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Journal
Cardozo Law Review, 37

Author
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Publication Date
2016

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FROM PATIENT RIGHTS TO HEALTH JUSTICE: SECURING THE PUBLIC'S INTEREST IN AFFORDABLE, HIGH-QUALITY HEALTH CARE

Lindsay F. Wiley[†]

Models emphasizing professional autonomy, patient rights, market power, and health consumerism are no longer adequate to address the increasingly social, collective nature of health law institutions, instruments, and norms. What is needed is a new model that expressly recognizes the public—alongside the patient, the provider, and the payer—as an important stakeholder and active participant in decisions about medical treatment, health care coverage, and allocation of scarce resources. In a previous article, the author looked to the environmental justice, reproductive justice, and food justice movements for inspiration in developing a "health justice" approach to eliminating social disparities in health. This Article further articulates the health justice model as an alternative to existing health law models or a supplement to the now-dominant patient rights model for examining questions of health care quality and access. It proposes four key commitments: First, the health justice model asserts the importance of collective interests, alongside individual interests, in decisions about medical treatment. Second, the health justice model emphasizes that universal access to affordable health care protects collective, as well as individual, interests. Third, because "upstream" prevention strategies have greater population-level impact, the health justice model prioritizes prevention and integration of health care with public health. Fourth, the health justice model asserts the role of collective oversight through democratic governance—much in the same way that the market power model champions the role of private payers and market dynamics—in managing resources and securing common goods.

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INTRODUCTION

Health reform is changing the way we think about health and social justice. Past shifts (for example, Medicare and Medicaid reforms, the introduction of prospective payment, the advent and rapid hegemony of managed care, and especially the Clinton-era "health security" proposal) have prompted periodic reexamination of the models,[1] or lenses, through which policymakers, judges, practitioners, scholars, and teachers view the field.[2] The current transformation raises several

1 Rand E. Rosenblatt, *The Four Ages of Health Law*, 14 HEALTH MATRIX 155, 162 (2004) [hereinafter Rosenblatt, *Four Ages*] (describing "the notion of a model [as] refer[ing] primarily to the assumptions, values, background norms, orientations, etc., of private and governmental decisionmakers," the influence of which can be seen in "legislation, judicial opinions, positions of the American Medical Association, and hospital bylaws and practices," and increasingly, in "academic literature").

2 *See, e.g.*, NORMAN DANIELS, JUST HEALTH CARE, at ix (1985) [hereinafter DANIELS, JUST HEALTH CARE] ("To find . . . principles of justice for health care we must address questions such as these: What kind of a social good is health care? What are its functions and do those make it different from other commodities?"); Ronald Dworkin, *Justice in the Distribution of*

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interrelated questions about health, law, and society: Is health care an individual entitlement or an economic good? A personal responsibility or a common concern? Should health care delivery and financing be governed by the aggregate power of individual consumption choices, or by public processes that address collective, as well as individual, needs? Does just distribution of health care resources demand actuarial fairness or mutual aid? Does sickness alone trigger mutual aid, or should prevention activities—in the community and the clinic alike—be collectively financed in recognition of our mutual interdependence?

A handful of legal scholars, political philosophers, and ethicists have lamented the individualistic bias of currently available health law models—professional autonomy, patient rights, market power, and health consumerism.[3] These models are indelibly marked by the insular

Health Care, 38 MCGILL L.J. 883, 898 (1993) ("[T]he question of health-care reform in America, including politically acceptable and fair health-care rationing, is ideologically leveraged. If we find, after all the fuss, that politically we can't do much to make the distribution of medical care more just, in spite of the apparent present opportunities to do so, then a pessimistic conclusion may be irresistible: we may abandon hope for any more widespread or general democratic concern for social justice. But if we do now make substantial and recognizable political progress in this one urgent matter, we may learn more, from the experience, about what justice itself is like, and we might find it to our taste, so that we can steadily, bit by bit, incrementally, fight the same battle in other areas. . . . Health might not be more important than anything else—but the fight for justice in health might well be."); Rand E. Rosenblatt, *Equality, Entitlement, and National Health Care Reform: The Challenge of Managed Competition and Managed Care*, 60 BROOK. L. REV. 105, 122 (1994) ("At best, the [Clinton-era Health Security Act proposal] invites Americans to participate in a very complex ongoing discussion about the nature of reform. This discussion addresses what kinds and patterns of health care (and for whom) 'we' want to pay for out of collective funds—through subsidies and tax exemptions—and what kinds will be considered individual consumption preferences to be paid for with individual, after-tax dollars, and thereby probably unavailable to the majority of the population."); Rand E. Rosenblatt, *Health Care Reform and Administrative Law: A Structural Approach*, 88 YALE L.J. 243, 244–45 (1978) [hereinafter Rosenblatt, *Health Care Reform and Administrative Law*] ("The absence of effective regulation to increase access to health care services, ensure quality, and control costs has . . . contributed to . . . severe inflation of health care costs, maldistribution of facilities and personnel, gross profiteering from public and private funds, and unnecessary, deficient, and often harmful care. Perhaps equally important, if less obvious, has been the impact of government passivity on the experience of citizenship itself." (footnotes omitted)); Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287 (1993) [hereinafter Stone, *The Struggle for the Soul of Health Insurance*] (describing "mutual aid" and "actuarial fairness" as competing principles for health care financing).

3 *See, e.g.*, NORMAN DANIELS, JUST HEALTH: MEETING HEALTH NEEDS FAIRLY 2 (2008)[hereinafter DANIELS, MEETING HEALTH NEEDS FAIRLY] (linking individualistic bias in health law and policy to the bioethics tradition, which, since its inception "has focused heavily on . . . the dyadic relationship between doctors and patients or research subjects, or on the potential benefits and risks for those individuals that arise from new [medical] technologies"); Nan D. Hunter, *Health Insurance Reform and Intimations of Citizenship*, 159 U. PA. L. REV. 1955, 1959 (2011) [hereinafter Hunter, *Intimations of Citizenship*] (arguing that practices arising out of the individual mandate and health insurance exchanges "have the potential to lead to new discourses and understandings about the interrelationship between individualism and collectivity, and about the public and private dimensions of the health system"); Rosenblatt, *Four Ages*, *supra* note 1, at 191 (describing "[t]he sense of a great fork in the road

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private law regimes (tort and contract),[4] relational professional ethics (bioethics),[5] and rescue-care oriented politics[6] out of which they emerged. Their explanatory power and transformative potential are limited in the face of health reform's shift toward public law governance to address collective, as well as individual, needs.

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between hyper-individualism and unrestrained competition, on the one hand, and some way of reconstituting solidarity and associated social policies, on the other"); William M. Sage, Lecture, *Over Under or Through: Physicians, Law, and Health Care Reform*, 53 ST. LOUIS U. L.J. 1033, 1036 (2009) [hereinafter Sage, *Over Under or Through*] ("[L]aw accedes too readily to physicians' declared (and ethically defensible) allegiance to each individual patient, and does not demand greater service to society as a whole."); William M. Sage, *Relational Duties, Regulatory Duties, and the Widening Gap Between Individual Health Law and Collective Health Policy*, 96 GEO. L.J. 497, 500 (2008) [hereinafter Sage, *Relational Duties*] ("[P]oliticians and policymakers apply the mental construct of the specific patient, and that patient's therapeutic relationship with a specific physician, to problems of collective costs and benefits for which such a starting point . . . is not appropriate."); Stone, *The Struggle for the Soul of Health Insurance*, *supra* note 2, at 290 ("The private insurance industry . . . is organized around a principle profoundly antithetical to the idea of mutual aid, and indeed, the growth and survival of the industry depends on its ability to finance health care by charging the sick and to convince the public that 'each person should pay for his own risk.'").

4 *See, e.g.*, ERNEST J. WEINRIB, THE IDEA OF PRIVATE LAW 1, 5, 8, 19 (1995) (describing private law as "connect[ing] two particular parties through the phenomenon of liability," arguing for the complete autonomy of private law, and observing that private law attends to justice between parties rather than to some social goal or public policy); Michael J. DeBoer, *Access Without Limits? Revisiting Barriers and Boundaries After the Affordable Care Act*, 44 CONN. L. REV. 1239 (describing the Affordable Care Act as eroding the private law foundation of health law and reasserting the importance of professional autonomy-based limits on patients' access to care in the context of hybrid public-private law governance); Sage, *Relational Duties*, *supra* note 3, at 502 ("[M]uch of what we now call 'health law' developed around discrete interactions between one patient and one physician, such as medical malpractice, in which private legal accountability both drew from and criticized the established ethics of personal medical care. Subsequent legislation and administrative law, whether associated with government health insurance programs such as Medicare, with private health care financing, or with assuring the safety and quality of medical care, layered atop this foundation of private legal governance.").

5 *See, e.g.*, DANIELS, MEETING HEALTH NEEDS FAIRLY, *supra* note3, at 2; Leslie P. Francis et al., *How Infectious Diseases Got Left Out—and What this Omission Might Have Meant for Bioethics*, 19 BIOETHICS 307, 307–08 (2005) (suggesting that the lack of collective ethics derived in part from the happenstance of bioethics developing when infectious diseases seemed to have been conquered); Sage, *Relational Duties*, *supra* note 3, at 503–05 ("The relationship between a single patient and a single physician is at the heart of medical ethics. . . . Although ethicists have long believed that the proper allocation of society's scarce resources is a key question solidly within their purview, their opinions about social responsibility and redistribution tend not to be as well received by the political process as their opinions about individual liberty.").

6 *See, e.g.*, Sage, *Relational Duties*, *supra* note 3, at 505 ("Political dynamics reinforce relational governance. Although some commentators criticize the notion of a 'statistical' life, regulatory policies that increase the risk of physical injury or death in tangential ways for faceless persons (for example, raising speed limits or relaxing environmental controls) are easier for politicians to adopt and maintain than policies that cost more immediate lives (for example, not paying for organ transplantation). Health care regulation is uniquely amenable to portrayal in terms of identified lives." (footnote omitted)).

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This Article argues that, in the aftermath of the Affordable Care Act,[7] conditions are ripe for the emergence of a new health law model—distinct from the patient rights, professional autonomy, market power, and health consumerism models—that brings collective problems and problem-solving to the fore. I have called this new model "health justice," in reference to the foundation in communitarian conceptions of social justice it shares with the environmental justice, reproductive justice, and food justice movements.[8]

Part I begins with the emergence and evolution of currently available health law models in response to the changing health care landscape. I focus on three key shifts: first, from professional autonomy to patient rights; then, the emergence of the market power model as an alternative to the patient rights approach; and finally, the emergence of health consumerism as a (somewhat uneasy) blend of the patient rights and market power models. I describe the other three models primarily in relation to the patient rights model because it represents the dominant—virtually exclusive[9]—model adopted by the progressive judges, policymakers, advocates, and scholars who are the most receptive audience for my proposed health justice model. The health justice model is workable as a fully realized alternative to currently

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7 Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1302(b)(1), 124 Stat. 119, 163–64 (2010), amended by Health Care and Education Reconciliation Act, Pub. L. No. 111-152, §§ 1302(b)(1), 2707(a) (2010) (codified as amended at 42 U.S.C. § 18022(b)(1) (2012)). This Article refers to the consolidated act, with amendments, as the Affordable Care Act or ACA.

8 *See* Lindsay F. Wiley, *Health Law as Social Justice*, 24 CORNELL J.L. & PUB. POL'Y 47 (2014) [hereinafter Wiley, *Health Law as Social Justice*] (drawing lessons from three recent movements—environmental justice, reproductive justice, and food justice—and the work of political philosophers and ethicists on health and social justice to articulate a health justice approach to addressing social disparities in health). The health justice label has been used by others. *See, e.g.*, SRIDHAR VENKATAPURAM, HEALTH JUSTICE: AN ARGUMENT FROM THE CAPABILITIES APPROACH (2011); *Health Justice*, PRAXIS PROJECT, http://www.thepraxisproject.org/tools/health-justice (last visited Dec. 22, 2015) (offering "resources to support organizing and policy advocacy to advance health justice in your community"); *Health Justice Project*, LOY. U. CHI., http://www.luc.edu/law/centers/healthlaw/hjp/index.html (last visited Apr. 3, 2014) ("The Health Justice Project was founded by Professor Emily Benfer in 2010 and is a medical-legal partnership clinic between Loyola University Chicago School of Law and Erie Family Health Center, a Federally Qualified Health Center that serves over 60,000 low-income patients annually at 13 different locations around Chicago. Students of law, social work, public health and medicine enrolled in the clinic engage in interprofessional collaboration to identify and address social and legal issues that negatively affect the health of low-income individuals."); *Mission*, ACCESS WOMEN'S HEALTH JUST., http://accesswhj.org/mission (last visited Apr. 3, 2014) (describing the work of a reproductive justice organization that has adopted "health justice" as part of its identity).

9 William M. Sage, *Should the Patient Conquer?*, 45 WAKE FOREST L. REV. 1505, 1505 (2010) [hereinafter Sage, *Should the Patient Conquer?*] ("[N]early all progressive impulses among American health lawyers and policy makers over the past half century have sought to liberate and empower the patient.").

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available health law models, but it is more likely to be adopted as a supplementary approach by those who primarily subscribe to the patient rights model.

In Part II, I argue that four key factors that have fostered individualistic bias in existing health law models are already changing: First, the ACA is accelerating a transition from private law to public law governance of health care. Second, concerns about rising health care costs, declining community immunity for vaccine-preventable diseases, increasing antibiotic resistance, and mutual vulnerability in the face of public health emergencies are prompting a shift within bioethics toward reconciling collective and individual interests. Third, the same collective concerns about costs, antimicrobial effectiveness, community immunity, and emergency preparedness are fostering increased integration between the practice of health care and public health. Fourth, budgetary politics that favor high-technology solutions and specialty care are softening somewhat in response to changes in health care reimbursement policies to reflect the priority of primary care. Nonetheless, the "prevention paradox," whereby rescue care that benefits identifiable individuals is favored over preventive interventions that save statistical lives,[10] continues to pose a formidable hurdle for the transformation of the health system envisioned by the ACA.

In Part III, I argue that a new health justice model rooted in a communitarian conception of social justice and committed to securing the public's interest in universal access to affordable, high-quality health care would simultaneously explain and support the transformative influences described in Part II. Each of the currently available models champions the role of specific players in health care transactions: the patient (patient rights and health consumerism), the provider (professional autonomy), and the third-party payer (market power and health consumerism). The health justice model seeks to transcend these insular transactions, opening the door "for law to serve truly 'public' policy."[11] I articulate four key commitments of the health justice model as an alternative to existing models or as a supplement to the now-dominant patient rights model. First, the health justice model asserts the importance of collective interests, alongside individual interests, in decisions about medical treatment. Second, the health justice model emphasizes that universal access to affordable health care protects collective, as well as individual, interests. Third, because "upstream"

10 *See* Geoffrey Rose, *Sick Individuals and Sick Populations*, 14 INT'L J. EPIDEMIOLOGY 32, 38 (1985).

11 Sage, *Relational Duties*, *supra* note 3, at 500 (criticizing currently available models on the grounds that "far more legal issues in health care are approached as relational than as regulatory problems, making it very difficult for law to serve truly 'public' policy").

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community and primary prevention strategies have greater population-level impact, the health justice model prioritizes prevention and the integration of health care and public health. Fourth, the health justice model asserts the role of collective oversight through democratic governance—much in the same way that the market power model champions the role of private payers and market dynamics—in managing resources and securing common goods.

I. THE INDIVIDUALISTIC BIAS OF AVAILABLE HEALTH LAW MODELS

A handful of scholars have described competing health law models, approaches, paradigms, or themes in varying terms, but they generally converge on the notion that three or four basic models have been dominant at one time or another and continue to have influence today.[12] I call these professional autonomy, patient rights, market

12 *See, e.g.*, WENDY E. PARMET, POPULATIONS, PUBLIC HEALTH, AND THE LAW 196–98 (2009) ("Initially, the laws relating to health care reflected the prestige and influence of the medical profession. . . . Then, in the late 1960s and 1970s, a new patients' rights paradigm developed. . . . In the last twenty-five years, another perspective emphasizing the role and values of the market has gained prominence."); James F. Blumstein, *Health Care Reform and Competing Visions of Medical Care: Antitrust and State Provider Cooperation Legislation*, 79 CORNELL L. REV. 1459, 1459 (1994) (describing "the competing visions of medical care represented by the professional paradigm and the market-based economic paradigm"); Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449, 1452 (1994) (identifying four different paradigms used in health law to allocate resources: market, professional, moral, and political); Jay Alexander Gold, *Wiser than the Laws?: The Legal Accountability of the Medical Profession*, 7 AM. J.L. & MED. 145, 149–50 (1981) (describing tensions in health law between the "democratic principle, [which] is that people have the right to make the decisions that affect their lives," and the "professional principle, which states that . . . issues that common knowledge and common sense are not equipped to resolve adequately, are best decided by experts who have specialized in dealing with those issues"); Mark A. Hall, *Law, Medicine, and Trust*, 55 STAN. L. REV. 463, 465–66 (2002) (identifying social justice and economic efficiency as proposed and competing "unifying themes" for health law, and advocating instead for the concept of "therapeutic jurisprudence"); Mark A. Hall & Carl E. Schneider, *Where is the "There" in Health Law? Can it Become a Coherent Field?*, 14 HEALTH MATRIX 101, 102 (2004) (describing "[t]he patients' rights approach[, which] at heart hopes that medicine can be regulated by endowing patients with rights of autonomy to which medical professionals and institutions must defer" and "[t]he law and economics approach[, which] at heart hopes that medicine can be regulated in the market, by consumers making purchasing decisions that discipline medical institutions," as the "two competing paradigms" of health law); James A. Morone, *The Health Care Bureaucracy: Small Changes, Big Consequences*, 18 J. HEALTH POL. POL'Y & L. 723, 723 (1993) ("There are at least three working models of authority in health care politics: professional, democratic, and bureaucratic (with an additional handful of largely theoretical alternatives, most notably the free market)."); Rosenblatt, *Four Ages*, *supra* note 1, at 155 (contrasting "the *modestly egalitarian social contract*" paradigm in which "[t]he role of law . . . is to achieve a fair resolution of conflicting interests, especially in the light of highly unequal information and power between patients and" physicians and other stakeholders with interests in the health care system, with the "*market competition*" paradigm, in which the role of law "is to ensure that choices about health insurance and health services are made by

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power, and health consumerism. These models encompass the "assumptions, values, background norms, orientations, etc., of private and governmental decisionmakers," the influence of which can be seen in legislation, judicial opinions, and the academic literature.[13] In this Part, I describe the evolution of currently available health law models in response to shifts in the health care landscape.

A. *From Professional Autonomy to Patient Rights*

The patient rights model initially emerged as a critique of the professional autonomy model that dominated (largely private law-based) regulation of health care during the field's infancy. "[F]rom roughly the 1870s to the 1930s—the process of social choice in health care was largely delegated by courts and legislatures to doctors and hospitals, subject to the significant constraints of the individual's ability to pay and the existing state of medical technology and organization."[14] Physicians' groups "use[d] legal authority to suppress professional rivals and fend off corporate influences while simultaneously keeping legal authority from exerting unwanted control over them."[15]

The influence of the professional autonomy model is readily apparent in the medical malpractice standard of care. Unlike in ordinary negligence cases, where evidence of customary practices adopted by an industry is highly persuasive—but not dispositive—as to the legal standard of care,[16] in professional malpractice cases, adherence to customary practice is a definitive shield to liability.[17] Physicians are thus left to self-govern, with the practical impact that in the vast majority of cases malpractice plaintiffs must proffer expert testimony by a physician establishing that the defendant deviated from prevailing professional practice.[18] Even in cases where plaintiffs are able to do so, a "no liability"

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individuals based on their own financial resources (assuming them to be above some specified minimum), and . . . to eliminate as much as possible hidden 'cross-subsidies'").

