

Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement “Newness”

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Shea Stadium is packed. As the Mets play the Astros, New York AIDS activists scream and shout along with the rest of the fans. Their cheers are somewhat different than the usual: “ACT UP! Fight back! Fight AIDS!” Their banners, unfurled in front of the three sections whose seats they have bought out, shout plays on baseball themes: “No glove, no love,” “Don’t balk at safer sex,” “AIDS is not a ballgame.” The electronic billboard flashes some of their messages, as well. The action gets wide coverage the following day. Later, in a 1988 *Newsweek* article on the activist group ACT UP, a baseball fan complains, “AIDS is a fearful topic. This is totally inappropriate.”¹

The fan is right, on both counts; in fact, I would suggest, he inadvertently sums up the point of the action. He also calls attention to the oddities: Why fight AIDS at a baseball game? Why mix fear and Americana? Who or what is the target here?

Susan Sontag and others have noted that the AIDS epidemic fits quite smoothly into a history of understanding disease through the “usual script” of the plague metaphor: originating from “outside,” plagues are visitations on “them,” punishments of both individuals and groups, that become stand-ins for deep fears and tools for bringing judgments about social crisis. “AIDS,” Sontag suggests in her essay “AIDS and Its Metaphors,” “is understood in a premodern way.”²

Yet the plague of AIDS has brought with it understandings and actions that are hardly premodern: civil disobedience at the Food and Drug Administration protesting the sluggish drug-approval process, guerrilla theater and “die-ins,” infiltrations of political events culminating in the unfurling of banners protesting government inaction, media-

geared “zaps,” illegal drug research and sales, pickets, and rallies. AIDS has given rise to a social movement. This is not, in fact, part of the usual script.

Perhaps, then, AIDS can be understood as part of a different script as well. Much has been written in the past decade about “new social movements” (NSMs); perhaps AIDS activism follows an outline particular to contemporary movements. This classification presents its own difficulties: social movements literature has a hard time clarifying what exactly is “new” about contemporary social movements and can, through its fuzziness, easily accommodate yet another social movement without shedding new light.

In this article, I examine AIDS activism—by which I mean an organized “street” response to the epidemic—through the activities of ACT UP (the AIDS Coalition to Unleash Power), its most widespread and publicly visible direct-action group.

ACT UP, which began in New York, has chapters in Chicago, Boston, Atlanta, Los Angeles, Houston, Rochester, Madison, Nashville, San Francisco, and a number of other cities. The groups are loosely federated under the umbrella of the AIDS Coalition to Network, Organize and Win (ACT NOW). New York’s is by far the largest chapter, with weekly meeting attendance in the hundreds and membership estimated near 3,000. San Francisco’s chapter, with a membership of over 700, averages 50 people at general meetings. My comparisons between ACT UP chapters in San Francisco, New York, and other cities are based on a national conference in Washington, D.C., internal publications, informal discussion and interviews, and newspaper reporting.

Using data from six months of participant-observation research (September 1988 through February 1989) in San Francisco’s ACT UP—general meetings, planning meetings, and actions—coupled with local and national internal documents and newspaper writings about the group, I develop an analysis intended both to sharpen focus on the struggle over the meaning of AIDS and to challenge some of the hazy understandings of social movement newness. The analysis here treats ACT UP not as an exemplar but rather as an anomaly, asking what unique conditions constitute the case and how the case can aid in a reconstruction of existing theory.

I begin with a brief review of approaches to contemporary social movements, locating ACT UP within this literature. I then turn to ACT UP’s activities and internal obstacles, looking at its response to the plague script, the alternative scripts it proposes and its strategies for doing so, and the difficulties it faces in this process. I argue that asking “who is the enemy?” provides a fruitful direction for making sense of these dynamics. Examining the forms of domination to which ACT UP

members respond, I argue that in addition to visible targets such as government agencies and drug companies, much of what ACT UP is fighting is abstract, disembodied, invisible: control through the creation of abnormality. Power is maintained less through direct force or institutionalized oppression and more through the delineation of the “normal” and the exclusion of the “abnormal.” I suggest that this “normalizing” process, taking prominence in a gradual historical shift, is increasingly uncoupled from state oppression in recent decades. Responses to normalization play themselves out in ACT UP activities: activists use the labels to dispute the labels and use their abnormality and expressions of gay identity to challenge the process by which normality was and is defined. Finally, I point to directions this framework provides for analyzing contemporary movement.

THE THEORETICAL CONTEXT: WHAT’S NEW?

Among the shifts provoked by the rise of massive social movements in the 1960s and 1970s was a rupture in theorizing about social movements. Until that time, the dominant paradigm of collective behavior theory treated noninstitutional movements as essentially nonrational or irrational responses by alienated individuals to social strain and breakdown.³ Many 1960s activists did not fit the mold. Neither anomie nor underprivileged nor responding to crises with beliefs, as Neil Smelser had argued, “akin to magical beliefs,”⁴ they in fact came together largely from the middle class, with concrete goals and rational calculations of strategies. The predictions of classical social movement theory—who made up social movements and how they operated—had broken down.⁵

In the last two decades, attempts to retheorize social movements have moved in two major directions. North American “resource mobilization” theory accounts for large-scale mobilizations by emphasizing rational calculations by actors, focusing on the varying constraints and opportunities in which they operate and the varying resources upon which they draw.⁶ This paradigm, directly challenging the assumptions of collective behavior theory, insists on the rationality of collective action. European theorists, on the other hand, have argued that rational-actor models are inappropriately applied to new groups seeking identity and autonomy. The movements of the 1960s and their apparent descendants—the peace movement, for example, or feminist, ecological, or local-autonomy movements—have been taken together by theorists as “new” phenomena to be accounted for; it is their nonrational focus on identity and expression that these theories emphasize as distinctive. They attempt to outline the characteristics shared by contem-

porary movements and to discern the structural shifts that might account for new dimensions of activity.⁷

