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Equality, Entitlement, and National Health Care Reform: The Challenge of Managed Competition and Managed Care

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EQUALITY, ENTITLEMENT, AND NATIONAL HEALTH CARE REFORM: THE CHALLENGE OF MANAGED COMPETITION AND MANAGED CARE

Rand E. Rosenblatt*

INTRODUCTION

This Symposium is about “ensuring equal and quality health care for poor Americans,” an issue of special importance as we struggle to achieve national health care reform. The topic was fittingly chosen to honor the work and vision of Professor Edward V. Sparer, an extraordinary lawyer, scholar, and activist in movements for equality and social justice.¹

This topic is also an appropriate focus for consideration of the Clinton Administration’s proposed Health Security Act (“HSA” or “the Act”).² The first section of the HSA proclaims

* Professor of Law, Rutgers University Law School—Camden. This Article expands on remarks made at the Symposium on *Ensuring (E)qual(ity) Health Care for Poor Americans* at Brooklyn Law School, December 3, 1993. I would like to thank Ann Freedman for her thoughtful comments, and Sylvia Law and other members of the Society for American Law Teachers (SALT) Committee on Access to Justice in Health Care Reform, for helping me think about justice issues in the Health Security Act.

¹ A 1959 graduate of Brooklyn Law School, Ed Sparer founded three major legal advocacy programs concerned with poverty law, welfare law, and health law, was Professor of Law and Social Welfare at the University of Pennsylvania Law School, and died in 1983 at the age of 55. Memorial essays and a bibliography of his work can be found in 132 U. PA. L. REV. 421 (1984); see especially Sylvia A. Law, *Dedication: Edward V. Sparer*, 132 U. PA. L. REV. 425 (1984). Sparer’s own perspective and his most comprehensive and last published statement can be found in Edward V. Sparer, *Fundamental Human Rights, Legal Entitlements, and the Social Struggle: A Friendly Critique of the Critical Legal Studies Movement*, 36 STAN. L. REV. 509 (1984).

² President Clinton’s Health Care Reform Proposal. Health Security Act, H.R. 3600, 103d Cong., 1st Sess. (1993) [hereinafter HSA]. At the time this Article was being written, in April 1994, it was not clear whether the HSA would be the base from which Congress designed national health care reform legislation. As of April 18, 1994, the only congressional vote on health care reform had occurred in the Health Subcommittee on the House Committee on Ways and Means, which had narrowly endorsed “amendments” to the Administration’s bill that made significant changes in it—notably leaving to state discretion whether to establish purchasing

that "each eligible individual"—meaning all citizens of the United States and non-citizen legal residents—"is entitled to the comprehensive benefit package [specified in the Act] through the applicable health plan in which the individual is enrolled."³ The HSA's stated purposes are, among others, "to guarantee comprehensive and secure health coverage," "to control the cost of health care," and "to ensure high quality care."⁴ But the Act's commitment to comprehensive and secure coverage, and to quality of care, is deeply ambiguous: the "entitlement"—the effort to "guarantee" and "ensure"—is to be realized "through" enrollment in primarily privately owned, for-profit health plans whose structure, incentives, and inner dynamics will significantly define, and perhaps undercut, the entitlement itself.⁵

alliances, and relying on an expansion of Medicare as the backup system to employment-based insurance. Many other subcommittee and committee votes in both the House and the Senate remained to be held. Meanwhile, Senator George Mitchell, the Senate Majority Leader, circulated several variations on the Clinton bill to Democratic senators. Adam Clymer, *Senator Outlines Cheaper Versions of Health Plan*, N.Y. TIMES, Apr. 18, 1994, at A1. The meanings of equality, quality, and entitlement discussed in this Article will be relevant to whatever legislation finally emerges from Congress.

³ HSA § 1001(a) (emphasis added). Eligible individuals include all citizens and legally resident aliens. *Id.* The exclusion of millions of other non-citizens remains a major gap in the Act's promise of universal coverage. The entitlement to health benefits does require individuals and families to pay partial premiums and copayment amounts. *See id.* §§ 1002, 1131-1136, 1343-1345, 6101-6105. Health Alliances are responsible for notifying families of their share and of collecting any amounts due that have not been paid through wage withholding or otherwise. *Id.* § 1344(a). Failure to pay premiums is supposed to lead to collection actions, but will not result in loss of health care coverage. *See id.* § 1344(d).

⁴ HSA § 3(1), (3), (5).

⁵ Enrollment in privately owned, for-profit health plans is not formally required by nor inevitable under the HSA, but it is highly likely. The HSA does permit states to establish state-wide or regional single-payer systems, HSA §§ 1221-1224, which would eliminate the need for for-profit plans. But given the political influence of the health insurance industry, it seems unlikely that more than a few states, if any, will choose the single-payer option. Those that do are likely to be small states. *But see* Seth Mydans, *Petitions Seek California Vote on Canada-Style Health Plan*, N.Y. TIMES, Apr. 27, 1994, at A15 (reporting submission of more than one million signatures, well over the 677,000 needed to put the issue on the November 8, 1994, ballot). In addition, a small number of consumers will be able to enroll in existing nonprofit, consumer-owned health plans, such as Group Health of Puget Sound, or in nonprofit programs based in low-income neighborhoods, such as the Bronx Health Plan. Given high start-up and administrative costs, and the lack of significant public-policy support for nonprofit, consumer-oriented plans, the choices likely to be offered to the overwhelming majority

This Article is about how we can struggle for the values of equality and quality of care, and of entitlement, in the face of this ambiguity and the political and social forces it reflects. The Article begins in Part I by proposing a practical version of what "equality," "quality" and "entitlement" might mean for poor Americans and, indeed, for all Americans, in the context of the Act's strategies of managed competition and managed care. Part II then explores lessons from Ed Sparer's work about what entitlement means in the context of pervasive inequality, with particular reference to health care. The main theme of this section is that the process of making entitlements real, particularly for poor Americans and for poorly organized groups such as health care consumers, is an intensely political, social, and cultural process, as well as a legal one, and depends centrally on building connections and coalitions between lower-income Americans and the great majority of Americans whose incomes occupy the middle range.⁶ Finally, Part III develops these points in a particular context by discussing the administrative claims provisions of the Health Security Act, in light of the government's traditional nonenforcement of consumer rights and the emerging dynamics of managed care.

I. EQUALITY, QUALITY, AND ENTITLEMENT IN HEALTH CARE: A (SEEMINGLY) SIMPLE PROPOSAL

Until recently, the terms "equality" and "quality" in health care had relatively clear meanings. "Quality" of care meant

of Americans will be privately owned, for-profit plans.

⁶ On the relationship of entitlements to larger social dynamics, see *infra* notes 12, 16, 17, 23, 25 and 26 and accompanying text; Joel F. Handler, "Constructing the Political Spectacle": *The Interpretation of Entitlements, Legalization, and Obligations in Social Welfare History*, 56 BROOK. L. REV. 899, 947-74 (1990); and Elizabeth M. Schneider, *The Dialectics of Rights and Politics: Perspectives from the Women's Movement*, 61 N.Y.U. L. REV. 589, 611-52 (1986). Regarding "middle range income," the median annual family income in 1992 was \$35,776. Bureau of the Census, U.S. Dep't of Commerce, STATISTICAL ABSTRACT OF THE UNITED STATES: 1993 427 (Table 672) (median weekly earnings of \$688 x 52 = \$35,776) [hereinafter STATISTICAL ABSTRACT]. The "middle range" of income is often conceived as stretching from one-half of the median (\$17,888) to double the median (\$71,552). The urban federal poverty line in 1994 was \$14,350 for a family of four. On the background of the federal poverty line, see Deborah A. Stone, *Making the Poor Count*, AM. PROSPECT, Spring 1994, at 84.

what well-trained and well-regarded physicians customarily did in treating patients. "Equality" meant that everyone should be able to have a good insurance policy that would cover most of the costs of such care.⁷ While poor, lower-income, and minority Americans often were excluded from these ideals, the ideals themselves were clear enough, and the Medicare and Medicaid statutes of 1965 attempted to realize them for aged and low-income Americans.

By 1994, however, the meaning of these terms has become much less clear. The traditional idea of quality has been profoundly challenged: the customary practice of well-regarded physicians is now seen by many analysts as flawed and corrupt, a "vast misallocation of resources"⁸ born of guild monopoly, deeply inefficient financing, excess technological capacity, overspecialization, irresponsible tax subsidies, defensive medicine, and gross profiteering.⁹ Not surprisingly, "equal" access to this morass is no longer viewed by many as a coherent and defensible ideal. Both "quality" and "equality" now frequently appear in policy discussions as concepts that must be redefined in a new context of economic competition, financial constraint, "managed" care, and explicitly stratified (i.e., unequal) benefit plans and practice standards.¹⁰

⁷ See, e.g., Daniel Fox, *From Reform to Relativism: A History of Economists and Health Care*, 57 MILBANK Q. 297, 307-14 (1979).

⁸ PAUL STARR, THE LOGIC OF HEALTH-CARE REFORM 31 (1992).

⁹ For articulation of these themes by advocates of managed competition, see STARR, *supra* note 8, at 25-32, and Alain C. Enthoven, *The History and Principles of Managed Competition*, 12 HEALTH AFF. 24, 25-27 (Supp. 1993). For articulation of similar themes by analysts who are neutral about or critical of managed competition, see Uwe E. Reinhardt, *Reorganizing the Financial Flows in American Health Care*, 12 HEALTH AFF. 172, 178-83, 187-89 (Supp. 1993), and Deborah A. Stone, *When Patients Go To Market: The Workings of Managed Competition*, AM. PROSPECT, Spring 1993, at 109, 111-12. From a very different perspective than that of managed competition, advocates of a greatly increased public health sector make a related point that improving access to doctors is not an efficient nor effective method of improving health, which, they argue, depends on access to and use of vaccinations, periodic tests, and examinations for cancer, and effective treatment for those with high blood pressure and cholesterol. See Michael Alderman & Douglas Shenson, *A Ton of Cure*, N.Y. TIMES, Apr. 24, 1994, § 4, at 17.