13 Rosenblatt, *Four Ages*, *supra* note 1, at 162.

14 Rand E. Rosenblatt, *Conceptualizing Health Law for Teaching Purposes: The Social Justice Perspective*, 38 J. LEGAL EDUC. 489, 491 (1988) [hereinafter Rosenblatt, *Conceptualizing Health Law*].

15 Sage, *Over Under or Through*, *supra* note 3, at 1034; *see also* PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE: THE RISE OF A SOVEREIGN PROFESSION AND THE MAKING OF A VAST INDUSTRY 3–9 (1982); JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 30–47 (1984).

16 *See* The T.J. Hooper, 60 F.2d 737 (2d Cir. 1932).

17 *See* Gold, *supra* note 12, at 153–54 (describing the medical malpractice standard of care in terms of conflict between professional self-governance and individual autonomy).

18 *See* WILLIAM L. PROSSER, HANDBOOK OF THE LAW OF TORTS § 32 (4th ed. 1971) ("It has been pointed out often enough that this gives the medical profession . . . the privilege, which is

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result is still possible if defense experts establish that the defendant's deviant approach represented a respectable minority practice or comported with reasonable professional judgment.[19] Judges have also historically deferred to the medical profession with regard to state agency licensing decisions.[20]

The patient rights model emerged as an effort to "hold experts accountable to non-experts,"[21] primarily via the informed consent doctrine.[22] In the early twentieth century, informed consent grew out of an effort to tailor the doctrine of consent as an intentional tort privilege in ways that reflect unique aspects of the doctor-patient relationship.[23] Later, judges and advocates transformed the typical informed consent case from an intentional tort claim into a subspecies of medical malpractice rooted in negligence principles.[24] Early elucidations of the

usually emphatically denied to other groups, of setting their own legal standards of conduct, merely by adopting their own practices." (footnotes omitted)).

19 *See, e.g.*, Hood v. Phillips, 537 S.W.2d 291, 293 (Tex. Civ. App. 1976) ("[C]ourts have also enunciated a corollary to the above rule that one should follow the 'better' method: that where there are several possible methods of treatment, a doctor will not be liable for a patient's injuries as long as the treatment used is one followed by a respectable minority of the medical profession and his care under that treatment conforms with the general practice of reasonable physicians utilizing the same treatment.")

20 *See, e.g.*, Brownlee v. D.C. Dep't of Health, 978 A.2d 1244 (D.C. 2009) ("Generally, '[w]e review the [Board's] legal rulings *de novo*, but otherwise defer to the [Board's] determination so long as it rationally flows from the facts and is supported by substantial evidence on the record.'" (alteration in original) (quoting Safeway Stores, Inc. v. D.C. Dep't of Emp't Servs., 806 A.2d 1214, 1219 (D.C. 2002)); *see also* Daniel B. Hogan, The Effectiveness of Licensing: History, Evidence, and Recommendations, 7 LAW & HUM. BEHAV. 117 (1983) (arguing that licensing boards fail to discipline incompetent or unethical practitioners, and that disciplinary actions are more often aimed at eliminating competition, not incompetence).

21 Sage, *Relational Duties*, *supra* note 3, at 498.

22 Nan D. Hunter, *Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms*, 45 WAKE FOREST L. REV. 1525, 1526 (2010) [hereinafter Hunger, *Rights Talk and Patient Subjectivity*] ("In the 1960s and 1970s, the law of informed consent brought the concept of patient autonomy into the constellation of metanorms shaping the idealized doctor-patient relationship. From that process, the patient as a rights-bearing subject emerged." (footnote omitted)).

23 *See, e.g.*, Pratt v. Davis, 79 N.E. 562, 564 (Ill. 1906) ("Ordinarily, where the patient is in full possession of all his mental faculties and in such physical health as to be able to consult about his condition without the consultation itself being fraught with dangerous consequences to the patient's health, and when no emergency exists making it impracticable to confer with him, it is manifest that his consent should be a prerequisite to a surgical operation."); Mohr v. Williams, 104 N.W. 12, 16 (Minn. 1905) ("[E]very person has a right to complete immunity of his person from physical interference of others, except in so far as contact may be necessary under the general doctrine of privilege; and any unlawful or unauthorized touching of the person of another, except it be in the spirit of pleasantry, constitutes an assault and battery."); *see also generally* RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 117–29 (1986) (surveying early informed consent cases based in the law of battery, assault, and trespass).

24 *See, e.g.*, Salgo v. Leland Stanford Jr. Univ. Bd. of Trs., 317 P.2d 170, 181 (Cal. Ct. App. 1957) ("A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the

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rationale for requiring informed consent emphasized patient autonomy—for example, on the New York Court of Appeals, Justice Cardozo famously declared that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body."[25] But professional, not patient, autonomy dictated the contours of the doctrine for many decades,[26] with courts adjudicating informed consent claims just like regular malpractice claims—by asking whether the defendant physician's disclosures to the patient comported with the customary practice of others in her profession.[27]

Beginning in the 1970s, the patient rights approach gained ground, eventually generating a roughly even split between jurisdictions that maintain the customary standard of care for informed consent claims and those that have abandoned the doctor-centered approach in favor of a patient-centered alternative.[28] Patient-centered jurisdictions ask what

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patient to the proposed treatment. Likewise the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent."); FADEN & BEAUCHAMP, *supra* note 23, at 129–30 (surveying cases indicating the emergence of negligence as the basis for informed consent claims).

25 Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).

26 In the 1980s, after the patient rights model had transformed informed consent doctrine, scholar Jay Katz noted that oft-quoted statements from Mohr, Pratt, and Schloendorff were susceptible to a misreading that exaggerated their basis in patient autonomy:

> *Pratt* and *Schloendorff* are memorable not for their pronouncements on self-determination—the egregious fact situations made such language unavoidable—but rather, for the necessity of having to remind physicians as late as this century's first and second decades of such elementary restraints on their professional authority in a democratic society. The physicians [in each case] had said nothing [to their patients] about their intentions. Since the justices only wished to impose on doctors an absolute duty to advise patients of *what* was going to be done, they had an easy time saying what they did. . . . The cases neither invited nor required a sophisticated examination of the relationship between disclosure and consent, on the one hand, and self-determination, on the other. The asking of questions such as "how much do patients need to know in order to give meaningful consent" and "what must be communicated to and understood by patients to insure self-decision making," was still decades away. . . . In the few cases in which courts noted the inadequacy of disclosure, they viewed it not as an interference with patients' liberty and self-choice but as an inadvertent lapse from good care and custody, for which physicians ought not to be severely blamed. Courts tended to be as oblivious as physicians to the idea that inadequate disclosure made meaningful consent impossible and thus constituted an interference with patients' liberty.

KATZ, *supra* note 15, at 52 (alteration added).

27 *See, e.g.*, Natanson v. Kline, 350 P.2d 1093, 1106 (Kan. 1960) (limiting the scope of the physician's duty to obtain informed consent "to those disclosures which a reasonable medical practitioner would make under the same or similar circumstances"); FADEN & BEAUCHAMP, *supra* note 23, at 129–31 (surveying the emergence of the physician-centered standard of care).

28 *See* Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429 app. A (surveying the even split between jurisdictions adopting the physician-based standard and those adopting the patient-based standard for informed consent).

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a reasonable patient would want to know to make a rational decision about medical treatment, rather than asking what information a reasonable doctor would customarily provide.[29] In 1974, Alexander Capron, a leading scholar of the patient rights movement, set forth the functions that might be served by this broader, patient-centered duty to inform, with a heavy emphasis on protecting individual autonomy, respect for human dignity, patient-driven decision-making, and consumer protection.[30] Capron also suggested that informed consent would involve the public generally in medicine, but the idea was that the public—as an aggregate of individuals rather than a body with uniquely collective interests—would be educated on a case-by-case basis via the experience of inhabiting the patient role.[31]

In either its physician-centered or patient-centered form, informed consent doctrine reflects a strong individualistic bias influenced by the private law regimes out of which it emerged. In the early case of *Mohr v. Williams*, for example, the Minnesota Supreme Court noted that

> [i]f the physician advises his patient to submit to a particular operation, and the patient weighs the dangers and risks incident to its performance, and finally consents, he thereby, in effect, enters into a contract authorizing his physician to operate to the extent of the consent given, but no further.[32]

Courts have blended two private law fields—tort and contract—to govern the formation and termination of the treatment relationship and the obligations of physician to patient within that relationship.[33]

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29 *Compare Natanson*, 350 P.2d at 1106, *with* Canterbury v. Spence, 464 F.2d 772, 786–87 (D.C. Cir. 1972) ("[T]he test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked."); *see also* FADEN & BEAUCHAMP, *supra* note 23, at 131–39 (surveying the emergence of the physician-centered standard of care, followed by the emergence of the patient-centered standard of care).

30 Alexander Morgan Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340, 365–76 (1974).

31 *Id.* at 376 ("A final function of informed consent in this model looks outside the physician-patient setting to an involvement of the larger society, since the obtaining of consent can be important for a doctor's, or a medical center's, public relations. Informed consent may also function beyond the area of public reputation and serve to increase society's awareness about human research. This phenomenon is particularly noticeable in the area of organ transplantation. The need to obtain consent from large numbers of potential donors for the removal of their kidneys after death has led to an extensive program of information about renal transplant programs. While the motivation for this information campaign was to recruit individual donors, it also enlightened the public at large about a new development in medicine. The general public thereby becomes an informed decisionmaker, able through legislative actions and the like to accelerate, halt, or alter transplant efforts according to its evaluation of the details disclosed." (footnote omitted)).

32 Mohr v. Williams, 104 N.W. 12, 15 (Minn. 1905).

33 *See, e.g.*, Saunders v. Lischkoff, 188 So. 815, 819 (Fla. 1939) ("A physician or surgeon, upon undertaking an operation or other case, is under the duty, in the absence of an agreement

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Building on the success of the patient-centered informed consent standard of care, some patient rights adherents have criticized the dominance of the doctor-centered customary standard of care for other kinds of malpractice claims.[34] One pioneering court sought to abandon the customary standard of care for negligent treatment decisions.[35] The Washington Supreme Court used the negligence calculus (a standard approach for all negligence claims other than professional malpractice) to reason that the minimal financial costs of performing a glaucoma screening test on all patients (rather than offering it only to patients who are at high risk) were outweighed by the benefits to individual patients like the plaintiff, who had suffered permanent vision lost as a result of a delayed diagnosis.[36] The court thus proclaimed that due care required ophthalmologists to perform glaucoma screening on all patients. As ophthalmologists in the state responded to the decision,[37] a few patients probably benefited from earlier detection of glaucoma, but on the whole, far more were probably subjected to a cascade of interventions with increasing cost and risk as a result of the screening test's high false positive rate when it is conducted on a low-risk population.[38]

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limiting the service, of continuing his attendance . . . so long as the case requires attention . . . . [T]he rule is that a physician is under the duty of treating a patient so long as the professional relation between them lasts. . . . In determining when his attendance may safely and properly be discontinued, a physician or surgeon is bound to use reasonable and ordinary care and skill. A physician who contracts without qualification to treat one person cannot excuse himself for failure to attend on the ground that another patient required his attention.").

34 *See, e.g.*, PARMET, *supra* note 12, at 197 ("Like the professional paradigm, [the patients' rights paradigm] was also concerned with questions of quality, but it sought to replace the professionally dominated standard of care with a more patient-centered one. In this effort, the patients' rights perspective was never triumphant. The common law of medical malpractice continues to apply a professionally based standard of care. Moreover, many state tort reform statutes have underscored that standard by requiring that malpractice claims be initially submitted to expert panels.").

35 *See* Helling v. Carey, 519 P.2d 981 (Wash. 1974).

36 *Id.* at 522 ("Although the incidence of glaucoma in the age range of the plaintiff is approximately one in 25,000, this alone should not be enough to deny her a claim. Where its presence can be detected by a simple, well-known harmless test, where the results of the test are definitive, where the disease can be successfully arrested by early detection and where its effects are irreversible if undetected over a substantial period of time, liability should be imposed upon defendants even though they did not violate the standard existing within the profession of ophthalmology.").

37 *See* Jerry Wiley, *The Impact of Judicial Decisions on Professional Conduct: An Empirical Study*, 55 S. CAL. L. REV. 345, 382–85 (1982) (demonstrating that the *Helling* decision had a statistically significant, though modest, impact on glaucoma testing in Washington).

38 The positive predictive value (PPV) of a screening test measures the proportion of people with positive test results who actually have the disease. *See* LEON GORDIS, EPIDEMIOLOGY 100–04 (5th ed. 2014). PPV is determined mostly by a test's specificity and the prevalence of the disease within the tested population. *Id.* Whereas the specificity (ability to correctly identify individuals who do not have the disease) and sensitivity (ability to correctly identify individuals who do have the disease) of a test are fixed, the positive predictive value and negative predictive value of the test vary depending on the population to which the test is applied. Unless the

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As health law's scope expanded beyond doctor-patient interactions to encompass regulation of relationships among patients, individual health care providers, institutional health care providers, and third party payers, individual interests continued to dominate the patient rights model. Over time, the individual interest in autonomous medical decision-making was reframed to encompass patient rights to quality and access. In the 1970s, many state legislatures adopted "Patients' Bills of Rights" to ensure autonomy, dignity, and quality of care in hospitals and other institutional settings.[39] Beginning in the 1980s, courts justified expansion of medical malpractice liability to reach hospitals and other institutional health care providers in terms of patients' subjective understanding that they go to a hospital not because it is a mutually convenient place for the doctor-patient interaction, but because they expect to receive medical care from the hospital itself, creating a hospital-patient treatment relationship.[40] In the Emergency Medical Treatment and Active Labor Act of 1986 (EMTALA),[41] Congress built on judicial expansion of common law duties of continuing attention within the context of an established treatment relationship by adopting statutory obligations for hospitals (and to a lesser extent, physicians) to provide non-discriminatory screening and stabilizing care for emergency medical conditions.[42] Both EMTALA and the common law

specificity of a test is perfect, the PPV will decrease with decreasing prevalence in the tested population. *Id.* Further complicating matters, specificity and sensitivity are often inversely related; high sensitivity is generally achieved at the expense of low specificity, and vice versa. Sensitivity is usually the greater concern and so many screening tests have less than ideal specificity. *Id.* This means that few people who actually have the disease will escape detection, but many healthy people will be mislabeled as having the disease, potentially subjecting them to more invasive follow-up tests. *Id.*

39 *See* Sage, *Should the Patient Conquer?*, *supra* note 9, at 1505 n.4.

40 *See, e.g.*, Williams v. St. Claire Med. Ctr., 657 S.W.2d 590 (Ky. Ct. App. 1983) ("Whether a patient enters a hospital through the emergency room or is admitted as a private patient by a staff physician, the patient is entering the hospital for only one reason . . . : 'Indeed, the sick leave their homes and enter hospitals because of the superior treatment there promised them.'" (quoting Univ. of Louisville v. Hammock, 106 S.W. 219 (Ky. Ct. App. 1907)). Thus, a hospital owes a duty to patients to enforce rules established for patient care. *See id.*

41 Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, § 9121(b), 100 Stat. 82, 164–67 (codified as amended at 42 U.S.C. § 1395dd (2012)). The Act was subsequently renamed the Emergency Medical Treatment and Labor Act to reflect amendments that imposed more rigorous provider obligations to patients in labor, regardless of whether they were in the "active" stage of labor. *See* Omnibus Budget Reconciliation Act of 1989, Pub. L. No. 101-239, §§ 6211(a) to 6211(h), 103 Stat. 2106, 2245.

42 Medicare-participating hospitals that offer emergency services are obligated to provide a medical screening examination (MSE) when a request is made for examination or treatment for an emergency medical condition (EMC), including active labor, regardless of an individual's ability to pay. § 1395dd(a). Hospitals are then required to provide stabilizing treatment for patients with EMCs. § 1395dd(b). If a hospital is unable to stabilize a patient within its capability, or if the patient requests, an appropriate transfer should be implemented. § 1395dd(c).

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duties on which it is loosely based are tied to narrowly defined needs for "emergency care."[43]

The patient rights model has also heavily influenced the adjudication of contract disputes between insureds and third party payers over coverage of medically necessary, non-experimental health care services.[44] To the extent that contract claims are not preempted by the Earned Retirement Income Security Act (ERISA),[45] courts routinely defer to professional autonomy where it serves the interests of individual patients seeking coverage of the services that they—and their providers—desire: "Coverage cases decided under state insurance law have consistently looked to plaintiffs' treating physicians for the best evidence of medical necessity, downplaying the significance of expertise regarding collective cost-effectiveness or even clinical benefit."[46]

This common judicial and legislative practice of deferring to the plaintiff's treating physician as the leading authority on what constitutes medically necessary care for the plaintiff—rather than as a party with a professional and economic interest in the patient's receipt of the services in dispute—has strong intuitive appeal, but it has led to several high-profile failures.[47] For example, by the time researchers had clearly established that high-dose chemotherapy with autologous bone marrow transplantation (HDC-ABMT) for patients with advanced breast cancer was medically ineffective, needlessly harming patients and wasting limited resources, "dozens of courts deciding individual claims had pilloried health insurers for ruling the treatment 'experimental' and hence not covered."[48] Legal scholar Nan Hunter, who has written critically of the patient rights model, situates the HDC-ABMT cases within a broader trend whereby "women's health advocates and AIDS patients brought a new level of militancy to the patient role, undertaking representation on their own behalf and on behalf of future patients with

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43 David A. Hyman, *Patient Dumping and EMTALA: Past Imperfect/Future Shock*, 8 HEALTH MATRIX 29, 32–34 (1998); David A. Hyman, *What Lessons Should We Learn from Drive-Through Deliveries?*, 107 PEDIATRICS 406, 407 (2001).

44 *See* Sage, *Relational Duties*, *supra* note 3, at 514–15.

45 29 U.S.C. §§ 1001–1461 (2012); Conkright v. Frommert, 559 U.S. 506 (2010) (granting judicial deference to ERISA plan administrators with regard to matters that the plan documents grant discretion to administrators to determine). For further discussion of ERISA preemption, see *supra* notes 69–72 and accompanying text.

46 Sage, *Relational Duties*, *supra* note 3, at 514–15.

47 *See, e.g.*, Mark A. Hall et al., *Judicial Protection of Managed Care Consumers: An Empirical Study of Insurance Coverage Disputes*, 26 SETON HALL L. REV. 1055 (1996); William M. Sage, *Judicial Opinions Involving Health Insurance Coverage: Trompe L'oeil or Window on the World?*, 31 IND. L. REV. 49 (1998).

48 Sage, *Relational Duties*, *supra* note 3, at 515; *see also* Michelle M. Mello & Troyen A. Brennan, *The Controversy Over High-Dose Chemotherapy with Autologous Bone Marrow Transplant for Breast Cancer*, HEALTH AFF., Sept. 2001, at 101.

