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Beneath The Abstractions Of Our Health Care Debate

by David A. Rochefort

Mama Might Be Better off Dead: The Failure of Health Care in Urban America
by Laurie Kaye Abraham
(Chicago: The University of Chicago Press, 1993), 289 pp., $22.50

Carl Sandburg called it the “city of the big shoulders” and “hog butcher for the world.” The poet loved his life-pulsing Chicago, but he recognized its brutal side, too, in the “marks of wanton hunger” on the faces of women and children. In her new book Laurie Kaye Abraham exposes a different side of brutality in this great midwestern city: the glaring disparity between the medical excellence and abundance that are theoretically available for all and the often subpar health care that is actually received by those who are poor.

The problem, of course, is not Chicago’s uniquely. Conditions here are a microcosm of a flawed arrangement of health care organization and finance that is national in character and that arises from a baffling patchwork of federal, state, and local public policies as well as decisions made by the private health sector. A journalist by profession, Abraham follows the workings of this “system” as it intersects with the lives of a single low-income, black family over the period of approximately one year. By this method, she takes us off the “treadmill of abstraction,” in Henry James’s phrase, that dominates the health policy debate in our nation’s capital. Writing in a clear, factual style that continually situates the personal within the social, Abraham has produced policy-relevant journalism of a type and caliber that recalls Susan Sheehan’s highly praised writings on mental illness, old age, and welfare.

The Banes family, which is at the center of attention in this book, includes the parents, Jackie and Robert; their children, Latrice, DeMarest, and Brianna; and Jackie’s grandmother, Cora Jackson. Among these persons are a number of severe medical problems. Tommy Markham, Jackie’s father, also figures significantly in this book, although only at the end does he become a Banes household member.

In discussions of national health care reform, one still hears the claim that while not every American may have health coverage, no one in need goes without care. Often employed as an argument against an expensive universal insurance program, the allusion is to the provision of charity and “uncompensated care” services by some physicians, hospitals, and community clinics. Such practices do exist, but no one reading this book can come away with the feeling that these services are adequate or equitable. The author shows how care received on this basis tends to come late, is episodic, often occurs in inappropriate settings (for example, the hospital emergency room), and imposes inconveniences, uncertainties, and stigma, all of which constitute real barriers. Abraham tells it without pulling her punch: “[P]erhaps the only time the uninsured have a good chance of getting timely, quality care is when they are damn near death.” During the period of this book, the Banes family members are more fortunate than many, in the sense that they have come to qualify for assistance under Medicare and Medicaid. But, as Abraham paints it, the various gaps,

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restrictions, and limitations found in these public programs hardly make for a rosy picture of easily accessible medical care, and she supplements her personalized tale of the Banes family with jolting statistics on treatment differentials for the uninsured, Medicaid recipients, and African Americans versus other Americans.

The author presents her characters as real human beings—not cardboard cutouts—living lives stressed by physical infirmity, impoverishment, and a dangerous environment. She does not hide their warts. It is Jackie who, growing despondent over the course of her grandmother's illness, gives the book its title by exclaiming, "Sometimes, it seems like Mama might be better off dead." If such a statement seems callous, it represents but the occasional expressions of exasperation from a woman who is otherwise performing a heroic job of caregiving without sufficient financial or emotional support.

The men in this family possess weaknesses of their own that are interwoven with their health problems. Tommy Markham had a paralyzing stroke when he went off his blood pressure medication because he didn't like its side effect of impotence. Afterward, he continued to smoke and to eat an improper diet against his doctor's advice. Robert had a drug habit he could not overcome, which may have contributed to the loss of his transplanted kidney. Waiting for a second transplant operation, he continued to take illegal drugs. The author uses these situations to consider the "individual responsibility movement" and its emphasis on voluntary adoption of healthy behavior as a cornerstone of health policy. She argues forthrightly that this perspective overlooks many factors that make it more difficult for the poor to follow healthy lifestyles: weak relationships with providers, mistaken medical beliefs, psychological denial, high costs, and a different set of environmental influences and life prospects. She also feels that this attempt to allocate personal responsibility for health problems deflects momentum from systemic reform by blaming the poor and minorities for making themselves sick. It is a controversy that will continue to burn, stoked by the growing prospect of explicit rationing in our individualistic culture.

