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Editor's Note

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Editor's Note

Padraig O'Malley

On occasion, the *New England Journal of Public Policy* will devote an entire issue to consideration of a public policy matter of major importance. The AIDS epidemic is such a matter, with a likely impact of overwhelming consequence well into the twenty-first century. The epidemic raises fundamental questions regarding the nature of individual freedom, our responsibilities to others, the always delicate balance between private rights and the public interest, and society's obligation to its "out" groups — whose members it has stigmatized, discriminated against, ridiculed, and treated as less than full and equal citizens. Indeed, it requires us to ask whether society can discharge its responsibilities in this regard without discarding some of its essential myths about itself.

These are questions which in the best of times we tend to avoid, because they raise issues about the nature of our most deeply rooted fears and anxieties and the role of repression and denial in the conduct of private morality and public affairs — issues that we find discomfiting at best and highly disconcerting at worst.

There is hardly an area of public policy that does not fall within the purview of the epidemic, and as the extent of infection and the illnesses associated with it multiply geometrically over the coming years, our cultural, social, religious, educational, financial, and political networks and institutions will be called upon to examine their practices and policies and to address what is found wanting. The purpose of this issue of the *New England Journal of Public Policy* is partly to facilitate that task.

AIDS has become encumbered by the trappings of metaphor. In *Illness as Metaphor*, Susan Sontag writes that "any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. . . . Contact with someone afflicted with a disease regarded as a mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo." But what Sontag wrote about cancer — that it "is felt to be obscene — in the original meaning of that word: ill-omened, abominable, repugnant to the senses" — is even more pertinent to our forebodings about AIDS. AIDS satisfies our predilection for punitive notions of disease. There is AIDS as "the killer disease," and there is the "war" against AIDS — allusions that evoke disturbing feelings of unease and dread. Ostensibly, the illness is the culprit, but it is also the AIDS patient who is held to account and to whom blame is imputed, whether implicitly or explicitly. Hence the voices of Fred Garnett, Ron McAvoy, Kevin Brown, Richard Broussard, Tema

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Luft, and Matilda, the persons with AIDS (PWAs) who gave witness on behalf of their illness at the Third International AIDS Conference in Washington, D.C., in June 1987. These are strong and vibrant voices, resonant with the possibilities of their own lives — not the voices of victims. But there are other voices, the voices of the very ill, who are without adequate care, who are treated as outcasts, who struggle to maintain some dignity amid the most extreme circumstances of adversity, who are physically deprived, psychologically isolated, denied the compassion we would extend to suffering animals, and who look only for some affirmation of their own humanity before it ceases. We must pay heed.

In the nine months during which this issue has been in the planning, the epidemiology of AIDS has changed significantly. The evidence now suggests that the once-feared explosion into the general population of HIV — the human immunodeficiency virus that may cause AIDS in as many as 55 percent of the people who become infected with it — will probably not occur; that the rate of new infections among gay men has declined to the point where the virus may have stopped spreading in this community; and that more and more, new cases of infection are being found among drug addicts, their sexual partners, and their babies.

AIDS, therefore, is becoming increasingly a disease of the poor, of blacks and Hispanics, of women, and of children — the population groups we have traditionally neglected or forgotten — rather than of the middle-class white gay men who were primarily afflicted during the epidemic's early years. And since infected intravenous drug addicts appear to be less geographically mobile than many of the infected gay men, AIDS is increasingly becoming a disease that manifests itself in communities with high concentrations of minorities.

Indisputably, despite the reduced spread of HIV among homosexual men, the upsurge in AIDS and AIDS-related disease and the toll of death associated with acquired immunodeficiency syndrome will continue to wreak their devastation: as many as one in every thirty American males between the ages of twenty and fifty are probably infected with the virus. Federal officials now believe that about 20 to 25 percent of the nation's estimated 2.5 million homosexual men and 25 percent of its almost 1 million intravenous drug users have the virus, and that overall, between 945,000 and 1.4 million people may be infected. Recent setbacks in the search for a vaccine make the likelihood of a cure in the near future more remote. The evidence suggests that unless a cure is found, most of the persons already infected will eventually develop AIDS and die — a human catastrophe of immense consequence.

As of February 1988, some 52,000 cases of AIDS had been reported in the United States, and approximately 29,000 of these persons had died. However, the Centers for Disease Control estimates that the number of new cases alone in 1991 will exceed 52,000, and it projects a cumulative total of 270,000 cases by the end of 1991. The actual case load may be 20 percent higher, since there are many undiagnosed cases.

Heterosexual spread of the disease has confined itself almost exclusively to the sexual partners of people who contracted the disease through established modes of transmission: sharing contaminated needles or other drug-injection equipment, receiving infected blood products before the spring of 1985, or engaging in male homosexual intercourse. There is little evidence that heterosexually active people with no known risk factors for AIDS for either partner will spread the disease to each other. In November 1987, the Centers for Disease Control projected that approximately 0.021 percent of this country's estimated 142 million heterosexuals without specific identified risks (30,000 people) are infected.

However, the growing number of infected addicts and their sexual partners in the primary and secondary transmission groups, and hence the reservoir of HIV-infected heterosexuals, will inevitably increase the likelihood of transmission to other groups as the epidemiological process works itself out. Women, who consistently account for 6 to 7 percent of AIDS cases, constitute an overall 27 percent of cases in those groups into which a woman can be assigned, a percentage that is on the increase. The total number of pediatric AIDS cases reported to the Centers for Disease Control was 820 in February 1988; this number is expected to increase to over 3,000 by 1991.

