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In Sickness and in Health: AIDS Activism, Illness, and the Politics of Identity

Michael Orsini

A Thesis

in

The Department

of

Political Science

Presented in Partial Fulfilment of the Requirements for the Degree of Master of Arts at Concordia University Montreal, Quebec, Canada

December 1995

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ABSTRACT

In Sickness and in Health:
AIDS Activism, Illness, and the Politics of Identity

Michael Orsini

This study traces the impact of AIDS activism from the perspective of identity politics. It is argued herein that much of the AIDS discourse is steeped in questions of identity, but, curiously, rarely expressed as such. From the furor over mandatory HIV testing to controversics surrounding the funding of AIDS prevention programs, notions of identity inform much of the debate over public-health responses to AIDS. Implicit in much of this discussion is a profound belief that to be labelled HIV positive is somehow worse than the disease itself. There is, however, a remarkable corollary to this: the collective identity of people with AIDS has helped to spawn the modern-day AIDS lobby, a diverse movement which has refused to bow to the official AIDS establishment. This research attempts to place this apparent paradox within the larger context of identity formation and examine how identity politics has both helped and harmed the fight against AIDS. Some of the topics addressed include: ACT UP, a directaction group; sexual identity; civil disobedience and political action; and those marginalized groups which remain underrepresented in AIDS activist circles. A crucial component of the thesis comprises a series of in-depth interviews with four AIDS activists.

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CHAPTER 1

INTRODUCTION

My friends have their own theories about why I've survived. Some say it's because I have a sense of purpose — a reason to live — and that I'm passionately committed to life. They point to my political activism as Exhibit A. But I've often wondered if they're right. The problem is, my AIDS activism has been a double-edged sword. It has given me a reason to live, but it has also nearly killed me. On the one hand, feeling the first warning signs of yet another bout of bacterial pneumonia, I've said to myself, "I can't die yet; I have congressional testimony to give!" On the other hand, my schedule would probably kill a healthy person!

The frenetic pace of my life has meant that I've been able to rationalize to myself that I mustn't be all that sick because if I was, I couldn't keep so busy; but the sheer, physical wear and tear on my body, combined with the viciousness of political battles, makes me wonder whether my activism has been good or bad for my health.

- Michael Callen

When people's dreams are withdrawn, they get real angry real fast.² - Edmund White

While it has not been portrayed as such, much of the current AIDS debate is steeped in issues of identity. From controversies that have erupted over mandatory screening programs that would identify People with AIDS (referred to herein as PWAs) to debates surrounding the funding of AIDS prevention programs, notions of identity permeate most of the discussion of public responses to AIDS.

Callen, Michael. "Luck, Classic Coke, and the Love of a Good Man," in Michael Callen. Surviving AIDS. New York: HarperCollins Publishers, 1990, 78.

"White, Edmund. "Aesthetics and Loss," in National Gallery of Australia. Don't Leave Me This Way: Art in the Age of AIDS. Melbourne, London and New York: Thames and Hudson, 1994, 137.

Some conservative commentators see in identity the locus for political (and punitive) action to stem the spread of HIV infection into the "general" population. William F. Buckley, for example, argued in the *New York Times* that "everyone detected with AIDS should be tatooed (sic) in the upper fore-arm, to protect common-needle users, and on the buttocks, to prevent the victimisation of other homosexuals." Not surprisingly, Watney says, proponents of such extreme measures temper their contempt for homosexuals with a seemingly genuine concern for their well-being. Hate the sin; love the sinner.

Recently, a French court ordered Benetton, a large Italian clothing retailer, to pay \$32,000 in damages to three HIV-positive people and an association of AIDS protesters after it ran advertisements that featured close-ups of parts of people's bodies tattooed with the words "HIV positive." Defending Benetton, Sean O'Brien Strub, the editor of *Poz*, a fledgling American glossy magazine for PWAs, says the advertising campaign is part of the Italian clothing company's efforts to put "AIDS directly in people's faces."

³ Buckley, William F., "Identify All the Carriers," The New York Times, 18 March 1986, A27.

⁴ O'Brien Strub, Sean, "French attitude toward AIDS is truly offensive," Poz, April/May 1995, 10.

Visible expressions of one's HIV status — namely, tattoos — are increasingly used as an empowerment tool ... to erase the shame and stigma so many associate with AIDS. That's the same reason why I and so many other people with AIDS have gone public with our status. Many Holocaust survivors wear death camp numeric tattoos for the rest of their lives, preventing the world from forgetting the genocide. Similarly, many people have had their HIV status written on their skin to fight society's denial of AIDS and to make sure the world will never forget the genocide we are in the midst of today.⁵

In Italy three HIV-positive men, dubbed "the untouchables" by the media, have turned to crime to voice their dissatisfaction with the country's health-care system. Because they are protected by a legal loophole that bars authorities from keeping PWAs in jail, each time they have been apprehended, they have been quickly released. Their cause has become a national drama. A columnist in Italy's *La Stampa* newspaper wrote of the case: "They seem to take some ultimate perverse pleasure from their impunity. It is as if knowing they are condemned by an incurable illness, they find psychological compensation in the fact that they were humiliating and making fun of the social order that was unable to find a way to help them in their fight against death." In their defense, the three men argue that by holding up banks they are attempting to expose the hypocrisy of the Italian government's policy on AIDS. The same government that

⁵ Ibid.

⁶ Williams, Daniel, "Trio turn to crime to expose Italy's policy on AIDS," reprinted in *The Gazette* from *The Washington Post*, 16 August 1995, B1.

introduced this compassionate policy regarding the detainment of PWAs has but little regard for their well-being, they contend. Identity, in this case, has become the untouchables' rallying cry. Paradoxically, their identity as PWAs affords them "compassionate" treatment under the law, but it too serves to isolate them from other criminals, and from society in general.

Controversies such as the ones noted above cut through the heart of the contemporary AIDS discourse, and are not easily resolved. Implicit in much of this discussion surrounding AIDS and identity is a profound belief that to be labelled HIV positive is somehow worse than the disease itself. Some activists suggest that even within the seemingly well-informed activist community, there is a reluctance to declare one's HIV status for fear of being ostracized from or judged by that community.

