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Book Review - Uninsured in America: Life and Death in the Land of Opportunity

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UNINSURED IN AMERICA: LIFE AND DEATH IN THE LAND OF OPPORTUNITY

SUSAN STARR SERED & RUSHIKA FERNANDOPULLE (University of California Press, Berkeley, California, 2007), 237 pages, $24.95.

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INTRODUCTION

Health care reform tops our national policy agenda, ranking second only behind Iraq as the issue that the public wants the 2008 Presidential candidates to address.[1] This is no surprise, as health care spending represents nearly one out of every six dollars spent in the national economy,[2] costs continue to climb, and health insurance is increasingly hard to get, keep, and afford. The numbers are staggering, and numbing. Most of us have heard that 46.5 million people were without insurance for the entire year in 2006,[3] and nearly 89.6 million people were without insurance for some period during 2006 or 2007[4]—but what does that mean?

In this vivid and moving book, Susan Starr Sered, an anthropologist,[5] and Rushika Fernandopulle, a physician specializing in health care policy,[6]

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[**] Editor's note: Numbers in brackets in the text refer to pages in the reviewed work.

[1] Kaiser Health Tracking Poll: Election Poll, Issue 4 (Oct. 2007), *available at* http://www.kff.org/kaiserpolls/h08_pomr102607pkg.cfm (last visited Nov, 28, 2007).

[2] KAISER FAMILY FOUNDATION, TRENDS IN HEALTH CARE COSTS AND SPENDING (Sept. 2007), *available at* http://kff.org/insurance/upload/7692.pdf (last visited Nov. 28, 2007).

[3] Paul Fronstin, *Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 2007 Current Population Survey*, EBRI ISSUE BRIEF No. 310 (Oct. 2007).

[4] WRONG DIRECTION: ONE OUT OF THREE AMERICANS ARE UNINSURED: A REPORT BY FAMILIES USA (Sept. 2007), *available at* http://www.familiesusa.org/resources/publications/reports/wrong-direction.html (last visited Nov. 28, 2007).

[5] Susan Starr Sered is Senior Research Associate at Suffolk University's Center for Women's Health and Human Rights and former Research Director at Harvard University's Center for the Study of World Religions. *See* http://www.ucpress.edu/books/pages/10379.html#bio (last visited Nov. 28, 2007).

[6] Rushika Fernandopulle is a physician on the clinical staff at the Massachusetts General Hospital and the faculty of Harvard Medical School. *See* http://www.ucpress.edu/books/pages/10379.html#bio (last visited Nov. 28, 2007).

set out to find some answers to these troubling and very important questions:

> Where are the uninsured? Who are they? Why are they uninsured, and how do they scrape by? What does the absence of consistent access to medical care mean in their lives? What is its impact on their jobs, their families, their aspirations? And, equally important, what does the fact that more than forty million Americans lack reasonable access to health care mean for our country as a whole? [p. 2]**

Together, they conducted in-depth interviews with 120 uninsured women and men, as well as numerous health care providers, researchers, policy makers, and advocates. Rather than examine "the problem of the uninsured," they let the uninsured speak to us of their problems in their own words. Facts and figures are woven in throughout, providing social, legal, and historical context to the lived experiences of the men and women interviewed.

Written in a readable, engaging style, this book is well-suited to a non-expert audience and offers something for experts in health law and policy as well. These well-chosen stories can serve as a test suite for evaluating proposals for reform at the dinner table, in the classroom, or as part of public debate. The authors' stated intention is to provoke discussion, and the original interviews were conducted with an eye toward the 2004 Presidential election. This revised edition has been updated with follow-up interviews and a new afterword linking their findings to some recent health care trends, just in time for the 2008 Presidential election.

