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HEALTH LAW AND THE ELDERLY: MANAGING RISK AT THE END OF LIFE: AN INTRODUCTION TO THE SYMPOSIUM

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The 2010 Widener University Law Review Symposium, *Health Law and the Elderly: Managing Risk at the End of Life*, was held on March 26, 2010 at the Widener University School of Law's Ruby R. Vale Moot Courtroom in Wilmington, Delaware. It was co-sponsored by the Widener University School of Nursing, the Medical Society of Delaware, the Delaware End-of-Life Coalition, and Delaware Hospice.

The Symposium brought together a group of thoughtful and accomplished scholars and practitioners to assess and improve how consumers and professionals plan for the end of life. Local and national experts addressed topics such as advance care planning, MOLST, decision-making capacity, end-of-life communication, fraud and abuse laws impacting hospice, professional ethics, and aid-in-dying.

End-of-life healthcare has been getting more attention than ever. However, there are serious ongoing problems. Many are due to the fact that lawyers lack a sufficient appreciation of the clinical reality and how decision-making standards are actually implemented. Analogously, healthcare providers lack a sufficient understanding of the governing legal standards.

To address both these shortcomings, the Symposium was directed not only to lawyers but also to physicians, hospital administrators, hospital ethics committee members, nurses, social workers, other health professionals, health policy experts, and academics involved in these disciplines. To enhance its value and interest to these professionals, the Symposium was approved for CLE credits (including ethics credits), CE credits for nursing, and CME credits for medicine.

This Symposium brought these various disciplines together to identify problems, challenges, strategies, and solutions. Both the Symposium, and the articles published in this issue of the *Widener Law Review* that stemmed from presentations at that event, make significant contributions to a critical and topical concern for contemporary society.

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I. EXPRESSION OF APPRECIATION

The Symposium could not have taken place without the contributions of many people. The Law School and I wish to thank the leading scholars and practitioners who participated. We also wish to extend appreciation for the extraordinary efforts of Debbe A. Patrick and Constance Sweeney in planning, organizing and executing the conference. Equally noteworthy are the efforts of 2009-2010 law review board members Lindsey Anderson and Dawn Kurtz Crompton and staff member Nathan Trexler.[1]

The Symposium benefitted not only from those who helped plan and organize but also from those who helped moderate the several sessions. We thank Professors Susan L. Goldberg, Andrew J. Fichter, and John G. Culhane. We also thank Susan Lloyd, the president and CEO of Delaware Hospice, for moderating the session on "The State of Hospice and Palliative Medicine."

II. THE THEME OF THE SYMPOSIUM

Two-and-one-half million people die each year in the United States.[2] Some die in car accidents, plane crashes, and in war. But most people die in the healthcare system. Indeed, most of them die as the result of a deliberate decision to stop medical treatment that might have prolonged their life. Unfortunately, a majority of these individuals do not die how they want. They do not have what they themselves would define as a "good death."

People differ on what is a good death. We have different values, preferences, and beliefs. That is why both health law and medical ethics place such a high premium on patient autonomy. You are in charge of your own body. The patient is in charge. Self-determination controls. But autonomy is a principle, a concept. To have meaningful impact, it must be translated into rules and tools. And for the past thirty-five years, state legislatures and state courts across the country have been doing just that.

But it has become increasingly obvious that there are two big problems. First, the tools that have been developed do not work very well. Advance directives are rarely completed. When they are completed, they are often unavailable. Even when they are available, they are often unclear. And even when clear, healthcare providers often ignore them.[3]

Second, the available tools focus on a narrow range of end-of-life options—usually withholding or withdrawing technology (like a ventilator) on

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1. The Symposium organization committee also included law review board members Ryan Carlson and Daniel Herr.

2. NAT'L CTR. FOR HEALTH STATISTICS, HEALTH, UNITED STATES, 2010 WITH SPECIAL FEATURE ON DEATH AND DYING 33 (2011).

3. *See generally* Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211 (2010).

which the patient is dependent. But these tools do not help patients who are not dependent on such interventions.