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the same disease."[49] While privately insured patients sued their health plans for coverage of desired services, Medicaid recipients and providers sued states to enforce federal Medicaid law.[50] Private Medicaid litigation played an important role in ensuring that the program meets recipients' needs.[51] In the late 1980s, for example, private parties used Section 1983[52] and the Supremacy Clause[53] to get the life-saving drug AZT added to the Missouri Medicaid program's formulary for AIDS patients.[54]

In the patient rights model, "fairness [is] typically . . . articulated [in individual terms] as access to care largely on the basis of medical need, high quality of care, and respect for patient autonomy and dignity."[55] Across diverse health care contexts, courts typically view themselves as balancing the interests of patients, physicians, and third party payers. They have recognized the interests of parties outside the health care transaction only rarely, and only when they are identifiable individuals.[56] As a result, courts routinely neglect the population perspective, overlooking the interests of society as a whole.

B. *Patient Rights vs. Market Power*

> Beginning in the 1970s, new concerns about
>
> government's fiscal obligations under Medicare and Medicaid[,] . . . coupled with a growing institutionalist critique focusing on the lack of proper incentives in the health arena, . . . prompted a new type of public policy awareness in the health field . . . emphasiz[ing] the establishment of proper market

49 Hunter, *Rights Talk and Patient Subjectivity*, *supra* note 22, at 1526.

50 *See* Ann B. Lever & Herbert A. Eastman, *"Shake It Up in a Bag": Strategies for Representing Beneficiaries in Medicaid Litigation*, 35 ST. LOUIS U. L.J. 863 (1991).

51 *See id.*

52 42 U.S.C. § 1983 (2012).

53 U.S. CONST. art. VI, cl. 2.

54 Gene P. Schultz & Charles A. Parmenter, *Medical Necessity, AIDS, and the Law*, 9 ST. LOUIS PUB. L. REV. 379 (1990).

55 Rosenblatt, *Four Ages*, *supra* note 1, at 155.

56 *See, e.g.*, Davis v. Rodman, 227 S.W. 612 (Ark. 1921) (holding that a physician owed a duty to warn an identified third party of the risk of exposure to typhoid posed by spending time in close proximity to a patient); Hofmann v. Blackmon, 241 So. 2d 752 (Fla. Dist. Ct. App. 1970) (same for tuberculosis); Jones v. Stanko, 160 N.E. 456 (Ohio 1928) (same for smallpox); *see also* Tarasoff v. Regents of the Univ. of Cal., 551 P.2d 334 (Cal. 1976) (holding that a psychologist owed a duty to warn a third party of threats made by a patient where the third party was an identifiable individual).

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> incentives with the dual objectives of conserving public funds and curbing inflation in health care costs.[57]

Health law scholars and policy analysts from the law and economics school brought a fresh perspective to the field, characterizing the health care sector as just another "economic system, subject to economic principles," albeit a largely dysfunctional one.[58] Insurance insulates health care consumers from full payment, they argued, and information asymmetries hinder the market's ability to achieve efficient distribution of health care resources.[59]

Managed care emerged as part of a deregulatory, market-based effort to control costs, increase efficiency, and ensure quality. Market-power proponents argued that the best strategy for curbing rising costs was to empower private health plans to adopt utilization controls, restrictive provider networks, and financial risk-sharing arrangements between the payer and the provider.[60] From the advent of health maintenance organizations (HMOs) in the 1970s, these practices grew rapidly, eventually becoming ubiquitous among all private health plans, regardless of the label they use to market themselves.[61] In the 1990s, as part of a patient rights backlash against these practices, many states adopted "Patient Protection" legislation requiring private health plans to adhere to internal and external review processes for coverage denials, to ensure adequacy of provider networks, and to protect providers who wish to disclose to patients the financial incentives under which they operate.[62] Market power adherents disparagingly referred to these statutes as "provider protection acts," noting that they served professional autonomy at least as much as, if not more than, patient

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57 James F. Blumstein & Frank A. Sloan, *Redefining Government's Role in Health Care: Is a Dose of Competition What the Doctor Should Order?*, 34 VAND. L. REV. 849, 852 (1981) (footnote omitted).

58 *Id.*

59 *See id.*

60 *See, e.g.*, ALAIN C. ENTHOVEN, HEALTH PLAN: THE ONLY PRACTICAL SOLUTION TO THE SOARING COST OF MEDICAL CARE 81 (1980); ALAIN C. ENTHOVEN, HEALTH PLAN: THE PRACTICAL SOLUTION TO THE SOARING COST OF MEDICAL CARE (Beard Books 2002) (1980); Alain C. Enthoven, *The History and Principles of Managed Competition*, HEALTH AFF., Jan. 1993, at 24; Clark C. Havighurst, *Controlling Health Care Costs: Strengthening the Private Sector's Hand*, 1 J. HEALTH POL. POL'Y & L. 471 (1977).

61 *See, e.g.*, Russell Korobkin, *The Failed Jurisprudence of Managed Care, and How to Fix It: Reinterpreting ERISA Preemption*, 51 UCLA L. REV. 457, 462 (2003) (explaining the transition from a "fee-for-service" system to the "managed care" system).

62 David Mechanic, *The Managed Care Backlash: Perceptions and Rhetoric in Health Care Policy and the Potential for Health Care Reform*, 79 MILBANK Q. 35, 37–38 (2001); Robert F. Rich & Christopher T. Erb, *The Two Faces of Managed Care Regulation & Policymaking*, 16 STAN. L. & POL'Y REV. 233 (2005).

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safety and autonomy.[63] Indeed, market power advocates often present themselves as revealing the extent to which patient rights reforms serve primarily to increase the power of health care providers.[64] Market power proponents also advocated for applying antitrust regulation to health care providers in a (largely futile) attempt to restrict collective price-setting and empower private payers to push down reimbursement rates.[65]

Patient rights advocates harshly criticize the market power model:

> Someone who is ill and seeking help—unlike someone who is purchasing a pair of socks or a pound of sausages—is often vulnerable, certainly worried, sometimes uncomfortable, and frequently frightened. [The term] [c]ustomer, like the other obvious choices—clients, consumers, and users—erases something that lies at the heart of medicine: compassion and a relationship of trust.[66]

Patient rights adherents firmly reject the market power view of society as "an aggregation of individuals for whom the meaning of freedom is choice within the scarcity of each person's 'own' resources."[67] Some suggest that the rhetoric of market efficiency is used cynically to advance the interests of the wealthy and the politically powerful.[68]

Bitter battles over preemption by ERISA of private contract claims by insureds against their employer-based health plans epitomize the

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63 *See* David A. Hyman, *Regulating Managed Care: What's Wrong with a Patient Bill of Rights*, 73 S. CAL. L. REV. 221, 223 (2000).

64 Clark C. Havighurst & Barak D. Richman, *Distributive Injustice(s) in American Health Care*, LAW & CONTEMP. PROBS., Autumn 2006, at 7, 9–10 ("[There is] a seemingly well-meant but essentially destructive policy bias—assiduously cultivated by the health care industry and shared by many commentators and policy analysts—in favor of more and better health care for all with only nominal regard for how much it costs or who bears the burden. Because unwillingness to view health care as an economic good accords so well with illusions about health care in the public mind, it has been easy for industry and other interests to manipulate people's thinking about health care issues, both as consumers and as voters." (footnote omitted)).

65 *See, e.g.*, Barak D. Richman, *Antitrust and Nonprofit Hospital Mergers: A Return to Basics*, 156 U. PA. L. REV. 121 (2007).

66 Mark A. Hall, *The Legal and Historical Foundations of Patients as Medical Consumers*, 96 GEO. L.J. 583 (2008) (quoting Raymond Tallis, Commentary, *Do We Need a New Word for Patients? Leave Well Alone*, 318 BRIT. MED. J. 1756, 1757–58 (1999)).

67 Rosenblatt, *Four Ages*, *supra* note 1, at 196.

68 *See, e.g.*, Robert G. Evans, *Going for the Gold: The Redistributive Agenda Behind Market-Based Health Care Reform*, 22 J. HEALTH POL. POL'Y & L. 427, 427 (1997) (arguing that "[a]nalytic arguments for the potential superiority of hypothetical competitive markets are simply one" expression of "a natural alliance of economic interest between service providers and upper-income citizens to support shifting health financing from public to private sources" based on the facts that "[a] more costly health care system yields higher prices and incomes for suppliers," that "[p]rivate payment . . . cost[s] wealthier and healthier people less than finance from (income-related) taxation," and that "[w]ealthy and unhealthy people can purchase (real or perceived) better access or quality for themselves, without having to support a similar standard for others").

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clash between the patient rights and market power models. Pursuant to a series of Supreme Court cases, employees were barred from bringing coverage disputes in state courts.[69] Coverage disputes can only be adjudicated in federal court under ERISA's private cause of action, which does not provide for compensatory damages, and grants judicial deference to the determinations of private health plan administrators under most circumstances.[70] Market power adherents on the Court characterize the federal employee benefits statute as creating important incentives for employers to offer health benefits by protecting them from frivolous lawsuits.[71] The aloofness of conservative Justices—whose only concern is the economic bottom line—to the plight of sick and injured patients dependent on private health plans makes an easy target for patient rights adherents.[72]

The market power paradigm represents collectivist impulses to some extent. Market power adherents "instruct[] courts and regulators to value medical services only insofar as they boost biological functioning and to decide controversies so as to maximize collective welfare."[73] They lament the "pernicious influence" of "the ideal of the trustworthy, independent physician delivering the best possible medical

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69 *See, e.g.*, Conkright v. Frommert, 559 U.S. 506 (2010); Aetna Health Inc. v. Davila, 542 U.S. 200 (2004); Pegram v. Herdrich, 530 U.S. 211 (2000).

70 *See* John H. Langbein, *What ERISA Means by "Equitable": The Supreme Court's Trail of Error in* Russell*,* Mertens*, and* Great-West, 103 COLUM. L. REV. 1317 (2003) (explaining the Supreme Court's interpretation of the ERISA statute's grant of "appropriate equitable relief" to bar compensatory damages for injuries consequential to wrongful denial of benefits); Theodore W. Ruger, *The Supreme Court Federalizes Managed Care Liability*, 32 J.L. MED. & ETHICS 528, 529 (2004) ("ERISA's remedial provisions are so penurious that . . . complete preemption produces a legal regime that vastly under-compensates plan members who suffer a wrongful denial of care.").

71 *Aetna*, 542 U.S. at 215 (ERISA represents a "'careful balancing' between ensuring fair and prompt enforcement of rights under a plan and the encouragement of the creation of such plans" (quoting Pilot Life Ins. v. Dedeaux, 481 U.S. 41, 55 (1987))).

72 In *Aetna v. Davila*, the Court held that claims challenging "mixed eligibility and treatment decisions" made by health care providers working for an ERISA health plan may not be brought in state court under state law, leaving an ERISA claim as the only available avenue. *Id.* at 218–21 (quoting *Pegram*, 530 U.S. at 229). The majority opinion implied that patients could have paid out of pocket for the services their health care providers recommended, and then sought compensation for wrongfully denied benefits from their health plans, in which case ERISA's relief would have been adequate. *See id.* at 211 ("Upon the denial of benefits, respondents could have paid for the treatment themselves and then sought reimbursement through a[n ERISA] § 502(a)(1)(B) action, or sought a preliminary injunction . . . ."); Margaret Cyr-Provost, Comment, Aetna v. Davila*: From Patient-Centered Care to Plan-Centered Care, a Signpost or the End of the Road?*, 6 HOUS. J. HEALTH L. & POL'Y 171, 199–202 (2005) (documenting the "strong reactions" on both sides of the manage care debate to *Aetna v. Davila*).

73 M. Gregg Bloche, *The Invention of Health Law*, 91 CAL. L. REV. 247, 253 (2003) (describing "the new, economic paradigm for health care law" as "instruct[ing] courts and regulators to value medical services only insofar as they boost biological functioning and to decide controversies so as to maximize collective welfare").

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care for her or his individual patients."[74] But utilitarianism is distinct from communitarianism.[75] Although the collective action challenges that market power adherents identify are equally important to those who adopt a communitarian social justice perspective, market power adherents have little interest in mutual social obligations, distributive justice, or participatory parity.[76]

C. *Market Power Reframed as Health Consumerism*

Although many patient rights advocates are harsh critics of the market power model, the two are not entirely irreconcilable. They are, to some extent, melded in the health consumerism movement.[77] Health consumerism represents a reframing of the market power model, informed by some aspects of the patient rights model. As health law scholar William Sage put it, "[i]nformational asymmetries between physicians and patients have been cited since the 1960s as the principal reason why efficient markets seldom emerge in health care. . . . [B]ringing patients' knowledge closer to physicians' would seem to benefit both autonomy and competition."[78] Some patient rights advocates shifted from vindicating the interests of "dependent 'patients'" to championing the rights of "demanding 'consumers.'"[79]

Many health consumerism reforms have emphasized the use of information to empower patients and payers to exert pressure on providers to improve quality and lower costs.[80] For example, many state

74 Rosenblatt, *Four Ages*, *supra* note 1, at 156.

75 *See* Amitai Etzioni, *On a Communitarian Approach to Bioethics*, 32 THEORETICAL MED. & BIOETHICS 363 (2011) (contrasting utilitarianism with communitarianism).

76 Deborah A. Stone, *Managed Care and the Second Great Transformation*, 24 J. HEALTH POL. POL'Y & L. 1213, 1214–17 (1999) [hereinafter Stone, *Managed Care*] (suggesting that managed care as the "logical endpoint" of the market paradigm generated a backlash because it "respects no human bonds, shows no mercy, and has no use for kindness, loyalty, and other moral qualities of community").

77 *See* CONSUMER-DRIVEN HEALTH CARE: IMPLICATIONS FOR PROVIDERS, PAYERS AND POLICY MAKERS, at xvii (Regina E. Herzlinger ed., 2004); JOHN C. GOODMAN & GERALD L. MUSGRAVE, PATIENT POWER: THE FREE-ENTERPRISE ALTERNATIVE TO CLINTON'S HEALTH PLAN 18–27 (Michael D. Tanner ed., Cato Institute abr. ed. 1994).

78 Sage, *Relational Duties*, supra note 3, at 517 (citing Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 949 (1963)).

79 *Id.* at 508.

80 *See* Kristin Madison, *Regulating Health Care Quality in an Information Age*, 40 U.C. DAVIS L. REV. 1577, 1577 (2007) ("Recent technological innovations have promoted widespread access to health-related information . . . should prompt a shift of focus from market-displacing regulations to market-channeling and market-facilitating regulations that will help consumers take advantage of newly available information about quality."); William M. Sage, *Regulating Through Information: Disclosure Laws and American Health Care*, 99 COLUM. L. REV. 1701 (1999) [hereinafter Sage, *Regulating Through Information*]; Sage, *Relational Duties*, *supra* note

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patient protection statutes rely on mandatory reporting and public disclosure by health plans of the number of claims denied or appealed, the number of providers disenrolled, and other statistics, in order to channel consumers toward better performing plans.[81] Other reforms have focused on the use of financial incentives to encourage patients to be more cost-conscious. For example, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, which garnered bipartisan support from market power and patient rights adherents alike, created a federal tax subsidy for money contributed to (and earnings accumulated on) health savings accounts (HSAs).[82] Advocates of "consumer-driven" health care champion HSAs as a means to control costs and improve quality by giving consumer's "skin in the game"—increasing their sensitivity to cost and effectiveness by making them spend their own money for health care.[83]

Many patient rights adherents have been critical of health consumerism, questioning its efficacy and pointing to negative impacts on vulnerable patients.[84] Health consumerism melds market power with patient rights in ways that reinforce the individualistic focus of each.[85] It orients physicians "to goals defined by patients, . . . free[ing] the medical profession from ethical responsibilities beyond the satisfaction of individual demand."[86] Market channeling regulations that rely heavily on public disclosure and consumer choice undermine collective goals by "assign[ing] government a facilitative rather than constitutive role in health care."[87] William Sage views health consumerism not as a distinct model, but rather as a melding of the professional autonomy, patient rights, and market power models via their shared foundations in the individualistic tradition of bioethics.[88] This tradition "reconcile[s] resistance to commercial exploitation of patients by profit-seeking corporations with overall support for patient autonomy, including

3, at 502 ("[I]nformation disclosure has been a mainstay of health care regulation for the last decade.").

81 *See* Madison, *supra* note 80.

82 Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Pub. L. No. 108-173, § 1201, 117 Stat. 2066, 2071 (codified as amended at 26 U.S.C. § 223 (2012)); Richard L Kaplan, *Who's Afraid of Personal Responsibility? Health Savings Accounts and the Future of American Health Care*, 36 MCGEORGE L. REV. 535 (2005).

83 Kaplan, *supra* note 82.

84 *See* Karen Davis, *Consumer-Directed Health Care: Will It Improve Health System Performance?*, 39 HEALTH SERVS. RES. 1219 (2004); John V. Jacobi, *Consumer-Directed Health Care and the Chronically Ill*, 38 U. MICH. J.L. REFORM 531 (2005).

85 Sage, *Relational Duties*, *supra* note 3, at 508 (arguing that health consumerism "has reinforced the non-collective, relational nature of most health care regulation").

86 *Id.*

87 *Id.*

88 *Id.* at 504.

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freedom to participate in the marketplace" through "an ethics of consumer protection" focused on ensuring that patients have access to information and are protected from coercion.[89] "Consumer protection, however, focuses on individual decisionmaking [offering] few opportunities to articulate collective, social goals."[90]

As political philosopher Deborah Stone put it, "the rhetorical emphasis on power and control for consumers disguises the real impact of market reforms, which is primarily to reduce the collective assistance and medical services that citizens receive."[91] Stone "cast[s] a skeptical eye on consumer choice as a mechanism to enhance social welfare,"[92] but her approach does not fit neatly within the patient rights paradigm either. Rather, like William Sage,[93] Wendy Parmet,[94] Nan Hunter,[95] Rand Rosenblatt,[96] and Norman Daniels,[97] she joins me in emphasizing uniquely collective concerns and solutions.

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89 *Id.*

90 *Id.*

91 Deborah Stone, *The False Promise of Consumer Choice*, 51 ST. LOUIS U. L.J. 475, 476 (2007).

92 *Id.*

93 *See, e.g.*, Sage, *Over Under or Through*, *supra* note 3, at 1048 ("American health care has serious systematic flaws. We spend too much and receive too little. People who could stay well get sick. Many people who get sick have nowhere to go for care. These are not just individual interests; they are collective ones.").

94 *See, e.g.*, PARMET, *supra* note 12, at 193 ("By ignoring the interdependency of health and the importance of populations, American health law has helped establish a health care system that is unprepared both for public health emergencies and the more common, everyday threats that populations face.").

95 *See, e.g.*, Nan D. Hunter, *Risk Governance and Deliberative Democracy in Health Care*, 97 GEO. L.J. 1, 4, 48, 51 (2008) [hereinafter Hunter, *Risk Governance*] (proposing "risk governance as a new theoretical paradigm for understanding the health care system and thereby for understanding health law as a field;" suggesting conceptualizing "health policy . . . debates as occurring within a 'public,'" understood in the Habermasian sense as a cultural and social space, not a physical space, for dialogue about shared concerns[;]" and noting that although "[a]nalysts often link a discourse of risk managerialism to economic models and market-based initiatives that are focused on efficiency rather than on equity[,] . . . a discourse of risk could just as naturally be invoked to further strategies of inclusion and collective responsibility").

96 *See, e.g.*, Rosenblatt, *Conceptualizing Health Law*, *supra* note 14, at 491 ("[T]he concepts of social choice and social justice acknowledge and respect, and also influence and go beyond, individual consumption choices and individual self-determination.").

