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**FACING
AIDS**

**A Special
Issue**

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*Considering how dangerous everything is
nothing is really very frightening.*

Gertrude Stein

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INTRODUCTION

To those who have died and to people with AIDS fighting for all our lives.

The dimensions of the AIDS epidemic, a fatal disease for which there is no known cure, are overwhelming. As of July 20, 1987, there were 38,808 diagnosed cases in the US alone; of those 22,328 have died.¹ It seems likely that AIDS will completely alter the political landscape wherever it appears. Despite, or perhaps because of this, the reactions to AIDS in the US, beyond the parameters of the gay community, have ranged from silence to hysteria to denial. In this special issue on AIDS, RA begins to look at those responses with the hope of opening a dialogue on future implications for the various communities affected by AIDS, for anti-AIDS organizing, for gay politics, and for the Left.

We began with a concern about the original construction of AIDS as a "gay disease," and its eventual description as Central African in origin, and the identification of women, especially prostitutes, as the principal carriers. The state began almost immediately to propose policies that identified, and sought to isolate, marginal groups. Despite the fact that the face of AIDS is rapidly changing, affecting growing numbers in every community, it remains a disease associated in the popular mind with marginality and as such carries an underpinning of further stigmatization for those groups. Much of the social response carries with it as well a notion of expendability which we find particularly offensive. But while breaking

¹First identified among gay men in urban areas, two-thirds of all people in the US diagnosed as having AIDS are dead. Projected estimates are 270,000 cases by 1991, with 179,000 deaths. The figures are even more startling in Central Africa. Underreporting by state and public health officials makes estimates unreliable, but projections of 2-5 million infected in Africa are not uncommon.

with the identification of AIDS as a "gay disease" is important, we should not bypass the ways in which homophobia infused the way reactions and policies were framed. As we examined the left press, we found nothing that exposed the political dimensions of what we felt we were confronting.

We set out to unlock the conceptual frame around AIDS and the credos which have contributed more to the spread of the disease than to its eradication. In that light we sought to challenge the framework of innocence vs. guilt, to declare the bankruptcy of testing as a substitute for public education, to refuse the panacea of merely more dollars, and to rebut the attacks on promiscuity. It is critical to expose the moral order which dominates discussion of the disease and focus on the specifics of sexual practice, culture and community which underlie both the story of transmission and hold the key to prevention. As we prepared this issue, we also wanted in some way to represent the pain and devastation that is occurring in people's lives, and communities, as their friends and lovers become sick, weaken, and die.

The original epidemiological risk groups were used to legitimize already existing bigotry against Haitians, gay men, and i.v. drug users and in turn shaped response to the disease. The epidemiological reality of who is vulnerable to AIDS has shifted, but popular consciousness still seeks to see AIDS as confined to the "unclean" and "deviant" prostitutes, the promiscuous, and partners of the outcast original risk groups. The ramifications of these distinctions have become apparent as the virus has moved beyond the boundaries of the original risk groups into the "general population." Media/popular culture, the state (including its public health arm) and the Left have all been part of upholding, albeit differently, a particular moral order which in turn has blocked attempts at prevention and contributed to the spread of AIDS. We want to challenge the notion that AIDS is acquired by being a particular kind of person, while simultaneously challenging the current mythology that "everyone is equally at risk" since it denies the special vulnerability and experience of gay men, blacks and Hispanics, i.v. drug users, and other

groups where cases have been concentrated.

In the last nine months, those of us following AIDS coverage have been startled by the frequency and prominence given discussion of the disease. Following the recognition that those outside the standard risk groups were not immune to AIDS, the response of the public has begun to surface. Since that time, the state has been scrambling to develop an appropriate plan of action. The Reagan administration offers testing as a solution. Liberal mainstream media have begun running safe sex guidelines as a public service. Condoms became a hot topic (as safe sex was equated solely with the use of condoms), and women's magazines ran columns eroticizing their use. It seems as if the aggressive public information campaign long called for by gay and AIDS activists had finally begun. In fact, now that the spread of the disease has crossed the established boundaries between normal and abnormal, between moral and immoral, the tension between stopping transmission and upholding a particular moral order intensifies. Structured into the language of those newly converted to "public education" are many of the same categories, the same assumptions of innocence vs. guilt, of who is worth protecting and who is expendable, as Deb Whippen illustrates.

The effort in regard to condoms has been recent. As Deb Whippen points out, prior to "heterosexual AIDS," the medical prescription for safe sex was abstinence. Sex, for gay men, was expendable. Clean needle programs remain stalled. I.v. drug users deserve to remain at risk as a consequence of their habit. While the debate rages about the propriety of enclosing "safe sex kits" in mainstream papers, little real effort is directed towards making safe sex information accessible to black or Latino communities where AIDS is spreading with alarming speed. Thus, the hysteria that identifies everyone as equally "at risk" obscures the true contours of the disease with devastating consequences for communities disproportionately affected. Simon Watney discusses the media campaign in Britain which has been heralded in the US as a model for public education on AIDS. Watney exposes that behind the pretense of openness lies the complete dehumanization of gay men. The orientation of the campaign to

the "general public" obscures the experience of gay men hardest hit by the epidemic.

Public health officials acknowledge that containment of the disease can only be accomplished by halting transmission. AIDS necessitates explicit education on practices around sexuality and i.v. drug use. The requirement of such a massive education campaign has created enormous contradictions in the rightward leaning social climate fostered by the state, and by institutions such as the Catholic Church and the Christian fundamentalists.

The Reagan administration has been intransigent. Educational materials which explicitly explored gay safe sex were proposed, but funding was denied. The Catholic Church discouraged the use of condoms, despite the lack of alternatives for penetrative sex. The Right cast AIDS as an extension of moral decay with victims deserving a disease brought on by their unclean acts. The medical establishment spent precious dollars researching the "lifestyles" of gay men, as if AIDS were a moral flaw rather than a disease caused by a virus. From all corners, it appeared that censorship of preventive measures (from public discussions of gay sexuality, to distributing sterile works) had more to do with imposing standards of respectability, with punishing sinful behavior, with regulating "marginal" populations and with containing the disease in bounded communities than with developing a comprehensive public health policy that valued the lives of everyone.

We might believe that *here* AIDS is an outsider disease and that the very number of afflicted in Africa makes the experience one of shared risk. *There*, everyone is afflicted and the numbers are so overwhelming, we turn away. We need to be alert to the continuities. As Bob Sutcliffe and Mark McGrath reveal, nations limited by the international monetary squeeze also identify who is expendable. In Brazil, safe sex campaigns are oriented to tourists and the urban elites. The poor go without information about transmission and without health care. Our desire to avoid the humans behind those numbers is closely connected to the false dichotomy in our country of who is and is not at risk for AIDS.

Haunted by the history of stigmatization as the carriers of venereal disease, the black com-

munity has until recently remained as silent as the mainstream media about the reality that "a black woman is 13 times more likely than a white woman to contract AIDS, [and] a Hispanic woman 11 times at risk," as Richard Goldstein reported. Evelyn Hammonds places the response of the black community in the context of "the historical construction of sexually transmitted disease as being the result of bad, inherently uncontrollable behavior of blacks"—most shockingly evidenced in the use of black men as dispensable guinea pigs in the Tuskegee syphilis experiments. She details how the "color-blindness" of the media and the silence of the black community result in "a failure to develop educational programs and materials that speak the language of our communities."

As Cindy Patton points out, there are also gender continuities in the history of sexually transmitted disease. As with syphilis, women are portrayed as vessels and carriers with the rounding up of 20,000 prostitutes proposed as a preventive method in Chicago. In fact, the current medical model places women more at risk for acquiring rather than transmitting the disease. Mythologies of who is contaminated and vicious appraisals of who is worth saving are at work as well.

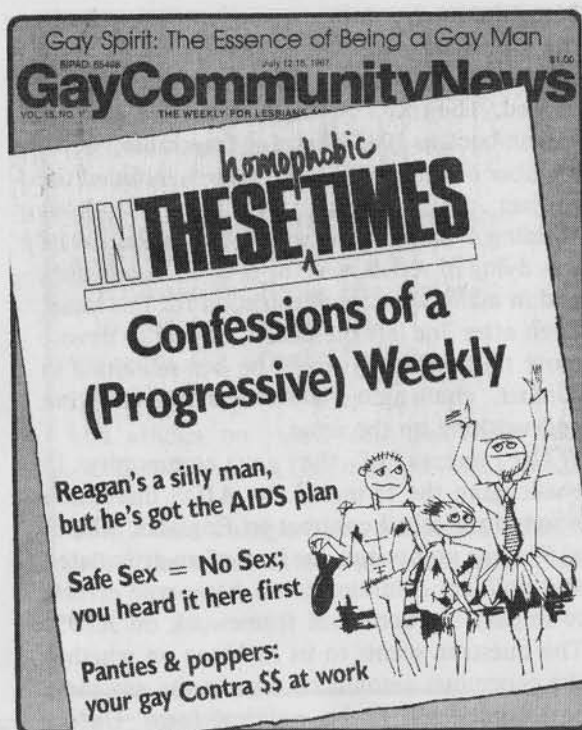
The heterosexual response has been complex. Jealousy, fear, fascination, uncertainty, sympathy, voyeurism, all exist. For heterosexual women, the absence of a women's movement means that safe sex has to be negotiated as a matter of "personal" life. The distance between those circumstances and the community-based erotic with which gay men have faced AIDS, is jarring. The difficulties women experience in negotiating safe sex may open up public conversations among heterosexual women and between heterosexual women and lesbians about sexuality and desire. AIDS necessitates a regeneration of the women's movement to explore the problematic of sexual power, passivity, helplessness, and negotiation. Between lesbians and gay men, AIDS has already opened a dialogue that previously surfaced only in very rare public moments or in conversations between friends. The barriers between us are deep and the differences are stark. The virus (that knows no morals) moves much more smoothly than we do across social boun-

daries, either conceptually or practically.

What roles have progressives played? What has been the contribution of left media? By and large, the response of the Left has been a resounding silence. What has been written has largely fallen into the already existing framework around AIDS. More government spending has been a popular demand. As Sutcliffe and McGrath argue, such demands don't address spending priorities. Funneling more money into dead-end research or testing is counterproductive. The Left has failed to challenge or even recognize the homophobia and the premise of expendability inherent in such strategies. The "progressive" response has been one of distance from the entire set of questions posed so starkly by the AIDS epidemic, most especially from groups more vulnerable as if "they" were not also "us." The Left should take up the need for education that addresses sexuality, and it also needs to take seriously questions of the erotic.

In These Times (ITT) warrants special mention. In an editorial this spring, ITT supported many components of the Reagan administration's AIDS plan, including mandatory testing. As Cindy Patton argues in her article, support for testing makes faulty assumptions about the preventive value of separating those who are HIV-positive from those who are not. Richard Goldstein also notes the particularly pernicious uses of testing against Afro-Americans in the case of sickle cell anemia. Here, too, testing positive had devastating effects on the lives of persons so labeled while contributing little or nothing to the treatment or prevention of the disease. Evelyn Hammonds takes Goldstein one step further by noting that the consequences of discrimination against one individual has implications for the entire community. ITT responded to challenges from its readers by evoking the distinction between affected groups and the general population. The evident disregard shown AIDS activists and the gay community spells out a clear message. In the world view of ITT, the concerns of gay people are not a consideration; they are expendable.

The question remains: why? What explains the Left's failure on AIDS? We believe that there are historical reasons and reasons par-



ticular to the epidemic itself. The reality of AIDS raises issues that have been absent from a heterosexual "progressive" agenda and brings to the center discussions that have been relegated to the margins. In particular AIDS represents the destruction of the split between private and public, especially the relegation of sexuality to a hidden sphere. Historically, it was the women's movement that insisted that sexuality, reproduction, the critique of the family, and the culture of daily life be central to the agenda of the Left. In recent years, the Left has failed to address questions of personal life and, indeed, it is primarily the gay and lesbian movements which have become the repository of a critique of personal life. An intertwined racism and homophobia in the white Left results in attributing high percentages of HIV infection in communities of color to drug use, thus rendering black and Latin gays and lesbians invisible. This failure to take up questions of how we live and love undermines the Left's ability to respond to AIDS.

The starting point of AIDS in the gay community, in the US, framed it as a "gay disease." Thus, the gay male community had to face its initial impact. We, on the board, have

learned a lot from their struggle to set terms in the discussion of sexuality (not to mention prevention, transmission and treatment) that ensued. The roots of this special issue actually extend back to 1985 when Joe Interrante, then a member of the RA editorial board, initiated the project. His piece, "To Have Without Holding," about living with his lover Paul as he was dying of AIDS, was the original submission and in many ways the inspiration for this issue. Even after Joe left the board, in part to devote more time to AIDS work, he has remained in contact, challenging us to continue thinking and working on the issue.

The success of the gay community in challenging the terms of the AIDS discussion stands in marked contrast to England, where, as Watney points out, the lack of an articulated and political community has hampered efforts to impact the dominant framework on AIDS. The question seems to us to hinge on whether the enormous amount of rage in the gay male community will find a political form. Unfortunately, even in the US, many AIDS organizations have been engulfed by bureaucratization, funding restrictions, and the increasing demand for services. Radical anti-AIDS groups, however, like the Lavendar Hill Mob of New York are springing up to provide a voice for the community anger.

The recent organizing for October's Gay and Lesbian March on Washington is also a forum where the growing political consciousness of gay men is emerging. We have been struck by the fervor and intensity among them, many of whom were previously unpolitical. The June arrests of AIDS demonstrators by Washington police wearing yellow gloves have become a symbol, triggering discussions of more militant actions. A groundswell of support, in fact, for the October civil disobedience at the Supreme Court is coming from the gay bars. Visibility actions in Boston, designed to claim public space for gay people, have attracted growing numbers of gay men.

AIDS has revealed both the limits of an insular subculture and the strengths of community. It has forced a reevaluation of organizing strategies, away from the "human rights campaigns" of several years ago. In discussions with veteran AIDS activists and young gay

men, "AIDS" is cited as a factor in coming out, i.e., locating oneself inside the gay community *and* pushing for increased visibility in straight society. AIDS organizing, in its earliest forms, meant creating a transformed erotic and the means to accommodate the needs of those who are sick, those who are dying, and those who survive. There is a sense that the most culturally radical strands of the gay liberation movement live and are being elaborated into a new definition of community even against the backdrop of devastation caused by AIDS.

The recent and growing response from the black and Latin communities opens one further possibility. A coalition between AIDS organizers and primarily gay and black or Latin groups would break the traditional left view of opposition between those communities and provide a space for the recognition of black and Latin gays and lesbians.

Those of us on the board have been required to go through changes as well as we constructed this issue. We are, after all, a left journal with an unusually high percentage of women readers. Although we currently have no gay men, a little less than half the board are lesbians. The unique composition of this issue owes much to the passion of the "lesbian faction." While the remainder of the board was deeply committed to this issue, the challenges for the Left and the gay/lesbian Left were confronted in microcosm. The debates were sometimes contentious, often frustrating, yet most of us emerged transformed by our experience.

A primary goal of radical AIDS activists has been to break the framework of risk groups while still providing the information necessary for people to accurately assess their relative degree of risk. Key to this process will be our ability to unpack false assumptions about identity which inform the definition of risk groups and lead to a false sense of security based on who you (or your partner) are, rather than what either of you do. For the non-gay Left to move in this direction would require a complete reorientation toward members of those groups, beginning with the gay male community and its organizing response to AIDS. To learn from the practices and perspectives of people with AIDS in all affected communities calls for the acknowledgement of very different starting

points and the capacity to challenge the definitions of normal, respectable, and safe. To assert that "gay sex" is not outside of sexual experience (and that gay life is not expendable) and that we all have something to gain from the reorientation that follows, is to begin to break down the fear and homophobia that help the spread of the disease. This is why, despite our doubts and disagreements, the questions we know remain unanswered, and the new information that breaks each day, we publish this issue.

The editorial board would like to acknowledge the following people for their help in putting together this issue: John Antonellis, Michael Bronski, Gregory Gazaway, Fred Gorman, Hershey Hirschkop, Joe Interrante, Marea Murray, Debi Samdperil, Ellen Shub, and Marc Stein.

FORTHCOMING in *Radical America*

"History and the Gay Community"
by Robert Padgug

"AIDS: Comparative State Response"
by Rosemary Taylor

"Death and the Erotic Imagination"
by Michael Bronski

"Women and AIDS"
by Margaret Cerullo

and articles on AIDS and the Third World, AIDS and i.v. Drug Use, more on Race and AIDS.

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GUATEMALA

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VOL. 19, NO. 5

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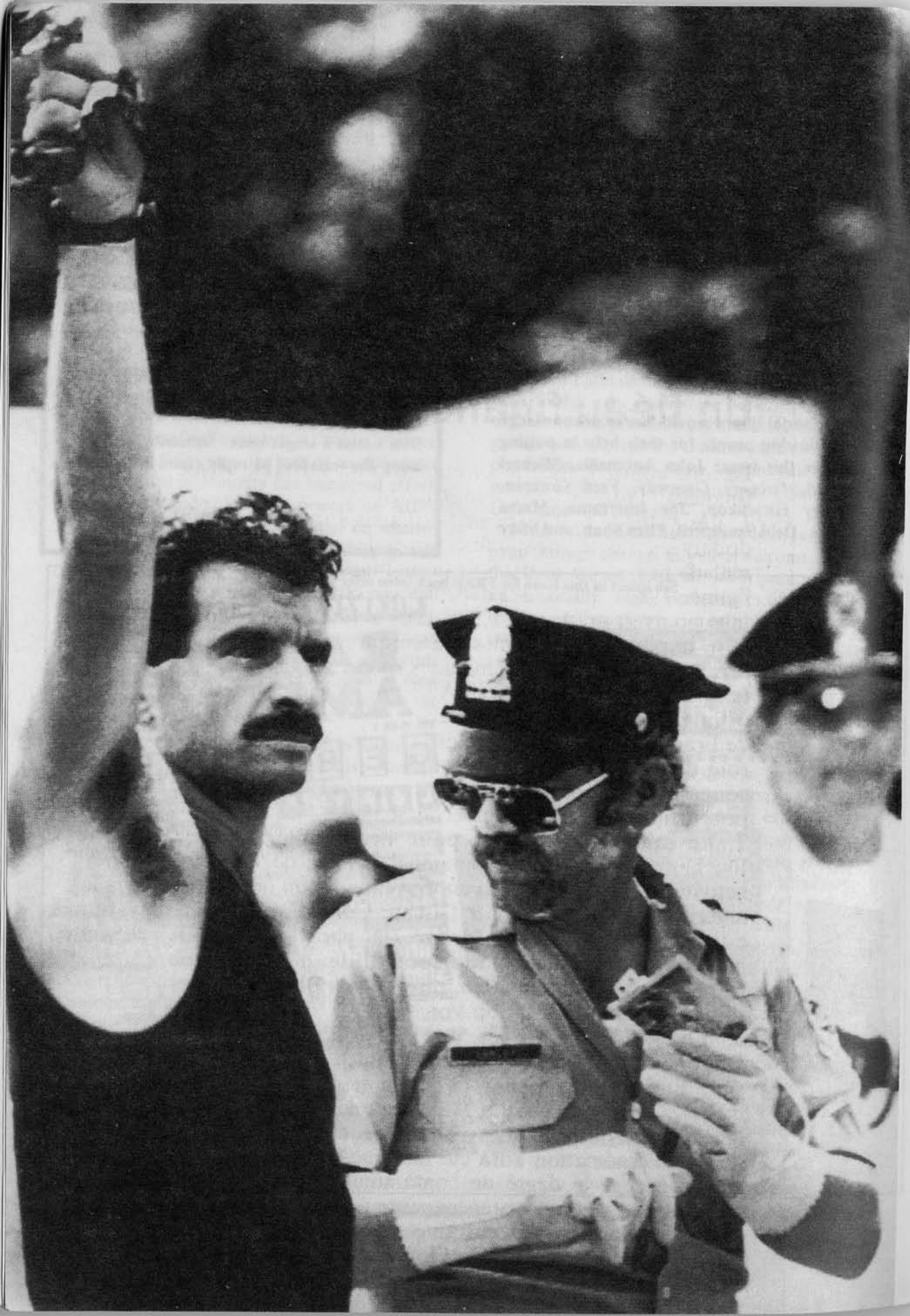
Bitburg

Fassbinder

Anti-
Semitism

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SPECIAL ISSUE ON WEST GERMANY TODAY. Featuring articles on Bitburg; Fassbinder; Anti-Semitism and the Left; Crisis of the Greens. Also, a report on the Guatemalan election, interviews with Nicaraguan coffee workers.



INSURING PROFITS FROM AIDS:

The Economics of an Epidemic

Mark McGrath and Bob Sutcliffe

In a cliché of cartoon movies a character marches unknowingly off the edge of a cliff but continues to walk along happily in mid-air until it looks down, realizes what has happened, screams with horror and then falls. The surreal moment is exploded.

In terms of its consciousness of AIDS much of the world looked down toward the end of 1986 and the screams of horror began. Until then governments, the media and most other people were content to regard the disease as containable within pathological pleasure-seeking communities who must learn to control their lascivious appetites or perish.

Even as late as November 1986 the surreal moment had not yet exploded for all. The *New York Times* in that month carried an editorial saying that there was no cause for panic since the epidemic was still overwhelmingly confined to homosexuals, I.V. drug users and Africans, none of whom are considered by that august bastion of liberal thought to be members of "the general public" whose interests it claims to represent.¹

The *Times* editorial was a late contributor to what had been a more common view, that AIDS might not be too bad a thing if it reduced the world's population of undesirables and deviants. Now, however, faced with the enormity of an epidemic that has breeched those boundaries, media opinion is swinging closer to the view, expressed in the *New African* in January 1987, that AIDS is "probably the most serious disease ever to afflict mankind."²

The Global Scale

What is now generally referred to as the Human Immuno-deficiency Virus (HIV, also known as HTLV-III/LAV) and its possible variants has engendered two epidemics—one medical, the syndrome known as AIDS; the other psycho-social, christened by some AFRAIDS. The presently incurable medical condition Acquired Immune Deficiency Syndrome and various related medical disorders are growing with alarming speed in virtually all countries of the world, though the figures publicly available are extremely incomplete. Many major human diseases are concentrated in either advanced or underdeveloped countries. AIDS, however, does not discriminate. In the United States, the world's richest country, as of March, 1987, 31,982 people had been diagnosed with AIDS, more than 16,000 had died. This represents three fourths of the world's 44,652 reported cases, although according to the World Health Organization (WHO), 100,000 actual cases may be a more realistic estimate. In June 1986 the US Public Health Service estimated that by the end of 1991 there will have been a cumulative total of more than 270,000 cases of AIDS with over 179,000 deaths.

In the advanced capitalist countries of Western Europe the spread of the disease has, with a few exceptions, taken a similar course to the U.S. with a lag of 2-3 years in the levels of incidence of infection. In June 1986 the rates of reported cases to date per 100,000 population were 10.5 for the U.S., and in Western Europe ranged between 2.8 in France and 0.46 in Spain.³ Such figures give a misleading impression of precision. In fact, knowledge of the spread of the virus remains limited even in countries with the most advanced public health system.

The lack of information is, of course, much greater in Third World countries with universally insufficient systems of public health care. Nonetheless, the same months which saw rising public disquiet in the West also saw a growing acknowledgement of what could already be a considerably more devastating epidemic in some Third World countries, for example Brazil and at least twenty-three countries in

Africa.

In Africa the following incidence rates have been reported: among blood donors in the Congo Republic—0.7%; among pregnant women in Gulu (Uganda) 13%; in Kigali (Rwanda) 18% of the population tested; in Kampala (Uganda) 18% of the women and 14% of men; among men aged 30-35 years in Lusaka (Zambia)—33%; among female prostitutes in Kinshasa—27%; among female prostitutes in Nairobi (Kenya)—88%; and among female prostitutes in Rakai, Masaka and Kydera (Uganda)—more than 75%.⁴ The World Health Organization which itself registered a sudden increase in its estimate of the seriousness of the epidemic during 1986, calculated the total number of infected people on the continent as between 2 and 5 million. This would mean a rate of infection similar to that of the U.S. with probably a higher rate of increase. By March 1987 AIDS had reached at least 127 countries.⁵

High Risk for Afraids

The psychological and social panic that has accompanied AIDS has adversely conditioned the medical response to the epidemic. In general this wave of panic has tended to create an atmosphere that worsens the prospects for containing and treating AIDS and dealing with the many social problems to which it gives rise. Bigotry and paranoia have substituted for accurate information, the only way of stopping the advance of a disease for which there remains no known cure. The first stage of AFRAIDS in the US and parts of Western Europe has consisted of an attempt to link the disease to social deviants, in particular gay men and drug users who are identified as "high risk groups." This then facilitates discrimination against such groups on the grounds of limiting the spread of the disease. Newspapers have been filled with stories about the exclusion of members of "high risk groups" from public facilities, from medical and dental treatment, from airplanes, from their homes and places of work. Such prejudice, based on sheer ignorance of medical facts, has been spread with evident venom by large sections of the capitalist media, most ably by the newspapers of Rupert Murdoch, who knows as well as anyone how to con-

vert sensationalized prejudice and misinformation into profit. In December 1986 Murdoch's British daily, *The Sun*, carried the following news (*sic*) report:

Grim-faced ministers emerged from a Cabinet meeting, fearful that the killer plague AIDS will spark violence on the streets of Britain. The prospect as terrified citizens make 'reprisal' attacks on homosexuals and drug addicts is now seen as a real threat [*note the difference between "citizens" and "homosexuals and drug addicts"*]. Some gays are expected to retaliate by spreading the virus to the rest of the community through 'revenge sex' with bisexuals.⁶

In the US and parts of Western Europe, an ideological commitment to those distinctions, between "normal" and "deviant" create the background against which attempts to confront AIDS have to be made. This atmosphere has helped the spread of the disease as well as intensified the suffering of those who have it and many who do not.

Public Health, Private Profit

The arrival of AIDS created needs for public health spending on basic research concerning the nature of the disease, possible treatments, prevention of its spread given current knowledge, and treatment of those with the disease. In some advanced capitalist countries, especially the US, AIDS has already led to a very large amount of spending, though we must raise serious doubts about its adequacy and the manner in which it has been distributed and financed.

All these questions have been influenced by the fact that, despite the existence of public health services, health is in many respects still a commodity provided for profit. Drugs are produced and marketed by the large capitalist drug companies; medical care is provided by private doctors (organized usually in immensely powerful professional bodies that preserve their monopoly) and often in private hospitals, and patients or potential patients are financed and protected by private insurance companies. Elements of this system still exist, in fact are



Marla Tarbox illustration

returning fast, even in those European countries with more developed public health schemes. We will show how the volume and priorities of AIDS spending have been crucially influenced by this structural fact as well as by the effects of the moral panic campaign.

Actual US Public Health Service spending on AIDS rose from \$30 million in 1983 to about \$240 million in 1986 and is expected to top \$400 million in 1987—still only a little more than one thousandth of the size of the defense program, and less than the cost of one of the more expensive nuclear missiles. The influential report of the Institute of Medicine of the National Academy of Sciences has recommended a total annual expenditure of \$2 billion by the year 1990.⁷

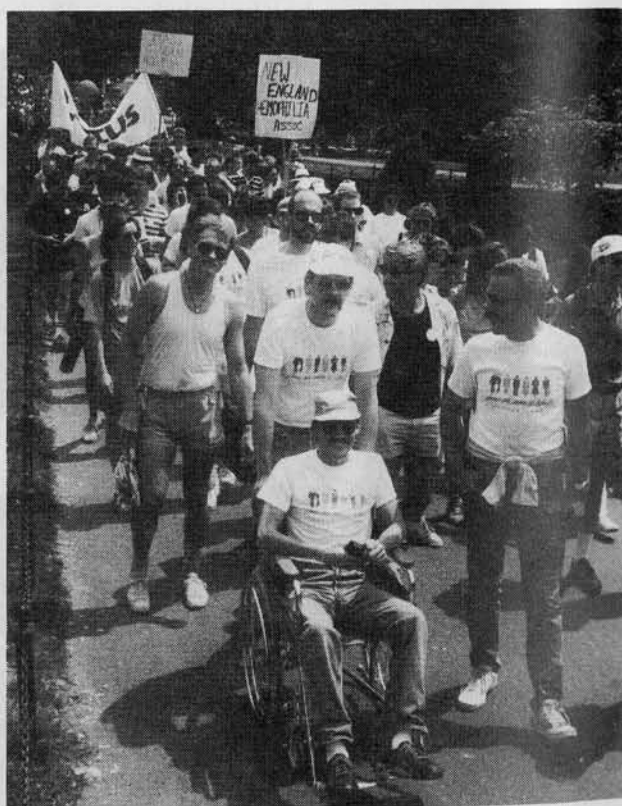
Despite its numerous declarations that AIDS is the “number one public health issue” the executive branch of the federal government has been in continual conflict with the Congress about the overall level of spending. Congress has on several occasions appropriated larger sums than those requested by the president. In fiscal year 1987, in direct defiance of the report issued by IOM/NAS, Reagan requested \$213 million for AIDS, \$20 million less than was spent in 1986; Congress voted to appropriate twice that amount, \$416 million, with the largest portion, \$65 million, allocated for public education.

The will of Congress to “do more” about AIDS however is hard to put into practice since more money does not by itself produce better results if the spending priorities are inverted. The total spending in the US has been less than completely effective for a number of reasons, among those:

- the absence of a national or international coordinating body has led to duplication of research and confusion in the presentation of results;
- the focus on testing and certain aspects of research have been at the expense of public information and education on the risks and routes of transmission;
- the skewed priorities of funded researchers have meant that an enormous amount of time has been wasted in which simple but effective experiments were not undertaken.