There is, however, a remarkable corollary to this: the collective identity of people with AIDS has helped to spawn the modern-day AIDS lobby, a diverse group of individuals that refuses to bow to the official AIDS establishment. The goal of this research is to place this apparent paradox within the larger context of identity formation and examine how the politics of identity has both helped and harmed the

⁷ This information was gleaned from an extensive interview with Michael Hendricks, one of the founders of ACT UP Montreal, on Aug. 15, 1995.

fight against AIDS. Has the preoccupation with identity muddied the political waters, so to speak, and hampered the pursuit of social justice? As Jewish feminist Jenny Bourne notes rather disparagingly, "Identity politics is in. Exploitation is out (it is extrinsically determinist). Oppression is in (it is intrinsically personal). What is to be done is replaced by who am I."8

In attempting to assess the impact of identity politics on AIDS activism, Chapter 2 emphasizes the malleability and contrasting meanings of the term itself. As Wolin asserts, one of the meanings of identity "appears to favor the recognition of difference, the other to oppose it." Herein lies the double-meaning of identity, which will be elaborated throughout the course of this work. Also, a discussion of identity in the age of AIDS would be incomplete without an examination of sexual identity, specifically gay identity, and its significant impact on the AIDS discourse. It is beyond the scope of this paper, however, to examine in any meaningful detail the nature of lesbian identity. 10

⁸ Bourne, Jenny, "Homelands of the mind: Jewish feminism and identity politics," Race and Class 29 (1987): 1, quoted in Liz Bondi. "Locating Identity Politics," pp. 84-101, in Michael Keith and Steve Pile, eds. Place and the Politics of Identity. London/New York: Routledge, 1993.

⁹ Wolin, Sheldon S. "Democracy, Difference, and Re-cognition." *Political Theory* 21, no. 3 (August 1993): 468.

In many cities throughout North America and Europe, a fierce commitment to identity has given rise to militant activism on the part of PWAs and their supporters. The AIDS Coalition To Unleash Power (ACT UP), which is the general focus of this study and the specific focus of the third chapter, is but one example of this "new" politics, but, I will argue, probably its most potent symbol. Not content to remain in the closet, many AIDS activists, who are often HIV positive themselves¹¹, have grasped hold of their society-imposed identity as the Arendtian pariah¹² and used it to their political advantage in pressing their respective governments to commit more money to AIDS research and prevention programs, transforming what was once a space of marginality into a site of resistance. This move, according to

others, Shane Phelan. *Identity Politics: Lesbian Feminism and the Limits of Community.* Philadelphia: Temple University Press, 1989, and Paula C. Rust. "The Politics of Sexual Identity: Sexual Attraction and Behaviour among Lesbian and Bisexual Women." *Social Problems* 39, no. 4 (November 1992): 366-386.

positive. AIDS activist and author David B. Feinberg notes that an ACT UP activist caused a mild controversy when he lied about his HIV status, telling a reporter he was positive. "Was he cheapening the suffering and nobility of someone who did have AIDS? But in ACT UP/New York, we have made a conscious decision to say we are all HIV positive if arrested so the police don't split us up. The HIV-negative person was acting in solidarity." (David B. Feinberg. Queer and Loathung: Rants and Raves of a Raging AIDS Clone, Vilsing Penguin, 1994. 65).

¹² See Jennifer Ring. "The Pariah as Hero: Hannah Arendt's Political Actor." Political Theory 19, no. 3 (August 1991): 433-452. In the article, Ring examines a dimension of Arendt's concept of political action which, she argues, has been long overlooked.

much of the literature, is unprecedented in the arena of health lobbying. Advocates for cancer and other life-threatening diseases have worked mainly within the strict confines of the system, in hospital auxiliary groups, for example, to effect change. Rather than rail against a singular authority — in this case, the medical establishment — these illness-related groups have aligned themselves closely with the Establishment.

The concept of civil disobedience, as elaborated by many political theorists, including Gandhi, Thoreau, and Arendt, is discussed in greater detail in Chapter 4, as it provides a theoretical/legal context within which to assess the moral justifications of AIDS activists. ¹³ Also, it paves the way to a deeper discussion of how a chosen form of political action can determine, in large measure, the outcome of those actions. Traditional interest groups, for example, define specific, attainable goals and, for the most part, can assess their effectiveness or influence by pointing to the adoption of legislation that favours their cause. The same, however, cannot be said of ACT UP. While several AIDS activists continue to press their respective representatives for government funding of AIDS

¹³ I should also note here that ACT UP itself, in its chronology, "ACT UP/N" Capsule History," refers to its use of "dramatic acts of civil disobedience" to focus "attention on the crucial issues of the AIDS crisis."

research and I realth prevention measures, ACT UP has a greater aim. Its literature states boldly that "ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis "14 This goal, however well-meaning, is open to several competing interpretations. How does one, in fact, declare an end to the crisis? Which criterion/criteria must be satisfied? And to which crisis is ACT UP referring? The crisis of government inaction? The crisis of unsafe sex in the age of AIDS? The crisis of media misinformation? Or all of the above?

The next section of the thesis, which brings to life much of the aforementioned theory, comprises a series of in-depth interviews with Canadian and American AIDS activists, some of whom are HIV positive. The intention of conducting these interviews was to give voice to those who are working on the frontlines, and for whom theory springs into practice. Unfortunately, as is the case with AIDS activism, many of the movement's loudest proponents have died as a result of the disease to which they dedicated their lives. (In Montreal alone four prominent AIDS activists died in 1995.)

Identity politics, while partly responsible for the birth of AIDS activism, is not without its share of pitfalls. In the case of gay men, it

¹⁴ Taken from ACT UP contact sheet, 24 April 1995.

has further reinforced the notion of them as somehow inherently diseased and has contributed to a hostile climate for gay men (and to a certain extent, lesbians), a climate that existed prior to the arrival of AIDS but one which many believed was beginning to disappear.

Identity in the age of AIDS can also mingle with other, more fragile identities, such as those of the drug user, the prostitute, or the member of a racial minority. Chapter 6 examines the identities of those groups who do not figure prominently in the AIDS activist agenda, but whose identities remain permanently marked by their association with HIV/AIDS. For example, in the case of Quebec, Haitians have been branded as potential carriers of disease, as members of a so-called "diseased nationality." As the head of a Haitian nurses' association testified recently at a public inquiry into Canada's blood system, the singling out of Haitians by the Red Cross dealt a devastating blow to the community: "Haitians taking a bus were told: I don't want to sit next to you, you have rotten blood, you have AIDS' ... The message that trickled down to the public was that Haitians were to be avoided like the plague." 6 Certainly, Haitians are

¹⁵ Fairchild, Amy L., and Eileen A. Tynan. "Policies of Containment: Immigration in the Era of AIDS." American Journal of Public Health 84, no. 12 (December 1994): 2016. Fairchild and Tynan contend that the U.S. policy which excludes immigrants with HIV resembles the 1924 tradition of selective racial restriction of immigrants from what they term "dangerous nations."

not the only minority to have suffered at the hands of well-meaning public health officials. They remain, however, a potent reminder of the Quebec government's inability to stem the rate of infection among women in the province, which remains the highest in the country.

