

Ulrike Boehmer. *The Personal and the Political: Women's Activism in Response to the Breast Cancer and AIDS Epidemics*. Albany: State University of New York, 2000. 208 pp. \$18.95 paper.

As a researcher in women's health policy, I was greatly intrigued by Ulrike Boehmer's examination of AIDS and breast cancer activists. AIDS and breast cancer can be described as the two largest women's health care advocacy issues of the late 1980s and 1990s. In *The Personal and the Political*, Boehmer examines both issues in the light of their political and social worlds and the activists living in them. The AIDS and breast cancer movements emerged in response to the diseases' having reached epidemic proportions and the recognition that not enough money, research, and prevention efforts were being employed. Boehmer compares AIDS advocates to breast cancer activists, with the particular connection being between the women's desire to be politically active and their various personal and collective identities. She interviews thirty-seven activists and argues that the advocacy work and its meaning for women are interlinked with their identities.

The individuals who are interviewed are fairly well divided between AIDS and breast cancer advocates, white women and women of color, straights and lesbians, and those with a disease and those without either disease. And though there are many differences between breast cancer and AIDS activists, the diseases share many similarities. "Health care

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practice, health care research, clinical research, and research funding have been shown to be discriminatory due to gender, race, and sexual orientation based biases" (25). Both movements are examined in the light of social movement and feminist theory.

Boehmer finds that breast cancer activists unite exclusively around their shared gender and their gender oppression. She also finds that their white middle-class values, tools, and resources uniquely color their perception of gender oppression. In contrast, "AIDS activism works with and caters to impoverished groups" (56), and the activists are united around their shared sense of oppression based on race, class, and sexual orientation. Boehmer finds that members of both groups become active because they develop a personal and a political relationship to the disease; at one end of the continuum are women who come to the activism with a personal identity that turns political and, at the other end, are women who come with a well-formed political awareness that gets linked to the personal issues of the disease. As one example of the latter, Boehmer notes, "First-time AIDS activists see their activism as just one more struggle in addition to the many other struggles and injustices they have experienced in their lives" (50). One lesson she draws from her research is that organizations, in order to motivate potential advocates, should recognize this personal and political relationship that women need. Her explanation of motivation to activism is an expansion of earlier, and more simplistic, explanations of solidarity and self-interest.

Not surprisingly, sexual orientation is a prominent issue within AIDS activism but remains invisible in breast cancer groups. Even though straight cancer activists state that a working relationship has been established between lesbians and heterosexual women, Boehmer notes that this relationship "takes place under heterosexual rules in a heterosexist environment that has been created by straight women due to their lack of awareness of their privileged position" (116). Furthermore, AIDS activists have a "keen awareness about power relationships," and cancer activists "lack an understanding of oppression based on race, class, sexual orientation and, at times, even gender" (71).

Boehmer finds that the activists group identity practices are expressed in each movement's cultures, organizational structure, and outside support and resources. Within AIDS activism, with its antiracism and anti-classism values, the framing of issues, choice of strategies, resources accessed, and building of alliances differ greatly from those of breast cancer groups. Multicultural issues are incorporated within AIDS messages, and alliances are built with other gay and lesbian organizations. Because

it is a more mobilized movement, Boehmer finds, it draws on a more diverse constituency because more resources are accessed and made available by a heterogeneous constituency. Within the breast cancer movement, alliances are built with other environmental and women's organizations, both of which tend to be white and middle-class.

The book follows a very structured and somewhat simplistic format. Chapter 1 presents a history of AIDS and breast cancer activism, and chapter 2 outlines the study and explains the criteria used for choosing activists who were interviewed. The heart of the research follows. Chapter 3 describes the political culture of the worlds of AIDS, and breast cancer activism is presented, and chapter 4 examines the personal characteristics of the women and their motivations for becoming active. The last two chapters explore the collective identities of the groups of AIDS and breast cancer activists, focusing on gender, sexual orientation, race, and class, and the differences and similarities between the two groups.

The description and analyses of the types of women who respond to political callings, and how they respond, constitute the centerpiece of this work. There are many similarities but also striking differences between the AIDS and breast cancer activists and organizations. I especially applaud Boehmer for her focus on diversity issues and how they shape advocacy organizations, their messages, strategies, and recruitment of activists. This research will appeal to social movement theorists, those interested in women and politics, and women's policy and advocacy researchers. Boehmer's research is extensive, and the book is well written.

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Maureen Hogan Casamayou. *The Politics of Breast Cancer.* Washington, DC: Georgetown University Press, 2001. 208 pp. \$60.00 cloth; \$19.95 paper.

Maureen Hogan Casamayou's objective is to explain how breast cancer research has changed with respect to its focus and level of funding and why breast cancer has so captured the media's attention. She names the women with breast cancer whose reaction to the disease was anger turned into activism as the foremost instigators of these changes. She aims to

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examine the emergence of breast cancer activism between 1990 and 1993 and, in particular, the founding and the early years of the National Breast Cancer Coalition (NBCC). Drawing on her background in political science, she introduces the concept of the “triple alliance,” which she defines as a political structure “composed of protective congressional representatives with important committee posts, skillful executive agency personnel, and aggressive and resourceful interest group supporters” (32) who together are able to shape policy making. *The Politics of Breast Cancer* comprises a description of strategies and actions of players from these three groups, which Casamayou deems responsible for policy changes, including the changes in the politics of breast cancer in the early 1990s. This choice of chronicling breast cancer activism as it relates to institutional politics positions her book in the arena of conventional government politics—a choice that has both advantages and disadvantages.

This is certainly the right book for those curious to know why the Department of Defense administers such large amounts of breast cancer funding. Those interested in understanding traditional lobbying tactics will find ample information about the NBCC’s strategy. Beginning with the 1920s, Casamayou chronicles how funding for breast cancer research was negotiated between governmental outsiders, such as cancer organizations, and political insiders, including government-funded cancer research organizations. Her historical account provides the sobering perspective that the early 1990s share similarities with earlier eras in the attention on breast cancer and the changes in its funding. She cites the signing of the National Cancer Act in 1937 and the declaration of a so-called war on cancer in the 1970s as examples of changes that occurred after cancer had become prominent in the public eye. Casamayou’s hope is that today’s attention on cancer can be maintained and that breast cancer will not disappear from the forefront of American politics as has happened before, when widespread attention on cancer was followed by politics as usual. She argues that the cancer politics of the 1990s were different from those in earlier times. Societal changes of the 1960s and 1970s influenced the women who created this movement. She also portrays breast cancer activism as different from earlier cancer organizing, in that it has developed as a grassroots movement under a collective leadership style, which she attributes to gender socialization.