Cindy Patton has pointed out how the “number one” priority commitment by the state was intended to protect the “innocent” but not the “guilty.”⁸ Thus a blood test to protect blood supplies for transfusion was fortunately developed with considerable speed. Yet an extraordinary amount of time passed before any authoritative information was available about whether or not the HIV virus would pass through a condom. Such an absurdity reflects the fact (still true) that the types of research undertaken have been determined largely by the medical profession and the drug corporations rather than by those who have seemingly been at greatest risk from the disease. As William Michaud observed in *Gay Community News*, “We’re hardly likely to see a prospective study of blow-jobs and HTLV-III infections being funded by the NIH, conducted by a consortium of major medical centers and published by the *New England Journal of Medicine*.”⁹

Despite the role of French scientists in basic research on the virus, the French government



Ellen Shub photo

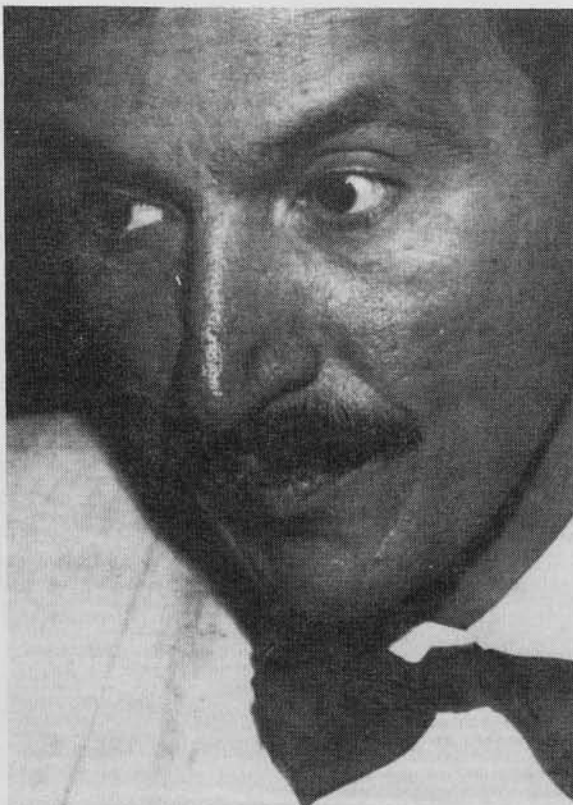
has been as slow as the US to respond to the public health challenge. Again its attitude changed toward the end of 1986 when the Minister of Health announced a new program of research and education to cost about \$60 million in 1987. The minister was frank about the reason: "Forty three per cent of new AIDS cases in the third quarter of this year were heterosexuals, and it is that which has led us to take these new measures." (reported in the *Financial Times*)

The US and French patterns of public spending have been repeated almost everywhere. Governments and international health agencies have chosen to minimize the danger and severely underspend until the evidence of the virus "leaking" into the "general public" was established beyond doubt. The result has been that all public health programs are several years behind where they could have been. As we will show, public spending on prevention measures is undercut by the ruling conservative ideology that condemns explicit information and the "condoning" of sexual and drug-related "vice."

Sex Goes Public

The complete destruction of the HIV virus depends in the long run on medical discoveries; but the short and medium term defeat of AIDS clearly rests on the priorities for public health expenditure. These include provision of accurate information about how the virus is spread and recognition that such education plus the availability of condoms and clean needle works are as essential in addressing the "general public" as for "high risk" groups.

For example, as the knowledge of the difference between safe and unsafe activities expanded within the gay community in large western cities, dramatic changes occurred in sexual behavior, even though the knowledge did not exist soon enough to prevent an extensive spread of the virus. But at the present time most of those who engage in high risk sexual behavior are not open members of their respective communities. They are either heterosexuals who have been conditioned by several years of misinformation to believe that since they are not in a deviant "high risk



Diego Lopez, innovator of the creation of social services for PWA's, 1945-1986, Native

group" they are not at risk, or they are closeted gay men who are ostensibly heterosexual and whose sexual life is clandestine. They do not go to gay bars and see safe sex posters; nor does the gay press arrive through their mail boxes. Most of them are, therefore, probably quite uninformed about any difference between safe and unsafe sexual practices. At present, these are the people who most need explicit accurate information about the means of transmission of the virus and how it can be avoided.

Once again the recent figures attesting to the increasing spread of the virus among heterosexuals has begun to stir a few governments from their criminal inertia. As they shift they all face the dilemma of whether to disseminate useless, bland advice which conforms to the ruling moral code (practice monogamy and avoid using drugs) or to disseminate useful advice that accepts that social practice is bound to diverge from that code (use sterile needles, use condoms, avoid swallowing semen).

This dilemma has provoked big splits inside ruling elites between moralists and realists

which are being resolved in a variety of ways. In some US states anti-sodomy and anti-drug laws are being re-enforced. In West Germany the Health Ministry has publicly discussed forced quarantine as an alternative to public information. In Britain the famous spirit of compromise has led to an expensive government campaign under the slogan "Don't Die of Ignorance."

The British campaign is the boldest thus far but seems flawed by the ideological straight-jacket in which it operates. There seems a danger that it is not explicit enough to change sexual practice and yet alarming enough to increase panic and place more strain on medical and counseling facilities that are ill prepared. Its attempt at compromise between moralism and realism (don't use drugs, but if you *must* then use clean needles), is denounced by the moral conservatives as implicitly condoning vice; their pressure will probably prevent the evolution of the campaign into something really effective in the prevention of AIDS. And the Rupert Murdochs are still spending far more on misinformation than governments are on education.

A campaign of information alone needs obvious supportive actions. There is little point in convincing an i.v. drug user who needs all the money possible to buy drugs to use clean needles unless steps are taken to distribute them free to those who need them. The proposal of the New York Health Commissioner, David Spencer, to do this fell victim to conservative morality, as have a number of attempts to make condoms more easily available in schools. In some towns in Britain such as in Edinburgh, London, Peterborough, Liverpool and Kingston, the distribution of free needles has been undertaken though, as in so many instances of public action, too late to stop the infection of a high proportion of the drug-using population.

In the context of capitalism, effective information without free needles can even make the situation worse. Reportedly in a number of cities in the US, the spread of information about the need for clean needles has led to the development of a market in used needles that are repackaged and sold as new. It is not clear how admirers of the profit motive and the

market mechanism as methods of meeting human needs will react to such examples of the market's famed ingenuity.

Patients At Risk

The ideological environment surrounding the growth of AIDS has meant that of all the new needs which AIDS raises, the treatment and care of those with the disease or the related physical and psychological conditions have been met least adequately. While millions of dollars (perhaps not enough) has flowed from states to highly paid medical researchers in gleaming laboratories which are the pride of their nation, and millions more flow to the profitable drug and condom producing companies, many people with the disease in the US have been obliged to exhaust their savings or beg on the street in order to survive let alone finance needed medical expenses.

In developed countries other than the US most of the responsibility for treatment, diagnosis and screening have fallen on the public health services against which many charges of inadequacy have been made. AIDS has constituted a net increase in total health needs since it has tended to attack groups which are normally in good health. Yet in many countries, especially in Britain, the epidemic has coincided with a campaign of austerity in government expenditures as a reaction to economic crisis and rising state deficits. The result has been both that the care of AIDS patients and public health action has been inadequate; and also that resources have been taken from other health needs to finance AIDS-related expenditures. Not until 1987 did the British government allocate a new sum to the National Health Service specifically for the care of AIDS patients though this was immediately denounced as inadequate by the doctors most involved with treating the disease.

In the US the image of the disease may be conditioned by its more renowned sufferers such as Rock Hudson and Liberace. But increasingly the statistics show that it is the already poorer and economically disadvantaged sections of the population which have been disproportionately hit by AIDS. This is especially true in the case of infection related to



Ellen Shub photo

drug use, an increasing proportion of the total. This disproportionate impact is also strongly related to race. The New York Health Commission reported in March 1987 that in the city 70% of women with AIDS were black or Hispanic, as were 93% of children and 73% of cases believed to have been heterosexually transmitted. A very large proportion of those with AIDS have therefore had to rely on free public health services in a country where the inadequacy of such services is notorious.

In the face of the failures and inadequacies of the public health system an enormous amount of the burden of care has fallen on voluntary activities and some of the organization which has developed, especially among the gay community, has been remarkable. But even the most active and successful anti-AIDS committees have not been able to help many people with AIDS, often because their social and economic situation makes it hard to identify them, or because they have not been interested

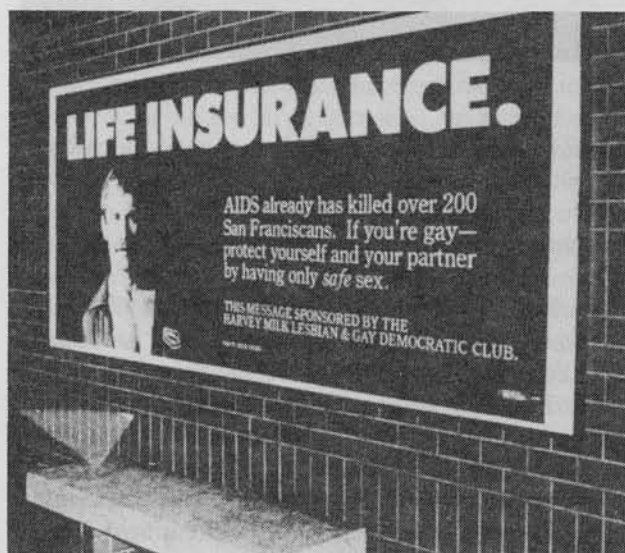
in help from sources which they might identify with the gay community.

Insuring Profits

If there is a disproportionate number of cases among sectors of the population who are least likely to have health insurance, the possession of health insurance does not always resolve the financial problems. Ever since the potential costs of the epidemic became clear, health insurance companies have sought ways of limiting their liability for AIDS treatment. The insurance companies have been very happy to use the concept of "high-risk groups." Many cases have been reported of insurance companies refusing coverage to people whom they suspect of being gay or drug users. And it has become increasingly difficult for gay businesses to get health coverage for their employees. A large number of states have now passed legislation or issued edicts banning such discrimina-

tion, though there is evidence that these are routinely flouted.

In Massachusetts for example, the state insurance commission specifically prohibits individuals being screened by insurance companies for antibodies to the AIDS virus; yet a majority of insurance firms in the state do exactly that as part of the normal blood-test requirement, usually without informing the applicant.¹⁰ In March of 1987, then Massachusetts State Health Commissioner Peter Hiam deferred to the intense lobbying effort of the insurance industry, and tentatively agreed to allow testing provided that insurers demonstrate a "financial need" to administer the test to applicants—the insurance industry has gleefully responded by inundating the state insurance commission with statistics that "prove" their need to test applicants. In July, over the objections and eventual resignation of Hiam, the state administration (of presidential candidate Michael Dukakis) opened the doors to even more wide-spread testing by permitting companies to test for most life or disability policies.



IGA Pink Book, 1985

In many European countries the question of who will pay the costs of health care is answered by state health insurance schemes, but life insurance has been a question there as well. As the London *Financial Times* has now reported on three separate occasions, AIDS has created a new kind of "dilemma" for life insurance com-

panies. These companies, the top 25 of which had a premium income in 1984 of about \$13 billion, now face the "problem" of how to avoid paying life insurance benefits because people die of AIDS.¹¹ Like the insurance industry in the US, the companies have tried to devise questions that will suggest whether people are in "high risk groups," and appealed for the "right" to test applicants.

On the issue of insurance some states have also passed specific non-discriminatory regulations. For instance in May 1986 the city of Washington, DC passed an exemplary law expressly forbidding insurance companies to refuse life insurance coverage to anyone with HIV exposure. The companies mounted a big publicity campaign against this and imposed higher premiums on DC residents as a kind of collective punishment. It is currently all but impossible to procure individual life insurance in the nation's capital as the insurance industry has decided to make Washington a "proving ground" by refusing to issue individual policies until companies are allowed to resume testing of applicants.

In December 1986 a meeting of State Insurance regulators in the US agreed to guidelines that would prohibit insurance companies from making inquiries about or making decisions based on the applicant's sexual orientation. But they declined to say anything about the propriety of insurance companies insisting on HIV antibody tests or inquiring about the results of previous tests. The American Council of Life Insurance and Health Insurance Associations welcomed this outcome even though they wanted the regulators explicitly to endorse tests.¹²

The British insurance companies' attempts to learn from the misfortunes of their US counterparts also highlight the importance of anti-discrimination legislation. Despite the abuses already mentioned, at least such legislation exists in the US and can be used in litigation. In most European countries, no such civil rights protection is available even in theory, though some progressive local authorities have attempted to introduce it, usually, however, without the force of law.

But even in the US the future of non-discriminatory legislation is uncertain. The

non-discrimination laws are undermined not only by conscious non-enforcement but also by the fact that courts have found that other—discriminatory—laws take precedence over them. So the army's right to discriminate in recruitment, even in areas where local anti-discrimination laws exist, has been upheld by federal courts.

The so-called US Justice Department under Attorney General Edwin Meese has taken an energetic line in justifying discrimination. Its July 1986 ruling on AIDS in the workplace was one of a series of discriminatory measures.¹³ Essentially, the ruling held "that an employer may discharge an infected worker if it honestly fears the employee might spread AIDS," regardless of whether the fear is reasonable or not.¹⁴ In fact since AIDS is not spread through casual contact and a person with AIDS is much more susceptible to contracting an illness from his co-workers than they are from him, all persons with AIDS or AIDS-Related Complex (ARC) should be protected by the Federal Rehabilitation Act. The Justice Department's ruling "left to the employees who are discriminated against the burden of proving that their employer fired them because they were handicapped, not because it feared they would transmit the disease."¹⁵ This type of institutional oppression and "blaming the victim" perpetuate not only misinformation about AIDS but also the false image of the workplace as pure and safe. Most states continue to maintain the position that people with AIDS are handicapped. It is not clear how much Meese's ruling will undermine this theoretical protection.

Who Owns the HIV Virus?

Despite the importance of public information, millions more are poured into funding research. Once again, spending levels alone are not indicative of "progress." The capitalist organization of medical research produces "intellectual property," patents and thus monopoly profits (and Nobel prizes). It may well be true that these incentives have been strong ones in the case of AIDS. The rapid spread of the disease has meant that the profit motive for developing blood screening techniques and a possible drug treatment or vaccine



Antonio Lopez, fashion illustrator who brought the ethnic and erotic to his field, 1943-1987, Village Voice

prevention has been strong. At the same time AIDS research goes close to a number of biological frontiers which has attracted some prominent scientists to it. On the other hand the regime of "intellectual property" prevents the sharing of information and can thus, for a given amount of total research expenditure, be expected to hold back the speed of useful discoveries.

While the AIDS virus is spreading its scourge around the world, those most capable of doing something to combat it at the scientific level are, it is hard to believe, putting a vast amount of energy into a dispute about whose private property this killer virus is. The long running squabble is between Dr. Robert Gallo and the National Institute of Health in the US and Dr. Luc Montagnier of the Institut Pasteur in France. The Institut Pasteur was the first to file a patent application regarding the discovery of the LAV (Lymphadenopathy Associated Virus) virus in late 1983. It has never been officially responded to by the US Patent Office, though recently the office belatedly recognized the prior role of the French in the discovery of the virus. But it gave the patent for the discovery to

Gallo on the basis of a later application in 1984. In late March of 1987, President Reagan and French Prime Minister Chirac tentatively agreed to have the NIH and the Institut Pasteur "co-own" the patent rights, but reached no agreement on how to distribute profits from the research.

Who cares?! The answer is many people care because the patent question decides who receives the royalties from antibody tests and possibly from vaccines or any other medical outcome of AIDS-related research. On the basis of Gallo's patent, Abbot Laboratories was granted a virtual monopoly right in 1984 by the Food and Drug Administration to market a blood screening test. In 1986 the FDA also very belatedly approved the US marketing of a rival screening test which was developed by Diagnostic Pasteur along with the Seattle-based company Genetic Systems. But until the patent issue is resolved there is the possibility that the possessors of the existing patent can sue their rivals for plagiarism. As a result the French have pressed the issue and are making a legal challenge to the Gallo/NIH patent. Because the lawyers need some time to get rich on this case the outcome will not be known probably until 1988 unless the tentative agreement between Reagan and Chirac is made specific. That will be difficult because the stakes are high: the total annual revenues associated with AIDS

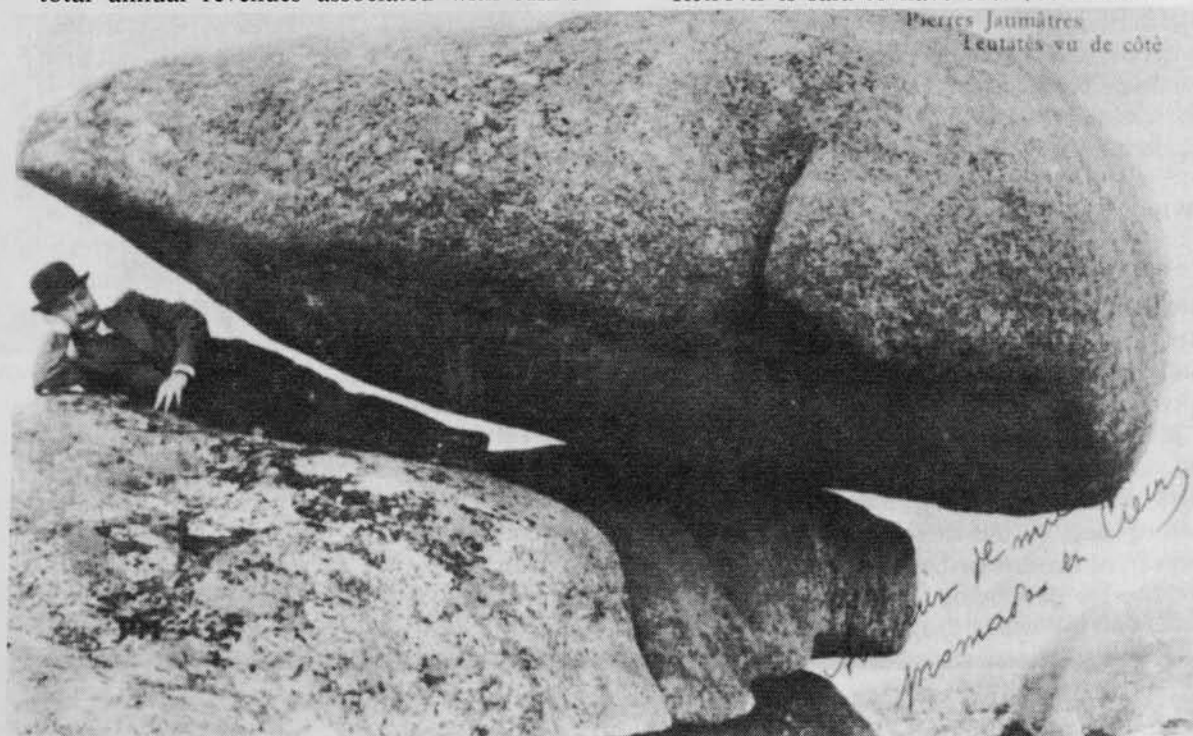
blood screening alone are expected to rise soon to around \$150 million a year.¹⁶

AIDS research has also been bedevilled by other kinds of destructive conflict among researchers. What appears to be primarily a bureaucratic dispute over resources has led to internal rivalries and even sabotage of AIDS-related experiments in the Centers for Disease Control.¹⁷

The contradictory effects of international rivalry and the patent system can be seen also in the belated decision of the British government in March 1987 to spend public money on AIDS research. The previous position of the Thatcher government had been to let other countries do the spending and then buy the results. It was presumably pressure from the British-based drug firms, who began to see themselves at a disadvantage in a rapidly growing drug market, which finally shifted the position of the Thatcher government.

By early 1987 AIDS was beginning to have a considerable effect on the international stock market performance of drug producing corporations. During January 1987 the share price of Burroughs Wellcome and the Wellcome Foundation, manufacturers of AZT (azidothymidine) or Retrovir, the drug with the most successful record to date in changing the course of AIDS, began to soar.

Retrovir is said to have cost \$80 million to



Between public health and private profit

produce. Despite its positive effect in at least slowing the progress of the disease, it has numerous undesirable aspects. It tends to produce anemia, requiring blood transfusions, as a side effect; it lasts for only four hours in the body and so the patient must take it six times a day (and thus may have to be awakened). If another company were to develop an alternative that did not have these defects then Wellcome might find that their \$80 million was spent in vain. It is presumably in large part to help Wellcome recoup some of its expenditure quickly that the US Food and Drug Administration has given its approval for the clinical use of Retrovir in a record time of 108 days, when the approval of a new drug can often take ten years. If there is no improvement on Retrovir, however, the London stockbroker quoted by the *Financial Times*, sees an alternative scenario, which will make Retrovir, for all its limitations as a weapon against AIDS, become from a financial point of view "the block busting drug of all time. . . ." He added, "If it takes five years to improve on Retrovir, there will be around half-a-million people in advanced countries by that time suffering from AIDS or severe AIDS-related complex. It is reasonable to believe that Retrovir will be used in virtually all those cases in the absence of something better, and perhaps in milder cases as well. On a fair speculative guess of \$5000 per patient, that is annual sales of \$2.5 billion a year." On the basis of the price announced by Wellcome in February 1987 the cost would in fact be \$15,000 per patient per year.

The Condom Market

The suspicion, early in the course of the disease, that condoms might act as an effective barrier against infection makes it puzzling that the condom manufacturing companies did not move more energetically to test the possibility and advertise their product accordingly. The reason lies partly in the fact that condom manufacturing companies have always behaved in a discreet manner as far as their advertising is concerned, out of recognition that their product was socially controversial. Whether or not to make the use of condoms officially sanctioned has been one of the most hotly debated

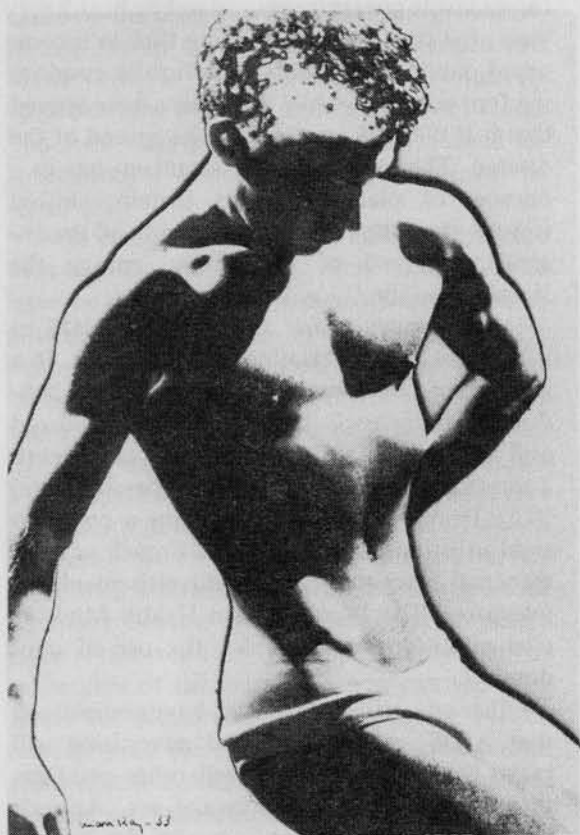
topics inside governments and public health services, the conservatives arguing that to recommend condoms amounts to officially condoning free sexuality, while the realists have argued that it is the only way to stop the spread of the disease. The balance of the argument has in a number of places, such as Britain, shifted toward the latter group as a result of the increasing spread of the disease among the "general public," i.e. heterosexuals.

It now appears that it has taken AIDS to break many taboos relating to this product. In a number of countries the promulgation of condom advertising is being actively considered and the companies themselves have changed to a much less discreet and more aggressive style. "Use Durex for safer sex" is now a common sight in Britain at least and the French government has permitted condom advertisements on television. The West German Health Ministry also publicly campaigns for the use of condoms.

Other advertisers, however, have complained that AIDS and AIDS-related advertising will make it more difficult to sell other products through association with casual sex. Appeals have been made for this reason for special AIDS advertising slots on television so that other ads should not be seen as "contaminated!"¹⁸

In its annual report London International Group (formerly the London Rubber Company) tried to play down the effect of AIDS on its sales. Nonetheless, to avoid the embarrassment of profiting from the fear of death, LIG in late 1986 pledged itself to use part of its increase in profits of 16% during the year to finance AIDS research; it also announced the development of a thicker condom to be test-marketed in the Netherlands and designed specifically for anal intercourse.¹⁹

The role which condoms are at present playing in the fight against AIDS makes it important to examine the conditions under which they are supplied. One country where these conditions were exhaustively studied a few years ago was Great Britain where London International supplied the national market in a virtual monopoly. Its trading practices were submitted for an examination by the Monopolies and Mergers Commission which reported in



Untitled, Man Ray photo

1975 that the company's returns on capital averaged around 70%, despite the ending of the growth of the overall market following the introduction of contraceptive pills in the mid-1960s. It recommended a drop in price of 40%. There seems to be no evidence that these recommendations were ever implemented. London International and other such companies are now presumably doing very nicely indeed as a result of the epidemic. In 1975 the company justified its high prices on the grounds that the market was likely to decline. Presumably it may now do the same on the grounds that improved drug treatments may be discovered. Meanwhile someone is getting rich quickly out of safer sex.²⁰

Testing, testing . . .

We believe that there may be a number of good reasons for antibody testing both for the benefit of the individual tested and for the purpose of preventing the spread of the disease.

This may be true despite the extreme ambiguity and unreliability of the results given by the test. It is neither a test of whether someone has AIDS nor whether they will eventually develop AIDS, nor whether they are even infectious. Nonetheless, the test has been essential in the routine screening of the blood supply for transfusions even though this began after the tragic infections of many hemophiliacs and others who received infected blood products. In this case the only test necessary is an anonymous test of blood, not identification of the particular donor. Second the test has considerable potential use in epidemiological research and can thus help in the prevention of AIDS. In this case what is necessary is the testing of individuals who can later be tested again and who therefore require, for their voluntary collaboration, guarantees that their anonymity will be preserved outside of the research. Third, the test may be useful as a diagnostic tool, especially in the elimination of AIDS as responsible for certain infections. In this case again the identity of the tested person needs to be known but only to his or her health care providers. Fourth, despite the deficiencies of the test, individuals may wish to know whether they test positive or negative as an aid to their person decision making. Here the only person who needs to know is the individual being tested, and any counselor chosen by them.

It seems to us that all other uses of the test are both an illegitimate attack on civil rights which will not only do nothing to control the spread of the disease but will also facilitate discrimination against those who may be infected. This will almost certainly encourage the further spread of the disease since it will discourage voluntary cooperation in legitimate uses of the test. Yet of the very many proposals for testing so far made and/or implemented in the US and other advanced capitalist countries, the great majority fall into the second illegitimate and damaging category.

The test has in many instances involved attacking civil liberties in the interests of the "general public." Testing has provided numerous examples in which the privacy, freedom, and mental stability of individuals are infringed upon. The lack of confidentiality in the test, the assumption of guilt imposed upon

people refusing to take the test, and the absence of legal recourse after a positive test result for insurance, work, housing, and basic health care purposes are all well-documented.

In late November of 1986, US Secretary of State George Schultz approved a plan to screen foreign service applicants, employees, and their dependents for exposure to the AIDS virus. The armed services as well as college and university ROTC programs began testing in 1983, but Schultz's proposal would initiate the first program for civilian federal workers. Any military or civilian federal worker or job applicant who receives a positive test result is restricted, on medical grounds, from government service or terminated if already an employee of the federal government.

Most of the discrimination surrounding the test is a thinly-veiled attempt to "root out" undesirables, specifically gay and bisexual men, whether in the workplace, in the armed services, or for insurance purposes. Many gay employees have lost their jobs as a result of compulsory testing at a time when job-related health benefits are critical.

In 1985 even an organization which has good reason to be conscious of civil rights, the National Education Association of the US recommended that schools ought to be able to require screening of students or teachers when grounds exist for suspecting exposure to AIDS.²¹

On Election Day 1986, voters in California defeated (62%-38%) the Lyndon H. LaRouche-sponsored Proposition 64, which was one of the most frightening instances so far of the discrimination and paranoia surrounding AIDS. The LaRouche initiative, in short, proposed: 1) mandatory testing of all California residents for antibodies to AIDS, and 2) quarantining all Californians who test positive. The logistical impossibilities of carrying out such a plan (according to conservative estimates, at least 300,000 residents would be subject to quarantine) notwithstanding, the economic cost, as estimated by two Berkeley economists, would most likely have cost the state of California "\$2.3 billion in economic output plus \$630 million in lost tax revenues, increase unemployment insurance premiums and testing costs."²²

In other countries, too, there has been grow-



Ellen Shub photo

ing support for compulsory testing. For instance, the Christian Social Union (CSU) of Bavaria, one of the parties of the West German coalition government, has proposed establishing a register of those found in blood donor screening to be HIV antibody positive.

According to the Panos Institute Report, at least fourteen countries by March 1987 had introduced restrictions on travelers, students and workers because of AIDS.²³ Belgium demands negative tests from foreign students (many of whom come from Zaire, its former colony); Finland and India have also demanded tests for traveling students. Saudi Arabia demands antibody tests for its vast number of immigrant workers from Pakistan and other South Asian countries; there is reportedly a market in the area for forged negative test certificates. Turkey and Austria are reported to have imposed tests on registered prostitutes.²⁴ The French Health Ministry has proposed obligatory tests as a condition for receiving a marriage license and US Education Secretary, William Bennett, has made the same proposal. So far Turkey and Hungary are the only two countries from which we have seen reports of compulsory tests on "homosexuals" but they will surely not be the last. A recent newspaper article in the USSR is reported to have suggested, Lyndon LaRouche style, that there was a health danger as long as homosexuals remained at liberty.²⁵

Antibody testing which could have a role to play in the struggle against AIDS is becoming associated with discrimination and the loss of rights and livelihood. If the main reasons officially advanced for testing are bad ones, it will become impracticable to use testing for good reasons. Ideology once more is on the side of the virus.

AIDS as Imperialism

The previous sections have only discussed the problems associated with AIDS in the advanced capitalist economies. Those which arise in the poorer economies where the virus is spreading are in many ways qualitatively different. For instance, to provide the best available health care to people with AIDS in the United States or Western Europe will be costly in relation to existing public health expenditure and will require

a significant increase in the health budget. In Africa the provision of such care would bankrupt nations. The cost of one year's Retrovir treatment for one person is equal to the annual income of 50 average Africans.

The costs of caring for an AIDS patient in the USA have been estimated as between \$50,000 and \$150,000 a year (plus \$15,000 a year for Retrovir treatment). If we assume that even the lowest of these estimates is inflated by factors peculiar to the US economy (such as the obscenely high salaries of senior medical personnel) and that a more realistic figure for Africa would be \$25,000 and if we take the lowest of recent estimates of the number of cases expected in Africa per year—13,000, then we arrive at a total figure of \$300 million as the annual expenditure necessary to produce recommended levels of health care. This figure is 10-15 percent of existing total public health expenditure in Africa south of the Sahara



Part of Uganda's public information campaign to "Love Carefully," available in only ten of the twenty-two languages spoken there.

(excluding South Africa), an area whose numerous endemic health problems are barely addressed. Taking these figures as a rough benchmark we may add a number of complications.