¹⁰ In addition to the sources cited *supra* note 9, see Richard A. Epstein, *Market and Regulatory Approaches to Medical Malpractice: The Virginia Obstetrical No-Fault Statute*, 74 VA. L. REV. 1451, 1459-63 (1988) (arguing that federal and state Medicaid officials should be authorized to bargain for a lower standard of care for the poor); E. Haavi Morreim, Commentary, *Stratified Scarcity and Unfair Liability*, 36 CASE W. RES. L. REV. 1033 (1986); and John Siliciano, *Wealth, Equi-*

Powerful criticism about managed competition and managed care continues and, at times, was expressed by this Symposium's participants.¹¹ While equally critical of the traditional system's many failings,¹² egalitarian analysts doubt

ty, and the Unitary Malpractice Standard, 77 VA. L. REV. 439, 465-66, 475-81 (1991) (arguing that "[i]n a very real sense . . . the [American] poor constitute a separate nation, and their health care needs should be assessed accordingly"). For a critique of these positions, see Rand E. Rosenblatt, *Quality of Care and the Law*, in GEORGE J. ANNAS, SYLVIA A. LAW, RAND E. ROSENBLATT, & KENNETH R. WING, *AMERICAN HEALTH LAW* 377, 419-21 (1990 & Supp. 1993). For other discussions of the impact of managed care on quality standards, see INSTITUTE OF MEDICINE, *GUIDELINES FOR CLINICAL PRACTICE: FROM DEVELOPMENT TO USE* (Marilyn J. Field & Kathleen N. Lohr eds., 1992) [hereinafter IOM/GUIDELINES]; INSTITUTE OF MEDICINE, *CONTROLLING COSTS AND CHANGING PATIENT CARE? THE ROLE OF UTILIZATION MANAGEMENT* (Bradford H. Gray & Marilyn J. Field eds., 1989) [hereinafter IOM/UTILIZATION]; Jonathan J. Frankel, Note, *Medical Malpractice Law and Health Care Cost Containment: Lessons for Reformers from the Clash of Cultures*, 103 YALE L.J. 1297 (1994).

¹¹ "Managed competition" is defined by Alain Enthoven as

a purchasing strategy to obtain maximum value for money [in health care]. . . . It uses rules for competition, derived from rational microeconomic principles, to reward with more subscribers and revenue those health plans that do the best job of improving quality, cutting cost, and satisfying patients. The "best job" is in the judgment of both the sponsor [e.g., a health alliance, health insurance purchasing cooperative, or large employer] armed with data and expert advice, and informed, cost-conscious consumers. The rules of competition must be designed and administered so as not to reward health plans for selecting good risks, segmenting markets, or otherwise defeating the goals of managed competition.

Enthoven, *supra* note 9, at 29. Enthoven earlier characterized these rules as promoting "socially desirable competition." ALAIN C. ENTHOVEN, *HEALTH PLAN* 126 (1980); see also STARR, *supra* note 8, at 47-50. "Managed care" has no single, well-accepted definition, but embraces "in the emerging conventional usage . . . any health plan that limits the choice of providers or regulates their treatment decisions to eliminate inappropriate care and reduce costs." *Id.* at 40; see also Elizabeth W. Hoy et al., *Change and Growth in Managed Care*, 10 HEALTH AFF. 18, 19 (1991). Managed competition at the level of competing health plans will almost certainly lead to managed care at the practitioner level. However, managed care could also be implemented without managed competition, for example by a single-payer system. For critical perspectives on managed competition in this Symposium, see Theodore R. Marmor, *The National Agenda for Health Care Reform: What Does it Mean for Poor Americans?*, 60 BROOK. L. REV. 83, 89-90 (1994); Ann C. McGinley, *Aspirations and Reality in the Law and Politics of Health Care Reform: Examining a Symposium on (E)qual(ity) Care for the Poor*, 60 BROOK. L. REV. 1, 22-26 (1994) (describing remarks of David U. Himmelstein).

¹² Ed Sparer himself, and those of us who learned from him, did not and do not defend the waste, unaccountability, profiteering, and inequality that have characterized much of American health care from the 1960s to the present. On the contrary, beginning in the early 1970s, when the market competition approach to

that a managed competition strategy can achieve its goals or contain costs in a responsible way. Many factors support this view: a competitive system will involve high costs of administration and profit, risk-selection will remain the most lucrative strategy, and egalitarian values will be in permanent tension with profit-making. In addition, integrated health care delivery systems will be too complex to permit coherent comparison shopping, and there is little knowledge or consensus about what separates "core benefits" from "incidentals," or justified conservative medicine from risky underservice.¹³ Analysts have also challenged the core premise of market competition, which denies society's capacity to think about these issues as a social or political matter, and instead asserts, through "authoritative stories," that these decisions must be made by an abstract "economic man."¹⁴

Related to these important debates over managed competition is the critical question of who will participate in the debates and on what terms. Especially in a period of transition regarding the values and structure of health care delivery, equality and quality of care have important "process meanings" that overlap with the meaning of "entitlement." First, equality means, at the very least, that health care consumers receive *whatever the rules in force at the time say they are entitled to receive*. This idea surely is at the core of President Clinton's famous phrase, health care "that can never be taken away,"¹⁵

health care was only beginning to emerge, Sparer and his colleagues, notably Sylvia Law, identified and criticized many of these problems. See, e.g., SYLVIA A. LAW, *BLUE CROSS: WHAT WENT WRONG?* (1974); Rand E. Rosenblatt, *Health Care, Markets, and Democratic Values*, 34 VAND. L. REV. 1067, 1068-69 nn.2-3 (1981); Edward V. Sparer, *Gordian Knots: The Situation of Health Care Advocacy for the Poor Today*, 15 CLEARINGHOUSE REV. 1, 10-21 (1981).

¹³ See David U. Himmelstein et al., *Mangled Competition*, AM. PROSPECT, Spring 1993, at 116 (1993); Rosenblatt, *supra* note 12, at 1088-1115; Stone, *supra* note 9, at 112-15.

¹⁴ See David M. Frankford, *Neoclassical Health Economics and the Debate Over National Health Insurance: The Power of Abstraction*, 18 L. & SOC. INQUIRY 351, 353 (1993); David M. Frankford, *Privatizing Health Care: Economic Magic to Cure Legal Medicine*, 66 S. CAL. L. REV. 1 (1992); Rosenblatt, *supra* note 12, at 1068-70, 1088-1115.

¹⁵ *Clinton's Health Plan: Transcript of President's Address to Congress on Health Care*, N.Y. TIMES, Sept. 23, 1993, at A24. President Clinton stated: "At long last, after decades of false starts, we must make this our most urgent priority: giving every American health security, health care that can never be taken away, health care that is always there. That is what we must do tonight." *Id.*

and it is also a core meaning of "entitlement." In addition, to the extent that the "rules" of health care—statutes, judicial doctrine, contracts, professional standards, practice guidelines, etc.—address issues of quality, they also define that term.

Second, to the extent that these rules confer discretion on many types of people—doctors, utilization managers, health plan and hospital executives, and government officials—both equality and quality mean that *the needs and interests of all identifiable groups of consumers should be fairly taken into account*. Although "fairly" may arguably be defined in different ways, at the very least it means that significant needs and interests will be given respectful and serious consideration. Third, to the extent that the rules and discretionary standards are in flux—as indeed they are—equality requires that *all significant groups or clusters of needs and interests have meaningful access to the process of discussion and decision regarding health care policy*. Again, there may well be debate about what "meaningful access" entails, and who and what are "significant" groups or clusters of interests, but surely a great many groups and interests—such as pregnant women, children, the disabled, HIV-positive people, underserved minorities—can easily be agreed upon.

These process meanings of equality and quality, then, overlap with a process approach to entitlement in complex regulatory and redistributive social legislation such as health care. Under this approach, entitlement and "rights" include not only rights to definite benefits or outcomes, but also rights to a process of decision or allocation that gives appropriate weight to the often vulnerable values and interests that the legislature wished to protect.¹⁶

¹⁶ See, e.g., Rand E. Rosenblatt, *The Courts, Health Care Reform, and the Reconstruction of American Social Legislation*, 18 J. HEALTH POL. POL'Y & L. 439, 440 n.2, 443, 444-49 (1993) (discussing the federal courts' "rights-enforcing" or "norm-realizing" role) [hereinafter Rosenblatt, *Social Legislation*]; Rand E. Rosenblatt, *Social Duties and the Problem of Rights in the American Welfare State*, in THE POLITICS OF LAW 90, 104-08 (David Kairys ed., rev. ed. 1990) (discussing a model in which courts, in dialogue with legislatures, create social duties that may or may not generate individual rights) [hereinafter Rosenblatt, *American Welfare*]; Rand E. Rosenblatt, *Health Care Reform and Administrative Law: A Structural Approach*, 88 YALE L.J. 243, 253-64 (1978) (discussing a "structural due process" approach to statutory interpretation) [hereinafter Rosenblatt, *Health Care Reform*].

II. EQUALITY, ENTITLEMENT, AND THE LEGACY OF ED SPARER

These three meanings of equality and entitlement, and particularly the first, may seem obvious and primitive. "Of course" people should receive the benefits to which they are entitled under the rules. Yet when Ed Sparer and his colleagues began fashioning modern poverty law at Mobilization for Youth ("MFY") in New York City in the early 1960s, they discovered that, for poor people, this obvious principle of entitlement was revolutionary. Sparer provided an example of this point in a speech in 1965:

A tired, haggard lady in her early forties came to our [MFY] office last week with her four children, ages four years to fifteen years. She was sent to us by a social worker in a local hospital to whom she had gone for help. The woman and her children had spent the preceding night sleeping on the floor of a church. The day before she had spent in a local welfare office and was rejected for even emergency assistance. She had spent several previous nights sleeping, with her children, on the floors of local tenement hallways. The Social Welfare Law of New York is crystal clear, I might add, that the lady in question and her children were entitled to, at the very least, emergency welfare assistance for shelter and food. They received the assistance when a mandamus proceeding was threatened.¹⁷

After describing this and two other cases,¹⁸ Sparer argued that these examples and many others illustrated "the frequently callous, the often just plain lawless manipulation of the poor by private trader and allegedly benevolent government agent alike."¹⁹ Overcoming these pervasive and long-standing practices would require a "contemporary American revolution."²⁰

It is a revolution that is concerned not with charity, but with justice—individual justice, equal justice, and social justice. The gap between the promise of justice and the practices that the impoverished, the uneducated and inarticulate have endured is what cannot be tolerated any longer. . . . A first practical step . . . is to close the gap between the theoretical legal rights of all our citizens and the

¹⁷ Edward V. Sparer, *The New Legal Aid as an Instrument of Social Change*, 1965 U. ILL. L. FORUM 57, 57-58.

¹⁸ These involved a young man about to be fired because of a false creditor's action and two brothers about to be evicted from public housing because of a rigid rule about family composition. *Id.*

¹⁹ *Id.* at 58.

²⁰ *Id.* at 57.

prevailing legal defenselessness of the poor. This means, of course, creating a vast new array of legal services. . . . The new legal aid lawyer's role should be defined by the broadest reaches of advocacy, just as is the role of the corporation lawyer. . . .²¹

Several themes are evident in Sparer's analysis. First, poor people's inability to obtain what they are due under the rules is not the result of isolated errors or deviant officials. Instead, the interlocking systems of procedural and substantive law and practice function systematically to deny the poor their often meager rights. Second, pro-active, expansively conceived legal services can help make those unenforced rights real and can also achieve new rights. Third, an effort of this sort clearly involves more than just legal advocacy and legal reasoning. To be made real, rights both must support and be supported by a culture and a constituency that has at least some self-awareness and organized form.