Her examination of breast cancer activism in relation to governmental insiders has, however, a number of shortcomings. Among them, she overlooks the diversity of the cancer activists. Her choice to describe power-brokering in Washington and the multiple access points used by the

NBCC to influence breast cancer policy comes with the cost of ignoring some hotly debated issues that occurred among cancer activists, who have more diverse goals than Casamayou lets on. For instance, a vocal segment of cancer activists made a case for environmental causes of breast cancer. They also demanded research exploring the link between environmental contamination and breast cancer. While she reiterates the activists' demand that research into breast cancer focus on causes and optimal treatments, rather than just on more research into different types of chemotherapy, the book largely neglects the debate about environmental causes, despite its prominence among breast cancer activists. Thus, her focus on lobbying on Capitol Hill neglects to explain how diverse groups of cancer activists negotiated different goals and a strategy to achieve them. Cancer activists have had to work toward a set of common objectives, and Casamayou does not illustrate how this has been achieved. Rather, she makes us believe that the goals and strategies of cancer organizations were always self-evident, noncontroversial, and singular. Her account overlooks controversies among cancer activists, coalition-building between cancer and environmental organizations, and strategies other than lobbying on the Hill. Some of the same activists who propose examining environmental links favor taking on directly the corporations that are known as environmental polluters, rather than working through the federal government. Moreover, some cancer activists draw a line between grassroots cancer organizations on one side and cancer establishment and pharmaceutical companies on the other side, but Casamayou's conventional political approach divides exclusively political insiders from outside interest groups.

Throughout her analysis, the author mentions AIDS activism in passing and the NBCC's use of strategies successfully implemented by AIDS activists. Again, her conventional approach to politics understates the diversity of the societal context in which breast cancer advocacy took shape. She devotes one chapter to exploring technological changes and societal changes that facilitated the emergence of breast cancer advocacy, such as the political savvy women developed from their activism during the 1960s. She neglects, however, to present in depth the changed societal landscape due to AIDS activism. Casamayou argues that the empowerment of a generation of women made breast cancer advocacy possible, without stating the degree to which AIDS activism created a window of opportunity for breast cancer activism to emerge. She rightfully contributes the successes of breast cancer advocacy to the fact that it is a safe issue for politicians to support and fund. But she fails to provide the con-

text that explains to what degree AIDS activism inadvertently helped position breast cancer as a family issue that united policy makers so that unprecedented increases in breast cancer funding became possible.

Casamayou exhaustively researched her analysis of breast cancer politics. She examined primary and secondary written sources and conducted ninety-two interviews, including many with breast cancer activists. Despite this richness of data, she pays little attention to the diversity of cancer activists themselves. Thus lacking is the social and cultural context of cancer activists with respect to their race and ethnicity, their socioeconomic status, and their sexual orientation. All of these factors certainly influenced the activists' resources for becoming active in this new movement, their definition of cancer activism, and how they were perceived by the political insiders and the access they had to them. Although she points to breast cancer activists' skills and their resources as middle-class professional women, she avoids discussing to what degree the cancer movement was exclusive of women who did not have the financial resources or the conditions to travel frequently to Washington for meetings. Further, the effect of breast cancer on the health of diverse populations has been largely unexplored. As she states, breast cancer activists include in their demands access to high-quality care, particularly for uninsured and underserved women, and Casamayou uncritically accepts that the cancer movement's goals are for the good of all. This simplification ignores findings of public health research that racial variations persist even when access to medical care is equal. Even though she is at times critical of the traditional biomedical framing of breast cancer, she does not fully develop this thought into a new framework that appreciates social and cultural differences with respect to breast cancer. Instead, she echoes the hope that more money for breast cancer research will move us closer to eradicating the disease. This hope fails to acknowledge that even when the causes for or the "cure" of breast cancer have been found they will most likely not translate into eradication and cure of breast cancer in all populations alike. Is this not a problem that deserves attention on Capitol Hill, an endeavor worthy of the attention of political insiders as well as aggressive and resourceful interest group supporters?

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Barron H. Lerner. *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America*. New York: Oxford University Press, 2001. 416 pp. \$30.00 cloth.

Barron H. Lerner traces the history of breast cancer treatments from the 1880s to the 1990s with a special focus on the years between 1945 and 1980. Motivated by his own mother's death from breast cancer, and noting the importance of social and cultural factors in shaping these "breast cancer wars," the author writes a meticulously detailed chronological account of the turbulent world of the medical profession in its earnest struggle to control breast cancer. The vehicle for describing these conflicts and differences of opinion among various physicians and women activists is the metaphor of war.

Lerner notes that the war metaphor was used during the late 1930s in the ongoing efforts of the relatively new Women's Field Army (later renamed the American Cancer Society) to encourage women to seek out early detection. He further explains that such a metaphor fits well with the cancer society's goal of maintaining "optimism in the face of danger and threat" (45). However, he focuses the bulk of his work on the breast cancer wars that began in the 1950s and surrounded the hitherto unquestioned practice of the Halsted radical mastectomy. In its time, this was an innovative procedure that reflected the energy and brilliance of its creator, William Stewart Halsted, a professor of surgery at Johns Hopkins School of Medicine during the late 1800s. He was known "as an icon, . . . a relentless innovator, challenging traditional surgical dogma and devising new techniques and operations" (24). Halsted's procedure was passed on to succeeding generations by his disciples, but this legacy became so entrenched that it was not until the early 1980s that the procedure was debunked. With meticulous attention to detail, Lerner describes the outdated assumptions as well as other more political reasons for perpetuating a procedure that instilled terror and dread in women but was revered by surgeons as the epitome of surgical skill and prowess.