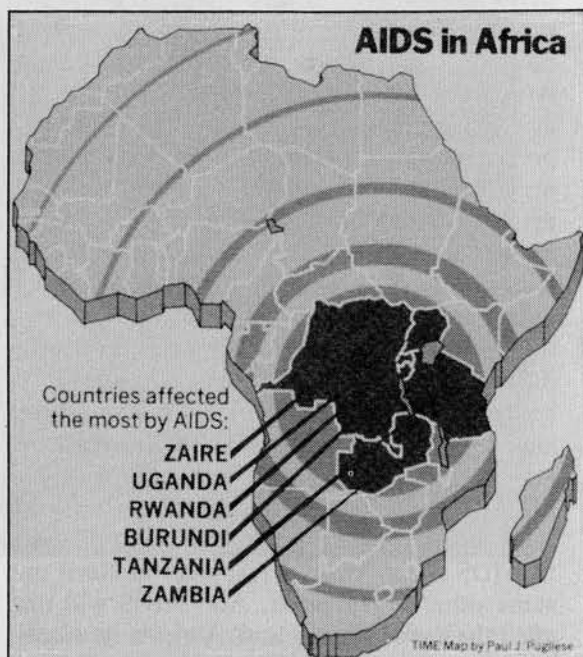
The figure of 13,000 cases has been widely quoted in the press but seems to be much too low from other fragmentary evidence. In Zambia alone, for instance, it is predicted that in 1987 6,000 babies will be suffering from AIDS.²⁶ Hence the needed expenditure on treatment, let alone education, research, prevention and blood testing, may already amount to far more than 15 percent of the continent's existing health budget. The predicted rate of growth would mean that before the end of the decade "necessary treatment cost" as here roughly defined would amount to more than the total health budget.

Such a vast increase in needed health spending comes on top of a situation where a number of other diseases and public health problems (such as malaria and alimentary tract infections due to infected water supplies) have hardly begun to be resolved. AIDS is therefore a health catastrophe on top of a health catastrophe. Thus it may be qualitatively more damaging than in the advanced countries.

AIDS and existing public health problems in Africa interrelate in particularly alarming ways. Those with AIDS are more likely to contract infections and to die rapidly because of lower living standards and the greater prevalence of debilitating endemic conditions. This suggests that for an AIDS patient in Africa to receive the equivalent of what is regarded as adequate treatment in the USA, and to be able to survive for a similar period, would require, in addition to expenditure on the treatment of AIDS, the resolution of other health problems. This interconnection implies that the rough figures used above underestimate the need. AIDS has to be seen in the context of Africa's existing health situation.

It has also been suggested that another tragic inter-connection exists. Inoculation against some diseases may be dangerous or even fatal for those whose immune system is already defective. And, inadequately funded inoculation programs often involve the reuse of needles and so may themselves directly spread HIV

virus. This carries the consequence that some of the existing public health expenditure in Africa is not only inadequate in relation to previous health problems but it actually has a perverse effect on health. For these reasons too it seems as if AIDS in Africa might involve a quantitatively and qualitatively more disastrous experience than in even the worst affected developed countries.



Time, AIDS in Africa, February 16, 1987

AIDS in Africa not only raises the need for a vast amount of new resources to be devoted to public health, it also reduces even further the possibility that African countries can themselves generate these resources. Even particularly inadequate spending on AIDS draws resources from potentially productive uses. AIDS attacks particularly people of working age and so will tend to reduce existing production. And knowledge of the extent of AIDS has already led to serious falls in international tourist revenues on which economies, such as Kenya's, depend for foreign exchange. Some African governments have been led to conceal the health problem, thus making it worse, as a response to this cruel dilemma. The dilemma is real because such economies are now locked in-

to dependence on such revenues and so their loss endangers economic survival, let alone economic growth and health expenditures. AIDS, therefore, in various ways has effects which will make the struggle against it economically more difficult—another of the vicious cycles of poverty.

These points carry added weight against the background fact that AIDS has hit Africa in a period in which most of the continent has for other reasons been in a state of vertiginous economic decline. Since 1973 sub-Saharan Africa as a whole has experienced either static or declining national income per capita. Its export earnings have declined rapidly. It has needed to import capital to the extent of over 5 percent of its continental income even to finance a low rate of investment. It has become increasingly indebted and its economies increasingly controlled by the creditors. In nineteen out of thirty-one African countries food production per capita has been declining. The continent has the highest death rates and the highest population growth rates in the world.²⁷ For these reasons there is no chance whatever of African countries raising the additional resources they now require. Every cent devoted to AIDS simply reduces resources destined for some other urgent need. And AIDS will not alter the fact that much of Africa's resources goes to non-urgent needs. But even if that problem were resolved, the new needs, like the old, require a vast influx of external economic and technical resources.

This new need for resources in Africa could hardly contrast more strongly with the existing reality of the economic relations between the continent and the advanced capitalist countries. The economic decline of Africa can only be understood in the context of a disastrous new economic order which has emerged during the 1970s and 1980s. This has left the continent with relatively low but completely unpayable debts and a very low credit rating. Economies have been pawned to their creditors and, as in the rest of the indebted world, efforts are made everywhere (through domestic austerity and export encouragement) to ensure that for the foreseeable future the poor countries of the world transfer resources to the rich ones, or at least to their banks. This is what the repayment

of debt would mean.²⁸

Such a perverse transfer of funds has already been taking place from Brazil, another country whose needs for AIDS related expenditures is vast, given that early in 1987 it was reporting over 1000 actual cases and its Ministry of Health estimated that 400,000 Brazilians were infected. In the years 1982-86 it was obliged by its creditors to produce a huge trade surplus out of which it could pay back some of its loans and reduce the dangers that some large American banks would collapse.

The international economic order has contributed to the past public health neglect which leaves underdeveloped countries now so extremely vulnerable to AIDS. And it helps to prevent emergency measures from being taken. AIDS is, of course, only one of the many problems which illustrate this point.

Neils Jerne, a prominent immunologist, recently argued that the AIDS crisis in the Third World has been exaggerated in relation to other diseases. "We have lived with diseases like malaria and sleeping sickness in Africa, which several million people die from every year. But because these diseases no longer occur in Europe and North America, the effort made to get them under control is not very great." His point seems to us to underestimate the problem of AIDS but there is clearly some substance to his explanation of the absence of economic and technical assistance for the control of other diseases. Such an imperialist approach to world disease control has clearly contributed to the intensity of the AIDS epidemic in Africa. It is also true that capitalist drug companies have no incentive to provide cures for diseases suffered only by those who have no money.

If the changing official attitude to AIDS in the advanced countries leads to proposals for more medical assistance to the Third World it will emerge that it is impossible to combat AIDS without combatting other diseases as well. If, as seems probable, the cost of that is regarded as prohibitive in the context of advanced country politics then a more likely response might be greater protectionism in the form of immigration controls directed against countries with a high incidence of AIDS.

This road will not lead to economic



Caring for each other... Blackout, Summer 1986

assistance but to quarantining of whole countries or even continents, a kind of genocide of neglect.

Conclusions

We are therefore drawn towards some far from comforting conclusions. It seems to us that there are strong grounds to believe that the present functioning of the health sector of advanced capitalist countries, and of related sectors such as insurance, is seriously failing to meet the social health needs of the present and potential suffers from AIDS and of society as a whole. It remains more profitable to spread disinformation, panic and bigotry than to spread accurate information. While there is some incentive in the system to advance research on possible drug cures, there is little, if any, to share and rationalize international activity in this direction. And there is no incentive to experiment with non-drug regimes which

might relieve suffering. The pursuit of profit by insurance companies is leading to an erosion of the civil and economic rights of many actual and potential sufferers from AIDS. In the Third World the conclusions suggested are grimmer: the present structure and working of the capitalist international economic order might lead to economic and social catastrophe on a scarcely imaginable scale.


It is not easy to draw conclusions from such a depressing perspective. The fight against AIDS highlights the need for radical changes with regard to patents, the direction of research and health and life insurance. It also points up the negative effect on health of conservative and reactionary ideology of sex and drugs. The reaction to AIDS, we believe, provides a number of examples of the way in which, in the words of Lesley Doyle, "the operation of a capitalist system creates contradictions between health and profit."²⁹

FOOTNOTES

1. *New York Times* Editorial: "Dark Panic, Yet, Over AIDS," November 7, 1986.
2. Alan Rake, "Africa: Frontline Against AIDS," *New African*, January 1987.
3. Richard Evans, "The UK Response to AIDS," *Financial Times*, November 22, 1986.
4. Alan Rake, *op. cit.*; The Pasteur Institut, *AIDS and the Third World*, London, November 1986.
5. The Panos Institute, "AIDS and the Third World," Second Edition, 1987.
6. Quoted in Jeremy Seabrook, "The Disease Waiting in the Wings," *The Guardian*, London, December 22, 1986.
7. Institute of Medicine, National Academy of Sciences (Eve K. Nichols, writer), *Mobilizing Against AIDS*, Harvard University Press, Cambridge, Massachusetts and London, England, 1986.
8. Cindy Patton, *Sex and Germs: The Politics of AIDS*, Boston: South End Press 1985. p. 100.
9. William Michaud, "A Blow to Research," *Gay Community News*, Boston, March 15, 1986.
10. Michael Kranish, "Foreign Service Staff Faces AIDS Tests," *Boston Globe*, November 29, 1986.
11. Eric Short, "Life companies react to AIDS fears," *Financial Times*, June 7, 1986; "AIDS . . . a new dilemma for Britain's life insurance companies," *Financial Times*, December 6, 1986; "AIDS policy . . . the problem faced by life companies considering insurance proposals," *Financial Times*, February 7, 1987.
12. *Wall Street Journal*, December 12, 1986.
13. Robert Pear, "States' AIDS discrimination laws reject Justice Department's stand," *New York Times*, July 17, 1986.
14. Saul Kramer, "A cruel step backwards in AIDS policy," *New York Times*, July 15, 1986.
15. Kramer, *op. cit.*
16. David March, "The Billion Dollar Squabble," *Financial Times*, June 28, 1986.
17. Jonathan Kwitny, "At CDC's AIDS Lab: Egos, Power Politics and Lab Experiments," *Wall Street Journal*, December 12, 1986.
18. Torin Douglas, "Will AIDS take the sex out of ads?," *The Observer*, London, January 11, 1987.
19. Clay Harris, "LIG pledges funds for AIDS research as profits rise 16%," *Financial Times*, November 19, 1986.
20. Monopolies and Mergers Commission, *Contraceptive Sheaths: a report on the supply of contraceptive sheaths in The United Kingdom*, London, Her Majesty's Stationery Office, 1975.
21. *New York Times*, October 10, 1985.
22. David L. Kirp, "Larouche Turns to AIDS Politics," *New York Times*, September 11, 1986.
23. The Panos Institute, "AIDS and the Third World," Second Edition, 1987.
24. Associated Press Dispatch, London, March 19, 1987.
25. Komsomolez, Moskovski, quoted in *Barricada*, Managua, March 23, 1987.
26. Pasteur Institut, *op. cit.*
27. Bob Sutcliffe, "Africa and the world economic crisis," in Peter Lawrence (editor), *World Recession and the Food Crisis in Africa*, London.
28. Sutcliffe, *op. cit.*
29. Lesley Doyle, *The Political Economy of Health* (Boston: South End Press, 1979), p. 23.

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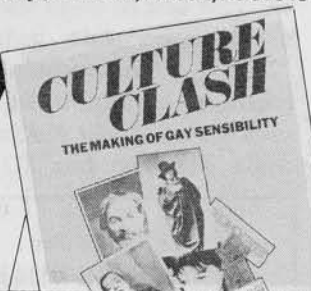
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RACE, SEX, AIDS:

The Construction of 'Other'

Evelynn Hammonds

In March of this year when Richard Goldstein's article, "AIDS and Race—the Hidden Epidemic" appeared in the *Village Voice*, the following statement in the lead paragraph jumped out at me: "a black woman is thirteen times more likely than a white woman to contract AIDS, says the Centers for Disease Control; a Hispanic woman is at eleven times the risk. Ninety-one percent of infants with AIDS are non-white." My first reaction was shock. I was stunned to discover the extent and rate of spread of AIDS in the black community, especially given the lack of public mobilization either inside or outside the community. My second reaction was anger. AIDS is a disease that for the time being signals a death notice. I am angry because too many people have died and are going to die of this disease. The gay male community over these last several years has been transformed and mobilized to halt transmission and gay men (at least white gay men) with AIDS have been able to live and die with some dignity and self-esteem. People of color need the opportunity to establish programs and interventions to provide education so that the spread of this disease in our communities can be halted, and to provide care so that people of color with AIDS will not live and die as pariahs.

My final reaction was despair. Of course I *knew* why information about AIDS and the

black community had been buried—by both the black and white media. The white media, like the dominant power structure, have moved into their phase of “color-blindness” as a mark of progress. This ideology buries racism along with race. In the case of AIDS and race, the problem with “color-blindness” becomes clear. Race remains a reality in this society, including a reality about how perception is structured. On the one hand, race blindness means a failure to develop educational programs and materials that speak in the language of our communities and recognize the position of people of color in relation to the dominant institutions of society: medical, legal, etc. Additionally, we must ask why the vast disproportion of people of color in the AIDS statistics hasn’t been seen as a remarkable fact, or as worthy of comment. By their silence, the white media fail to challenge the age-old American myth of blacks as carriers of disease, especially sexually transmitted disease. This association has quietly become incorporated into the image of AIDS.

The black community’s relative silence about AIDS is in part also a response to this historical association of blacks, disease, and deviance in American society. Revealing that AIDS is prevalent in the black community raises the spectre of blacks being associated with two kinds of deviance: sexually transmitted disease and homosexuality.

As I began to make connections between AIDS and race I slowly began to pull together pieces of information and images of AIDS that I had seen in the media. Immediately I began to think about the forty year-long Tuskegee syphilis experiment on black men. I thought about the innuendoes in media reports about AIDS in Africa and Haiti that hinted at bizarre sexual practices among black people in those countries; I remembered how a black gay man had been portrayed as sexually irresponsible in a PBS documentary on AIDS; I thought about how little I had seen in the black press about AIDS and black gay men; I began to notice the thinly veiled hostility toward the increasing number of i.v. drug users with AIDS. Goldstein’s article revealed dramatically, the deafening silence about who was now actually contracting and dying from AIDS—gay/bisexual black and Hispanic men (now about 50% of

black and Hispanic men with AIDS); many black and Hispanic i.v. drug users; black and Hispanic women and black and Hispanic babies born to these women.

In this culture, how we think about disease determines who lives and who dies. The history of black people in this country is riddled with episodes displaying how concepts of sickness, disease, health, behavior and sexuality, and race have been entwined in the definition of normalcy and deviance. The power to define disease and normality makes AIDS a political issue.

The average black person on the street may not know the specifics of concepts of disease and race but our legacy as victims of this construction means that we know what it means to have a disease cast as the result of the immoral behavior of a group of people. Black people and other people of color notice, pay attention to what diseases are cast upon us and why. As the saying goes—“when white people get a cold, black people get pneumonia.”

In this article I want to address the issues raised by the white media’s silence on the connections between AIDS and race; the black

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media's silence on the connections between AIDS and sexuality/sexual politics, the failure of white gay men's AIDS organizations to reach the communities of people of color, and finally the implications for gay activists, progressives and feminists.

It is very important to outline the historical context in which the AIDS epidemic occurs in regards to race. The dominant media portrayals of AIDS and scientists' assertions about its origins and modes of transmission have everything to do with the history of racial groups and sexually transmitted diseases.

The Social Construction of Disease

A standard feature of the vast majority of medical articles on the health of blacks was a sociomedical profile of a race whose members were rapidly becoming diseased, debilitated, and debauched and had only themselves to blame.¹

One of the first things that white southern doctors noted about blacks imported from Africa as slaves, was that they seemed to respond differently than whites to certain diseases. Primarily they observed that some of the diseases that were epidemic in the south seemed to affect blacks less severely than whites—specifically, fevers (e.g. yellow fever). Since in the eighteenth and nineteenth centuries there was little agreement about the nature of various illnesses and the causes of many common diseases were unknown, physicians tended to attribute the differences they noted simply to race.

In the 19th century when challenges were made to the institution of slavery, white southern physicians were all too willing to provide medical evidence to justify slavery.

They justified slavery and, after its abolition, second-class citizenship, by insisting that blacks were incapable of assuming any higher station in life. . . . Thus, medical discourses on the peculiarities of blacks offered, among other things, a pseudoscientific rationale for keeping blacks in their places.²

If as these physicians maintained, blacks were less susceptible to fevers than whites, then



Melvin Boozer, gay rights activist, founder of the Langston Hughes-Eleanor Roosevelt Democratic Club of Washington, DC, 1946-1987, Native

it seemed fitting that they and not whites should provide most of the labor in the hot, swampy, lowlands where southern agriculture was centered. Southern physicians marshalled other "scientific" evidence, such as measurement of brain sizes and other body organs to prove that blacks constituted an inferior race. For many whites these arguments were persuasive because "objective" science offered validity to their personal "observations," prejudices and fears.

The history of sexually transmitted diseases, in particular syphilis, indicates the pervasiveness of racial/sexual stereotyping. The history of syphilis in America is complex, as Allan Brandt discloses in his book *No Magic Bullet*. According to Brandt, "venereal disease has historically been assumed to be the disease of the 'other'." Obviously the complicated interaction of sexuality and disease has deep implications for the current portrayal of AIDS.

Like AIDS, the prevailing nineteenth century view of syphilis was characterized early-on in moral terms—and when it became apparent that a high rate of syphilis occurred among blacks in the South, the morality issue heightened considerably. Diseases that are acquired

through immoral behavior were considered in many parts of the culture as punishment from God, the wages of sin. Anyone with such a disease was stigmatized. A white person could avoid this sin by a change in behavior. But for blacks it was different. It was noted that one of the primary differences that separated the races was that blacks were more flagrant and loose in their sexual behavior—behaviors they could not control.

Moreover, personal restraints on self-indulgence did not exist, physicians insisted, because the smaller brain of the Negro had failed to develop a center for inhibiting sexual behavior.³

Therefore blacks deserved to have syphilis, since they couldn't control their behavior and as the Tuskegee experiment carried that logic to extreme—blacks also deserved to die from syphilis.

[B]lacks suffered from venereal diseases because they would not, or could not, refrain from sexual promiscuity. Social hygiene for whites rested on the assumption that attitudinal changes could produce behavioral changes. A single standard of high moral behavior could be produced by molding sexual attitudes through moral education. For blacks, however, a change in their very *nature* seemed to be required.⁴

If in the above quotation, you change blacks to homosexuals and whites to heterosexuals then the parallel to the media portrayal of people with AIDS is obvious.

The black community's response to the historical construction of sexually transmitted diseases as the result of bad, inherently uncontrollable behavior of blacks—is sexual conservatism. To avoid the stigma of being cast with diseases of the "other," the black media, as well as other institutions in the community, avoid public discussion of sexual behavior and other "deviant" behavior like drug use. The white media on the other hand is often quick to cast blacks and people of color as "other" either overtly or covertly.

Black Community Response to AIDS

Of 38,435 diagnosed cases of AIDS as of July 20, 1987, black and Hispanic people make up 39% of all cases even though they account for only 17 percent of the adult population.⁵ Eighty per cent of the pediatric cases are black and Hispanic. The average life expectancy after diagnosis of a white person with AIDS in the US is two years; of a person of color, nineteen weeks.⁶

The leading magazines in the black community, *Ebony* and *Essence* carried no articles on AIDS until the spring of this year. The journal of the National Medical Association, the professional organization of black physicians, carried a short guest editorial article in late 1986 and to date has not published any extensive article on AIDS. The official magazines of the NAACP and the National Urban League make no mention of AIDS throughout 1986 nor to date this year. Only the Atlanta-based SCLC (Southern Christian Leadership Conference) has established an ongoing educational program to address AIDS in the black community.

When I examined the few articles that have been written about AIDS in the national black press, several themes emerged. Almost all the articles I saw tried to indicate that the black people are at risk while simultaneously trying to avoid any implication that AIDS is a "black" disease. The black media has underemphasized, though recognized, that there are significant socioeconomic cofactors in terms of the impact of AIDS in the black community. The high rate of drug use and abuse in the black community is in part a result of many other social factors—high unemployment, poor schools, inadequate housing and limited access to health care, all factors in the spread of AIDS. These affect specifically the fact that people of color with AIDS are diagnosed at more advanced stages of the disease and are dying faster. The national black media have so far also failed to deal with any larger public policy issue that the AIDS crisis will precipitate for the community; and most importantly homosexuality and bisexuality were dealt with in a very conservative and problematic fashion.



Claire Preito/Roger McTair photo, Rites

Testing

In terms of testing *Ebony* encourages more opportunity for people to be tested anonymously; *Essence* recommends testing for women thinking of getting pregnant. Both articles mention that exposure of test results could result in discrimination in housing and employment but neither publication discusses the issue at any length. There is no mention of testing that is going on in the military and how those results are being used nor is there mention of testing in prisons. It is clear from the sketchy discussion of testing that the political issues around testing are not being faced.

Sexuality

The most disappointing aspect of these articles is that by focusing on individual behavior as the cause of AIDS and by setting up bisexuals, homosexuals, and drug users as "other" in the black community, and as "bad," the national black media falls into the trap of reproducing exactly how white society has defined the issue. But unlike the situation

for whites, what happens to these groups within the black community will affect the community as a whole. Repressive practices around AIDS in prisons will affect all black men in prison with or without AIDS and their families outside and any other black person facing the criminal justice system; the identification of significant numbers of people of color in the military with AIDS will affect all people of color in the military. Quarantine, suspension of civil liberties for drug users in the black community with AIDS will affect everyone in the community. Healthcare and housing access will be restricted for all of us. If people with AIDS are set-off as "bad" or "other"—no change in individual behavior in relation to them will save any of us. There can be no "us" or "them" in our communities.

The *Ebony* article entitled: "The Truth about AIDS: Dread Disease is Spreading Rapidly through Heterosexual Population," while highlighting the increase of AIDS among heterosexuals in the black community, makes several comments about black homosexuals. The author notes that there is generally a negative attitude towards homosexuals in the community and quotes several physicians who emphasize that the reticence on this issue is a hindrance to AIDS education efforts in the community. It does not emphasize that, because of this "reticence," only now as AIDS is being recognized as striking heterosexuals, is it beginning to be talked about in the black community.

One of the greatest problems in the black community, other than ignorance about the disease, is the large number of black men who engage in sex acts with other men but who don't consider themselves homosexuals.⁷

The point is then that since AIDS was initially characterized as a "gay disease" and many black men don't consider themselves gay in spite of their sexual practices, the black community did not acknowledge the presence of AIDS.

The association of AIDS with "bad" behavior is prominent in this article. Homosexuals and drug users are described as a "physiologically and economically depressed subgroup of the black community."⁸

The message is that to deal with this disease the individual behavior of a deviant subgroup must be changed. Additionally, the recommendation to heterosexuals is to "not have sex" with bisexuals and drug users. There are no recommendations about how the community can find a way to deal with the silence around the issues of homosexuality/bisexuality, sexual practices in general and drug use. The article fails to say what the implications of the sexual practices of black men are for the community.

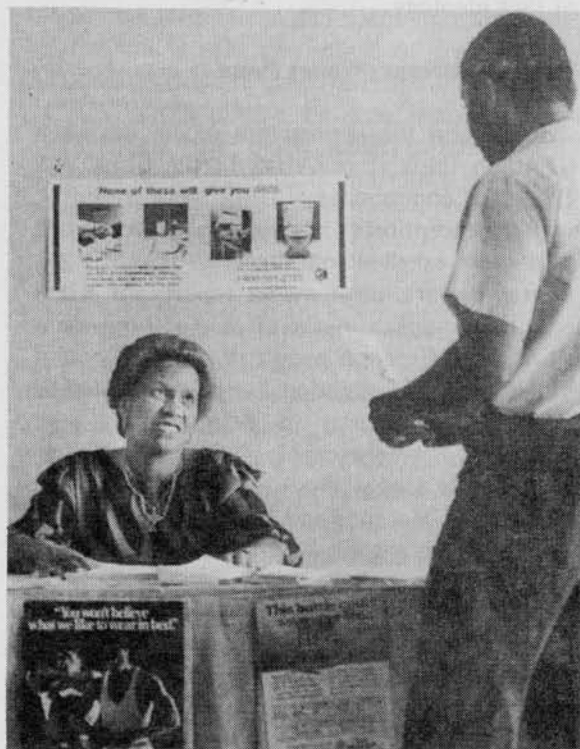
The *Essence* article, entitled *Nobody's Safe* avoids the issue as well.⁹ The authors describe a scenario of a 38 year-old middle-class professional woman who is suddenly found to have AIDS. Her husband had died two years earlier due to a rare form of pneumonia. After testing positive for AIDS she is told by one of her husband's relatives that he had been bisexual. The text following this scenario goes on to describe how most women contract AIDS; it gives a general sketch of the origins of the disease and discusses the latency period and defines asymptomatic carriers of the virus. There is no mention of bisexuality or homosexuality. The implication is again—just don't have sex with those people if you want to avoid AIDS. It avoids discussion of the prevalence of bisexuality among black men, and consequently the way that AIDS will ultimately change sexual relationships in the black community.

Education Efforts and Sexual Behavior in the Age of AIDS

The implications of this silence on sexuality are obvious when education efforts for black people are being discussed. But there is more at stake here than simply an acknowledgement. Both articles note the desperate need for education and material that speaks directly to the black community, so that black people can recognize that they too are at risk. But the other part of the message one gets from these articles is that black children must be taught the "facts about sex, AIDS and drug use and abuse" not about sexuality. *Essence* reports that a new group has formed in Atlanta which sponsors "Play Safe Parties" to teach women how to practice safer sex. In effect AIDS is described in terms of individual behavior. There are no

specific guidelines about what safer sex is—that it is about a community response as much as it is about individual behavior; instead, there is a push for people to return to monogamous, traditional relationships without analysis as to what that means for heterosexuals in a community where women far outnumber men in the population; where traditional patriarchal relationships are not easily accepted anymore. What about discussions about "safer sex" for men? What about sexual pleasure for women and who negotiates it? These articles do not recognize that you can't simply separate sex from AIDS, nor can you respond to it by a call to a return to traditional values while not exploring the implications of that move.

What white gay men have been able to do in the face of the AIDS crisis is to use the connection between sex and community. They succeeded in validating and mobilizing the gay community to the deadly implications of AIDS while preserving their right to define sexual expression and therefore challenge the conception of homosexuality as bad. For the black community, however, "the fear of a racial backlash against minorities as they become more iden-



Angry bishop speaks out

'AIDS COULD
END US ALL'

Story on page 2

tified with AIDS is one of the reasons the black community has been slow to address this issue, to put it on our agenda."¹⁰ What's at issue here is how to break the dominant culture's association of blacks with disease and immorality. The response so far has been to appeal to blacks to demonstrate our "traditions of respectability," e.g., to embrace monogamy in the face of the dominant culture's association of black people with promiscuity, and to deny the existence of homosexuality in the black community. But such a response means that the racist ideology that gives white culture the power to define morality and immorality remains intact. Black gays are rendered invisible and efforts at educating the community and providing care for people with AIDS is hampered by the need to preserve the notion that gaining respectability involves gaining authority.

Sexuality and sexual politics never came to the forefront of the civil rights agenda because of the reaction of the black community to the way in which race and sex had historically been used against the black community. What the AIDS epidemic raises is that the black political agenda has not been able to dethrone the power of that ideology.

The Mainstream (White) Press

In general the mainstream media has been silent on the rise of AIDS in the black and Hispanic communities. Until very recently, with the exception of a few special reports, such as a quite excellent one on the PBS' McNeil-Lehrer Report, most media reports on AIDS continue to speak of the disease without mention of its effects on people of color. In recent months specific attention has been paid to the "new" phenomenon of heterosexuals with AIDS or "heterosexual AIDS." This terminology is used without the slightest mention that among Haitians and extensively in Africa, AIDS was never a disease confined to homosexuals.

The assumption in reports about the spread of AIDS to heterosexuals is that these heterosexuals are white—read that as white, middle-class, non-drug-using, sexually-active people. The facts are that there are very few cases of AIDS among this group. As many as 90 percent

The girl
daddy
tried
to sell

Four-year-old Rachal Rausser, whose father allegedly tried to sell her for \$100,000 in Giants Stadium parking lot, clings to her aunt, Deborah Stern, as she arrives at Bergen County Court for custody hearing yesterday. Judge will rule today whether she'll go to aunt and uncle or stepmother.

Page 6

of the cases of AIDS among heterosexuals are black and Hispanic. In many media reports blacks and Hispanics with AIDS are lumped in the i.v. drug users group. What the media has picked up on is that heterosexual transmission in the US now endangers middle class whites.

A good example of the mainstream media approach is an article by Kate Leishman in the February, 1987 issue of *Atlantic Monthly*. She writes that most Americans even liberals, have the attitude that AIDS is the result of immoral behavior. Leishman lists the statistics on heterosexual transmission of AIDS at the beginning of her article. Fifteen pages later the following information appears:

In the case of sexually active gay men [AIDS] is a tragedy—as it is for poor black and Hispanic youths, among whom there is a nationwide epidemic of venereal disease, which is a certain cofactor in facilitating transmission of HIV. This combination with the pervasive use of drugs among blacks and Hispanics ensures that the epidemic will hit them hardest next.¹¹

Her first explicit mention of people of color

describes them as a group that uses drugs extensively, and as also riddled with venereal disease (a fact she does not support with any data). The image is one of the "unregenerate young street tough" that causes all the trouble in our cities, in short the conventional racist stereotype of black and Hispanic youth displayed in the press almost everyday. Her use of the word tragedy because of the risk to blacks, Hispanics and gays is gratuitous at best. The main focus of the article is the risk of AIDS to white heterosexuals and the need for them to face their fears of AIDS so they can effectively change their behavior.

In a passage reminiscent of 19th century physicians' moral advice she notes the problems associated with changing people's behavior and promoting safe sex, and wonders if one can draw any lessons for heterosexual behavior from the gay male experience.

Many people believe that the intensity or quality of homosexual drives is unique, while others argue that the ability to control sexual impulses varies extraordinarily within groups of any sexual preference.¹²

What I find striking in this passage is that there is still debate over whether certain "groups" of people have the same ability to exercise control over their sexual behavior and drives as "normal" white heterosexuals do. The passage also suggests that while heterosexuals are still the only group who have the strength, the moral fortitude, the inherent ability if educated, to control their sexual and other behavior. After all, is this a disease about behavior and not viruses, right? Leishman doesn't interview any blacks or Hispanics about their fears of AIDS, or how they want to deal with it with respect to sexual practice or other behavior.