In short, the realization of what seemed to be a simple, obvious entitlement—applying the rules even when they benefited poor people—would require a kind of revolution, a significant redistribution of resources, power, and self-respect in favor of a group that had been politically and legally silenced.²² Sparer's goal, as he defined it, was to empower the poor themselves—to achieve “the engagement into the democratic process of the dark-skinned, whether rich or poor, and the poor, whether dark-skinned or light . . . so that [they] may . . . make their own voices heard, and assert their human and legal rights to the fullest.”²³

In many respects, Sparer and his comrades in the legal services and welfare rights movements were remarkably successful. They persuaded state and federal courts, including the United States Supreme Court, to define statutory and constitutional rights and entitlements in new ways that brought the

²¹ *Id.* at 59-60.

²² *See, e.g.*, *Smith v. Board of Comm'rs*, 259 F. Supp. 423 (D.D.C. 1966) (holding that cash welfare assistance is a gratuity, not a legal obligation of government and, “being absolutely discretionary,” there can be no judicial review of recipient allegations that welfare department officials were using illegal methods of investigating eligibility), *aff'd on other grounds*, 380 F.2d 632 (D.C. Cir. 1967) (court of appeals assumed that these propositions were incorrect, but affirmed summary judgment for defendants on the ground that the plaintiff welfare recipients had failed to exhaust their administrative remedies).

²³ Sparer, *supra* note 17, at 57.

poor closer to first-class citizenship.²⁴ They established a nation-wide program of legal services which has provided extremely important advocacy for the poor, both in individual cases and at the level of judicial, executive, and legislative policy. These advocates obtained increased material resources for millions of people and, to varying degrees at different times, helped mobilize the poor as an organized political presence in local, state, and national politics.

At the same time, these efforts had a paradoxical, self-limiting quality even when (as was certainly not always the case) they seemed most "successful." Analysts on the left, center, and right, have pointed to these limits²⁵ and, indeed, Sparer himself recognized what he termed "binds," "traps," and "Gordian Knots."²⁶ At the most general level, the problem was that most non-poor Americans viewed successful advocacy for rights of the poor not as bringing the poor into the family of citizenship, but rather as creating "special" rights for "them" which undermined the income and culture of the majority. Sparer saw that no matter how formally the rights of the poor were defined in law, they would never be secure or, for that matter, adequate as long as they were perceived as different than, and antagonistic to, the needs and rights of the majority of Americans who identify themselves as hard-working taxpayers.²⁷

Professor Sparer explained how these dynamics worked in the area of health care. First, because health care for the poor is significantly financed by regressive federal, state, and local payroll, property, and sales taxes (and surcharges on hospital

²⁴ See, e.g., Rosenblatt, *Social Legislation*, *supra* note 16, at 439, 444-49; Rosenblatt, *American Welfare*, *supra* note 16, at 90, 92-95; Edward V. Sparer, *The Right to Welfare*, in *THE RIGHTS OF AMERICANS* 65 (Norman Dorsen ed., 1970).

²⁵ For quite diverse expressions of these and other themes, see JERRY MASHAW, *DUE PROCESS IN THE ADMINISTRATIVE STATE* 34-35 (1985); Richard A. Epstein, *No New Property*, 56 *BROOK. L. REV.* 747 (1990); Handler, *supra* note 6, at 958-60; William H. Simon, *The Rule of Law and the Two Realms of Welfare Administration*, 56 *BROOK. L. REV.* 777, 782-88 (1990); William H. Simon, *Legality, Bureaucracy, and Class in the Welfare System*, 92 *YALE L.J.* 1198 (1983).

²⁶ See Sparer, *supra* note 12; Edward V. Sparer, *Welfare Reform: Which Way Is Forward?*, 35 *NAT'L LEGAL AID & DEFENDER ASS'N BRIEFCASE* 110, 144 (1978) [hereinafter *Welfare Reform*].

²⁷ See Edward V. Sparer, *Legal Services and Social Change: The Uneasy Question and the Missing Perspective*, 34 *NAT'L LEGAL AID & DEFENDER ASS'N BRIEFCASE* 58, 60-62 (1977).

reimbursement), advocacy that succeeds in expanding access for the poor imposes costs on those not much financially better off, and leads almost inevitably to a political backlash and program cutbacks.²⁸ Second, merely getting poor patients access to health care delivery is an ambiguous triumph; while some will be helped, others will be harmed by unnecessary or poorly delivered care. Although these dangers face all patients, they are particularly acute in the case of the poor, who traditionally have been the victims of professional power, silence, and discrimination on grounds of race, gender, and class.²⁹

Third, Sparer identified an especially painful paradox: expanding access to health care for the poor may actually increase economic, political, and social inequality. Briefly summarized, powerful political actors—hospitals, physicians, pharmaceutical companies and, since Sparer's time, myriad health care entrepreneurs—reap the lion's share of greatly increased governmental health care funding for the poor and the aged. Thus in the "name" of the poor, money is significantly redistributed from middle- and lower-middle class payers of taxes and premiums to upper-middle class and wealthy professionals, managers, and investors. Part of this wealth is then fed back into the political system to pay for campaign contributions and lobbying, forming a potent barrier to egalitarian change. Most ironically, the funds flowing to the well-off "on behalf" of the poor are "charged" to what might be termed the poor's "social account": assistance for food, housing, transportation, and education must be slashed to "pay for" the rising health care "benefits." Indeed, poverty itself is said to be "eliminated" because ever-increasing billions for health care are being "transferred to" the poor.³⁰

To overcome these painful dilemmas, Sparer tried to identify advocacy issues and strategies that would unite low-income patients with most other patients and with potentially sympathetic elements among providers and other groups. He saw that issues of quality, patient and consumer empowerment, accessible and humane primary care, non-physician

²⁸ See Sparer, *supra* note 12, at 2-9. For a recent analysis of how people with modest incomes pay substantially higher tax rates than the wealthy, see DONALD L. BARLETT & JAMES B. STEELE, *AMERICA: WHO REALLY PAYS THE TAXES?* (1994).

²⁹ See Sparer, *supra* note 12, at 10-15.

³⁰ See Sparer, *supra* note 12, at 16-21.

providers, occupational health, and fair cost control spanned almost all socioeconomic groups. These issues provided a potential basis for rights that would flow from and support a broader social-political movement for equality in health care.³¹

As Professor Sparer's later writings suggested, litigation on behalf of the poor, while often necessary and sometimes helpful, may be a symptom of political and social failure. If minorities and the poor were really accepted and supported in the democratic process, if their needs and interests were a legitimate part of our governmental and social culture, then the gap between legislative promise and social reality would not be so large, and the need for litigation would be substantially less. Sparer always asked whether advocacy, litigation and rights contributed to a broader process of egalitarian social change, or did they accomplish the opposite through the paradoxes discussed above? Of course, answering this question always has been a very uncertain enterprise. Yet that is the question that I think Professor Sparer would have seen as being posed by the title of this Symposium. He was highly aware of the importance of recognizing and protecting the needs of the poor, both those that they share with others and those that are special in kind or degree. Yet he also was aware that to meet even the special needs, it is critical to find political and cultural connections and support in the broader population.³² The good and bad news, apparent during Sparer's life and even more so in the years since his death in 1983, is that increasingly large numbers of middle-class Americans are being subjected to the kinds of insecurity and disregard in health care once reserved primarily for minorities and the poor. Indeed, because of this trend, national health care reform is on the political agenda. Whether that insecurity can be fashioned into an egalitarian cross-class coalition for genuine health security is the great hope and the great unknown.

³¹ See generally Sparer, *supra* note 12, especially at 22-23; Sparer, *supra* note 27, at 61-62.

³² On the Clinton Administration's efforts to wrestle with the politics of building broad public support for programs to help low-income citizens, see Jason DeParle, *Euphemisms Mask Fervor in Latest Attack on Poverty*, N.Y. TIMES, Apr. 17, 1994, § 4, at 5. The author does not explain why he believes describing the Head Start program as an "investment in children" is a "euphemism." See *id.*

III. EQUALITY, ENTITLEMENT, AND THE CLINTON ADMINISTRATION'S HEALTH SECURITY ACT

The Health Security Act would make very large contributions to equality and quality of care for all Americans, including poor Americans. Three features of the plan deserve special mention. First, the Act clearly creates an entitlement to health insurance for all American citizens regardless of income, employment status, or health condition.³³ This would enormously improve equality and quality for the estimated fifteen percent of Americans who are currently uninsured. It particularly benefits millions of lower-income workers whose employers do not provide health insurance and whose income exceeds Medicaid's low eligibility levels. Second, the Act specifies a "comprehensive benefit package" which would create a floor of equal coverage, while also allowing consumers to buy additional benefits.³⁴ Third, Medicaid recipients—by definition low-income consumers—would choose health plans and receive care through the same regional alliances as most other consumers, thereby helping to overcome the long tradition of segregated and inferior care for the poor.³⁵ More generally, the Act attempts in various ways, in the words of the White House Domestic Policy Council Report, to "provid[e] care based only on

³³ HSA § 1001. See *supra* note 3.

³⁴ See HSA §§ 1101-1128.

³⁵ See HSA §§ 1001(d), 1002(b)(2), 4201. On the tradition of segregated and inferior care for the poor, see Rand E. Rosenblatt, *Dual Track Health Care—The Decline of the Medicaid Cure*, 44 U. CIN. L. REV. 643, 643-46 (1975). The degree to which the Act would integrate low-income consumers into a larger pool of consumers is made uncertain by its delegation to the states of substantial discretion to designate the geographic boundaries of the regional alliances. States must designate a geographic area for each alliance. HSA § 1202(b)(1). The alliance must have "a population large enough to ensure that the alliance has adequate market share to negotiate effectively with health plans," *id.* § 1202(b)(2)(A), and the state may not divide "a metropolitan statistical area." *Id.* § 1202(b)(5). Moreover, in drawing alliance boundaries states "may not discriminate on the basis of or otherwise take into account race, ethnicity, language, religion, national origin, socioeconomic status, disability, or perceived health status." *Id.* § 1202(b)(4). Despite this last prohibition, the HSA's failure to define clearly "a metropolitan statistical area" ("msa") (as between a "primary" msa, which typically includes a city and only a few nearby suburban areas, and a "consolidated" msa, which typically includes a much larger area) leaves open the distinct possibility that many suburban areas will be separated from urban areas, thereby isolating disproportionately poor and minority consumers from a larger consumer pool. See STATISTICAL ABSTRACT, *supra* note 6, at 916-17. I am indebted to Professor Rashi Fein for pointing out this ambiguity.

differences of need, not individual or group characteristics," and assure that "fair and open democratic procedures . . . underlie decisions concerning the operation of the health care system and the resolution of disputes that arise within it."³⁶ Implementation of these two principles would greatly facilitate realizing the meanings of equality and quality of care, and of entitlement, proposed above. At the same time, the Act has serious shortcomings, and changes are needed to support the fulfillment of those principles.