In short, the law may not go far enough in protecting patient autonomy. And to the extent that the law does aim to protect autonomy, it may not succeed. There is, in short, a wide gap between principle and rule. Furthermore, there is a second gap. This gap lies between rule and practice, between law and clinical reality. This Symposium represents an effort to engage the participant and the reader to help think about how to bridge these gaps.

III. PRESENTATIONS AT THE LIVE SYMPOSIUM

In addition to those presentations represented in this issue of the *Widener Law Review*, the live Symposium event also included a number of other presentations. These were grouped into the following eight sessions.

A. MOLST and Advance Care Planning

Patricia Bomba, M.D., FACP, is the Vice President and Medical Director of Geriatrics at Excellus BlueCross BlueShield. Particularly relevant is the central role she served in implementing the MOLST program in New York. A Medical Order for Life-Sustaining Treatment (MOLST) is an order form that records a patient's preferences regarding several key types of life-sustaining medical interventions such as CPR and mechanical ventilation. The MOLST is intended to supplement, not replace, a patient's advance directive for those with a life expectancy of under one year.

In contrast to an advance directive, MOLST secures higher adherence from medical professionals. First, since it is on a bright pink form that travels with the patient from one care setting to another, the MOLST is more available. Second, it more clearly conveys the patient's treatment preferences. Third, as an order it is more respected by healthcare providers. Fourth, as an order, MOLST is immediately actionable. In short, MOLST significantly improves the agreement between a patient's wishes and the treatment that a patient receives.

Dr. Bomba's presentation was particularly valuable for a Delaware audience. Since 2009, a task force has been working on implementing MOLST in Delaware.[4] It was valuable for the task force to learn positive and negative lessons from the MOLST implementation experience in New York.[5] And it was valuable for other legal and medical professionals to learn about

4. *See* Thaddeus Mason Pope & Monyeen Klopfenstein, *MOLST: A Cure for the Common Advance Directive*, DNA REP., Sept.-Dec. 2010—Jan. 2011, at 6; DELAWARE MOLST, http://delawaremolst.org/. The Delaware Department of Health and Social Services published proposed MOLST regulations in May 2011. 14 Del. Reg. Regs. 1195-1202 (May 1, 2011).

5. Dr. Bomba was gracious enough to do a special workshop for the Delaware task force the morning after the Symposium.

MOLST, both to spur the ongoing efforts and to facilitate provider and public education.

B. Healthcare Decisions Law

In the second session, the Symposium moved from the clinical context to the legal context. The first speaker on this panel was Charles P. Sabatino, J.D., the director of the American Bar Association Commission on Law and Aging. The second speaker was the Honorable Edward D. Reibman, J.D., a judge on the Lehigh County Court of Common Pleas.

Mr. Sabatino painted a broad and rich landscape of the laws controlling healthcare decisions at the end of life. He identified and reviewed eight predominant features of state legislation: (1) default surrogates, (2) advance directives, (3) out-of-hospital DNR orders, (4) organ donation, (5) guardianship, (6) physician aid-in-dying, (7) palliative care, and (8) MOLST.

With respect to advance directives, Mr. Sabatino contrasted the traditional "legal transactional approach" with the "communications approach." The traditional approach focused on prescribed phrases, statutory forms, and other formalities. But thirty years of research has shown that "cookbook instructions" do not work. Most people do not complete these forms; they are hard to understand; people change their minds; and the forms are often "lost in space." The result is that both healthcare surrogates and providers are as clueless with, as without, such advance directives. In contrast, the communications approach focuses less on formal instructions and documents and more on the designation of a proxy and the discussion of goals and values.[6]

Following Mr. Sabatino's comprehensive overview, Judge Reibman engaged the audience in a practical exercise to help them appreciate what a judge sees when asked to appoint a guardian on behalf of an incapacitated patient. How should the court rule when the expert medical testimony is inconsistent? When directions from the patient's family contradict the instructions in the patient's advance directive? Do a patient's eye blinks constitute a repudiation of her advance directive? Using actual petitions and opinions from his own recent cases, Judge Reibman incrementally presented evidence and asked the audience to make tough decisions as if they were on the bench.