Two months later in May several letters to the editors of *Atlantic Monthly* appeared in response to Leishman's article. In particular one reader observed her omission of statistics about the risk of AIDS to blacks and Hispanics. She responded in a fairly defensive manner:

My article and many others have commented on the high risk of exposure to AIDS among blacks and Hispanics. Mr. Patrick's observa-

tions that blacks and Hispanics already account for ninety per cent of the case load seems oddly to suggest that AIDS is on its way to becoming a disease of minorities. But the Centers for Disease Control has stressed that the overrepresentation of blacks and Hispanics in AIDS statistics is related not to race per se but to underlying risk factors.¹³

The risk factor she mentions is intravenous drug use. Leishman fails to deal with the "overrepresentation" of blacks and Hispanics in AIDS statistics. To mention our higher risk only implies that AIDS is a disease of minorities if you believe minorities are inherently different or behave differently in the face of the disease or if you believe that the disease will be confined to the minority community.

So pervasive is the association of race and i.v. drug use, that the fact that a majority of black and Hispanic men who have AIDS are gay or bisexual, and *non* i.v. drug users, has remained buried in statistics.¹⁴ In the face of the statistics, *The New York Times* continues to identify i.v. drug use as the distinguishing mode of transmission among black and Hispanic men, by focusing not on the percentage of black and Hispanic AIDS cases that are drug related, but on the percentage of drug related AIDS cases that are black or Hispanic, which is 94%. This framework, besides blocking information that the black and Hispanic communities need, also functions to keep the white community's image "clean."

Conclusion

As this article goes to press, media coverage of the extent of AIDS in the black and Hispanic communities is increasing daily. These latest articles are covering the efforts in the black and Hispanic communities both to raise consciousness in these communities with respect to AIDS and to increase government funding to support culturally specific educational programs. Within the black community, the traditional source of leadership, black ministers, are now publicly expressing the reasons for their previous reluctance to speak out about AIDS. The reasons expressed tend to fall into the areas I have tried to discuss in this article, as indicated by the following comments that recent-

ly appeared in the *Boston Globe*:

Although some black ministers described gays as the children of God and AIDS as just another virus, many more talked about homosexuality as sinful, including some who referred to AIDS as a God-sent plague to punish the sexually deviant.¹⁵

There's a lot of fear of stigmatization when you stand up. . . . How does this label your church or the people who go to your church? said Rev. Bruce Wall, assistant pastor of Twelfth Baptist Church in Roxbury. Rev. Wall said ministers may also fear that an activist role on AIDS could prompt another question: 'Maybe that pastor is gay.'¹⁶

The arguments I have made as to the background of these kinds of comments continue to come out in the public discourse on AIDS and race in the national media. As the public discussion and press coverage has increased, one shift is apparent. The media is now focussing on why the black and Hispanic communities have not responded to AIDS before as a "problem" specific to these communities, while there is no acknowledgement that part of the problem is the way the media, the CDC, and the Public Health Service prevented race-specific information about AIDS from being widely disseminated. Or, to say it differently, there is no recognition of how the medical and media construction of AIDS as a "gay disease," or a disease of Haitians has affected the black and Hispanic communities.

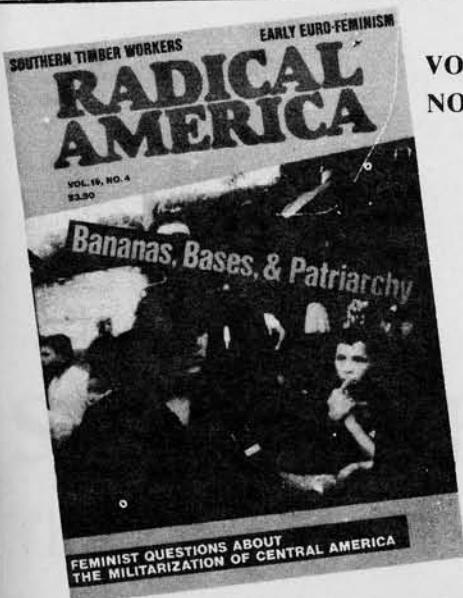
Finally, as the black and Hispanic communities mobilize against AIDS, coalitions with established gay groups will be critical. To date, some in the black community have noted the lack of culturally specific educational material produced by these groups. Some gay groups are responding to that criticism. For progressives, feminists and gay activists, the AIDS crisis represents a crucial time when the work we have done on sexuality and sexual politics will be most needed to frame the fight against AIDS in political terms that move the politics of sexuality out of the background and challenge the repressive policies and morality that threaten not only the people with this disease but all of us.



FOOTNOTES

1. James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: Free Press, 1981), p. 21.
2. *Ibid.*, p. 17.
3. *Ibid.*, p. 23.
4. *Ibid.*, p. 48.
5. "High AIDS Rate Spurring Efforts for Minorities," *New York Times*, Sunday, August 2, 1987.
6. *Mother Jones*, Vol. 12, May 1987.
7. *Ebony*, April, 1987, p. 128, quoting a Los Angeles AIDS expert.
8. *Ibid.*, p. 130.
9. *Essence*, June 1987.
10. John Jacob, President, National Urban League, *New York Times*, Sunday, August 2, 1987.
11. *Atlantic Monthly*, February 1987, p. 54.
12. *Ibid.*, p. 40.
13. *Atlantic Monthly*, May 1987, p. 13.
14. *New York Times*, Sunday, August 2, 1987.
15. *Boston Globe*, Sunday, August 9, 1987, p. 1.
16. *Ibid.*, p. 12.

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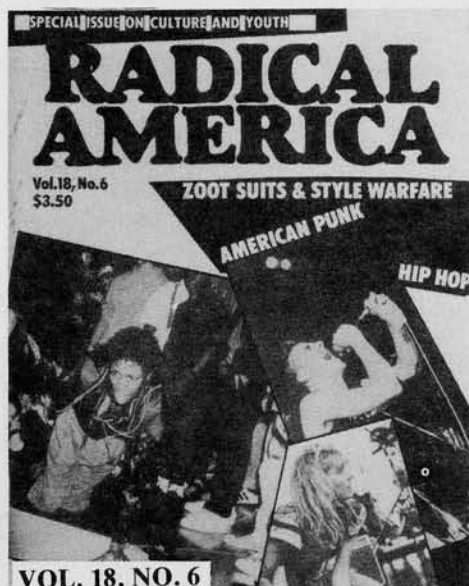


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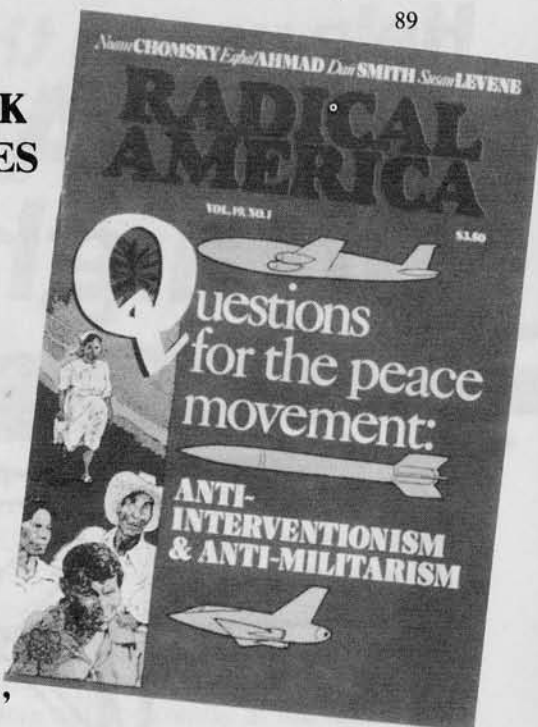


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SCIENCE FICTIONS:

The Making of a Medical Model for AIDS

Deb Whippen

A fan of radio talk shows, I tuned into a local station one morning recently while driving my lover to work. The publisher of the *Boston Phoenix* magazine was discussing the controversy over the "ethics" of circulating a "Safer Sex Kit" and including a condom with each issue of the May 29th *Phoenix*. He was responding to editorial charges in the Rupert Murdoch-owned *Boston Herald* that called the kit and condom "sleazy" and a "cheap promotional trick."

Never once in the discussion did the word "risk groups" resound. There was no fearful mention of closeted bisexual men. Diseased prostitutes were not apparently at the center of the men's concerns. Instead, there was a frank acknowledgement of the explosive AIDS epidemic in the United States, and the declaration that now "it's time to put public health before public morality."

At first I reacted with agreement, but then increasingly with annoyance and anger. I realized that what defined AIDS as a "public health" issue was its spread to heterosexuals. The clear message was that now that the number of AIDS cases in the United States has reached 33,500, and an increasing number of heterosexuals who do not use i.v. drugs are getting the disease, now is the time for organizing and educating everybody about AIDS. The

two self-proclaimed straight men on the radio portrayed their involvement with AIDS as stemming from a gracious civic-mindedness. Their comments reveal the contradictions in popular consciousness about AIDS: when AIDS seems contained within risk groups, those with identifiably "deviant" lifestyles, public reaction is one of outraged morality; when AIDS moves beyond the margins of risk groups into the "general" population, the issue of public health suddenly enters the discussion.

It is true that now is the time to organize around AIDS. It is also true that three years ago was the time. Seven years ago was the time. Since the late 1970s and early 1980s, hundreds and thousands of people have been fighting and coping with AIDS worldwide. In the US, the fight against AIDS has been organized primarily by gay men as they struggled personally and politically against the disease. The information contained in the "Safer Sex Kit" grew out of their work, despite isolation and tension with traditional public health and research agencies. Now "Safe Sex," once a gay code word, has been legitimated as a public health approach because now the goal is to prevent widespread transmission among the "public," not just to permit gay men to have sex safely.



In this essay, I examine the (brief) history of AIDS research and argue that research has not been immune from the tension I have identified between public health and public morality. In fact, the history of AIDS research reveals how views of "public morality," specifically of the character of homosexuality, have impeded research and actually contributed to the transmission of the disease. Science is guided by the questions and assumptions scientists bring to it. In the case of AIDS research, scientists' homophobic fictions determined their questions and blocked recognition of evidence that challenged their preconceptions.

Science Fictions

If a viral agent were imported into the United States from Haiti by vacationing homosexuals, it might quickly spread within the homosexual community by means of frequent, often anonymous sexual encounters, in bathhouses and elsewhere. Homosexual drug addicts, in turn, might introduce the agent via the parenteral route [through shared needles] in the heterosexual addict population.¹

The above quotation is taken from a scientific article, "Acquired Immune Deficiency in Haitians," published in *The New England Journal of Medicine* in 1983. In it, we see the three major "risk groups" established for AIDS—gays, Haitians, and i.v. drug users ("addicts")—linked via the imagination of the authors. Mysterious, dark Haiti is assumed to be the source of AIDS. "Vacationing homosexuals" brings to mind images of men in pink shorts lying around in bright hammocks, only to return home to have frequent anonymous sex in bathhouses. The final sentence reveals a major flaw in the statistical categories devised for AIDS. Homosexual i.v. drug users are counted only in the category of homosexuals, whereas drug users are tabulated only as heterosexuals. This method of statistical tabulation compounded the isolation of gay men as a risk group for AIDS and erroneously reduced the numbers of i.v. drug users in need of outreach and intervention. These artificial and misleading categories have had a major impact on research and prevention as the disease moved beyond the original risk groups.

This quotation, published in the third year of intensive medical research on AIDS, illuminates the "medical model" for AIDS. This model is the medical establishment and federal health agencies' portrait of AIDS—who gets it, how they get it, why they get it, and what they can do not to get it. The picture as constructed shows gay men, i.v. drug users, and Haitians getting AIDS, with women who relate to these groups sexually as invisible sidekicks. Foreign-born people, especially from Africa, also get AIDS. The true *victim* in the medical model is the hemophiliac or blood transfusion recipient because they didn't do anything *themselves* to



Cover from *Konkret*, special issue on AIDS

get AIDS, unlike the type of people in "risk groups." Risk groups are subpopulations of individuals in whose communities the virus was ideologically centered and in which the state attempted containment. Except for Haitians, these people have AIDS-producing "lifestyles," behaviors they themselves choose. Gay men have unnatural sex; drug users shoot up. Haitians always represented something of a puzzle in this model. The question about Haitians became what about their *lifestyles* connected them to gay men and i.v. drug users. For prevention, the model mandates that persons in risk groups abstain from all behaviors connected to the identity that places them in a high risk category.

Inversely, and with serious consequences, the medical model contains an erroneous message

about who *won't* get AIDS. AIDS is disproportionately represented in the black and Latin communities, including a high incidence of AIDS among women of those communities, yet the medical model obscures this fact, by institutionalizing the idea of transmission by "lifestyle" rather than specific behavior. Virologists and epidemiologists particularly contributed to the construction of a medical model for AIDS. In order to understand this model and its political implications, it is necessary first to review the early literature.

The Construction of the Medical Model

In June 1981, five cases of *Pneumocystis carinii* pneumonia and twenty six cases of Kaposi's sarcoma were reported to the Centers for Disease Control (CDC).² These cases were unusual in that the individuals were young, previously healthy men. Kaposi's sarcoma was considered a rare type of cancer, usually affect-

ting elderly men. In addition, the symptoms were typically accompanied by other secondary infections, called "opportunistic infections," illnesses that "took advantage" of the men's weakened immune systems. What was also unusual about these cases was that the men were not recovering, and more cases were being reported daily.

In hindsight it is clear that AIDS had been treated in the United States for several years earlier on a case-by-case basis.³ However, mid-1981 marked the entrance of governmental health agencies and leaders of the national medical establishments into a hastily constructed mobilization. The earliest identified characteristics of the disease were that it was fatal after a relatively short illness (1-2 years) and disproportionately affected male homosexuals. Initial theories of causation identified not an infectious agent, but an immune deficiency caused by use of amyl nitrates (poppers) or exposure to multiple sperm sources. Researchers and laboratories were put into motion to construct a model for the disease through which an understanding of its causes and thus a cure could be developed. I argue that the subsequent model contained the social, political, and class biases of the investigators/tions themselves.

The attempt to isolate the disease as affecting only certain populations, to conceptually contain it within bounded communities, blocked understanding of AIDS transmission, contributing to the spread of the disease. And, precisely this aspect of the model also contributed to repression, such as the insurance redlining of gay neighborhoods and the detention and harassment of Haitian immigrants. The medical establishment as a community of power, in collaboration with the federal government, has had great license to wield authority over designated subject communities, in part because it seemed repression could *also* be contained within these "deviant" communities.

It is important to note the deficits of the medical model. It is equally important to analyze the medical establishment in the United States as itself a bounded community, distinctive and self-contained. It is a community unified by common histories, professional interests, values, and loyalties to itself. These

values have guided, impacted on, and impeded AIDS research so that there has been very little success. Crucial time has been spent building a case for AIDS as a disease of communities, not of individuals; as a consequence of non-heterosexual, unknown and popularly immoral "lifestyles" rather than of a particular mode of transmission. And, likewise, valuable time has *not* been spent reaching within and beyond established risk groups to others affected by AIDS, including blacks and Hispanics. The ways in which early on the medical establishment conceptualized and approached AIDS in some ways is more revealing of the establishment as a community, than of the disease. The consequences have been grave.

What's in a Name?

AIDS is an acronym for the Acquired Immune Deficiency Disease. This was not the first name suggested for the disease. The first name was "GRID," the Gay-Related Immune Deficiency, a name which was dropped when "... gay activists objected to naming what was then an unresearched syndrome after an already stigmatized group."⁴ The final selection of AIDS as the name was to differentiate the disease as acquired behaviorally rather than developed genetically. At the same time, the term "acquired" symbolically implicates people with AIDS as having acted in a manner that brought the disease upon themselves. Indeed, researchers focused heavily on the lifestyles through which it was thought members of a community passed on the disease.

Of the first officially registered persons with Kaposi's sarcoma (twenty-six), and *Pneumocystis carinii* pneumonia (five), 100 percent were homosexual men, twenty-five were white, one was black, and five were racially undefined.⁵ In early 1982, of the 159 cases reported to the CDC "over 92 percent of the patients were reported to be homosexual or bisexual men."⁶ These figures represent the highest percentage of gay men having AIDS ever reported, and the lowest percentage of blacks and Hispanics with the disease. And yet, until very recently, these initial terms of the medical model—that AIDS is a disease in large part unique to the white, male homosexual



Traffic police wearing protective mask during the 1918 influenza epidemic.

community—remained central to the popular, and medical, approach to AIDS.

What's "At Risk"? Who's in Danger?

"Even before the cause of AIDS was known, the understanding of risk factors for AIDS made opportunities for its prevention available. . . ." The medical model did not focus on understanding or preventing high risk modes of transmission in general. Rather, the focus was limited to the particular risk factors imagined to cause AIDS within the designated risk groups. Among researchers, the initially designated risk group was the male homosexual community, and the specific risk factor identified was gay male sexuality.

The fact that these patients were all homosexuals (the first five men diagnosed with *Pneumocystis carinii* and AIDS in 1980-1981) suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact in this population.⁸ (parenthesis, mine)

No previous association between Kaposi's sarcoma and sexual preference has been reported.⁹

By 1986, the medical literature included more than 10,000 research papers on AIDS, and was growing at a rate of 600 citations per month.¹⁰ In 1982-84, a large part of the literature focused on the lifestyles and sexual practices of gay men. One conclusion reached was that gay men's "promiscuity" was the behavior that caused AIDS, and that to remove themselves from risk, gay men should not have sex at all.

The variables most strongly associated with Kaposi's sarcoma or *pneumocystis* pneumonia were those related to number of male sex partners and to meeting such partners in bath-houses.¹¹

The authors wish to prove the distinctiveness of a gay lifestyle, centered on sex, is itself a cofactor in the development of AIDS. This completely blurs the distinction between safe and unsafe sexual practices. Moreover, the researchers' concentration on the gay lifestyle as causal obscures the more crucial insights into the specific transmission of the disease contained in their own research.

Fifty men with Kaposi's sarcoma and *Pneumocystis carinii* pneumonia were subjects. Of these men, thirty-eight were white, seven black, and five Hispanic. The controls were *healthy homosexual men*, each matched by age, race, and metropolitan area to a subject. A comparison was made between the sexual activities of men with AIDS and the controls.

Cases were more likely than controls to have reported inserting their tongue ('rimming') or hand ('fisting') into a partner's rectum at least once during the year before onset of illness. Because cases had had more sex partners per year than controls, their number of anal exposures was also greater than for controls. The differences are small between cases and controls in the frequency of taking the receptive role in 'fisting,' oral, or rectal intercourse.¹²

... The occurrence of Kaposi's sarcoma and *pneumocystis pneumonia* in the homosexual men we have studied is associated with certain aspects of their lifestyle.¹³

The article under question is traditionally structured in that it has a hypothesis, makes a case measuring controls against subjects, states the evidence and compares the results with the hypothesis. The authors conclude that the men with AIDS had more varied sex with more sexual partners, and thus support their hypothesis that the more gay sex a man has, the more at risk he is for AIDS. Safe and unsafe gay sex are no more distinguished at the end of the research than at the beginning, because it was assumed

that *gay* sex was dangerous, and *proven* that the more of "it," the more danger.

The present context of AIDS knowledge shows that this conclusion is wrong. AIDS is passed through an exchange of body fluids, and only one exchange is needed for transmission. **It is not the frequency or quantity of activity, but the type of sexual practice through which AIDS can be transmitted that is the key. As is indicated, researchers had information about types of sexual practices, but chose to reduce their data to critiques of "lifestyle."**

Here again, the article reveals more about the politics embedded within the research structure, than about the subject it claims to investigate. Using healthy homosexual men as controls is common in AIDS research papers, and is often defensible. However, in many papers, the use of healthy gay men as controls suggests that, according to the medical model, gay men are a separate and distinct species of human.

Undeniably, AIDS crosses the boundaries between culture and biology—it is a physical disease that can be transmitted through many kinds of social and sexual activities, those involving an intimate exchange of body fluids. However, to presuppose that gays are biologically susceptible to AIDS while heterosexuals are not is homophobic. Further, it speaks to prejudice that already exists (gay sex is dangerous and gay people are a distinct species of human) and hardens those images of gayness in the mind of the public. By so doing it solidifies an image about who is safe that undercuts prevention beyond the risk group. Prevention efforts within the gay community suffered because many erroneously thought that AIDS was a condition particular to gay men. Outside that community, prevention efforts did not exist.

The "Spread" of AIDS

As the epidemic grew in the US, it soon became clear that the disease was not contained within, or unique to, the homosexual community and that it was also spreading out beyond the initial three geographical areas (New York, LA, and San Francisco). By January 1982, 22 i.v. drug users contracted AIDS and were included



Protective clothing worn by doctors in Marseilles, France during an 18th century plague.

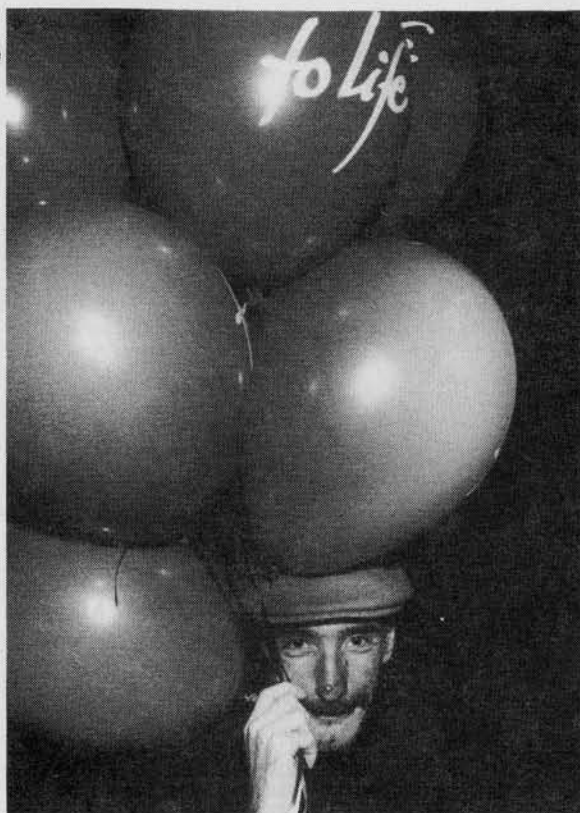
within the statistical records. By 1983, the number had risen over six times to 138, and continued to rise. This increase was located primarily in New York City and New Jersey. I.v. drug users were established as another risk group who "acquired" the disease through self-elected behavior, in this case sharing needles. State-sponsored education efforts have been practically non-existent towards persons at risk for AIDS through drug use.

Although, to our knowledge, specific studies of AIDS in i.v. drug users have not been done, sharing needles has been noted to be very common among AIDS cases in i.v. drug users in New York City. This practice, as well as other potential risk factors, such as using 'shooting galleries' (where drug users rent unsterile injection equipment used by an unknown number of people), may be more common in New York and New Jersey than in other parts of the country. Alternatively, i.v. drug users may be less likely to travel widely than homosexual or bisexual men. Thus, a disease like AIDS, once introduced into a drug-using population, may not spread quickly to drug users in noncontiguous geographic areas.¹⁴

Aside from traveling homosexuals and needle-sharing drug users, early statistical records identify Haitians as a risk group for AIDS. Having established "lifestyle" to be the risk factor for homosexuals and drug users, investigators were puzzled by the presence of AIDS in thirty-four immigrants in the United States in 1983. One study, published in *The New England Journal of Medicine* on January 20, 1983, examined this enigma in an article titled "Acquired Immune Deficiency in Haitians" (Vieira, *et al.*). Focusing on ten of the thirty-four cases, the authors state:

The epidemiologic features common to most of the cases in homosexuals and drug abusers including multiple sexually transmitted infections and frequent use of prescription or recreational drugs, were generally absent in the Haitians. . . .

Recreational drugs, such as marijuana, cocaine, and amyl or butyl nitrite are used commonly by homosexuals. Some of these agents may have immuno-suppressive effects in vivo (in the body). Because of recurrent venereal infections, homosexuals are also likely to take



John Pascarelli, demonstrated at Stonewall, AIDS activist, a few weeks before his death from AIDS.

repeated courses of antibiotics, including tetracyclines, metronidazole, and trimethoprim-sulfamethoxazole. These agents may be immunosuppressive at therapeutic doses, although the clinical relevance of the observation is speculative. All the Haitians described in our series state that they do not use illicit drugs and none were taking antibiotics before present to us.

To substantiate any hypothesis about the pathogenesis of AIDS with respect to Haitians, we will need to learn more about the Haitian lifestyle in both the United States and Haiti. The assumption that heterosexual Haitians and homosexual Americans have little in common may prove erroneous when epidemiologic and anthropologic surveys are completed.¹⁵

The number of Haitians with AIDS increased after 1983, but slowed and then abated altogether. By 1986, the number had reached 226; 129 cases in New York, and ninety-seven in Florida.¹⁶ By 1985, Haitians were removed from the official "risk group" list, and the puzzle of locating the origin and cause of AIDS in that particular community subsided from medical investigators' priority research.



“With the increasing number of priests being diagnosed with AIDS, the Catholic Church will finally be forced to admit how many of its clergy are practicing i.v. drug users.”

New York Native

However, Haitian immigrants in this country experienced severe oppression for their brief assignment to the AIDS risk group list. Many were held for months and sometimes years in federal detention centers, to prevent their entering the “general” US population. Immigration was made more difficult, and for those Haitians already living and working in this country, racist fears and discrimination around them increased.

The statistics for people of color and AIDS in the US are today at disproportionately high levels. However, this is not a new phenomenon. The high incidence of AIDS in communities of color has been consistent throughout the entire six year course of the epidemic. Of the first 159 cases reported in 1981, 16 percent were Hispanic men, and 14 percent were black.¹⁷ At a combined 30 percent, this is a disproportionately high level. Yet, this was also the lowest percentage for the incidence of AIDS among blacks and Hispanics to date. Particularly in the urban areas of New York City, New Jersey, San Francisco, and Los Angeles, the disproportion of AIDS affecting people of color is exceedingly high. One study, on the impact of AIDS on patterns of premature death in New York City found that:

The rates of AIDS mortality differs markedly by race. Among males aged 15 to 64 years, AIDS mortality rates were significantly higher for both blacks and Hispanics.¹⁸

Given this information, and based on an analysis of the medical model in general for AIDS, two possibilities arise: (1) that black and Hispanic communities would be identified as

risk groups, and (2) that State educational efforts be made to specifically reach members of those two groups about AIDS as a prevention effort. In fact, neither happened. The reasons for this are a matter of informed conjecture.

The numbers of blacks and Hispanics with AIDS were smaller in 1980-82 when the medical model for AIDS was constructed by the medical community and health agencies. As the numbers have increased, the efficacy and usefulness of “risk groups” for AIDS has been questioned both in terms of research and prevention. Also, the notion that epidemiologically homosexual men and possibly Haitians were distinct from the “general population,” an idea which erroneously was relied upon as one explanation for the high incidence of AIDS, was not applied to Afro-Americans and Hispanics. Identifying risk groups was thought to indicate the definite and particular explanation of transmission in those groups. A 1986 statistical study claimed that “A total of 94% of patients with AIDS can be placed in *groups* (emphasis, mine) that suggest a possible means of disease acquisition.”¹⁹

Yet, racial statistics broke this understanding of risk groups, a fact that was not confronted within or against the medical model by researchers. On the one hand, ethnic identities (with the exception of Haitians) were correctly assessed as a non-factor in the transmission of the disease. On the other, communities of color are affected disproportionately. Because of the structure of the medical model, communities not labelled as risk groups and for whom one identifying set of behaviors has not been established as the method of transmission, these communities are not targeted for

outreach. Race has been enveloped within the established risk groups and discounted as a priority issue. As ethnicity is not a factor in transmission of the disease biologically, some activists agree with this conceptualization of the medical model. Having seen the resulting oppression against gays, Haitians, and i.v. drug users increase once labelled as risk groups for AIDS, Afro-American and Hispanic leaders do not wish similar reactions targeted toward their communities. And yet, the end result of discounting and underrating the impact of AIDS on the Afro-American and Hispanic communities means that targetted outreach to understand or prevent transmission in those particular communities is non-existent.

The last study mentioned also found that:

Among women, AIDS was among the five leading causes of death for those between ages 25 and 29 years. . . .

Black and Hispanic women aged 15 to 64 years were also at higher risk of AIDS than white women.²⁰

Women comprise another category that, *because of* the concept of "risk groups," has been discounted concerning AIDS until the number of cases demanded attention. Much of this attention has been potentially prohibitive rather than educational.

In 1985, the CDC officially established that AIDS can be transmitted from mother to infant prenatally. Recommendations and guidelines were established for "intervention" in cases where women have AIDS or have tested positive for the AIDS antibody; have used intravenous drugs; have been born in countries where heterosexual transmission is thought to play a major role in transmitting the disease; have engaged in prostitution; or finally, associated with men in high risk groups. In addition, women who have AIDS, or who test positive are recommended to delay getting pregnant until more is known about prenatal transmission.

Without doubt, women have distinct vulnerabilities to AIDS, different from men. In 1986, the World Health Organization established that women who are infected with AIDS have a 50% chance of passing the disease to their babies if they become pregnant.²¹ Women

need to be concerned and knowledgeable about prenatal transmission, and methods for safe sex. Yet, especially given the current power dynamics between the State, medicaid and welfare systems, and women recipients, it appears likely that educational efforts toward poor and working-class women will be morally prohibitive, and create a more intimate opening for further State intervention into women's lives.