A. *The Tradition of Resistance to and Nonenforcement of Egalitarian Statutory Provisions*

The admirable principles of equality and quality health care will encounter resistance. Economic, budgetary, and interest-group pressures create strong incentives to avoid serving the higher-cost and/or currently uninsured patients whom the Act is designed to protect. Bureaucracies created by insurance companies, providers, and government agencies historically have operated with little consumer input and have systematically failed to enforce provisions meant to protect vulnerable groups.³⁷ A long tradition of inadequately funded, inferior, and segregated health services for low-income and minority patients remains entrenched by widespread racial, gender, ethnic, and class bias in many parts of the system.³⁸

³⁶ WHITE HOUSE DOMESTIC POLY COUNCIL, THE PRESIDENT'S HEALTH SECURITY PLAN 11, 13 (1993).

³⁷ See, e.g., LAW, *supra* note 12 (discussing the role of Blue Cross as Medicare intermediary); Elizabeth Jameson & Elizabeth Wehr, *Drafting National Health Care Reform Legislation to Protect the Health Interests of Children*, 5 STAN. L. & POLY REV. 152, 166-68 (1993) (discussing coverage provisions of the federal HMO Act); Rosenblatt, *Social Legislation*, *supra* note 16 (discussing the Boren Amendment and other legislation); Rosenblatt, *Health Care Reform*, *supra* note 16 (discussing the Hill-Burton Act, Medicaid and national health planning); Sidney D. Watson, *Health Care in the Inner City: Asking the Right Question*, 71 N.C. L. REV. 1648, 1666-71 (1993) (discussing Title VI of the 1964 Civil Rights Act).

³⁸ See, e.g., AMA Council on Ethical & Jud. Aff., *Black-White Disparities in Health Care*, 263 JAMA 2345 (1990); Kenneth C. Goldberg et al., *Racial and Community Factors Influencing Coronary Artery Bypass Graft Surgery Rates for All 1986 Medicare Patients*, 267 JAMA 1473 (1992); Jane Perkins, *Race Discrimination in America's Health Care System*, 27 CLEARINGHOUSE REV. 371 (1993); Vernellia R. Randall, *Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans*, 3 HEALTH MATRIX 127 (1993); Mark Schlesinger, *Paying the Price: Medical Care, Minorities, and the Newly Competitive Health Care*

Against this background, it is virtually certain that the goals of equal access, quality assurance, and fair procedures will come under serious attack. Whatever the shape of the national health reform law enacted by Congress, many levels of government and the health care industry will play a large role in further defining the meaning of rights and remedies through regulations and on-the-ground operations. Legal rights, process, and advocacy will play an important role in the struggle to define and implement health care as a right "that can never be taken away."

At this critical moment in the design and implementation of reform, the federal courts have largely abandoned their important supporting role. From the early 1970s until the early 1990s, the federal courts generally had permitted beneficiaries of federal statutes to enforce judicially statutory provisions against state and federal agencies and, at times, against private entities, even in the absence of explicit statutory language granting beneficiaries specific "rights."³⁹ For example, Justice Brennan, writing for a five-justice majority in *Wilder v. Virginia Hospital Ass'n*, explained that in lawsuits against state agencies, the proper method of statutory interpretation was not to search for magic words such as "right" or "cause of action," but rather to inquire whether the statute created a "binding obligation" on a government agency to act.⁴⁰ If that obligation was intended to benefit the party seeking to enforce it, then that party—in this case, hospitals—had a federal right under the statute and a federal cause of action under 42 U.S.C. § 1983, unless the opposing party—in this case, the state agency—could show, by clear evidence, that Congress did not intend to create enforceable rights or had foreclosed enforcement under 42 U.S.C. § 1983.⁴¹

In 1992, however, after the retirement of Justices Brennan

System, 65 MILBANK Q. 270 (1987); David B. Smith, *The Racial Integration of Health Facilities*, 18 J. HEALTH POL. POL'Y & L. 851 (1993); Watson, *supra* note 37.

³⁹ See generally Rosenblatt, *Social Legislation*, *supra* note 16.

⁴⁰ 496 U.S. 498, 510-12 (1990).

⁴¹ *Id.*; see also Rosenblatt, *Social Legislation*, *supra* note 16, at 459-60; Rand E. Rosenblatt, *Statutory Interpretation and Distributive Justice: Medicaid Hospital Reimbursement and the Debate Over Public Choice*, 35 ST. LOUIS U. L.J. 793, 801 (1991).

and Marshall, and the appointment of Justices Souter and Thomas, the Supreme Court revisited this issue. In *Suter v. Artist M.*, a new majority, in an opinion by Chief Justice Rehnquist, held that a statutory funding requirement—that child protection agencies make “reasonable efforts” to prevent the removal of children from their homes—was not sufficiently clear in its language to create an enforceable right under 42 U.S.C. § 1983 or that, if it did, the “right” required only that the state file the appropriate forms with the federal government, which had been done.⁴² Although *Wilder* technically was not overruled, the Supreme Court has adopted a new approach to interpreting federal statutes that could undercut the enforceability of many of the responsibilities created by the Health Security Act and other federal legislation. Therefore, it is critical that any legislation specify duties, rights, and remedies in very clear terms.⁴³

B. *The Importance of Process in the Dynamics of Managed Competition and Managed Care*

As noted at the beginning of this article, the HSA is constructed around a central ambivalence. On the one hand, the Act promises all Americans entitlement to a comprehensive benefit package. On the other hand, it delegates the power to fashion most of the details of how the benefits will be delivered to states, regional and corporate alliances, and health plans competing to offer the lowest price and reap the highest profits. For example, all Americans will have “coverage” for hospitalization and referrals to specialist physicians, but the rules and policies that will determine whether and how patients receive those services will vary considerably among geographic areas, health plans, and income groups.⁴⁴

⁴² 112 S. Ct. 1360, 1370 (1992).

⁴³ Compare *Evelyn V. v. Kings County Hosp. Ctr.*, 819 F. Supp. 183 (E.D.N.Y. 1993) (holding, on the basis of *Suter*, that numerous federal statutory provisions and regulations regulating quality of care in the Medicaid program did not create enforceable federal rights on behalf of patients against a public hospital or local government) with *Wellington v. District of Columbia*, No. 93-452, 1994 U.S. Dist. LEXIS 4508, at *6-*9 (D.D.C. Mar. 31, 1994) (harmonizing *Wilder* and *Suter* and finding several sections of the Medicaid Act judicially enforceable against the District of Columbia).

⁴⁴ For an example of how this problem has already arisen in the Medi-

Advocates of managed competition realize that unregulated market competition in health care would have a devastating effect on patient well-being, because insurers and providers would rush to enroll healthy people and avoid patients who need services (a practice known as "preferred risk selection"). Thus, in the words of Alain Enthoven, managed competition is "not no rules," but "new rules,"⁴⁵ most of which are embodied in the Act. Because the profit motive is so powerful, and preferred risk selection so profitable, the new rules have to be very complicated and sophisticated. They begin by requiring all plans to offer a standardized benefit package, to accept all applicants during open-enrollment periods, to engage in non-discriminatory marketing, and to provide consumers with information about quality of care.⁴⁶

But even with all these protections, it is likely, either by accident or design, that some plans will enroll a significantly different range of risks than others. Therefore, the new rules also include "risk-adjusted premiums" to even out the financial playing field.⁴⁷ The goal is to direct the powerful engine of profit-seeking toward eliminating wasteful, inefficient or marginally useful service, staffing, and reimbursement practices. Yet, while there is a great deal of interesting research and argument on these topics, there is relatively little clear knowledge or consensus about what these practices are.⁴⁸ Indeed,

care/HMO context, see GERALDINE DALLEK ET AL., MEDICARE RISK-CONTRACT HMOs IN CALIFORNIA: A STUDY OF MARKETING, QUALITY, AND DUE PROCESS RIGHTS 113-20 (1993) (reporting up to six-fold variations among three California HMOs in the rates per 1,000 Medicare enrollees of coronary bypass and other surgical procedures) [hereinafter MEDICARE RISK]; see also Geraldine Dallek, Quality Assurance in the Clinton Health Plan 4 (Feb. 3, 1994) (testimony before the Subcomm. on Health & Env't of the House Comm. on Energy and Commerce) (on file with author). To be sure, comparable variations in hospitalization and surgical rates have existed for years in the traditional fee-for-service system. See, e.g., John Wennberg, *Dealing with Medical Practice Variations: A Proposal for Action*, 3 HEALTH AFF. 6 (1984). The differences between managed care and fee-for-service are that under fee-for-service, patients are at least formally free to seek second opinions or alternative sources of care, and providers' financial incentive is generally to provide rather than to withhold services.

⁴⁵ Enthoven, *supra* note 9, at 44.

⁴⁶ See HSA §§ 1401-1414; Enthoven, *supra* note 9, at 29-35.

⁴⁷ See HSA §§ 1351, 1541; Enthoven, *supra* note 9, at 33-34.

⁴⁸ See, e.g., Robert H. Brook et al., *Geographic Variations in the Use of Services: Do They Have Any Clinical Significance*, 3 HEALTH AFF. 63 (1984) (reviewing the literature and concluding that "no one can really say" whether geographic

Alain Enthoven, one of the leading managed care advocates, believes that the situation is so complex and fluid that government may be unable to specify new "rules" of socially desirable competition. In his view, a new kind of organization representing collective consumer interests (regional alliances, purchasing cooperatives, and large employers in a reconceived role) will have to engage in complex, ongoing negotiations with health care plans and providers about these issues, thereby "managing" the dynamics of health care market competition.⁴⁹

At best, the Act 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. This "discussion" will take place in many forums, including National Health Board decisions about the necessity and appropriateness of care; decisions by state governments establishing alliances or single-payer systems; decisions by alliances about health plan performance, risk-adjusted premiums, and innovative services; health plan decisions about utilization management, practice guidelines, reimbursement, staffing, and a host of other issues; and consumer decisions about where to enroll, what to ask for, and whether to complain if expectations are thwarted. The fulfillment of the principles of equality, quality, and entitlement set forth in Part I of this Article depends upon how this discussion is structured and, indeed, whether it takes place in any meaningful form.

variations mean that high-use or low-use rates, or both, are appropriate, and outlining research agenda); Mark R. Chassin et al., *Does Inappropriate Use Explain Geographic Variations in the Use of Health Care Services?*, 258 JAMA 2533 (1987) (study largely cannot confirm hypothesis that higher use is correlated with higher inappropriate use); Kathleen N. Lohr & Marilyn J. Field, *A Provisional Instrument for Assessing Clinical Practice Guidelines*, in IOM/GUIDELINES, *supra* note 10, at 346; Stone, *supra* note 9, at 113-14. The Institute of Medicine ("IOM") studies make clear that the IOM's perspective is to build on the strengths of clinical practice guidelines and utilization management, rather than engage in wholesale critique. IOM/UTILIZATION, *supra* note 10, at 4.