At one point Cora Jackson develops serious depression, a predicament illustrating plainly the discontinuities of care. Nothing was said about needed treatment to Jackie, who was playing a central role in organizing her grandmother's care. Other difficulties entered in as well. The Illinois Medicaid program does not pay for outpatient psychological care, and Medicare covers it with a steep 50 percent copayment. So Cora would have been hard-pressed to afford the care recommended. Moreover, she lacked transportation to get to the treatment locations.

During one of her frequent hospitalizations Cora was given antidepressants by a consulting psychiatrist. Inexplicably, however, the physician took her off the medication at discharge, after only thirteen days, contrary to indicated usage. The patient's chart recorded a recommendation for outpatient psychiatric follow-up, but again no one spoke to Jackie Banes about it. The author reports that the hospital at which this series of events occurred had an innovative home psychiatric program exactly suitable for patients like Cora Jackson. But no one on staff made the referral. In all, it is a sad chronicle of substandard treatment because the payment and administrative mechanisms needed to protect multiply disadvantaged patients are lacking or incomplete.

Based on the insights of her study, Abraham closes her book with brief general recommendations for the direction of national health reform. She also calls for a new vision of health care that limits the endless pursuit of curing at the expense of caring.

Yet one can also find in this sophisticated case analysis support for a host of practical policy suggestions relating to special financial aid to inner-city hospitals, subsidization of primary care clinics for the poor, health provider training for underserved areas, comprehensive mental health care benefits, improved public health services, and the further development of coordinated health care management and delivery structures. Whether or not such elements are incorporated in the health policy overhaul now being designed in Washington will determine
how much of a “reform” we get from the process.

Abraham warns that her story of one struggling family speaks directly to the risks that more and more middle-class Americans face as the wave of uninsurance swells. But what comes through most strongly from her book is a world that most of mainstream America is not likely to experience firsthand. In this light, the greatest danger to comprehensive change in health care lies in those proposals that would use modest insurance reforms to ease the principal fears of the middle class without grappling with the essential questions of social justice so eloquently framed by Abraham.

Clear-Headed Answers To The Obvious Questions

by Theodore R. Marmor

Your Money or Your Life: The Health Care Crisis Explained

by Marc J. Roberts with Alexandra T. Clyde

(New York: Doubleday, 1993), 160 pp., $9.95 (paper)

Disputes over public policy in the United States are notably noisy, messy matters. This is the case whether the issue is support for Star Wars or Supreme Court nominees, tax increases or prayer in the schools, welfare reform or universal health insurance. The particular groups and advocates obviously vary, but there clearly is a recurrent process at work.

Claims of crisis are used to attract attention, and charges of emotionalism and publicity-seeking follow soon after. Seemingly appropriate statistical aggregates are trotted out: American health expenditures, deficit levels here and abroad, numbers of Soviet missiles (when that was relevant). Estimates of the number of homeless, fearful, fearful, or homely are presented in print, speeches, and interviews as if their particular truth entailed a discrete policy remedy. Factthrowing begets a familiar form of policy exchange—ridicule for the other side and relief that one’s own position is the right answer. Audiences are told that there will be difficulties, of course, but with political will and a modicum of good luck, the nation can choose the course and move toward the desirable state of affairs—lower infant mortality, better education, more effective defense, more readily available drugs, control over Alzheimer’s disease, reduced levels of cancer, lower health costs, and on and on. This is the kind of policy talk I call “crisis mongering.”

The supply of American problems is by definition enormous. The simple citation of facts can always establish a gap between aspiration and actuality. Compelling, appealing illustrations can demonstrate the character of present difficulties and suggest the crafting of appropriate remedies. “There ought to be a change in the law. There must be something we can do about this,” runs the familiar refrain. Precisely what change and what remedy are right is the real core of the dispute.

The recent politics of health care reform are no exception to this pattern. Crisis-mongering, fact-throwing, and heady explanations of one remedy after another—all of this has marked the period since Harris Wofford’s 1991 senatorial campaign brought America’s health problems to the top of the nation’s public agenda. The debate has hardly been illuminating. A year after President Clinton presented the product of his enormous task force on reform, the American public is more confused and the legislative context more stalemated than it was before all of this happened.

It is in this context that Marc Roberts and Alexandra Clyde’s recent paperback deserves special attention. Any citizen puzzled by the feverish claims and counterclaims of what passes for our national health reform.

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