(Almost 60 per cent of Canadian women with AIDS reside in Quebec; 252 of the 276 AIDS cases in Quebec attributable to heterosexual contact with a person from a country where AIDS is endemic have been traced to Haiti.)¹⁷

For those who already suffer on the margins of society, it is even more difficult to resist or erase the stereotypes that are commonly summoned to explain disease. For instance, despite overwhelming evidence that prostitutes practice safe sex more frequently than members of the general population, the identity of the prostitute remains inextricably linked to her/his potential to infect "innocent" people. While prostitutes' rights organizations have

¹⁶ Picard, André. "Labelling of Haitians as blood-donor risks called devastating." *The Globe and Mail*, 27 September 1994, A6.

¹⁷ "Surveillance des cas de Syndrome D'immunodéficience acquise (SIDA), Québec, cas cumulatifs 1979-1994," Centre québécois de coordination sur le sida, le 15 janvier, 1994.

¹⁸ The work of Concordia University sociologist Frances Shaver is especially helpful in debunking some of the myths that surround prostitutes and AIDS. In interviews with about 80 prostitutes, Shaver found that more than 90 per cent of them had been tested for HIV, allaying any fears that prostitutes are not concerned about their health or the health of their clients. All of the women prostitutes whom were interviewed said they had used condoms during penetrative sex with customers. "The women said if they got sick, they couldn't work. They're not

flourished in recent years, their lobbying power still pales in comparison with the influence of the AIDS lobby. 19

In the final chapter I attempt to assess the impact of AIDS activism, both within the AIDS arena and without. In the latter case, I cite as an example breast cancer advocates, who are beginning to mirror AIDS activists in their militancy. A sad footnote to this recent trend is the tendency to pit AIDS against breast cancer, as if it were possible to rank diseases neatly in order of their importance.²⁰

Since its inception in the early 1980s, the AIDS movement, in general, can be credited with many accomplishments, including, among others, ACT UP's well-orchestrated campaign to force

Burroughs Wellcome, a pharmaceutical giant, to lower the price of azidothymidine (AZT)²¹, an anti-viral drug. Generally, AIDS activists

interested in risking their livelihood." (AIDS: A Community Responds, supplement to Concordia's Thursday Report 17, no. 12, 3 December 1992, 6)

¹⁹ Here, I depart somewhat from the views expressed by political scientist Shannon Bell in her otherwise compelling book, *Reading, Writing, and Rewriting the Prostitute Body.* Bloomington and Indianapolis: Indiana University Press, 1994.

²⁰ For an example of this viewpoint, see Claire Hoy, *The Truth About Breast Cancer* (Stoddart, 1995), in which the author claims that research into AIDS is advancing at the expense of other life-threatening diseases, such as breast cancer.

²¹For a unique discussion of technomedicine's response to the AIDS crisis, and of AZT as a social and political phenomenon, see Erni, John Nguyet, "Paralysis or Breakthrough: The Making and Unmaking of AZT" (pp. 1-33) in Erni, John Nguyet. Unstable Frontiers: Technomedicine and the Cultural Politics of "Curing" AIDS. Minneapolis and London: University of Minnesota Press, 1994.

have succeeded in initiating a sorely needed discussion of the often explosive issues surrounding sexuality. What is as yet unclear, and the focus of this work, is the impact they have had on the dangerous interplay of illness, activism, and identity.

CHAPTER 2

THE RISE (AND FALL?) OF IDENTITY POLITICS

The term "identity" must be understood before we can begin to articulate the meaning of identity politics in the age of AIDS. Wolin asserts that identity holds two meanings, both of which pose a unique challenge to democracy. Identity, he says, "may mean absolute sameness, as when I say 'Jane and Jill have an identity of purpose,' or it may mean individuality, as when someone says, I am determined to defend my own identity." ²² In the first meaning, identity is synonymous with a sharing or commonality; in the second, it is antagonistic, pitting its members against the dominant class. Wolin believes that proponents of postmodernism²³ are thoroughly confused as regards these differences: "(T)hey assert the value of identity as meaning individuality and — often at the same time — they proclaim the value of identity as sameness that is simultaneously differentiating and exclusionist, as in those who employ gender, race,

²² Wolin, "Democracy, Difference, and Re-cognition," 468.

²³ For a postmodern perspective on identity, see, among others, Stanley Aronowitz. *The Politics of Identity: Class, Culture, Social Movements.* New York: Routledge, Chapman, and Hall Inc., 1992.

ethnicity, or sexual preference to construct a community of grievance or special qualities."24

Wolin's views should not be dismissed, but his rigid classification denies the possibility that the full meaning of identity may be embraced in both strands presented above. The two meanings of identity may appear to conflict with one another, but this may reflect the weakness of the term itself, not the deficiency of identity politics. It is not surprising that, as Wolin states, the sameness that is used to establish the community turns around to become the difference that distinguishes members of this community from nonmembers. Also, it is not surprising that proponents of the politics of difference act on two seemingly opposed fronts: on the one hand, they want to be bound only by a weak bond of inclusion; on the other, their demands presume a strong state apparatus, a state which is expected to protect disadvantaged members of society from the ravages of poverty, sexism, racism, and homophobia. Wolin is correct to point out this contradiction, for it appears that the goals of those adherents of identity politics cannot be realized fully unless there is state co-operation. For example, it is unlikely that AIDS prevention programs would have entered public schools were it not for the active

²⁴ Wolin, "Democracy, Difference, and Re-cognition," 468.

participation of states, which have immeasurable resources at their disposal. It is doubtful that AIDS activists could have achieved this goal single-handedly.

The paradox then, to correct Wolin, does not reside in the double meaning of identity, but rather in how practitioners of identity politics pursue political action.