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6. Sabatino recommended a few workbooks to facilitate these discussions. *See, e.g.*, ABA COMM'N ON LAW & AGING, CONSUMER'S TOOL KIT FOR HEALTH CARE ADVANCE PLANNING (2d ed. 2005), *available at* http://apps.americanbar.org/aging/publications/docs/consumer_tool_ kit_bk.pdf; CAL. DEP'T OF DEVELOPMENTAL SERVS., THINKING AHEAD: MY WAY, MY CHOICE, MY LIFE AT THE END (2007), *available at* http://www.dds.ca.gov/ConsumerCorner/docs/ThinkingAhead_English.pdf.

C. Implementing Treatment Instructions: Clinical Reality

In the third session, the Symposium moved from the legal context back to the medical context. The objective was to illustrate the gap between law and clinical reality. The first speaker on this panel was Donna Casey, R.N., B.S.N., M.A., NE-BC, FABC, the nurse manager at the Wilmington Hospital ICU and the Co-Chair of the Christiana Care Health System Ethics Committee. The second speaker was Eileen M. Gleasner, R.N., B.S.N., M.S.N., N.P., a nurse practitioner with Van Buren Medical.

Donna Casey shared a number of cases that she has seen in the intensive care unit. Sometimes, the instructions in a patient's advance directive direct ongoing aggressive treatment, even though that causes suffering and is probably not what the patient really wanted. Other times, patients clearly specify that they would *not* want such treatment, but their family members override the advance directive and demand continued treatment. These cases not only cause significant distress among nurses but also visibly disturbed the audience.

While Donna Casey illustrated the challenges of implementing advance care planning laws in the hospital context, Eileen Gleasner illustrated those same challenges in the long-term care context. End-of-life planning is significantly more common in long-term care than in hospitals or in the general population.[7] But, as Gleasner explained, there is still plenty of room for improvement.

D. Ethical Issues in Representing/Treating the Incapacitated Client/Patient

In the fourth session, the Symposium moved back to the legal context to examine the ethical responsibilities of legal and medical professionals when dealing with incapacitated individuals. The speaker was the Honorable Susan Del Pesco, J.D., M.A., a retired Superior Court of Delaware judge and the Director of the Division of Long Term Care Residents Protection in the Delaware Department of Health and Social Services.

Judge Del Pesco effectively used the case of Mary Ellen Bendtsen to illustrate the all-too-common tragedy of elderly Americans becoming victims of financial exploitation.[8] Using compelling video clips from 20/20's coverage of the case,[9] Judge Del Pesco explored issues such as how judges can and should determine an individual's capacity, candor to the court, and attorney conflict of interest.

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7. Adrienne L. Jones et al., *Use of Advance Directives in Long-Term Care Populations*, 54 NAT'L CTR. HEALTH STATISTICS DATA BRIEF (Jan. 2011), *available at* http://www.cdc.gov/nchs/data/databriefs/db54.pdf.

8. *See generally* Lee Hancock, *Mary Ellen's Will: The Battle for 4949 Swiss*, DALLAS MORNING NEWS (2006), http://www.dallasnews.com/sharedcontent/dws/spe/2006/4949swiss/.

9. Andrew Paparella, *Mary Ellen's Mansion: Friendly Care—or Con?*, ABC 20/20 (Nov. 3, 2009), http://abcnews.go.com/2020/mary-ellens-mansion-elder-abuse/story?id=8974477.

E. Effective End-of-Life Communication

In the fifth session, the Symposium explored how physicians can engage in effective communication about end-of-life treatment with patients and surrogates. The first speaker was Dr. Bomba. The second speaker was Dr. John Goodill, M.D., the Director of the Pain and Palliative Care Service and Co-Chair of the Ethics Committee at Christiana Care Health System.

Dr. Bomba offered a staged approach to delivering bad news and gave specific examples of appropriate language at each stage. First, providers should prepare for the discussion by understanding the patient's prognosis, getting the advance directive, and determining the agent. Second, the provider should determine what the patient and family already know about the patient's condition and prognosis. Third, the physician should explore the patient's goals, hopes, and expectations. Finally, the physician should suggest realistic goals and respond empathetically.