DESCENT INTO THE DEATH SPIRAL

Starr Sered and Fernandopulle frame their stories by recasting two familiar concepts—the "death spiral" and the caste system. The death spiral is a term used to describe the process by which a pool of people covered by an insurance plan loses its relatively healthy members, causing costs to increase for the remaining members. Unchecked, the spiral continues until the insurance plan can no longer be sustained and ultimately "dies." Starr Sered and Fernandopulle use this concept to describe the descent of an increasing number of uninsured Americans into unrelieved sickness and suffering, unemployment, financial ruin, and even death. It is a terrifying vision, made more so by the fact that their research was aimed not at the "horror stories" but, instead, at "those who had 'done all the right things' but still found themselves pulled in." [p. 172]

Chapters One through Nine are organized around different portals to the death spiral, including: corporate restructuring; low-wage, self- or small-business employment; divorce and domestic violence; family care-giving; dangerous workplaces; mental illness; and racism. These are concrete and

detailed portrayals, allowing the subjects to speak to us in their own voices—voices that are seldom heard. A great achievement of this book is that it turns statistical lives into people that we know and care about, people that we root for.

UNRELIEVED SICKNESS AND SUFFERING

In terms of physical health, many readers already will be familiar with what happens when insurance coverage is lost, as it is well documented that people without insurance receive less care, delayed care, and suffer worse outcomes than people with insurance.[7] Starr Sered and Fernandopulle show us what this means: teeth rot; marred bodies stiffen and scar; diabetes leads to amputations; depressions deepen; and, of course, pain rages despite attempts at self-medication with an alarming mix and quantity of drugstore remedies. As for "safety net" programs, such as workers' compensation or Medicare and Medicaid, shifting income and employment rules, lack of a stable home address, and lack of time, knowledge, and energy to navigate a bureaucratic and medical maze appear to riddle them with sizeable holes.

FINANCIAL RUIN

If lack of insurance can destroy physical health, it can also bring financial ruin. Several of the portals to the death spiral revolve around work—vanished, low-wage, part-time, entrepreneurial, dangerous, or unpaid jobs. Often the loss of a job (or a job with benefits) begins the descent, underscoring one of the authors' strongest points, that the link between employment and health insurance must be severed. Some of the people interviewed had access to some type of coverage through employment but were unable to afford the premiums, deductibles, and co-payments.

What does it mean to say coverage is "unaffordable?"[8] For some, paying for coverage (adequate or not) would not leave enough to pay for basic necessities, such as food, housing, or diapers. Roberta, the "trailing spouse" of an academic who lost coverage when her husband left, explains it this way: "[D]o you feed your child and keep your house going, or do you insure yourself for the one time a year that you might go to the doctor because you have the flu?"

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[7] *See, e.g.*, INSTITUTE OF MEDICINE, CARE WITHOUT COVERAGE: TOO LITTLE, TOO LATE, http://www.iom.edu/includes/dbfile.asp?id=4160; AMERICAN COLLEGE OF PHYSICIANS—AMERICAN SOCIETY OF INTERNAL MEDICINE, NO HEALTH INSURANCE? IT'S ENOUGH TO MAKE YOU SICK, http://www.acponline.org/uninsured/lack-contents.htm (last visited Nov. 28, 2007) (summarizing research over a 10-year period).

[8] *See* M. Kate Bundorf & Mark V. Pauly, *Is Health Insurance Affordable for the Uninsured?*, NBER Working Paper No. 9281 (Oct. 2002), *available at* http://www.nber.org/papers/w9281 (last visited Nov. 28, 2007) (depending on the definition, health insurance was "affordable" for one- to three-quarters of the uninsured during 2000).

[p. 62] Of course, that question arose before she found the malignant lump in her breast.

For others, paying for coverage may have been possible but appeared to pose an unreasonable burden in light of the benefit. Jessica and her husband, Justin, a self-employed construction worker, discontinued a catastrophic coverage policy, leaving them without insurance when he fell off a horse and broke his neck. Jessica explained: "[W]e paid and we paid and we paid. Then we would go to the doctor, and we would still have to pay the doctor bill. Then we decided we don't want to do this anymore. We just wanted to pay our medical bills and save the money that we had been paying on premiums." [p. 108] Although Jessica recognized the importance of insurance for herself, her husband, and their three children, they could not afford the premiums of $500 or more on top of $45,000 in medical bills.