Altman expresses this contradiction in tracing the origins of ACT UP, which he says almost defies categorization. AIDS, he says, has produced a fundamental shift in the gay movement, from an emphasis on rights to the allocation of resources, and has complicated any attempts to understand fully the nature of AIDS activism: "For if demands concerning rights tend to be symbolic and call for expressive politics and expressions of solidarity with other groups, a focus on resources tends to make a movement more akin to a traditional interest group, more concerned with professional leadership and access to the back rooms of power." Herein lie the tensions that threaten the future of the AIDS movement: should it focus its energies on compelling the state to act, and, in so doing, legitimize the state, which has a consistently poor track record when it comes to defending the rights of gays and lesbians, or should it act

²⁵ Altman, Dennis. AIDS and the New Puritanism. London: Pluto Press, 1986, 103.

affected communities? New York's Gay Men's Health Crisis, mindful of the fact that the state was slow to respond to AIDS in the early 1980s, chose the latter route, and, in so doing, has been castigated for being too bureaucratic. ²⁶ ACT UP, it will be argued in greater detail in the next section, appears to operate on both fronts.

For Cornel West, a Black Studies scholar and cultural critic, identity "is fundamentally about desire and death. How you construct your identity is predicated on how you construct desire and how you construct death... It's the longing to belong, a deep, visceral need that most linguistically conscious animals who transact with an environment (that's us) participate in." Although he approaches his analysis from the perspective of black identity, West's observations bring light to bear on the identity of the AIDS activist, who is almost always concerned with death, whether or not the activist is infected.

²⁶ In a letter to GMHC's leader, Larry Kramer, one of the founders of the GMHC, had this to say about the organization: "You have become simply another city social service agency, and at the rate one hears about your inner squabblings, the rapidly declining quality of the staff you are hiring, and the increasing unhappiness of those who work for you, it will not be long before you are indistinguishable from any of the city departments ... that serve us so tepidly." (Kramer, Larry. Reports from the holocaust: The Story of an AIDS Activist. New York: St. Martin's Press. 1994, 104.)

²⁷ West, Cornel. "A Matter of Life and Death." October 61 (Summer 1992):

West maintains the discourse of identity cannot be divorced from death because death is identity's reason for being; identity is our attempt, in the face of mortality, to endow ourselves with significance. Death, says West, is also a permanent feature of other identities, namely young black men who have died at the hands of xenophobes and women who have fallen victim to men entrapped in patriarchal identities. Several authors have argued in a similar vein that, due in large part to the arrival of AIDS, the gay label has become synonymous with death. As Watney explains, "Aids (sic) offers a new sign for the symbolic machinery of oppression, making the rectum a grave." ²⁸

Touraine, a sociologist, distinguishes "defensive" from "offensive" identity, and is concerned primarily with how social movements vacillate between the two. For Touraine, groups that appeal to a defensive identity will eventually be forced to cross over to the offensive realm if they wish to maintain any form of political pressure. He cites several examples to bolster his position, including the anti-nuclear and women's movements. In the latter case, he notes, the women's movement only gains in strength and power once it moves from a passive defense of difference to an attack against "a type

²⁸ Watney, Simon. *Policing Desire: Pornography, AIDS, and the Media.* Minneapolis: University of Minnesota Press, 1994, 126.

of social power ... against the power and the wealth identified with male power."29

It cannot be stressed enough here that Touraine's conception of identity is bereft of any discussion of how identities are formed. The "what" of identity politics replaces the "who", which is often the subject of much scholarly debate. As he explains, "Identity is no longer an appeal to a mode of being but the claim to a capacity for action and for change. It is defined in terms of choice and not in terms of substance, essence, or tradition."³⁰

Identity politics would, after all, be a useless maxim, and perhaps much less controversial, were it not followed by some form of political action or demand. Proponents of identity politics are not simply demanding to be heard; they want their identities to be reflected back to them, whether that be in the hiring of minorities or in the reading lists of university literature courses. Todd Gitlin, for one, explains that "What began as a claim to dignity, a recovery from exclusion and denigration, and a demand for representation, has also developed a hardening of the boundaries." Gitlin unfurls a laundry

²⁹ Touraine, Alain. Return of the Actor: Social Theory in Postindustrial Society. Minneapolis: University of Minnesota Press, 1988, 81.

³⁰ Ibid.

list of the ravages of identity politics in the modern-day university, from Women's Studies students who stormed out of a classroom protesting the paucity of readings by women of colour to a group of graduate Sociology students who boycotted a class on race relations because it was being taught by a white male. "The proliferation of identity politics leads to a turning inward, a grim and hermetic bravado which takes the ideological form of paranoid, jargon-clotted, postmodernist groupthink, cult celebrations of victimization, and stylized marginality."32 The examples provided by Gitlin, however, serve only to illustrate his myopic understanding of issues surrounding identity politics. While one cannot deny the divisi less of such controversies in the hallowed halls of academe, Gitlin's treatment of the issue suggests that "certain" groups almost always behave in a predictable fashion. His attitude views all identity-based claims as illegitimate because they are being advanced by groups attempting to revise the canon by any means necessary.

I should note, however, that Gitlin makes at least one compelling, but equally troubling point regarding priorities: "The specialists in difference may do their best to deny the fact that, for a

³¹ Gitlin, Todd. "From Universality to Difference: Notes on the Fragmentation of the Idea of the Left," in Craig Calhoun, ed. Social Theory and the Politics of Identity. Oxford UK and Cambridge USA: Blackwell Publishers, 1994, 152.

³² Ibid., 156.

quarter of a century, they have been fighting over the English department while the Right has held the White House as its private fiefdom."³³ Have successful battles to revamp university curriculums to reflect the nature of our diverse society been purchased at the price of pursuing change in the larger social world? In other words, can we demonstrate how those disenfranchised members of the greater society benefit directly from the inclusion of, for example, affirmative-action hiring in a given academic department or the inclusion in reading lists of books written by women or minority voices?

Like Gitlin, Rosalind Brunt situates the identity politics debate within the purview of Left activism. Too often, she argues, there is a false, essentialist assumption that political activists have no other identity; they are prisoners, as it were, of their political action:

"Indeed, it's a common tribute to people who have dedicated their energy and experience to left and labour politics to say, 'The trade union movement is in his blood', 'She was a lifelong Communist' or 'He is a born socialist'."³⁴ Similar charges have been levelled at, for example, gay men who have become vocal AIDS activists. Sadly,

³³ **Ibid.**, 155.

³⁴ Rosalind Brunt. "The Politics of Identity," in Hall, Stuart and Martin Jacques, eds. New Times: The Changing Face of Politics in the 1990s. London: Lawrence & Wishart, 1989, 151-152.

however, there appears a lack of critical research on this phenomenon. One thing, however, is certain: several AIDS activists have emerged to challenge notions of what it means to be political. Some of them do not identify with the gay rights movement, which has a long, illustrious tradition of political action. For some PWAs, AIDS activism represents their first real foray into interest-group politics. Brunt's point, therefore, is well taken: "No comrades spring class-conscious from the womb and metaphors that suggest they do indicate how the already-politicised forget the circumstances of their own politicisation and the extent to which these were both product and process of life-choices and contingencies." Activists, like the identities to which they cling or resist, are made, not born.