97 *See, e.g.*, DANIELS, MEETING HEALTH NEEDS FAIRLY, *supra* note 3, at 2 (focusing on "social obligations to promote population health and distribute it fairly through its distribution of health care" in ways that are "concerned with more than the benefits that individuals get from public health and medical interventions . . . [and] the distinctive relationship through which doctors help deliver those medical benefits to individuals who need them").

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II. HEALTH REFORM'S TRANSFORMATIVE INFLUENCE

Each of the models described in the previous Part continues to influence health law in countless ways, and each is evident in the Affordable Care Act's new framework for health governance. The "patient protection" label used in the Act's full title and the "patient centeredness" of some of its quality reforms reflect the influence of the patient rights model.[98] The ACA's quality reforms also reflect the market power model (at least, in its softened "health consumerism" form)—relying on public disclosure of information about the performance of health plans and health care providers to channel the market power of consumers.[99] On the other hand, the ACA's insurance underwriting reforms represent a reinforcement of state managed care laws' "cold shudder against the market paradigm."[100] Compared to state managed care laws, however, the ACA reforms represent a mutual aid approach to health care financing that expands far beyond the narrow confines of the consumer protection paradigm. The ACA's core compromise—continued reliance upon a fragmented array of private employer-based, exchange, and Medicaid plans—reflects the influence of the market power paradigm (competition among private health plans will improve efficiency) and the patient rights paradigm (individual health care consumers should remain free to choose among private health plans, rather than being covered by a government-run plan). But

98 *See* Sage, *Should the Patient Conquer?*, *supra* note 9, at 1505–06 ("Phrases used to express this desire [to liberate and empower the patient] include 'patient autonomy,' 'patients' rights,' 'patient self-determination,' 'patient preferences,' 'patient protection,' and, recently, 'patient-centeredness'—as in the 'patient-centered medical home.'" (footnotes omitted)). With regard to some ACA provisions, it is unclear whether "patient-centeredness" is a mere gloss. For example, the patient-centered outcomes research initiative authorized a nongovernmental institute, the Patient-Centered Outcomes Research Institute, to develop and fund comparative effectiveness research "to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions." 42 U.S.C. § 1320e(c) (2012). The patient-centeredness of this investment may come by way of two important limitations on the Institute's mandate: First, the ACA states that the Institute is not authorized "to mandate coverage, reimbursement, or other policies for any public or private payer." *Id.* § 1320e(j)(1)(A). Second, the Institute is expressly prohibited from "develop[ing] or employ[ing] a dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual's disability) as a threshold to establish what type of health care is cost effective or recommended." *Id.* § 1320e-1(e). For a good discussion of comparative effectiveness research and the Patient-Centered Outcomes Research Initiative, see Elizabeth Weeks Leonard, *Death Panels and the Rhetoric of Rationing*, 13 NEV. L.J. 872 (2013) [hereinafter Leonard, *Death Panels*].

99 *See* Hunter, *Intimations of Citizenship*, *supra* note 3, at 1969 n.59 ("PPACA itself contains the term 'educated health care consumer,' defined as 'an individual who is knowledgeable about the health care system, and has background or experience in making informed decisions regarding health, medical, and scientific matters.'" (citing 42 U.S.C. § 18024(e) (2012))).

100 Stone, *Managed Care*, *supra* note 76, at 1214.

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none of the available models is adequate to fully explain health reform's vision of the health system as serving uniquely *public*—as opposed to the mere aggregation of *private*—interests.

Commentators have attributed the individualistic bias in existing health law and policy models to a range of influences, including: the fact that they developed in the context of private law (i.e., tort and contract) governance of the health care system; the individualistic focus of the bioethics tradition; the segregation of public health practice, law, and ethics from the practice and ethics of medicine and the law of health care financing and delivery; and political influences that favor specialty-based rescue care that saves identifiable, rather than statistical, lives.[101] In this Part, I argue that these determinants of individualistic bias are already transforming in important ways as a result of health reform, making conditions ripe for the emergence of a new "health justice" model that emphasizes collective interests in health.

As part of a broader social transformation, health law is evolving from a field dominated by insular, private law governance of the relationships among patients, providers, and third party payers, to one dominated by public governance aimed at serving collective—as well as individual—interests. Our approach to health care financing is evolving away from actuarial fairness and toward mutual aid. Private health care providers are called upon to serve the public interest by responsibly allocating scarce resources; providing preventive services to forestall the need for costlier, downstream interventions; ensuring community immunity via vaccination; ensuring the continued effectiveness of antimicrobials by resisting patient demands for their indiscriminate use; and ensuring preparedness for disease outbreaks and other emergencies. These collective concerns are prompting an expansion in the scope of bioethics and increasing integration of health care and public health. Budgetary politics that favor rescue interventions and highly specialized care are softening somewhat in response to cost concerns, tax reforms that incentivize hospitals to take on a greater role in community prevention, and reimbursement reforms that aim to restrike the balance

101 DANIELS, MEETING HEALTH NEEDS FAIRLY, *supra* note 3, at 2 (linking the individualistic bias in health law and policy to the bioethics tradition, which, since its inception "has focused heavily on . . . the dyadic relationship between doctors and patients or research subjects, or on the potential benefits and risks for those individuals that arise from new [medical] technologies"); PARMET, *supra* note 12, at 196–97 (noting that the 'patients' rights paradigm was "[i]nfluenced by the constitutional rights movement of the 1960s and 1970s, the women's health movement, and the emerging field of bioethics, [and] it emphasized individual autonomy and the legal rights of patients" (footnote omitted)); Sage, *Relational Duties*, *supra* note 3, at 501–10, 519–21 (identifying health law's private law foundation, basis in bioethics, budgetary politics, and health consumerism as "sources of health law's relational bias" and pointing to the lack of integration between public health and health care as one among several areas in which there is a need for "collective goals and regulatory governance").

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between primary and specialty care. These developments simultaneously reflect the emergence of a proto-health justice model and pave the way for its full realization.

A. From Private Law to Public Law

In contrast to the European civil law approach, whereby health law has traditionally been studied and practiced in ways that follow a division between public law and private law components, "health law in the United States [has] coalesced intellectually and academically . . . as the doctrinal and public policy study of law that applies to the health care industry."[102] Thus, "the field continues to expand and evolve to follow changes in the industry and shifts in public policy."[103] However, this industry-centered approach—in which various models advance empowered patients (patient rights and health consumerism), providers (professional autonomy), or payers (market power and health consumerism) as the best hope for efficient, effective, and fair functioning of the health system—does not adequately take into account broader social concerns of the people, not as individual patients interacting with individual providers and payers, but as interdependent members of communities.

As the discussion in Part I demonstrates, health law initially emerged, somewhat unselfconsciously, as a field dominated by private law governance with regard to medical malpractice and formation of the treatment relationship. Increasingly, however, the rights and obligations of health care providers, payers, and patients are governed by state and federal statutes.[104] Along with increasing regulation by statute, recent decades have seen decreasing reliance on private rights of action within those statutes.[105] The Health Insurance Portability and Accountability

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102 Mark A. Hall, *The History and Future of Health Care Law: An Essentialist View*, 41 WAKE FOREST L. REV. 347, 353–54 (2006).

103 *Id.* at 354.

104 DeBoer, *supra* note 4, at 1242 ("[O]ver the last century, health care has evolved from being a matter of private ordering governed by private law to a hybrid blend of private and public ordering governed by both private and public law. During this period, pursuit of the public policy goals of increasing access to health care, reducing barriers, and creating an environment in which individuals can pursue their own goods have guided many of the most important developments in health care law and policy.").

105 Sage, *Relational Duties*, *supra* note 3, at 502–03 (suggesting that "[t]he decision whether or not to include a private right of action in a regulatory regime gives some indication—although one cannot control for partisan politics—of the priority given to enforcing relational claims" and noting that ERISA limited private rights of action to contractual damages only, EMTALA recognized a private right of action against hospitals, but not doctors, and the Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule does not include a private right of action).

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Act (HIPAA), which imposed community rating requirements and other reforms on group health insurance plans, did not include a private cause of action.[106] The Standards for Privacy of Individually Identifiable Health Information, known as the "Privacy Rule," promulgated by the Department of Health and Human Services (HHS), also relies solely on administrative enforcement,[107] though it does leave state statutory and common law causes of action intact.[108] As policymakers have been more reluctant to create statutory causes of action, courts have simultaneously become less receptive to implied rights of action and the use of mechanisms external to the substantive statute at issue (i.e., Section 1983 and the Supremacy Clause) for private suits to enforce federal Medicaid law against the states.[109]

The ACA follows this trend, expanding the role of public law in defining the rights and responsibilities of health care industry actors and eschewing reliance on private enforcement mechanisms.[110] Although the ACA makes some gains in bringing U.S. health policy into line with international norms regarding the "right to health,"[111] the notion of an individual right to basic health care services continues to have limited influence on American health law.[112] The omission of private enforcement mechanisms from the ACA likely made the bill more politically palatable in the short run. Counterintuitively, it may also strengthen the ACA's emphasis on equitable distribution of health care resources in the long run. Patient rights commentators rightly point out

106 *See* Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of 18 U.S.C., 26 U.S.C., 29 U.S.C., and 42 U.S.C.).

107 *See* 45 C.F.R. §§ 160, 164 (2015).

108 *See, e.g.*, R.K. v. St. Mary's Med. Ctr., Inc., 735 S.E.2d 715 (W. Va. 2012) (describing HIPAA's floor preemption with respect to state law claims).

109 *See* Armstrong v. Exceptional Child Ctr., Inc., 135 S. Ct. 1378 (2015) (holding that the Supremacy Clause does not confer a private cause of action to challenge state Medicaid reimbursement rates that are inconsistent with federal law); Douglas v. Indep. Living Ctr. of S. Cal., 132 S. Ct. 1204 (2012) (declining to decide whether Medicaid providers and recipients had a private right of action to enforce federal Medicaid law under the Supremacy Clause); Gonzaga Univ. v. Doe, 536 U.S. 273, 283 (2002) (rejecting the notion that the Court's precedents "permit anything short of an unambiguously conferred right to support a cause of action brought under § 1983" and noting that "implied right of action cases should guide the determination of whether a statute confers rights enforceable under § 1983").

110 DeBoer, *supra* note 4, at 1242 ("[T]he ACA put forward an array of access-increasing, barrier-reducing, and environment-altering initiatives that are predicated upon this hybrid blend of private and public ordering but that also amplify the role of public law in ordering relationships in the health care and health insurance settings.").

111 *See* Gwendolyn Roberts Majette, *Global Health Law Norms and the PPACA Framework to Eliminate Health Disparities*, 55 HOW. L.J. 887 (2012).

112 *See* TIMOTHY STOLTZFUS JOST, DISENTITLEMENT? THE THREATS FACING OUR PUBLIC HEALTH-CARE PROGRAMS AND A RIGHTS-BASED RESPONSE 23–109 (2003) (analyzing the ways in which American law and policy do and do not recognize a right to health care).

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that administrative enforcement is hindered by lack of funding and bureaucratic inefficiency, necessitating private enforcement as a gap-filler.[113] In some cases, however, private enforcement risks widening disparities between poorer, disenfranchised beneficiaries and those who are better off.[114] Private enforcement introduces the possibility that narrow interest-group advocacy might undermine the ability of public programs to pursue rational policies.[115] An individual right of access to essential health care goods and services might be a natural extension of the patient rights model. But in some countries, individual rights to health care have been used to undermine universal access as well as to strengthen it.[116] The erosion of private enforcement by the Court and Congress makes stronger administrative enforcement a pressing priority. HHS is stymied by limited resources and a sharply limited range of enforcement mechanisms (to put it mildly—the agency's only tool is to withdraw or threaten to withdraw Medicaid funds).[117]

B. *From Actuarial Fairness to Mutual Aid*

In a seminal article published in the midst of the Clinton-era push for health reform, Deborah Stone contrasted the principle of mutual aid, whereby "sickness is widely accepted as a condition that should trigger mutual aid," and the principle of actuarial fairness, which holds that "each person should pay for his own risk."[118] Although in many other contexts, sickness is understood as triggering mutual aid in the United States—we help our friends, neighbors, congregation members, and colleagues with meals, housework, and childcare—the same approach has not traditionally been applied to health care financing for the

113 *See, e.g.*, Nicole Huberfeld, *"Very Real Consequences" for States, Medicaid and Beyond*, AM. CONST. SOC'Y FOR L. & POL'Y: ACSBLOG (April 3, 2015), http://www.acslaw.org/acsblog/%E2%80%9Cvery-real-consequences%E2%80%9D-for-states-medicaid-and-beyond ("HHS relies on private actions to enforce the Medicaid Act, in part because the law has such a broad reach and the agency's staffing is so limited. In the Medicaid program, private enforcement is vital for fulfilling the goals of the law—especially 30(A), which requires on-the-ground observation for assessing states' payment adequacy.").

114 *See* Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 NOTRE DAME L. REV. 1413 (2011).

115 *See* Matthew C. Stephenson, *Public Regulation of Private Enforcement: The Case for Expanding the Role of Administrative Agencies*, 91 VA. L. REV. 93 (2005).

116 *See generally* THE RIGHT TO HEALTH AT THE PUBLIC/PRIVATE DIVIDE: A GLOBAL COMPARATIVE STUDY (Colleen M. Flood & Aeyal Gross eds., 2014).

117 *See* Nicole Huberfeld, *Bizarre Love Triangle: The Spending Clause, Section 1983, and Medicaid Entitlements*, 42 U.C. DAVIS L. REV. 413, 462–69 (2008) (proposing legislative reforms to expand the Medicaid enforcement toolbox).

118 Stone, *The Struggle for the Soul of Health Insurance*, *supra* note 2, at 289–90.

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majority of the population.[119] Stone argued that a competitive insurance industry fosters in people "a sense of their differences, rather than their commonalities, and their responsibility for themselves only, rather than their interdependence,"[120] leading to the fragmentation of "communities into ever-smaller, more homogeneous groups, . . . [and] to the destruction of mutual aid."[121]

The ACA's core compromise preserves the fragmentary, largely privatized system, rather than replacing it with a unified system.[122] Coverage and access are expanded via a hodge-podge of public insurance programs, regulation of private insurance plans, and direct public delivery of care. Undocumented immigrants are excluded from benefits, as are many poor people in states that rejected federal financing for Medicaid expansion. Nonetheless, the ACA represents a major shift in how health insurance is regulated.[123] Working within significant political constraints, the ACA's framers dramatically expanded access and fundamentally altered the basic business model of health insurance within its last bastion—the individual and small group markets.[124] By expanding Medicaid eligibility beyond traditional categories characterized as the "deserving poor," offering subsidies to offset the cost of private insurance for many additional low- and middle-income households, and prohibiting most forms of risk-based underwriting, the ACA represents a major shift from an actuarial fairness approach to health care financing to one premised largely on mutual aid.[125]

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119 *Id.*

120 *Id.* at 290.

121 *Id.* at 287.

122 Alice Noble & Mary Ann Chirba, *Individual and Group Coverage Under the ACA: More Patches to the Federal-State Crazy Quilt*, HEALTH AFF. BLOG (Jan. 17, 2013), http://healthaffairs.org/blog/2013/01/17/individual-and-group-coverage-under-the-aca-more-patches-to-the-federal-state-crazy-quilt.

123 *See* Wendy K. Mariner, *Health Insurance Is Dead; Long Live Health Insurance*, 40 AM. J.L. & MED. 195 (2014).

124 *See id.* Most of the ACA's reforms limiting risk-based underwriting (for example, guaranteed issue and renewability, community rating, and limits on pre-existing conditions exclusionary clauses) were already applicable to group health plans under HIPAA. *See, e.g.*, Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73, 75 (2005) (suggesting that while anti-discrimination provisions in HIPAA and other laws represent a mutual aid approach to some extent, "HIPAA's prohibitions of overt discrimination based on health status may have helped stimulate the development of forms of employer-provided coverage that discriminate more subtly against unhealthy persons").

125 Tom Baker, *Health Insurance, Risk, and Responsibility After the Patient Protection and Affordable Care Act*, 159 U. PA. L. REV. 1577, 1579–80 (2011) ("The Affordable Care Act embodies a social contract of health care solidarity through private ownership, markets, choice, and individual responsibility. While some might regard this contract as the unnatural union of opposites—solidarity on the one hand and markets, choice, and individual responsibility on the other—those familiar with insurance history will recognize in the Act an effort to realize the

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"[I]nsurance is a technology of governance which *invites* contemplation about issues of social responsibility because it requires resolution of questions about compassion and collective responses to suffering."[126] Public insurance programs are obviously social in nature, but private insurance is also characterized by an inherently social, collective dimension.[127] The Clinton-era push for sweeping health reform faltered because "a uniform national entitlement to health insurance came to be perceived as sacrifice rather than security, not only calling for increased financial contributions but threatening unacceptable constraints on individual choice and self-determination."[128] Obamacare nearly succumbed to the same framing, but didn't. Heated debate surrounding the ACA's passage and the Supreme Court litigation regarding its constitutionality prompted Americans to "realistically and squarely acknowledg[e] the unavoidable interconnectedness of the complex, United States health care system."[129] The ACA's survival alone indicates a shift toward viewing health care

dream of America's early insurance evangelists: a 'society united on the basis of mutual insurance.' Public ownership and pure, tax-based financing are technically easier and almost certainly cheaper routes to health care solidarity, but they come at a cost to the status quo that Congress was not prepared to pay." (footnote omitted) (quoting D.R. Jacques, *Society on the Basis of Mutual Life Insurance*, 16 HUNT'S MAG. & COM. REV. 152, 158 (1849))); Timothy Stoltzfus Jost, *A Mutual Aid Society?*, HASTINGS CTR. REP., Sept.–Oct. 2012, at 14. Although the ACA's underwriting reforms are largely premised on mutual aid, important exceptions honor the principles of actuarial fairness and personal responsibility. *See* Wendy K. Mariner, *Social Solidarity and Personal Responsibility in Health Reform*, 14 CONN. INS. L.J. 199 (2008); Lindsay F. Wiley, *Access to Health Care as an Incentive for Healthy Behavior? An Assessment of the Affordable Care Act's Personal Responsibility for Wellness Reforms*, 11 IND. HEALTH L. REV. 635 (2014) [hereinafter Wiley, *Access to Health Care*].

126 Hunter, *Risk Governance*, *supra* note 95, at 50 (citing Deborah A. Stone, *Beyond Moral Hazard: Insurance as Moral Opportunity*, 6 CONN. INS. L.J. 11, 16 (1999)).

127 Hunter, *Intimations of Citizenship*, *supra* note 3 ("[T]he essential functions and components of social insurance systems . . . exist in PPACA's structure."); Jeffrey W. Stempel, *The Insurance Policy as Social Instrument and Social Institution*, 51 WM. & MARY L. REV. 1489, 1495 (2010) ("In addition to functioning as contracts, products, and statutes, insurance policies exist as social institutions or social instruments that serve important, particularized functions in modern society—often acting as adjunct arms of governance and reflecting social and commercial norms.").