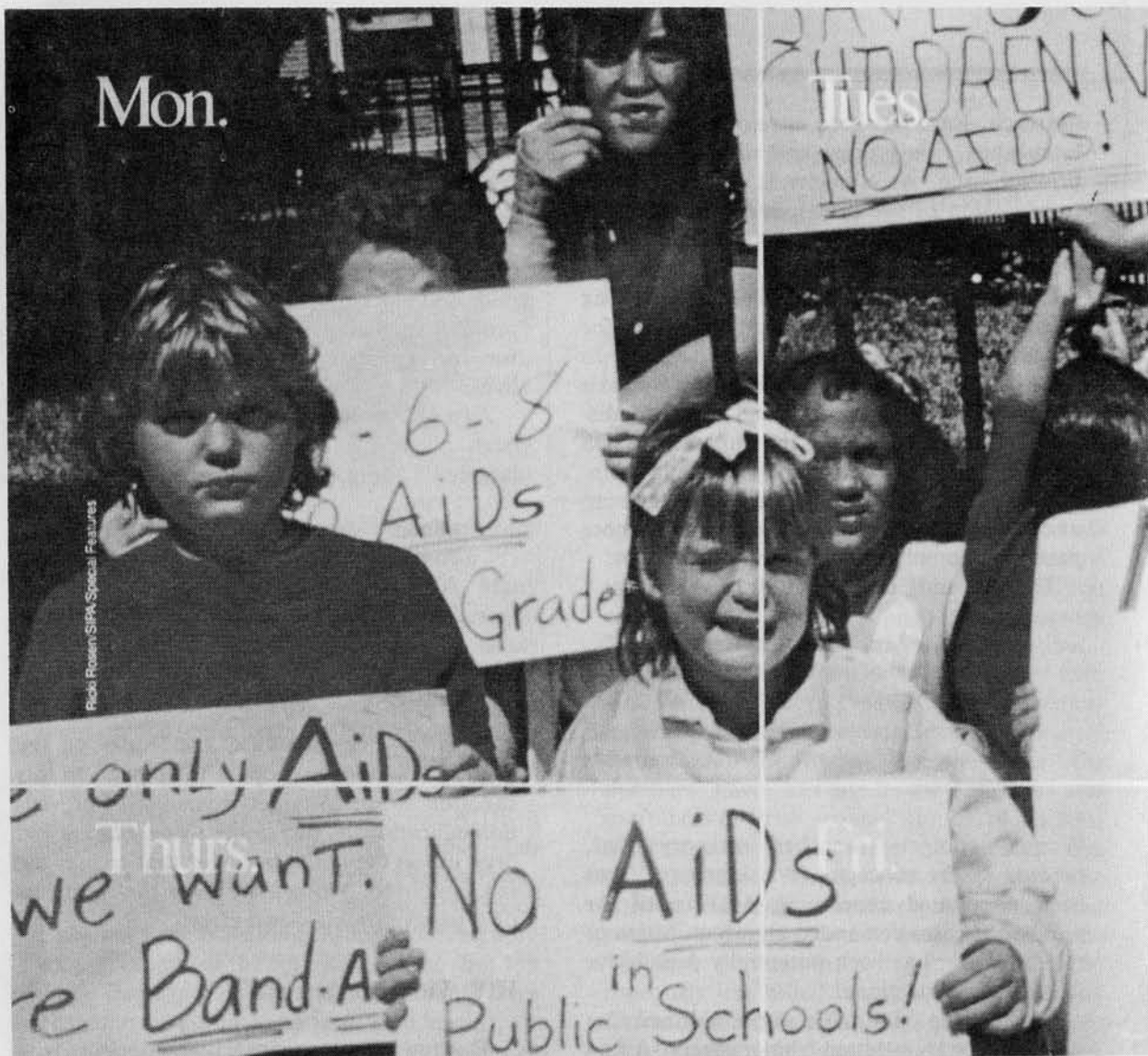
As a risk category, women and children have been placed as associates of infected men, largely i.v. drug users. For example:

Minority women and children . . . disproportionately suffer from heterosexually spread AIDS . . . Heterosexual encounters pose a fourfold higher risk . . . for women than men because there are many more infected men . . . one in every 30 American men between the ages of 20 and 50 carries the disease.²²

The action which the CDC and leaders of the medical community propose to respond to this situation is not to target women with prevention educational, but rather to only target i.v. drug use as the initial behavior that creates the risk condition. Women are to be the recipients of a passive trickle-down effect.

HIV: Virus Not Lifestyle

The number of persons with hemophilia who contracted AIDS jumped from seven in 1982 to ten in 1983 to thirty-eight in 1984, and finally peaked at 124 in 1986. The estimates of the percentage of hemophiliacs among the total cases reported in the United States ranged from 0.8 to 1.67 percent.²³ Given this information, combined with the results of virological research, medical investigators concluded that, in addition to sexual transmission, AIDS is carried through blood and blood-by-products. As early as 1983 blood and plasma centers received recommendations from the CDC to ask people "at risk" for AIDS to refrain from donating. A second policy, instituted in early 1985, was the licensing of marketed HTLV-III antibody tests to blood and plasma centers for the routine testing of all donations. (By this time it was determined that the HTLV/HIV virus was the etiologic factor causing AIDS). Lastly, also in



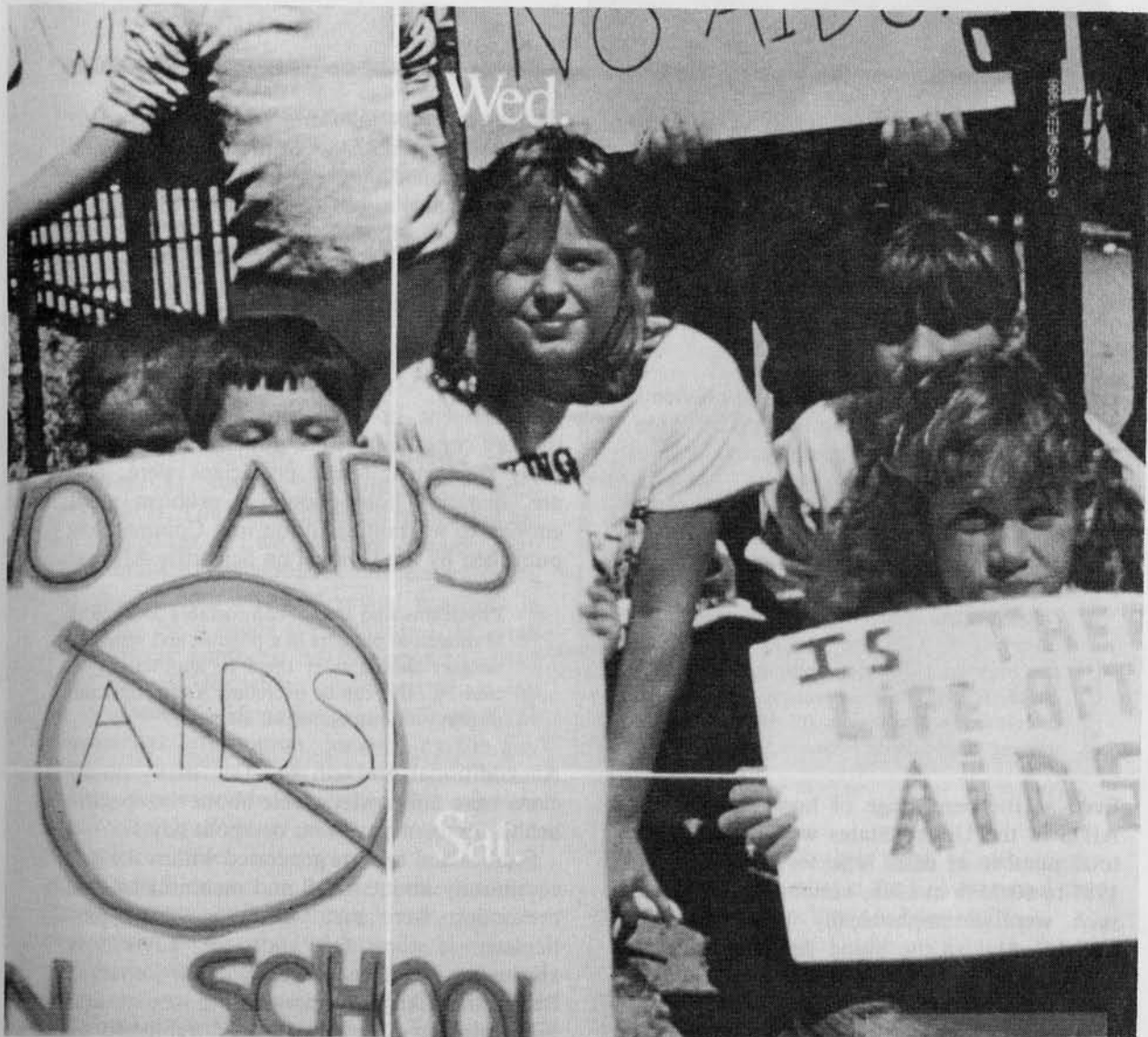
Advertisement from the New Republic, August 11-18, 1986

1985, the CDC again revised its "Definition of Persons who Should Refrain from Donating Blood and Plasma" to read:

... the donor-referral recommendations state that *any man who has had sex with another man since 1977 should not donate blood or plasma. This applies even to men who may have had only a single contact and who do not consider themselves homosexual or bisexual...* This revised wording of the deferral recommendations is intended to inform persons who may have been infected with HTLV-III through occasional or intermittent homosexual activity that they should not donate blood or plasma, even if they do not believe they are at risk of having been infected through their contacts.²⁴ (italics, mine)

Activists did not object to routine testing of blood donations for the AIDS antibody, though they did point out that testing positive did not mean a person had, or would get, AIDS. Additionally, the tests themselves had a high "false positive" error rate. Asking individuals who thought they might have had contact with AIDS not to donate blood seemed reasonable. But the above blood deferral policy misidentified the issue, insuring a purge of male homosexual blood donors rather than of HTLV-infected blood donations.²³

The 1985 CDC Blood Deferral Policy, while blindly purging all men who had had homosexual experiences as donors, did acknowledge that it was not a gay identity per se which put a man at risk for AIDS. This provided the opportunity



for all men (and women) to be educated about the potential modes of transmission and to take responsibility in an informed manner for their own health. But the opportunity was not taken advantage of—AIDS still conceptually remained in risk groups; it still was seen to affect only certain “types” of people. Bisexual men were eventually treated as dangerous anomalies, gay agents passing for straight, infecting the innocent and blameless. (Unlike the situation for sexual partners of i.v. drug users, who rather than innocent or blameless, are self-incriminated by AIDS via their relationships and their sexuality.)

The Social Geography of a Disease

The social boundaries between people labeled at risk for AIDS, and those not, are thin and imaginative, and were strengthened by fear, homophobia toward gay men, racism and xenophobia toward Haitians, and class and/or race oppressions toward i.v. drug users. The early five cases of *Pneumocystis carinii* pneumonia reported in 1981 and the twenty-six cases of Kaposi's sarcoma reported shortly thereafter were “clustered” within three geographical areas (Los Angeles, San Francisco, and New York City). AIDS clustering influenced the medical conceptualization of the disease as an epidemic.

Since the geographical data indicated par-

ticular regions where many people contracted the disease at the same time, clustering could also have provided evidence that it was not a "gay" disease.

If the geographic clustering of cases is in fact real, it suggests that risk factors for these diseases are not randomly distributed in the homosexual community.²⁵

However, establishing risk groups symbolically transformed the clustering of AIDS from regions to communities of people, regardless of regionality.

Since more than 90% of AIDS cases occur in a small number of well-defined groups in the US population, group- or risk factor-specific incidence rates would be more descriptive and extremely useful. These specific incidence rates are important for determining the risk for AIDS for persons in various groups, for calculating relative risks of disease, and for making comparisons between groups.²⁶

Even as the percentage of homosexuals with AIDS in the United States went down in the total number of cases reported, from 92% in 1981 to 60-75% in 1986, nationally gay men *as such* were homophobically identified with AIDS.²⁷ And as the blood deferral policy of 1985 stated, a man who had had one sexual experience with another since 1977, whether self-identified as gay or not, became part of the homosexual "risk group."

The terms of gay identity used by the medical establishment were not reflective of the gay male community, although they heavily impacted on that community. This was double-edged. Men who identified as gay were seen as undiversified by medical researchers who grouped them analytically. Important differences, such as varying accessibility to sources of prevention education, relationship to gay identity, unique health histories, different sexual practices, experiences, and relationships, geographical histories, were neglected, and homophobic assumptions were imposed. On the other hand, men who did not themselves identify as gay, but who were deemed at risk due to homosexual behavior (bisexual men, or men who slept with men but did not call themselves gay) were actually one "unsafety" link to

the "general population." The health needs and transmission impact of these men remained invisible, while "out" gay men were rigorously targeted, many times to the point of oppression.

"Safe Sex Equals No Sex"?

Attempts by gay men and gay agencies concerned with AIDS to work with the medical establishment, or to educate researchers about the gay community were initiated but not entirely welcomed. Many physicians were, and are, blatantly homophobic, a problem great enough to warrant attention in a Commentary published by the Council on Scientific Affairs:

Physicians who are not comfortable counseling homosexual patients in a positive and sensitive manner should refer them to another physician . . . this can be overcome if the physician displays a nonjudgmental attitude.²⁸

An additional problem was that many physicians were unknowledgeable about the specific health needs of gay men, or about gay sex.

Studies and reports generated within the gay community about AIDS and measures toward prevention were met with skepticism, particularly if they fell short of advocating abstinence. One such study, "Self-Reported Behavior Changes Among Homosexual and Bisexual Men—San Francisco," published by the San Francisco AIDS Foundation was undertaken to "... encourage homosexual and bisexual men to avoid 'unsafe' sexual practices."²⁹ The results showed a significant increase (69% to 81%) in monogamous, celibate, and "no unsafe sexual activity outside a primary relationship" between 1984 and 1985. Oral sex decreased 17 percent; anal intercourse without a condom decreased from 18 percent to 12 percent. This report was important, for it clearly reflected the gay community's "safe sex" responses developed to cope with and prevent AIDS. As such, it was also of use as a "safe sex" educational piece, where gays could learn about safe sex practices as measures toward stopping transmission of the disease.

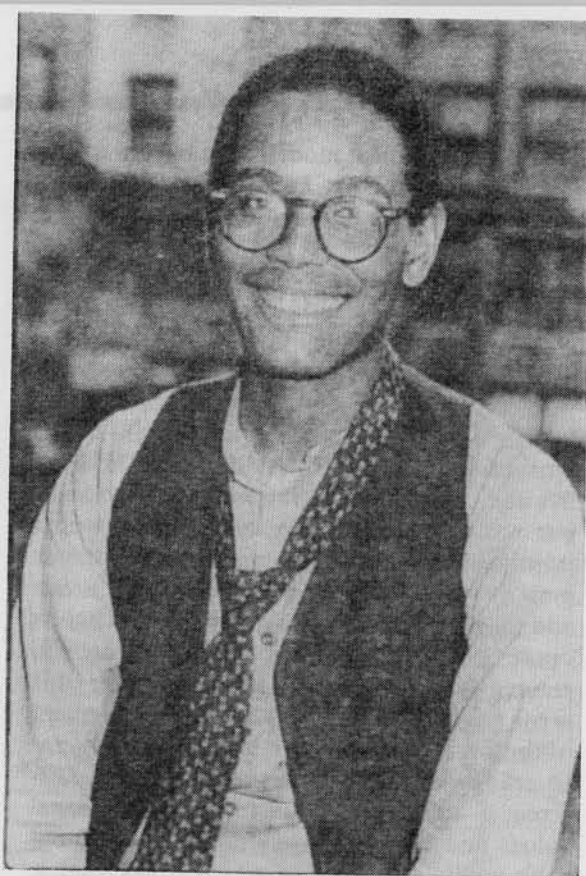
As its response to the study, the CDC proposed that "... much larger changes in sexual practices will be necessary to achieve a substan-

tial reduction of risk among those who remain uninfected.”³⁰ The CDC, and much of the medical literature, did not believe in “safe sex” for homosexual men, and was reluctant to test, much less promote, such prevention measures as condoms. The medical model for AIDS instructed gay men to abstain.

Time has provided us with a perspective, albeit brief, through which to appraise the circuitous route of “safe sex.” In the early to mid-1980s, the medical establishment recommended abstinence to gay men, and treated the value of gay sexuality as a non-issue, since homosexual sex is deviant, and non-procreative. The gay community responded no, we are pro-sex and we can have safe sex. Activists organized educationals, and recommended the use of condoms and sexual practices in which no body fluids are exchanged. In small but growing numbers, AIDS begins to afflict heterosexuals, for whom one aspect of sex can be procreation. Heterosexuals “borrow” the educational information designed by the gay community and promote “safer” sex. Conservative heterosexuals say no, safer/safe sex blocks “natural” procreation, and recommend abstinence. Safer sex promoters claim that public health must come before public morality (and distribute condoms through “alternative” newspapers such as the *Phoenix*). Yet, in doing so, liberal advocates skirt the real history and political force surrounding AIDS activism, of which morality is the very core. To recommend obliterating gay male sexuality in the name of health is a moral judgment that, unlike for the rest of the population, sex for gays is expendable. The gay community’s response, that gay sex is part of life and safe sex practices are possible and responsible, is a moral assertion as well. (The “immorality” of sex also extends as a prohibitive judgment on other risk groups in a more subtle and insidious manner, but just as damning.)

Conclusion

The present context provides a constantly shifting lens through which to view the past as well as the future. Concerning AIDS, the view is grim, both of the disease, and of the medical model designed to combat it. The state of AIDS research in the US is conceptually at a stand-



Willi Smith, fashion designer, creator of WilliWear, 1948-1987, Village Voice

still. Isolated within their myth of objectivity, researchers seem unable to move beyond the use of “risk groups” as study of analyses.

The medical model developed in the early years of the epidemic conceptualized the disease as affecting specific groups of people who presumably shared common behaviors deemed to put them “at risk.”

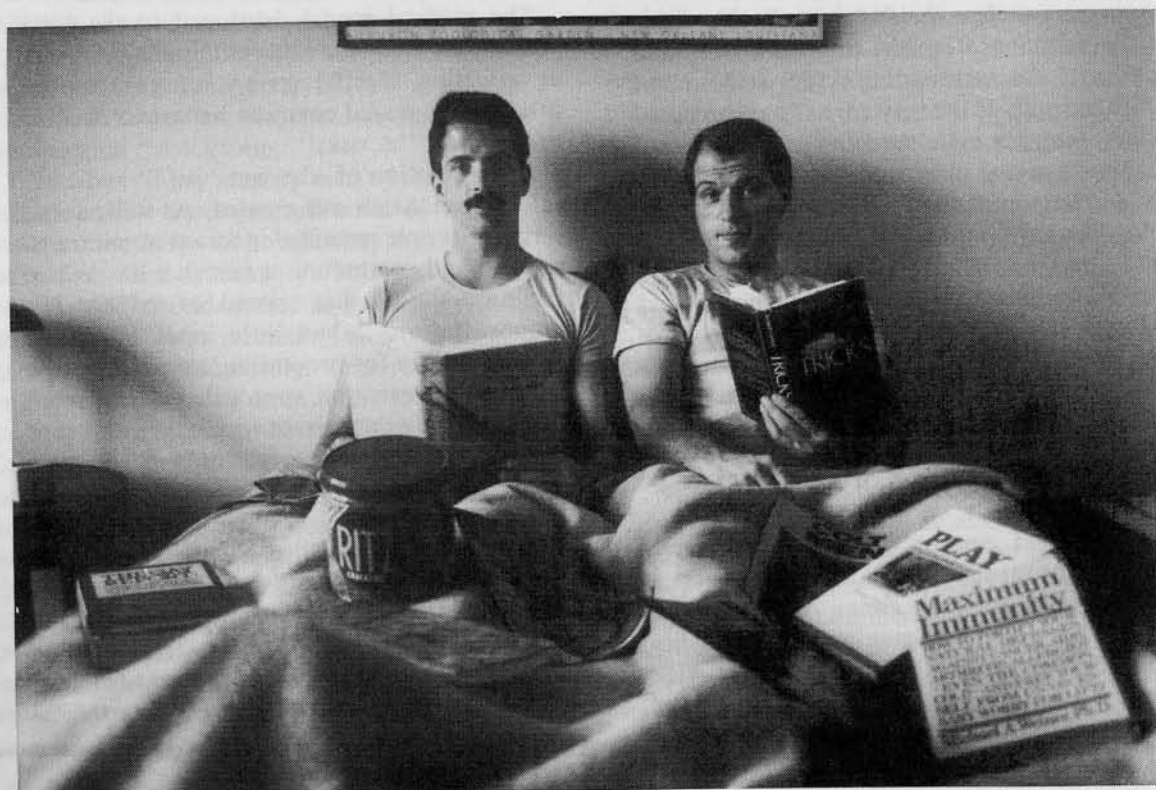
A false notion of who was “safe” and “unsafe” from AIDS was created. As well, a majority of people remained ignorant about transmission and prevention, a fact that has helped facilitate the further spread of AIDS. The groups “at risk” had little input into their responsibilities for prevention, or coordination with what prevention approaches would work best, and what they meant within the context of their lives. People who were not labelled in risk groups started to get AIDS: women, particularly in urban areas; blacks; Hispanics; infants; bisexual men who called themselves straight and were out of reach of the gay community’s educational networks. The hysterical fear of who tests positive and of not being able to tell who carries HIV-antibodies is a direct result of the severe limitations of the early terms set

forth in the medical model. Proponents of the model thought they knew who could and couldn't, would and wouldn't, get AIDS and have been proved wrong. At all our expenses.

AIDS can be transmitted in the most intimate of terms, as a sexually transmitted disease, or prenatally from mother to infant; or, in the most powerless of terms, as in i.v. drug users who share needles for the survival of their habits. Above all, it can be transmitted in the most ignorant of terms. AIDS reveals how we live and love, and as such unearths and exposes our most private and personal values, which translated publically become the basis of our most firmly held politics. To enter this arena and judge differences as a question of morals is oppressive, as it was when medical researchers entered the gay communities. To enter this arena and say that morality is not a key element of the issues provoked is to be naive or not want to acknowledge that differences do exist. Differences of identity can transform personal values and community culture, but not build walls within or outside of which AIDS resides. The medical model unfortunately has attempted to do just that. Fortunately through activism, organizing, education, and opposition, the walls are tumbling down.

FOOTNOTES

1. J. Viera, S. Landesman, *et al.*, "Acquired Immune Deficiency in Haitians—Opportunistic Infections in Previously Healthy Haitian Immigrants" *New England Journal of Medicine* (*N Engl J Med*) 1983; 308:128.
2. J. Curran and M. Morgan, "Acquired Immunodeficiency Syndrome—The Beginning, the Present, and the Future" in *AIDS—From the Beginning*, H. Cole and G. Lundberg, eds. (Chicago: American Medical Association) 1986, p. xxi-xxvi.
3. *Ibid.*
4. C. Patton, *Sex and Germs—The Politics of AIDS* (Boston: South End) 1985, p. 24.
5. Curran and Morgan, *AIDS—From the Beginning*, p. xxi and *Morbidity and Mortality Weekly Report (MMWR)* July 3, 1981; 30:305-308.
6. Curran and Morgan, *AIDS—From the Beginning*, p. xxi.
7. *Ibid.*, p. xxii.
8. *MMWR*, June 5, 1981; 30:250-252.
9. *MMWR*, July 3, 1981; 30:305-308.
10. H. Cole and G. Lundberg, "Preface" in *AIDS—From the Beginning*, p. xvii-xix.
11. H. Jaffe, J. Curran, *et al.*, "National Case-Control Study of Kaposi's Sarcoma and *Pneumocystis carinii* Pneumonia in Homosexual Men: Part 1, Epidemiologic Results" *Annals of Internal Medicine* 1983; 99:145.
12. *Ibid.*, p. 148.
13. *Ibid.*, p. 150.
14. A. Hardy, J. Curran, *et al.*, "The Incidence Rate of Acquired Immunodeficiency Syndrome in Selected Populations" *Journal of American Medical Association (JAMA)* 1985; 253:219.



Hot, Healthy and Horny: safe sex workshops. Ellen Shub photo

15. J. Viera, S. Landesman, *N Engl J Med*, p. 127-8.
16. "Update: Acquired Immunodeficiency Syndrome—United States" *MMWR* in *JAMA* 1986; 255:185.
17. "Special Report—Epidemiologic Aspects of the Current Outbreak of Kaposi's Sarcoma and Opportunistic Infections" *N Engl J Med* 1982; 306:250.
18. Kristal, *et al.*, "The Impact of the Acquired Immunodeficiency Syndrome on Patterns of Premature Death in New York City" *JAMA* 1986; 255:2306-10.
19. "Update" *MMWR* in *JAMA* 1986; 255:185.
20. Kristal, *JAMA*.
21. "AIDS Monthly Information Update" World Health Organization, October 1986, p. 5.
22. R. Knox, "Drugs Cited in Fast Rise of Heterosexual AIDS" *Boston Globe*, June 3, 1987, p. 14.
23. "Update" *MMWR* in *JAMA* 1986; 255:185.
24. "Revised Definition of Persons Who Should Refrain From Donating Blood and Plasma" *MMWR* in *JAMA* 1985; 254:1886.
25. "Special Report" *N Engl J Med*, 1982; 306:251.
26. Hardy, Curran, *et al.*, *JAMA*, 1985; 253:215.
27. Cole and Lundberg, eds. *AIDS—From the Beginning* (Chicago: American Medical Association) 1986.
28. "The Acquired Immunodeficiency Syndrome—Commentary: Council on Scientific Affairs" *JAMA* 1984; 252:2041.
29. "Self-Reported Behavioral Changes Among Homosexual and Bisexual Men—San Francisco" *MMWR* in *JAMA* 1985; 254:2537-8.
30. *Ibid.*

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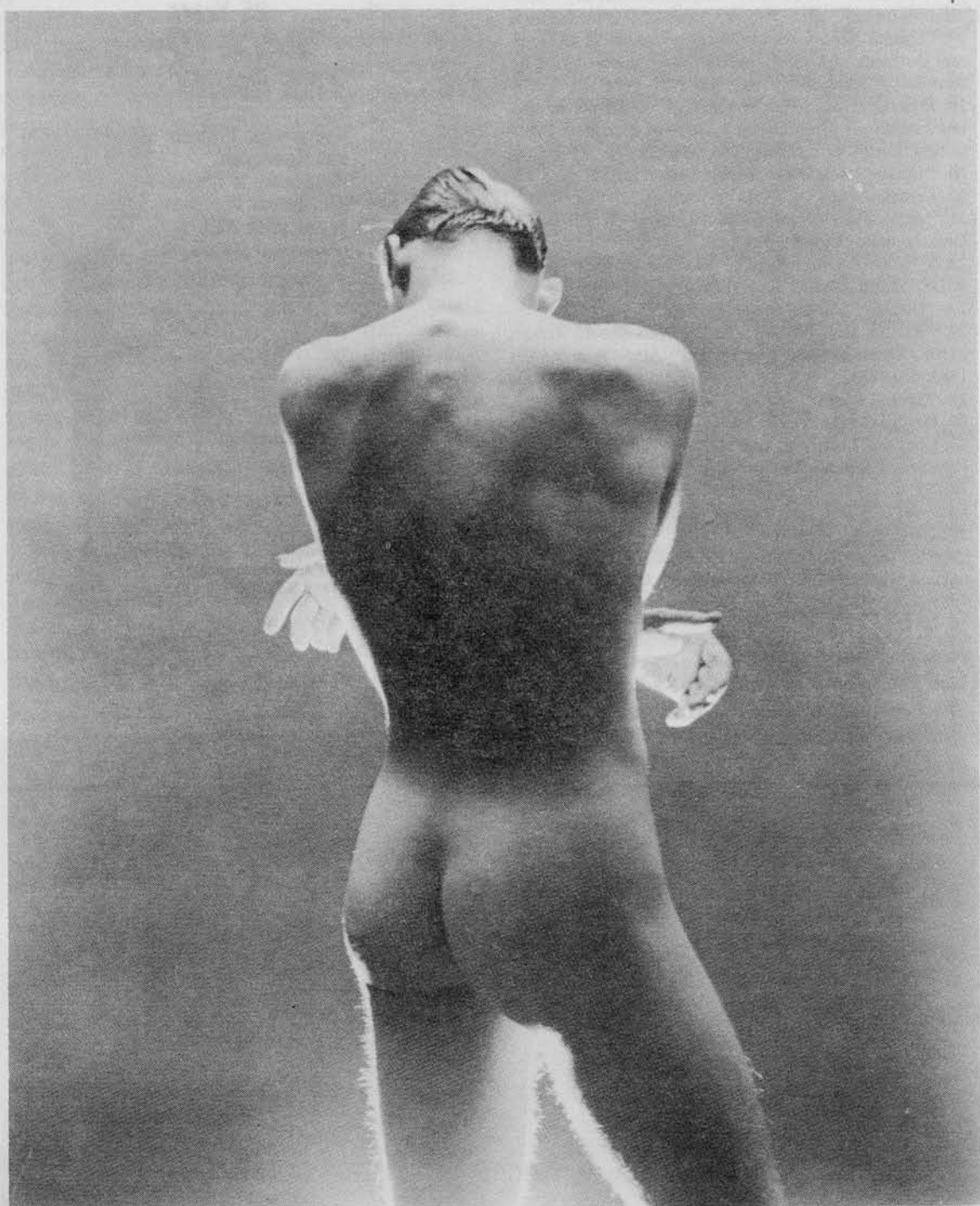
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TO HAVE WITHOUT HOLDING:

Memories of Life With a Person With AIDS

Joseph Interrante

Our love and hate for the body remain inaccessible to and unreconciled with each other so long as the full recognition of our mortality that would bring them together remains beyond our emotional strength. And the pooled inventiveness and striving which constitute our species' self-creation have been from the outset contaminated . . . by these unreconciled feelings for the flesh: the basic way of life that distinguishes us from other creatures is distorted . . . by this refusal to face death.

—Dorothy Dinnerstein

*The Mermaid and the Minotaur*¹

The fear of death hovers over all physician-patient encounters and not only over those with dying patients. . . . Doctors have an intriguing love-hate relationship with death: It is both their ally and their enemy. In trying to defeat death, physicians are death's adversaries. When physicians borrow the power engendered by patients' fear of death for purposes of control, death is their ally. . . . Physicians struggle against and embrace of death can cast a dark shadow over another covert struggle between physicians and patients: how life is to be lived. Life, including the life of illness, can be lived in myriads of ways, and not only according to the views of physicians. . . . [But] doctors view death as a personal defeat rather than an eventual inevitability to which they, like their patients, must submit.