⁴⁹ See Enthoven, *supra* note 9, at 28-31.

C. *The Health Security Act and the Problem of Entitlement*

By this point it should be clear that statutory language and establishment of formal regulatory structures alone will not guarantee the Act's promise of universal entitlement to a comprehensive health benefit package, particularly for consumers with average or below-average incomes. Bringing this entitlement into being will require information, advocacy, public awareness, and resources. How does the HSA measure up against these realities?

The Act relies on three mechanisms to define and protect entitlements. First, it establishes a system for bringing claims almost exclusively through a new administrative process. Second, it acknowledges the existence of pre-existing health benefits law (largely state law) that is judicially enforceable, and creates new federal litigation rights and resources. Third, it creates new regulatory structures at the federal, state, and regional (within a state) levels. To some extent, these initiatives represent an advance over the current fragmented, highly inadequate non-system of rights and remedies. Yet, the new mechanisms nevertheless contain major omissions and limitations. Although the flaws in all three mechanisms are serious, this Article focuses on the administrative claims process.⁵⁰

Under the HSA, an individual patient must file a "claim" with a health plan for "payment" or "provision" (including pre-

⁵⁰ For analysis of all three statutory systems, see Rand E. Rosenblatt, *On Access to Justice, Discrimination, and Health Care Reform* (Jan. 31, 1994) (testimony before the Subcomm. on Health & Env't of the House Comm. on Energy and Commerce) (revised text for the record Feb. 14, 1994) (on file with the *Brooklyn Law Review*). The major defects of the judicial enforcement system are: (1) its failure to repeal or modify the ERISA preemption of state tort and contract law, thereby arguably leaving consumers covered by self-funded employer plans, and certainly consumers within corporate alliances, without adequate judicial remedies for negligent utilization management, and (2) its failure to specify comprehensive, uniform, and sufficiently effective standards of antidiscrimination law. For example, the judicial enforcement system fails to specify sexual orientation as a prohibited ground of discrimination. The major defects of the regulatory system are: (1) its failure to require collection of data on the race and ethnicity of patients served; (2) its failure to secure independent governance and funding of the ombudsman office; (3) its failure to provide for independent and organized consumer advocacy at various points in the system; and (4) its failure to require more explicitly states and alliances to serve traditionally disfavored interests.

authorization) of services.⁵¹ Upon receiving the claim "in complete form" the health plan must notify the patient within 30 days of its disposition. This notification must include specific reasons for a denial and, if applicable, a description of necessity/appropriateness guidelines and of the process used in making the determination, together with notice of the right to appeal for reconsideration by the plan.⁵² "Urgent Requests to Plans for Preauthorization" must be acted upon within 24 hours, or else the plan is deemed to have approved the claim.⁵³

In the event a plan denies a claim, the claimant-consumer or "any person aggrieved . . . by a denial of payment or provision of benefits under the plan" may file a complaint, under oath or affirmation, with the complaint review office for the appropriate regional alliance within one year.⁵⁴ The complaint review office will then notify the complainant of three options: (1) to forego further administrative proceedings and rely on any available judicial remedies; (2) to submit the complaint to an alternative dispute resolution program; or (3) to proceed with an administrative hearing.⁵⁵ If the third option is chosen or is pursued after failure of alternative dispute resolution, a *de novo* hearing is held before a state hearing officer in the complaint review office established by the state for each regional alliance.⁵⁶ Regional alliances are also required to establish "an office of an ombudsman to assist consumers in dealing with problems that arise with health plans and the alliance."⁵⁷

Further appeal may be had to a five-person Federal Health Plan Review Board ("FHPRB") under appellate stan-

⁵¹ HSA § 5201(a)(1).

⁵² *Id.* § 5201(b)(1), (e). Amazingly, the HSA does not appear to require plans to notify consumers of their clear statutory right to appeal beyond the plan itself. Section 5201(b)(1) states that the plan must notify the denied claimant of "the right to appeal the denial under paragraph (2)." *Id.* Paragraph (2) in turn deals with the plan's own review or reconsideration of its denial. *See id.* § 5201(b)(2).

⁵³ *Id.* § 5201(c).

⁵⁴ *Id.* § 5202(a), (b), (e), (g).

⁵⁵ *Id.* § 5203(a).

⁵⁶ HSA §§ 5202(a)(1), 5204(a)(1). Qualifications, training and conflict-of-interest issues with respect to hearing officers will be regulated by the federal Secretary of Labor. *Id.* § 5204(a)(1)(B).

⁵⁷ *Id.* § 1326.

dards of review and, if the amount in controversy is over \$10,000, an additional appeal may be taken to a United States Court of Appeals.⁵⁸ Claimants who prevail at the complaint review office stage or higher are entitled to a reasonable attorney's fee, expert witness fees, and other reasonable costs.⁵⁹

These provisions represent an advance over the current situation, in which claimants often are not informed of any rights of appeal or reconsideration, the existence of administrative remedies varies from state to state, and compensation for litigation costs and ombudsperson assistance is rarely available. At the same time, however, many improvements are needed.⁶⁰ The most important of these improvements relate to the changing nature of health financing and delivery, and to consumers' need for advocacy assistance to present their positions effectively.

If advocacy resources were available, the Act's claims system would function well to protect participants in traditional insurance plans, where patients typically receive services from independent physicians and then submit claims for reimbursement. The system will not be adequate, however, for the millions of patients who will enroll, and whom the HSA encourages to enroll, in Health Maintenance Organizations ("HMOs") and other capitated managed care plans. In these settings, patients typically do not submit "claims" for services already received, and "pre-authorization requests" may apply to only a limited number of services. Rather, patients' explicit or implicit requests for services will occur primarily in discussions with individual health care providers, whose response may be influenced by practice guidelines and financial incentives structured by the plan.⁶¹ If providers do not inform patients that certain

⁵⁸ *Id.* § 5205.

⁵⁹ *Id.* §§ 5204(f)(2), 5205(g).

⁶⁰ For example, the 30 days given to plans to decide a claim, and another 30 days for reconsideration, are too long for many conditions that may not qualify as "urgent requests," see HSA § 5201(b), (c), and should be shortened. Denials of urgent requests should be appealable beyond the hearing officer level. *See id.* § 5204(e)(2). There should be time limits for decisions by hearing officers and the Federal Health Plan Review Board ("FHPRB"). The independent judgment of the hearing officers and FHPRB members should be explicitly protected by statute. Many of these points are presented in Rosenblatt, *supra* note 50.

⁶¹ *See, e.g.,* BRADFORD H. GRAY, *THE PROFIT MOTIVE AND PATIENT CARE: THE*

service options are or might be helpful, patients likely will not be able to submit a claim for those services. Utilization management guidelines or financial incentives may also lead to the termination or reduction of a course of treatment, including hospitalization, nursing home care, or home health services, without the patient even knowing that a coverage decision—rather than a decision focusing on the patient's individual welfare—has been made.

Effective procedures for reviewing low-visibility decisions to deny or reduce care are essential for patient well-being and equity of treatment, particularly because the increasing efforts by payors (including HMOs) to influence the care of individual patients are diverse, changing, and the subject of vigorous debate. As the 1989 Institute of Medicine ("IOM") study of utilization management stated, "we find a series of working hypotheses and partial solutions that are continually revised, discarded, and even reinvented as changes occur in medical technology, social values, economic conditions, and other circumstances."⁶² Insurance contracts typically use terms such as "medically necessary" and "experimental treatment" without clear definition. Yet there is no authoritative national body to clarify their meaning, and their proper application in individual cases is hotly disputed.⁶³ Moreover, the IOM study found

CHANGING ACCOUNTABILITY OF DOCTORS AND HOSPITALS 228-33 & *passim* (1991) (reviewing a wide range of financial incentives and noting that "[w]hat is clear . . . is that the arrangements in some plans create some very strong disincentives against physicians' making patient care decisions (regarding hospitalization, diagnostic services, specialist referrals) that would cost the plan money").

⁶² IOM/UTILIZATION, *supra* note 10, at 1. A study of California HMOs serving Medicare patients surveyed hospital social workers and home health agency and rehabilitation hospital staff—professionals who are often seeking HMO approval for costly specialty services on behalf of patients—to determine who actually authorized coverage for care. A majority of the respondents reported that while treating physicians may play some role in the process, the ultimate decision was made by medical group utilization review departments or managers. MEDICARE RISK, *supra* note 44, at 80.

⁶³ Compare *Fuja v. Benefit Trust Life Ins. Co.*, 809 F. Supp. 1333 (N.D. Ill. 1992) (finding high dosage chemotherapy with autologous bone marrow transplant ("HDC/ABMT") a covered treatment for breast cancer), *rev'd*, 18 F.3d 1405 (7th Cir. 1994) with *Farley v. Benefit Trust Life Ins. Co.*, 979 F.2d 653 (8th Cir. 1992) (finding HDC/ABMT to be not covered as a treatment for skin cancer); see also *Spain v. Aetna Life Ins. Co.*, 11 F.3d 129 (9th Cir. 1993) (insurance company approves ABMT for treatment of testicular cancer and patient undergoes first two stages of treatment; company then withdraws approval for third stage of treat-

that in 1989, “[s]ystematic evidence about the impact of utilization management methods on the quality of care and on patient and provider costs is virtually nonexistent.”⁶⁴ Given the wide variety of criteria, incentives, training, supervision, and implementation methodologies, the IOM recommended that utilization management criteria—including those used by hospitals and HMOs—be made available for outside scrutiny by physicians, purchasers, and patients. The IOM study further determined that a system for patients and physicians to appeal utilization management decisions “*is an essential protection for patients.*”⁶⁵

Four changes in the HSA are critical if this protection is to be achieved. First, there must be an extensive system of notice and explanation to consumers about the existence of the appeals process and how it works, and about advocacy resources to assist them. The notice provision in § 5201(b)(1), which appears to require plans only to notify claimants of their right to appeal *within the plan*, is totally inadequate. Consumers should receive notice of the appeals system both upon enrollment and whenever the plan denies a request or payment for services. “Notice” must include addresses and telephone numbers of the alliance complaint review office and of the ombudsman and other advocacy offices. In addition, plans should be required to provide consumers with periodic notice of their appeal rights, and prominently place notices describing appeal rights and advocacy resources in provider offices and waiting rooms.⁶⁶

Second, the term “claim” must be broadened to fit the

ment, then reverses itself again and approves third stage after notification of lawsuit by patient; wrongful death action based on effects of delay in treatment held preempted by ERISA, *cert. denied*, 114 S. Ct. 1612 (1994); *\$90-Million Lawsuit Award Cuts to the Core of Managed Care Debate: Critics See the Case as an Example of Cost Obsession; A Cancer Patient Died After Her HMO Refused to Pay for an Expensive Treatment*, L.A. TIMES, Feb. 7, 1994, at D4 (summarizing *Nelene Fox v. Health Net*, No. 219692 (Cal. Super. Ct. Dec. 23, 1993), and quoting officials of other HMOs to the effect that companies make exceptions to guidelines for “business reasons” not related to medical outcomes).

