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# Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement "Newness"\*

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*Examining the dynamics and activities of the AIDS activist movement—here, through an analysis based on a participant-observation study of the AIDS Coalition to Unleash Power (ACT UP) in San Francisco—provides an opportunity to clarify issues on which social movements literature tends to be hazy. ACT UP mixes strategic action and material targets with expressive action and cultural targets; their cultural activity takes the form of boundary-crossing and the contesting of images. They often have difficulty distinguishing their targets, and are caught both denying and affirming that AIDS is a gay disease. I argue that these actions and dilemmas are best understood in the context of changed forms of domination, more and more an invisible and disembodied process of "normalization," with the state gradually less directly involved. This argument not only explains the particulars of ACT UP's activism, but also poses challenges to theorizing on contemporary ("new") social movements.*

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 unusual: "ACT UP! Fight back! Fight AIDS!" Their banners, unfurled in front of the three sections they have bought out, shout plays on baseball themes: "No glove, no love," "Don't balk at safer sex," "AIDS is not a ball game." The electronic billboard flashes some of their messages as well. The action gets wide coverage the following day. Later, in a *Newsweek* (1988a) article on the activist group ACT UP, a baseball fan complains, "AIDS is a fearful topic. This is totally inappropriate."

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, they become stand-ins for deep fears and tools for bringing judgments about social crises. "AIDS," Sontag (1988:89) suggests, "is understood in a premodern way."

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-gear "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

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own difficulties: social movements literature has a hard time clarifying exactly what is “new” about contemporary social movements and can, through its fuzziness, easily accommodate yet another social movement without shedding new light.

In this paper, 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 is by far the largest ACT UP, with weekly meeting attendance in the hundreds and membership estimated at nearly 3,000, while the others are smaller. San Francisco, with a membership of over 700, averages 50 people at general meetings. My comparisons between ACT UP in San Francisco and chapters in New York and other cities are based on a national conference in Washington, DC, internal publications, informal discussion and interviews, and newspaper reports.

Using data from six months of participant-observation research (September 1988 through February 1989) in San Francisco’s ACT UP, 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. Micro- and macro-level analyses are linked through seeking out an “explanation for uniqueness” such that “we are compelled to move into the realm of the ‘macro’ that shapes the ‘micro’ that we observe in face-to-face interaction” (Burawoy 1989:7).

In the first part of the paper I briefly review approaches to contemporary social movements, locating ACT UP within this literature. I then turn to ACT UP’s activities and internal obstacles, looking at their response to the plague script, the alternative scripts they propose and their strategies for doing so, and the difficulties they face in this process. I argue that asking “who is the enemy?” provides a fruitful direction for making sense of these dynamics because ACT UP members often have trouble finding their “enemies.” The paper continues with an examination of why this may be so, and what light it may shed on contemporary movements. Borrowing from Michel Foucault (1979), I turn to an examination of 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 unlocked from state oppression in recent decades. State figures and institutions—though certainly still deeply involved in this domination—are now less apt to contribute to the production and dissemination of labels, making the process itself, abstracted, the hazy focus of protest. The paper then traces how responses to normalization play themselves out in ACT UP activities: activists use the labels to dispute the labels, use their abnormality and expressions of gay identity to challenge the process by which this identity was and is defined. Finally, I suggest directions this framework provides for analyzing contemporary movements.

### **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 (for example, Smelser 1963). Many 1960s activists did not fit the mold. Neither anomic nor underprivileged nor responding to crises with beliefs "akin to magical beliefs" (Smelser 1963:8), 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 regarding who made up social movements and how they operated had broken down (see Cohen 1985, McAdam 1982).

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, focussing on the varying constraints and opportunities in which they operate and the varying resources upon which they draw (see McCarthy and Zald 1977, Oberschall 1973, Tilly 1978, and Jenkins 1981). 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 contemporary movements and to discern the structural shifts that might account for new dimensions of activity (see Kitschelt 1985, Cohen 1985, Eder 1985, Habermas 1981, Offe 1985, and Touraine 1985).

With some exceptions (see, for example, Doug McAdam's 1982 study of black insurgency), 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 (see Eder 1985 and Kreisi 1989); indeed, the fact that NSMs are *not* working-class movements focussed 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" (Offe 1985:832); they use different tactics from their predecessors (Offe 1985); their conflicts concern not "problems of distribution" but "the grammar of forms of life," arising in "areas of cultural reproduction, social integration and socialization" (Habermas 1981:33); they "manifest a form of middle-class protest which oscillates from moral crusade to political pressure group to social movement" (Eder 1985:879); they are "both culturally oriented and involved in structural conflicts" (Touraine 1985:766), 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" (Cohen 1985:664).

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 "lifestyle" 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 (1985:665) 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 identi-

ties, forms of organization, and scenarios of conflict." 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 it that 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 towards 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 their 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 20s and 30s. The core membership—an informal group of about 25 activists—draws from both established activists (gay rights, Central American politics, etc.) and those newly politicized by AIDS.<sup>1</sup> 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 semi-professional: legal and health care professionals, writers, political organizers, students, artists with day jobs. ACT UP/New York and ACT UPs in other cities exhibit similar profiles (Green 1989).

