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Edited by Dorothy Nelkin, David P. Willis and Scott V. Parris

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Introduction: A Disease of Society

Cultural and Institutional Responses to AIDS

DOROTHY NELKIN, DAVID P. WILLIS,
and SCOTT V. PARRIS

AIDS IS NO “ORDINARY” EPIDEMIC. MORE THAN A devastating disease, it is freighted with social and cultural meaning. More than a passing tragedy, it will have long-term, broad-ranging effects on personal relationships, social institutions, and cultural configurations. AIDS is clearly affecting mortality and morbidity—though in some communities more than others. It is also costly in terms of the resources—both people and money—required for research and medical care. But the effects of the epidemic extend far beyond medical and economic costs to shape the very ways we organize our individual and collective lives.

Social historians in recent years have pursued their studies of epidemics beyond the charting of pathogenesis and mortality to explore how diseases both reflect and affect specific aspects of culture. In writing about nineteenth-century cholera, for example, historian Asa Briggs (1961) called it “a disease of society in the most profound sense. Whenever cholera threatened European countries it quickened social apprehensions. Wherever it appeared, it tested the efficiency and resilience of local administrative structures. It exposed relentlessly political, social, and moral shortcomings. It prompted rumors, suspicions, and, at times, violent social conflicts.” Similarly, historian Gordon Craig (1988) observed: “It was no accident that preoccupation with the dis-

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ease [cholera] affected literature and supplied both the pulpit and the language of politics with new analogies and symbols.”

The literature describing the impact of AIDS is burgeoning. But most studies have focused on the medical and social epidemiology of the disease: how, for example, the virus entered the population and how it spread to different groups. Those analyses that deal with institutional responses suggest how norms and values have influenced various aspects of AIDS epidemiology and the efforts to control and to treat the disease; that is, the ways in which social values have shaped specific efforts to deal with the disease and its consequences. These contributions—for example, on public health agencies (Bayer 1989), public schools (Kirp 1989), the U.S. Public Health Service (Panem 1988)—have been central to our understanding of the past and present forms of the epidemic.

But AIDS will also *reshape* many aspects of society, its institutions, its norms and values, its interpersonal relationships, and its cultural representations (Bateson and Goldsby 1988). Just as the human immunodeficiency virus mutates, so too do the forms and institutions of society. Current clinical, epidemiologic, demographic, and social data about AIDS suggest that the future will be unlike both the present and the past.

How can we grasp the complexity of a society's response to disease? We need, surely, to avoid the tendency among many contemporary scholars and analysts to approach social problems by relying on public opinion polls or surveys, which may “confuse . . . cultural history with market research” (Lasch 1988). Rather, we must explore the accommodative process between disease and social life in its multiple dimensions, and the language and images that mediate their interaction. As the effects of the epidemic—and the numbers of persons infected—widen over the next five, ten, or twenty years, there will be many changes in our social institutions. Some will be adaptive and temporary, likely to change again; others will be more permanent, structural, and likely to persist.

Our intention in this book is to explore the impact of AIDS on American culture and institutions from the perspective of the humanities and social sciences. The notion of culture, as we embrace the term, is an elusive concept. In past decades culture has been conceptualized as a complex but relatively coherent and enduring “web” of beliefs, meanings, and values. Recently, however, scholars have emphasized the

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truly volatile nature of cultural constructs. Political scientists write of “fragile values,” referring to the very tentative and recent cultural acceptance of the rights of homosexuals, women, and various ethnic groups (McKlosky and Brill 1983). Sociologists studying the social construction of knowledge reject the concept of “enduring values,” arguing that situations, interests, and organizational pressures influence cultural definitions (Berger and Luckmann 1966). Contemporary anthropologists write of the “predicament of culture,” thinking of culture “not as organically unified or traditionally continuous, but rather as negotiated present process” (Clifford 1988). They argue that changes in technology and communication affecting patterns of social mobility and migration have substantively reshaped culturally accepted ways of thinking and acting.

AIDS demonstrates how much we as a “culture” struggle and negotiate about appropriate processes to deal with social change, especially in its radical forms. The contributions in this volume suggest that the institutions we have created to provide social and health services, make laws, enforce regulations, and represent ourselves in the arts and media are less monolithic and more malleable than we generally suppose. In confronting AIDS and its sequelae, these institutions are compelled by external and internal pressures to re-examine their objectives, operations, or methods, and to adapt in order to remain functional, effective, or meaningful. Clearly, no change stemming from this process is permanent. Rather, AIDS induces us to keep appraising the complex and fluid array of benefits and risks that may result from pursuing particular courses of action.