With some notable exceptions,⁸ American theory, with its insistence on instrumental rationality, tends to pass over these distinctive characteristics—feminist attention to “consciousness,” for example, and black and gay “pride”—to which European theories of “new social movements” (NSMs) direct attention. The European literature, then, in that it attempts to explain these apparently new characteristics found also in AIDS activism, provides the stronger conceptual tools with which to approach ACT UP. Yet what is actually “new” according to European NSM theory is both disputed and unclear. Most agree that a middle-class social base is distinctive;⁹ indeed, that NSMs are *not* working-class movements focused primarily on economic distribution seems to be a characteristic on which there is clarity and agreement. From here, the range of characteristics expands and abstracts: NSMs claim “the sphere of ‘political action within civil society’ as [their] space”¹⁰; they use different tactics than their predecessors¹¹; their conflicts concern not “problems of distribution” but “the grammar of forms of life,” arising in “areas of cultural reproduction, social integration, and socialization”¹²; they “manifest a form of middle-class protest which oscillates from moral crusade to political pressure group to social movement”¹³; they are “both culturally oriented and involved in structural conflicts”¹⁴; and they involve a “self-limiting radicalism” that “abandons revolutionary dreams in favor of the idea of structural reform, along with a defense of civil society that does not seek to abolish the autonomous functioning of political and economic systems.”¹⁵

Common to this list is a recognition that the field of operation has shifted, broadly put, to “civil society” and away from the state; that culture has become more of a focal point of activity (through “life-style” and “identity” movements, for example); and that this shift has to do with broad changes in the “societal type” to which movements respond and in which they act. Common to the list is also an unclear answer to the question of how new the shift really is. As Jean Cohen points out, the theme of defending civil society does not in itself imply something new; the question “is whether the theme has been connected to new identities, forms of organization, and scenarios of conflict.”¹⁶ New social movement theorists—even those, like Touraine and Cohen, who address these questions directly—seem to be unclear on what these shifts and changes really are: What exactly is the “cultural field” of “civil society,” and what do these movements actually do there? What is different about contemporary society that accounts for the characteristics of new social movements? When and how did these changes take place?

ACT UP AS A NEW SOCIAL MOVEMENT

ACT UP provides an opportunity both to examine some of these issues concretely and to offer new hypotheses. The AIDS activist movement appears to share the most basic characteristics of “new social movements”: a (broadly) middle-class membership and a mix of instrumental, expressive, and identity-oriented activities. Rather than exclusively orienting itself toward material distribution, ACT UP uses and targets cultural resources as well. What, this examination asks, does ACT UP *do* on the cultural terrain? What light does its activity shed on the question of “newness”? How can a study of this group contribute to an understanding of shifts in the nature of social movements and in the nature of the social world in which they operate?

The answer begins with the group’s overall profile. ACT UP/San Francisco grew out of the 1987 San Francisco AIDS Action Pledge, becoming ACT UP in the fall of that year after New York’s ACT UP began to gain recognition. In addition to planned and spontaneous actions, the group meets weekly in a church in the predominantly gay Castro neighborhood. ACT UP/San Francisco is made up almost exclusively of white gay men and lesbians, mostly in their twenties and thirties. The core membership, an informal group of about forty activists, draws from both “old-time” activists (gay rights, Central American politics, etc.) and those newly politicized by AIDS.¹⁷ Some, but by no means all, of ACT UP’s membership has either tested positive for HIV antibodies or been diagnosed with AIDS. As one member said, “I’m here because I’m angry and I’m tired of seeing my friends die.” The membership is typically professional and semiprofessional: legal and health care professionals, writers, political organizers, students, and artists with day jobs. ACT UP/New York and ACT UPs in other cities exhibit similar profiles.¹⁸

Self-defined in its flyers and media kits as “a nonpartisan group of diverse individuals united in anger and committed to direct action to end the AIDS crisis,” ACT UP pushes for greater access to treatments and drugs for AIDS-related diseases; culturally sensitive, widely available, and explicit safe-sex education; and well-funded research that is “publicly accountable to the communities most affected.”¹⁹ Moreover, the group pushes for the participation of people with AIDS (PWAs) in these activities.²⁰ The idea here is to change the distribution of resources and decision-making power; the principle guiding actions is strategic, aimed at effecting policy changes. “People have been fighting for social justice in this country for centuries,” says one member. “We’re going to get aerosol pentamidine [a treatment drug for pneumocystis pneumonia] a lot quicker than we’re going to get social justice.”

ACT UP is also often involved in actions, however, whose primary principle is expressive. They focus inward, on "building a unified community" (the gay and lesbian community and, increasingly, a subcommunity of PWAs and the HIV-infected) and on the "need to express the anger and rage that is righteous and justified" from the community outward. They organize at times around actions in which AIDS is not the central issue or in which AIDS activism is incorporated into the project of "recreating a movement for gay and lesbian liberation." This orientation toward identity and expression, while not excluding older-style strategic action, is one key characteristic cited by students of post-sixties social movements.

Most interestingly, though, one hears and sees in ACT UP a constant reference to theater. ACT UP operates largely by staging events and by carefully constructing and publicizing symbols; it attacks the dominant representations of AIDS and of people with AIDS and makes attempts to replace them with alternative representations. At times, ACT UP attacks the representations alone; at times it combines the attack with a direct one on cultural producers and the process of AIDS-image production.

Another action principle weaves through ACT UP. As *Newsweek* put it, ACT UP has often "deliberately trespassed the bounds of good taste"²¹: throwing condoms, necking in public places, speaking explicitly and positively about anal sex, "camping it up" for the television cameras. This trespassing, or boundary-crossing—and we can include in it the infiltration of public and private spaces (the Republican national convention, for example, where activists posing as participants unfurled banners)—both uses and strikes at the cultural field as well. In this case, rather than reacting to images of AIDS, activists use a more general tactic of disturbing "good taste" and, in a point *Newsweek* characteristically misses, calling attention to the connection between cultural definitions and responses to AIDS. Boundary-crossing, along with theatrical and symbolic actions, makes clear that ACT UP operates largely on the cultural field where theorists situate new social movements. (By way of comparison, most AIDS politics does not operate according to this description, but according to a more conventional political model. "Most AIDS politicking," as Dennis Altman describes it, "has involved the lobbying of federal, state, and local governments. . . . [This] has meant dependence upon professional leaders able to talk the language of politicians and bureaucrats."²²) It also suggests that an examination of the specific patterns of culturally oriented actions may be especially revealing. By focusing on the cultural activities of AIDS activists as a key *distinctive* element, I by no means want to suggest that this activism is primarily cultural. In fact, treatment issues, needle-exchange pro-

grams, and access to health care are all common subjects of action. Pursuing this via ACT UP's peculiarities, I hope to generate possibilities for grounding and developing social movement theory.