Self-defined in their 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 1988a), 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" (ACT UP 1988a). Moreover, the group pushes for the participation of people with AIDS (PWAs) in these activities (ACT UP 1989). The idea here is to change the distribution of resources and decision-making power; the principle guiding actions is strategic, aimed at affecting policy changes. "People have been fighting for social justice in this country for centuries," says one member (September 1988). "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 sub-community of PWAs and the HIV-infected), and on the "need to express

1. Unless otherwise noted, quotations and descriptions of actions are drawn from the author's field notes from September 1988 through January 1989 (ACT UP weekly general meetings; Media Committee weekly meetings and activities, and other committee meetings; ACT NOW AIDS Activism Conference, October 8-11, 1988, Washington, DC; ACT UP/San Francisco actions). For a sampling of published reporting on ACT UP, see Green 1989, *US News & World Report* 1989, Linebarger 1989, Tuller 1988, Ford 1988, Johnson 1988, Okie 1988, Connolly and Raine 1988, Morgan 1988.

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 towards identity and expression, while not excluding older-style strategic action, is one key characteristic cited by students of post-60s 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 the attack is combined with a direct one on cultural producers and the process of AIDS-image production.

Another action principle weaves through ACT UP. As *Newsweek* (1988a) puts it, ACT UP has often "deliberately trespassed the bounds of good taste": 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* quite 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.<sup>2</sup> It also suggests that an examination of the specific patterns of culturally oriented actions may be especially revealing. By focussing 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 programs, and access to health care, for instance, are all common subjects of action. Pursuing this examination via ACT UP's peculiarities, I hope to generate possibilities for grounding and developing social movement theory.

### ACT UP's Internal Obstacles

The examination turns, then, to ACT UP's distinctive characteristics. ACT UP's strong cultural orientation has already been noted. In addition, buried in its various strategies are three fundamental confusions. First, ACT UP's orientation towards theatrics suggests a clear delineation of performer from audience, yet actions are often planned by ACT UP members without an articulation of whom they're 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 clearly needs a 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" (reported in "Workshop on Creative Actions," ACT NOW Conference, Washington, DC, October 8, 1988), was important not for what it showed about the Republicans' AIDS consciousness, which came as no surprise. Instead, it was important for what it showed the activists about their own power. They were, in effect, their own audience, performing for themselves and making

2. By way of comparison, it's important to notice that most AIDS politics does not operate according to this description, but according to a more conventional political model. "Most AIDS politicking," as Dennis Altman (1986:105) 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."

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 Dukakis, for example, with no media coverage, Dukakis nowhere in sight, and no one to witness the protest but passing cars (San Francisco, September 30, 1988). 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 would 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 focussed planning and action. I argue, however, that the roots are deeper.

A second point of confusion is that, while ACT UP professes to be inclusive, and ideas are often brought up that target non-gay aspects of AIDS (issues of concern to intravenous 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 non-gay members. This does not mean that the membership is exclusively gay men; in fact, a good portion of the activists are women.<sup>3</sup> 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 little 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, this tradition has meant that “AIDS groups have found it very difficult to establish themselves as non-gay, even where they have deliberately presented themselves as such” (Altman 1986:90). 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 San Francisco’s 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 speakers for the rally, he and others quickly generated a long list of possibles—from the gay political community. Here, AIDS issues often get buried.

For others, it’s 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 (“Media Workshop” at ACT NOW Conference in Washington, DC, October 8, 1988). The ACT UP

3. Why so many women are attracted to the AIDS movement is an interesting question to which I’ve accumulated only brief, speculative answers: some because their friends are dying, some because of a history of working in health politics through women’s health issues. One woman suggested an answer that seems to run deeper and along the lines suggested by this study. Oppression through AIDS, she said, is the most severe end of a spectrum of violence to which “all gay people are subject.” For her, while silence might not mean literal death, it would mean a symbolic death (not being allowed to live as “me”).

agenda, when the balance is towards distinctive 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 argued 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" (ACT UP 1988b:1). 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 will 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 will 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 labelling in which everyone except one's own "community" of the de-normalized (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.

This second enemy forms the basis of my core theoretical claim: that ACT UP is responding to a gradual historical shift towards a form of domination in which power is maintained through a normalizing process in which "the whole indefinite domain of the non-conforming is punishable" (Foucault 1979:178). Through labelling, 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 Michel Foucault (1979:183) 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.