128 Sage, *Regulating Through Information*, *supra* note 80, at 1703.

129 Elizabeth Weeks Leonard, *What I Talk About When I Talk About Health Law*, 19 ANNALS HEALTH L. (SPECIAL EDITION) 9, 12 (2010); *see also* Leonard, *Death Panels*, *supra* note 98, at 874 ("One of the most beneficial effects of the otherwise rancorous national health care reform debate over the last few years is that we have become more informed as a nation about the realities of our health care system and all of its complexities. Lawmakers and the electorate better appreciate the interdependencies and policy choices that underlie our particular blend of public and private health care delivery. Perhaps building on that understanding, we can begin to confront the taboos of taxation and rationing."); David A. Super, *The Modernization of American Public Law: Health Care Reform and Popular Constitutionalism*, 66 STAN. L. REV. 873, 931 (2014) ("If our nation is willing to abandon legislation providing as important a service as health care to tens of millions of people, a denial of social responsibility will remain a politically credible response to human needs." (footnote omitted)).

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through the lens of mutual aid. Nan Hunter has suggested that the process of implementation and the "citizenship practices" that are entailed in signing up for insurance and pooling risks has the potential "to instantiate a new reciprocal covenant of mutual security, and . . . to enhance participatory self-governance."[130]

In addition to meeting individual needs for health care coverage, the ACA also aims to serve collective interests. As Hunter put it, the ACA

> creates a system of multiple mutual benefits among individual participants. The benefits to each person are unpredictable and contingent: Person A may reap only modest value from years of investment through the payment of premiums, but she is virtually certain to realize some significant benefits over time. In such a system, formal constraints are necessary to prevent free-rider problems.[131]

Furthermore, Hunter points to "[o]ther mutual financial benefits," including reduction of wasteful spending and transaction costs.[132] Beyond these financial benefits, she notes, "[t]here is also mutual benefit in the spillover of positive externalities that accrue to population health and thus to participants collectively."[133] The strengthening of our health care system and assurance of more universal access to it serve public health goals. With regard to non-communicable diseases like heart disease and diabetes, the hope is that access to care and improved disease management will reduce costs that would otherwise overwhelm our economy. Our interdependence is particularly unavoidable with regard to infectious disease threats. The emergence and proliferation of drug-resistant strains of infectious diseases such as tuberculosis and gonorrhea; diminishing community or "herd" immunity for vaccine-preventable diseases like measles and pertussis; and the emergence of new threats, such as Ebola virus, for which effective medical countermeasures are not available—have caused us to look at our health care system in new ways.[134]

130 Hunter, *Intimations of Citizenship*, *supra* note 3, at 1995–97.

131 *Id.* at 1995.

132 *Id.* at 1995–96.

133 *Id.* at 1996.

134 *Id.* ("[T]he [ACA] will strengthen social norms of solidarity and responsibility and extend a deeper consciousness of these norms to public discourse related to the health care system.").

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C. *From Patient-Centered Bioethics to Population Health Ethics*

The collective concerns that the ACA aims to address—and more—have also generated an expansion in the scope of bioethics. In step with the transformation of informed consent doctrine described in Part I, "the principle project of bioethics [since the 1950s] has been to convert the tradition of professional beneficence into a commitment to patient autonomy, ethical impulses that could nearly as easily have been channeled into social responsibility."[135] Some have suggested that the lack of attention to collective concerns in bioethics is at least partly attributable to the fact that modern bioethics came into being during a time when infectious diseases seemed to have been conquered by vaccines and antimicrobials.[136] As the United States and similarly situated countries experienced an epidemiological transition from infectious diseases to non-communicable diseases as the leading drivers of premature death and morbidity, "medical ethics began to concentrate less on the duties of doctors towards their patients individually and en masse, but increasingly . . . on the 'rights' of potential and actual patients."[137]

Sage argues that the individualistic focus in bioethics during the second half of the twentieth century on mediating the relationship between one doctor and one patient and demanding undivided loyalty of the former to the latter has "allow[ed] physicians to rationalize inattention to alternative sources of care, wasteful clinical decisions, and financial self-interest."[138] Beyond these economic concerns about fraud and waste, the impoverishment of professional medical ethics may also be implicated in the indiscriminate use of antibiotics,[139] and the

135 Sage, *Relational Duties*, *supra* note 3, at 503 (footnote omitted).

136 *See* Francis et al., *supra* note 5, at 307–08; Peter J. Lachmann, *Public Health and Bioethics*, 23 J. MED. & PHIL. 297, 298 (1998).

137 Lachmann, *supra* note 136, at 298.

138 Sage, *Should the Patient Conquer?*, *supra* note 9, at 1509.

139 *See, e.g.*, PARMET, *supra* note 12, at 200 ("Consider, for example, the application of informed consent to the treatment of a patient with a painful ear infection, the cause of which is not yet known. Should the patient be given an antibiotic? Under traditional informed consent law, the physician must inform the patient, based on either a reasonable patient or reasonable physician standard, of the medical risks and benefits to the patient of possible antibiotic therapy. Because there is no obvious and direct harm to specific third parties, the duty to warn [identifiable third parties] would not require the physician to warn the patient about the social consequences of antibiotic use."); Lachmann, *supra* note 136, at 298–99 ("[Antibiotic abuse] may seem to be justified by some 'ethical' doctrines. In some parts of the world the freedom of patients to have whatever drugs they wish to buy, and in others the right of a doctor to prescribe any drug which he thinks to be in the best interests of an individual patient, have taken precedence over any public health considerations. This has led to the use of new antibiotics in ways that are clearly inimical to preserving efficacy against resistant micro-organisms.").

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clustering of parents who refuse vaccination for their children.[140] As Peter Lachmann has argued, "[s]ome *mantras of bioethics*—beneficence, absence of maleficence, autonomy . . . are not necessarily congruent with the greatest benefit to the greatest number."[141]

In response to these concerns, however, the scope of inquiry in bioethics is already expanding. In a seminal 1994 article, legal scholar Sandra Johnson documented

> clear signs that point to significant change in the field of bioethics . . . includ[ing]: (1) a shift in the basic paradigm; (2) an increase in public debate, political compromise, and direct democracy; and (3) the reassertion of both physician and social control over decisionmaking, especially in regard to treatment decisions with noticeable allocative effects.[142]

Notably, Johnson predicted that "[i]n light of the new pressures on health care allocation, the individual rights approach probably will not survive as the dominant legally recognized method for treatment decisionmaking. The challenge to bioethics is to move beyond the bedside and beyond the physician-patient dyad."[143] Johnson also suggested that these pressures would "expand bioethics beyond the focus on the individual medical treatment decision" to address other concerns.[144]

Indeed, a growing number of physicians are asserting that the profession as a whole must face "the fact that physicians live and work in a medical commons and bear responsibility for it"[145] and that "a broader community focus and a shared responsibility are needed to build the ethical base for clinician management of health care

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140 Lachmann, *supra* note 136, at 300 ("For vaccination to be able to eradicate an infectious agent, the use of the vaccine has to be high—probably well over 90%—and this gives rise to problems of consent. There is the temptation for parents to wish to include their children in the few percent who do not need to be vaccinated, and who, therefore face no possible vaccine-related risk, while the disease is being eradicated by virtue of everybody else being vaccinated. However, this course, if at all widespread, will lead to the failure of the eradication campaign. . . . [Mandatory vaccination] conflict[s] with strong views of patient autonomy . . . . But the potential gain would be so large to public health that to reject such a course on ethical grounds would seem perverse.").

141 *Id.* at 302.

142 Sandra H. Johnson, *The Changing Nature of the Bioethics Movement*, 53 MD. L. REV. 1051, 1059–60 (1994).

143 *Id.* at 1062. Johnson cautioned that bioethics must move beyond the patient-physician dyad "while maintaining the patient-centered moral aspect of treatment decisions," and thus reasserting a patient centeredness that is in tension with the communitarian bioethics discussed below. *See id.*

144 *Id.* at 1061.

145 Christine K. Cassel & Troyen E. Brennan, *Managing Medical Resources: Return to the Commons?*, 297 J. AM. MED. ASS'N 2518, 2518 (2007).

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resources."[146] A communitarian strand has always been evident within the field of bioethics, but in response to collective concerns about stewardship of scarce resources, threats to the effectiveness of available medical countermeasures, and declining community immunity, it is asserting its importance in new ways.[147] As Amitai Etzioni explained in 2011:

> A communitarian approach to bioethics adds a core value to a field that is often more concerned with considerations of individual autonomy. Some interpretations of liberalism put the needs of the patient over those of the community; authoritarian communitarianism privileges the needs of society over those of the patient. Responsive communitarianism's main starting point is that we face two conflicting core values, autonomy and the common good, and that neither should be a priori privileged, and that we have principles and procedures that can be used to work out this conflict but not to eliminate it.[148]

Broader conceptions of bioethics are also reflected in judicial decision-making regarding access to treatment. The D.C. Circuit Court of Appeals, for example, struck a difficult balance between heart-wrenching individual needs and more abstract communal needs in *Abigail Alliance v. von Eschenbach*.[149] The full court overturned a three-judge panel's decision recognizing a substantive due process right of terminally ill patients to freedom from government interference with access to treatments that have not been approved by the FDA.[150] The court pointed to collective interests in generating accurate information about safety and efficacy through a regulatory process reliant upon clinical trials.[151]

The expanding emphasis within bioethics on collective concerns is occurring alongside the emergence around the turn of the twenty-first

146 *Id.* at 2519.

147 *See* KATZ, *supra* note 15; Jeffrey Blustein, *The Family in Medical Decisionmaking*, HASTINGS CTR. REP., May–June 1993, at 6 (discussing the conflict between autonomy and communitarianism within bioethics); Cassel & Brennan, *supra* note 145; Etzioni, *supra* note 75; Willard Gaylin, *Introduction: Autonomy, Paternalism, and Community*, HASTINGS CTR. REP., Sept.–Oct. 1984, at 5 (discussing the claims of the community versus the autonomous rights of the individual); Rosemary A. Stevens, *Public Roles for the Medical Profession in the United States: Beyond Theories of Decline and Fall*, 79 MILBANK Q. 327, 344–47 (2001) (urging the profession to redefine patients as groups, physicians as teams and organizations, and science as a "positive joint effort of numerous organizations and interests").

148 Etzioni, *supra* note 75, at 363.

149 *See* Abigail All. for Better Access to Developmental Drugs v. von Eschenbach, 495 F.3d 695 (D.C. Cir. 2007).

150 *See id.* at 700–01, 711–13.

151 *Id.* at 703, 712–14.

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century of public health ethics as a distinct field.[152] Ethicists focused primarily on public health, as opposed to health care, grapple with important questions that extend well beyond the doctor-patient dyad and focus particularly on the relationships between the individual and the state, and on the role of the common good. Dan Beauchamp began a seminal 1985 article on the "neglected tradition" of community in public health by asking: "What are the limits of government in protecting the health and safety of the public? . . . Can there be good reasons for public health paternalism in a democracy? Are health and safety individual interests, or also common and shared ends?"[153] Whereas bioethics focuses on patient autonomy within the treatment relationship, public health ethics is aimed at "advanc[ing] traditional public health goals [of improving the health of populations rather than of individuals] while maximizing individual liberties *and furthering social justice*."[154] Nancy Kass, a public health ethicist, proposes, for example, that

> data must substantiate that a [public health] program [under consideration] . . . will reduce morbidity or mortality; burdens of the

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152 *See, e.g.*, Daniel Callahan & Bruce Jennings, *Ethics and Public Health: Forging a Strong Relationship*, 92 AM. J. PUB. HEALTH 169, 169–70 (2002) ("As the field of public health becomes more prominent, so will the ethical issues associated with it. As more teaching and research are done on ethics in public health, it is important to begin a focused conversation within the field and between the field and others. What are the basic ethical issues of public health? What ethical orientations are most helpful in the clarification and resolution of these issues? How are ethical principles and concepts incorporated into decision making in public health agencies and programs? How adequately are the ethical dimensions of public health policy identified and debated? What are the chances for a fruitful collaboration between public health and bioethics, and what factors would be conducive to its success?" (footnote omitted)); Jonathan M. Mann, *Medicine and Public Health, Ethics and Human Rights*, HASTINGS CTR. REP., May–June 1997, at 6 (noting that "the shock of the worldwide epidemic of human immunodeficiency virus and AIDS, continuing work on diverse aspects of women's health, and challenges exemplified by . . . complex humanitarian emergencies" have highlighted "the long-standing absence of an ethics of public health" and the "human rights-related roles and responsibilities of physicians and other medical workers"); Marc J. Roberts & Michael R. Reich, *Ethical Analysis in Public Health*, 359 LANCET 1055, 1055 (2002) ("Medical ethics, focused on doctor/patient relationships, is widely discussed and taught to medical students. But a comparable field of public-health ethics is not as well developed to guide public-health practitioners. We seek to fill that gap by providing a method for describing and analysing the major ethical ideas invoked in discussions of public-health policy." (footnotes omitted)); James C. Thomas et al., *A Code of Ethics for Public Health*, 92 AM. J. PUB. HEALTH 1057, 1057 (2002) ("Medical institutions have been more explicit about the ethical elements of their practice than have public health institutions. However, the concerns of public health are not fully consonant with those of medicine. Thus, we cannot simply translate the principles of medical ethics to public health. In contrast to medicine, public health is concerned more with populations than with individuals, and more with prevention than with cure.").

153 Dan E. Beauchamp, *Community: The Neglected Tradition of Public Health*, *in* NEW ETHICS FOR THE PUBLIC'S HEALTH 57, 57 (Dan E. Beauchamp & Bonnie Steinbock eds., 1999).

154 Nancy E. Kass, *An Ethics Framework for Public Health*, 91 AM. J. PUB. HEALTH 1776, 1776 (2001) (emphasis added).

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> program must be identified and minimized; the program must be implemented fairly and must, at times, minimize preexisting social injustices; and fair procedures must be used to determine which burdens are acceptable to a community.[155]

D. *From Treatment to Prevention*

The impoverishment of bioethics with regard to collective concerns is intimately intertwined with the longstanding segregation of health care from the discipline of public health.[156]

> Public health is the societal approach to protecting and promoting health. Generally through social, rather than individual, actions, public health seeks to improve the well-being of communities. By maintaining a safe water supply, immunizing schoolchildren, or engaging in epidemiologic research, public health seeks to ensure societal conditions under which people can lead healthier lives, minimizing threats to our health "that can be averted or lessened only through collective actions aimed at the community."[157]

Public health *law* is often described as a distinct (and often neglected) sub-discipline within health law. As Lawrence Gostin and I define it in our foundational treatise:

> Public health law is the study of the legal powers and duties of the state to assure the conditions for people to be healthy (to identify, prevent, and ameliorate risks to health in the population) and the limitations on the power of the state to constrain the autonomy, privacy, liberty, proprietary, or other legally protected interests of individuals for the common good. The prime objective of public health law is to pursue the highest possible level of physical and mental health in the population, consistent with the values of social justice.[158]

Unlike the law of health care delivery and financing, public health law is intrinsically focused on the common good, tempered by limits based on individual autonomy. Indeed, Sage has suggested that one factor contributing to the individualistic focus of modern bioethics might be the fact that "'[p]ublic' health law evolved separately [from health care

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155 *Id.*

156 Cassel & Brennan, supra note 145, at 2518 ("In the United States, this disconnect between responsibility over the management of resources and responsibility to the individual patient is made even greater by the historical disconnect between the public health sectors and the world of medical practice.").

157 Kass, *supra* note 154, at 1776 (footnote omitted).

158 LAWRENCE O. GOSTIN & LINDSAY F. WILEY, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT 4 (3d ed. 2016).

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law] as 'public health law' . . . [with] little connection to the medical profession or to the large and expensive institutions that supply and fund it."[159]

In the early twenty-first century, health care and public health are each under pressure to reintegrate. Policymakers and private health plans facing escalating health care costs are increasingly interested in community prevention as a strategy for reducing the need for more expensive disease management in the long run. Medicaid programs and private health plans are adopting financial incentives and wellness programming to encourage healthier behaviors, and some employers are changing the work environment to promote employee health.[160] At the same time, underfunded state and local health departments are turning to private health care providers to meet public health needs. Sequestration, coming in the wake of state budget cuts, has forced many public health departments to reduce their services, including health care screenings, immunizations, maternal and child health care, and smoking cessation.[161] When the District of Columbia Department of Health lost federal funding for its infant-mortality reduction program—which uses community outreach workers to identify new and expectant mothers and connect them with home visits from nurses and other services—officials pointed to the expansion of insurance coverage due to health reform and suggested that private health care providers could meet the needs of the community.[162]

The integration of health care and public health goals is evident in the ACA.[163] In addition to increasing public and private insurance

159 Sage, *Relational Duties*, *supra* note 3, at 502.

160 For a review of employee and Medicaid wellness programs, and a critique of behavior-focused incentives, see Wiley, *Access to Health Care*, *supra* note 125.

161 *See* JEFFREY LEVI ET AL., TR. FOR AM.'S HEALTH, INVESTING IN AMERICA'S HEALTH: A STATE-BY-STATE LOOK AT PUBLIC HEALTH FUNDING AND KEY HEALTH FACTS (2014) (surveying federal, state, and local budget cuts and reporting that 48% of local health departments cut services in at least one program area in 2012); Kim Krisberg, *Budget Cuts Straining Capacity of Public Health Departments: Services in Demand*, NATION'S HEALTH, May–June 2010, at 1.

162 *See* Mike DeBonis, *D.C. Government's Infant-Mortality Program Eyed for Cuts as Mayor Touts New Initiative*, WASH. POST (Sept. 29, 2014), https://www.washingtonpost.com/local/dc-politics/dc-governments-infant-mortality-program-eyed-for-cuts-as-mayor-touts-new-initiative/2014/09/29/5b1fe058-47e7-11e4-891d-713f052086a0_story.html ("[E]ven if the direct federal funding is lost, the city will do what it can to prevent a lapse in services for mothers and infants as efforts shift to community providers and other organizations outside the government. . . . One development prompting the changes . . . was the implementation of federal health-care reform, which has resulted in more families being covered by private insurance or Medicaid.").

163 *See* Gwendolyn Roberts Majette, *PPACA and Public Health: Creating a Framework to Focus on Prevention and Wellness and Improve the Public's Health*, 39 J.L. MED. & ETHICS 366 (2011) [hereinafter Majette, *PPACA and Public Health*] (documenting the legislative history supporting integration of health care and public health as among the ACA's goals).

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coverage, the ACA seeks to improve the quality of coverage. Preventive care was a particular focus for the law's drafters. Minimum benefit standards—called Essential Health Benefits—emphasize preventive care.[164] But another, initially more obscure provision of the health reform law is being used more heavily by federal regulators to expand meaningful access to preventive care.[165] The ACA mandates that private health plans provide "first-dollar" coverage for preventive services that are recommended by the U.S. Preventive Services Task Force and other specified groups.[166] Privately insured individuals can obtain these services (including vaccinations and screening tests) without being subject to a deductible, co-payment, or co-insurance.[167] The ACA's explicit focus on public health and community-level prevention (and not merely preventive clinical care for individuals) represents a shift in focus on collective concerns.

The ACA also includes incentives aimed at increasing the role health care providers and payers play in population-oriented community prevention. Prompted by the ACA's modification of community benefit requirements attached to their tax-exempt status,[168] non-profit hospitals are engaging in community needs assessments that have the potential to address the social determinants[169] of population health, rather than focusing more narrowly on charity care and debt collection practices.[170] Along the same lines, some of the performance

164 The ACA obligates private health plans offered on subsidized Health Insurance Exchanges, as well as privatized Medicaid "benchmark" plans to provide an Essential Health Benefit package, including the following ten categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services, and chronic disease management; and pediatric services, including oral and vision care. 42 U.S.C. § 300gg–6(a) (2012). In 2013, HHS opted not to define the essential health benefits package in more detail, ceding its authority to the states to specify which services are required following a benchmark approach. *See* Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12834 (Feb. 25, 2013) (codified at 45 C.F.R. §§ 147, 155, 156 (2015).