ACT UP'S INTERNAL OBSTACLES

Let us examine ACT UP's distinctive characteristics. ACT UP's strong cultural orientation has already been noted. In addition, buried in its various strategies are several fundamental confusions. First, an orientation toward theatrics suggests a clear delineation of performer from audience, yet actions are often planned by ACT UP members without an articulation of whom they are meant to influence. If one wants to affect an audience—for example, by invoking a symbol whose meaning is taken for granted and then giving it a different meaning—one needs a clear conception of who that audience is. In ACT UP planning meetings, there is often an underlying confusion of audiences, and more often the question of audience is simply ignored. When activists in New York infiltrated a Republican women's cocktail party and later unfurled banners ("Lesbians for Bush," read one), the response of the cocktail partiers, a defensive singing of "God Bless America,"²³ was important not for what it showed about the Republicans' AIDS consciousness but for what it showed the activists about their own power. They were, in effect, their own audience, performing for themselves and making others perform for them. In "brainstorms" for new actions, there is almost never a mention of audience, and action ideas with different audiences proliferate. ACT UP protested Michael Dukakis's visit to San Francisco in September 1988, for example, with no media coverage, Dukakis nowhere in sight, and no one to witness the protest but passing cars. In the meetings I observed, I commonly heard suggestions for actions that bypassed any actual event, heading straight for the at-home audience through "photo opportunities," mixed in with suggestions for actions that almost no one will see. Much of this confusion is exacerbated by an openness of exchange and decentralized decision making born of ACT UP's democratic structure (in San Francisco, decisions are made consensually). The loose organizational structure acts against focused planning and action.

A second point of confusion is that while ACT UP professes to be inclusive, and ideas are often brought up that target nongay aspects of AIDS (issues of concern to injection drug users, for example, or access to health care for those who cannot afford it), there are few signs that ACT UP in fact succeeds at including or actively pursues nongay members. This does not mean that the membership is exclusively gay men; in fact, a good portion of the activists are women.²⁴ The formation of

coalitions is sometimes brought up as a good idea—"we need to join with others in solidarity around common suffering and common enemies," said the keynote speaker at the ACT NOW conference in October 1988—but generally not effected. Cooperative actions with other groups generate less excitement in San Francisco meetings. Actions are aimed mainly at targets with particular relevance to lesbians and gays; there are few black or Hispanic members, gay or straight. Despite the goal of inclusiveness, ACT UP continues to draw from and recreate the white middle-class gay and lesbian community.

A third and related problem is perhaps even more fundamental: AIDS politics and gay politics stand in tension, simultaneously associated and dissociated. ACT UP is an AIDS activist organization built and run by gay people. Historically, this is neither surprising nor problematic; among the populations first hit hardest by AIDS, gay people were alone in having an already established tradition and network of political and self-help organizations. Still, it has meant, as Dennis Altman writes, that "AIDS groups have found it very difficult to establish themselves as nongay, even where they have deliberately presented themselves as such."²⁵ AIDS activists find themselves simultaneously attempting to dispel the notion that AIDS is a "gay disease" (which it is not) while, through their activity and leadership, treating AIDS as a gay problem (which, among other things, it is).

While this dilemma is in part due to the course the disease itself took, how it plays itself out in ACT UP is instructive. For some—particularly those members who are not newly politicized—ACT UP is gay politics, pure and simple, a movement continuous with earlier activism. They emphasize the need for "sex positive" safe-sex education, for example, linking AIDS politics to the sexual liberation of earlier gay politics. The main organizer of a November 1988 election-night rally in the Castro district, for the gay community to "Stand Out and Shout" about results, envisioned it as a return to the "good old days" of gay celebration. In planning the rally, he and others quickly generated a long list of possible speakers—from the gay political community. Here, AIDS issues often get buried.

For other members, it is important to maintain some separation, albeit a blurry one, between the two sets of issues. In New York, for example, when a newspaper calls ACT UP a "gay organization," ACT UP's media committee sends out a "standard letter" correcting the error.²⁶ The ACT UP agenda, when the balance is toward distinctively AIDS politics, often focuses more narrowly on prevention and treatment issues—as in, for example, a San Francisco proposal for an "AIDS treatment advocacy project," which argues that "whether it is an entire family with AIDS in Harlem or an HIV+ gay man in San Francisco,

treatment is ultimately the issue they are most concerned with."²⁷ More commonly, though, ACT UP actions don't fall on one side or the other, but combine an active acceptance of the gay-AIDS connection with an active resistance to that connection.

VISIBLE AND INVISIBLE ENEMIES

Why do these particular confusions occur? They eventually come to make sense as the particularities of ACT UP's actions are examined. These three confusions within ACT UP, which seem to give its action a somewhat unfocused character, in fact prove to be core elements of the group's being. Explaining ACT UP's confusions, and those of social movements like it, hinges on the answer to a pivotal question: *Who is the enemy?* Asking this question of ACT UP, one often finds that the enemies against which their anger and action are directed are clear, familiar, and visible: the state and corporations. At other times, though, the enemy is invisible, abstract, disembodied, ubiquitous: it is the very process of "normalization" through labeling in which everyone except one's own "community" of the denormalized (and its supporters) is involved. At still other times, intermediate enemies appear, the visible institutors of the less visible process: the media and medical science.