⁶⁴ IOM/UTILIZATION, *supra* note 10, at 4; *see also* MARC A. RODWIN, *MEDICINE, MONEY, AND MORALS* 163 (1993).

⁶⁵ IOM/UTILIZATION, *supra* note 10, at 6 (emphasis supplied).

⁶⁶ *See* Geraldine Dallek, Will Patients and Doctors be Protected Under Health Care Reform? 3 (Feb. 3, 1994) (testimony before the Subcomm. on Labor of the Senate Comm. on Labor and Human Resources) (on file with author).

existing realities of health care delivery. Specifically, the decision of a plan to reduce or terminate an ongoing service, such as hospitalization or home health care, should trigger notice from the plan to the patient of the basis for the decision and of the patient's right to seek review. More generally, following current Medicare regulations regarding HMO grievances and appeals, the Act should make clear that consumers have a right to file a complaint and obtain a hearing whenever they believe that services or coverage *required by the comprehensive benefit package* have been wrongfully denied.⁶⁷ The obscure phrasing of § 5202(b)(1), allowing complaints only for denial of benefits "under the plan," could lead to artfully drafted plans that attempt to insulate themselves from administrative or judicial review.

Third, patients, particularly elderly and low-income patients, must have access to free or low-cost advocacy assistance if their cases are going to have any chance of being fairly heard. Physicians traditionally have acted as advocates for their patients in dealing with coverage and reimbursement issues.⁶⁸ But, as third-party utilization management and review has become more widespread and aggressive, there has been a "reportedly high level of physician compliance with the determinations of utilization managers."⁶⁹ Disturbingly, at the same time "almost one-third of the physicians who responded to a 1988 American Medical Association ("AMA") survey said that they had patients who had suffered an aggravation of an illness or injury as a result of delays or denials in a prior-authorization process."⁷⁰

The Health Security Act recognizes that physicians' opin-

⁶⁷ See 42 C.F.R. § 417.606 (1992); see also Rosenblatt, *supra* note 50, at 8-9; ASSOCIATION OF THE BAR OF NEW YORK CITY, COMM. ON FED. LEGIS., PROCEDURAL ISSUES IN THE 1994 HEALTH SECURITY ACT 3-4 (Apr. 1994) [hereinafter ASSOCIATION OF THE BAR REPORT].

⁶⁸ See, e.g., Sarchett v. Blue Shield of Cal., 729 P.2d 267 (Cal. 1987).

⁶⁹ GRAY, *supra* note 61, at 309. Gray quotes one medical journalist as reporting that when utilization review companies determine that further hospital care is not medically necessary, "[i]n almost all cases, the attending physician will discharge the patient." *Id.*; see also MEDICARE RISK, *supra* note 44, at 81, noting that according to some survey respondents, "there is little conflict over referrals between primary care doctors and utilization review departments. This apparent harmony is attributable to, as one respondent put it, 'physician's sensitivity to overutilization and financial risk issues.'" *Id.*

⁷⁰ GRAY, *supra* note 61, at 303.

ions are vital evidence in the resolution of many disputes, and requires plans to rely on qualified physicians to resolve medical issues raised by claims.⁷¹ But how claimants will obtain access to independent medical expertise to assist them in evaluating their own cases is unclear. Enrollees in managed care plans ordinarily have coverage only to see physicians associated with the plan. "Current experience with Medicare HMOs is that plan physicians will not offer evidence that contradicts their plan [or] employer's decision to deny a service."⁷² While some patients may be able to afford a second opinion from an out-of-plan physician, and later hope to re-coup such costs through a successful appeal, most low- and moderate-income patients will not be able to afford such an up-front expense, with only a contingent and delayed hope of later recovery. Thus, many meritorious claims may be foreclosed.

The integrity of the claims process requires a source of advocacy assistance for participants so that they can understand the process, present their claims appropriately and effectively, and have access to medical expertise where needed. The most efficient way of providing such assistance is through a system of qualified non-attorney patient advocates, backed by legal and medical expertise. A logical location for these advocacy services is the office of the ombudsman, which the Act creates. According to § 1326(a), "[e]ach regional alliance must establish and maintain an office of an ombudsman to assist consumers in dealing with problems that arise with health plans and the alliance."⁷³ These offices could train and employ patient advocates, organize and pay for appropriate medical expertise, and assist the private bar (through continuing legal education) in representing consumers. To perform these advocacy functions effectively, the ombudsman offices should be substantially independent of the regional alliances, with their

⁷¹ See HSA § 5201(b)(4)(C).

⁷² Alfred J. Chiplin & Sally H. Wilson, Proposed Revisions to Health Care Reform Act 1 (Nov. 4, 1993) (unpublished manuscript on file with the *Brooklyn Law Review*).

⁷³ HSA § 1326(a). The Act also permits states to exercise an option of permitting alliance consumers to designate voluntarily one dollar of the premium paid for their enrollment in an alliance health plan to pay for the operation of the office of the ombudsman. *Id.* § 1326(b). The Act does not further address the governance, funding, structure, authority, or functions of the ombudsman's office.

own boards of directors chosen on the basis of appropriate advocacy criteria and their own secure source of funding, ideally calculated as a percentage of alliance premiums.⁷⁴ Similar agencies already exist in the form of nursing home ombudsmen, protection and advocacy agencies for the developmentally disabled and mentally ill, and legal services programs, public defenders, and consumer or public advocates specializing in the area of health care delivery.

The fourth change, and perhaps most difficult, involves the substantive standards to be used in deciding claims and appeals. The Act currently contains no explicit standards.⁷⁵ Where a service is determined by a health plan to be "experimental," "investigatory," "not medically necessary or appropriate," or "inconsistent with the plan's practice guidelines," however, the Act does require plans to reveal the basis of such a determination. The Act also requires plans to disclose the "medical basis" of their determinations and "the process used in making [them]."⁷⁶ But how should a hearing officer, and those at higher levels of review, evaluate a plan's claim that its "practice guidelines" justify withholding a certain service or procedure in a particular case? Assuming the guideline was sufficiently clear and internally coherent, a hearing officer, with the assistance of expert testimony, could probably determine whether the practice guideline was accurately applied according to its own frame of reference. But, given the lack of national or professional consensus about what an adequate practice guideline is, the validity of the guidelines themselves will inevitably be challenged.

Indeed, as with many other important concepts in the rapidly changing health care context, no consensus exists even about the definition of the term "practice guideline." As the *IOM 1992 Guidelines Report* ("Report") notes,

[s]ometimes the term *practice guideline* serves as an umbrella label for practice standards, protocols, parameters, algorithms, and various other types of statements about appropriate clinical care; at other times, sharp distinctions are drawn. Debate about terminology reflects, in part, controversy and disagreement about the uses of

⁷⁴ Accord Dallek, *supra* note 66; ASSOCIATION OF THE BAR REPORT, *supra* note 67.

⁷⁵ See *infra* notes 95-100 and accompanying text (discussing HSA § 5006).

⁷⁶ HSA § 5201(e)(2), (3).

guidelines and related materials.⁷⁷

The *Report* defines the term “practice guidelines” as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.”⁷⁸ The *Report* draws a distinction between practice guidelines and “medical review criteria,” which are “systematically developed statements that can be used to assess the appropriateness of specific health care decisions, services, and outcomes.”⁷⁹ This distinction appears to concern function. Practice guidelines are to be used prospectively by practitioners and patients to “assist” in decisions about “appropriate” care, although how and through what mechanisms remains unclear. Medical review criteria, by contrast, are to be used by persons or entities outside the physician-patient relationship to “assess” the appropriateness of care for both quality assurance and cost containment purposes.⁸⁰ The *Report* notes that medical review criteria and related tools “should and do build on guidelines and may in some cases be virtually identical.”⁸¹ The Health Security Act refers only to “practice guidelines,” and evidently contemplates their use in health plan decisions denying claims for payment or provision of services.

Buried in the detached language of these definitions are important, even explosive, questions of social policy. Is it possible to construct guidelines that are “valid,” i.e., that “lead to the health and cost outcomes projected for them?”⁸² The *Report* advocates that medical review criteria should identify a role for patients in assessing the appropriateness of care or, at least, take into account patient preferences. It also advocates providing “explicit guidance about the considerations to be

⁷⁷ IOM/GUIDELINES, *supra* note 10, at 26.

⁷⁸ IOM/GUIDELINES, *supra* note 10, at 27.

⁷⁹ IOM/GUIDELINES, *supra* note 10, at 27.

⁸⁰ In either context, the IOM report defines “appropriate” care as “care for which the expected health benefit exceeds the expected negative consequences by a sufficient margin that the care is worth providing.” IOM/GUIDELINES, *supra* note 10, at 28. The IOM report also states that the use of practice guidelines to assist practitioners in making decisions “should not preclude their use for other purposes including quality assurance and payment policymaking.” *Id.* at 27.

⁸¹ IOM/GUIDELINES, *supra* note 10, at 27. There was disagreement on the IOM Committee about whether this distinction made sense, or whether the same term should be used in different contexts. *See id.* at 27 n.3.

⁸² IOM/GUIDELINES, *supra* note 10, at 8.

taken into account when adverse review decisions are appealed by professionals or patients.⁸³ This is particularly important because, as Dr. Robert H. Brook, a leading researcher on guidelines, points out, varying economic perspectives can influence the definition of "appropriateness."⁸⁴

None of this is to say that guidelines may not be useful in different contexts and for different purposes. But guidelines are currently being developed by a wide range of entities—for example, professional societies, hospitals, HMOs, insurance companies—for many different purposes, including payment policy and utilization management, and there is little consensus on methodology or criteria for guideline evaluation. In 1990, an IOM study committee on clinical practice guidelines found that "no explicit method was available for assessing existing or emerging practice guidelines. . . . [that is,] nothing existed to judge the quality, reliability, and validity of the content of the guideline itself."⁸⁵ To remedy this situation, in 1992, the IOM articulated eight "desirable attributes" of practice guidelines, and a separate list of eight such attributes for medical review criteria,⁸⁶ and set forth a provisional instru-

⁸³ IOM/GUIDELINES, *supra* note 10, at 9.