—Jay Katz

*The Silent World of Doctor and Patient*²

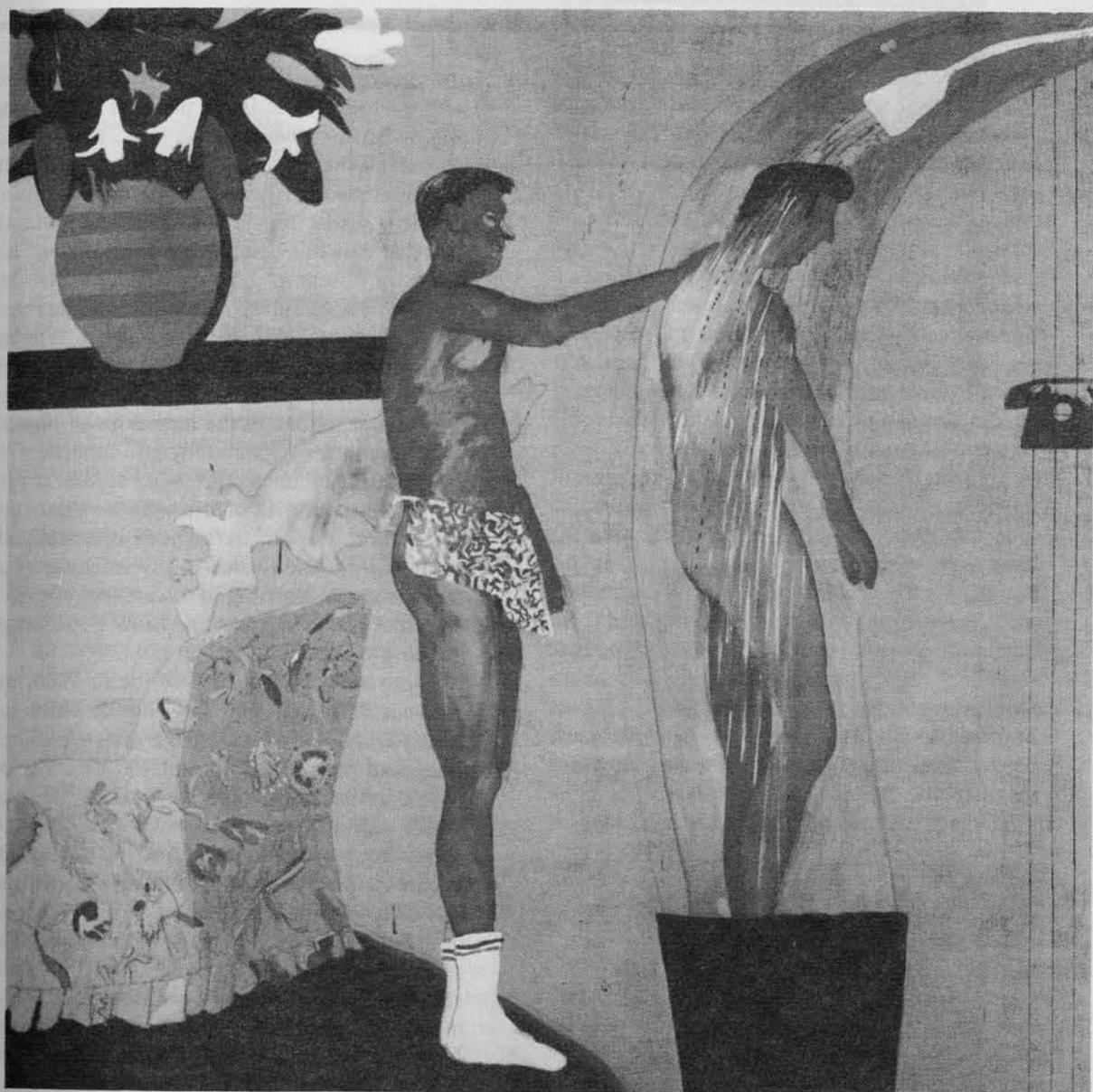
The following is a slightly edited version of a talk delivered at the Public Responsibility in Medicine and Research (PRIM&R) conference on "AIDS—The Ethical, Legal and Social Considerations," April 24-25, 1985, in Boston, MA. I was part of a panel on "The Impact of AIDS on the Patient, Family, Friends, and Community." I later delivered it at the AIDS vigil in Provincetown, MA, on May 27, 1985. It is part of a work-in-progress.

I speak today as the life partner of a gay man who died from AIDS in October 1983. Our experience during the seven months of life that followed Paul DiAngelo's diagnosis in March of that year was shaped by our social backgrounds, the history of our relationship, the particular configurations of Paul's illness, and the specific place in the history of AIDS in which our experience occurred. As white, professional men in our early thirties who had been together for 5½ years, Paul and I had settled into a relationship with its own rituals and traditions, with a network of friends tied to us as a couple and/or to one of us as individuals, and with an accumulation of trust and mutual dependence that facilitated rather easily the reordering of our lives around Paul's illness.³ The merging of financial resources and the drawing up of legal protections, for example, raised no questions about the durability of our relationship, questions that might have occurred had our relationship been younger. At the same time, the fact that Paul was one of the first fourteen confirmed cases of AIDS in Boston, at a time when AIDS was still a foreign experience to most people inside and outside the Boston gay community, also colored our life with it. Paul's, and through him my, work with the AIDS Action Committee—as media “representatives” of the AIDS experience—forced us consciously to think about and to articulate our changing perspectives on life with AIDS. This intensified our processes of self-reflection and evaluation, and also helped to alleviate some of the isolation that characterized living with AIDS in Boston in 1983.

AIDS fundamentally restructured the rhythms and routines of our life together. My memories of those seven months are marked by the milestones in Paul's illness: the flu that would not go away in late February, the diagnosis of Kaposi's sarcoma and interstitial pneumonitis in March, the increasing fatigue and diarrhea in April, the visits to Paul's health center for intravenous treatments for his dehydration in early May, his admission to the hospital in late May, the diagnosis of cryptosporidiosis a few days later, his inability to absorb nutrition and the i.v. feeding in June, the spreading cancer and recurrence of pneumonia in July, the surgery to implant a

Hickman line in his chest in August, his return home later that month, the steady decline in weight and strength and the hallucinations in September, his death in October. Similarly, daily life became ordered by the demands of health care: the trips by taxi to health center and social service agencies in March, April and May; the daily visits to the hospital in June, July and August; the scheduling of AIDS Action Committee support service volunteers and friends while I was at work, the routines of home health care and housework in September and October. Days, nights, weeks, months of turning on and turning off the IVAC pump, of ordering and storing medical supplies, of fetching this and taking that away—errands of sorrow and joy, errands of mercy, errands of hopeful and despairing love.⁴ And within those rhythms and routines, the carving out of a time for us alone; a time to recount and share the events of the day, to weigh the possibilities and probabilities of illness and recovery; a time to maintain and sustain a life, and gradually to create a death, of our own.

As Paul slowly realized and came to terms with the probability of his death, he began to settle what he called the “unfinished business” in his life, to “complete” his relationships with his parents, sister, former lovers, and friends. And to complete our relationship. So that his physical decline was accompanied by psychological and emotional growth. In that sense, AIDS condensed and compressed into months, decades of living. Paul's life and our relationship together had been based upon openness and communication; AIDS informed those patterns of interaction with intensity and urgency. Particularly with me. Because of the trust and honesty in our relationship which was confirmed in the face of this crisis, Paul allowed himself to rely, physically and emotionally, upon me. He let himself go in unique ways with me. With friends and kin he struggled to maintain his self-reliance, to struggle out of bed (until he could no longer lift himself) into the bathroom—an event that took place at least twenty times a day. With me, he would allow himself to be lifted and carried, to have his food cut up and to be fed, to be washed. With me he would explore the conflicting emotions raised by his increasing physical dependence:



Domestic Scene, Los Angeles, 1963, David Hockney

his hopes for recovery, his anger at the illness, his disappointment over reversals and relapses. Together we worked through his sense of powerlessness, his feelings of resignation, his gradual acceptance of death.

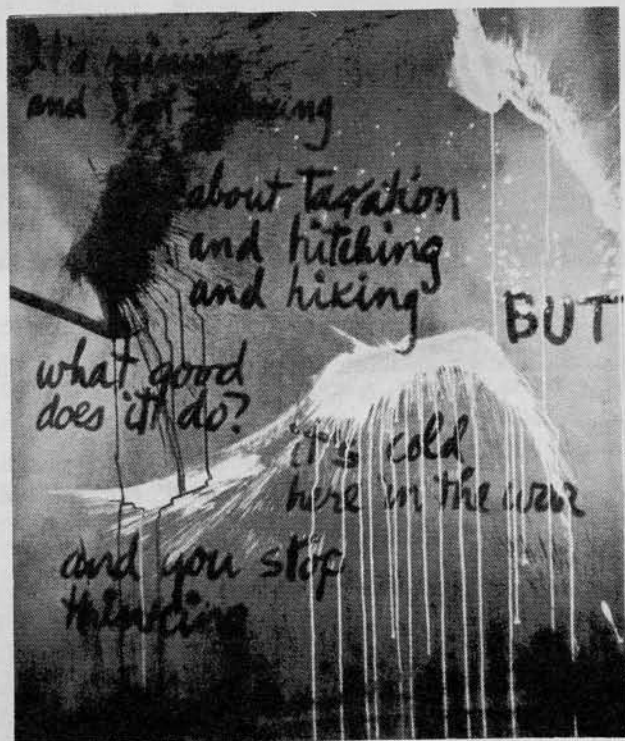
Rather, I should say *our* feelings. For I was drawn into Paul's illness in a way that not only ordered my own life but tempered my emotional states. His needs became my needs, his hopes and disappointments mine. When asked by friends, "How are *you* doing?", I would often reply with an account of Paul's current condition and his psychological state, and with my feelings *about* his. In fact, I think at times

that my disappointment over changes, my anger at callous treatment by friends, was more intense than his—because I didn't have the physical symptoms to contend with. I watched him struggle with his illness, and saw how events and people hurt him. But I couldn't eliminate the symptoms or the pain. I could only help him persevere.

The closest model with which to compare my experience during those seven months of life with Paul is the experience of mothering. (My mother brought this home to me when she said, after being told of Paul's death, "The hardest thing in the world to bear is the death of a child

or a mate.”) By this analogy I mean the cluster of activities, characteristics and emotions associated with the *social role* of motherhood.⁵ Whether performed by women or men, mothering—and its analogue within the health care system, nursing—involves the intimate physical care of another being, the provision of unconditional care and love, the subordination of self to others, and an investment in separation. Indeed, as Paul’s condition worsened and his body became hypersensitized to pain, our ability to use touching to express love narrowed. An arm draped lightly over his chest while he slept eventually created too much pressure, so that we learned to sleep together without touching. A hug caused pain not pleasure, so that we restricted ourselves to his resting his hand over mine, or my lightly caressing his cheek with my forefinger. As his body became bloated from inactivity, his speech slurred from medication, his talking painful because breathing was painful, we learned to communicate love through a glance. As the forms of erotic touch disappeared, my consciousness of the love infusing acts of physical care was heightened.

Many of my memories of those seven months



It's Raining, Frank O'Hara and Norman Bluhm, 1960

are visceral: memories of the body associated with the touch of intimate physical care. Shampooing his hair, washing his back, and shaving his face in the hospital. At home, changing the bandages on his Hickman line, moving him on the bed, lifting him out of bed and onto the portable toilet, cleaning and changing him when he became incontinent, feeding him crushed frozen juices. Watching the gay man carry his lover upstairs in Lanford Wilson's *Fifth of July* triggers a somatic response in me that is inadequately described in words. It is a response grounded in the memories of physical care; memories of watching his capacities for physical self-reliance regress to those of a year-old child; memories of life with a vibrant and young mind trapped in the body of a feeble old man. A response rooted in my learning to accept his death, learning to thwart the reflexes of grab and of clutch, learning to love and let go, learning to have and not to hold.⁶

These are Paul's legacy to me in 1985, as I reinvent forms of gay singlehood, build new relationships with old friends as well as new ones, and reenter a community more conscious of and intimately involved with AIDS. Through Paul's willingness to draw me into his illness, he taught me to face death. And by facing and becoming part of his death, I have confronted my own love and hate for the body, for the limits and mortality of my own existence. That sense of mortality, of judicious responsibility for myself and for others, has become a part of me. Like wearing a ring or a pair of eyeglasses, I have grown used to it, and I'll never forget it.⁷ Beyond the partially successful efforts to articulate this experience through language, my body will remember it. I will never forget it, because I don't want to forget.

POSTSCRIPT: 1987

Although neither Paul nor I realized it in March, his illness turned into a slow process of dying. That simple fact—Paul's death—colors all my memories of those seven months. I attempted in this talk, through its rhythm and momentum as much as its literal content, to convey a sense of how his eventual death came to shape our existence; how we came to accept and transform his increasing physical dependency into a giving interdependence; and how I learned to help Paul die his own death and thus to share his death and to carry that experience with me as a living person.

My reasons for this focus are both personal and political. First, it is part of my own existential process of survival. Second, I hope that this experience, in particular my efforts to recollect and articulate it, can contribute to the current attempts by gay men to negotiate the immediacy of mortality within everyday life. Integrating a sense of mortality into daily living has become a community as much as an individual gay experience. Neither American (Western?) culture in general, nor the Left in particular, has much to say about death and mortality, except in body counts or the clichéd images of passive "victims." I tried to emphasize in the talk that Paul, like other PWAs, was *not* a victim. He was certainly "innocent" and "undeserving" of this terrible illness, for in spite of conservative rhetoric and media misrepresentations, no one "deserves" AIDS. But he was never passive or utterly helpless in the face of his illness and death. Paul and I struggled to accept and to transform his dying in an active way, and out of that experience I learned a lot about life and death, masculinity and the body, indeed, all those issues with which the gay and lesbian movement has been concerned throughout its thirty-seven years of continuous activity. As AIDS is finally recognized as a "public health" problem, as it becomes a chic philanthropy ("We are the Well") and a vehicle for careerist advancement ("visions of monographs danced in their heads"); as services become increasingly professionalized and bureaucratized; and as gay health activists who have worked for years on AIDS are pushed to the institutional periphery; this point must be



Joe Interrante and Paul DiAngelo, Boston Magazine

emphasized: everyone could learn a lot from the way gay men (and the lesbians and heterosexual women who have worked with them) have been dealing with AIDS personally and collectively.

The experience of death and attitudes toward it are not merely natural or personal. A number of writers have shown that death is a social construct, that how we view and experience death is changed over time.⁸ And writers like Dinnerstein also suggest that it is a gendered experience. Given the particular moment in AIDS when Paul's illness occurred, these points became obvious to me. When Paul's deteriorating condition required his hospitalization in May, we found ourselves ensnared in the institutional practices designed to handle illness and death in our culture. In particular our desire to maintain a life and create a death of our own conflicted with what Katz calls "the silent world of doctor and patient"—an unwillingness or inability to involve Paul in discussion and decision-making about how his illness was to be lived. However, the lack of knowledge about AIDS—this was 1983, before HTLV

3/LAV/HIV was discovered and embraced as the "AIDS virus"—created a space in which we were able to struggle over the control of Paul's body. We had enough experience with gay health treatment (or mistreatment), we knew the feminist critique of medical practice, and I had studied the historical evolution of medical authority sufficiently to recognize the social and political character of what was going on.⁹ At the same time, we have developed our own network of information and referrals, collected through gay doctors and researchers and kept by Paul in notebooks at the hospital, to contest the terrain and eventually become part of the decision-making process. I especially witnessed a dramatic change in Paul's primary physician, who did learn to listen, to discuss, to accept, and to support Paul's wishes about his illness and death. In the few years following Paul's death in 1983, it seems that this pattern of physician involvement, acceptance, and acquiescence is becoming more common. This transformed interaction has tremendous potential for breaking through the "silence" that customarily governs the relationship between doctor and patient. Despite this potential (or perhaps because of it), the focus on medical research has almost completely overlooked it.

After three months in the hospital, Paul came home. Doctors were unable to alleviate his constant diarrhea and dehydration, and the constant presence of someone in or about to enter the hospital room had made it difficult for us simply to be with each other. It was after Paul returned home that I experienced the profoundest changes in our relationship. I described that experience as mothering, but I realize in retrospect that my discussion may have portrayed my experience too simplistically. Learning to let go, to have without holding, entailed acceptance of my own dependence, different in nature from Paul's dependence.

As Paul became imprisoned in his weakened and inefficient body, so I became imprisoned within his illness and dependent upon the help of others. During the first months and throughout his stay in the hospital, I tried to manage things by myself. I realize that my initial reluctance to delegate tasks was partly a failure of trust, and partly an unwillingness to lose some of the control I thought I could retain over the

situation as a whole by managing the minutiae of our daily lives. And also a fear of losing some of my "specialness" along with the caretaking tasks that had become the gestures of love with the disappearance of erotic touching. But it became literally impossible to continue doing it all. Indeed, my initial stubbornness against "giving up" my responsibilities (and imagined power?) left me at times feeling frustrated and resentful: frustrated with the tasks that left no opportunity just to spend time, resentful of the time Paul spent with others, resentful of being "taken for granted." To need help from others and to learn to accept help without false pride—these, too, were part of my experience of mothering.

Ironically, I discovered that dependence did not lessen my participation in his life or death. We retained the special kind of communication, the trust, that develops over years of living together. There was a special degree of dependency, of letting go, which Paul shared with me—and was able to share with me because friends and people who became friends through support work gave us the time and opportunity to do so. During those final weeks at home I learned (to borrow from Gerda Lerner's memoir of her husband's death) that accepting help openly, honestly, graciously, was simply acceptance of our common limitations as human beings; acknowledgement of our common, mortal frailties; and transcendence of them through acts of unattached and unadorned kindness.¹⁰ Paul's illness taught me the kindness of strangers.

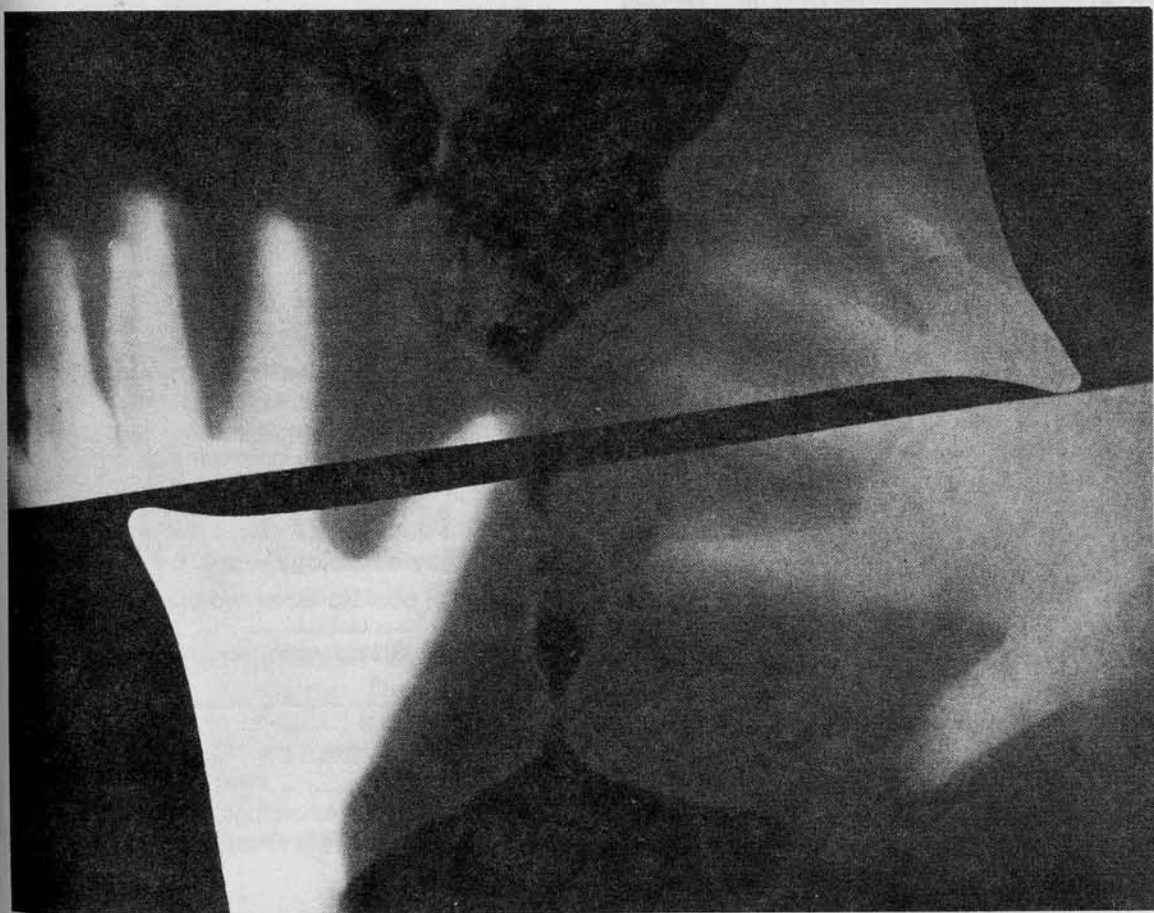
As there was kindness, there was also cruelty. Nothing made me so angry as what I viewed as rejection by others: the fleeting concern of some friends who visited at first and then disappeared, the empty curiosity of some acquaintances, the frightened turning away by friends from whom I expected acknowledgement and assistance. In retrospect, I understand these behaviors. I realize that Paul and I, simply by our existence, were confronting each person with the need to define his or her own attitude toward death. This is a tremendous burden to place on people. For some friends it was simply too painful to stay through those final weeks. But neither of us had strength for tolerance; we had to face our fears and get beyond them. At

the time I felt abandoned and bitter, feelings I used to mobilize my physical and emotional resources. In retrospect I realize that I was making these people scapegoats for my own despair. And despair was something I had to learn to live with.

During the final months of his illness, I struggled to help Paul die his own death. That required my separating myself from him, separating my survivor-needs, my guilt about his contraction of AIDS, my guilt about the ravaged condition of his body and my good health, my guilty feelings about sex, my need to comprehend my feelings about his death, separating my needs from his needs. His need was to live as fully as his body would permit. It still seems remarkable to me that even during those terrible last weeks Paul retained the vitality and energy to build new relationships, to project himself as a person in relation to another, to give of himself through interdependence. When I recognized his need to live his death, then I was able to let go and share his death with him.

Some pundits, inside as well as outside the gay community, have suggested that AIDS is a

“good” thing in that it has led to a sudden “maturation” of the gay community, especially a movement away from the “promiscuity” of the past. I haven’t talked about sex here, but let me simply say that Paul did not become an asexual person when he contracted AIDS, that he retained sexual desire even after he lost interest in sexual performance, and that I did not and have not stopped being sexual even though we both were handling our sexual selves differently as early as 1982. More to the point, I do not want anything I have written to be misconstrued as romanticizing the AIDS experience. Paul’s illness and death condensed our life experience, and we grew and changed through it as we would through any experience, albeit at a greatly accelerated pace. But Paul’s death, and AIDS generally, was not a good thing. It was not romantic, it was not heroic, it was not kind. We shared it, and I discovered, to quote Gerda Lerner, that it is “like life—untidy, tangled, tormented, transcendent. And we accept it finally because we must. Because we are human.”¹¹



Rayograph, 1922, Man Ray

FOOTNOTES

I want to thank members of the AIDS Action Committee/Boston, members of the Lovers and Friends of People with AIDS support group, other lovers of PWAs in Boston, and especially my co-conspirators in "The Widows' Threeway," for the opportunity to explore my ideas about the experience of living with a Person with AIDS.

1. Dorothy Dinnerstein, *The Mermaid and the Minotaur: Sexual Arrangements and Human Malaise* (Harper and Row, 1976), p. 120.
2. Jay Katz, *The Silent World of Doctor and Patient* (Free Press, 1984), pp. 208, 213-14m, 219.
3. See David McWhirter and Andrew Mattison, *The Male Couple: How Relationships Develop* (Prentice-Hall, 1984).
4. The phrases are adapted from Joseph Hansen, *Death Claims* (Harper and Row, 1973), ch. 13.
5. See: Dinnerstein, *Mermaid and Minotaur*; Nancy Chodorow, *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender* (Univ. of California Press, 1978); Diane Ehrensaft, "When Women and Men Mother," *Socialist Review*, 49 (Jan.-Feb., 1980), pp. 37-73.
6. The phrases come from a poem by Marge Piercy, "To Have Without Holding."
7. The analogy comes from Harvey Fierstein, *Torch Song Trilogy*, "Widows and Children First!", scene 4.
8. See, for example: James Farrell, *Inventing the American Way of Death, 1830-1920* (Temple University Press, 1980); Norbert Elias *The Loneliness of the Dying* (Basil Blackwell Inc., 1985); Susan Sontag, *Illness as Metaphor* (Random House, 1978); and also the sources in note 9.
9. See, for example: Susan Reverby and David Rosner, eds., *Health Care in America* (Temple University Press, 1979); Barbara Melosh, *The Physician's Hand* (Temple, 1982); Paul Starr, *The Social Transformation of American Medicine* Basic Books, 1983; Katz, *Silent World of Doctor and Patient*; Charles Bosk, *Forgive and Remember: Managing Medical Failure* (University of Chicago Press, 1979).
10. Gerda Lerner, *A Death of One's Own* (Harper & Row, 1978).
11. *Ibid.*, the final lines of the book.

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Joseph Interrante is an Associate Editor of Radical America. From 1983 to 1986, he was active in the AIDS Action Committee of Boston, where he was variously Chair of Education and a member of the Steering Committee. He recently moved to Ohio, where he is becoming involved in the Health Issues Task Force of Cleveland.

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LATINA WOMEN AND AIDS

Although many have only recently become aware of the increase of AIDS in women, within the next two years AIDS will be the leading cause of death for all women of child-bearing age in New York City. At the present time, AIDS is the leading cause of death of women aged 25-29 in New York City. Most of these deaths occurred among poor black and Latina women.

Despite the availability of extensive information on how AIDS is transmitted, most women do not realize that they may be at risk of contracting and developing AIDS. Those most at risk are the most poorly informed. A recent Gallop Poll conducted for the New York City Department of Health showed that only a small number of teenage women understood that they could catch AIDS through having sex with their boyfriends.

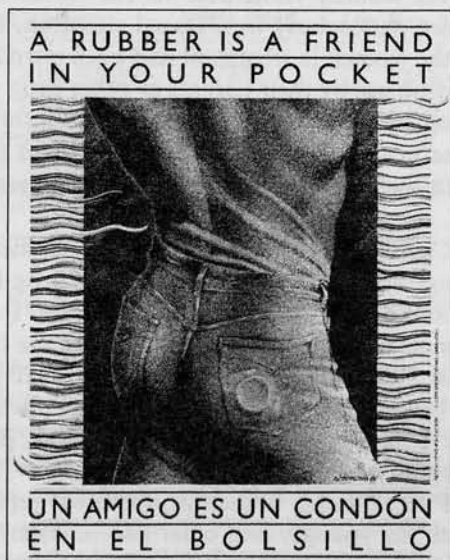
The incidence of AIDS in Latina women is over 11 times that of white women (CDC, 1986). In New York City, the incidence of the disease among Latina women is almost three times that of white women. Women account for 13% of all Latino AIDS deaths since 1980. Yet, there has been little work detailing the specifics of the impact of AIDS on Latina women. In an attempt to bridge this gap of information, this examination of the impact of AIDS on Latina women concentrates on Manhattan's Lower East Side.

This New York City neighborhood was chosen for the study because it has a sizeable population of low-income Latinos—a large Puerto Rican population settled there after World War II—and because of its high rate of AIDS mortalities. In 1985, over 40 percent of all AIDS deaths on the Lower East Side occurred in the Puerto Rican community. The Lower East Side was also an appropriate site to study because it has a high incidence of intravenous drug abusers, and the number of AIDS cases in drug abusers is on the rise. The AIDS deaths among Puerto Rican women in this neighborhood are predominantly intravenous drug abuse related.

AIDS Deaths Rise

Deaths due to AIDS on the Lower East Side have nearly quadrupled in the first nine months of 1986, as compared with the period 1980-1985. Latina women accounted for more than half of all female AIDS deaths on the Lower East Side during the 1980-1985 period. Although the Latina AIDS mortality pattern in this neighborhood differs from the rest of New York City, the age range is parallel, with the exception of a higher number of deaths on the Lower East Side in the age ranges 15-19 and over 40. This difference may be accounted for by an aging population of i.v. drug users who have been using drugs since the 1960s and an increase in i.v. drug use among young Puerto Rican women. This supposition is supported by data from the New York State Division of Substance Abuse.

Of the estimated 50,000 women in New York City who are i.v. drug users, it is not known how many reside in the Lower East Side or what their average age is. However, statistics



from the Division of Substance Abuse do show an increase in both the number of women and Latinos who are heroin abusers. While the exact extent of i.v. drug abuse among Puerto Ricans on the Lower East Side cannot presently be determined, the incidence of i.v. related AIDS deaths in Latinos clearly indicates that there is a problem.

Factors Related to Drug Abuse

Narcotics addiction is often related to drug dealing, a way of making a living for marginal urban families. The high rate of un- and underemployment among Latinos in poor communities such as the Lower East Side forces many into the world of drugs, which provides not only an "escape" from the problems of poverty but also a means of obtaining additional income through dealing. This raises questions of what is known about drug use among Puerto Rican women in New York City. Due to a lack of readily available research on the subject, interviews were conducted with drug treatment programs to gain some understanding of the problem.

These interviews indicated that Puerto Rican women in treatment were "turned on" to drug use at an early age (12-14), the majority of them, by men. The promotion of female acquiescence in Latino culture as a positive trait leaves women vulnerable to the influence of males particularly in a sexual situation. Some of the women in treatment had been introduced to drug use by their parents or other drug using relatives in the home, others at school through peer pressure. Most of the women had begun with the use of pot and pills and progressed to i.v. drug use by the age of 15 or 16.

Currently, young Puerto Rican women are being introduced to crack as a first drug in the school setting as well as on the street. Professionals working in drug treatment on the Lower East Side fear that many crack users will go on to become heroin addicts. Young men who sell the drug on the street are often addicts, paid in heroin.

Puerto Rican women in treatment represent both the younger and older addict. Many have several children, and it is not uncommon for them to have alcoholic partners who are



Pauline Teal-el, mother of six children, 1952-1987, Newsweek

sometimes but not necessarily i.v. drug users. Those with alcoholic partners are often physically abused, and alcohol abuse also contributes to high risk sexual behavior, increasing the risk of contracting AIDS.

Obstacles to AIDS Prevention

Serious obstacles exist to providing AIDS risk reduction information to Puerto Rican women and their sex partners. Many of the obstacles are cultural. To be successful, AIDS risk reduction education among Latinos must be culture-specific. This means taking into account familial and cultural values and dynamics that have an impact on both sexuality and drug use.

Latinos account for 11% of all US AIDS cases among gay and bisexual men (CDC, October 24, 1986). The cultural proscription against these sexual practices in the Puerto Rican community makes AIDS education related to such practices extremely difficult. Many of the female sex partners of these men are unaware of their bisexuality, and, therefore, not aware that they are at risk of HIV infection. Some sex partners of i.v. users are also unaware of their partners' current or former drug use. It is not known what percentage of the partners of Latinos, who comprise 30% of all US i.v. drug abuse-related AIDS cases, are themselves i.v. drug users, or may be unaware of their partners' drug use.

The Latina women most at risk are young

(one-third of the US Latino population is under 15, the median age is 23), poor (40% of Latino families are female headed, 51.3% of these live below the poverty line), and have low educational levels (Giachello, 1985).

Ethnic Breakdown Female AIDS Cases NYC Through Mid-April 1986

<i>Ethnic Group</i>	<i>% of AIDS Cases</i>
Black	50.8%
Latino	33.9%
White	14.9%

Source: Centers for Disease Control. *Mortality and Morbidity Weekly Review*, Vol. 35, No. 42, October 1986.

