

Searching Eyes: Privacy, the State, and Disease Surveillance in America, Amy L. Fairchild, Ronald Bayer, and James Colgrove (University of California Press, 2007)
Reviewed by Alan Rubel, in *Review of Policy Research* (2009)

Disease surveillance is an integral part of public health practice in the United States, but the methods and scope of surveillance has long generated controversy. In *Searching Eyes: Privacy, the State, and Disease Surveillance in America*, Amy L. Fairchild, Ronald Bayer, and James Colgrove provide a novel and important account of the history of disease surveillance in the U.S. by examining the evolution of the controversies surrounding surveillance and viewing those controversies “against the backdrop of the changing role and importance of privacy...in American life.” (p. xvi).

Part one (chapters 2-3) examines the advent of systematic surveillance of infectious diseases, in particular tuberculosis and syphilis. Debates regarding name reporting for TB centered not on patient privacy, but on the proper roles of physicians and public health officials. Resistance to compulsory reporting of TB cases came largely from physicians concerned that patient care would devolve to public health officials or that patients would avoid physicians who reported TB cases. Similarly, resistance to compulsory reporting of syphilis cases was led by physicians. However, resistance was less a matter of political opposition than physicians’ failure to actually report cases, in effect unilaterally preserving patient confidentiality. The authors’ view is that TB and syphilis reporting mark the era of “paternalistic privacy,” insofar as physicians paternalistically sought to preserve privacy of their patients rather than patients seeking to preserve privacy for themselves.

Part two (chapters 4-6) addresses the politics of reporting occupational disease, cancer, and birth defects, where surveillance was motivated in large part by the need to determine causes of disease. The key feature of these debates was that the potential beneficiaries, or their surrogates, demanded reporting of conditions. Labor opposed some early efforts to document workplace hazards for fear that sick employees would lose their jobs. However, as it came to recognize that greater information about occupational disease could galvanize support for regulation and worker protection, labor support grew for reporting occupational disease and for worker access to information regarding hazards. Primary opposition came from industry seeking to avoid government oversight of operations, arguing that disease reporting conflicted with the privacy rights of businesses. Support for surveillance of cancer presents a similar dynamic in that members of the public demanded disease registries as a way to identify potential environmental causes of cancer. Likewise, tracking of birth defects gained popular support with the rise of the environmental movement and in the wake of the thalidomide disaster as a means to determine whether birth defects were clustered, and if so, why.

In part three (chapters 7-9) the authors describe a shift toward “democratic privacy,” the paradigm example of which is the raft of battles surrounding name reporting of HIV and AIDS. These disputes involved gay activists, civil liberties advocates, public health officials, and legislators, and extended to the purposes of reporting (e.g., study, treatment, quarantine), the scope of reporting (AIDS only, or HIV as well), whether reports should include names or be coded, whether there should be partner notification, and proper security of registry information. A second example of democratic privacy is opposition to immunization registries based on anti-governmental views and the belief that vaccines are unsafe. In both cases, popular opposition has had the effect of circumscribing surveillance measures.

As an account of the politics surrounding disease surveillance, *Searching Eyes* is indispensable. By detailing the disputes, showing how they have changed over time, and examining recurring themes the book provides insights into the likely shape of future debates. Particularly noteworthy is the effort to link disease surveillance to privacy disputes in other domains. Contentious issues such as the Patriot Act and the Total Information Awareness initiative, for example, inevitably affect debates regarding disease surveillance. Too often public health surveillance is treated discretely from other sorts of information gathering.

However, despite the fact that it is one of the book's central ideas, it is unclear how one should understand the concept of "democratic privacy." The defining feature of democratic privacy is that members of the public participate in the debate to determine the contours of disease surveillance (pp. 28-29). In many cases, this participation is motivated by distrust of public officials handling information and the fear that persons could be subject to ill-treatment on the basis of information collected (p. 205). The confusion is that on the book's account, the era of democratic privacy appears to begin in the 1980s with the debates over HIV and AIDS reporting. But as part two of the book makes clear, members of the public were crucial in determining the contours of occupational disease, cancer, and birth defects surveillance well before the HIV/AIDS era. Moreover, it was precisely distrust of public officials and fear of ill-treatment that motivated first labor and then industry to oppose occupational disease surveillance. These privacy debates appear every bit as democratic as those about HIV/AIDS and immunization registries, yet there is no discussion of the concept of democratic privacy in the chapters devoted to occupational disease, cancer, and birth defects surveillance.

Regardless, the book will be an important resource for anyone seeking to understand and shape future disease surveillance and health privacy initiatives, as well as for those interested in broader debates about privacy. Although the book explicitly avoids weighing in on the merits of privacy debates, it will help guide those debates for some time.