During the 1950s, however, well-meaning surgeons that supported the status quo of the Halsted radical braced themselves for the "slings and arrows" from maverick physicians and others of the school of breast conserving surgery. This courageous and determined minority, including George Crile Jr. and Bernard Fisher and the breast cancer activist Rose Kushner, promoted the lumpectomy (often followed by radiation) and less

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extensive mastectomies as a more enlightened approach to the control of breast cancer. In so doing, they challenged the appropriateness of the Halsted radical, the standard surgical “cure” for breast cancer, especially in its very early stages. Equally important, this minority also challenged the one-step procedure associated with the Halsted radical.

Lerner notes the pivotal connection between the paternalistic and “established” opinion on controlling this disease and the contemporary attitude toward women in American society. How else can we explain why a woman, already the product of a “successful surgery,” endured unending pain and social stigma from losing not only her breast but also her chest muscles and acquiring a dysfunctional and often permanently swollen arm? In a nutshell, surgeons, for whatever reasons, were cutting off breasts and extensive muscle and tissue in the chest and arm for more than half a century without even giving the woman time to consent emotionally and to adjust to the reality of having cancer and of losing her breast. And yet, a far less intrusive surgery for early stage breast cancer, the lumpectomy, was already an accepted procedure in Europe as early as the 1950s, offering the same survival rates as the Halsted radical. In the United States, however, the Halsted radical reigned supreme until the early 1980s.

Most important, both men and women alike trusted the infinite wisdom of the surgeon’s “cure.” In this case, the surgical cure, even for tiny cancers, was very aggressive, “producing crippling debilities even as they potentially extended life” (88). For example, men generally received a radical prostatectomy, when cancer, no matter how small, was discovered during surgery to remove an enlarged prostate obstructing the urinary tract (88–89). The standard treatment was to remove not only the prostate gland but also the seminal vesicles and a portion of the bladder. Incontinence and impotence were the tremendous price that men paid for an extension of their lives.

Lerner relates that with women, however, there was a critical difference in the way that surgeons, who were predominantly male, viewed breasts when they belonged to the post-menopausal female body. In this circumstance, surgeons considered the female breast to be “one of the most dispensable parts of the body”; it drooped or was wasting away and they therefore encouraged the notion that it was “defective and thus especially expendable if cancer was present” (89). Lerner may be right in his attribution of this mentality, but he hardly makes a convincing case since those surgeons who believed in the Halsted surgical technique used it on all women patients, regardless of their age, because of the belief that can-

cer spreads “in a slow, orderly, centrifugal manner before spreading to the lymph nodes” (21).

And this brings me to what I perceive to be a mild shortcoming of Lerner’s work. There is neither synthesis nor analysis and no systematic attempt to make sense of the vast amount of factual material that he has so conscientiously compiled. He is unquestionably thorough in his research but, without analysis, his thoroughness does a disservice to his findings. There is no follow-through on statements that are begging for his thoughts, and I found myself asking, “So what?” at various points in this narrative. Also, Lerner makes no attempt to distill the findings and present the reader with a coherent conclusion that answers the numerous questions he raises in his introduction and at the beginning of each chapter. The reader is left to sort out the facts and draw his or her own conclusions about how well substantiated is the theme of his book that a disease “cannot be understood outside its social and cultural context” (5). Moreover, the actual account of these breast cancer wars is so antiseptic, so scrupulously neutral and risk averse that any real passion about this subject is relegated to the preface, where Lerner discusses his mother’s ordeal with the disease.

Finally, the author’s own clarification of key terms, such as *war* and *cure*, would have been most helpful. He freely uses these terms but never puts himself out on a limb by giving the reader the benefit of his thoughtful opinion on their meaning. After all, he is a physician.

These thoughts aside, which some may protest as being overly picky, this is a very well written book and a fine piece of research that greatly enriches the existing historical literature on this controversial and compelling health issue.

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Susan Greenhalgh. *Under the Medical Gaze: Facts and Fictions of Chronic Pain*. Berkeley: University of California Press, 2001. 371 pp. \$48.00 cloth; \$18.95 paper.

The anthropologist Susan Greenhalgh tells the compelling story of her experience with chronic pain that worsens with the misdiagnosis and treatment of an ambiguous, debilitating illness. Her sensitive rendering of the story builds on a medical anthropologist's awareness of the construction of pain within a politicized medical culture. Greenhalgh covers being diagnosed with fibromyalgia, suffering through grueling treatments, and, ultimately, rejecting the diagnosis, the treatment, and the physician who specialized in aggressive measures for the condition. The goals for her ambitious book are (1) to redress the balance between narratives of medical triumphs and failures that favor the former, (2) to illuminate how physicians can define treatment successes despite the havoc experienced by those treated, (3) to demonstrate and understand biomedical power, and (4) to advocate for political intervention that takes into account the individual patient's plight, the discourse surrounding chronic pain in fibromyalgia, and the culture of medical institutions. She attempts to show how the power of medical rhetoric and the power of gender relations reach deep into the patient's self and limit her resistance. Greenhalgh's intended audience is students of and within biomedicine but she also wishes to forewarn unwitting patients of the medical power that may take over their lives.

Under the Medical Gaze is divided into the following six parts: "Understanding Chronic Pain," "Doing Biomedicine," "Doing Gender," "A Losing Battle to Get Better," "Rebellion and Self-Renewal," and "Narrating Illness, Politicizing Pain." To craft her material, she combines the tools of a dispassionate ethnographer with those of a reflexive feminist scholar. The narrative structure of the book is at first disconcerting, although it makes sense. Much like an anthropologist viewing some distant "other," Greenhalgh takes herself as an object of study. When describing herself as person and patient in the unfolding events and scenes, she calls herself "S." and uses the pronoun "she" to distinguish between past and present selves and to maintain a critical posture toward S., whom Greenhalgh sees as an active participant in the unfolding events. S. is juxtaposed against "D.," the specialist at the margins of medicine who treated Greenhalgh until she and a different rheumatologist, who had treated her ear-

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lier, challenged his diagnosis and treatment. When reflecting upon her earlier experiences as the author, she refers to herself as “I.” Greenhalgh’s reasons for these distinctions transcend maintaining analytic distance. She argues that S.’s medical travails effectively obliterated her sense of self, subjectivity, and place in the world.