Social Perceptions of Risk

AIDS appears at a time when risks to health are a priority on the public agenda. The effects of toxic substances, chemical wastes, pesticides, food additives, and radiation are a persistent source of fear. We are preoccupied with health—with biological fitness, diet, and exercise regimes. We are bombarded with “data” about risks and benefits, and confronted with seemingly impossible choices. Even the egg—once a symbol of aesthetic design and nutritional perfection—is now the “Trojan Egg.” “There are no risk-free lunches. Or breakfasts. Or dinners,” say the health authorities (Hanson and Bennett 1989). But then, we

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are even losing our unquestioning trust in authority—government bodies, medical organizations, scientific experts—to protect our health. Metaphors of contamination and pollution, of death and dying pervaded cultural discourse in the 1980s and persist today.

The public fear of AIDS reflects more general risk perceptions. Psychologists suggest that the characteristics of risk will influence their acceptability; that people underestimate familiar risks and overestimate those that are unfamiliar, involuntary, invisible, and potentially catastrophic (Fischhoff, Slovic, and Lichtenstein 1979). Anthropologists emphasize the political, cultural, and social factors that influence risk perception (Douglas 1985). Attitudes toward risk are often subjective, embodied in a complex system of beliefs, values, and ideals. Thus, different social groups will emphasize certain risks and minimize others, or perceive similar risks in quite different terms (Nelkin and Brown 1984). Most important for the analysis in this volume, perceptions of risk are closely connected to moral principles (see the chapters in this volume by Ronald Bayer, Thomas H. Murray, and Thomas B. Stoddard and Walter Rieman). A judgment about risk can be a social comment, reflecting points of tension and moral conflicts in a given society.

In the case of AIDS, social and moral issues have compounded technical uncertainties. There is little consensus about the extent of danger, and still less about the nature of evidence or the court in which the facts are to be adjudicated. Is fear of AIDS irrational or justified by the actual risk? Are experts to be trusted or are they suspect? And, in fact, who are the experts? Nor, in the context of changing values, is there consensus about the appropriate responses to this disease. Despite strong scientific agreement that AIDS is not transmitted through casual contact, controversial proposals—enforced quarantine, mandatory screening, closing of gay bars, constraints on marriage and childbearing, and exclusion of infected persons from work, restaurants, and schools—have been fueled by prejudice and fear. AIDS, to some, symbolizes the problems posed by the dramatic challenges to traditional values that began in the late 1960s, developed during the 1970s, and still polarize the public.

When people see their “way of life” at risk, they characteristically become less tolerant of social differences. In their quest for order and control, they construct distinctions between normal and perverse, legal and criminal, innocent and culpable, healthy and diseased. Labeling AIDS as a disease of certain groups becomes a way to focus blame, to

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isolate the sources of contamination and contagion, and to deny the vulnerability and responsibility of the wider population.

Social Tensions and the Quest for Order

This quest for order reflects certain social and political tensions that are inherent in American culture. Our very nationhood and its defining Constitution are premised upon the ebb and flow of conflicts; they are never resolved, only checked and balanced. Many of these tensions have shaped, and will continue to shape, the response to AIDS in an array of social institutions—schools, prisons, the military, hospitals, the law, the church. Institutions address dissension in ways that reflect their ideology and professional ethos. But ideology and ethos themselves are not “organically unified or traditionally continuous.” AIDS has been not only a catalyst for change in a continuing process of institutional and professional adaptation, but also a source of visible strain. Debates over many institutional and professional tensions—once largely confined to boardrooms, governing councils, journals, and courts—are now more often conducted in open and ad hoc forums. They are diversely, and often graphically, expressed in cultural representations through art and entertainment, music, and the media.

Certain values in American society have always been contested. We prize individual autonomy *and* social order, for example. Both are important to our personal and collective lives. Yet, increments to one value often compromise the other. Similarly, we prize both free choice *and* equity, but these too exist as dynamic constructs rarely, if ever, poised in equilibrium. And we value cultural diversity while imposing conforming norms. The tensions in American values are reflected in a set of questions that recur as we seek to deal with AIDS:

- *What is society's commitment to individual autonomy when communitarian values and objectives are at risk?* AIDS exacerbates the latent tensions between individual rights and social goals, as the need to protect the public health confronts the norms of privacy and confidentiality in personal life. Americans voice support of civil liberties, but often reject their concrete application. Even within the realm of private relations, such contradictions lead to interpersonal tensions: an infected person's “right to confidential-

ity” is pitted against the partner’s “right to know”; the infected woman’s right to “reproductive choice” is poised against the right to be “well born.” Social policies may constrain an individual’s reproductive choices in ways recalling the eugenic policies of an earlier age. Such tensions are at the heart of Ronald Bayer’s essay.