165 *See id.* § 300gg-13(a); 45 C.F.R. § 147.130 (2015).

166 *See* § 300gg-13(a).

167 *See id.*; 45 C.F.R. § 147.130 (2015).

168 I.R.C. § 501(r) (2012); Additional Requirements for Charitable Hospitals, 77 Fed. Reg. 38148 (June 26, 2012) (codified at 1 C.F.R. § 1 (2015)).

169 For an exposition of the social determinants of health, see SOCIAL DETERMINANTS OF HEALTH (Michael Marmot & Richard G. Wilkinson eds., 2d ed. 2005).

170 MARTHA H. SOMERVILLE ET AL., HILLTOP INST., HOSPITAL COMMUNITY BENEFITS AFTER THE ACA: COMMUNITY BUILDING AND THE ROOT CAUSES OF POOR HEALTH 5 (2012) ("National health reform will present nonprofit hospitals with unique opportunities to enhance their upstream investments in health—investments that create conditions that enhance health and wellbeing before illness occurs. . . . 14 million currently uninsured Americans are expected to gain access to health coverage in 2014. As a result, it is likely that the demand for free care will lessen, presenting nonprofit hospitals with the opportunity to shift a portion of their

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criteria adopted pursuant to Medicare "pay for performance" initiatives reflect collective, rather than purely individual concerns.[171] Under the Hospital Value-Based Purchasing Program, incentive payments for hospitals are conditioned on a wide range of performance measures, including the percentage of patients who are assessed for influenza immunization and then vaccinated (if medically indicated), and process-based measures aimed at reducing hospital acquired infections (such as removal of post-operative urinary catheter within one or two days of surgery) and related outcome measures (such as central line-associated bloodstream infections)[172] could play a role in addressing drug resistance.[173] Under the Medicare Hospital Acquired Condition Reduction Program, twenty-five percent of hospitals—those with the highest rates of select hospital acquired infections and other iatrogenic conditions such as falls and bedsores—are penalized by having their Medicare reimbursements docked by one percent across the board for the fiscal year.[174] These approaches to paying on a curve are intended (like public reporting) to foster a "race to the top" among hospitals.

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community benefit investments from the provision of free and discounted care to activities that address the root causes of poor health." (footnote omitted)); Jessica Berg, *Putting the Community Back into the "Community Benefit" Standard*, 44 GA. L. REV. 375 (2010); Stephen M. Shortell et al., *The Contribution of Hospitals and Health Care Systems to Community Health*, 30 ANN. REV. PUB. HEALTH 373 (2009).

171 In 2008, Sage questioned

> [w]hether "value," "quality," and "performance" are to be judged by individual or by collective criteria. . . . What will the next generation of pay-for-performance represent? Pay for physician loyalty to individual patients, based on subjective satisfaction, accessibility of desired treatment, and individual health outcomes? Or pay for compliance with cost-effective best practices and population-based disease prevention and lifestyle modification that improves society's productivity and reduces its disease burden? If the latter, how will these practices be selected and how will the results be measured? This choice is more than a technical one. It goes to the heart of assessing health care in individual relational versus collective regulatory terms.

Sage, *Relational Duties*, *supra* note 3, at 516.

172 Samuel K. Peasah et al., *Medicare Non-payment of Hospital-Acquired Infections: Infection Rates Three Years Post Implementation*, 3 MEDICARE & MEDICAID RES. REV. E1 (2013), https://www.cms.gov/mmrr/Downloads/MMRR2013_003_03_a08.pdf (finding that implementation of the Medicare pay for performance initiative was associated with a reduction in vascular catheter-associated infections and catheter-associated urinary tract infections).

173 Hospitals are ideal breeding grounds for drug-resistance because of the high concentration of seriously ill patients treated with antimicrobials. One patient might come to the hospital with an infection or a non-symptomatic colonization acquired in the community. That infection can then spread rapidly via health care workers and contaminated surfaces and equipment. *See* GOSTIN & WILEY, *supra* note 158, at 383–88.

174 Jordan Rau, *More Than 750 Hospitals Face Medicare Crackdown on Patient Injuries*, KAISER HEALTH NEWS (June 22, 2014), http://kaiserhealthnews.org/news/patient-injuries-hospitals-medicare-hospital-acquired-condition-reduction-program.

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In subtle ways that are vulnerable to repeal, manipulation, and abuse by financially powerful interests, the ACA also seeks to restrike the balance between primary care and specialty care in reimbursement policies. In spite of evidence that primary care has a far greater impact on population health, specialty-based, "rescue" care dominates public investment in health care in the United States.[175] Specialty health care providers sell patients on the concept of "customized care"—whether in the form of concierge primary care practices in which a physician is available for long talks with wealthy patients about their health status, or personalized cancer treatment.[176] Patients often prefer to seek treatment from over-qualified (and well-reimbursed) specialists, rather than from primary care doctors, even in cases where treatment outcomes between the two groups of providers are similar.[177] Primary care doctors make up less than one-third of practicing physicians in the United States;[178] the inverse of the ratio found in many European countries with lower health care expenditures and better health outcomes.[179] Public investments in medical technologies, goods, and services, are more easily captured by a defined and politically powerful constituency than investments in prevention.[180]

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175 Sage, *Relational Duties*, *supra* note 3, at 505 ("[P]reventive care is not as compelling politically as treatment of manifest disease because its effects are less salient.").

176 Charles E. Dean, *Personalized Medicine: Boon or Budget-Buster?*, 43 ANNALS PHARMACOTHERAPY 958, 958–60 (2009); Sage, *Should the Patient Conquer?*, *supra* note 9, at 1510 ("The apparent need for customized treatment . . . discourages standardization and therefore efficiency.").

177 *See, e.g.*, Timothy S. Carey et al., *The Outcomes and Costs of Care for Acute Low Back Pain Among Patients Seen by Primary Care Practitioners, Chiropractors, and Orthopedic Surgeons*, 333 NEW ENG. J. MED. 913 (1995) (finding that outcomes are similar for patients with low back pain whether they receive care from primary care practitioners, chiropractors, or orthopedic surgeons, while primary care practitioners provide the least expensive care for acute low back pain); Leiyu Shi, *Primary Care, Specialty Care, and Life Chances*, 24 INT'L J. HEALTH SERVICES 431 (1994) (finding that, among the medical care variables, primary care is the most significant variable related to better health status, correlating with lower overall mortality, lower death rates due to diseases of the heart and cancer, longer life expectancy, lower neonatal death rate, and decreased low birthweight, and suggesting that policymakers should reorient the medical profession from its current expensive, clinically based, treatment-focused practice to a more cost-effective, prevention-oriented primary care system).

178 AGENCY FOR HEALTHCARE RES. & QUALITY, PRIMARY CARE WORKFORCE FACTS AND STATS NO. 1: THE NUMBER OF PRACTICING PRIMARY CARE PHYSICIANS IN THE UNITED STATES (2014), http://www.ahrq.gov/sites/default/files/publications/files/pcwork1.pdf.

179 *See* Barbara Starfield, *Primary Care and Health: A Cross-National Comparison*, 266 J. AM. MED. ASS'N 2268 (1991); Barbara Starfield & Leiyu Shi, *Policy Relevant Determinants of Health: An International Perspective*, 60 HEALTH POL'Y 201 (2002); Barbara Starfield et al., *The Effects of Specialist Supply on Populations' Health: Assessing the Evidence*, HEALTH AFF., June 2002, at 201.

180 *See, e.g.*, Leonard, *Death Panels*, *supra* note 98, at 877 ("[I]n the 1960s, when kidney dialysis became available, there were not enough machines to treat all of the patients. Attempts to define relevant criteria, such as medical condition, age, educational background, economic status, and occupation, generated considerable controversy. To resolve the situation, in 1972,

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The Medicare Shared Savings Program initiated by the ACA offers financial incentives to Accountable Care Organizations (ACOs) "to foster change in patient care so as to accelerate progress toward a three-part aim: better care for individuals, better health for populations, and slower growth in costs through improvements in care."[181] The shift within the health care system toward greater emphasis on primary care, and all providers practicing "at the top of their licenses," motivated by the ACA's reimbursement incentives, has significant potential to soften the politics that favor downstream rescue care.[182] But more is required to better integrate health care and public health. "[T]he core concept envisions a local entity and a related set of providers, including primary care physicians, specialists, and hospitals that can be held accountable for the cost and quality of the entire continuum of care delivered to a defined population . . . ."[183] Although some kinds of specialist physicians are included in ACOs, primary care physicians are the key to the ACO model. Commentators have expressed hope that ACOs "might be the vehicle that finally elevates primary care to a status equal to specialty care, because primary care is the key to ensuring ACO revenue streams."[184]

Like all of the transitions described in this Part, the move upstream—by prioritizing preventive care and integrating health care with public health—is incomplete in a multitude of ways. The full realization of the potential these transitions hold faces a significant barrier in the form of the prevention paradox. The prevention paradox has hindered all manner of upstream prevention efforts, from vaccination[185] to environmental regulation, occupational safety and food

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Congress authorized Medicare coverage for all end-stage renal disease (ESRD) patients. Medicare coverage ameliorated the first-order supply limit, making dialysis available to every patient meeting the Medicare eligibility requirements. By increasing the supply of dialysis, the policy largely avoided the difficult second-order rationing decisions. To this day, ESRD is the only diagnosis-specific Medicare coverage category." (footnotes omitted)); Sage, *Relational Duties*, *supra* note 3, at 505 ("[P]reventive care is not as compelling politically as treatment of manifest disease because its effects are less salient.").

181 Donald M. Berwick, *Launching Accountable Care Organizations—The Proposed Rule for the Medicare Shared Savings Program*, NEW ENG. J. MED. (Apr. 21, 2011), http://www.nejm.org/doi/full/10.1056/NEJMp1103602.

182 *See* Sage, *Over Under or Through*, *supra* note 3, at 1046 ("[S]urprisingly little liberalization of practice rights has occurred in the United States despite the creation of a large pool of "mid-level" providers whose competence has been repeatedly demonstrated in research studies.").

183 Thomas L. Greaney, *Regulators as Market-Makers: Accountable Care Organizations and Competition Policy*, 46 ARIZ. ST. L.J. 1, 5–6 (2014).

184 *See, e.g.*, Beth Thomas Hertz, *ACOs Redefine Relationships with Specialists*, MED. ECON. (Mar. 25, 2013), http://medicaleconomics.modernmedicine.com/medical-economics/news/user-defined-tags/acos/acos-redefine-relationships-specialists?page=full.

185 Lachmann, *supra* note 136, at 299–300 ("Even where the prevalence of [a vaccine-preventable] disease and its severity may result in the saving of lives of between 1: 100 and 1:

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regulation.[186] The problem, of course, is that identifiable lives rescued by medical treatment generally trump the statistical lives saved by a preventive approach. We tend to view rescue of identifiable lives as a more pressing concern than prevention of harm to "statistical lives," even though prevention may be more cost-effective and more humane.[187]

III. "HEALTH JUSTICE": TOWARD A NEW MODEL FOR SECURING THE PUBLIC'S INTEREST IN AFFORDABLE, HIGH-QUALITY HEALTH CARE

As health law's focus has broadened from the individual doctor-patient encounter to encompass health care financing and access to care via insurance and protection of common resources (economic and otherwise), the individualistic professional autonomy, patient rights, market power, and health consumerism models are no longer adequate to address the increasingly social, collective nature of health law institutions, instruments, and norms. Collectivist impulses have been reflected, from time to time, in the establishment and reform of public insurance programs and regulation of private insurance and the treatment relationship.[188] And the patient rights model sometimes

1000 of those vaccinated, this risk benefit ratio does not necessarily impress the general public. Those who do not develop the disease and do not die from it are statistics and not identifiable human beings. On the other hand, an individual child who falls sick or dies as a consequence of vaccination is very much an identifiable individual whose picture can appear in the papers and whose parents can sue the vaccine company or health authorities. There is an important ethical dimension to achieving realistic and accurate perceptions of risk.").

186 *See* Lisa Heinzerling, Comment, *The Rights of Statistical People*, 24 HARV. ENVTL. L. REV. 189 (2000) (arguing that the use of cost-benefit analysis to evaluate and in many cases reject life-saving regulatory programs has been justified by framing life in statistical, rather than identifiable, terms).

187 Sage, *Should the Patient Conquer?*, *supra* note 9, at 1510 ("[P]olitical decisions regarding health-system design are dominated by what one might call the myth of the identified life. The 'rule of rescue' posits that humans will make much larger sacrifices to save those already in trouble than to reduce the statistical risk of future peril. In health policy, moreover, even prospective social choices tend to be guided by a mental image of ourselves or our loved ones facing a dreaded disease." (footnote omitted)).

188 *See, e.g.*, Nicholas Bagley, *Bedside Bureaucrats: Why Medicare Reform Hasn't Worked*, 101 GEO. L.J. 519 (2013) ("Congress's persistent failure to address weaknesses in Medicare's administrative structure has stymied a series of major reform efforts that have sought to make the program's physicians more attentive to the cost and quality of the medical care for which it pays. This dismal history suggests that crafting an effective internal law for Medicare will require Congress to refashion the program around private organizations with the capacity, incentives, and legitimacy to align the practice patterns of private physicians—its bedside bureaucrats—with federal priorities. Measured against that baseline, the set of Medicare reforms included in the Affordable Care Act is a disappointment. A more muscular, thoughtful, and sustained effort is needed."); Nicholas Bagley, *Medicine as a Public Calling*, 114 MICH. L. REV. 57, 60 (2015) ("In the last decades of the twentieth century, some of this economic

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accommodates a communitarian strand emphasizing collective concerns.[189] But the collectivist strand in health law too frequently loses out to the dominant—nearly exclusive—individualistic approach. What is needed is a new approach that expressly recognizes the public—alongside the patient, the provider, and the payer—as an important stakeholder and active participant in decisions about treatment, coverage, and allocation of scarce resources.[190]

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regulation gave way in the face of the resurgent belief that market forces, not state control, ought to guide the distribution of health-care services. But a durable strain of the law has always treated modern medicine as a public calling—even today. The fit is natural. Public utility regulation aims to address the sorts of problems in market ordering—supply imbalances, access restrictions, and abusive and discriminatory pricing—that have long afflicted the medical industry. Now that the Affordable Care Act (ACA) has eased public concerns about the uninsured, the serious economic challenges facing those with insurance are likely to become more salient. Should the ACA fail to remedy a number of disturbing practices in the medical marketplace, policymakers may find public utility regulation increasingly attractive." (footnote omitted)); Rosenblatt, *Health Care Reform and Administrative Law*, *supra* note 2 (analyzing hurdles encountered by legislative and administrative attempts to define redistributional social contracts in health care).

189 For example, in 2004, Rand Rosenblatt described what I have referred to as the patient rights model as

> the *modestly egalitarian social contract*[,] . . . [which] holds that patients and society as a whole, as well as physicians and other stakeholders, have legitimate rights and interests in the health care system. The role of law in this model is to achieve a fair resolution of conflicting interests, especially in the light of highly unequal information and power between patients and other actors. Given this model's egalitarian values, fairness has typically been articulated as access to care largely on the basis of medical need, high quality of care, and respect for patient autonomy and dignity. By the standards of the rest of the developed world, notably western Europe and Canada, the American social contract has been limited and uneven—hence the phrase "modestly egalitarian."

Rosenblatt, *Four Ages*, *supra* note 1, at 155. Rosenblatt's description reflects some emphasis on collective concerns, but his social contract model, by which he "refer[red] to statutes and judicial doctrines that seek to articulate an explicitly social or political, as distinguished from what is known as a professional or market, conception of fairness and good policy," *id.* at 161, was perhaps more prescriptive than descriptive. In his previous work, Rosenblatt articulated a collective vision for health law that closely resembles the health justice model I propose here. *See generally* Rosenblatt, *Conceptualizing Health Law*, *supra* note 14. Similarly, in 2010, Bill Sage cautioned that "[a] patient-centered system has benefits, but it also perpetuates and exacerbates gross inefficiencies and inequities in the health care system. Instead, the best response to the challenges of health care reform should be a collective one." Sage, *Should the Patient Conquer?*, *supra* note 9, at 1511.

190 For an account of how the public has historically been excluded from these decisions, see KATZ, *supra* note 15, at 30 ("This account of medicine's history as a political institution is intended to demonstrate that physicians' political and social philosophy about public health only gave more far-reaching expression to what they believed to be true for the more intimate interpersonal context: that lay persons, like patients, had little to contribute to medical decision making, that fundamental inequalities between doctors and the laity created an unbridgeable chasm."). *Cf.* JOHN COGGON, WHAT MAKES HEALTH PUBLIC?: A CRITICAL EVALUATION OF MORAL, LEGAL, AND POLITICAL CLAIMS IN PUBLIC HEALTH 1–2 (2012) ("[A]nyone concerned about health, and about whether, when, how, and why it gives rise to meaningful responsibilities, needs to address the question *what makes health public?* . . . Concern is not

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In a previous article, I explored a health justice approach to eliminating racial, ethnic, economic, geographic, and other social disparities in health, with an emphasis on centering the lived experience of socially marginalized groups; putting access to health care in its place as one among many social determinants of health; probing the effects of class, racial, and other forms of social and cultural bias on the design and implementation of measures to reduce health disparities; and supporting collective action grounded in community engagement and participatory parity.[191] Here, I shift my focus to articulate four key commitments of the health justice model as an alternative to existing models, or as a supplement to the patient rights model, for examining issues of health care quality and access.[192] First, the health justice model asserts the importance of collective interests, alongside individual interests, in decisions about medical treatment. Second, the health justice model emphasizes that available, affordable, accessible health care protects collective, as well as individual, interests. Third, because "upstream" community and primary prevention strategies have greater population-level impact, the health justice model prioritizes community and primary prevention strategies and integration of health care and public health. Fourth, the health justice model asserts the role of collective oversight through democratic governance—much in the same way that the market power model champions the role of private payers and market dynamics—in managing resources and securing common goods.

limited to (public) healthcare systems: the entire social and physical environments are the context of contemporary analysis of 'health law and ethics'[sic]. . . . There has been much consideration of questions such as the regulation of tobacco, alcohol, and food; resource allocation, especially within healthcare; containment and control of contagious diseases; bioterrorism; and climate change. All of these, and many other issues, are portrayed as public health problems, demanding public health solutions.").

191 *See* Wiley, *Health Law as Social Justice*, *supra* note 8.

192 Elsewhere, I have argued that a nascent health justice framework suggests three commitments for the use of law to reduce health disparities: First, to a broader inquiry that views access to health care as one among many social determinants of health deserving of public attention and resources. Second, to probing inquiry into the effects of class, racial, and other forms of social and cultural bias on the design and implementation of measures to reduce health disparities. And third, to collective action grounded in community engagement and participatory parity. *Id.* Here, my focus is broader in keeping with this Article's proposal of health justice as a model on par with the four existing health law models. Rather than describing the health justice model's approach to reducing health disparities here, I direct the reader to my previous examination of the topic.