Greenhalgh joins an increasingly vocal group of articulate critics whose experience of biomedicine imposes a credible voice that cannot be dismissed. She offers one of the most detailed and poignant empirical accounts of what Arthur W. Frank (2000) calls “the Ride,” an accelerated manifestation of Weberian disenchantment with the Western World. In medical care, the Ride forces patients’ experiences into institutionalized objectified images, sweeps them into the technical and bureaucratic machinery, and reduces them to objects to manipulate. Unlike many women who find their lives swept up and away by biomedicine, Greenhalgh was a sophisticated and critical patient advocate on her own behalf. She researched her condition and chose her physician, whose daring treatments and claims to cutting-edge expertise seemed to fit her needs—initially. In addition, she entered the experience with substantial resources—a feminist consciousness, caring friends and family, health care options, the means to seek long-distance expertise continually, and a sufficiently flexible professional position that permitted major encroachments upon her work schedule. Greenhalgh’s story takes on added dramatic power because she acknowledges her complicity in her plight as step by step she becomes persuaded by D.’s view of her life and of what to do about it. She acknowledges relying on her skills in enacting gender to further her relationship with D. and to maintain his interest in her progress.

Greenhalgh’s situation and story gave me pause when I thought of the much greater vulnerability of women I have interviewed recently. One woman remains married only to avert homelessness. Another’s isolation in pain and poverty allows her no validating friends. Most cannot work. All have few choices, if any, in health care. If Greenhalgh could expertly select a physician and even so end up on the Ride rather than in a cooperative partnership, then what chances do less privileged women have to control their fates in U.S. medical care?

Autoethnography proves to be a powerful vehicle for telling Greenhalgh’s story. She gives readers a full view of an insider’s emergent understandings of illness, as well as a view of symptoms, pain, despair, and desperation. I found autoethnography less useful for showing the dynamics between S. and D., though I do not doubt Greenhalgh’s assessments. Exactly how D. used rhetorical skills and power and how subtle nonver-

bal meanings emerged in their immediate interaction remain less clear than S.'s strategies and emotional responses. Nonetheless, this book marks new development in autoethnographic methods. The book is painstakingly detailed. One back cover quotation is particularly telling. Virginia Olesen writes, "She sets a new standard for the practice of autoethnography." I agree. Greenhalgh's book is more than a mere selective reconstruction of the past from the vantage point of the present. In the future, autoethnographers will need to replicate Greenhalgh's honesty, depth, and meticulous ethnographic skills when chronicling their experiences.

Greenhalgh's story suggests how ambiguous conditions, particularly emergent illnesses, allow openings for medical contests and claims-making to be played out in the medicalization of patients' lives. Although medical researchers might argue that such practices are inevitable if biomedicine is to progress, patients' losses of self, livelihood, and life suggest otherwise. Greenhalgh's book is a courageous effort to bring the voice of the patient into the discourse of medicine. Her book is a must for students of chronic illness, contested illnesses, and medical dominance throughout the social sciences and health professions.

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Ruth O'Brien. *Crippled Justice: The History of Modern Disability Policy in the Workplace*. Chicago: University of Chicago Press, 2001. 302 pp. \$50.00 cloth; \$19.00 paper.

Crippled Justice tells the story of the disability rights movement that began in the 1940s and 1950s. Although there are many books and articles that discuss the foundations of Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA), this is the first book that extends that discussion back to the earlier times.

Chapter 1 begins the story in World War II, tracing the values and ideas that eventually were cultivated into the rehabilitation movement, including the whole-man theory advocated by Howard Rusk and Henry Kessler. This is not the “medical model of disability” that is often criticized by the modern theorist Harlan Hahn. Instead, it is a “much more sweeping and ambitious plan that medicalized not just disability but the whole of society. Rehabilitation was promoted to ensure the health of the individual and that of society. According to them, an unrehabilitated person could weaken and erode society’s health” (27–28).

Chapters 2 and 3 discuss the rehabilitation movement up to the 1960s. O’Brien argues that the federal government was adamantly opposed to employment rights for individuals with disabilities as part of this movement. Chapters 4, 5, and 6 cover the modern disability rights era. O’Brien draws on the work of others to describe how Section 504 was created in a rather unintentional atmosphere of rights protection. She shows how the federal government was not prepared to enforce this provision after its enactment. Her discussion of legal decisions under Section 504 and the ADA suggests that the courts have always had a very narrow conception of who should be protected by these statutes.

O’Brien again takes up the “whole man theory” in the afterword, claiming that recent court decisions under the ADA have returned us to this theory of rehabilitation. Courts feel comfortable now “probing and investigating every minute detail about how a person can mitigate his or her disability. Instead of asking who is whole and can be brought back into the work force because they compensate for their respective impairments, the federal court judges allow into the courtroom only those they regard as ‘unwhole’ to protest employment discrimination” (25).

Although I enjoyed the book and learned a great deal about the disability rights movement from the 1940s through the 1960s, I have some

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reservations about O'Brien's discussion of the ADA. She borrows from my work (Colker 1999) to argue that the "lower federal courts decided 94 percent of all litigation in the employer's favor" even before the Supreme Court's recent decisions offering a narrow interpretation of the ADA (14). In the afterword, she expands on this argument to state that the figures changed to 71 percent after the Supreme Court's mitigating measures rulings (217). (The mitigating measures cases narrowed the definition of disability by finding that an individual is disabled only if he or she has a substantial limitation in the ability to perform one or more major life activities after using mitigating or corrective devices, such as eyeglasses.) Her support for this figure is the "168 cases the author found in the federal courts that were issued from June 1999 until May 2000" (275).