The second enemy forms the basis of my core theoretical claim: that ACT UP is responding to a gradual historical shift toward a form of domination in which power is maintained through a "normalizing" process in which, as Michel Foucault describes it, "the whole indefinite domain of the nonconforming is punishable."²⁸ Through labeling, or socially organized stigmatization, behaviors and groups are marked as abnormal; in the last two centuries, the norm has largely replaced the threat of violence as a technique of power. As Foucault argues, individuals are differentiated "in terms of the following overall rule":

that the rule be made to function as a minimum threshold, as an average to be respected or as an optimum towards which one must move. It . . . hierarchizes in terms of values the abilities, the level, the "nature" of individuals. It introduces, through this "value-giving" measure, the constraint of a conformity that must be achieved. Lastly, it traces the limit that will define difference in relation to all other differences, the external frontier of the abnormal.²⁹

In this process, the dominator becomes increasingly abstracted and invisible, while the dominated, embodied and visible (and, importantly, "marked" through stigmatization), becomes the focus of attention. In effect, people dominate themselves; rather than being confronted with a punishment (physical, material) as a mechanism of control, they confront themselves with the threat of being devalued as abnormal.

These ideas are not incompatible with those put forward by the sociology of deviance and discussions of stigmatization, which of course call attention to the process of labeling and its impact on the "deviant." However, the various forms of labeling theory have also been challenged by collective action since the 1960s. Those theories, by studying how one "becomes deviant," and the defensive reaction of "deviants" to an identity defined for them—the "management of spoiled identities," in Erving Goffman's terms, and "secondary deviation" as a "means of defense" against the "problems created by the societal reaction to primary deviation," in the words of Edwin Lemert³⁰—are ill equipped to explain the organization of the stigmatized into social movements. As John Kitsuse argues, the accommodative reactions analyzed by deviance sociology (retreat into a subculture, nervously covering up or denying aberrations) do not "account for, nor do they provide for an understanding of, the phenomenal number of self-proclaimed deviant groups that have visibly and vocally entered the politics" of recent decades.³¹ Earlier theories are hard pressed to account for historical change and for the assertive building of collective movements based on self-definitions that reject the dominant definitions. Foucault, on the other hand, treats pressure for conformity not as a given problem for the "deviant," but as a technique of power with a variable history.

Identity strategies are particularly salient and problematic within this domination form. When power is effected through categorization, identity is often built on the very categories it resists. ACT UP's expressive actions, in this light, are part of a continuing process of actively forging a gay identity while challenging the process through which it is formed for gay people—at a time when the stigma of disease has been linked with the stigma of deviant sexuality. ACT UP members continue to organize around the "deviant" label, attempting to separate label from stigma. Identity-oriented actions accept the labels, and symbolic actions disrupt and resignify them.

Identity actions and representational strategies thus stand in awkward relationship: they are increasingly linked in the attack on the normalization process itself. In a simpler identity politics—the celebration of gay liberation, for example—labels are important tools for self-understanding. That sort of politics involves what Kitsuse calls "tertiary deviation," the "confrontation, assessment, and rejection of the negative identity . . . and the transformation of that identity into a positive or viable self-conception."³² ACT UP members, however, push past this "new deviance" to use stigmas and identity markers as tools against the normalization process. The representation of oneself as abnormal now becomes a tool for disrupting the categorization process; the labels on which group identity is built are used, in a sense, against themselves.

Why, though, is this response to "normalizing power" coming into its own now? Stigmatization is certainly not new. Foucault, in *Discipline and Punish*, traces a shift in the eighteenth and nineteenth centuries, a shift that takes place primarily in technologies of control—the rise of surveillance techniques and the constitution of the subject by "experts" and scientific discourse. This shift has arguably solidified in this century in Western societies. Yet, while state institutions and actors in the twentieth century certainly have still been involved in the normalization process (as well as in direct repression), they have evidently been *less* involved in the latter half of this century (or, stated less strongly, less visibly involved). One sees this in the history of civil rights: racism continues while state-sponsored racism and racist policies become less acceptable.³³ Similarly, state definitions of women's "roles" have been liberalized, as the state has withdrawn somewhat from prescribing "normal" female behavior. One sees this as well in the response to AIDS: the federal government, while conservative or split in its policies, has over time become somewhat more liberal in terms of labeling. Public health officials advertise AIDS as an "equal opportunity destroyer," the Surgeon General warns against treating AIDS as a gay disease and argues in favor of protections against discrimination; the Presidential Commission calls for "the reaffirmation of compassion, justice, and dignity" and indicts, among other things, "a lack of uniform and strong antidiscrimination laws."³⁴ State institutions increasingly refuse to "discriminate," that is, to set policies based on social labels. As the state becomes less directly involved in normalization, the process itself necessarily becomes more an independent point of attack by the denormalized—and is resisted as a process. It is within this overall historical shift in methods of domination, I propose, that ACT UP's social movement activity makes sense.

ACT UP AND NORMALIZATION

How does this resistance play itself out? What is the link between enemies and actions? Let's begin with the old forms of domination, which are very much still at work. The state is certainly involved in the domination of people with AIDS, as it is in the repression of sexual minorities. The federal Food and Drug Administration has been sluggish in approving AIDS-related drugs; it is perceived as allowing bureaucracy to get in the way of saving or prolonging lives. In October 1988 ACT NOW organized a conference, teach-in, rally, and day of civil disobedience in Washington, D.C., to "seize control of the FDA."³⁵ The Reagan and Bush administrations have been notoriously inattentive to the AIDS epidemic. Reagan first mentioned AIDS publicly at a time when

over 36,000 people had already been diagnosed and over 20,000 had died from the disease. While subsequently calling AIDS "America's number one health problem," the administration has consistently avoided initiating a coordinated, adequately financed attack on that problem.³⁶ Reagan and Bush have become common targets of ACT UP "AIDSgate" signs and t-shirts, of "zaps," of posters charging that "the government has blood on its hands," of disruption and protest during campaign speeches. In this case, specific state institutions and actors are targeted, mostly through conventional protest actions and media-gearred actions. In these cases, it is quite clear who is responsible for needless death and who is controlling resources, and ACT UP functions as a pressure group to protest and affect policy decisions. Here, AIDS politics and gay politics are quite separable and separated.