Dr. Goodill explored how very difficult such conversations can be. Contributing to the difficulty are the material limits of prognostication. Moreover, individuals differ not only in their treatment preferences but also as to whether or not they want the physician to offer a recommendation. Still, notwithstanding these challenges of end-of-life communication, Dr. Goodill emphasized that such communication is very important. The physician must build trust, so that the patient/surrogate is willing to share.

F. State of Hospice and Palliative Medicine

In the sixth session, the Symposium turned to examine hospice. The first speaker was Jonathan Keyserling, J.D., the Vice President of Public Policy and General Counsel for the National Hospice & Palliative Care Organization. The second speaker was Kathy Cerminara, J.D., LL.M., J.S.D., Professor of Law at the Nova Southeastern Shepard Broad School of Law. The third speaker was Margaret L. Hutchinson, J.D., Assistant U.S. Attorney and Civil Chief of the U.S. Attorney's Office for the Eastern District of Pennsylvania.

Mr. Keyserling explained how hospice is, at once, a philosophy, a place, a payment stream, and a healthcare delivery system. The purpose of hospice is to preserve the quality of life for those who have six months or less to live. For a per diem of approximately $140, the hospice benefit provides doctor services, durable medical equipment (such as wheelchairs or walkers), medical supplies (such as bandages and catheters), drugs for symptom control or pain relief, nutritional and dietary counseling, hospice aide and homemaker services, grief and loss counseling for the family, and other services.

Hospice has been growing over the past decades in terms of both providers and patients. It has also been growing in terms of federal spending. After all, Medicare is the payer for eighty-five percent of hospice and Medicaid is the payer for five percent. But while hospice is appropriate for sixty percent to

seventy percent of the two and a half million people that die each year, only forty percent use it. And fully one-third of those who elect hospice use it for only one week or less. They thereby fail to obtain its maximum value.

Mr. Keyserling explained that some of the underuse of hospice is due to a misunderstanding that electing hospice means the patient must renounce all curative treatment. In fact, the patient need only give up curative treatment for her terminal illness (e.g. cancer) but not for other conditions (e.g. dialysis). Mr. Keyserling further explained that the very wisdom of the long-standing Medicare requirement to choose between curative treatment and hospice will be tested in new demonstration projects of a concurrent care model.[10]

While the concurrent care model may expand the use of hospice, other new Medicare regulations may restrict its use. Professor Cerminara explained that while hospice is for patients with a prognosis of six months or less, many patients remain in hospice care for much longer. To ensure that these re-certifications are appropriate, they must now include narratives based on a face-to-face encounter with the patient.[11] Professor Cerminara concedes that these safeguards are well-intended. But she argues that they may impose a chilling effect on hospice re-certification.

Finally, Margaret Hutchinson explained the role and operation of the U.S. Attorney's Office, especially as it pertains to using the False Claims Act to address quality of care issues.[12] Looking to recent work plans and audits from the U.S. Department of Health and Human Services Office of the Inspector General,[13] Ms. Hutchinson explained that hospice may be a growing target of investigation and prosecution. Among other risk areas, Ms. Hutchinson identified staff credentialing and new quality measures reporting.[14]

G. Underexplored Options: Voluntarily Stopping Eating and Drinking

In the seventh and eighth sessions, the Symposium moved from an examination of the law and medical practice concerning settled end-of-life options and interventions, to an examination of legally less-settled ones. In

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10. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3140, 124 Stat. 119, 440-41 (2010).

11. *Id.* § 6407; *see also* Department of Health and Human Services, Medicare Program; Home Health Prospective Payment System Rate Update for Calendar Year 2011; Changes in Certification Requirements for Home Health Agencies and Hospices, 75 Fed. Reg. 70372 (Nov. 17, 2010).

12. Ms. Hutchinson carefully explained that she was offering her own views and not the official position of the Department of Justice on any topic in her presentation.