⁸⁴ See Robert H. Brook, *Practice Guidelines and Practicing Medicine: Are They Compatible?*, 262 JAMA 3027, 3029 (1988). Brook reports on a RAND Corporation study of the appropriate use of three diagnostic and treatment procedures in the Medicare population. After a literature review, nine-member multispecialty physician panels were assembled for each procedure. Using a modified Delphi process (a process for arriving at group consensus out of individual judgment), each panel ranked "indications" for the medical procedure on a scale of 1 (low appropriateness) to 9 (high appropriateness). The rankings were then applied to the case records of over 4500 patients who had undergone the medical procedures. In 12% of the cases there was "agreement" (as defined by the process) that the medical procedure had been inappropriate, and in 36% of the cases there was agreement that the care had been appropriate, with the remainder of the cases being subject to various degrees of disagreement. Brook asks: "[W]hat did we find?", and notes that the answer depends "on how and from what perspective one views the data." A physician who believes in clinical freedom might argue that only the 12% of the cases in which the panel agreed on inappropriateness should be so labeled (and perhaps not covered by Medicare), while a budget-pressed Medicare official might argue that the program should pay only for the 36% of the cases in which the panel agreed on appropriateness. As Brook notes, "a lot of medicine exists between these two extremes." *Id.*

⁸⁵ Lohr & Field, *supra* note 48, at 346.

⁸⁶ The desirable attributes for practice guidelines are: validity, reliability/reproducibility, clinical applicability, clinical flexibility, clarity, multidisciplinary process, scheduled review, and documentation. IOM/GUIDELINES, *supra* note 10, at

ment for assessing clinical practice guidelines.⁸⁷ These commendable initiatives, however, do not provide hearing officers or other non-medical decisionmakers—or even most physicians—with usable standards of evaluation. As Lohr and Field point out, the provisional instrument form “is not simple,” and “the IOM does not expect practicing physicians or other clinicians, patients, other nonprofessionals, or policymakers to apply this instrument.”⁸⁸

The *Report* also raises important questions about whether and how patients should be informed about clinical practice guidelines, both as a matter of fair decisionmaking about which plan to join, and informed consent to particular treatments. The *Report* states:

[B]y enrolling in certain types of health plans, should patients forfeit their right to information—at the point of service—about treatment options of some benefit that are not (or may not be) covered by the plan? If so, is such a forfeiture absolute, or is it conditional on the provision to patients of clear advance warning that such limits may be applied? If the latter, who is responsible for that advance warning—government, an employer, the health plan, or the practitioner? How detailed should the warning be with respect to how limits are set and which specific treatment options are not available (taking legal, organizational, and other practical issues into account)? Should the warning meet certain readability standards (e.g., eighth-grade reading level)?⁸⁹

These questions, raised by a prestigious national committee, suggest that the widespread development and use of practice guidelines and protocols has proceeded without sufficient consideration, let alone resolution, of fundamentally important questions. The Act's few references to these issues are exceedingly brief. Health plans are required to “disclose to enrollees (and prospective enrollees) the protocols used by the plan for

8. The desirable attributes for medical review criteria are: sensitivity, specificity, patient responsiveness, readability, minimum obtrusiveness, feasibility, computer compatibility, and appeals criteria. *Id.* at 9.

⁸⁷ See Lohr & Field, *supra* note 48, at 346.

⁸⁸ Lohr & Field, *supra* note 48, at 347. The provisional instrument is designed to be used by individuals or groups with three types of expertise: clinical experience treating conditions covered by the guideline, research experience in the conditions or technologies covered, and methodological skills in developing guidelines. See *id.*

⁸⁹ IOM/GUIDELINES, *supra* note 10, at 150-51.

controlling utilization and costs,"⁹⁰ and "procedures for assuring and improving the quality of care."⁹¹ Regional alliances must make available, in "an easily understood" form, information that allows individuals to make valid comparisons among health plans concerning costs, characteristics, and availability of providers, and "any restrictions on access to providers and services under the plan."⁹² As previously discussed, health plans must disclose clinical practice guidelines when used as a basis for denial of claims.⁹³ While, in theory, these simple, skeletal provisions could generate substantial pro-consumer information and review, the track record of federal and state agencies on collecting, disseminating, and using even more elementary information about HMO utilization and grievances is not encouraging.⁹⁴

Eventually, some usable standards may come into existence through federal guidelines. The HSA does direct the National Quality Management Council ("NQMC") and the Administrator for Health Care Policy and Research ("AHCPR") "to develop and periodically review and update clinical practice guidelines that may be used by health care providers in determining how diseases, disorders and other health conditions can most effectively and appropriately be prevented, diagnosed,

⁹⁰ HSA § 1412.

⁹¹ *Id.* § 1404(b)(1)(D).

⁹² *Id.* § 1325.

⁹³ *Id.* § 5201(e)(3).

⁹⁴ See MEDICARE RISK, *supra* note 44, at 105, 113-20 (although many HMOs have extensive data on utilization, they do not release this data to the public; data reported to government agencies, such as the federal Health Care Financing Administration ("HCFA") and the California Department of Corporations ("DOC"), are virtually useless for evaluating HMO performance because of lack of consistent definition of "hospitalization" among HMOs and lack of age- and sex-adjusted data); *id.* at 95-97 (HCFA's Beneficiary Inquiry Tracking System ("BITS"), while of some use, must be read with caution because HCFA does not systematically collect inquiries/complaint data, beneficiaries are not informed that they can submit complaints to HCFA, and there is no information about the seriousness or validity of the inquiries/complaints); *id.* at 99-100 (DOC purports to rely primarily on consumer complaints to monitor HMOs, but does not inform Medicare HMO beneficiaries that they can submit complaints to DOC, has no formal record of complaints, and could not supply researchers with any information about number of complaints regarding each HMO or breakdown of the type of complaint); *id.* at 103-04, 133 (no federal or state agency supplies the public with any information on HMO complaint records; it took the Medicare Advocacy Project "almost a year and substantial effort, including litigation, to obtain what is, by law, public information" from HCFA).

treated, and managed clinically.”⁹⁵ Such guidelines must incorporate or be consistent with six factors or standards. For example, guidelines must “be based on the best available research and professional judgment regarding the effectiveness and appropriateness of health care services and procedures.”⁹⁶ Moreover, the NQMC is directed to “establish standards and procedures for evaluating the clinical appropriateness of protocols used to manage health service utilization.”⁹⁷ Finally, the NQMC is required to direct the AHCPH to “develop and publish standards relating to methodologies” for development of clinical practice guidelines, and to “establish a procedure by which individuals and entities may submit [clinical practice guidelines to the NQMC] for evaluation and certification” using the developed standards.⁹⁸

While these and other provisions may help shape, and be shaped by, an eventual professional or national consensus on practice guidelines, they will not provide usable standards of decision for the administrative claims process within the short or perhaps even medium term. As the IOM reports make clear, such consensus and standards do not now exist, and are likely to take a considerable time to develop. Furthermore, the Act itself does not appear to require the use of these standards in the administrative process. While the HSA is careful to state that clinical practice guidelines developed or certified by the NQMC “may” be used by the Secretary of Health and Human Services (“HHS”) in the medical malpractice liability pilot program,⁹⁹ the Act does not require hearing officers to use such guidelines or standards as the basis of decision, nor does it appear to require health plans to use them in setting their own practice guidelines or utilization protocols.¹⁰⁰

⁹⁵ HSA § 5006(a)(1). See generally *id.* §§ 5002-5007.

⁹⁶ *Id.* § 5006(a)(2)(A).

⁹⁷ *Id.* § 5006(a)(3).

⁹⁸ *Id.* § 5006(b)(1), (2)

⁹⁹ See *id.* § 5006(a)(4), (b)(3), referring to § 5312, which requires the Secretary of HHS, if NQMC guidelines are available, to establish and fund a pilot program in one or more states to determine the effect of allowing provider compliance with such guidelines to be “a complete defense” in a medical malpractice liability action.

¹⁰⁰ The requirement in § 5006(a)(1) that the NQMC and the AHCPH review and update “guidelines that *may* be used by health care providers” (emphasis added), could be interpreted as a prohibition on the use of any guidelines not so “reviewed.” This interpretation is not consistent with other sections of the Act (e.g., §

Against this background of transition and uncertainty, two issues may prove to be of critical importance: (1) the allocation of the burden of proof in the administrative process; and (2) incorporation of patient interests and perspectives into the guidelines themselves. Regarding the burden of proof, the Act states that hearing officers make decisions based "upon the preponderance of the evidence," but does not state who has the burden of proof or persuasion.¹⁰¹ If the claimant has the burden of proving that a clinical practice guideline is "invalid," doing so may well be impossible because of the absence of professional consensus concerning standards for guideline validity, and the possibly large costs involved in trying to present such proof. In contrast, placing the burden on the plan to prove the guideline "valid" or at least "not invalid" is defensible on several grounds. First, the health plan has far greater resources to conduct research and mobilize medical expertise. Second, the plan will, of course, be knowledgeable about its own process of guideline development. Third, placing the burden on the plan would have the beneficial effect of providing plans with an incentive to be careful to use the best available methods in their development of guidelines.

Regarding patient interests, the *IOM 1992 Guidelines Report* recommends several "desirable attributes" of medical review criteria.¹⁰² Addressing patient responsiveness, the *Report* stated "review criteria should specifically identify a role for patient preferences or ensure that the process for using them allows for some consideration of patient preferences." The *Report* also called for readability, noting that "review criteria should be presented in language and formats that can be read and understood by nonphysician reviewers, practitioners, and patient/consumers."¹⁰³ Focusing on appeals criteria, the *Report* recommended that "criteria should provide explicit guidance about the considerations to be taken into account when adverse decisions are appealed by professionals or pa-

5201(e)(3), which requires disclosure of a plan's practice guidelines if used as the basis of a claim denial, but which makes no reference to certification or other regulatory process), nor is it likely that such a major policy judgment would be left to obscure inference from a single word.

¹⁰¹ HSA § 5204(d)(1).

¹⁰² See *supra* note 86 and accompanying text.

¹⁰³ IOM/GUIDELINES, *supra* note 10, at 9.

tients."¹⁰⁴ Finally, the *Report* called for development of "general guidelines on patient information and informed consent" through "a more inclusive development process involving . . . more representation of health care purchasers and third-party payers, consumers and patients, and the legal profession."¹⁰⁵ As currently written, the Health Security Act does not explicitly address any of these issues. The NQMC, perhaps in conjunction with the National Health Board, should be required to develop policies within a set period (e.g., two years) on these matters, which would be binding on the administrative review and plan certification process, or report to Congress on why such a mandate could not be achieved and what legislative changes should be enacted as a consequence.