Similarly, pharmaceutical companies are manifest enemies; they control the price of treatment drugs and make decisions about whether or not to pursue drug development. That drug company decisions are guided by considerations of profit is a direct and visible instance of oppression and represents an embodied obstacle to the physical survival of people with AIDS. For example, AZT (azidothymidine, the only drug approved at this writing for treatment of AIDS illnesses) cost \$13,000 a year in 1987. Again, ACT UP attacks these targets with pressure tactics: boycotting AZT manufacturer Burroughs-Wellcome, zapping that company and others with civil-disobedience actions, publicizing government-drug company relations.³⁷ In this example, again, the focus is specifically on issues of relevance to all people with AIDS.

Yet AIDS has also been from the outset a stigma, an illness constructed as a marker of homosexuality, drug abuse, moral deficiencies—stigmas added to those of sexual transmission, terminal disease and, for many, skin color.³⁸ AIDS has

come to assume all the features of a traditional morality play: images of cancer and death, of blood and semen, of sex and drugs, of morality and retribution. A whole gallery of folk devils have been introduced—the sex-crazed gay, the dirty drug abuser, the filthy whore, the blood drinking voodoo-driven black—side by side with a gallery of "innocents"—the hemophiliacs, the blood transfusion "victim," the newborn child, even the "heterosexual."³⁹

Bolstered most commonly by the image of the male homosexual or bisexual AIDS "victim" or "carrier," vaguely responsible through deviant behavior for his own demise, AIDS has been appropriated to medicalize moral stances: promiscuity is medically unsafe while monogamy is safe; being a member of certain social groups is dangerous to one's health, being a member of the "general population" is dangerous only

when the un-general contaminate it. As Simon Watney notes, in AIDS "the categories of health and sickness . . . meet with those of sex, and the image of homosexuality is reinscribed with connotations of contagion and disease, a subject for medical attention and medical authority."⁴⁰

The construction and reconstruction of boundaries has been an essential aspect of the story of AIDS. The innocent victim is bounded off from the guilty one, pure blood from contaminated, the general population from the AIDS populations, risk groups from those not at risk. Those who span the boundaries arguably become the most threatening: the promiscuous bisexual, the only one who can "account for and absolve the heterosexual majority of any taint of unlawful desire," and the prostitute, with her longstanding position as a vessel of disease.⁴¹

Who achieves this demarcation of boundaries? Who has made AIDS mean what it does? Who is the enemy? Two manifest producers of stigmas appear (in addition to certain public figures who disseminate them): the mass media, on whose television screens and newspaper pages the stigmatized are actually visible, and medical science, which translates the labels into risk-group categories. ACT UP thus challenges the medical establishment, largely by undermining the expertise claimed by them: activists keep up to date on and publicize underground and foreign treatments, sell illegal treatment drugs publicly, yell the names of known AIDS-illness drugs in front of the FDA ("Show them we know!" the organizer calls). They wear lab coats, and prepare a "guerrilla slide show" in which they plan to slip slides saying "He's lying" and "This is voodoo epidemiology" into an audio-visual presentation by a health commissioner.

ACT UP also sets up challenges to the media. An ongoing San Francisco battle had ACT UP shutting down production and members negotiating with producers over the script of an NBC drama, "Midnight Caller." In the script a bisexual man with AIDS purposely infects others and is shot and killed in the end by one of his female partners. It was objected to by ACT UP members as playing on "the great fear of the 'killer queer'"⁴² and implying that, as an ACT UP representative put it, "basically it's justifiable to kill a person with AIDS."⁴³ A similar response has been discussed for the San Francisco filming of Randy Shilts's *And the Band Played On*, a controversial history of the American AIDS epidemic. The media are usually treated by ACT UP as allies in the public-relations operation of garnering coverage. As one New Yorker put it in October 1988, "the media aren't the enemy, the media are manipulated by the enemy, and we can manipulate them too." When actively involved in the labeling of people with AIDS as murderers, however, the media become the enemies to be fought. This

ambivalence makes sense: the media, as the institutional mechanism through which normalization is most effectively disseminated, are both a visible enemy and a necessary link to a more abstract form of domination.⁴⁴

The question of who is behind the generation and acceptance of stigmas, though, for the most part doesn't get asked as activists plan and argue, perhaps because the answer is experienced daily: everyone and no one. No one actually does it and everyone participates in it—your family and your neighbors as well as the blatant bigots farther way. It's a process that appears usually as natural, as not-a-process.

PLAYING WITH LABELS, CROSSING THE BOUNDARIES

Fighting this largely hidden process calls for different kinds of strategies, mostly in the realm of symbols. Examining the symbolic maneuverings of ACT UP, we can begin to see how fighting the process calls for particular strategies. ACT UP's general strategy is to take a symbol used to oppress and invert it. For example, ACT UP makes explicit challenges, guided by other AIDS activists and particularly by PWAs, on the kind of language used to discuss AIDS. In place of the "AIDS victims," they speak of "people with AIDS" (or "people living with AIDS"); in place of "risk groups," they insert the category of "risk practices." They talk about blood and semen rather than "bodily fluids" and challenge the exclusionary use of "general population."⁴⁵

The strategy runs much deeper than speech, however. The visual symbol most widely publicized by American AIDS activists—"SILENCE = DEATH" written in bold white-on-black letters beneath a pink triangle, the Nazi mark for homosexuals later coopted by the gay movement—provides a snapshot look at this process. Here, ACT UP takes a symbol used to mark people for death and reclaims it. They reclaim, in fact, control over defining a cause of death; the banner connects gay action to gay survival, on the one hand, and homophobia to death from AIDS, on the other. ACT UP's common death spectacles repeat the inversion. In AIDS commentary death is used in a number of ways: it is either a punishment (the image of the withered, guilty victim), an individual tragedy (the image of the lonely, abandoned dying), or a weapon (the image of the irresponsible "killer queer").⁴⁶ A "die-in," in which activists draw police-style chalk outlines around each other's "dead" bodies, gives death another meaning by shifting the responsibility: these are deaths likened to murders, victims not of their own "deviance," but shot down by the people controlling the definition and enforcement of "normality." You have told us what our deaths

mean, their actions say; now we, who are actually dying, will show you what they mean.