13. *See, e.g.*, OFFICE OF THE INSPECTOR GEN., DEP'T OF HEALTH & HUMAN SERVS., WORK PLAN FOR FISCAL YEAR 2011, http://oig.hhs.gov/publications/workplan/2011/FY11_WorkPlan-All.pdf; OFFICE OF THE INSPECTOR GEN., DEP'T OF HEALTH & HUMAN SERVS., MEDICARE HOSPICE CARE FOR BENEFICIARIES IN NURSING FACILITIES: COMPLIANCE WITH MEDICARE COVERAGE REQUIREMENTS (2009), *available at* http://oig.hhs.gov/oei/reports/oei-02-06-00221.pdf.

14. Beginning in fiscal year 2014, hospices that do not report quality data will receive a 2 percentage point reduction in their annual payment update. Patient Protection and Affordable Care Act § 3004.

the seventh session the speaker was Judith K. Schwarz, R.N., M.S., Ph.D., the clinical coordinator for Compassion and Choices of New York. Compassion and Choices is a nonprofit, national advocacy organization whose goal is to improve care and to expand choice at the end of life.[15]

For some individuals, the burdens of living consistently and completely outweigh the benefits of life. Many of these individuals contact Compassion and Choices because they want to talk about death and "least bad" dying. They want information regarding control over the circumstances and timing of death. One option is voluntarily stopping eating and drinking (VSED) in which an individual who is physically able to eat and drink chooses not to do so with the intention of hastening death. Ms. Schwarz explained how this is an ethical, palliatively-supported option for decisionally capable, terminally ill & suffering patients.

H. Future Directions in End-of-Life Healthcare Decision Making

The speaker in the final session of the day was Kathryn Tucker, J.D., the Director of Legal Affairs for Compassion and Choices. She reviewed some of the ways in which Compassion and Choices has taken cutting-edge legislative and judicial action to improve care at the end of life.

First, pain is often undertreated. Up to fifty percent of dying patients die in severe pain. Only a small fraction of these individuals have intractable pain. To address this problem, Compassion and Choices has lobbied for mandatory provider education on pain management. It has also lobbied for safe harbors for aggressively treating pain. And Compassion and Choices has brought litigation to hold accountable providers who under-treat pain.[16]

Second, many patients are unaware of their options at the end of life. They do now know about their right to pain medication, about their right to refuse life-sustaining medical treatment, or about their right to hospice. Compassion and Choices has pushed for policies that ensure terminally ill patients are informed about their end-of-life options. Notable among these are new "Right to Know" laws in California and New York.[17]

Third, Ms. Tucker, who litigated many of the seminal cases on physician aid-in-dying,[18] reviewed its legal status across the country. She explained that physician aid-in-dying has broader support than ever, both from medical and health policy organizations and from the public. Ms. Tucker reviewed the positive twelve-year history in Oregon and how that data led Washington to

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15. COMPASSION & CHOICES, http://www.compassionandchoices.org (last visited May 11, 2011).

16. *See, e.g.,* Complaint, Hargett v. VITAS Healthcare Corp., No. RG10547255 (Alameda Cty. Sup. Ct., Cal. Nov. 18, 2010).

17. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2010).

18. *See, e.g.*, Vacco v. Quill, 521 U.S. 793 (1997).

follow.[19] While both Oregon and Washington legalized aid-in-dying through ballot initiatives, Montana did so through a court decision. Ms. Tucker reviewed the *Baxter* case, and suggested it will have impact even outside Montana.[20]

Finally, Ms. Tucker reviewed the more recent case, *Blick v. Connecticut*, in which she argued that a statutory criminal prohibition of "assisted suicide" does not apply to physician aid-in-dying. Only Arkansas specifically criminalizes a "health care provider participating in a medical procedure or knowingly prescribing a drug . . . for the express purpose of assisting a patient to intentionally end the patient's life."[21] In most other states the prohibition is not directed specifically at physicians.[22] Compassion and Choices argues that physician aid-in-dying does not constitute "suicide" as the term in used in those statutes.[23]

IV. THE PRINTED SYMPOSIUM

In *Speech: A Perspective from the Bench*, Judge Edward D. Reibman presents a compelling case that came before him on the Lehigh County, Pennsylvania Court of Common Pleas just a few weeks before the conference. The mother and guardian of an incapacitated and debilitated patient refused to consent to placement of a Do Not Resuscitate Order recommended by the treating clinician. Through his presentation of the K.K. case, Judge Reibman illustrates that while the standards for substitute decision making are seemingly straightforward, applying them to the evidence can be extremely difficult. Various pieces of evidence (eye blinks, a prior written advance directive, the mother, the physician) are in all conflict. Moreover, it is unclear how the eye blinks or advance directive should be interpreted.