The problem with that argument is that no one (including me) knows what decisions all of the lower federal courts have made, especially the lower trial courts. In my study that she cites, I report that "defendants prevail in more than 93 percent of reported ADA employment discrimination cases decided on the merits at the trial court level. Of those cases that are appealed, defendants prevail in 84 percent of reported cases" (Colker 1999: 100). In a section of my article that O'Brien does not mention, I discuss the methodological problems that arise when one examines litigation outcomes. I expound on these methodological problems in a later article (Colker 2001: 244–247), concluding with the following observation: "There is no way that someone who relies on computerized search techniques can have the perspective of the district court judge, because the majority of filings result in settlement and many decided cases do not result in opinions made available to the public. I therefore cannot claim that my research gives us much, if any, insight on the perspective of the district court judge" (*ibid.*: 247). For that reason, I focus my discussion of the empirical data on appellate courts whose decisions are more widely available and whose decisions create important precedent. I am alarmed, however, by the tendency of the media and researchers to continue to misreport the trial court figure with which I have never had much confidence.

But even if one were to assume that the trial court data are reasonably accurate, the question would be what do we learn from that figure? What I find interesting about the data, particularly the appellate court data with which I have more confidence, is that they are so consistent over time. As I report in a recent article, defendants have prevailed in approximately 86.5 percent of ADA appellate, employment discrimination cases that are available on Westlaw for the period January 1994 through 30 July 1999 (Colker 2002). I found very little fluctuation in that rate during that

period. Given that plaintiffs' lawyers frequently take cases on a contingency fee basis, the question that arises is why are plaintiffs' lawyers consistently miscalculating their chance of success? Irrespective of whether the courts are hostile or receptive to ADA cases, we should expect plaintiffs' lawyers to pursue only those cases that they are confident will be successful. I speculate that the problem for plaintiffs' lawyers is that the ADA is a moving target that is increasingly heading in a pro-defendant direction. Hence, as soon as plaintiffs' lawyers adjust their behavior in order to increase their success rate, the courts create new legal hurdles that make it even more difficult to prevail. The mitigating measures cases, for example, can be understood as part of that moving target story. As plaintiffs' lawyers began to use the ADA with some success to attain positive results for their clients, the Supreme Court readjusted the statute to make it harder to prevail. The consistent nature of the pro-defendant data is what is so interesting rather than the actual value of those figures.

Viewed in that light, it would be interesting if O'Brien is correct that the trial court results have changed from 94 percent pro-defendant to 71 percent pro-defendant since the Supreme Court decided the mitigating measures cases. Because O'Brien gives the reader no indication of her research methodology to arrive at that figure, it is hard to have confidence in its accuracy. There have been hundreds of remands to the trial courts after the Supreme Court's decisions in the mitigating measures cases. I would expect that most of those cases would have settled with a voluntary dismissal because the plaintiffs' lawyers would have realized that there was little point in continuing to proceed in the light of the more stringent definition of disability reflected in the Court's mitigating measures rulings. If O'Brien's statistic is correct, then we have seen plaintiffs adjust their litigation behavior rationally in response to the Supreme Court rulings to pursue court cases that were meritorious and should not be voluntarily dismissed. The fact that plaintiffs may have correctly modified their litigation behavior, however, does not tell us that the courts are growing more receptive to their claims. It simply may mean that the target has stopped moving so that plaintiffs can properly adjust their litigation behavior.

In sum, I did very much enjoy O'Brien's book for its discussion of the early history of the disability rights and rehabilitation movements. I would simply caution readers to take her consideration of statistical evidence with a grain of salt.

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Peter P. Budetti, Richard V. Burkhauser, Janice M. Gregory, and H. Allan Hunt, eds. *Ensuring Health and Income Security for an Aging Workforce*. Kalamazoo, MI: W. E. Upjohn Institute for Employment Research, 2001. 519 pp. \$43 cloth; \$25 paper.

When policy discussion turns to issues of old age, attention usually focuses on the shifting ratio of younger to older Americans, the future of Social Security and Medicare, and how better to address the vulnerabilities facing growing numbers of the very old and frail. However, nestled between concerns about “young versus old,” on the one hand, and the needs of “the oldest old,” on the other hand, is an emerging population variously referred to as the “young-old,” the “productive old,” or people in “the third quarter of life.”

Analysts and stakeholders have viewed the rise of this young-old population from a variety of perspectives. Sociologists and psychologists debate whether the growth in numbers and well-being of these persons—chronologically understood to be between their mid-fifties and their mid-seventies—represents an extension of middle age, an early beginning to old age, or something different entirely. Economists and political scientists, more concerned with productivity and budgetary issues, center their attention on the nation’s need to revisit public- and private-sector retirement policies. The young-old themselves must wrestle with how to weigh the work/leisure trade-off central to decisions about retirement. And, for their part, employers find themselves revisiting a long-standing preference to be rid of older workers in the face of labor market pressures and antidiscrimination legislation that give such workers new standing.

There was a time, dating roughly to the mid-1970s, when these tensions were much less in evidence. The older population itself, to say nothing

of its young-old fragment, had yet to attain broad institutional standing. Older Americans remained a largely residual population, with even their growing numbers offset by the yet faster growing number of baby boomers entering the labor force and contributing to retirement systems. Older workers often found themselves in ill health, mandatory retirement was still widespread, and discrete and total exit from the labor force was the modal pattern of retirement.

Today, the work and retirement patterns of older individuals are more variegated than they were during this earlier period. The ambiguous hyphenation “older worker–younger retiree” now found in the work and retirement literature captures the role tensions represented by the rise of the young-old. In this context *Ensuring Health and Income Security for an Aging Workforce* makes a notable contribution. As the editors point out in their introduction, far more attention has been paid to the status and concerns of those who are retired than to those young-old individuals who have remained in the labor force. Exploring how to rework public and employer-based health and income policies in ways to better meet the needs of these workers is the overarching objective of the volume.

The book contains much insightful material in its five-hundred-plus pages. It will be most valuable to employment and retirement specialists, who will encounter comprehensive data about trends, gaps, and prospects in labor force participation, program coverage, and emerging work and retirement trends. Social scientists interested in life-course transitions and structural lag will also find useful material. The book is a compilation of papers and commentaries presented before the 2000 Annual Meeting of the National Academy of Social Insurance, the national organization made up of leading experts in the area of social insurance and related programs (www.nasi.org).