A similar shift of responsibility takes place around the symbol of blood. In popular discussions of AIDS, blood typically takes its place in discussions of "purity" and a benevolent medical establishment working to keep "bad blood" out of the nation's blood supply. In many ACT UP activities, "blood" is splattered on t-shirts or doctor's uniforms. Members want to shoot it out of squirt guns, blood-balloon it onto buildings, write "test this" with it on walls. Here, on one level, they use the established discourse of purity against its users as an angry weapon: "infected" blood is everywhere. On another level, though, the frame is shifted from purity (in which the blood supply is "victimized") to crime (in which PWAs are victimized). The blood becomes evidence not of infection, but of murder. The activists are blood-splattered victims, as was made explicit in posters originally directed at Mayor Koch in New York and later translated into an indictment of the federal government. "The government has blood on its hands," the sign says, "One AIDS death every half hour." Between the two phrases is the print of a large, bloody hand. In a San Francisco rally against Rep. William Dannemeyer's Proposition 102, which would have required by law that doctors report those infected and those "suspected" of infection, require testing at the request of doctors, employers, or insurers, and eliminate confidential testing, ACT UP carried a "Dannemeyer Vampire" puppet. The vampire, a big ugly head on a stick, with a black cape and with blood pouring from its fangs, was stabbed with a stake later in the action. Here, ACT UP activates another popular code in which blood has meaning—the gore of horror movies—and reframes blood testing as blood sucking. It's not the blood itself that's monstrous, but the vampire who would take it. By changing the meaning of blood, ACT UP activists dispute the "ownership" of blood; more importantly, they call attention to the consequences of the labels of "bad" blood and "purity" and implicate those accepting the labels in the continuation of the AIDS epidemic.

Boundary-crossing, although tactically similar, goes on the offensive while inversions are essentially reactive. The spectacle of infiltration and revelation runs through real and fantasized ACT UP actions. Members speak of putting subversive messages in food or in the pockets of suit jackets, of writing messages on lawns with weed killer, of covering the Washington Monument with a giant condom, of replacing (heterosexual) bar ashtrays with condom-shaped ashtrays. They place stickers saying "Touched by a Person with AIDS" in phone booths and stage a mock Inauguration through the San Francisco streets during rush hour. The idea, as one activist puts it, is to "occupy a space that's not

supposed to be yours," to "usurp public spaces." San Francisco's underground graffiti group, specializing in "redecorating" targeted spaces, sums up the principle in its humorous acronym, TANTRUM: Take Action Now To Really Upset the Masses.

The ideas that charge brainstorming sessions and the eventual choices for visual and theatrical activity at actions are not arbitrary. The selections are revealing. Spaces and objects are chosen that are especially American (that is, middle American—lawns, cocktail parties, baseball games, patriotic symbols, suits) and presumably "safe" from the twin "threats" of homosexuality and disease. ACT UP here seizes control of symbols that traditionally exclude gay people or render them invisible, and take them over, endowing them with messages about AIDS; they reclaim them, as they do the pink triangle, and *make them mean* differently. In so doing, they attempt to expose the system of domination from which they reclaim meanings and implicate the entire system in the spread of AIDS.

It is important to notice that ACT UP's identity-oriented actions often revolve around boundary-crossing and label-disruption. These are strategies for which these mostly white, middle-class gay people are particularly equipped, largely because their "stigma" is often invisible (unlike, for example, the stigmatized person of color). They can draw on a knowledge of mainstream culture born of participation rather than exclusion and thus a knowledge of how to disrupt it using its own vocabulary. Here the particular cultural resources of ACT UP's membership become important; they are resources that other movements (and gay people from other races or classes) may not have to the same degree or may not be able to use without considerable risk.

Gay campiness, raunchy safe-sex songs in front of the Department of Health and Human Services, straight-looking men in skirts wearing "Fuck Me Safe" t-shirts, lesbians and gay men staging "kiss-ins," a general outrageousness that "keeps the edge"—these actions simultaneously accept the gay label, build a positive gay identity, challenge the conventional "deviant" label, connect stigmatization to AIDS deaths, and challenge the very process of categorization. This is the power of the pink triangle and "Silence = Death": the building of an identity is linked with the resistance of a stigma as the key to stopping the AIDS epidemic. "We are everywhere," says a sign at an ACT NOW rally, a sign common at gay political demonstrations, and the noisy expressions of collective anger and identity add up to the same claim. Here, the gay "we" and the AIDS "we" are melded; the destabilizing effect of the suddenly revealed homosexual is joined with the fear that suddenly no space is safe from AIDS. A chant at several San Francisco protests captures the link between asserting an identity and challenging the la-

bels: "We're fags and dykes," the activists chant, "and we're here to stay." Meaning: we are what you say we are, and we're not what you say we are. "We're here," they chant, "we're queer, and we're not going shopping."

What exactly is being challenged in these symbolic inversions? Certainly, in symbols like the Dannemeyer vampire and the bloody hand attributed to the government, the old and consistent enemy, the state, is mixed in; but it isn't exclusive. ACT UP disrupts symbolic representation, heeding the call to "campaign and organize in order to enter the amphitheater of AIDS commentary effectively and unapologetically on our own terms."⁴⁷ It does so, moreover, often through symbols that are not tied to the state but to "mainstream" American culture. In the case of inversions, AIDS and gay labels are not necessarily linked: any oppressive marker is taken over. In the case of boundary-disruption, AIDS and gay labels are connected: the fear of gay people and the fear of AIDS, now linked in the normalization process, are used to call attention to themselves. In both cases, the *process* of stigmatization, by which symbols become markers of abnormality and the basis for decisions about "correcting" the abnormal, is contested.

STRATEGIES AND OBSTACLES REVISITED

The mix of strategies can be seen in terms of the visibility of enemies.⁴⁸ More familiar, instrumental pressure-group strategies attempt to change the distribution of resources by attacking those visibly controlling distribution. Identity-forming strategies are particularly crucial and problematic when the struggle is in part against a society rather than a visible oppressor. Label disruption—contained in identity-forming strategies, and the core of symbolic strategies—is a particular operation on the cultural field. It is made necessary by a form of domination that operates through abstractions, through symbols that mark off the normal. (I am not suggesting, of course, that these are discrete types in concrete actions; actions are always mixed exactly because the forms of domination are simultaneous.)

