confronts this argument head-on and persuasively concludes that hospice is not just a place to die or to "give up," but is rather a group of professionals helping their patients understand and take advantage of all available health care options.³⁰² Hospice's goal of providing comfort to its patients does not demand the conclusion that, in all cases, the only way to achieve this end is with treatment that ultimately hastens the patient's death.

Second, critics might further claim that allowing seriously ill children to access hospice at an earlier point in their illnesses is tacitly encouraging these young people to accept their terminal diagnoses and to stop fighting for a cure. Although some children and their families might decide that the benefits of hospice care vastly outweigh any further aggressive treatment, Section 2302 and this Note's proposals do not force that choice, but rather merely expand the array of available options. Section 2302, by its very language, allows children to simultaneously enjoy the benefits of both curative and hospice or palliative care. This is a significant improvement over former Medicaid laws, which restricted children's choices by requiring them to choose one or the other. Similarly, this Note's proposals are designed to both supplement the benefits of Section 2302 and provide

<http://www.pewstates.org/projects/stateline/headlines/in-search-of-a-gentler-end-85899386692>.

298. LARRY BERESFORD, IRA BYOCK & JEANNE SHEILS TWOHIG, THE ROBERT WOOD JOHNSON FOUND., FINANCIAL IMPLICATIONS OF PROMOTING EXCELLENCE IN END-OF-LIFE CARE: EXECUTIVE SUMMARY 2 (2002), available at http://www.promotingexcellence.org/downloads/finance_summary.pdf.

299. GANS ET AL., *supra* note 236, at 3.

300. See A CALL FOR CHANGE, *supra* note 295, at 24 (noting that family members of sick children often lose income when those children are cared for at home).

301. Cerminara, *supra* note 281, at 149.

302. *Id.*

much-needed palliative care that might not otherwise be available.³⁰³ Neither Section 2302 nor this Note's proposals commit children to a plan of health care that is entirely inflexible or from which they may not deviate.³⁰⁴

Third, some may raise concerns that relaxing the hospice eligibility criteria for seriously ill children could open the door to Medicaid fraud and abuse.³⁰⁵ Assuming that "fraudulent hospice programs easily can certify a patient with any false prognosis," there will always be some who flout the eligibility rules, regardless of their strictness.³⁰⁶ However, in the context of terminally ill children, the magnitude of any fraudulent activity is likely to be slight. Given the relatively small number of children who die each year³⁰⁷ and, among them, the even smaller proportion who likely could have benefited from palliative care,³⁰⁸ it stands to reason that the government could counter fraud in the program by continually comparing the actual and projected enrollment figures and scrutinizing any hospices with numbers far exceeding these benchmarks. Methods similar to this outlier-focused approach have been successfully used on prior occasions to combat other forms of fraud in health care.³⁰⁹

V. CONCLUSION

In bridging the traditional barrier between curative and hospice treatment, Section 2302 of the ACA represents a sizable shift in the legal framework governing children's end-of-life care under Medicaid. As a

303. See *supra* Part III.C.2.

304. See Cerminara, *supra* note 281, at 151 (noting that eliminating the distinction between curative and hospice care in Medicare law does not irreversibly bind the patient to one course of treatment over another).

305. See Jacobowski, *supra* note 195, at 216 (stating the argument in the context of the Medicare hospice benefit).

306. *Id.* at 217.

307. FRIEBERT, *supra* note 43, at 3 (noting that, in 2005, 53,552 children died—representing approximately 2.2 percent of total deaths in the United States).

308. See *id.* at 4 (noting that, in 2005, 27 percent of deaths among children ages one to nineteen were caused by accidents, unintentional injuries, assaults, and homicides). Given the often sudden nature of death from such causes, it is unlikely that any of that 27 percent would have benefited from palliative care.

309. See Jacobowski, *supra* note 195, at 208 (discussing Operation Restore Trust). For two years in the mid-1990s, Operation Restore Trust audited a number of health care providers, including several hospices, for fraud. *Id.* at 208–10. In determining whether to investigate a hospice, the government "focused on providers with longer lengths of stay, higher rates of non-cancer diagnoses, and large numbers of nursing home enrollees." *Id.* at 208 (quoting Judy Zerzan et al., *Access to Palliative Care and Hospice in Nursing Homes*, 284 J. AM. MED. ASS'N. 2489, 2492 (2000)) (internal quotation marks omitted). Operation Restore Trust was successful in identifying \$187.5 million in Medicare and Medicaid fraud and abuse. *Id.*

result, more children will gain access to hospice care and, when they do, will no longer be required to forgo curative treatment. This substantive change promises to have very real, positive effects on the quality of care given to seriously ill children, and should be applauded.

Yet, by leaving untouched one of the more noteworthy barriers to hospice care—the six-month prognosis requirement—Section 2302 only partially fulfills its promise. To remedy this shortcoming, this Note proposes that the federal government follow the lead of states like Florida, California, and Washington, and take steps to relax the prognosis eligibility requirement for pediatric palliative care. Although scholars in medicine and nursing have debated the practical realities of such change, this Note is one of the only pieces in the law review literature to address the laws governing children’s end-of-life care. Accordingly, this Note does not set forth a panacea for the current problems in the area but, rather, is meant to draw attention to an otherwise overlooked part of the law and to suggest possible incremental improvements. By further modifying the rigid Medicaid eligibility rules for children’s hospice and affording more patients and families with the opportunity for much-needed, earlier access to hospice and palliative services, lawmakers will more completely meet the promise of ACA Section 2302. Ultimately, these efforts will mark a significant step in ensuring that the needs of seriously ill children and their families no longer go unnoticed or unserved by America’s health care system.