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A. *Securing the Public's Interest in Decisions About Medical Treatment*

The Supreme Court's jurisprudence on abortion and the right to refuse unwanted medical care suggests that the Constitution safeguards treatment decisions as among "the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy."[193] This characterization of medical treatment decisions as exclusively personal, private matters has nearly irresistible intuitive appeal and figures prominently in both the professional autonomy and patient rights models. But there has always been a counter-narrative. The state's interest in preserving life and health has been legitimated and balanced against individual interests in the same line of cases.[194] Similarly, the state's interest in protecting the public's health and safety has often been held to outweigh the individual's right to refuse vaccination[195] or medical treatment[196] to reduce infectiousness or

193 Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 851 (1992); *see also* Washington v. Glucksberg, 521 U.S. 702 (1997) (upholding a ban on doctor-assisted suicide); Vacco v. Quill, 521 U.S. 793 (1997) (same); Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990) (upholding Missouri's requirement for clear and convincing evidence of a patient's wishes before withdrawing treatment from a patient in a persistently vegetative state).

194 *See, e.g.*, *Glucksburg*, 521 U.S. at 730 ("The State has an interest in preventing suicide, and in studying, identifying, and treating its causes."); *Vacco*, 521 U.S. at 808 ("New York's reasons for recognizing and acting on th[e] distinction [between refusing treatment and assisting a suicide]—including prohibiting intentional killing and preserving life; preventing suicide; maintaining physicians' role as their patients' healers; protecting vulnerable people from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards euthanasia—are . . . valid and important public interests . . . ."); *Casey*, 505 U.S. at 846 ("[T]he State has legitimate interests from the outset of the pregnancy in protecting the health of the woman and the life of the fetus that may become a child."); *Cruzan*, 497 U.S. at 280 ("Missouri relies on its interest in the protection and preservation of human life, and there can be no gainsaying this interest. . . . We do not think a State is required to remain neutral in the face of an informed and voluntary decision by a physically able adult to starve to death."). In a future project, I plan to explore the complex and potentially fraught relationship between public health communitarianism and communitarianism based on religious values, particularly in light of the Court's shifting rational basis jurisprudence.

195 *See, e.g.*, Prince v. Massachusetts, 321 U.S. 158, 166–67 (1944); Zucht v. King, 260 U.S. 174 (1922); Jacobson v. Massachusetts, 197 U.S. 11, 38 (1905); George v. Kankakee Cmty. Coll., No. 14-CV-2160, 2014 WL 6434152 (C.D. Ill. Nov. 17, 2014) (dismissing a claim that a vaccination requirement imposed on students in a public community college paramedic training program violated the First Amendment, the right to privacy, and substantive due process); Phillips v. City of N.Y., 27 F. Supp. 3d 310 (E.D.N.Y. 2014) (dismissing claims that denials of religious exemption violated the First Amendment, substantive due process, and equal protection); Caviezel v. Great Neck Pub. Sch., 739 F. Supp. 2d 273 (E.D.N.Y. 2010); Boone v Boozman, 217 F. Supp. 2d 938, 954 (E.D. Ark. 2002) (rejecting Plaintiff's argument that *Jacobson*, *Zucht*, and lower court precedents upholding mandatory vaccination "were decided on the basis of a declared health emergency involving smallpox, while in this case Hepatitis B presents no 'clear and present danger'"); People *ex rel.* Hill v. Bd. of Educ., 195 N.W. 95 (Mich. 1923).

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dangerousness. In all of these decisions, courts have acknowledged the impact of medical treatment decisions on common concerns.[197] In keeping with the individualistic focus of available models, health law scholars and advocates tend to emphasize the importance of patient autonomy to the detriment of state-protected, collective interests in the preservation of life and health. The health justice model would facilitate further exploration and more explicit articulation of the balancing that courts do, viewing individual and collective interests as equally relevant to health policy goals.

The common law doctrine of informed consent is perhaps the strongest expression of the patient rights model.[198] In keeping with the expanding emphasis in bioethics on collective concerns, however, legal scholar Wendy Parmet has proposed that informed consent doctrine can and should balance the public's interest—for example, in preserving the effectiveness of antimicrobials,[199] and protecting community immunity from vaccine-preventable diseases[200]—alongside individual interests in patient autonomy and professional beneficence. It might also accommodate collective interests in controlling costs by detecting disease early and ensuring that providers are practicing at the top of their licenses by incorporating provider obligations to inform patients regarding the economic consequences of proposed treatment and the availability of more economical alternatives. Informed consent

196 *See, e.g.*, Washington v. Harper, 494 U.S. 210 (1990) (upholding involuntary administration of antipsychotic medication where a prisoner was found to be dangerous to himself or others, treatment was in the prisoner's medical interest, and the provision for review by an administrative panel including medical professionals provided procedural due process); Reynolds v. McNichols, 488 F.2d 1378 (10th Cir. 1973) (upholding a mandatory physical examination, treatment, and detention of a person suspected of having a venereal disease); People *ex rel.* Baker v. Strautz, 54 N.E.2d 441 (Ill. 1944) (same); Rock v. Carney, 185 N.W. 798 (Mich. 1921) (upholding physical examinations, but only upon reasonable grounds); *In re* City of N.Y. v. Doe, 614 N.Y.S.2d 8 (App. Div. 1994) (upholding a continued detention for tuberculosis treatment based upon the fact that public health could not be protected by less restrictive means); *In re* City of N.Y. v. Antoinette R., 630 N.Y.S.2d 1008 (Sup. Ct. 1995) (finding clear and convincing evidence existed to detain a woman for treatment of tuberculosis based on her past non-compliance); Ronald Bayer & David Wilkinson, *Directly Observed Therapy for Tuberculosis: History of an Idea*, 345 LANCET 1545 (1995).

197 *See* sources cited *supra* notes 195–96.

198 *See supra* notes 21–28 and accompanying text.

199 *See* PARMET, *supra* note 12, at 200 ("From a population perspective . . . the traditional approach to informed consent law is unsatisfactory. Although the risk that the overuse of antibiotics poses to any single patient may be trivial, the societal consequences of frequent misuse are far from trivial. . . . [O]nce we recall that individual autonomy properly understood depends on the risks and opportunities that individuals have within their populations and environments, we might conclude that the contemporary approach to informed consent law, which emphasizes the physician's duty to warn only about risks to the patient, fails to protect that patient's own autonomy.").

200 *See id.* at 201 ("[A] population perspective . . . would require manufacturers and physicians to provide patients with information about the social benefits of vaccination.").

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doctrine's championing of the patient as ultimate arbiter of appropriate medical treatment has always been subject to common law and regulatory restraints, even for patients who are willing to pay. For example, licensing regulations restrict patients from obtaining certain services from providers deemed unqualified by regulators.[201] The health law doctrine of futility—codified by statutes in many jurisdictions—also places limits on the care that a patient or proxy can demand, even if they are able to pay.[202] The notion that requested care would be scientifically or ethically futile (defined in varying terms) has been used to withdraw life-sustaining treatment for patients in a persistent vegetative state (or those who are brain dead), but it could also be applicable to patients' demands for medically inappropriate or unnecessary treatments, such as antibiotics for patients who do not have a bacterial infection. The health justice model would embrace the balancing between individual and collective interests represented in these doctrinal tensions, highlighting it as a common thread throughout health law and policy.

In practice (and by design in many cases), licensing and futility laws may reflect deference to professional autonomy,[203] rather than collective interests, but limits on patients' demands for treatment (again, even where they have the funds to buy it without the assistance of government or private insurance) have also been articulated in contexts that go beyond conflicts between the doctor and patient. In *Abigail Alliance v. von Eschenbach*, for example, the Court of Appeals for the

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201 *See, e.g.*, Madison, *supra* note 80 ("Perhaps the most visible and straightforward example of a market-displacing regulatory approach to addressing health care quality issues is medical licensure. . . . [I]f the prohibition against unauthorized practice is enforced, patients will be unable to contract with providers who do not fulfill licensure requirements. . . . To the extent that the board sanctions physicians by suspending, restricting, or revoking medical licensure, professional discipline precludes future market transactions—the delivery of health care services—between the sanctioned physician and patients.").

202 *See, e.g.*, UNIF. HEALTH-CARE DECISIONS ACT § 7(f) (UNIF. LAW COMM'N 1993) ("A health-care provider or institution may decline to comply with an individual instruction or health-care decision that requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health-care provider or institution."); TEX. HEALTH & SAFETY CODE ANN. § 166.046 (West 2010) (setting forth procedures triggered when "an attending physician refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient" based on a decision that the requested life-sustaining treatment is inappropriate); *see also* Eric Chwang, *Futility Clarified*, 37 J.L. MED. & ETHICS 487 (2009) (surveying the divide between legislative and private governance approaches that set forth a substantive definition of futility and those that abandon substantive definitions in favor of defining procedural mechanisms to resolve disputes between patients or families and providers).

203 *See, e.g.*, Lewis A. Grossman, *The Origins of American Health Libertarianism*, 13 YALE J. HEALTH POL'Y L. & ETHICS 76 (2013) (discussing the rise of medical licensing laws and tying their development to professionalism concerns); Robert M. Taylor & John D. Lantos, *The Politics of Medical Futility*, 11 ISSUES L. & MED. 3 (1995) (discussing the historical development of the futility doctrine and tying it to respect for professional ethics and judgment).

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District of Columbia Circuit rejected the argument that patients with terminal illnesses had a constitutionally protected liberty interest in accessing treatments that had not yet been approved by the FDA, even where some safety testing had been completed and a physician was willing to prescribe and administer them.[204]

The result in *Abigail Alliance* was contrary to what many patient rights adherents and libertarians would have preferred.[205] A more optimistic view of the decision, taken by Elizabeth Weeks Leonard, exemplifies the health justice model's emphasis on collective interests.[206] Leonard identifies a collectively held right to health, distinct from individual rights to health or health care, which she argues justifies limits on access to experimental treatments for the purpose of securing collective interests in the production of scientific knowledge and the development of proven therapies:

> The public health right contemplates that the public, as a body, merits protection from interference by individual members of society. In the case of access to experimental drugs, the potential harm to so many other patients who also await the promise of a cure or benefit from scientific developments, justifies the decision to deny access to experimental drugs to currently terminally ill patients.[207]

B. *Securing the Public's Interest in Access to Affordable Health Care*

Throughout our intense public debate over health reform, various justifications for pursuing universal access to health care have been advanced. Most of these are primarily individualistic—including the notion of access to health care as an individually held human right. But

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204 Abigail All. for Better Access to Developmental Drugs v. von Eschenbach, 495 F.3d 695, 711–13 (D.C. Cir. 2007).

205 *See, e.g.*, John A. Robertson, *Controversial Medical Treatment and the Right to Health Care*, HASTINGS CTR. REP. Nov.–Dec. 2006, at 15, 15; Eugene Volokh, Essay, *Medical Self-Defense, Prohibited Experimental Therapies, and Payment for Organs*, 120 HARV. L. REV. 1813 (2007).

206 *See* Elizabeth Weeks Leonard, *The Public's Right to Health: When Patient Rights Threaten the Commons*, 86 WASH. U. L. REV. 1335 (2009) [hereinafter Leonard, *The Public's Right to Health*]; *see also* Peter D. Jacobson & Wendy E. Parmet, *A New Era of Unapproved Drugs: The Case of* Abigail Alliance v. Von Eschenbach, 297 J. AM. MED. ASS'N 205, 205 (2007).

207 Leonard, *The Public's Right to Health*, *supra* note 206, at 1384. For Leonard, "[t]he public health right is grounded in the 'old' public health, which aims at collective action problems, not the 'new' public health, which aims broadly to ensure the 'underlying determinants' for people to be healthy." *Id.* The health justice model I propose would not necessarily draw the same line between "new" and "old" public health, particularly with regard to integration of primary prevention and community prevention to reduce non-communicable disease risks. *See generally* Lindsay F. Wiley, *Rethinking the New Public Health*, 69 WASH. & LEE L. REV. 207 (2012).

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others point to interdependence and collective concerns.[208] Unequal access to health care undermines the productivity of the American workforce, makes us more vulnerable to infectious disease outbreaks, and fosters drug resistance.

From a socially-situated, population health perspective, access to health care is not an end in itself, but rather a means to improved health at the individual—as well as at the population—level. There is disagreement on this point.[209] From a patient rights perspective, access to health care may be conceived as a human right in and of itself, without much regard to whether it improves health outcomes to an extent that justifies prioritization of health care access over public investment in social services that may play a greater role in preventing premature death, improving quality of life, and ameliorating health injustices. From a population-based health justice perspective, however, access to health care is primarily a means to an end. The health justice perspective would emphasize that those ends include protecting collective, as well as individual interests. A communitarian might add that the collective action of ensuring health care access for all plays a constitutive role in defining mutual obligations that reflect and reinforce the community's values.

The experience of countries with public health care financing and delivery systems may be instructive for U.S. policymakers and judges as our health care system transforms. For example, the patient rights argument that access to lifesaving health care is an individual right was dealt a blow in the South African Constitutional Court in *Soobramoney v. Minister of Health*,[210] a case that garnered considerable attention from

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208 *See* Majette, *PPACA and Public Health*, *supra* note 163 (detailing legislative history supporting public health concerns, including about mutual interdependence, as aims of the ACA); Kristen Underhill, *Paying for Prevention: Challenges to Health Insurance Coverage for Biomedical HIV Prevention in the United States*, 38 AM. J.L. & MED. 607, 625–26 (2012) ("The ACA has come closer to embracing the idea that insurance is a means of achieving optimal health, rather than a market mechanism to reduce the risk level or to insulate voluntary purchasers from future losses. The Act's prohibition of discrimination based on health status, like its requirement that insurers cover preventive interventions specified by the U.S. Preventive Services Task Force (USPSTF), is a fundamental policy decision intended to promote the health of the general U.S. population." (footnote omitted)).

209 *See, e.g.*, WORLD HEALTH ORG., HEALTH IN THE POST-2015 DEVELOPMENT AGENDA 2 (2012), http://www.who.int/topics/millennium_development_goals/post2015/post2015_thematic_consultation_health_process_20121003.pdf (posing as a guiding question: "Should indicators and targets be framed in terms of health status (e.g. life expectancy, years of healthy life) or could they be framed in terms of the conditions and means that create better health and can protect people from poverty (including universal health coverage)?").

210 *Soobramoney v. Minister of Health* 1998 (1) SA 765 (CC). The appellant based his claim on section 27(3) of the 1996 South African Constitution, which provides that "[n]o one may be refused emergency medical treatment," and section 11, which stipulates that "[e]veryone has the right to life." *Id.* at para. 7 (quoting S. AFR. CONST., 1996). He did not raise an argument pursuant to sections 27(1) and (2), which provide that "[e]veryone has the right to have access

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American academics. Chief Justice Arthur Chaskalson's opinion denying an individually-held right to life-saving, but non-emergency health care expressed concern that if the South African constitution's guarantee that "[n]o one may be refused emergency medical treatment" were construed to encompass an affirmative right to any life-saving treatment,

> it would make it substantially more difficult for the state to fulfill its primary obligations . . . to provide health care services to "everyone" within its available resources. It would also have the consequence of prioritising [sic] the treatment of terminal illnesses over other forms of medical care and would reduce the resources available to the state for purposes such as preventative health care and medical treatment for persons suffering from illnesses or bodily infirmities which are not life threatening.[211]

Some patient rights advocates criticized the reasoning in *Soobramoney*[212]—although they failed to find libertarian allies as they

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to 1. health care services, including reproductive health care; 2. sufficient food and water; and 3. social security, including, if they are unable to support themselves and their dependants, [sic] appropriate social assistance," and that "[t]he state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation [sic] of each of these rights." *See id.* at paras. 7–14 (quoting S. AFR. CONST., 1996).

211 *Soobramoney v. Minister of Health* 1998 (1) SA 765 (CC) at 774 para. 19. In a subsequent case, the South African Constitutional Court again adopted a population, rather than individualistic, perspective. Addressing section 26's guarantee that "[e]veryone has the right to have access to adequate housing," the court rejected the notion that the state's obligation to take reasonable steps to realize the right to housing amounted to an obligation owed to the individual appellant, but nonetheless found the state's housing program unreasonable and, therefore, unconstitutional, because "[a] programme that excludes a significant segment of society cannot be said to be reasonable." *Government of the Republic of South Africa v. Grootboom* 2000 (1) SA 46 (CC) at paras. 43, 69. And the following year, the court returned to health rights, ordering the government to remove regulatory restrictions on pregnant women's access to Nevirapine, a drug that prevents transmission of HIV from mother to child. *See Minister of Health v. Treatment Action Campaign* 2002 (5) SA 721. Following *Grootboom*'s reasonableness framework, the court again emphasized collective concerns, which coincided with the individual interests of the appellants. *See id. Treatment Action Campaign* shares some similarities with *Abigail Alliance*. In both cases, the government pointed to the unproven safety and efficacy of the treatment at issue. In *Treatment Action Campaign*, however, the court rejected the idea that the government's concerns about safety and efficacy had any scientific basis. *See* Audrey Chapman, *Core Obligations Related to the Right to Health and Their Relevance for South Africa*, *in* EXPLORING THE CORE CONTENT OF SOCIO-ECONOMIC RIGHTS: SOUTH AFRICAN AND INTERNATIONAL PERSPECTIVES 35, 56–58 (Danie Brand & Sage Russell eds., 2002); Karin Lehmann, *In Defense of the Constitutional Court: Litigating Socio-Economic Rights and the Myth of the Minimum Core*, 22 AM. U. INT'L L. REV. 163 (2006) (discussing *Soobramoney*, *Grootboom*, and *Treatment Action Campaign* in terms of a conflict between individual interests and the common good).

212 *See, e.g.*, Craig Scott & Philip Alston, *Adjudicating Constitutional Priorities in a Transnational Context: A Comment on Soobramoney's Legacy and Grootboom's Promise*, 16 S. AFR. J. HUM. RTS. 206, 252 (2000) (arguing that the court's interpretation of section 27(3) and

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did in their opposition to *Abigail Alliance*. *Abigail Alliance* and *Soobramoney* illustrate the entrenched nature of the ethical and political divide between population-level considerations, like comparative effectiveness and stewardship of limited resources, and the prioritization of specialty-based rescue care that saves identifiable lives. The health justice model would highlight the explicit treatment of this divide in such cases and point to the ways in which such tensions are also implicit in many other health law disputes.

C. *Maximizing Public Benefits by Moving Health Care Upstream*

Many lawmakers, judges, and commentators concerned about cost and access have called for greater prioritization of preventive services and interventions,[213] and greater integration of health care and public health.[214] Realizing these goals will require a new health law model that recognizes the importance of collective needs alongside individual interests and seeks to balance the two. The health justice model would integrate its focus on "preventive care for identified patients"[215] with concern for the "pre-patient"[216] lives of people and the social, economic,

its failure to articulate a minimum core of obligations to ensure health care access could lead to a situation in which "[t]he individual is quickly sacrificed to an amorphous general good").

213 See Majette, *PPACA and Public Health*, *supra* note 163 (documenting copious congressional testimony supporting prioritization of preventive care in the ACA as a cost-conscious strategy). For a contrary view, see Bloche, *supra* note 73, at 310 (advocating for an approach to tort and contract disputes that "reflect[s] the priority of rescue over population-wide efficiency"); David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 J. AM. MED. ASS'N 2218, 2218–19 (1991) (explaining how the original methodology of Oregon's priority-setting list for coverage under its Medicaid program failed to give primacy to life-saving treatment); *see also* Paul Menzel et al., *Toward a Broader View of Values in Cost-Effectiveness Analysis of Health Care*, HASTINGS CTR. REP., May–June 1999, at 9 (explaining the "rule of rescue").