We can also make sense of ACT UP's internal obstacles through this lens. It is not surprising that the question of audience becomes a difficult one to address. First of all, the audience often *is* the group itself when identity formation becomes a key part of the struggle. Yet at the same time, we have seen that identity struggles involve pushing at the very labels on which they are based, and here the audience is the entire society. Actions are thus often founded on a confusion of audiences. More commonly, the question of audience is simply lost as the underlying target of action is the normalization process. While it might be

more “rational” for ACT UP activists to try to spell out the particular audience each time they design an action, the struggle in which they are involved makes the particularity of an audience difficult to see. When stigmatization is being protested, the audience is the undifferentiated “society”—that is, audience and enemy are lumped together, and neither is concretely graspable.

Understanding that ACT UP is attacking this particular form of domination, we can also see why ACT UP is caught between association and dissociation of AIDS politics from gay politics. Clearly, PWAs and gay people are both subject to the stigmatization process; this process, as it informs and supports responses to AIDS, has become literally lethal for PWAs, gay and nongay, and dangerous for those labeled as “risk group” members, gay men (and often by an odd extension lesbians), drug users, prostitutes, blacks, and Hispanics. Socially organized labels that, before AIDS, were used to oppress are now joined with the label of “AIDS victim.” This form of domination is *experienced* by ACT UP members as a continuous one. AIDS is a gay disease because AIDS has been made to attribute viral disease to sexual deviance. Separating AIDS politics from gay politics would be to give up the fight against normalization.

Yet joining the two politics poses the risk of losing the fight in that it confirms the very connection it attempts to dispel. This is a familiar dilemma, as Steven Epstein points out, and one that is not at all limited to the gay movement: “How do you protest a socially imposed categorization, except by organizing around the category?”⁴⁹ Organizing around a resisted label, in that it involves an initial acceptance of the label (and, in identity-oriented movements, a celebration of it), can tend to reify the label. Identity politics thus contain a danger played out here: “If there is perceived to be such a thing as a ‘homosexual person,’ then it is only a small step to the conclusion that there is such a thing as a ‘homosexual disease,’ itself the peculiar consequence of the ‘homosexual lifestyle.’”⁵⁰ The familiarity of the dilemma, though, should not obscure its significance. This is a dilemma attributable neither simply to the random course of AIDS nor to mistakes on the part of activists, but to the form of domination to which social movements respond.

In this light, it is not surprising that ACT UP has difficulty including nongays and forming coalitions. In some ways, ACT UP is driven toward inclusiveness because AIDS is affecting other populations and because the fight includes more broad-based struggles over resources. But, as we have seen, resistance to labeling involves accepting the label but redefining it, taking it over. Group identity actions are bound up with this resistance. This drives ACT UP strongly away from inclusive-

ness. The difficulty in walking these lines—between confirming and rejecting the connection between gay people and AIDS, between including and excluding non-gays—is built into the struggle against normalization in which ACT UP is involved.

BODIES AND THEORIES

I have argued that ACT UP responds to the script of the AIDS plague by undermining that script, resisting the labeling through which contemporary domination is often effectively achieved. This seems to be missed by most observers of AIDS, who interpret the politics of AIDS on the model of conventional politics. Randy Shilts’s 1988 bestseller, for example, ignores the development of grassroots AIDS activism even in its updating epilogue. AIDS serves as a particularly vivid case of disputed scripts in American politics, in that the epidemic of disease, as others have noted, has occurred simultaneously with what Paula Treichler calls an “epidemic of signification”; AIDS exists “at a point where many entrenched narratives intersect, each with its own problematic and context in which AIDS acquires meaning.”⁵¹ ACT UP illustrates this, treating the struggle over the narratives opened and exposed by AIDS as potentially life-saving.

ACT UP also illustrates major effects of this historical shift. If, as I propose in drawing on Foucault, domination has gradually come to operate less in the form of state and institutional oppression and more in the form of disembodied and ubiquitous processes, it is hardly surprising that diseased bodies become a focal point of both oppression and resistance. As the enemy becomes increasingly disembodied, the body of the dominated—in this case, primarily the diseased, gay male body—becomes increasingly central. The AIDS epidemic itself fits this process so well as to make it seem almost inevitable: the terror of the disease is that it is an enemy you cannot see, and, like the labels put to use in normalizing power, it is spread invisibly. AIDS activism in part struggles against this disembodied type of power by giving that body—its death, its blood, its sexuality—new, resistant meanings. The plague script meets here with the script of new social movements.

But what does this tell us about theorizing new social movements? First, it calls into question the value of “newness” as a reified category of analysis. In suggesting that the history of “enemies” and types of domination is central to understanding ACT UP, this study points to a gradual shift rather than a radical break in movement activity; “newness” militates toward a focus on a moment (the sixties) rather than a history that reaches back into, for example, the eighteenth and nine-

teenth centuries (as in the historical transformation that Foucault describes). It obscures what may be instructive continuities across time.

Second, this study points toward ways of distinguishing among contemporary movements. To assert that ACT UP exemplifies contemporary movements would clearly be to overstate the case; rather, this analysis demonstrates the insufficiency of analyzing different movements as like phenomena simply because of a shared cultural and identity focus. Operating on the "cultural field" means something more specific than focusing on problems that "deal directly with private life"⁵² or even targeting and using narrative and artistic representation. ACT UP's cultural strategies reclaim and resignify oppressive markers. Orienting actions toward identity formation means something more specific than "defend[ing] spaces for the creation of new identities and solidarities."⁵³ Identity assertions in ACT UP point up boundaries, using the fear of the abnormal against the fearful. These are specific operations that may be shared by other contemporary social movements—those subject to stigmatization, for example, and which are also in a position to "shock"—and not by others. Stigmatization, moreover, may take different forms and give rise to different types of movement activity. Whether in Shea Stadium or at the FDA, discerning the types of enemies to whom movements are responding is a task for analysts of social movements as well as for activists within them.