The book is organized into four sections, a feature that helps the reader negotiate this complex and shifting terrain. Section 1 reviews the provisions and many shortcomings found in programs designed to protect older workers when illness, disability, or unemployment occurs: health insurance (before Medicare eligibility), workers' compensation, unemployment insurance, and Social Security. Section 2 focuses on the consequences of job loss among older workers and reviews some of the relatively modest provisions that have been put in place to extend private health insurance coverage. Section 3 addresses coverage and consequences of chronic illness and disability from the perspective of older workers and their employers. Section 4, which might well have been placed first, presents useful trend data on overall work and retirement patterns, the (dis)abil-

ity profile of older workers, and the perspective of employers on retaining and retraining older workers. A short final section addressing health insurance issues could have been usefully placed with two earlier chapters on the ins and outs of extending health insurance to pre-Medicare-aged workers.

Three themes in particular emerge from the fifteen chapters and nine short commentaries found in these pages. First is the precarious position in which many older workers find themselves, given a frequent commingling of declining individual abilities, limited job opportunities, and inadequate health care and income security programs. To highlight just a few of the many observations and findings along these lines: Sewin Chan and Ann Huff Stevens document the effects of job loss on subsequent employment opportunities for older workers; Karen Pollitz highlights the absence of health insurance subsidies for both older workers and younger retirees despite the coverage contributions of HIPAA and COBRA; and Jeff Biddle, Leslie Boden, and Robert Reville review the labor market consequences of work-related disabling injuries and illnesses, noting that these are important sources of disability throughout working life, “but that they are particularly so for older workers” (284).

A second theme centers on the more nuanced linkage between work and retirement that has emerged in the past twenty years or so. Part-time or intermittent jobs increasingly fall between full-time work and full-time retirement (Robert Haveman). “Bridge jobs”—those characterized by Christopher O’Leary and Stephen Wandner as “a chain of employment transitions from career job to bridge job, between bridge jobs, perhaps back from a bridge job to a career job, and finally a gradual movement into full retirement”—are increasingly in play (123). Partial disability may limit workers’ opportunities, creating a precarious income base located somewhere between the labor market and worker compensation or disability programs (Biddle, Boden, and Reville). Also, access to health insurance may strongly condition the work and retirement decision and, if work continues, how much of it (Pollitz; Katherine Swartz and Betsey Stevenson). Whereas historically most workers were understood to have been either “pushed” (by ill-health or unemployment) or “pulled” (through accumulated wealth or defined benefit plan incentives) from full-time employment into full-time retirement, changes in well-being, public programs, and job characteristics have muddied this earlier picture.

A third theme that cuts across the first two themes centers on the distribution of work and retirement opportunities and options. In speaking of older workers, Mark Nadel pointedly notes that “health status is not ran-

domly distributed in the population. Minorities and those with low educational levels are more likely to have impairments affecting their employment” (157). Similarly, Swartz and Stevenson conclude that their fifty-five- to sixty-four-year-olds needing health insurance prior to Medicare eligibility fall into two groups: “The fortunate group consists of people who are able to work until at least age 65; this group is more likely to have higher education and income levels, and better health, as well as employer-sponsored insurance. The unfortunate group is that who either have developed health conditions or otherwise finds it difficult to continue working and have fewer financial resources in the years before they reach age 65” (24).

More pointed yet are the comments of Theresa Ghilarducci centered on individual and social preferences around work and retirement. Reflecting on the article by Gary Burtless and Joseph Quinn (and, inferentially, many others), she asks questions counter to today’s widely accepted wisdom that young-old workers must keep working in order that demography be acknowledged and retirement systems be saved. Policies such as eliminating the earnings test, liberalizing the earned income tax credit for older workers, and making Medicare the first payer for older workers, she argues, have the effect of subsidizing employers, benefiting high-income older workers, and disadvantaging low-income older blue-collar workers. For these blue-collar workers, additional years of physical toil would be imposed on bodies ill-suited to handling it (as at least three chapters in this volume make very clear).

Ensuring Health and Income Security for an Aging Workforce contains a substantial amount of information directed to the “older worker–younger retiree” conundrum. The chapters vary in length, approach, and sophistication, but the volume as a whole clearly succeeds in bringing multiple perspectives to this issue. Roughly paralleling the book’s section divisions, the workings of policies, the concerns of workers, and the presumed imperatives of demographic trends are all on display here. In a dramatic reversal of thinking dating to the original Social Security legislation, today it is widely held that we need to encourage greater labor force participation of young-old Americans. It is in comprehensively presenting health, income, labor force participation, and program information about this emerging population that *Ensuring Health and Income Security for an Aging Workforce* makes its contribution. Yes, added work years may be a good idea, but many workers and retirees may be left behind if major adjustments are not made to employment practice, disability determination, and health and pension coverage in the years ahead.

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Deborah R. McFarlane and Kenneth J. Meier. *The Politics of Fertility Control: Family Planning and Abortion Policies in the United States*. New York: Chatham House, 2001. 197 pp. \$22.95 paper.

Deborah R. McFarlane and Kenneth J. Meier examine fertility control policies in the United States in historical and contemporary context. The authors adopt the framework developed by implementation scholars Paul Sabbatier and Daniel Mazmanian to understand the policy-making process regarding fertility policy. The book relies on both historical analysis of the development of fertility control policies and cross-sectional analyses of state variation in policy adoption and implementation.

The approach adopted by the authors requires the discussion of the role of federalism and the interaction between court and legislature, and the authors handle both tasks extremely well. They show that one consequence of the combination of separated and divided governmental powers is lots of contradictory and overlapping signals about the course of fertility policy, and fits and starts in the adoption of policies at the state level. Different policy dynamics in states and this complex pattern of legislative-court-state interaction lead to great variety in the implementation and success rates of state-level policies.

The book's major strength lies in the development of the interaction of the federal- and state-level roles in policy development. Any policy specialist in health care or family planning would do well to read and ponder chapter 3 on the development of federal-level policies in the area, and state responses to them. This framework allows a state-by-state analysis of the adoption, implementation, and impact of fertility control policies, an analysis that is ably done. The authors model and test it in each stage of the policy process: adoption, outputs (commitment to the policy), and impacts (the extent of success of the policy in affecting social indicators).

