Stakeholders in Misfortune

The Disability Business. Rehabilitation in America. GARY L. ALBRECHT. Sage, Newbury Park, CA, 1992. viii, 328 pp., illus. $46; paper, $22.95. Sage Library of Social Research, 190.

In 1990 Congress passed the Americans with Disabilities Act, and President Bush eagerly signed it. Hedged with many qualifications, the act nonetheless prohibits discrimination against persons with disabilities in employment, state and local services, transportation, public accommodations, and telecommunications. Passage of this act highlighted the problems and accomplishments of persons with disabilities, who, almost alone among minority groups, appeared to be winning political battles in the Bush administration.

As the president proudly pointed to the passage of the act as a sign of his administration's commitments to civil rights and social progress, he voiced his hope that persons with disabilities would enter the labor force and become less dependent on welfare and other income supports. He neglected to mention that disability was also a major concern of a whole host of profit-seeking businesses dedicated to rehabilitation. He did not speak of regulating this "disability business" in the interests of its consumers.

Similarly, the academic community has not addressed many aspects of the disability business, as differentiated from the phenomenon of disability itself. Economists have contributed a raft of articles that explain that, as the size of disability benefits rises, incentives to join the labor force decline. Our nation's social welfare programs, such as Social Security Disability Insurance, force people with disabilities to prove they are "unable to engage in substantial gainful employment" before the government will come to their aid.

Political scientists, notably Harlan Hahn of the University of Southern California, have produced a series of explorations of the concept of the disabled as a minority group. It is the insight of this literature that the "locus" of disability does not lie so much in impaired individuals as in the nation's social, economic, and political environments.

A more specialized literature on the rehabilitation of persons with disabilities exists, but it has either a bitter or a celebratory quality, with little in the way of detached analysis. Instead, disability rights activists bitterly criticize public vocational rehabilitation programs, and former administrators tend to praise them.

Now Gary Albrecht, a medical sociologist, has produced a comprehensive academic monograph on what he would describe as the "production of disability" by societal forces and on the development of a "rehabilitation industry" as a response to disability. He argues that large and growing numbers of persons with long-lasting disabilities have combined with a large and growing health insurance industry to produce a large and growing rehabilitation industry. Nearly 1000 hospitals provided some sort of rehabilitation facility in 1988, for example.

In the book, Albrecht manages to merge his interest in medical sociology and his interest in the politics of disability. Like other medical sociologists, he subscribes to the notion that disease, illness, and disability are all socially produced phenomena. He also attempts to delineate differences between ideal and actual systems. His focus tends to be on the process of medical rehabilitation, rather than on income maintenance programs that serve people with disabilities.

In an ideal system, a man would enter a hospital with a heart condition, receive acute care, and begin a coordinated, well-managed process of rehabilitation that would take him from the emergency room back to the workplace. In the real world, a man who enters the hospital with a heart condition might never see a rehabilitation specialist. Instead, he might be dismissed as soon as his condition had stabilized because he lacked the medical insurance to pay for an extended rehabilitation regime. Alternatively, his acute-care doctor might be unaware of the benefits of rehabilitation or unable to gain access to a rehabilitation doctor. Or perhaps the cardiologist and rehabilitation doctor would fight to see who gained the ultimate control of the patient; or perhaps the man would see only a physical therapist, rather than a rehabilitation doctor. In other words, there are many stakeholders in the rehabilitation process, and often the interests of these financial and professional stakeholders do not coincide with those of the patient.

Indeed, as medical sociologists often point out, the system places a high value on conformity in the patient. Albrecht tells the stories of a woman who was labeled a difficult patient because she refused to wear a bra and a man who found that, every time he tried to assert control over his treatment, his doctors increased his medication, making him increasingly drowsy.

It does not have to happen that way, of course. Albrecht points to the Rehabilitation Institute of Chicago as a medically oriented facility that nonetheless works with and not against its patients. This facility is located in the middle of a major university hospital complex. The sheer size of the Chicago metropolitan area has enabled the center to build an efficient spinal cord injury system that tracks the patient throughout his or her hospital stay and consistently intervenes to increase the patient's residual functional capacities. The center has a charismatic leader who maintains good relations with leaders of the disability rights movement and of the city's financial and philanthropic communities.

In order to tell his story of how rehabilitation goods and services became commodities, bought and sold for a profit in a growing market, Albrecht must synthesize information from many different sources. Hence he has to explain the confusing history of American disability programs, the complex relationship between morbidity and mortality, the many disparate ways in which researchers define the concept of disability and count the number of people with disabilities, and the transformation of hospitals from community to corporate entities. It is easy for anyone to stumble over the resulting details, as Albrecht sometimes does in his recitation of the history of disability programs. Assigning dates to historical events often trips him up. In the text, the dates for the beginnings of the workers' compensation, the Randolph-Sheppard, Medicare, and Medicaid programs appear to me to be wrong. Albrecht also makes a dubious connection between the rise of medicine as a big business and the creation of government programs like the Hill-Burton Hospital Construction Program. He appears to confuse Benjamin Rush, the famous physician of the early Republic, with Howard Rusk, the dynamic rehabilitation doctor of the postwar era. But these are errors of transcription and translation, and they seem to be limited to the few instances where Albrecht depends on secondary sources rather than on his own pioneering research in the disability field.