Medical debt has a devastating effect on many families without insurance. When a health crisis becomes an emergency, a trip to the hospital results in unpaid and unpayable medical bills that tax family budgets, ruin credit, and threaten economic destitution. Homelessness was an ever-present fear for many of the men and women interviewed, and became a reality for some.

Stress, fear, and shame are also a burden. Gina, a young Idaho hairstylist with debilitating stomach pain, needed her gallbladder removed. Unable to afford health insurance or the surgery on her per-customer paycheck, she lived with the constant fear that her gallbladder would rupture. Loretta spoke of "the stress of choosing between buying food and buying medicine, the stress of working in temporary and seasonal jobs, the stress of feeling trapped in circumstances of poverty that she cannot control, the stress of living with a man who is often angry and frustrated that he cannot provide for his family, and, above all, the stress of living with chronic illnesses and chronic pain that she does not have the resources to remedy." [p. xxi] Significant and long-lasting depression was not uncommon.

THE MAKING OF A NEW CASTE

Awaiting people at the bottom of the death spiral is membership in a new caste, comprised of "those who are fated to become and remain sick." [p. 6] Not everyone descends at the same rate, and not everyone becomes a permanent member of the caste. Resources such as "a healthy spouse, homeownership, strong community networks, insider knowledge about how to access free or low-cost care, and hearty mental health" can be handholds, breaking or slowing the fall. [p. 169] However, it is difficult not to notice that there are many portals into the death spiral, but very few ways out.

One of the authors' most powerful insights is that descent leads to visible, recognizable markers of caste membership on the bodies of the uninsured.

Several of the men and women interviewed in the book were embarrassed about their crooked, rotting, or lost teeth. In the most unforgettable image of the book, Loretta tells us: "I've gotten toothaches so bad, so that I just literally pull my own teeth. They'll break off after a while, and then you just grab a hold of them, and they work their way out." [p. xvi] Untreated dental problems affect diet, self-esteem, and presentability for employment, further solidifying caste membership. "[A]s a result of health problems and visible indicators of poverty, such as obesity and rotten and missing teeth, securing anything more than the most minimal status job becomes difficult, and health coverage is unattainable." [p. 4]

Unable to escape, members of the caste are blamed for their own situation. Failure to make the "right choices" is seen as a personal failure rather than a failure of the system to provide adequate options. The authors draw attention to this cruel Catch-22: "Inasmuch as the association between employment and health coverage conjoins core American beliefs in the merit of work and the virtue of health, the possibility that unemployment can serve as a 'punishment' for poor health and poor health can serve as a punishment for unemployment is compelling indeed." [p. 165]

OFFERING PRINCIPLES, NOT SOLUTIONS

Despite the diversity of circumstances presented, the authors identify certain repeating patterns and themes that run through many of the life experiences presented. Drawing on these, they offer six principles for reform: (1) incremental solutions may help some, but are inadequate to help the majority of the most vulnerable; (2) mandatory participation programs for employers or consumers may also help some, but are also inadequate for the majority of the most vulnerable; (3) the link between employment and health insurance must be severed; (4) purely market-based solutions will not work; (5) basic, comprehensive health care for all Americans should be a public rather than a private responsibility; and (6) universal coverage should ensure choice and innovation.

These statements of principle break no new ground. Most Americans believe in the ideal of equal access to health care for the rich and the poor. In a recent poll, 69% of respondents agreed that "the government should do whatever is necessary, whatever it costs in taxes, to see that *everyone* gets the medical [care] they need"[9]—but we do not agree on how to structure and pay for expanded coverage. The authors lay out a convincing case for what will not work, but they offer no specific ideas on how to operationalize their principles into a policy or program of reform. There is also curiously little mention of

[9] *Fundamental Health Care Values*, 3(3) HEALTH CARE NEWS (Mar. 14, 2003) (emphasis in original), *available at* http://www.harrisinteractive.com/news/newsletters_healthcare.asp (last visited Nov. 28, 2007).

politics or the political process, either in the stories or the policy section. Still, while expert readers may wish for more, it is valuable and important for those less familiar with health care law and policy to see the case against our current system made so persuasively and memorably.