- *What are the limits of tolerance about nonconformity to mainstream values?* Only in recent times have we as a society come—very tentatively—to accept a variety of sexual orientations and life styles. AIDS has put new strains on public tolerance, reflecting old struggles between puritanism and hedonism. Our society today exploits—even markets—certain aspects of sexual behavior, while it also condemns those who practice them. Thus the association of AIDS with sexual behavior has subjected some individuals to stereotype and stigma while deflecting attention from the vulnerability of others. Richard Goldstein, in his chapter on cultural representation of AIDS, characterizes this as a tension between the “implicated” and the “immune.” Writing on discrimination, Thomas B. Stoddard and Walter Rieman address the legal implications of the tensions over social and sexual conformity.
- *What are the appropriate roles and responsibilities of government in managing disease?* The federal government was extraordinarily slow in recognizing the seriousness of AIDS, so that state and local government first assumed primary responsibility. Even then, traditional strains over respective responsibilities in a federal system, and public ambivalence about appropriate interventions, obstructed concerted action. Debates over government involvement have continued in discussions of both therapeutic measures and public health policies. Observe, in the chapter by Harold Edgar and David J. Rothman, the changing views of risk as the Food and Drug Administration (FDA), a normally conservative organization, has begun to remove procedural obstacles to the availability of innovative therapies. Note the debates over the government role in dispensing free needles, promoting sex education in the schools, and closing bathhouses. Far less contentious, and surprising to many observers, has been an emerging congressional consensus about the resources needed to treat those with AIDS. However, the belated appropriation of federal emergency relief funds to hospitals is unlikely to avert further crisis in those cities and states hardest hit, especially in the public hospital systems

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where the demands of AIDS compete with the compelling needs of other diseases.

- *What are the roles and responsibilities of the "family"?* AIDS places family relationships—between parents and children, between married and unmarried partners—under intense strain. The disease has mirrored the confusion caused by changing definitions of the family and shifting assumptions about its role. The United States Bureau of the Census has documented the extraordinary variety of nontraditional patterns of household formation, including those of single individuals, pair bondings, and cohabitating but otherwise unrelated adults. AIDS, as Carol Levine's chapter shows, gives poignancy to these impersonal findings. It underscores the changing role of the family as a reproductive unit and the difficulty of developing socially sensitive approaches to adolescent sexual behavior, reproductive choice, and contraceptive use. Tensions arise between the experimentation of teenagers convinced of their invulnerability to physical and sexual "accidents," disease, and even death, and the efforts of adults to temper their behavior.
- *What are the roles and responsibilities of professionals?* The constant struggle among equally honored yet competing values in the society has complicated professional roles and responsibilities. Charles L. Bosk and Joel E. Frader show how AIDS aggravates conflicts inherent in the professions. The physician, for example, traditionally honors a professional duty to several, often conflicting, parties—to science, to the primacy of the patient, to the society at large, and, importantly, though not always explicitly, to his or her self-protection. AIDS has challenged the relative priorities among these values; self-protection, for example, has become an unprecedented concern in the course of clinical practice. The disease has also challenged the hierarchical relationships in hospitals. In the past, specialization in medicine has increased professional dominance. Nurses, paraprofessionals, and volunteer groups inevitably have subordinate social status, reflected in social tensions and low morale (Freidson 1970). Their critical participation in the care of AIDS patients may be a source of change. Now, as Renée C. Fox, Linda H. Aiken, and Carla M. Messikomer observe, the nursing profession has opportunities to reestablish the importance of its caring mission.

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Institutional Responses to AIDS

The chapters in this book illuminate in the American context the responses to these and other tensions dramatized by AIDS. And they suggest possible directions for change as we confront AIDS in the future. Social responses over the past decade have ranged from denial to heroic action, from apathy to creativity, from withdrawal to activism, and from prejudice to promotion of communities of shared identity. By understanding the present social context and current strategies of adaptation and accommodation, we aim in this book to shed light on a continuing social process.

Richard Goldstein opens the analysis by examining the epidemic's extraordinary impact on our cultural vision. Some works in the fine arts reflect the perspectives of the "implicated," that is, people with AIDS or human immunodeficiency virus (HIV) infection; others, especially those in popular forms of entertainment, represent the views of the "immune." AIDS in art is an emblem of the involved "insider" or the stigmatized "other." The two themes embody enduring tensions between different approaches to social life. Yet, some television and commercial films have begun to portray AIDS from the "implicated" perspective; more Americans, Goldstein suggests, are coming to experience the epidemic closer to home.