Despite their high fertility and birth rates, Latina women seriously underutilize ongoing primary health care, family planning, prenatal or pediatric care. Fewer than one-half of Puerto Rican mothers in the United States receive prenatal care in their first trimesters and 10% receive no care throughout their pregnancies (Giachello, 1985). Their youth, poverty, poor education, language barriers, and cultural factors often militate against utilization of these much needed services. Yet public and private health and education agencies have done little to adapt services to meet the particular needs of this population. In light of the AIDS epidemic, this neglect becomes particularly deadly.

Latino Gender Roles

Attempts to reach Latina women with AIDS risk reduction education must contend with not only a lack of general health information but issues such as cultural gender roles. In many Latin cultures the male is seen as being innately superior to the female (Rivera, 1985). This encourages female dependence and women deferring to men in decision making related to sexual practices. Furthermore, communication between men and women, or parents and children, regarding sex is not the norm.

Latina women traditionally define themselves primarily through their role as mothers. Attractiveness is seen as being synony-

mous with sexual inexperience or "purity." The males are seen as the "seducers" of the inexperienced (sexually uneducated) women. A woman "prepared" for sex (e.g., carrying condoms) is perceived to be experienced, "loose," and therefore unattractive. It is important to note that these are stereotypical gender associations, which remain at the core of a cultural belief system that affects how Latino women and men view and value themselves and each other. Many Latino men and women have non-traditional lifestyles, yet traditional gender roles continue to be an issue in their lives.

The implications of such values in the promotion of safe sex practices among Latino couples are far-reaching. Puerto Rican women interviewed in drug treatment programs professed the wish to have their partners use condoms, but felt unable to ask them to do so for fear of being rejected or superceding their defined role. Conversely, men may not want to be seen as proposing protected sex, which carries the connotation for women of not being "serious," in other words, desiring sex which does not lead to pregnancy and marriage, the desired goal of most Puerto Rican women.

Lower East Side Latina AIDS Deaths by Risk Group 1980-1986

Risk Group	1980-1985	Jan-Sep 1986
IV Drug Abuse	77%	85%
Sex Partner	23%	15%
Other	0%	0%

Source: Based on New York City Department of Health Surveillance Data

Need for Culturally Sensitive Education

The danger of maternal transmission of AIDS, especially among IV drug users, has led to recommendations that women at risk or who have tested positive for the HIV antibody postpone pregnancy until more is known about transmission rates. Preliminary studies conducted by the NYC Department of Health in several drug treatment centers indicate that the rate of maternal transmission of the AIDS virus

is less than 40-60%. Given the importance of motherhood to Latina women, being asked to postpone childbearing for an indefinite period can have devastating consequences. This fact further underscores the need for AIDS prevention education targeted toward Latina women.

The decreased incidence of new AIDS cases among gay men is believed to be a result of prevention education. Culturally sensitive risk reduction and AIDS prevention education for Latinos must seriously consider the impact of cultural attitudes toward gender roles. Although these attitudes are changing, the change is slow, and AIDS educators must therefore expect to encounter a higher degree of adherence to sex role behavior among Latinos than among other non-Latin groups" (Stanton, 1985).

Latino adolescents are particularly at risk of infection with the HIV virus because the desire for peer acceptance often leads to experimentation with both drugs and sex. Among Latino adolescents, the role of "Machismo" may lead young men to feel that impregnating a woman "is proof of virility and manhood." Machismo and its feminine counterpart, "Marianismo," require the young Latina female to defer to the male, making it difficult for her to introduce the idea of protected sex or to resist the efforts of the male to have sex without condoms (Aroba, 1985). These attitudes must be taken into account by AIDS educators attempting to reach young Latinos and promote condom use as part of AIDS prevention programs. The negative aspects of these attitudes are usually emphasized; the real challenge to AIDS educators is to use the positive aspects of these attitudes (men and women protecting each other, parents protecting children) to convey the message that initiating safer sex, such as the use of a condom, is a better indicator of both manhood and womanhood.

AIDS also affects Latina women as traditional caretakers. It is the women who must provide care for the men, children, and other family members who become ill. A woman may be sick herself, have a child with AIDS, a deceased spouse, and other uninfected children for whom to provide. Support in times of crisis is normally sought within the extended family

framework. However, due to fear of AIDS contagion, this framework has been destabilized.

Unaccustomed to seeking help outside of the extended family, Latina women become isolated when stripped of family support. The lack of AIDS education specific to the Latino community has resulted in unfounded fears of contagion. This makes it difficult for the female careprovider or AIDS patient to obtain the needed support from her community. The denial surrounding the disease in the Latino community also contributes to the lack of support. Fear and denial result in some Latinos with AIDS being rejected by their families and becoming homeless.

Conclusion

The lack of substantiated research on the problems related to the spread of AIDS in the Latino community will make the planning and implementation of such programs difficult. Funding is needed, not only for culturally sensitive AIDS education, but for research which will enable policymakers to effectively help the Latino community to address AIDS and other health-related problems.

In formulating policy regarding services and education toward the Latino community, it is essential to involve the leadership within the Latin community. Decisions and education campaigns cannot be relevant if they do not originate within the Latino community.

The National Academy of Sciences has called for the funding of a massive education campaign against the spread of AIDS. Cultural and language barriers make it particularly difficult to reach the Latino community with such an education campaign. Public and private agencies that have attempted to reach the Latino community with similar education efforts in the past have been largely ineffective. The AIDS epidemic does not allow us the luxury of making the same mistakes. In order that the Latino community will adopt AIDS prevention measures, the message must be delivered by the existing Hispanic leadership and communication network. The Latino community must be helped to reach its own people. Existing popular means of communication should be explored and utilized in order to "sell" AIDS risk

reduction to the Latino community. Writers, newscasters, artists, actors, and producers, who successfully reach Latino households through Spanish language radio and television soap operas, "foto-novelas" (a popular comic-book style depicting romantic stories with photographs), posters, and printed materials, must be tapped in developing an education campaign that is based on a firm understanding of the cultural possibilities for adaptive behavior.

Dooley Worth and Ruth Rodriguez

References

- Arbona, Rebecca. "Adolescent Pregnancy: An Overview." New York: Hispanic Women's Center, August 1985.
- Centers for Disease Control. *Mortality and Morbidity Weekly Review*, Vol. 35, No. 42, October 24, 1986.
- Giachello, Aida. "Hispanics and Health Care." *Hispanics in the United States: A New Social Agenda*, eds. Cafferty and McCready. New Brunswick, NJ: Transaction Books, 1985, pp. 160-176.
- Moore, Joan, and Pachon, Harry. *Hispanics in the United States*. Englewood Cliffs, NJ: Prentice-Hall, 1985, pp. 84-85.

This piece originally appeared in the "Research Notes" section of the SIECUS Report, January-February 1987. Dooley Worth, PhD, is the Community Health Planner at Stuyvesant Polyclinic in New York. Ruth Rodriguez, MHS, is on the Executive Committee of the Hispanic AIDS Forum in New York.

- Rivera, Carmen. "Hispanics and the Social Service System." *Hispanics in the United States: A New Social Agenda*, eds. Cafferty and McCready. New Brunswick, NJ: Transaction Books, 1985, p. 201.
- Stanton, Norma. Unpublished paper. New York: Hispanic Women's Center, 1985.
- Ventura, Stefanie J. "Births of Hispanic Parentage." *Latino Families in the United States*, ed. S. Andrade. Planned Parenthood Federation of America, Inc., 1982, p. 14.





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RESISTANCE AND THE EROTIC:

Reclaiming history, setting strategy as we face AIDS

Cindy Patton

In the past year, there has been a surge of interest in the topic of AIDS. Yet the history of resistance to the crisis is in danger of being lost to a revised history that counts only the actions and concerns of the professionals who have taken up AIDS as an issue. The instant experts of 1987—well intentioned and intelligent people with the power to convey information and set policy—are not largely the true experts, those who have been involved in sorting out the wide ranging effects of AIDS since the epidemic began. It is critical that the experience of the gay community in AIDS organizing be understood: the strategies employed before 1985 or so grew out of gay liberation and feminist theory. It is also axiomatic that those most affected—the gay, i.v. drug, black, Hispanic, and sex work communities—be listened to when we set new strategies and draw lines of resistance.

Claiming Safe Sex History

At the 1987 lesbian and gay health conference in Los Angeles, many longtime AIDS activists were surprised by the extent to which safe sex education had become the province of high level professionals. The fact that safe sex organizing began and is highly successful as a grassroots, community effort seemed to be forgotten. It was as if the professionals had invented safe sex. Although professional health and sex educators have made important contributions to AIDS education, their work came long after a community under siege had mobilized to protect itself.

Mainstream accounts of AIDS provide even less reference to the roots of safe sex organizing in the gay community. Heterosexuals—and even gay people only beginning to confront AIDS—express panic about how to make appropriate and satisfying changes in their sex lives, as if no one had done this before them. It is a mark of the intransigence of homophobia that few look to the urban gay communities for advice, communities which have an infrastructure and a track record of highly successful behavior change.

The overprofessionalization of safe sex organizing—and the lack of historical insight by professionals—has a direct effect on the style of education for gay men and heterosexuals. Many lesbians and gay men just laughed at the silly pronouncements of Reagan officials, but there is a hidden price to this smugness. Innovative programs such as one that trained bartenders as educators, and zap actions where leather-clad hunks raided bars to pass out condoms and literature, have fallen by the wayside. Most educators are no longer willing to take social risks in order to promote sexual safety.

It is essential that those concerned with the broader implications of AIDS understand the history of the gay community's safe sex organizing. These successes are derived from gay activists, not from the professionals who came late and reluctantly to the health crisis. If we embrace a revised history in which professionals imagine that they conjured safe sex out of formulas and studies, we will become even more dependent on the medical establishment that is so callous toward women's and gay

health concerns.

"How to Have Sex in An Epidemic"

Safe sex organizing began almost as soon as AIDS was recognized. Organizing within the gay community originated in opposition to pronouncements of doctors ignorant about gay male sexuality. Their advice assumed that all gay men did the same thing, or that any individual gay man did only one of a set of practices—for example, that a man was exclusively the object of anal sex, or only sucked cock (the stereotypical "queer" activities, with, no doubt, "real men" on the other end of the bargain).

Badly designed studies and homophobia combined to create a flurry of nonsensical, insulting advice. At the 1985 International AIDS Conference in Atlanta, for example, a Center for Disease Control (CDC) official proposed that all gay men take the then-new (and not extensively tested) HTLV-III antibody test (here after called by its current name, HIV antibody test). He suggested that gay men only have sex with men of the same antibody status, as if gay male culture is little more than a giant dating service. This advice was quickly seen as dehumanizing and not useful because it did not promote safe sex, but renewed advice of this type is seen as reasonable within the heterosexual community of late. Gay men quickly came up with their own advice, and coined the term "safe sex." Sorting through the same data, and adding knowledge about other sexually transmitted diseases (STDs) among gay men, activists created safe sex guidelines even before the virus was identified.

By May, 1983, so much material about safe sex had been distributed through clinics and in the gay press that a group of men—including men with AIDS—produced a 40-page pamphlet called "How to Have Sex in An Epidemic." This still stands as one of the best and most comprehensive explanations of transmission models, safe sex and psycho/social guidelines for effecting risk reduction. Most importantly, it proposes a plan for change that is couched in terms of a community resistance.

Considerable controversy surrounded the

publication of this booklet, foreshadowing the political struggles which engaged sex educators and community activists. Two principle criticisms of the booklet emerged; some thought the only sound advice was to advocate celibacy, while others thought it irresponsible to offer specific advice until there was certainty about the transmission and cause of the disease. The celibacy argument is still promoted by rightists, and continues to affect public policy and federally funded educational programs. In addition to right-wing homophobes, some politically conscious AIDS activists, when pushed do advocate celibacy for some groups—usually for gay and straight youth.

Responsible Advice? or the Responsibility to Advise?

The second objection—when is it responsible to give advice?—has been played out in more insidious ways. The inability to decide specifically what is safe and unsafe, has prevented many groups from recommending what is safe in broad terms. Counselors and safe sex educators, especially doctors, are often unwilling to say that anything is safe. They are afraid someone will get AIDS while taking their advice. This mixed message leaves people confused about what is unsafe and gives an underlying impression that everything is equally unsafe. This is a troublesome misperception; studies of changes among gay men showed that changes made early in the epidemic were based on perceived need to change or reduce the least favorite activity, not the most dangerous activity. Ironically, a different attitude is now taken in educating youth; a New York City project advocates telling youth that unprotected anal and vaginal sex are absolutely unsafe, and if youth feel they can give up only one thing, using condoms or refraining from these activities will result in significant risk reduction.

The early guidelines by grassroots organizers were sensible, logical, and based on a good epidemiological model generated by gay men with an understanding of the range of sexual behaviors and institutions in their community. It remains solid advice. But many people, including leaders in AIDS organizations, were uncomfortable with this advice until doctors



Charles Ludlam, actor, in his memorable role, "Maria Gallus," founder of the Ridiculous Theatre Company, 1943-1987, Village Voice

lent their stamp of approval. Condoms in particular were a source of equivocation. The Federal Government is largely culpable here; they refused to fund direct research on the efficacy of condoms. Even after HIV was identified, they said no technology existed to test condoms for HIV permeability. Finally, in the summer of 1986, some California researchers constructed an ingenious device consisting of plungers to which condoms could be attached. Their studies showed that even under the extreme conditions, no virus leaked through the latex.

Today public discourse on AIDS focuses on condoms for heterosexuals. Little mention is made of the now longstanding use of condoms by gay men.

"Whatever You Want to Do, You Can Probably Do Safely"

It has been hard for many people to hear the safe sex message. Despite the best intentions of AIDS activists, guidelines are perceived as limiting or judgmental. This is largely due to

the conflation of sexual practice and sexual identity in US culture. Gay men often initially feel that eliminating a central sexual practice means they are "no longer gay." In addition, sex is perceived as the cement in the gay male community: gay men fear that if sexual ties are reduced or deemphasized, the community will lose its unique identity and disintegrate.

Despite the complex elements that form our sexual identity and community, the safe sex message is about sexual practice and is quite simple. It was eloquently stated by a gay man with AIDS who is a safe sex educator: "Whatever you want to do, you can probably do it safely." That means continuing activities that do not involve exchange of semen and blood, and under some circumstances, feces, urine or saliva, if there is reason to believe quantities of blood may be in them. When you engage in activities where these fluids have direct access to absorptivetissueslike anal and vaginal tissue, or abraded tissue, like open cuts in the mouth or

hands, then you should use barriers like condoms, surgical gloves, or dental dams. It's that simple.

This conflation of condoms (or celibacy) and safe sex leads those reading advice pamphlets to make risk reduction choices by identifying or not identifying with categories of people officially seen at risk rather than evaluating which of their own behaviors need to be changed. Thus, a man who does not identify as gay might categorically decide not to make changes rather than going through the assessment process that is really the hallmark of the safe sex package. Women especially have difficulty applying safe sex information if it is couched in the "safe sex = condoms" equation.

The ultimate problem with this pared down message about safe sex is that it leads people to the conclusion that risk assessment is best accomplished by taking the HIV antibody test. It leads to the assumption that risk reduction is based on antibody status and reduces the



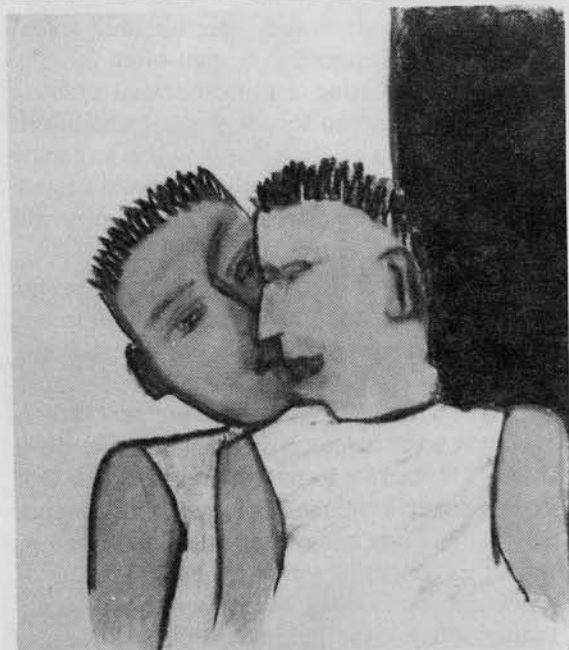
The Lovers, Rene Magritte, 1928

responsibility for change to the level of individual protection rather than the transformation of group mores and expectations.

The elaborateness of gay male sexual culture which may have once contributed to the spread of AIDS has been rapidly transformed into one that inhibits spread of the disease, still promotes sexual liberation (albeit differently defined), and is as marvelously fringe and offensive to middle America as ever. Heterosexuals in the US, who do not as often participate in an articulated sexual culture, may initially experience few opportunities for exposure to AIDS but also have fewer experiences of sexual community which provide the locus for transformation to safe sex values. Women, for example, in the absence of a women's movement, must fight their battle for safer sex on the carefully guarded and privatized domain of relationships with individual men. Gay men can find empowerment among a community of men who demand the practice of safe sex. Safe sex norms will ultimately be more difficult to achieve among heterosexuals than in the urban gay world. The history of women and birth control does not give cause for optimism about the ability of straight sexual culture to achieve safe practices that respect all partners involved.

The Attack on Promiscuity

Perhaps the single most misunderstood "fact" about transmission of HIV is that promiscuity is the chief culprit. Despite wide media and even scientific reporting, epidemiologic studies show that it is not primarily number of sexual partners, but rather exchange of infected semen or blood that creates risk for contracting the virus. Number of partners is significant only to the extent that those practices involve an exchange of semen or blood through a direct route—anally or vaginally, or through cuts in the hands or mouth. Conversely, monogamy per se doesn't decrease risk if one or the other partner is virus positive or transmits an unknown cofactor during unsafe sex. Even those who accept this reality often argue that monogamous relationships provide a better context for discussing risk history and preferred methods of risk reduction. Studies of gay men show that coupling does not necessarily pro-



"Yeah?," Gregory Gazaway

duce more discussion of safer sexual practices. They show that men give the same reasons for not practicing safe sex whether they are in a monogamous relationship, a primary relationship with occasional other partners, or involved in primarily anonymous sex. Indeed, in the sexual economy of the baths, bars, or bushes, it may be much easier to refuse a sexual encounter with an unreformed stranger than to deal with safe sex with a reluctant longterm lover with whom one shares more complicated relationship issues.

Safe Sex May Be Hazardous to Women

While it is unequivocally true that women are more likely to get than to give an HIV infection when having sex with a man—thus requiring more "protection"—monogamy and condom use as promoted in the media are fraught with danger.

The current technology for AIDS risk reduction and the fact that no major campaign has insisted on the responsibility of straight men (as opposed to the campaign to protect one's self from prostitutes, a transmission link that is not demonstrable) mean that women must ask men to wear condoms. Women exist in a sexual economy where they have unequal power in relationship to potential sex partners; this in-

hibits their ability to make a risk evaluation and reasonable changes. While gay men complain of boredom or loss of gay identity when they try to practice safe sex, women fear their sexual partner's responses to their safe sex requests. In addition, because heterosexuality proposes fewer activities that count as "real sex" (fucking is the model, as opposed to the entire hanky code of activities articulated in urban gay male culture), women find it difficult to direct their male partners away from the hazardous activity of intercourse.

Successful safe sex education for women depends on politicizing women about the same issues feminists raised in dealing with birth control: a woman's right to choose how she will use her body and men's obligation to take responsibility for sex.

In this era when most birth control is designed to exist hidden inside a woman's body, people in the age groups most affected by AIDS have never had to negotiate male-centered contraception. This is strongly reflected in the condom marketing campaigns. By several counts, women now comprise 70% of the condom buying market. If we consider that gay men constitute a large percentage of the male condom buyers, we can only conclude that straight men represent the greatest stumbling block in heterosexual safe sex.

Safe Sex Is Sexual Liberation

Safe sex describes specific practices that prevent hazardous exchange of infected or possibly infected body fluids. It is not a moral category to sweep up sexual practices with which we feel uncomfortable for other reasons. Gay sex can be safe. S/M can be safe. Anonymous sex can be safe. Bisexual sex can be safe. Monogamy in itself is not safe, and, though a valid option for any number of reasons, carries its own dangers—spouse abuse and all the traditional hazards of "marriage." Celibacy prevents spread of HIV, but it carries psychological hazards.

Safe sex should be a key agenda item for progressives, but it must be pursued in a context that gives us control over how the safe sex message is articulated and how safe sex norms are enforced. It is hard to persuade those who do not yet engage in safe sex to do so if the state

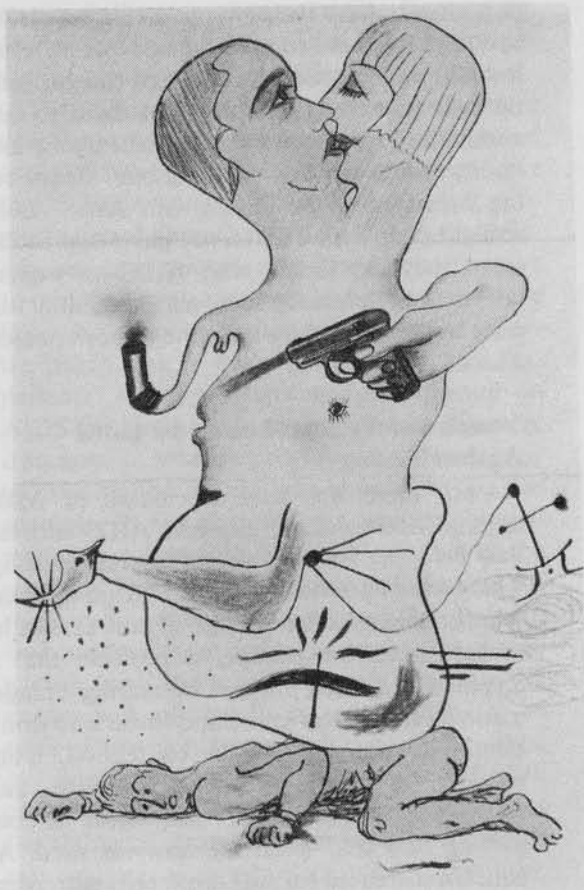
continues to have the power to arrest people for sodomy. It is hard to promote self-esteem when lesbians and gay men are declared categorically unfit as parents or teachers. It is hard to talk about the experience of AIDS when jobs and homes can be lost for "coming out" or for being perceived to be linked with AIDS. Even straight people have suffered "gay" oppression when they are linked with AIDS—a woman lawyer was detained, strip searched, and forcibly tested when she was found to be in possession of condoms.¹

Vessels and Vectors: Losing the Battle Against Testing

Until there was wide discussion of AIDS among heterosexuals, gay and AIDS activists had held the line against widespread testing. There were currents of dissent, including those who believe that knowledge of test results increased behavior change, a position that is disputed. Research projects measuring changes made by those who know and those who don't clearly do not support the contention. Until recently, gay activists, civil libertarians, and AIDS activists were quite successful in controlling how and when the test was used. As concern increased (or was displaced) onto pregnant women and "innocent" victims about to be married, testing policy headed down the slippery slope of medical abuse.

This was primarily because the Right occupied the corner of the AIDS discourse that concerned women and children. Feminists had not taken AIDS or HIV testing on as an issue, and gay men had ignored, or been too busy to recognize that the social control of women in US society is still so keenly sought by the Right that testing of women would become the linchpin in the plan to test and isolate those infected with HIV.

The fact is that women, described by the Right and many epidemiologists as the "vector" for moving AIDS between communities, have long been viewed as the reservoir of disease. Further, women are the "vessels" of procreation, which gives men an additional stake in controlling women's bodies. If you believe that women (read: prostitutes) are spreading AIDS to nice men who then take it home to their wives (vessels for producing the next generation),



Exquisite Corpse, Man Ray, Yves Tanguy, Joan Miro, Max Morise, 1928

then it makes a certain perverse sense to step up testing of women. If you imagine that gay men are a hermetic community (that is, no straight men get their virus in the bus station toilets while engaging in queer acts) then who cares if they take the test? There are a plethora of right wing and left wing rationalizations for letting gay men decide for themselves, but forcing women who intend to have sex and babies to be tested against their will. It is astonishing to those of us who have been involved in holding the line on testing to see how quickly programs to test pregnant women and marriage applicants were put into place last spring. There was remarkably little protest about the domino effect such policies would have on the logic for testing other groups. Apparently many people who can see the civil rights arguments against testing gay men are attracted to the idea that testing protects innocent women and babies.

Evolution of Testing Ideology

In 1984, the US announced the development of a test for the antibody to the recently identified HTLV-III—the putative AIDS agent. CDC and National Institute of Health (NIH) officials early advocated widespread testing—even before the test was through its trials, and despite the fact that it had no diagnostic value. It did not show who would get AIDS or ARC and who would not, who was infectious and who was not. The test had been designed to accept a high false positive rate as a trade-off for decreasing the number of false negatives. Early estimates placed the false positive rate at 10 to 30 percent. Subsequent protocols augmented the so called ELISA test with the more expensive Western blot, but at the time of initial calls for mass testing, the test protocol to be used had a very high false positive rate. No one knew the exact incubation period for the virus, at that time, estimates were five to seven years. No one knew the length of time between initial infection—that is, viremia—and seroconversion of antibodies.

Certainly, the wish to prevent any more suspect blood from entering the blood supply prompted quick government action. But it is important to remember that at the time testing became feasible, CDC and NIH officials widely believed that transfusion and blood products were the principal route of transmission from the gay and i.v. drug populations into the general population. Foisting the test on risk groups gave society at large a sense that something was being done—and only these unpopular groups would suffer any ramifications of testing. Testing was in place, and large numbers of people had been tested before a full policy analysis of the effect on insurance, civil liberties, individual mental health, and general health actions could be determined. There have clearly been disastrous side-effects for the at risk communities. But testing has lulled the “general population” and promoted the widespread misunderstanding that a vaccine and cure were around the corner.

AIDS activists and gay leaders moved quickly to discredit the testing programs. Citing not only the problems with the test and the psychological impact of those tested, they

argued that at least those testing positive would be at risk for losing insurance (insurers had already tried to claim AIDS was a pre-existing condition, and in some cases, claimed it was an "elective" illness), jobs, housing. Some feared that positive test lists would leak from agencies and might be used to "round up" people for quarantine, legally harass prostitutes, or merely expose anyone who sought the test as gay or a drug user, statuses not protected under most civil rights laws.

The government countered these concerns by offering to fund anonymous sites called, in true government doublespeak, "alternative test sites." In addition, at the request of health activists, testing was mandated to take place with pre- and in some cases post-test counseling and referrals. Although a few major AIDS organizations attempted to block creation of the alternative test sites in their areas (notably, Chicago and Philadelphia) most took the attitude that sites would be created anyway, and that AIDS groups should cooperate in their creation in order to get control over them.

At this time, most AIDS groups strongly counseled against test taking. At best, they saw alternative test sites as a way to get the state to pay for AIDS activists to talk gay men out of taking the test. Groups in Chicago and New York produced material for wide public distribution that admonished "don't take the test." Soon, however, some gay activists began to argue that it was good to take the test, that men would change their behavior. Properly designed record systems could assure the confidentiality of those taking the test—this in the face of at least four documented cases of government agencies "accidentally" releasing test lists. Some went so far as to accuse anti-test activists with irresponsibility in counseling against taking the test. The ethics argument soon devolved into a contention that "anyone has a right to take the test" and that it was possible to counsel people in such a way as to obtain meaningful consent. Few included the possibility of civil rights infringements in their attempts to gain "consent."

The media misunderstood or misrepresented the antibody test, which within months became known as the "AIDS test." Testing gained tremendous credibility, and new reports

TESTING THE BLACK COMMUNITY

Richard Goldstein

To the officials who proposed testing all hospital patients for AIDS antibodies, the gain in research more than offsets the threat to civil rights. But every black physician interviewed for a recent *Village Voice* article (March 10, 1987) had grave reservations about the plan. "I'm shocked," says Wayne Greaves. "I think it will lead to a breakdown in confidentiality and discrimination against those who test positive, whether or not they have symptoms. I can't believe they would do a thing like that."

For blacks, the issue is hardly academic. In any mandatory screening of the general population, minorities are more likely than whites to come up positive. And many black physicians bitterly remember what happened when the military decided to test for sickle-cell trait in 1971. About 8 per cent of blacks carry the trait, which is harmless in itself; but two parents with the trait have a 25 per cent chance of producing

represented AIDS organizations as offering a much needed service by providing testing. The counseling style changed substantially from an attempt to talk people out of taking the test to offering "only the facts." The gay run alternative test sites ceased to be a ruse for getting government money to do education at a time when no education money was available.

When the CDC, in late 1985, requested proposals for the first education dollars, it mandated that testing must be incorporated into education, implying that they would only accept projects where the educational process centered around testing. Many organizations and health care providers (even some CDC officials) protested this emphasis on testing. Yet, most organizations applied for money. Testing was seen as benign, as magical at worst.

Consequences of Taking the Test

Some people feel their anxiety will be relieved by being tested. This is true for some people,

a child with sickle cell disease, an ultimately fatal form of anemia.

The military, however, became convinced that blacks with sickle-cell trait might be disposed to sudden death. Soldiers who tested positive were barred from parachuting and diving. At least one civilian agency, the National Institute of Health, tested employees without their knowledge. Airlines became especially concerned: some blacks with the trait were barred from working as pilots and stewards. As word got out, more and more private employers began to screen for the sickle-cell trait, sometimes requiring black applicants to be tested. An indeterminate number of people lost jobs.