Unless we consider the question of identity, which Brunt claims is at the heart of the transformatory project, we will be left with an empty politics, and only a muted understanding of what propels citizens to political action.

While identity remains a constant rallying cry in the discourse of gay liberation and AIDS activism, it has been hotly contested by proponents of deconstructionism, who believe that identity politics should be discarded because it is exclusionary and anti-democratic.

³⁵ Ibid., 152.

Gay identity, they would argue, is personified in the white, liberal, middle-class male; it fails to accommodate the particular, distinct identities of, for example, gay blacks or Asians³⁰, not to mention the countless lesbians who have lent their support to the AIDS movement.

Quoting Fuss and her Derridean understanding of identity,
Seidman argues that appealing to one's sexual, gender or ethnic
identity is insufficient because it reinforces exclusion and perpetuates
histories-old discrimination:

Deconstruction dislocates the understanding of identity as self-presence and offers, instead, a view of identity as difference. To the extent that identity always contains the specter of non-identity within it, the subject is always divided and identity is always purchased at the price of the exclusion of the Other, the repression or repudiation of non-identity.³⁷

In other words, in the contemporary liberal discourse, identity is invariably expressed in relation to the Other; homosexuality remains a significant marker of sexual identity as long as it exists in

³⁶ For an interesting discussion of AIDS as experienced by members of the gay Asian community, see X.J. "A View on Gay Asians and AIDS." FUSE 15, no. 5 (Summer 1992): 13-15. In it, the author says, "The low and distorted profile that gay Asians are assigned mystifies us into exotic delicacies. We are, therefore, treated as objects of desire as one would go for dim sum, or chop suey, on a particularly adventurous night. We are not generally thought of as human beings with strengths and vulnerabilities. This more subtle form of oppression also makes AIDS services in the gay community less accessible to gay Asians. (X.J. 1992: 13)

³⁷ Diana Fuss, quoted in Seidman, Steven. "Identity and Politics in a Postmodern' Gay Culture: Some Historical and Conceptual Notes." in Warner, Michael, ed. Fear of a Queer Planet: Queer Politics and Social Theory. Minneapolis: University of Minnesota Press, 1993, 130.

relation to its polar opposite, heterosexuality. The latter, Fuss says, depends for its establishment as an institution on the exclusion of homosexuality, "the contaminated other."³⁸ She defines this as the inside/outside dialectic:

Inside/outside functions as the very figure for signification and the mechanisms of meaning production. It has everything to do with the structures of alienation, splitting, and identification which together produce a self and an other, a subject and an object, an unconscious and a conscious, an interiority and an exteriority.³⁹

While at times compelling, the Derridean argument still leaves many unanswered questions. As Seidman explains, deconstructionism "aims to destabilize identity as a ground of politics and theory in order to open up alternative social and political possibilities." These alternative possibilities, however, are rarely expressed in any meaningful detail. Also, in devising a new terrain for political expression, one which is devoid of any relationship with the dominant class, proponents of this new theory of politics may be giving the lie to those members of the dominant class who have long

³⁸ Fuss, Diana. "Inside/Out," in Fuss, Diana, ed. *Inside Out: Lesbian Theories/Gay Theories*. New York and London: Routledge, 1991, 2.

³⁹ Ibid., 1-2.

⁴⁰ Seidman, Steven, "Identity and Politics in a Postmodern' Gay Culture: Some Historical and Conceptual Notes," 130.

argued that AIDS is the "gay plague," and that government money—taxpayers' money to be precise—should not be used to eradicate what is strictly a "gay" problem, one that should be the sole concern of the community in question. The argument that AiDS is no longer the exclusive domain of gays does not appear to hold sway.

While not dismissing its utility as a critique of identity politics as normalizing and exclusionary, Seidman argues that poststructuralism's "troubled relation to identity edges toward an empty politics of gesture or disruptive performance that forfeits an integrative, transformative politic." Proponents of identity politics are also preoccupied with the politics of representation, he says. (Crimp was even more direct, claiming that AIDS activists have had to wage a "war on representation [emphasis added]" in order to counteract the dominant media images of PWAs as helpless victims to be pitied.)

Seidman urges us to rethink the politics of identity, and divest it of its preoccupation with the self — not to dismiss it categorically. He favours instead a political world in which decision making is imbued with a sense of pragmatism. In his own words: "I imagine critical analyses that address specific conflicts, aim to detail the logics

⁴¹ Ibid., 134-135.

⁴² Crimp, Douglas, "Mourning and Militancy," October 51 (Winter 1989): 16.

of social power, and do not shy away from spelling out a vision of a better society in terms resonant to policy makers and activists."⁴³ Unfortunately, Seidman's new-found brand of political behaviour could be construed as a defense of the status quo. What is really *new* about a politics of pragmatism? Is this not in fact a redundant term, since politics is, by its very nature, pragmatic?

Patton proposes to treat identities as a "series of rhetorical closures linked with practical strategies, implicitly or consciously defined..." Acknowledging the reluctance of those groups who have based their political action on identity claims to dispense with identity politics, Patton argues that "reinterpreting identities as strategic systems with pragmatic purposes and unintended effects may make it easier to forge new strategies (with or without 'identities')..." We should question identity, she says, because identity rhetoric leads us right back to the vicious circle of oppression and stereotyping. The identity, for example, of the PWA as a political activist, creates an

⁴³ Seidman, "Identity and Politics in a Postmodern' Gay Culture: Some Historical and Conceptual Notes," 137.

⁴⁴ Patton, Cindy. "Tremble, Hetero Swine!" in Warner, Michael, ed. Fear of a Queer Planet: Queer Politics and Social Theory. Minneapolis: University of Minnesota Press, 1993, 147.

⁴⁵ Ibid., 175.

Other: the passive PWA. Illness, in effect, becomes synonymous with activism; it renders unimaginable the belief that PWAs can be politically passive yet still concerned about their illness. As Patton and others have suggested, identities assume a degree of political action on the part of the persons who share that identity. The failure to "act up", or follow the leader, places in peril a person's membership in this identity.