We then explore the changes AIDS has evoked in three systems of socialization and control—the family, prisons, and regulatory agencies. These three institutions' experiences with AIDS—and other social upheavals—testify to their capacity for change when confronted with profound threats to their normative character or hegemony. Jurisdictions across the country have reinterpreted what constitutes a family when those individuals responsible for each other's health and welfare, through affirmed affectional commitment and adoption as well as kinship and marriage, press for recognition of the functional similarity of these bonds. As the incidence of HIV disease has risen sharply in correctional facilities, some jail and prison officials have been forced to deal with the reality of drug use and same-sex intercourse in their midst—and to take (thus far, extremely limited) steps to improve health care and health education in those facilities. The FDA has now approved a "parallel track" system for expanded use of experimental drugs for AIDS, a procedure that loosens the agency's direct control over monitoring drugs' safety and effectiveness.

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As more people live in nontraditional arrangements, Carol Levine observes, the gap between their needs and official designations of the “family” has widened. AIDS has exacerbated tensions over the family, affecting legal definitions, medical decision making, and questions of child custody and housing rights. Existing families must adapt to the exigencies of AIDS: changing laws and customs may condition how new families form. HIV disease threatens the intimacy and acceptance ideally characteristic of family ties, yet at the same time reinforces their necessity.

Nancy Neveloff Dubler and Victor W. Sidel report that AIDS heightens long-standing tensions over jurisdictional matters in jails and prisons, including issues of health care. Despite court decrees that the incarcerated have a constitutional right to health care, judicial decisions have often expanded correctional officials’ discretionary powers, effectively limiting delivery of many AIDS services. Inmates and parties representing them have thus brought suit against correctional authorities over basic problems of inadequate medical treatment, overcrowding, and drug use in urban and rural facilities. How we care for incarcerated people today, Dubler and Sidel state, will directly affect future use of community services for AIDS and other conditions.

AIDS is also evoking new policies and practices in drug regulation and usage. Harold Edgar and David Rothman argue that the rigorous procedures developed by the FDA prior to the 1980s to minimize risks to human subjects is changing in order to maximize innovation. The FDA is hastening access to investigational drugs and easing drug importation for personal use. In effect, decisions about benefits and risks are being transferred to patients and their physicians—a policy with far broader implications for the entire medical care system.

Our next section explores how AIDS bears on tensions over the role of health care professionals and service providers. The three chapters offer complementary portraits of those dealing with AIDS on the front lines of medical and political battles, and reveal in depth the conflicts nurses, physicians, and voluntary associations and their members face over professional, organizational, and personal objectives. The “culture of caring” that nurses bring to bear on the epidemic, Renée Fox, Linda Aiken, and Carla Messikomer note, can make a palpable difference in patients’ lives. Indeed, the nursing profession has been prominent in organizing systems of care for people with AIDS. Many nurses testify to the redeeming significance they find in their work, but caring for AIDS

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patients is also stressful. It remains to be seen whether nursing's visible contribution to creating and managing forms of care will endure.

AIDS, along with other institutional factors, is also remolding the "shop-floor" culture of house officers and students in urban medical centers. Charles Bosk and Joel Frader relate how, prior to the epidemic, medical workers felt powerless and exploited within the system, yet proud in their clinical coups and generally physically invulnerable. Arriving at a time of heightened economic competition in medical settings, the HIV epidemic subjects house officers to still more demanding schedules, increasing their sense of powerlessness and limiting their possibilities of professional achievement. Fears of contagion, meanwhile, are eroding assumptions of invulnerability in the medical workplace.

Suzanne Ouellette Kobasa treats the voluntary associations formed to respond to AIDS as an example of Tocqueville's classic model of American associations, defining and providing services beyond the government's compass. Particular organizations have had considerable—possibly unique—success in influencing government policies. Yet voluntary associations face daunting challenges of tending to newly affected groups, devising new tactics to pressure official bodies, and avoiding bureaucratization or fragmentation.

Our final section focuses on the epidemic's effects on current debates about American rights and reciprocities. All three chapters, albeit in different ways, question how society as a whole is reckoning with individuals' and groups' desire to exercise their rights and privileges in the face of AIDS. How do we balance a collective interest in seeing a child born well with a woman's right to reproductive freedom when she carries HIV? How are we to preserve a sense of national solidarity when we restrict certain groups from giving blood to the community at large, even though tests let us detect HIV's presence in specific donations? How are we to extend Fourteenth Amendment rights to counter the contemporary diversity and complexity of bias, including discrimination against people with HIV infection? Each chapter, in short, illuminates how AIDS is contributing to reframing the American social contract.

Ronald Bayer shows how the specter of pediatric AIDS challenges assumptions about women's reproductive freedom. Many health officials hold that HIV-infected women should not become pregnant. But this conflicts with the views of genetic counselors, feminists, and medical