214 Rosenblatt, *Four Ages*, *supra* note 1, at 158–59 ("Many of the advances in health status and outcomes in the United States and other developed countries between 1850 and 1950 occurred not because of hospital science or individual treatment, but because of public health science: scientifically-informed sanitation, water supply, food inspection, housing reform, vaccination, public health education, and accurate diagnosis and isolation of the contagiously ill. However, the influence of the public health model was effectively marginalized by the medical profession (and other powerful economic and political actors) for most of the twentieth century, because it threatened to drain resources from profitable fee-for-service treatment of individual patients and, more broadly, to criticize social inequality. In the late twentieth century, increasing evidence of the link between low income and other oppressive social conditions and poor health has resurrected the egalitarian side of nineteenth-century public health, thereby potentially linking it (once again) to a strongly egalitarian version of the social contract paradigm." (footnotes omitted)); Sage, *Should the Patient Conquer?*, *supra* note 9, at 1509 ("[W]e partition investment in care for the individual from investment in public health, and often stuff the former while starving the latter.").

215 Sage, *Should the Patient Conquer?*, *supra* note 9, at 1509.

216 *Id.*

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and environmental factors that shape their health-related behaviors and exposure to infectious and toxic agents.[217]

In thinking about how to foster greater integration of public health and health care, it is helpful to conceptualize prevention activities as falling into four stages: community (also referred to as "pre-primary" or "primordial"), primary, secondary, and tertiary. Community prevention reduces exposure to health hazards by addressing environmental, economic, social, and cultural determinants of health at the community level.[218] Primary prevention averts the onset of disease or injury by enhancing protective factors, reducing risk factors, and influencing individual behavior.[219] Secondary prevention minimizes the impact of disease or injury through early detection and treatment.[220] Tertiary prevention slows the progression of disease or injury to minimize premature death and morbidity.[221] These stages mark a continuum in which public health and medicine, prevention and amelioration are intertwined. Public health experts often think of this continuum in terms of upstream versus downstream interventions, echoing a parable in which the residents of a riverside village become so overwhelmed by rescuing people who are drowning that they do not have time to travel upstream to discover why so many people are falling in.[222]

Many of public health's most potent activities are oriented toward community prevention (for example, sanitation and waste removal systems to reduce exposure to infectious agents; commercial regulation to reduce exposure to environmental toxins; water fluoridation to avert dental caries; occupational and consumer product safety regulations to reduce exposure to hazards; and safety net programs to ensure adequate nutrition for pregnant women, infants, and schoolchildren) and primary prevention (for example, vaccination against infectious diseases, health education to reduce risk behavior, and the use of seat belts or motorcycle helmets to avoid injuries).[223] Medicine, by contrast, is often focused on secondary prevention (for example, screening tests for concussion, blood pressure, blood sugar, cholesterol, and cancer and treatment of coronary artery disease to prevent heart attack) and tertiary prevention (for example, management of diabetes with insulin to

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217 In this regard, the health justice model reflects the influence of the environmental justice, reproductive justice, and food justice movements, which each represented an expansion beyond narrow, rights-based advocacy. *See* Wiley, *Health Law as Social Justice*, *supra* note 8.

218 *See* A DICTIONARY OF EPIDEMIOLOGY 224 (Miquel Porta ed., 6th ed. 2014); R. BEAGLEHOLE ET AL., BASIC EPIDEMIOLOGY 85–88 (1993).

219 *See* A DICTIONARY OF EPIDEMIOLOGY, *supra* note 218, at 224.

220 *Id.*

221 *Id.* at 225.

222 *See* GOSTIN & WILEY, *supra* note 158, at 16.

223 A DICTIONARY OF EPIDEMIOLOGY, *supra* note 218, at 224.

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prevent complications, surgical removal of an arterial blockage to prevent heart attack, antimicrobial drugs to cure infection, and repairing injuries suffered in a motor vehicle crash).[224] Increasing affordable access to high-quality medical care to promote early detection (secondary prevention) and effective treatment (tertiary prevention) of disease are public health goals because they serve population health, as well as individual health needs. The goals of medicine and public health are particularly intertwined with regard to infectious disease prevention and control, where medical treatment can reduce the patient's infectiousness: the individual benefits from treatment, and society benefits from reduced exposure to disease.[225] But they are also interdependent in the fields of non-communicable disease and injury prevention, where upstream prevention reduces costs and disease burden while improving quality of life for individuals and communities alike. The many interrelated determinants and consequences of social disparities in premature death, injury, and illness operate at the population, community, and family levels as much, if not more, than at the individual level.[226]

It is not only a prevention orientation, but also a population focus that demarcates the permeable boundary between public health and medicine.[227] When physicians and other health care providers engage in primary prevention (for example, by counseling patients to adopt healthier behaviors and administering vaccinations) and secondary prevention (for example, by screening patients for risk factors and asymptomatic, early-stage disease), their efforts remain focused on individuals. By the same token, when public health officials engage in secondary prevention, tertiary prevention, and treatment (for example, local health departments frequently offer clinical services, especially for infectious diseases, reproductive health, non-communicable disease screening, and child health) their efforts remain focused on populations.[228] Whereas medicine tends to focus almost exclusively on addressing individual risk factors and behaviors (for example, genetic predisposition, blood pressure, susceptibility to infection, tobacco and alcohol use) and agent-specific countermeasures (for example, antibiotics to kill bacteria, and chelation therapy to remove toxic lead

224 *Id.* at 225.

225 GOSTIN & WILEY, *supra* note 158, at 18.

226 This is a point I am exploring in a work in progress on disparities surrounding diabetes and the inadequacy of current frameworks for addressing them.

227 GOSTIN & WILEY, *supra* note 158, at 18; *see also* Nan D. Hunter, *"Public-Private" Health Law: Multiple Directions in Public Health*, 10 J. HEALTH CARE L. & POL'Y 89, 89 (2007) ("No public law is more public than public health law."); PARMET, *supra* note 12 (describing the population perspective of public health and applying it to diverse areas of the law).

228 A DICTIONARY OF EPIDEMIOLOGY, *supra* note 218, at 224–25.

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from the blood), public health broadens the focus to encompass environmental factors (for example, roadway and motor vehicle design features, advertisements promoting harmful products, and climate conditions that foster exposure to disease-carrying pests).[229]

Health care providers and third party payers are already shifting toward the prevention orientation, but can they adopt a population perspective? Two examples are instructive: First, with regard to providers, community benefit laws imposing enhanced obligations on non-profit hospitals to maintain their tax-exempt status have the potential to push the boundaries of the patient/community divide. Community benefit requirements promulgated pursuant to the ACA encompass community prevention activities that address "the root causes of poor health in areas such as education, employment, income, housing, community design, family and social support, community safety, and the environment"[230] alongside individual patient-focused activities, such as the provision of charity care. The two categories are not, however, treated equally.[231] Second, with regard to payers, expansion of health plan wellness programs could be channeled in ways that emphasize the population perspective. Current wellness program guidelines, which determine whether a wellness program falls within an exception to the ACA's prohibition on rate discrimination based on health status related factors, focus almost exclusively on prevention activities that put the onus on individuals to improve their health related behaviors (for example, to lose weight, quit smoking, or lower blood pressure) without necessarily facilitating those behavioral changes with environmental changes to the workplace or community.[232]

D. *Balancing Access, Cost, and Quality Through Public Engagement*

On a fundamental level, most health law and policy is aimed at balancing the "iron triangle" of access, cost, and quality.[233] We may, at

229 *See generally* GOSTIN & WILEY, *supra* note 158 (contrasting public health with medicine); Geoffrey Rose, *supra* note 10(same).

230 SOMERVILLE ET AL., *supra* note 170, at 4.

231 *See id.* (calling on the Internal Revenue Service to modify reporting of community benefit activities to treat community activities as equal to patient-focused activities); I.R.S. Form 990, Schedule H (facilitating reporting of community building activities, but neglecting to resolve ambiguity regarding whether those activities count equally toward community benefit requirements).

232 *See* Wiley, *Access to Health Care*, *supra* note 125 (describing wellness program provisions in HIPAA and the ACA and identifying missed opportunities to emphasize environmental changes to facilitate healthier behaviors).

233 *See* WILLIAM L. KISSICK, MEDICINE'S DILEMMAS: INFINITE NEEDS VERSUS FINITE RESOURCES 150 (1994) ("While needs are infinite, resources are finite; the iron triangle of

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times, overstate the extent to which lowering costs and increasing access must always come at the expense of quality. For example, there is evidence that shifting some health care responsibilities to registered nurses or nurse practitioners may actually improve health outcomes while reducing costs.[234] And more care is not always better care—far from it. Wasteful health care services often carry health risks of their own.[235] Nonetheless, the fact remains that limited health care resources must be allocated one way or another. This can happen in more or less visible ways: by deferring to the expertise of the patient's treating physicians (as in the professional autonomy model and, for the most part, the patient rights model as well), or by willingness to pay (as in the market power model). It can also happen via a more public process via legislative mandate and regulatory oversight. The health justice model would emphasize the role of public governance, viewing health insurance as "a common-pool resource requiring stewardship"[236] and access to basic health care as an entitlement of citizenship, "the proper design and operation [of which] . . . are collective responsibilities."[237]

In some countries with public health care financing and delivery systems, the judiciary has generally been reluctant to adjudicate allocation of scarce resources, deferring to the political branches. In *Regina v. Cambridge Health Authority*, for example, the English Court of Appeal emphasized the difficult choices facing National Health Service authorities:

> I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet. They cannot pay their nurses as much as they would like; they cannot provide all the treatments they would like; they cannot

health care cannot be ignored."); Richard P. Wenzel & James E. Rohrer, *The Iron Triangle* of *Health Care Reform*, 2 CLINICAL PERFORMANCE & QUALITY HEALTH CARE 7 (1994).

234 Thomas Bodenheimer & Alicia Fernandez, *High and Rising Health Care Costs. Part 4: Can Costs be Controlled While Preserving Quality?*, 143 ANNALS INTERNAL MED. 26 (2005) (discussing several examples of cost-reducing, quality-enhancing strategies, with an emphasis on the use of nurses, nurse practitioners, and primary care physicians, reduction of costly medical errors, and reduction of wasteful services through improved decision tools).

235 *See* A DICTIONARY OF EPIDEMIOLOGY, *supra* note 218, at 225 (describing "quarternary prevention" as "procedures and policies that identify individuals and groups at risk of overdiagnosis or overmedication, and that decrease excessive medical and sanitary intervention").

236 Sage, *Should the Patient Conquer?*, *supra* note 9, at 1510.

237 *Id.* at 1508.

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> purchase all the extremely expensive medical equipment they would like; they cannot carry out all the research they would like; they cannot build all the hospitals and specialist units they would like. Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make.[238]

In the United States, however, where judges have frequently adjudicated access to treatment in the context of private law contract and tort claims,[239] government regulators are reluctant to tackle determinations regarding which health care needs trigger the obligation to provide mutual aid (through public insurance coverage or pooling of resources via private insurance), and how those needs will be prioritized in light of limited resources.[240] For example, when Medicare was first established to provide public coverage for the elderly and disabled, Congress delegated most decisions regarding coverage determinations to private contractors, with the federal agency stepping in to make National Coverage Determinations in exceptional cases.[241] Over time, the role of private corporations in public health care programs has only expanded, with thirty percent of Medicare dollars paying for beneficiaries to enroll in private health plans in 2014.[242]

Judgments about allocation of scarce resources remain largely decentralized and hidden from view, even after ACA implementation. The ACA obligates private health plans offered on subsidized Health Insurance Exchanges, as well as privatized Medicaid "benchmark" plans, to provide an Essential Health Benefit package, including the following ten categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices;

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238 *Regina v. Cambridge Health Authority* [1995] 1 WLR 898 at 906–07.

239 *See, e.g.*, Katskee v. Blue Cross/Blue Shield of Neb., 515 N.W.2d 645 (Neb. 1994) (adjudicating contract claim against insurer); Shannon v. McNulty, 718 A.2d 828 (Pa. Super. Ct. 1998) (applying the corporate liability doctrine to allow tort claim to proceed against HMO).

240 Sage draws on the work of "Lawrence Jacobs [who] distinguishes America's politics of health care supply from Europe's politics of health care access, . . . [making] U.S. health policy vulnerable to interest group pressure in support of narrowly defined services and providers." Sage, *Relational Duties*, *supra* note 3, at 506 (citing Lawrence R. Jacobs, *Politics of America's Supply State: Health Reform and Technology*, HEALTH AFF. Mar.–Apr. 1995, at 143).

241 Timothy Stoltzfus Jost, *The Medicare Coverage Determination Process in the United States*, *in* HEALTH CARE COVERAGE DETERMINATIONS: AN INTERNATIONAL COMPARATIVE STUDY 207, 209–19 (Timothy Stoltzfus Jost ed., 2005).

242 HENRY J. KAISER FAMILY FOUND., FACT SHEET: MEDICARE ADVANTAGE (2015), http://files.kff.org/attachment/fact-sheet-medicare-advantage.

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laboratory services; preventive and wellness services, and chronic disease management; and pediatric services, including oral and vision care.[243] For now, at least, HHS has delegated authority to the states, via a benchmark approach, to define the details of what services must be provided within each of these broad categories.[244] The fact that the Obama administration has, thus far, disclaimed responsibility for defining the Essential Health Benefits in any substantive way speaks to the fact that any kind of rationing process generates enormous political controversy—something the administration could not afford much more of in late 2011 when the HHS benchmark rule was announced.[245]

Health law and policy experts are afflicted with "rationing anxiety."[246] Most attribute the politically untouchable nature of rationing to near-universal cultural and social values that favor virtually limitless health care expenditures to save identifiable lives. A few have also noted, however, that health care provider and private insurance industry groups have influenced this seemingly inherent cultural and social norm in important ways. For example, the "Harry and Louise" advertising campaign depicting a middle-class, middle-aged couple from Middle America worrying about government restrictions on their individual choices about medical care is widely credited with killing the Clinton-era health reform push.[247]

There are also concerns about the role of democratic public engagement in distribution of health care resources. Without any restrictions, a politically accountable allocation process is likely to drive up costs because politicians always want to be able to answer "yes" to constituent questions about whether a health reform proposal would

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243 42 U.S.C. § 18022(b)(1) (2012).

244 *See* 45 C.F.R. §§ 147, 155, 156; Nicholas Bagley & Helen Levy, *Essential Health Benefits and the Affordable Care Act: Law and Process*, 39 J. HEALTH POL. POL'Y & L. 441 (2014) (documenting the process by which HHS first announced its approach in 2011); B. Jessie Hill, *What is the Meaning of Health? Constitutional Implications of Defining "Medical Necessity" and "Essential Health Benefits" Under the Affordable Care Act*, 38 AM. J.L. & MED. 445, 445–46 (2012) ("In a decision that was hailed as both 'politically astute' and problematic for the goals that the ACA itself was supposed to accomplish, HHS shunted off the task of defining the term 'essential health benefits' to the individual states." (footnote omitted)).

245 *See* Hill, *supra* note 244, at 445–46.

246 M. Gregg Bloche, *Beyond the "R Word"? Medicine's New Frugality*, 366 NEW ENG. J. MED. 1951, 1951 (2012) ("The R word's power to stop conversation reflects the popular belief that cost should be no object at the bedside."); Sage, *Relational Duties*, *supra* note 3, at 504 (describing how bioethicists advising the White House on health reform in 1993 arrived "expect[ing] rationing to be their most important agenda item" but were "explicitly forbidden from mentioning the word by the administration's reform czar").

247 *See* Raymond L. Goldsteen et al., *Harry and Louise and Health Care Reform: Romanticizing Public Opinion*, 26 J. HEALTH POL. POL'Y & L. 1325 (2001).

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give them or a loved one access to desired treatment.[248] It is far from clear that the American public (particularly under the influence of well-monied health care provider groups that know their way around a public relations campaign) would be more comfortable with government stewardship of limited health care resources than they are with managed care companies doing so.[249] Elizabeth Weeks Leonard encapsulates the quandary well:

> The government's role is to protect certain values in society and promote the common good. Justice and fairness require that people be treated equally unless they are sufficiently different. Accordingly, to have our government, our parens patriae, making decisions about who is in and who is out of medical treatment requires admitting, first, that we are making a choice and, second, that the government is the one brushing aside those core societal values.[250]

The disconnect between public administration and public engagement breeds deep distrust of health officials playing a visible role in allocating scarce resources for health. The ACA brings the United States a big step closer to universal access, to realizing the ideal of access to health coverage as a (statutorily guaranteed and administratively enforced) right of citizenship. The health justice model would seek to foster collective deliberation on what the content of that right entails—the services that are covered and the reimbursement policies that will apply to various types of services and practitioners—as an expression and obligation of citizenship.

CONCLUSION

Like previous transitions, health reform under the ACA's mutual aid framework is prompting policymakers, judges, and scholars to rethink the lenses through which they view the complex relationship

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248 *See* Sage, *Relational Duties supra* note 3, at 505 (2008) (describing Oregon's Medicaid rationing plan as having "increase[ed] public budgeting for health care by forcing state legislators to cast votes on coverage of specific treatments that have direct implications for identifiable people").

249 Leonard, *Death Panels*, *supra* note 98, at 876 ("[T]he seismic shift that the public would have to make to become comfortable with rationing, as with taxation, is around that 'we.' Who is the 'we' that is doing the rationing? In the above examples, it is private insurance companies, or individuals themselves, under the influence of managed care restrictions. Perhaps that makes it particularly offensive: money-grubbing, financially motivated, unfeeling insurance companies are deciding what care we do and do not receive. That is certainly the message of Michael Moore's docu-tainment feature film, Sicko: private insurance companies are the problem with our health care system. But would we be any more comfortable with government officials making those choices?" (footnote omitted)).

250 *Id.*

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between law and health and the role of the public's interest in health care. The solidaristic impulse of the 1990s managed care backlash was largely channeled into highly individualistic state "patient protection" laws that do little to serve collective interests.[251] The impact of backlash against the ACA (thus far, largely ineffectual, but noisy all the same) is still playing out. It could do lasting harm to efforts to increase the role of government as the single largest payer for health care services in negotiating re-tooled reimbursement rates and other policies that reflect greater emphasis on community prevention and primary care. Or, it could increase public engagement on issues of medical treatment and access decisions with collective implications. Health reform has already increased interest in the role of health care providers and third party payers in creating healthier communities, allocation of scarce health care resources, and efforts to bring down spending. My hope is that we are nearing a grace point, at which the process of grappling with these issues—forced upon the public by a rancorous, high-stakes political process and hard-fought legal battles—gives way to greater fellow feeling. As Ed Sparer wrote decades ago, "the very struggle to reconstruct health care, organized along mutual aid lines which stress cooperative and caring relations, helps to provide a grace . . . and character to society and to each person who struggles for it."[252] The struggle surfaces our mutual interdependence and our support for mutual aid.

251 Managed care was seen as a threat to individuals: "The commercialization of medicine . . . tends to be perceived as a threat to individual patients and corresponding professional values rather than as a perversion of collective interest." Sage, *Relational Duties*, *supra* note 3, at 504.

252 Ed Sparer, *Fundamental Human Rights, Legal Entitlements, and the Social Struggle: A Friendly Critique of the Critical Legal Studies Movement*, 36 STAN. L. REV. 509, 551 (1984).

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