Dismissing the argument proposed by deconstructionists,

Epstein says it is trapped in the familiar dualism of classical
liberalism: the individual versus society. Liberal discourse, he says,
struggles with two extreme views of the relation between the
individual and society. Individuals are regarded either as free-thinking
persons who are thus able to control their own lives, or they are seen
as virtually helpless, the unwitting product of their social
environment. As he notes, "people who base their claims to social
rights on the basis of a group identity will not appreciate being told
that identity is just a social construct."⁴⁶

Like liberalism, constructionism vacillates between a form of individualism in which sexual categories can be formed and discarded at will, to the opposite, a view of the individual's sexual identity as a

⁴⁶ Epstein, Steven. "Gay politics, ethnic identity: The Limits of Social Constructionism." Socialist Review 17, Nos. 3 & 4 (May-August 1987): 22.

social and historical construct. Either option pits the individual against society and lacks "any dynamic sense of how society comes to dwell within individuals or how individuality comes to be socially constituted." Epstein also discards constructionism's ideological nemesis, essentialism, which focuses on the natural dimensions of sex. According to proponents of this school of thought, homosexuals are born gay — end of story. The author, however, is unable to resolve the moral dilemma he so eloquently characterizes, because, as he says, "neither constructionism nor strict essentialism are capable of explaining what it means to be gay." His analysis, however, remains instructive as it represents a forceful critique of constructionism, which is rarely present in the work of Left-leaning academics.

In a discussion of the links between personal and collective identity, author William Connolly suggests that marginalized or stigmatized groups should not adhere to identity politics because it places them in double jeopardy. First, he says, the collective identifications inscribed on you impinge on your freedom to define yourself. Second, any attempt by a member of such a group to reverse or shift these terms of identification is almost futile, given the fact

⁴⁷ Ibid., 23.

⁴⁸ Ibid., 43.

that you will be viewed, almost assuredly, by these categorizations which have been applied to you. Hence, Connolly states: "Here the politics of collective identity sustains the negative definitions it bestows by insisting that the categories up for political contestation be applied to those contesting them." Connolly understands that there is a drive to present and defend a true identity, one that will always stand in fierce opposition to other identities attempting to forge ahead. These other identities need not be in direct competition with the powerful identity; their presence alone is enough to warrant serious concern, as they illustrate the failure of the powerful identity to subsume them.

...a powerful identity will strive to constitute a range of differences as *intrinsically* evil, irrational, abnormal, mad, sick, primitive, monstrous, dangerous, or anarchical — as other. It does so in order to secure itself as intrinsically good, coherent, complete or rational and in order to protect itself from the other that would unravel its self-certainty and capacity for collective mobilization if it established its legitimacy.⁵⁰

As a way out of the trappings of essentialism, on the one hand, and constructionism, on the other, some authors, most notably Chantal Mouffe, have proposed a radical theory of politics. This new

⁴⁹ Connolly, William E. Identity\Difference: Democratic Negotiations of Political Paradox. Ithaca and London: Cornell University Press, 1991, 200.

⁵⁰ Ibid., 65-66.

notion of radical democratic citizenship is Mouffe's panacea: it holds the promise of a brighter political future, one in which, by some bizarre twist of fate, we, paradoxically, learn to live together alone. While distancing herself from the likes of communitarian heavyweights such as Charles Taylor, Mouffe cannot help but wish that her notion of a radical democratic citizenship "could provide a form of identification that enables the establishment of a common political identity among diverse political struggles." Mouffe fails to acknowledge, however, that, as she herself explains, in order to radicalize this new notion of pluralism, "we have to break with rationalism, individualism and universalism." How can one achieve a common political identity without appealing to universalism?

While at times a compelling argument, the new political order envisaged by Mouffe leaves us pondering the precise nature of a new politics of identity, a politics in which identity is synonymous with difference. Mouffe's failure to spell out to which identities she is referring also clouds the notion upon which this new theory of politics is to be founded. Despite some obvious similarities, such as general

⁵¹ Mouffe, Chantal. The Return of the Political. London, New York: Verso, 1993, 6.

⁵² Ibid., 7.

feelings of oppression, nationalist identities, for example, differ markedly from those of gay men or lesbians. With few exceptions, the lesbian separatist movement being the most notable, the identities that are constructed around sexuality do not seek isolation from others; rather, they demand societal recognition and, in several instances, official recognition in the form of pro-active laws or policies. This official recognition may come in the form of repealing laws that, for example, outlaw homosexuality, or, recently, in the case of Canada, in the enactment of laws that would regard gay-bashing as a hate crime punishable under Canada's Criminal Code. Conversely, the identities tied to race or nationality are more concerned with achieving sovereignty, freedom from the oppressive shackles of the state, and, as such, differ significantly from the abovementioned identities.

Dismissing the appeal to sexual identity ("There is no reason why sexual difference should be pertinent in all social relations"53), Mouffe instead envisages the creation of a political identity that is aligned closely with the political tenets of modern pluralist society, namely liberty and equality for all. The members of this radical democracy need not be united in their conceptions of the good, but

⁵³ Ibid., 82.

only bound by their adherence to a set of political values. How, for example, would AIDS activists fare in such an identity? Because AIDS is often viewed through the filter of homosexuality, and since many groups oppose equal rights for gays and hold that homosexuals are responsible for the terrifying course of the AIDS epidemic, it is seemingly unlikely that this common ground, of liberty and equality for all, is attainable. Mouffe reiterates that this political identity need not be homogenous, that it allows room for competing interpretations of citizenship. That may be indeed true, but how does one proceed when those groups with differing perceptions of political identity fail to agree on what appears to be of fundamental concern?

While arguing that a democratic theory must accommodate competing conceptions of our identities as citizens, and restating throughout her book, *The Return of the Political*, that modern democracies must accept conflict and division as unavoidable, Mouffe does not have a prescription for those groups attempting to forge a viable identity in the current political sphere. She repeats the concerns of those who hold that the creation of a truly inclusive political community cannot be achieved, since its realization is predicated on a form of exclusion: "...(I)n order to construct a 'we' it

must be distinguished from a 'them,' and that means establishing a frontier, defining an 'enemy."⁵⁴

These concerns are echoed by Iris Marion Young in her work. Justice and the Politics of Difference. The difference, for lack of a better word, between Young's work and Mouffe's is that Young is more optimistic about the possibility of incorporating difference in political life. It would seem that she, too, believes it is possible to celebrate and incorporate difference under the current system. This would require nothing less than a radical break from the rules of interest group pluralism, which, according to Young, must be discarded because they are undemocratic. Instead, she counsels, we must implement group representation and participate in the creation of a truly heterogeneous public, "where participants discuss together the issues before them and come to a decision according to principles of justice."55 But exactly who would articulate these principles of justice? Her silence on this issue leads us to believe that these principles would be, almost invariably, expressed by the dominant class, and may be incompatible with those principles shared by other groups.