D. *The Paradox of Entitlement and Inequality*

Up to this point, this Article has discussed barriers to achieving entitlements that affect the great majority of Americans who likely will receive some version of managed care. The struggle for effective consumer information, rights to claims and appeals, advocacy assistance, and substantive standards of decision benefits a wide range of consumers from all income groups and social classes and, hence, could be the basis of the kind of "cross-class coalition" for which Ed Sparer worked and advocated. In theory, low-income and minority consumers would benefit especially from these developments, because they are most at risk of lack of access, underservice, and oppressive rationing of care.¹⁰⁶

Unfortunately, there is reason to believe that lower-income and minority Americans often benefit disproportionately less from entitlements, rights, and appeal procedures than other citizens with more political, economic, and social resources and support. A well-known example is that of special education for handicapped children. A federal statute establishes extensive rights of parental notice, hearing, and consent,¹⁰⁷ but, accord-

¹⁰⁴ IOM/GUIDELINES, *supra* note 10, at 9.

¹⁰⁵ IOM/GUIDELINES, *supra* note 10, at 152; *see also id.* at 204, 217-19.

¹⁰⁶ *See, e.g., supra* note 38; Rand E. Rosenblatt, *Rationing "Normal" Health Care: The Hidden Legal Issues*, 59 TEX. L. REV. 1401, 1407-20 (1981); Andreas Schneider & JoAnne Stern, *Health Maintenance Organizations and the Poor: Problems and Prospects*, 70 NW. U. L. REV. 90 (1975); Watson, *supra* note 37.

¹⁰⁷ *See* Individuals With Disabilities Education Act, 20 U.S.C. §§ 1400-1461

ing to Professor Joel Handler,

[t]here seems little doubt . . . that the procedures designed to give the parents a participatory role in decisions affecting their children do not work. . . .

. . . .

The average parent, especially in lower socio-economic classes, does not have the ability to participate. In addition to the psychological burdens of coping with a handicapped child, most parents lack the information and the resources to deal with the school bureaucracy. . . . While the articulate, knowledgeable, middle and upper-middle class parents, pressing for expensive out-of-school placements for severely handicapped children, hold their own, the average lower class or minority parents are silenced by administrative domination. . . .¹⁰⁸

Handler generalizes this point as follows:

[In the 1960s and mid-1970s, t]here was a vast outpouring of substantive entitlements and due process remedies. Yet, for the most part, the reforms [did] not work because most dependent people are unable to take advantage of their rights. Our legal system is not proactive. In order for the system to work there must be a *complaining client*. People have to know they have suffered a harm, they have to blame someone rather than themselves for that harm, they have to know how to pursue the remedy, they have to have resources to pursue the remedy, and the potential benefits of winning have to outweigh the potential costs. All of these conditions are essential; . . . All of the[se] conditions present formidable barriers to dependent people who deal with large-scale public bureaucracies.¹⁰⁹

These barriers to effective entitlement are particularly powerful in the context of health care delivery. Ill patients from all socioeconomic classes are "dependent" people, suddenly separated from "normal" humanity and enmeshed in complex dependency with their caregivers. Medical authority is

(1988 & Supp. V 1993).

¹⁰⁸ Joel F. Handler, *Dependent People, The State, and the Modern/Postmodern Search for the Dialogic Community*, 35 UCLA L. REV. 999, 1009-10 (1988); see also Howard Lesnick, *The Wellsprings of Legal Responses to Inequality: A Perspective on Perspectives*, 1991 DUKE L.J. 413, 419-39 & *passim* (exploring the law's response to inequality in common law and theoretical contexts).

¹⁰⁹ *Id.* at 1019-20. Handler does not explicitly define the term "dependent people." His examples refer to welfare recipients, most patients, most handicapped children and their parents, and the frail, elderly poor. He appears to equate "dependency" with relationships that are, "at least initially, characterized by great disparities in power, . . . strongly hierarchical, and, for all practical purposes, coercive." *Id.* at 1001.

large and mysterious; insurance policies are complex and unknowable; and there is relatively little tradition or knowledge of "consumerism" or advocacy on behalf of patients.¹¹⁰ The expanded rights and procedures advocated in this Article, in theory, would be available to all patients. In practice, however, they might result in *more* inequality, as well-off, articulate patients successfully challenge practice guidelines while the great majority of patients are found to have "less persuasive" claims or do not attempt to pursue them.

What is the significance of pervasive social inequality for the desirability and meaning of rights? Some legal academics view the high transaction costs and uneven benefit distribution of contested rights as reasons to abolish rights as much as possible and to rely on market mechanisms and charitable and professional norms to provide services to the poor.¹¹¹ The United States Supreme Court considered a similar issue in *Griffin v. Illinois*, in the context of criminal appeals.¹¹² The state conceded that two defendants convicted of armed robbery needed a trial transcript in order to get adequate appellate review, could not afford to pay for one, and had filed a timely motion requesting that a transcript be provided without charge. Because the state appellate courts had exercised no substantive review, the Supreme Court assumed for purposes of decision "that errors were committed in the trial that would merit reversal," and that defendants would not receive a reversal solely because they could not afford a transcript.¹¹³

Even given these assumptions, Justice Harlan and three other dissenting justices found no constitutional violation in

¹¹⁰ See, e.g., Ann Hood, *I'm Insured—I Think*, N.Y. TIMES, Apr. 13, 1994, at A21 (op-ed article by novelist recounting how she was denied maternity coverage without notice in March 1993 on the ground that she had moved from New York to Rhode Island, and how she spent one year without success seeking a remedy from the insurance company, the membership organization who sponsored the policy, and the Rhode Island Department of Insurance, all apparently without consulting a lawyer; coverage was eventually restored with "no apology, no explanation").

¹¹¹ See, e.g., Epstein, *supra* note 10; Epstein, *supra* note 25. Other analysts want to restrict opportunities for litigation in favor of bureaucratic rationality, relying primarily on management norms and incentives and "adequate and expeditious administrative remedies" to achieve fairness and maximum social utility. See, e.g., Michael J. Graetz & Jerry L. Mashaw, *Praise Reform and Start the Litigation?*, 329 NEW ENG. J. MED. 1735 (1993).

¹¹² 351 U.S. 12 (1956).

¹¹³ *Id.* at 16.

the state's refusal to provide a transcript. In the dissenter's view, economic inequality pervasively affected the realization of rights. This disparity determined (in that pre-*Gideon* era) whether counsel could be obtained at all, the quality of counsel, and the thoroughness of investigation. The state had no duty to moderate the inequalities flowing from these circumstances. It could charge tuition for state university, even though that might bar a poor but qualified student. This inability to realize a right—to appeal a criminal conviction—was no different in principle from any of these other market-created barriers.¹¹⁴

In reply, Justice Frankfurter's concurring opinion conceded that "[a] man of means may be able to afford the retention of an expensive, able counsel not within reach of a poor man's purse," and that the state had no duty to correct these "contingencies of life."¹¹⁵ But that did not justify a state denying poor—and by hypothesis, erroneously convicted—defendants the practical opportunity to *any* appellate review, as long as it provided the general opportunity for such review. "The State," wrote Frankfurter, "is not free to produce such a squalid discrimination. . . . [It] cannot keep the word of promise to the ear of those illegally convicted and break it to their hope."¹¹⁶ Whatever the merits of Justice Frankfurter's particular drawing of lines, the challenge for persons committed to equality and quality in health care is to devise egalitarian ways of securing rights in a pervasively unequal world.

History and scholarship suggest two potential solutions to this challenge, although each solution is itself hard to achieve. The first, eloquently advocated by Ed Sparer and many others in the labor, civil rights, antipoverty, and feminist movements, involves the existence of "social movements." As individuals, people are often overwhelmed by economic, physical, and emotional needs, and disempowered through fear and self-blame. "The successful appropriation of rights depends on empowerment," which can occur "through group identification and soli-

¹¹⁴ See *Griffin v. Illinois*, 351 U.S. 12, 26 (1956) (Burton & Minton, JJ., dissenting); *id.* at 29 (Harlan, J., dissenting); see also *Douglas v. California*, 372 U.S. 353, 358 (1963) (Clark, J., dissenting); *id.* at 360 (Harlan, J., dissenting).

¹¹⁵ *Griffin*, 351 U.S. at 23 (Frankfurter, J., concurring).

¹¹⁶ *Id.* at 24.

darity."¹¹⁷ To mention only one of many examples, advocates for pay equity for women used federal statutory rights as tools in a broad-based movement that drew its energy from many other cultural sources as well. "[T]hrough organization, people's feelings about themselves changed. Women were now fighting for the recognition of their own worth."¹¹⁸ One of the great unknowns is whether there are social groupings and organizations in the United States with sufficient vision and resources to bring a broad-based health consumers movement into existence, with connections to other social movements such as those for equality based on race, gender, ethnicity, sexual orientation, disability, and economic class. Efforts along these lines are taking place,¹¹⁹ and only after years of sustained work will we know their potential for influence and success.

A second direction for effort, which might complement social movements, involves strengthening and expanding an ethic of dialogue and empowerment between health care providers and consumers. Joel Handler, William Simon and others have identified situations in which rights have had a "regenerative" character because the relevant professionals treated the autonomy of the client as a goal to be actively and supportively achieved rather than as a formal and unrealistic premise or assumption.¹²⁰ The IOM reports reflect this ethic by calling for new ways of incorporating patient preferences and rights into the development and implementation of practice guidelines. But whether this kind of professional ethic can flourish against the large forces of traditional hierarchical professionalism, on the one hand, and de-professionalization characteristic of market competition (e.g., doctors being increasingly treated as skilled employees under the control of higher management),

¹¹⁷ Handler, *supra* note 6, at 971.

¹¹⁸ Handler, *supra* note 6, at 964 (citing Michael McCann, Legal Mobilization, Rights Consciousness, and the Politics of Pay Equity Reform (June 8-11, 1989) (paper delivered at the 1989 Annual Meeting of the Law and Society Association).

¹¹⁹ See, e.g., Mydans, *supra* note 5.

¹²⁰ See, e.g., Handler, *supra* note 6, at 1096 & *passim*; Handler, *supra* note 108; William H. Simon, *Rights and Redistribution in the Welfare System*, 38 STAN. L. REV. 1431 (1986); William H. Simon, *The Invention and Reinvention of Welfare Rights*, 44 MD. L. REV. 1 (1985); see also Anthony V. Alfieri, *Impoverished Practices*, 81 GEO. L.J. 2567 (1993) (analyzing growing literature and exploring philosophical context).

on the other, is a sobering question, and one that suggests the degree of conscious effort that will be required to achieve the ethic's development.

CONCLUSION

I remember reading that Justice Holmes once said, presumably in one of his more cynical or despairing moments, something to the effect that his work as a judge was not doing justice, but "just following the rules." For poor Americans and, I have argued, for most Americans, "following the rules" under health care reform is not opposed to justice. It *is* justice, if "following the rules" is understood as a process of fair notice, fair application, and fair dialogue over discretion and evolving standards. Achieving entitlement to equality and quality of care depends on building such fairness into our legal structures and creating a culture that understands and supports them.