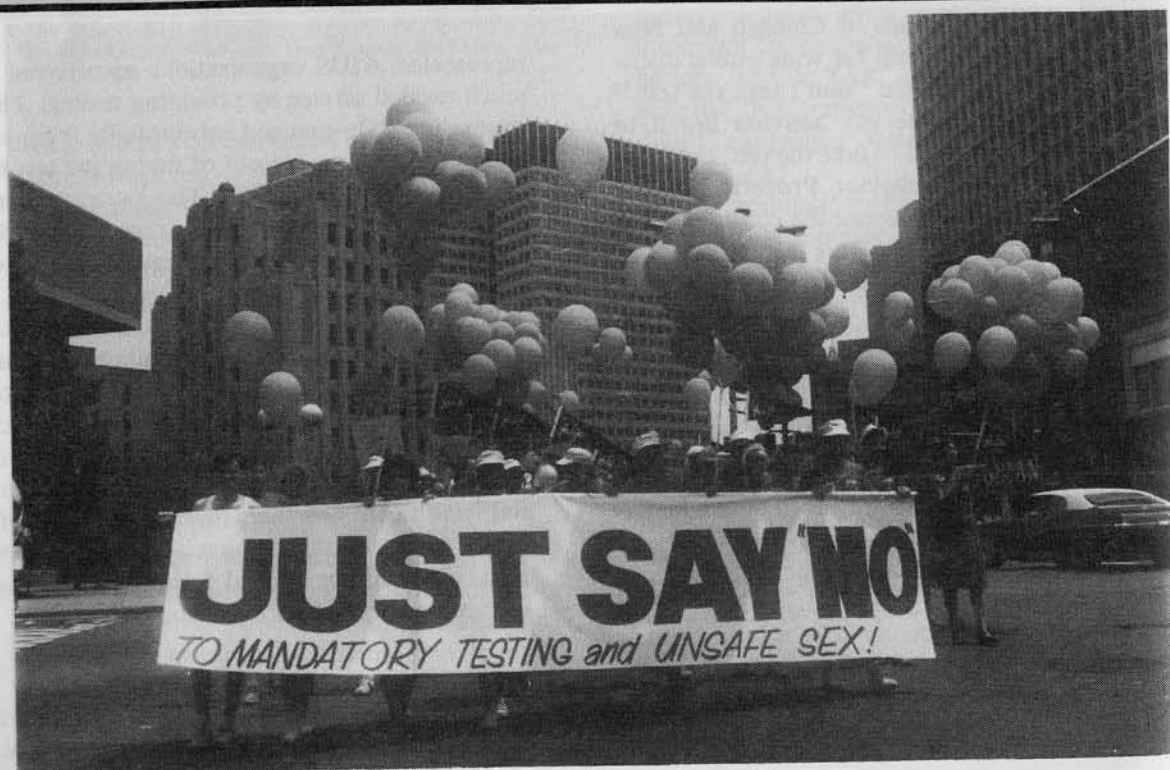
"We know these difficulties existed, and we can apply the knowledge as a model for AIDS testing," says Robert F. Murray, chief of medical genetics at Howard University College of Medicine. "It certainly suggests that, where minorities are concerned, the worst use is likely to be made of such information, rather than the best." Murray urges that AIDS-antibody screening be kept voluntary and anonymous.

But not all blacks are opposed to screening marriage candidates: women interviewed by

the *Voice* were more likely than men to find some merit in that plan. "Increasingly, responsible people in this society know we have got to find out early who has AIDS, or it's going to become an international catastrophe," says Eleanor Holmes Norton. "The trade-off is that there has got to be a guarantee of confidentiality. It seems clear to me that larger numbers of people would be open to considering these proposals if there were a stronger antidiscrimination law. We have to face the fact that the trade-off for openness about AIDS is the strongest kind of protection. We must do the trade-off right away, build it into law. Then people will not object to having AIDS discovered in this mandatory way."

Testing for sickle-cell trait was also supposed to be confidential, but somehow, the word got out. "To be honest with you," says Murray, "I am skeptical about pledges of confidentiality. In an institution of any kind, it is very difficult to maintain."

Excerpted from "The Hidden Epidemic: AIDS and RACE" by Richard Goldstein, *Village Voice*, March 10, 1987.



Ellen Shub photo

but the test often raises as many anxieties as it quells. In one study, many men expected to test positive and were negative. Far from being relieved and returning to a "normal" life, they increased stress-outlet behaviors like binge drinking and drug abuse. They expressed feelings of survivor guilt toward sick friends or lovers. About a third of these men became hooked on testing, going back for many repeat tests and living in constant anxiety between test results.² In couples tested together, a negative sometimes broke up with a positive. If both were positive, they often tried to assess blame, assuming one had infected the other, even when both could have been infected independently.

Ultimately, individuals decide whether it makes sense for them to take the test. But it should be a rigorous part of the "informed consent" process that everyone understands the wide range of psychological responses and legal hazards of the test.

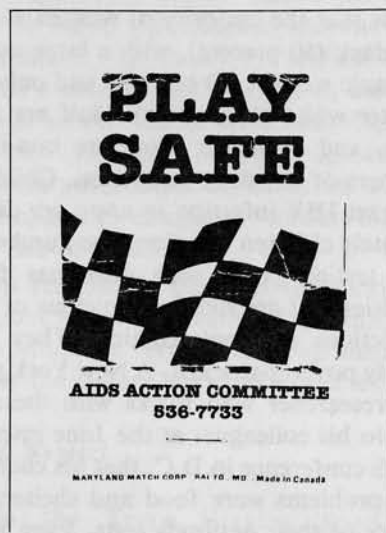
The Obligation to Know

The Reagan administration is fond of claiming that people have a moral obligation to know their test result and should be legally culpable for behavior after being so informed. This is a wrongheaded way to make people take responsibility for their behavior.

There are several cases where HIV-positive people have been accused of attempted murder for spitting on or biting someone. This is a ruse to arrest HIV-positive people for things that could not transmit AIDS. The state would rather spend money on testing to define who should be rounded up than spend money on education. Education could teach people that they cannot contract AIDS by being spat upon. They could learn about studies of the 30-odd people bitten by institutionalized patients with AIDS who did not contract an HIV infection.

There are other cases of people prosecuted for attempted murder for having sex with a partner who subsequently decided that the accused knew or *should have known* that they were HIV-positive. This says that people who test positive are responsible for making sure safer sex is practiced, but people who are negative are not. The idea that one has a moral obligation to know rests on the wish to believe

that only those who are positive need change their behavior. It comes from the mistaken idea that if only the HIV-positive people could be isolated, AIDS would go away. They ignore a much simpler method of isolating the virus: putting a little latex between sexual partners of either status.



The Hidden Agenda: Racism and Classism

With the new testing mandates, the Reagan administration—and its New Right constituency—is testing the waters for future measures like quarantine. Further, the effects of widespread testing on women would be at cross-purposes with the reproductive rights movement agenda of the last fifteen years. Testing pregnant women can only lead to forced sterilization and forced abortion (long-time abortion foe, Surgeon General C. Everett Koop, now concedes that HIV-positive status is a condition under which abortion should be available to women). Women with HIV infection give birth to HIV-infected babies in about 20 to 40 percent of cases. New research suggests that the probability of *in utero* infection varies with the degree of infection of the mother. While women who are at risk may well want to get tested in order to help them make a child-bearing decision, it does not make sense for all pregnant women to be tested. If women intend

to have the baby anyway (and certainly, we grant women in this society the right to carry out high risk pregnancies) or if they will not consider abortion if they are already pregnant, then test-taking can only be an anxiety-producing event which yields little useful information.

The agenda behind required testing of all pregnant women is racist and classist. The plain fact is that the majority of women with AIDS are black (50 percent), with a large number of Hispanic women (20 percent) and only about a quarter white (27 percent). Half are i.v. drug users, and a quarter more are non-i.v.-using partners of i.v. drug-using men. Children who contract HIV infection *in utero* are disproportionately children of color. The numbers reveal why testing poses such dilemmas for communities that are rightly suspicious of limits or restrictions on contraception. They are also largely poverty-stricken. A New York physician and researcher who works with these women said to his colleagues at the June international AIDS conference in D.C. that his clients' biggest problems were food and shelter, not the results of their antibody tests. Even Koop has joined the ranks in opposition to mandatory testing of pregnant women, on the grounds that it would cut down on access to pre-natal care among women who believe they may be at risk. Mandatory testing of these women, irrelevant to the real conditions of their lives, only compounds the obstacles they already face in terms of jobs, housing and access to services.

Making Sexual Choices

Taking the test will not settle personal AIDS fears or cause AIDS to disappear. Allowing the test to be widely used will not solve the crisis for society. AIDS is with us as a disease and a social phenomenon, and will not go away no matter how many people take tests. AIDS has changed our concept of sexuality by heightening our fears and requiring us to talk about and plan our sexual activities, something that makes Americans very uncomfortable. The media's crass summary of the situation is that we should just stop having sex outside of marriage.

This message is especially troublesome for women, who have long been told they cannot



Nathan Fain, founder of GMHC, 1942-1987, Village Voice

make good choices about sex. The message we must take from AIDS is that we *can* choose wisely, and we can protect the health of ourselves and our partners. But the choice is not based on a test result; it is based on understanding how transmission occurs and on taking the simple steps to avert it. The message is to expand our concept of sex, to increase the discussion of pleasurable possibilities, to eroticize measures that reduce transmission of all sexually transmitted diseases.

FOOTNOTES

1. *National Coalition of Gay STD Services Newsletter*, Spring 1987
2. Study from the Howard Brown Memorial Clinic, Chicago, presented at the Center for Disease Control conference, Washington, DC, June 1987.

REFERENCES

- Berkowitz, Richard, Callen, Michael and Dworkin, Richard. *How to Have Sex in an Epidemic*. News from the Front Publications, May 1983.
- Foucault, Michel. *The History of Sexuality*.
- Rubin, Gayle. "Thinking Sex: Notes for a Radical Theory on the Politics of Sexuality." *Pleasure and Danger*, Carol S. Vance, Ed. Routledge and Kegan Paul, Boston, 1984.

Cindy Patton is a journalist, who has been involved in AIDS organizing for five years. She is the author of *Sex and Germs: The Politics of AIDS* (South End Press, 1985) and *Making It: A Woman's Guide to Sex in the Age of AIDS* (Firebrand Press, 1987).

VISUAL AIDS: Advertising Ignorance

On the last Sunday of 1986, the *Observer* informed its readers with a bracing mixture of ignorance and insensitivity that "1987 will be the Second Year of AIDS for Britain." It had evidently not occurred to journalist Nicholas Wapshott that ever since the HIV virus was identified in 1983, every year has been a "Year of AIDS"—as he so crassly put it—for the gay population. That is, for the one to two million gay men who have been living through these terrible times with varying degrees of anxiety and fear, courage and dignity.

Wapshott may observe that "AIDS is not a gay plague, nor ever was," but his words ring hollow in the context of his metaphor of unexploded bombs for those infected by the virus, and sickeningly hypocritical cant about the need for "sympathy and understanding for those trapped by their own proclivities." Such euphemistically stilted language makes it painfully clear that AIDS is still being handled right across the media with all the most up-to-date medical, psychiatric and sociological resources of the late 19th century.

According to Wapshott's standardized version of recent events, "[Health Minister] Norman Fowler emerges as an unlikely hero in this miserable story." It is certainly a miserable tale, but if Fowler has been heroic it is only in forcing the present government to recognize something of the full enormity of an epidemic which the rest of Europe faced up to some years ago. The official campaign that Fowler has launched suggests that government understanding of AIDS remains lamentably defective. 1986 was undoubtedly the first "Year of AIDS" as far as British politicians of all persuasions were concerned. What this means in simple terms is that thousands will now inevitably die, as the direct result of Tory prudery, moralism, and an exaggerated faith in the medical profession's ability to find a cure or vaccine for HIV infection, aided and abetted by the resounding silence of the entire British party political system.

In Britain the number of newly reported

AIDS cases doubled between October and November 1986, bringing the total to 599, of whom 296 are dead. This total includes seventeen women, two babies, eleven patients infected by blood transfusions, and twenty-two hemophiliacs. The Center for Disease Control reported a total of 27,773 cases in the United States as of November, of whom 15,597 are dead. This is the grim backdrop against which the British government has launched a "forceful" propaganda campaign "to alert the public to the risk of AIDS."

What remains so particularly shocking and obnoxious about the treatment in Britain is the way in which the very social group most devastated by the disease has simply been left to rot.

Official Neglect

Thus the Terry Higgins Trust, until recently the only voluntary organization providing information and counselling services to gay men and the rest of the population, has had to struggle through each year with a mere \$160,000 of public assistance. The Trust needs a minimum of \$400,000 for its educational work and support services, and the shortfall has had to be met by intensive fundraising among gay men themselves. And all along the line its activities have been hampered by doctors and politicians holding the purse strings, who have refused to support the production and distribution of explicit Safer Sex materials for gay men.

Safer Sex videos, like the New York Men's Health Crisis' *Chance of a Lifetime*, are banned over here by our ludicrous censorship laws. And until Her Majesty's Customs dropped their charges against London's *Gay's the Word* bookshop last summer, none of the leading American or European gay newspapers containing the most up-to-date information and debate about AIDS were available here—they could not be safely imported. Hence the all but incredible story of how the government's own chief medical officer had to have copies of *The*

Advocate and *New York Native* smuggled into England in diplomatic bags to avoid the possibility of their seizure as the AIDS campaign was first being drawn up!

As long ago as August 1983 the British *Medical News* recommended gay men start using condoms as a matter of routine sexual practice, and more recently the respected American medical correspondent Ann Guidici Fettner has pointed out that "AIDS education should have been started the moment it was realized that the disease is sexually transmitted." Which is precisely what the Terrance Higgins Trust has been saying all along. But as long as AIDS was perceived as a "gay plague" the entire problem was only calculated in terms of the possible "leakage" from affected groups to the "general public"—from which gay men are evidently categorically excluded.

The belated recognition that it is not "just" prostitutes and drug-users and "queers" who are at risk, but even the Tory counties, explains much of the energy behind the current campaign. Thus an ad appeared in many magazines at Christmas, spelling out the word "AIDS" in

seasonal wrapping paper, with the accompanying question: "How many people will get it for Christmas?" Another ad conveys the message that "Your next sexual partner could be that very special person," framed inside a heart like a Valentine card, beneath which we read: "The one that gives you AIDS." The official line is clearly *anti-sex*, drawing on an assumed rhetoric concerning "promiscuity" as the supposed "cause" of AIDS, in order to terrorize people into monogamy. But monogamy is no more intrinsically safe than any other kind of sex, unless precautions are taken. Mortal fears are being whipped up, as if sexuality were entirely within the control of rational consciousness, and as if sexual desire were a tap with just two simple positions—On and Off.

Education or Homophobia?

Still more problematic is the ubiquitous series of posters which have recently appeared all over Britain, their messages seemingly carved into granite-like tombstones. Thus we read the solemn injunction: "AIDS: DON'T DIE OF



English cabaret group Bloodips, one of the best known gay cabaret groups in the world. IGA Pink Book

IGNORANCE," with the secondary advice that "Anyone can get it, gay or straight, male or female. Already 30,000 people are infected. At the moment the infection is *mainly confined to relatively small groups of people* in this country. But it is spreading."

Something extraordinary is going on here. On the one hand the government appears to acknowledge the actual diversity of sexual identities in the modern world—yet this is evidently not the case since we are simultaneously intended to dismiss all of the vast majority of people with AIDS as members of "relatively small groups of people." At the same time the poster peddles a mischievous implication of responsibility onto people with AIDS as if they'd somehow set out to contract it by ignoring advice and information which has never been widely available. It also cynically looks entirely over the heads of everyone most immediately affected by the epidemic. Apart from lesbians and gay men, what other social group with almost 600 dead and dying could be so casually erased from all public consideration?

"AIDS IS NOT PREJUDICED: IT CAN KILL ANYONE" screams another poster, this time with the subheading: "It's true more men than women have AIDS. But this does not mean it is a homosexual disease. It isn't." Here is the astounding implication either that there *are* viruses which consciously select their victims, motivated by sexual desire, or that some diseases are the intrinsic properties of gay men. There is of course no such thing as a virus which only affects men *or* women, but medical facts are irrelevant here, since what the poster is actually saying is that it doesn't matter if you *are* prejudiced, as long as you don't make the mistake of thinking that AIDS is "only" killing off the queers!

Yet another poster proclaims that "*THE LONGER YOU BELIEVE AIDS ONLY INFECTS OTHERS, THE FASTER IT'LL SPREAD.*" While the "you" addressed here is at least open to all readers to identify with, there is still no information and advice—beyond the totally incorrect implication that AIDS is itself infectious. The inability to distinguish between AIDS and the HIV virus is typical of a campaign which is evidently not educational in any useful sense, but which aims

only to frighten and alarm as many people as possible.

The worst poster simply asks: "AIDS: HOW MUCH BIGGER DOES IT HAVE TO GET BEFORE YOU TAKE NOTICE?" It is, however, far from clear what we are expected to take notice of, beyond the poster itself, which again suggests that the campaign is largely diversionary, giving the impression that the government is doing something about AIDS and that the epidemic is in hand. The question which we should be asking some five years into the epidemic is, how big did it have to get before *they* took any notice? The folly of the entire campaign is its total failure to talk to people in any but the most abstract and over-generalized terms. We thus still face the nightmarish situation of an epidemic running out of control, under a government and opposition totally unable to acknowledge or assess the actual social and sexual diversity of the society they purport to represent!

The same obituary graphics are used in front of the leaflet distributed recently to every household. Like the posters, it was drawn up without any consultation whatsoever with the Terrence Higgins Trust or any organization with direct experiences of AIDS educational work. To add insult to injury, the Trust's telephone number was placed on the leaflet without permission, and in belated recognition of the fact that it will now be swamped with calls the government has agreed to install a number of extra telephone lines. While the leaflet offers a lot of straightforward and helpful information, it nonetheless proceeds from the statement that AIDS is "not just a homosexual disease." This is a shocking and disgraceful statement, and if anyone still doubts that gay men are officially regarded *in our entirety* as a disposable community, they need look no further.

Taking AIDS Seriously

In 1983, when there were less than 3000 recorded cases of AIDS in the United States, Richard Goldstein wrote that "for heterosexuals to act as if AIDS were a threat to everyone demeans the anxiety of gay men who really are at risk, and for gay men to act as if

AIDS DON'T DIE OF IGNORANCE

[GAY OR STRAIGHT. MALE OR FEMALE. ANYONE CAN GET AIDS FROM SEXUAL INTERCOURSE.]
[SO THE MORE PARTNERS, THE GREATER THE RISK. PROTECT YOURSELF, USE A CONDOM.]

we're all going to die demeans the anguish of those who are actually ill." His message is as timely as ever. Millions of pounds have been squandered in a face-saving exercise which directs its crude, loud-hailing machinery at nobody in particular, least of all towards those who are in most need of a positive health education program. How could this be otherwise from a government which is profoundly hostile to sex education as such, and which in all other circumstances regards gay men only as the target for punitive legislation, prosecution, and surveillance?

The government's AIDS campaign offers no correction whatsoever to the chorus of stubbornly opinionated ignorance which constitutes most AIDS commentary in the British Isles. In the absence of a strong affirmative national gay culture, British gays are especially vulnerable to AIDS. This is why the didactic call not "to die of ignorance" is so insufferable, since gay men have been so efficiently kept in ignorance throughout the 1980s by courtesy of this government and its various agencies. British gay culture is fragmentary and atomized, lacking even the most elementary civil rights consciousness, unable even to organize a proper national newspaper. In this respect we are victimized by the direct legacy of centuries of British homophobia, active at every level of culture and the state in ways that clearly mark Britain apart from the rest of Europe, as is reflected in a host of archaic and fundamentally undemocratic laws.

The AIDS initiative is no more than an exten-

sion of the familiar public agenda which has proved so stubbornly resistant to the actual complexity of issues raised by the epidemic. It is a discourse whose words are sticky with blood-lust, hatred and thinly-veiled contempt for the thousands of sick and dying, offering a heady brew of racism, misogyny and homophobia, which speaks volumes about the real moral condition of contemporary Britain. That socialists and feminists alike have so totally failed to grasp the implications of AIDS for the future politics of Britain is particularly regrettable. We are living through a catastrophe that has systematically been denied the status of a natural disaster, let alone a tragedy.

This terrible epidemic should teach us once and for all that if our species has any worth or beauty it lies in its diversity, and in our capacity to embrace and celebrate all our variously consenting states of desire. And if in these dreadful times we should wish somewhat to alleviate the pain of our losses—of freedoms and friends—then we might possibly think of AIDS as a monstrously ironic means to that end.

Simon Watney

This article originally appeared in *NEW SOCIALIST* (England) March 1987. Simon Watney's latest book, on US and British media treatment of pornography and of AIDS, will be published this fall by University of Minnesota Press.

protocols

so now the test is back:
positive. no surprise.

"maybe that qualifies you
for a protocol," I say.

"I'll get disability,"
John says. either way

he's qualified. he'll be
home in two days — medication

oral. Dr. Tagliaferro
mentioned "control groups,"

an easier term than protocol.
but John doesn't like the

idea of being used as a
guinea pig. or the possible

side effects, which, he says,
could kill him.

but what
if he says yes? is hope
a chimera without even a

gold ring in its nose?
or is it possibility, slowly

creeping through a crack in
the stone door, wriggling

its slimy body into a
kind of tentative life?

4/16/86

your life

right now it's all I care about
& you're going to lose it

(wrong head, I know, but it's
late & I'm scared & tired).

first there's your health: I
want you to have it. you were

exhausted & sun-dazed when I
brought you back from the hospital

— after stopping to get your drugs —
& you were sleeping when I called

downstairs just now. I am tired
beyond anything my body tells me

is fatigue. & when you're sick,

when I look into your tired, lovely
eyes, I want you well. right now

I'm trying to find the railroad cap
I lost on the long flight wait

in Florida last winter, when I was
there & you were home & healthy,

& put it on my head firm & screw it
on. I want you to get back your

health or at least its shimmering
surface. right now.

4/18/86

John MacDonald, Jr. was born in Dorchester June 10, 1951; he died in Holbrook, his parents' home, November 5, 1986. John graduated from Holbrook High School, attended Northeastern and graduated from the University of Hawaii with a degree in marine biology. He had done various things in his teens and 20s, since he was kicked out of his parents' home by his father when he was 15 (for being gay). He'd done a night club act in New York, cut demo records, modeled, worked as a geisha in Kyoto for three months. He worked for some years for New England Telephone Company and for many years for Winston Flowers on Newbury Street in Boston. He arranged the flowers for the 100th Anniversary of the Boston Pops. But his passions were plants — he planted whole gardens, grew orchids and camellias — and animals — he had three chows and two shih-tzus, five cats, a blue-and-gold macaw and many lesser birds and fish. He'd been crosspollinating flowers since he was five.

Ron Schreiber

Sunday morning 4/20/86

John got out of the hospital Thursday morning. We did not know whether he'd be able to leave or not, since his white blood count was low Wednesday night, and they had to get the results of another blood test Thursday morning. They called the lab for results, and got them at 10. OK — so we left.

The sun hurt his eyes coming home. We stopped at the pharmacy to pick up his drugs, and they were expensive: over \$100. for four prescriptions. When we got home he was very tired and he was nauseous again, but John noted that his first day out was bad the first time he came back from the hospital, two weeks ago.

When John came upstairs Friday morning, I was momentarily elated: he must be better, I thought. But that was not the case: his fever had returned, the rash had begun again, and he was very weak. While he lay on my bed, I kept trying to reach his doctor, who was not in yet. The intern, Steve Boswell, called about an hour later, and told me to bring John in. Then, as John was walking down the stairs, the phone rang again, and this time it was Nettie Tagliaferro, his doctor, and she said to bring John in.

He was very bad when we reached the emergency room, and I was unwilling to leave until I thought he would be all right. I left about 11, and went into work, as I had done the day before. This time they will keep John two weeks, although apparently the new drug they are using could be administered on an out-patient basis; we would come in for an hour every day. But John does not want that, and I don't think I could stand it.

When I talked to Steve Friday afternoon, he asked me how I was doing. — Not very well, I said, though also, — as well as can be expected, I think. I asked Steve whether it was life-threatening this time, and Steve said no, not this time. We talked a little about protocols. — I want to be with John when he dies, I said. Steve assured me that they would call me right away if anything should happen.

But this time they think it will be all right. We don't know yet what the side effects of this drug will be. Probably we will have to wait ten days and then find out. So far, whenever there are potential side effects, John gets them. They just have to keep trying new drugs. Probably the rash, though, is not a side effect (though it could be), but another opportunistic disease.

Last night I slept nine hours, from 9 to 6; I had also fallen asleep in the afternoon. I am still tired this morning. I hope I can use each weekend to recuperate, for my job is very busy. This is only the second day of a three-day weekend, so I can't tell yet whether the weekend will be long enough. I may have to live with this fatigue. But that is not so difficult as what John has to do, which is to live with his various illnesses and side effects as long as he wants to, as long as he can.

back in

Saturday I waited for the plumber
all morning, & he came at one, but

I'd left the door open & visited
you in the morning. yesterday I

came by twice, & in between got
potting soil so Sue could put up

the plants we'd ordered & dog &
cat food for your larger animals.

today I'm waiting for the extermi-
-nator & trying to read the book

I'm teaching tomorrow. when I come
by this afternoon it will be mask

& gloves & paper gown again, not
because you're contagious but for

fear of what I might bring in,
your white count down again.

we'll relate to each other as if
you're living, we said, but this

way it's hard: you in the hospital
& very sick, your whole attention

focused on your body & your illness.
sure, you're living, but I get left

out of the equation, except for job
& chores, the structure of routine,

& thinking of you, thinking of you
all the time.

4/21/86

moving towards memory

what scares me most is that the
virus often goes to the brain.

such a sharp mind, tongue like
a razor, but beard now unshaved

for weeks. then, yesterday (so
soon), John could not remember

the end of a sentence he'd begun.
at noon, when he seemed to be

miserable from the blood samples
of the morning; in the evening

when his left arm was swollen.
it's happening fast, but this

part is — now at least — more
gentle than I'd expected, like

waking from calm sleep, too
early to be able to piece

sentences together, or remember
what it was one wanted to say.

4/22/86

still alive

he slept through the night:
four to eight — no pain

when he sleeps. I slept:
eight to eleven; eleven

to three; three to four;
up at six. worked.

typed two documents,
played solitaire. mailed

letter at the corner
store, where I got cig-

arettes but no paper
(they didn't have one).

came back. played soli-
taire. till John screamed

just now, & I gave him
a morphine capsule.

he's on his stomach.
wet? I don't know; I

didn't turn him over.
I love you, he said.

I'd said that to him
first, and — let it go now;

I'm all right. I *am*
all right, whatever

that means. it means
ready. & I told him so

& he understands me. it's
time for the others to

tell him too.

10/25/86

10/29/86

I tried, last weekend, to convince John's sister Nancy and his parents John & Lucille to give John the peace & the encouragement to die. With Nancy it was clear; she could not wish it. His father said, "We don't think that way. It's God's will." "Fine," I said, "but let John know that you accept it either way." No luck. I lost the argument.

I did convince his mother, who is a home health aid, to come both weekend days. I was glad Lisa was not available. When I was out on errands Saturday morning, a decision was made to which I was asked to acquiesce: that John would go home with his mother (to his mother) in Holbrook. "That's what John wants," they said. And "we had been thinking about it, but we didn't want to say anything until Johnny said something." Not to me either, who had no notion what they had been thinking about. (The house queer; the house nigger. He's done his job — back to the family into which he was born.)

How could I tell what John wanted. He has been alert these last three weeks only for visitors. To Lisa he says, "I want to die." Sometimes that's what he says to me. Friday night he slept 16 hours. 20 hours Sunday night, when his family had gone.

Tuesday morning I was able to determine that John does want to go. The result is OK with me. We've done our closure really. We love each other.

It's Wednesday now, 9:30. His parents will be here soon. Lisa is here now. Gail has just arrived. I'm doing a laundry. The ambulance is coming at 11 to take John to his parents' home.

how did it end?

when they carried John out of the house (on his way to Holbrook) he

looked up at me as they put him in the ambulance & screamed "Ron! Ron!

Ron!" then they closed the doors, his mother with him, & drove off.

what happened next?

John went to Holbrook, where they set him up in a hospital bed. On

Thursday I visited. the nurse asked me to help her turn John over,

though his mother was there, & trained, as I was not. by Saturday his mother

was less helpless, more in charge. his father was pleased to have John

(who was not queer, who had acknowledged Jesus) home & smiling at him.

what else happened?

Wednesday morning, before his family arrived to take him "home," John said

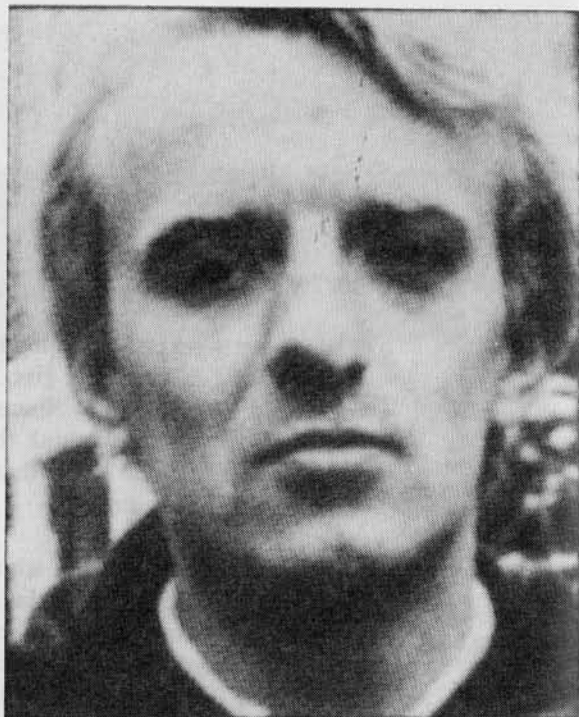
to Lisa: "look after Ron because my family surely won't."

how did it end?

I visited the third time on Tuesday, & spoke with John. when I left the

room to drive home, Nancy went in, but John had already fallen asleep.

11/4/86



how did it end (2)?

I wasn't there. twice before — when John was home with me —

he'd slept a long time: 16 hours, 20 hours. the second time

I'd called Lisa — how do I know if he's died? I asked. & she told me.

I was at a meeting when the call came. Mary, my secretary, came in & signaled

to me. I knew what it was.

Gail was there. his mother was there. John had not awakened but Gail was

talking to him. "I have to go in ten minutes," Gail said. & then

John's hand went limp as she held it. John's mother did not realize, though

she held his other hand. "he's gone," Gail said. & he is.

11/5/86

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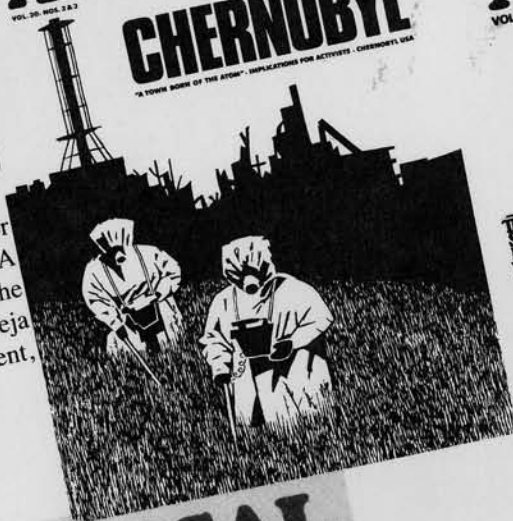
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