⁵⁴ Ibid., 114.

⁵⁵ Young, Iris Marion. Justice and the Politics of Difference. Princeton, New Jersey: Princeton University Press, 1990, 190.

Young's important work in this field, although eloquently articulated, has been criticized mainly for what it appears to presume. According to Angelia Wilson, Young's view of group difference "fails to consider the possible inability of some groups to offer a coherent account of exactly who they are." Moreover, Wilson says, Young fails to practice what she preaches. In lumping together gay men and lesbians as if they formed a coherent community, she assumes that both share an affinity, a sense of belonging.

The differences within the lesbian, gay and bisexual "community" — and the quotations marks are necessary here — may be loosely held together by a shared oppression experienced in our heterosexist society. But do we all share the same way of life? The fundamental tensions that arose in the early days of activism between gay men and lesbian separatists undoubtedly prove that we do not, and do not wish to, share a way of life.⁵⁷

⁵⁶ Wilson, Angelia. "Which Equality? Toleration, Difference or Respect," in Bristow, Joseph, and Angelia R. Wilson, eds. *Activating Theory: Lesbian, Gay, Bisexual Politics.* London: Lawrence and Wishart, 1993, 180.

⁵⁷ Ibid., 181.

SEXUAL IDENTITY

Sexual identity remains a constant preoccupation of feminist academics, and can help to further our understanding of the logic of identity. Author Judith Butler devotes an entire essay to this issue, in which she criticizes Foucault's analysis of sexuality. Among other contentious arguments, Foucault has asserted that there occurred a historical break between a regime in which sex existed as an attribute, and a more recent regime in which sex became established as an identity. According to Butler, Foucault is wrong to suggest that we did not always have a sex: Perhaps the historical scandal is that we were not always our sex, that sex did not always have the power to characterize and constitute identity with such thoroughgoing power. In other words, she contends, sex did exist as a vital component of our identity, but has only begun to manifest itself recently.

However, Foucault's biggest gaffe, according to Butler, was his failure to recognize that sex "is not only constructed in the service of

⁵⁸ See Foucault, Michel, *The History of Sexuality*, Vol. 1, tr. Robert Hurley, New York: Vintage Books, 1990.

⁵⁹ Butler, Judith. "Sexual Inversions" in Stanton, Domna, ed. *Discourses of Sexuality: From Aristotle to AIDS*. Ann Arbor: The University of Michigan Press, 1992, 344.

life or reproduction but, what might turn out to be a logical corollary, in the service of the regulation and apportionment of death."60

In seeking to liberate sex from its conflation with death,

Foucault found in the eighteenth century a move from a power that
was concerned primarily with the warding off of death to a

preoccupation with the maintenance and regulation of life. It is in the
course of this new-found regulation that the category of sex is
established, says Butler. The realization of this shift, however, was
contingent on the disappearance of famines and epidemics. Foucault
may have been correct for a time, Butler says, but the advent of AIDS
seriously calls into question his previously held observations.

The sexual identity of the male homosexual, Butler explains, even when he has not succumbed to AIDS, seems marked by death. She cites as an example a memorial story that appeared in the venerable *New York Times* on gay conductor Leonard Bernstein, who had died of lung disease. The story, she says,

tacitly constructs the scene of his death as the logical consequence of a life, which, even in the romantic music he liked, seemed to know that "death was always standing in the wings." It is usually friends, admirers, lovers who stand in the wings when a conductor performs, but here it is somehow death who is uneasily collapsed into the homosexual phantasm ... Here death is understood as a necessary compensation for homosexual desire, as the *telos* of male homosexuality, its genesis and its demise, the principle of its intelligibility.⁶¹

⁶⁰ Ibid., 345.

The identity of the male homosexual is also tied closely to sexual expression. In his autobiographical novel, author John Rechy explains that promiscuous gay men, whom he dubs "sexual outlaws", derive their pleasure from and find a thrill in impersonal sex: "The promiscuous homosexual is a sexual revolutionary. Each moment of his outlaw existence he confronts repressive laws, repressive 'morality.' Parks, alleys, subway tunnels, garages, streets — these are the battlefields."62 Furthermore, as Goldstein explains, sexual intercourse

satisfies a constellation of needs that are dealt with in straight society outside the arena of sex. For gay men, sex, that most powerful implement of attachment and arousal, is also an agent of communion, replacing an often hostile family and even shaping politics. It represents an ecstatic break with years of glances and guises, the furtive past we left behind. Straight people have no comparable experience, though it may seem so in memory. They are never called upon to deny desire, only to defer its consummation. 63

Tucker is even more direct in his defense of gay sexual expression, although in noting the difference between homosexual and heterosexual sex, fails to distinguish gay sex from lesbian sex:

⁶¹ Ibid., 359.

⁶² Rechy, John. The Sexual Outlaw. New York: Grove Press, 1977, 28.

⁶³ Richard Goldstein quoted in Watney, Simon. *Policing Desire: Pomography, AIDS* & the Media. Minneapolis: University of Minnesota Press, 1989, 13.

"Women are likelier to lose identity in sex; gay people are likelier to find an identity in sex (and sometimes nowhere else)..."64 On the surface, Tucker's observations may appear exaggerated or inflammatory, and perpetuate a false image of the gay male as a sex-obsessed individual.65 But, while a damaging stereotype of all gay men, Crimp argues that promiscuity remains an undeniable and defining characteristic of gay male identity. It has taught gay men not only about the pleasures of sex, but the diversity of those pleasures. Crimp says promiscuity should be revered as a model of how sexual pleasures could be pursued and granted to everyone if those pleasures were not confined to the straitjacket of institutionalized sexuality.66 In fact, it is precisely the absence of promiscuity that will make it more difficult for heterosexuals to learn how to have sex in an epidemic. This explains why Crimp can boldly proclaim that despite

⁶⁴ Tucker, Scott. "Gender, Fucking and Utopia: An Essay in Response to John Stoltenberg's *Refusing to Be a Man." Social Text* 27 (1991): 21.