In *Death by Voluntary Dehydration: Suicide or the Right to Refuse a Life-Prolonging Measure*, Judith K. Schwarz, like Casey and Walker, focuses on the clinical reality of healthcare decision making at the end of life. Schwarz provides a case study that illustrates how the decision to voluntarily stop eating and drinking (VSED) can be an appropriate option for some suffering patients who wish to hasten their deaths. But Schwarz also explains that many clinicians have concerns about facilitating death by VSED.

In *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, Lindsey Anderson and I address concerns about the legality of VSED that Schwarz has seen in her practice. We clarify the legal status of VSED. Specifically, we argue that a competent individual's decision to VSED is legally permissible. Individuals may refuse nutrition and hydration just as they may

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19. OR. REV. STAT. § 127.800-.995 (2005); WASH. REV. CODE § 70.245.010-904 (2009).

20. Baxter v. Montana, 224 P.3d 1211 (Mont. 2009).

21. ARK. CODE ANN. § 5-10-106 (2010).

22. Still other states have no law either way. In these states, the issue could be addressed as a standard of care issue on which medical professionals could take control.

23. The case was subsequently dismissed. Blick v. Office of the Div. of Criminal Justice, No. CV095033392, 2010 WL 2817256 (Conn. Super. Ct. June 2, 2010).

refuse other intrusions on their personal autonomy. This right is grounded in the common law of battery, statutes, state constitutions, and even the United States Constitution. Moreover, we argue that VSED does not, as many believe, constitute abuse, neglect, or assisted suicide. Even ex ante decisions for VSED (exercised through an advance directive or a surrogate decision maker) are legal in most United States jurisdictions.

In *Clinical Realities of Advance Directives*, Donna A. Casey and David M. Walker explain how advance directives are not as effective in the clinical setting as the individuals who wrote them may have hoped. After outlining key features of the Delaware Health Care Decisions Act, Casey and Walker provide case studies from clinical experience to demonstrate how the law functions (or fails to function) in a real-life hospital environment.

In *Hospice and Health Care Reform: Improving Care at the End of Life*, Kathy L. Cerminara explores the impact of the Patient Protection and Affordable Care Act on hospice. She first explains the system pursuant to which Medicare covers the cost of hospice. Professor Cerminara then lauds Congress for changing that payment system in a way that promotes earlier access to hospice care for many patients. Indeed, she vigorously defends the expansion of "concurrent care."

But while Professor Cerminara praises Congress with one hand, she criticizes it with the other. She concedes that Congress is rightly concerned about fraud and abuse. She agrees that there must be some oversight of hospices' certification and recertification of patients as terminally ill. But Professor Cerminara worries that the new (and burdensome) documentation requirements could inappropriately chill (appropriate) hospice re-certification of patients as eligible for hospice. She argues that there are better ways to address fraud and abuse concerns.

In *Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning*, Patricia Bomba reviews recent programs and legislation in New York that are directed at ensuring patient treatment preferences are honored at the end of life. Specifically, Dr. Bomba explains the development and implementation of both the MOLST program and the Community Conversations on Compassionate Care program. Dr. Bomba further explains the impact of two important statutes that New York enacted in 2010: the Family Health Care Decisions Act and the Palliative Care Information Act.[24]

V. CONCLUSION

Americans are engaged in an earnest and profound debate about how to best manage legal and medical risks at the end of life. The Symposium presentations and the resulting articles in this issue not only advance the ongoing debate but also offer a number of fresh ideas on the subject.

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24. N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2007); *id.* § 2997-c.