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 (e.g., Lemert 1967, Goffman 1963), which, of course, call attention to the process of labelling and its impact on the "deviant." However, the various forms of labelling 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" (Goffman) and "secondary deviation" as a "means of defense" against the "problems created by the societal reaction to primary deviation" (Lemert 1967:17)—are ill-equipped to explain the organization of the stigmatized into social movements. As John Kitsuse (1980:5) 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. 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—in the celebration of gay liberation, for example—labels are important tools for self-understanding. That sort of politics involves what John Kitsuse (1980:9) 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." 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 (see Omi and Winant 1986:89ff). 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 labelling. 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" (Johnson and Murray 1988). 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 de-normalized and resisted as a process. It is within this overall historical shift in methods of domination, this study proposes, 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. For example, the Federal Food and Drug Administration approves drugs and has been sluggish in approving AIDS-related drugs; it is perceived as allowing bureaucracy to get in the way of saving or prolonging lives (*Newsweek* 1988b). In October 1988, ACT NOW organized a conference, teach-in, rally, and day of civil disobedience in Washington, DC, to "seize control of the FDA" (Okie 1988, Connolly and Raine 1988). 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 consistently avoided initiating a coordinated, adequately financed attack on that problem (see Shilts 1988). 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 effect 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 (Eigo et al. 1988) 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 (Eigo et al. 1988). 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.<sup>4</sup> 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 new born child, even the "heterosexual" (Plummer 1988:45).

Associated most commonly with the image of the male homosexual or bisexual AIDS "victim" or "carrier" who is 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 while being a member of the "general population" is dangerous only when the un-general contaminate it. As Simon Watney (1987:126) 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."

The construction and reconstruction of boundaries has been, then, 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

4. The activist response of black communities to AIDS has, though, differed greatly from that in gay communities, and this merits careful examination not allowed for here. The lag in black and Hispanic activism has been attributed by one observer to a combination of lack of material and political resources (minority PWAs are disproportionately lower class or underclass) and "denial" on the part of minority leadership (because of the dangers posed by feeding racism with the stigma of disease, and because of strong anti-gay sentiments in black and Hispanic cultures); (see Goldstein 1987).

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” (Grover 1987:21) and the prostitute, with her longstanding position as a “vessel” of disease (Grover 1987:25).

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 (e.g., Eigo et al. 1988), 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 “guerilla 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 that 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’”<sup>5</sup> and implying that, as an ACT UP representative put it, “basically it’s justifiable to kill a person with AIDS” (Ford 1988). 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 (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.<sup>6</sup>

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 far away. 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 or phrase used to oppress and invert it. For example, ACT UP makes explicit challenges, guided by other AIDS activists and particularly PWAs, on the kind of language used to

5. The figure of the irresponsible killer-victim was popularized by Randy Shilts in the character of Gaetan Dugas, an airline steward Shilts labels “Patient Zero.” Shilts charges that Dugas knowingly spread the virus throughout the continent. For a critique of Shilts, see Crimp, 1987b.

6. The mass media clearly play a very central and complex role in contemporary activism (see, for example, Gitlin 1980), an examination of which is unfortunately beyond the scope of this paper. It’s quite likely that much of the escalation of symbols comes from the need by social movements to compete for attention in an increasingly message-dense environment; this does not explain the content of those symbols, though, nor does it explain why the media at times become explicit enemies.

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 they challenge the exclusionary use of "general population" (see Grover 1987).

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 emblem for homosexuals later co-opted 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 (Gilman 1987); 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"). 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, blood is talked about in terms 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 (San Francisco, October 3, 1988) or doctor's uniforms (Washington, DC, October 11, 1988). Members want to shoot it out of squirt guns, blood-balloon it onto buildings, write "test this" with it on walls ("Creative Actions" workshop, Washington, DC, October 8, 1988). 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 (October 3, 1988), 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 black cape and 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, though 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 presidential inauguration through the San Francisco streets during

rush hour (January 1989). The idea, as one activist put 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 (Washington, DC, October 1988), 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 a DC 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 labels: “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” (Watney 1987:54). 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, then, can be seen in terms of the visibility of enemies. 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's 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 struggle. Yet at the same time, we have seen that identity struggles involve pushing at the very labels on which they're 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 because 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 the 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 non-gay, and dangerous for those labelled 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 Steve Epstein (1987:19) 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?" 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'" (Epstein 1987:48). The familiarity of the dilemma, though, should not obscure its significance. This is neither a dilemma attributable 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's not surprising that ACT UP has difficulty including non-gays and forming coalitions. In some ways, ACT UP is driven towards inclusiveness since AIDS is affecting other populations and since the fight includes more broad-based struggles over resources. But, as we have seen, resistance to labelling 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 inclusiveness. The difficulty in walking these lines—between confirming and re-

jecting 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 labelling 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 best-seller, 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 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" (Treichler 1987:42, 63). 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 an historical shift. If, as I've proposed 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 towards a focus on a moment (the 1960s) rather than a history that reaches back into, for example, the eighteenth and nineteenth centuries (as in the historical transformation that Foucault describes). It obscures what may be instructive continuities across time. Secondly, this study points towards 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 focussing on problems that "deal directly with private life" (Touraine 1985:779) or even targeting and using narrative and artistic representation. ACT UP's cultural strategies reclaim and resignify oppressive markers. Orienting actions towards identity formation means something more specific than "defend[ing] spaces for the creation of new identities and solidarities" (Cohen 1985:685). 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.

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