The burden of AIDS cases has been greatest in the Middle Atlantic and Pacific states, where, in the metropolitan areas of New York City, San Francisco, and Los Angeles, the original cases of AIDS were recognized. The six-year cumulative incidence rates in these two regions are approximately twice the national average and three to four times the rate in New England.

Within New England, where the six states accounted for 1,500 cases of AIDS in the last six years, variations exist in state-specific incidence rates. New Hampshire and Vermont have rates among the lowest in the nation; only four states have reported fewer actual cases than Vermont. Rates in Rhode Island and Maine are below the national average; among the fifty states, these two hold ranks of thirty and forty, respectively, for total cases reported. However, only five states have reported more pediatric cases than Massachusetts and Connecticut; fourteen children under age thirteen have developed AIDS in each of these states. Moreover, current studies of seroprevalence in newborns indicate that in the inner city of Boston, one in fifty-five babies may be seropositive at birth.

Much has been written about the nation's slow response — nonresponse, some would argue — to the AIDS epidemic, and the absence of strong federal leadership. Although the picture has improved in the past year, efforts to contain the disease remain for the most part belated, disjointed, occasionally misguided, and too often inadequate. Much of the problem, of course, has to do with the nature of the disease and the manner in which it first manifested itself. "AIDS requires," Marshall Forstein writes in this issue of the journal, "that we take the most difficult, most emotionally charged concerns of our civilization and within the extremes of existing values, morals, social structures, and economics cut through to the essential tasks involved in halting a sexually transmitted disease." Thus, the prolonged silence, especially at the federal level, is due to the fear of addressing the fundamental issues of sexuality, especially homosexuality, and drug addiction. The fear and anxiety-propelled irrational responses, such as calls for quarantining AIDS patients, and even all HIV-infected individuals, are related to what drug use and sex symbolize and mean in our culture. Forstein raises the issue that still bedevils us: "How does a society begin to address the medical and psychological needs of homosexually oriented people who are intentionally invisible within the fabric of American life, and whose basic civil rights are not clearly guaranteed by the Constitution," especially when many states regard the very sexual activity that is associated with the transmission of the disease as criminal? Moreover, as Forstein argues, there is "something quite different about sex than almost any other human activity which psychologically makes our culture respond regressively and often punitively," and "the association of sex and death, now profoundly etched in our consciousness, and the basic fears of intimacy and sexual expression which have always been a part of our society have created special barriers to the development of coherent, reasonable approaches to this disease." Similarly, the conflict around drug addiction "represents an underlying psychological ambivalence about

whether an individual is to blame for his or her addiction or whether, in fact, it is a disease." We are still, it would appear, susceptible to the proposition that disease can be cured by willpower.

The situation is changing, albeit slowly — far too slowly for those who already have the virus. Above all, there is no well-thought-out, rational policy, and the federal government continues to neglect issues of prevention, civil rights, and health care. Increasingly, state and local governments have been left to fend for themselves. The result is a fragmentation of effort, a mishmash of guidelines, widely varying policy, disparity in distribution of services, and a set of often unsettling contradictions. For example, condoms are distributed free to homosexual men in New York City jails but are contraband in New York State prisons; Connecticut and Massachusetts require applicants to be tested for the AIDS virus for life insurance purposes, but New York does not.

Of course, the AIDS epidemic cannot be considered only within the context of the United States. The disease has already appeared in 160 countries, with a worldwide estimate of 150,000 cases through 1987. The World Health Organization (WHO) expects 150,000 new cases to be reported in 1988, bringing the world case load up to 300,000 by the end of this year. But that, unfortunately, is not the worst prediction. WHO estimates that 5 million to 10 million people are infected with HIV, perhaps 3 million in Africa, in which case anywhere from 500,000 to 3 million new cases of AIDS will develop within the next five years in people already carrying the virus.

In the face of the international disaster posed by the epidemic, we will be forced to examine the nature of our global interdependence, and the appropriateness of our concepts of national autonomy. We must examine the foolhardiness of implementing short-term measures that give the appearance of benefit but that are in fact inimical to the public interest, and we are compelled to address the overriding need for cooperation, consultation, and joint action among nations. Already, countries are moving to protect their own perceived interests, however narrowly they may be defined. Thus, in the United States, illegal aliens who are applying for permanent residence under the revised resident alien law are required to be tested for HIV. If they test positive, they are denied residence and are deported to their country of origin, although it is all but certain that they became infected in the United States. In short, the United States is becoming an exporter of the AIDS virus. In China, Japan, India, the Soviet Union, several Soviet bloc nations, Belgium, and Germany, all foreign students are required to take AIDS blood tests. If they test positive, they are sent home. Such measures invite retaliatory responses on the part of other governments, actions undertaken not as a matter of sound policy but simply to reciprocate in kind.

The last words belong to Camus, from *The Plague*. Dr. Rieux, when the epidemic has ended, resolves to compile his chronicle so that "he should not be one of those who hold their peace but should bear witness in favor of those plague-stricken people; so that some memorial of the injustice and outrage done them might endure; and to state quite simply what we learn in a time of pestilence: that there are more things to admire in men than to despise.

"None the less, he knew that the tale he had to tell could not be one of a final victory. It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers." 🍷