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 ***Narrative Matters: The Power of the Personal Essay in Health  
Policy (review)***

Kohar Jones

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REVIEW

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**In lieu of an abstract, here is a brief excerpt of the content:**

**Reviewed by:**

*Reviewed by*

*Kohar Jones, MD (bio)*

*Narrative Matters* is an ode to democratic policymaking, with the voices of Everypatient, Everyprovider, and Everypolitician weighing in on the public debate on health policy.

The book is a compilation of columns from the “Narrative Matters” section in the policy journal *Health Affairs*, most written in the first person. They form a new genre, dubbed *policy narrative*; typical papers in this section are 4/5 personal story, 1/5 pure policy. Each story provides an anecdotal window onto the ways that legislation may affect individuals—and, in return, provides a forum for individuals to shape policies.

The stories in the volume under review are grouped into eight sections, the first expanding the idea of policy narrative, and the later ones expounding a series of related themes.

The first section establishes the foundation for the use of narrative in health policy with the argument that painstaking statistics are no match for a well told story in the power to educate, entertain, and persuade readers on the importance of and possibilities for policy change and social transformation. As John E. McDonough, a Massachusetts politician active in health policy, observes of the legislative process, “Personal observation can easily trump hard data.”

Another section, “Dollars and Sense: Hard Financial Realities,” explores the difficult decisions that go into allocating our limited health care dollars. A governor laments [End Page 1011] the choice of using state dollars to provide basic health care for all or a world class transplant center in Denver. A policy analyst describes the transparent allocation decisions in the United Kingdom, as retired community members sit around a table and discuss whether it makes sense to fund expensive enzyme replacement therapy for a rare disease. A pediatrician describes the lifesaving wonders of the neonatal intensive care unit, then comments on the societal choices that have led to ever increasing need

for the most profitable unit in a hospital. Why do we have so many preterm births? Why don't we support community education, comprehensive prenatal care, prevention rather than profitable cure?

The section, "Bearing Witness: Patients' Stories," tells the stories of patients, some real, some fictional, some who fell through the cracks, others who receive unnecessarily duplicated public-paid services. It contains a powerful story by a New Mexico doctor who recalls kneeling at a roadside attempting to resuscitate a boy who would never live as his father yells, "Wake up!" The immediate story of tragic loss serves as a springboard for reflections on driving laws, drinking, rural care, and the back story of how the accident came to be. Personal tragedy refracts social tragedy.

"The Maddening System: Frustrations and Solutions," contains stories by patients and their families fighting to get their needs met: a father seeking to help his troubled suicidal son defeated by the mental health system; belt-tightening at an insurance company leading to the denial of needed new wheelchair to a highly functioning quadriplegic; the bewildering, debilitating "choice" of end-of-life care providers for a consummate shopper who lacks the will and the mental capacity to shop the medical marketplace. Problems beget suggested solutions.

"Learning Genetics" is the profoundly inspirational story of a family's reaction to the diagnosis of a rare inherited disorder in both children. The parents learn all they can, and when they are frustrated by the limitations of medical research, found a foundation, create a blood bank, and demand research system overhaul.

"Trouble in the Ranks: Professional Problems," includes a disproportionate number of stories from nurses, fired when they spoke about unsafe work conditions with too few nurses for too many patients. "Accountable but powerless," is how one nurse summarizes the profession's position. There is also a heartbreaking story about a medical intern's suicide, prompting her residency director to muse on work hours, sleep, and moonlighting.

“Drug Resistance: Battling Undue Influence,” is an important, but unfortunately one-sided nod to the huge impact of pharmaceutical companies on doctors in training...

2. Mental health services: Jurisdictions must “develop a more expansive understanding of mental health services” and the broader integration of that system into the public health infrastructure.
3. Communication: The “failure to communicate honestly about uncertainty” is a serious mistake.
4. Chain of command: There must be “clear lines of federal and other authority.”

As no other type of book can, a contemporary history logs the opinions, views, and paradigms of those who directly participate in the historic event into a literary form. Taken as a whole, this history is very useful. Unfortunately, disasters occur in poor areas just as much as anywhere else, and often more often (witness recent hurricanes, cyclones, and earthquakes). Those who create policy with underserved populations should not only read this history but also apply it. *Are We Ready?* provides insight and perspective that is missing to those of us who saw 9/11 from our desks or homes.

—reviewed by Tim J. S. Heise

**Narrative Matters: The Power of the Personal Essay in Health Policy.** Edited by Fitzhugh Mullan, Ellen Ficklen and Kyna Rubin, with foreword by Abraham Verghese. Baltimore: The Johns Hopkins University Press, 2006. 320 pp.

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