Starr Sered and Fernandopulle do return to the stories to show how the principles would work in individual cases. In this way, the stories provide a set of test cases for evaluating more specific proposals. It would be interesting to go back through stories as an aid to evaluating the health care reform proposals of various Presidential candidates.[10] Who would be helped under their various approaches and who would not? This could be particularly useful in the classroom, as these intimate stories dramatize and personalize issues in a way that statistics and data often do not, and would make the legal concepts, relationships and issues surrounding health care reform "come alive." In their new afterword, the authors do this with "consumer-driven health plans," which are typically health savings accounts offered in connection with a high-deductible insurance policy.[11] One could do the same with other specific proposals, such as tax-credits for the purchase of individual policies, Medicaid expansion, or state law mandates such as in Maryland or Massachusetts.

CONCLUSION

These stories are terrifying because they force us to gaze on the physical and economic vulnerability of our fellow citizens and, ultimately, to recognize our own vulnerability. Starr Sered and Fernandopulle have presented what Deborah Stone would call a "moral opportunity" to identify with and improve the lives of our fellow citizens: to realize that insurance is a form of mutual aid and collective responsibility, and that redistribution from the healthy to the sick is a necessary part of health insurance.[12] The wish of David Himmelstein and Steffie Woolhandler, writing for the *Journal of the American Medical Association*, that *Uninsured in America* would "awaken the conscience of the nation" was carried on the inside flap of the original edition.[13]

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[10] For a side-by-side comparison of the candidates' positions on health care prepared by the Kaiser Family Foundation with the assistance of Health Policy Alternatives, Inc., see http://www.health08.org/sidebyside.cfm (last visited Nov. 28, 2007).

[11] For a comprehensive discussion of the concept, pros and cons of consumer-driven health care, see the symposium in Volume 28, No. 1 of the *Journal of Legal Medicine* (Jan.-Mar. 2007).

[12] Deborah A. Stone, *Beyond Moral Hazard: Insurance as Moral Opportunity*, 6 Conn. L.J. 11, 12 (1999-2000).

[13] David U. Himmelstein, M.D. and Steffie Woolhandler, M.D., M.P.H., faculty at the Harvard Medical School, reviewed the original version of this book for the *Journal of the American Medical Association*, 293 J.A.M.A. 2538, 2539 (2005). Physicians Himmelstein and Woolhandler are outspoken advocates for a single-payer universal health care system and, as such, are frequent targets of those opposed to reform approaches they see as steps toward socialized medicine. *See, e.g.*, Judy Foreman, *A Conversation with Steffie Woolhandler: Heal Health Care*

The afterword, new in this edition, contains the results of follow-up interviews with the uninsured. Some of them slipped farther down, some disappeared, and some escaped the death spiral, at least for now. The fact that we care suggests that this book may be more about reminding us of the problem than solving it. The struggle for adequate, affordable health care continues to be long and difficult; and these heartrending stories remind us what is at stake. Moreover, the fact that at least a few people are holding on offers a ray of hope. The authors note: "[T]his observation carries with it a certain optimism, but even more it carries a call to action. It is not yet too late to turn things around for these individuals, for this society." [p. 202]

System? Start Anew, N.Y. TIMES, Dec. 2, 2003, *available at* http://www.nytimes.com/2003/12/02/health/02CONV.html?ex=1385701200&en=154b9f2001dce8b2&ei=5 (last visited Nov. 28, 2007); Michael P. Tremoglie, *Farenheit 98.6*, FRONTPAGEMAGAZINE.COM, Feb. 23, 2005, *at* http://www.frontpagemag.com/Articles/Read.aspx?GUID={D0B78287-F0AE-4FEE-9324-F3717142FP}.