One can read this book to gain a sense of the vast sweep of the literature on disability and to receive a detailed description and analysis of the rehabilitation process. The book marks an impressive beginning to what should become a growing literature on disability policy now that the Americans with Disabilities Act has been passed. It reveals some disturbing details about that policy that the debate over the act left almost completely unaddressed.

Edward D. Berkowitz
Department of History,
George Washington University,
Washington, DC 20052

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A Sometime Specter

Dirt and Disease. Polio before FDR. NAOMI ROGERS. Rutgers University Press, New Brunswick, NJ, 1992. xii, 258 pp., illus. $39; paper, $15. Health and Medicine in American Society.

If you grew up before the advent of polio vaccines in the 1950s, mention of the disease probably conjures up images of "iron lungs," Sister Kenny, and the dread inspired by infantile paralysis. Yet the disease did not always raise such a specter. In the 19th century exposure to the polio virus commonly occurred in infancy and resulted merely in a mild fever and then life-long immunity. By the 1890s, poorer children whose environments lacked the accoutrements of modern sanitation were still likely to develop such immunity, while, ironically, middle-class and upper-class children exposed to the virus later in life developed the paralytic form of the disease.

Little was understood about the cause and transmission of polio before the 1930s and '40s. During the epidemics of the early decades of this century, the focus of this well-written book, healthfulness and cleanliness were so firmly linked in the public mind and in medical thinking that polio cases seen among the middle class were viewed as anomalies.

Even as late as 1920 most of those practicing medicine had trained in an era that connected disease with dirt; it was only during their years of practice that bacteriological explanations had taken hold, and despite developments in theory and increasingly sophisticated laboratory methods researchers and physicians in the early 20th century could do little to halt the spread of epidemics. Lacking any efficacious treatment, analysts returned to traditional beliefs; they blamed unsanitary conditions, most notably the living conditions of recent immigrant families from southern and eastern Europe. Even the most progressive public-health departments reverted to 19th-century sanitation efforts such as fumigation and disinfection, focusing on immigrant and working-class areas of the city. Though epidemiological evidence demonstrated greater occurrence of polio in the supposedly cleaner rural and suburban environments, scientists continued to concentrate their research on urban immigrant neighborhoods.

In this era—the Progressive period—all levels of government were coming to rely more and more on scientific experts and expertise in the shaping of public policy in general and of health policy in particular. The search for modes of disease transmission between working-class and middle-class homes led them to the fly as the vector of polio. Thus public health officials found a concrete, manageable target, as well as an explanation for the spread of polio into "clean" districts. In her account of the anti-fly campaigns Rogers shows the clear ethnic and class dimensions of early-20th-century public health efforts. Faced with a situation that bacteriology could not resolve, officials placed the veneer of the germ theory over 19th-century theories of filth and disease, positioning middle-class children as victims and working-class and immigrant children as guilty carriers of polio. Only in the 1920s with the emergence of Franklin Delano Roosevelt as polio patient did this image begin to change.

Focusing on the 1916 epidemic, Rogers ably presents the beliefs and activities of scientists, physicians, and the public, analyzing the tensions between traditional explanations of disease causation and the promise of scientific medicine. Throughout the period, disagreements among scientists about causation, mode of transmission, and therapeutic agents demonstrated the limitations of scientific medicine. One of Rogers's most interesting chapters describes alternative theories and therapies devised by lay and domestic healers, which often incorporated contemporary scientific rhetoric. In this fascinating history, Rogers demonstrates how old and new theories of medicine defined a disease within a culture that was granting increasing authority to scientific medicine.

Drawing on an impressive array of published sources, including medical journals and popular newspapers and magazines, as well as private unpublished sources, *Dirt and Disease* tells the story of scientific confusion, medical frustration, and public dread in the years when the spread of polio seemed inexplicable despite the evident promise of modern scientific medicine. Through Rogers's analysis we can appreciate the complex array of factors that shape the understanding of disease in our culture.

Rima D. Apple
Department of Consumer Science,
University of Wisconsin,
Madison, WI 53706

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Analysis of Dynamic Psychological Systems. Vol. 2, Methods and Applications. Ralph L. Levine and Hiram E. Fitzgerald, Eds. Plenum, New York, 1992. xvi, 404 pp., illus. $60.

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Bone Marrow and Stem Cell Processing. A Manual of Current Techniques. Ellen M. Areman, H. Joachim Deeg, and Ronald A. Sacher. Davis, Philadelphia, 1992. xxxii, 487 pp., illus. $145.

Brain Sex. The Real Difference between Men and Women. Anne Moir and David Jessel. Dell, New York, 1992 x, 242 pp., illus. Paper, $10. Reprint, 1989 ed.