The major weakness of the approach lies in the incompleteness of its theoretical underpinning. On the one hand, federalism is a major theme of the historical and quantitative parts of the book, and, I believe, its major strength. On the other hand, the introductory theoretical chapter does not dwell on these critical aspects of governmental structure. Rather, it attempts to see fertility control as an aspect of morality policy—that is, to categorize the policy and deduce its dynamics based on this categorization. I am somewhat suspicious of such attempts, because there seems to me to be drift in how people understand an issue over time. Actually,

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much of policy making involves contention over the categorization of issues.

But even given the policy-category approach, I find some limits. McFarlane and Meier see morality policy as demand driven: demand for the behavior that is to be regulated by the government is highly inelastic, at least for a sizable subset of the population. As a consequence, control of the behavior is ill advised, and the desired course of events is to channel the behavior in a manner that minimizes the undesirable consequences of the behavior.

This definition of policy allows the use of the Sabbatier-Mazmanian implementation framework. In my opinion, this approach is right but somewhat misleading. Morality policy as defined here does not capture the essentially political character of family planning, especially abortion. Morality policy is characterized by some citizens' imposing strict limits on the utility functions of others as well as highly inelastic demand structures for the behavior on the targets of regulatory control. Collectively, Americans have not come to view family planning as a goal; consequently, the implementation perspective adopted here conceals the value conflicts that underlie fertility control. Unfortunately, there are trade-offs: the deaths of fetuses by abortions imply serious value conflicts. Here, unlike in the debate over evolution, modern science and technology add support to the views of the religious right as "viable fetus" becomes younger and younger. At present, at least, this value conflict is not reducible to an implementation framework. Similarly, many on the right object to making contraceptives available in high schools as a case of government encouraging undesirable behavior.

Trade-offs are always present in politics, and the Sabbatier-Mazmanian framework is capable of incorporating them. In morality politics, however, the trade-offs involve not only the insight of McFarlane and Meier concerning inelastic demand curves and the strong desire of one group to specify the utility functions of others but justification as well in religious or moral black-and-white logic. The book's failure to incorporate this dimension more seriously into the analysis limits its utility as political analysis.

In sum, this is a very useful book for students of family planning. It provides a historical and analytical study of these policies in the United States and subjects the area to serious quantitative scrutiny. The book is generally cleanly written, and the tables are clear and do not burden the flow of the analysis. If more substantive specialists would discipline themselves to doing the hard historical and quantitative work in the man-

ner of McFarlane and Meier, we would have far better policy debates. Since encouraging policy debate is a major aim of the book, in this respect it is a strong success. For the policy generalist, the book is a lesson in the need to understand federalism in any serious study of public policy in the United States. Thus, it should be useful in courses in public policy, health policy, and social work.

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Kaja Finkler. *Experiencing the New Genetics: Family and Kinship on the Medical Frontier*. Philadelphia: University of Pennsylvania Press, 2000. 296 pp. \$65.00 cloth; \$24.95 paper.

Experiencing the New Genetics is an interesting, provocative, data-rich, ambitious, and ultimately frustrating book. Kaja Finkler's central thesis is that kinship has become medicalized by the new genetics. To support this view she makes the interesting choice of interviewing not only those touched by an illness that may be genetic but also healthy adoptees with no expressed phenotype. In fact, Finkler devotes half of what is a relatively short book to a presentation of the stories of twenty-two women, with and without breast cancer, recruited from a genetic counseling setting, and of fifteen adoptees who have undertaken a search for their biological mothers. These stories are rich and engaging and have much in them that will be of use to readers interested in the experiences of individuals from families at increased risk of cancer and for that, quite different, audience of readers with interest in issues of family and adoption.

The empirical data presented are bookended by a discussion of kinship, at one end, and on the concepts of medicalization and genetic determinism at the other. The sheer scope of this material is impressive. It represents the multiple separate threads of Finkler's argument, specifically, that genetics has medicalized kinship and that genetics itself has become a powerful and overwhelmingly determinative ideology. Unfortunately, however, these separate threads are never braided convincingly into anything that supports this contention.

The material on kinship is particularly problematic. First, it is overly ambitious, rather in the extreme. The first kinship chapter is called "The

Role of Kinship in Human Life” and it is ten pages long; it is followed by another ten-page chapter titled “Family and Kinship in American Society,” beginning with antecedents in sixth-century Europe and ending with the new reproductive technologies and changing legal norms involving surrogacy cases. The final eight pages undertake an examination of varying concepts of heredity in Western society. One has to be absolutely impressed with the amount of work Finkler has done and the amount of data and theory she has amassed, summarized, and interpreted. But it is just too much. Sizable corners of libraries could be filled with point and counterpoint on the issues in any one of these chapters.

Ultimately, however, the adequacy of Finkler’s discussions of kinship does not matter, because the material she presents actually contradicts the point she is trying to make, to wit, that “in contemporary times, with their emphasis on genetic inheritance, biomedicine forcefully contributes to defining who is included in the ‘significant same’ circle and to the meaning of family and inheritance” (42). Yet, the case Finkler herself builds in these chapters is that in the United States, the role of kinship in general and of genetic kinship (kinship through “blood” if you will) has dwindled, replaced by associations of choice, of people selecting whom they are going to regard as “significant same,” with an emphasis on “autonomy, independence, and detachment from kinship ties” (37). As Finkler states, a tendency in this direction was cited by Tocqueville, who saw it as a concomitant of a society based in democracy; and Finkler shows that this tendency got a very significant boost in the era of the 1960s. Whether or not one agrees with this argument, it certainly significantly undercuts the ground on which Finkler is building her argument that kinship has been medicalized and “geneticized,” leading to a social world in which ever more distant relatives are made vivid and salient through their shared genes.