AFTERWORD: THE PROBLEM OF PROBLEMLESSNESS

At the end of my first week in the field, having been to one ACT UP meeting, I had lunch with a fellow graduate student, whose expertise in the sociology of AIDS I wanted to tap. As I described the meeting I'd attended, he detected a certain irritation. He recommended that I pay close attention to that irritation—some of which was simply discomfort with being in a new situation and with being in an explicitly gay situation—and not let it get in the way. Good advice.

The substantive target of my irritation, though, was that ACT UP couldn't seem to successfully distinguish between gay politics and AIDS politics. That was something, my colleague said, that was simply taken for granted—perhaps a problem for the actors but not central to discussions of the politics surrounding AIDS. So I dropped the issue. It wasn't until two months later that I returned to this as a central problem, a central dilemma to be explained. This is odd: a problem that no one has been able to resolve, that I was able to dismiss as simply part of a description of the field. Why couldn't I see it?

Observing myself in retrospect, I see that I stumbled on some major obstacles built into the method of participant observation. Basically, I suffered chronically from the *problem of problemlessness*. The block was not just my stupidity, although my stubborn insistence that each new perception of mine was "obvious," and my stubborn drive to disdain the obvious, certainly exacerbated the problem. The first major barricade was what I would call the problem of obviousness. The roots of this problem, I think, were a too-closeness, an overlap between my background and experience and the people I was observing, and an immersion in the field.

I had worked in political organizations before; I had made consensus decisions with sixty people before; I had sat through discussions pulling in different directions before; I had even been in anti-Vietnam War demonstrations, albeit in a baby carriage. These people were around my age, with the same sort of socioeconomic backgrounds; I had gone to college and graduate school with people very much like this, people who looked like this, dressed like this, talked like this, joked like this. In fact, I was very much like this. Although gay culture, with which I was not especially familiar at the time, played an important part, ACT UP members didn't seem much different from the primarily straight social and political settings to which I'd been accustomed. I may not have been comfortable in ACT UP at first, but it certainly felt like a familiar scene. Thus, in my first set of field notes, I complain of feeling, "Oh, this again": "The same shoestring radical organization shtick, trying to do everything, pulls in a million different directions. The same questions for me of how effective things really are. The same liberal-radical tensions, the same lofty ideals vs. realistic goals tensions."

I wasn't feeling that I knew it all, that I had it pegged, but that I needed to find the "unfamiliar elements." The more I became immersed in the research, the more used to ACT UP modes and ACT UP meetings, the more obvious everything seemed. Because I was so much the same as the people I was studying, and because I became so easily involved in what they were doing, every new problem or observation made me think, "Of course"—of course AIDS politics and gay politics are meshed, everybody knows that, now let's get on with it. What was going on seemed too obvious because it was too like my experience; I longed for a project on old people, fascists, primitive tribes.

The sense of obviousness became a constant frustration and source of anxiety: Am I really seeing anything distinctive or new? Am I really saying anything distinctive or new? Where's the problem? This dynamic itself now seems to me, of course, obvious. The deeper problem, though, was not anxiety, but a genuine sense of being stuck. I was

registering what would later become core problems, but registering them descriptively: symbolic politics, blood-throwing and kiss-ins, identity politics, all got detailed play in my field notes, but without a sense of strangeness.

How, then, to get on with it? Apparently, I needed a distance from my “subjects” that I wasn’t likely to find or able to create in the field. At Michael Burawoy’s suggestion, I turned to the literature on new social movements as a way of pulling back from the field site. It did provide distance, but also led me to what I would call the problem of theory worship. Riding my bicycle to campus after a day of reading, I pulled over suddenly to scribble a theoretical framework that would bridge the theory and the interest I had started with: I could ask how the balance between strategic and identity-oriented actions (which the new social movements were reputed to involve) affects the production and power of representations that challenge the dominant discourse (my original interest). From here, I went into a period of wild abstractions; the problem for me—and I was still in search of something that felt like a genuine problem to be worked through—was how to use the theory to shed light on ACT UP. More accurately, I was trying to squish my data into a somewhat prefabricated theoretical framework, to make them fit.

This meant that I wasn’t attentive to exactly what’s interesting in a setting: the things that don’t fit. Having found at first that the way ACT UP worked was obvious, and obvious things weren’t problematic, I had run to theory; there, from the great distance provided by theory, I approached ACT UP as data to be taken as instances of already developed theory, again militating against seeing problems as problems. The question of why particular characteristics were found in my setting was already answered by the theory. So, still, no problem.

Interestingly, I think it is a move toward arrogance, a principled chutzpah, that allowed me to see, at least hazily, the problems in front of me as problems. Rather than allow the theory to tell me what ought to be going on in ACT UP, I would use ACT UP to show what was wrong with, or incomplete about, the theory. This approach directed me toward those distinctive components that the literature didn’t anticipate or couldn’t make sense of—the weird symbol plays, the AIDS-gay inseparability—as well as alerting me to vagueness and slippage in the literature. It directed me, that is, to see the most obvious characteristics and dilemmas of ACT UP as crucial ones rather than dismissible ones; these were the data that the theories should be able to make sense of, and these were the data that would challenge the theories and force revisions in theorizing.

The arrogance, though, however useful in direction, led me to a final obstacle, in presentation: the problem of overstatement. I had tried not only to trip up the theories I was addressing, to point to weaknesses and directions for reconstruction, but to make a positive claim about what was “really new” in new social movements. In fact, my data were not in a position to make such a broad claim. In writing, I could feel myself slipping into rhetorical devices that would assert this bigger claim despite my knowledge that it wasn’t justified; it wasn’t conscious, though, until a friend pointed it out. Attempting to allow the data to challenge the theory, I wound up distorting, and in some sense betraying, what I knew to be the situation in the field: for example, asserting before revisions that the disputes were over “cultural resources rather than material ones” (when in fact much crucial action is over material resources), or implying that the state is not overly involved in the oppression of PWAs and gays (when in fact it is still very involved). This was to bolster the argument that I was on to something distinctive and new—an overcompensation, perhaps, for the discovery of a problem after months of problemlessness.