Finkler is not completely unaware of the fact that her argument has slipped away from her. She attempts to deal with this problem through a discussion of very recent court cases involving surrogacy. These legal cases, Finkler states, citing Janet Dolgin, are moving from an initial privileging of gestational or contractual ties toward a standard that favors relationship based on shared genetics. Even if true, it seems far too little, too late to save the destruction of Finkler’s argument by her own hand. What, after all, is the actual impact of a few legal cases on people’s conceptualizations of kinship? Most people are not involved in surrogacy battles, and this case law is far too recent and too thin to be presented as an argument for an underlying sea change in an entire society’s view of kinship.

Another thread in this argument concerns the general concept of medicalization. From Foucault on, social scientists have observed that increasingly numerous aspects of life are falling under the scrutinizing gaze of biomedicine. Finkler covers this material well, perhaps a little too well, since it is not really crucial to her argument that kinship and the family are now being medicalized through the medium of genetic determinism. Finkler states that “in day-to-day life people are bombarded with the view that they have inherited most diseases from their family” (6). And she tries to use her empirical data to demonstrate that this bombardment has strongly affected the way people think about, and construct definitions of, their kin. But sadly, as interesting as this material is, it does not support her point.

Finkler’s sample consists of thirty-seven individuals, twenty-two of whom are women referred by a genetic counselor who had seen them in regard to breast cancer, and fifteen of whom were adopted and who were recruited into the study because they had attempted to locate their biological mothers. Of the twenty-two women in the breast cancer sample, seven came from families in which there was some history of breast cancer but had not themselves developed the disease; the other fifteen had had breast cancer themselves. The subtitle of the first empirical chapter “Patients without Symptoms,” makes it clear that Finkler is assuming a stance that the very discussion of genetic risk with these women constitutes a pernicious “medicalization” of their life and experience. Yet—and this is a fatal flaw in Finkler’s sample selection—it is very unlikely that these women needed any help from the new genetics to tell them they were at risk for breast cancer. Rather, there is much clinical, as well as empirical, data (for example, the work of Kathryn Kash) to support a view that women whose mothers have breast cancer have long been extremely likely to feel themselves at risk. To state this another way, an internist of my acquaintance, who has considerable expertise in genetics and has been in practice long before the identification of the BRCA1 mutation or the current enthusiasm in regard to genetics, once told me that she has no difficulty convincing patients that a disease that they and another relative had might have a genetic component. The problem was convincing such an individual that there was little likelihood that the disease had a genetic component and that the fact that a relative also had it was merely a coincidence.

But two brief excerpts from Finkler’s interviews with the women in the breast cancer sample will perhaps provide the best insight into both the strengths and weaknesses of this book. Dorothy is a woman whose

mother had ovarian cancer and who, once having a nonmalignant ovarian mass found, wishes to have her physician remove it. The physician, however, is not convinced and wants to hold off on surgery until obtaining a pathology report on the mother. Dorothy, however, is in a hurry because, “the closer I get to 48 I know that I am going to be [more worried] than I am now” (61). When Finkler asks what it is about forty-eight that seems so momentous, Dorothy replies that forty-eight was her mother’s age when she died and that Dorothy believes that if she “makes it past 48, then maybe I am home free.” Finkler implicitly assumes that this is a demonstration of the power of the “new genetics.” Yet, to this reader, it seems to be neither a genetic nor a medical model but rather a common and spontaneous folk model.

The second example involves a woman who, in contrast to her genetic counselor, does not consider her cousins as kin and has also lost contact with her brothers. She tells Finkler that she defines her family now as consisting only of her husband and children. Despite this lack of attention to her genetic connections, the woman has consulted a genetic counselor and is now considering a prophylactic mastectomy based on her family history. This, despite the fact that, as a devout Christian, she “feels protected by God” (68). Clearly things are a lot more complex and messy than fitting within the rubric of the medicalization of kinship through the new genetics. And, in fact, much of what Finkler’s participants say shows a highly syncretic view—taking a bit from genetic and other medical understanding, a bit from broader folk beliefs, much from other current views about the power of the “healthy lifestyle,” and some as well from spiritual and religious beliefs. In fact, Finkler’s respondents show an amazing breadth of understandings and beliefs, and a strength of this work is how Finkler lets the women talk, even when what they are saying does not support her points.

The sample of adoptees has its own problems. Finkler’s purpose in presenting these stories is to suggest that a new genetic ideology is creating a situation in which adoptees are more likely to feel a need to find biological relatives and to believe that they are going to be more like their biological family, whom they have never known, than like their adopted families. Yet, as Finkler herself cites, less than 50 percent of adoptees search for their biological relatives. In another example of Finkler’s rich data not supporting her argument, one of her adopted interviewees states her reasons eloquently for searching: “There is a great loneliness when you live among people who look different from you. . . . You feel sort of dropped on the planet somewhere. You don’t have an origin. And then I

wanted to know why I was given away. I wanted to know what the circumstances were” (133). This sounds to me like a pretty universal description of why someone might try to find a biological parent. If it is remembered that until the 1970s someone who found out he was adopted could do virtually nothing about finding his true “roots,” it seems likely that this legal change is a much more potent force behind an increase in searching than is the new genetics.

Finkler’s sample selection is also highly problematic. The breast cancer sample comprises women who *sought* genetic counseling—that is, a sample likely to be biased by an interest in the genetics of their disease. One must therefore ask how representative they are of either the entire population of women or of even the smaller group of women who may have a familial breast cancer risk? To repeat, the adoptees represent the smaller portion of adopted individuals who choose to search for their biological relatives. And then the size of the sample itself is so very small, a total of thirty-seven individuals. Although small samples are not unusual in qualitative research, especially in a hypothesis-generating study, this still seems a peculiarly small sample for a book-length analysis. For all these reasons it would clearly be very difficult to generalize from this study to women at risk of breast cancer or to adoptees and completely impossible to use these data convincingly to support a view that the new genetics has led to profound changes in the way we experience family and kinship. Thus, although the book is, in many ways, a tour de force, this reader finds herself unconvinced by Finkler’s claims that the new genetics has changed either individuals’ beliefs that diseases tend to “run in families” or that the disorientation of adoption has been created, or even significantly increased, by the new genetics. In general, it would seem that much scholarship has been led astray by the odd and contingent manner in which genetics has been separated from the rest of the medical, legal, and ethical world and this work, sadly, is another example.

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