⁶⁵ For a good example of this image at work, see Randy Shilts, And the Band Played On: People, Politics and the AIDS Epidemic. New York: St. Martin's Press, 1987, in which the author, who is now deceased, tries to bolster his now-discounted Patient Zero theory. Shilts contended that Gaetan Dugas, a Quebec flight attendant who had a "voracious sexual appetite," brought AIDS to the United States, hence the moniker ascribed to him. "Lovers were like suntans to him: They would be so wonderful, so sexy for a few days and then fade." (Shilts 1987: 22).

⁶⁶ Crimp, Douglas. "How to Have Promiscuity in an Epidemic," in Crimp, Douglas, ed. *AIDS: Cultural Analysis/Cultural Activism.* Cambridge: The MIT Press, 1993, 253.

all claims by liberals that "our promiscuity will destroy us ... it is our promiscuity that will save us." 67

Leo Bersani, in his provocatively titled essay, "Is the Rectum a Grave?", follows Crimp, arguing that promiscuity "is the sign of infection." 68 Commenting on a Florida case in which citizens set fire to the home of three hemophiliac boys who were infected with HIV, Bersani makes an interesting ideological connection between the 19th-century portrait of the sexually licentious prostitute and the contemporary picture of the gay man who is obsessed with receptive anal sex. Both, he says, are viewed as having little regard for their and their partner's health:

(I)f the good citizens of Arcadia, Florida, could chase from their midst an average, law-abiding family, it is, I would suggest, because in looking at three hemophiliac children they may have seen — that is, unconsciously represented — the infinitely more seductive and intolerable image of a grown man, legs high in the air, unable to refuse the suicidal ecstasy of being a woman.⁶⁹

⁶⁷ Ibid. For a radically opposing view, see Kramer, Larry. Reports from the holocaust: The Story of an AIDS Activist. New York: St. Martin's Press, 1994. Of gay men's refusal to refrain from risky sex, Kramer fires: "I am sick of guys who moan that giving up careless sex until this blows over is worse than death. How can they value life so little and cocks and asses so much? Come with me, guys, while I visit a few of our friends in Intensive Care at NYU. Notice the looks in their eyes, guys. They'd give up sex forever if you could promise them life. I am sick of guys who think that all being gay means is sex in the first place..." (Kramer 1994: 46)

⁶⁸ Bersani, Leo. "Is the Rectum a Grave?" in Crimp, Douglas, ed. AIDS: Cultural Analysis/Cultural Activism. Cambridge: The MIT Press, 1993, 213.

The popular belief that homosexuals who engage in "risky" behaviour are somehow fulfilling a death wish, that their identity as homosexuals is defined by the frequency of sex in which they engage, has not abated. It is present in the angry musings of agent provocateur Larry Kramer, who has castigated fellow homosexuals for not fighting back: "I think we must want to die … I have heard of denial, but this is more than denial; it *is* a death wish (emphasis in the original)."

While lashing out at the common assertion that activists and/or gay men have a death wish, Crimp suggests rather that the drive to death is not acknowledged: "...We disavow the knowledge that our misery comes from within as well as without ...By making all violence external, pushing it to the outside and objectifying it in 'enemy' institutions and individuals, we deny its psychic articulation, deny that we are effected, as well as affected by it."71

Douglas and Calvez observe that homosexuals, as a population at risk, are part of a community in which risk is glorified: "Many in such a community would deride the cult of safety. Death comes to all

⁷⁰ Kramer, Reports from the holocaust, 128.

⁷¹ Crimp, "Mourning and Militancy," 16.

in the end. Who would rightly want to live a safe life if that means no passion, no ecstasy, no abandon? ...Life without risk is not worth living. Love is the greatest risk of all."72 The authors' assessment, however, fails to take account of the enormous strides made in eroticizing safer sex, and conveniently ignores the history of homosexual oppression. It also creates a either/or binary in which either you value life (the authors don't believe gay men do) or you don't.

A more reasonable discussion of risky sexuality is advanced by Pinkerton and Abramson, who suggest that "given certain sets of values and perceptions, engaging in unsafe behaviours may appear to the individual to be a reasonable gamble."⁷³ Risky sex, the authors explain, may be rational in the sense that the benefits derived from sexual expression may far outweigh the threat of loss from AIDS.

On the subject of risky behaviour, philosopher Patricia

Illingworth argues that gay men and intravenous drug users should
not be viewed as autonomous because they are not acting in

⁷² Douglas, Mary and Marcel Calvez. "The self as risk taker: a cultural theory of contagion in relation to AIDS." *The Sociological Review* 38, no. 3 (August 1990): 461.

⁷³ Pinkerton, Steven D., and Paul Abramson. "Is Risky Sex Rational?" The Journal of Sex Research 29, no. 4 (November 1992): 561.

accordance with the desires they have come to support. She quotes Gerald Dworkin to support her claim:

It is the attitude a person takes toward the influences motivating him which determines whether or not they are to be considered his. Does he identify with them, assimilate them to himself, view himself as the kind of person who wishes to be motivated in these particular ways? If, on the contrary, a man resents his being motivated in certain ways, is alienated from those influences, resents acting in accordance with them, would prefer to be the kind of person who is motivated in different ways, then those influences, even though they may be causally effective, are not viewed as his.⁷⁴

Illingworth uses this argument to substantiate her assertion that gay men and IV drug users should receive financial compensation for the societal condemnation they have had to endure. Men who engage in impersonal sex, best expressed in Rechy's image of the sexual outlaw, are responding to the repressive morality of a society that still squirms at the mention of sex. Had society not discriminated against them in the first place, she argues, the need for liberation from an effeminate, passive stereotype would not have existed: "American homosexuals were cultivating the macho

⁷⁴ Dworkin, Gerald. "Autonomy and Behaviour Control." *Hastings Center Report* 6, no. 1 (1976): 25.

⁷⁵ The idea that gay men are owed monetary compensation was advanced originally in Richard D. Mohr. *Gays/Justice: A Study of Ethics, Society, and Law.* New York: Columbia University Press, 1988. In his book, Mohr argues that because gay men have been prohibited by the state to form families of their own, they are owed, especially in the form of patient care, the nurturing and protection such families would have otherwise provided.

stereotype ... that straight men under the influence of feminism, were abandoning. Giving up promiscuous sex meant giving up a hard-won positive identity, going back to the Nellie stereotype ..."76

As for IV drug users, because the behaviour in which they engage is illegal, they are *forced* to perform these activities in ways that ultimately endanger their lives (emphasis in the original)."77 Illingworth employs the term "forced" here to amplify her contention that the activities performed by IV drug-users are only *deemed* illegal by the state. The burden rests on law-makers to prove that legal intervention is justified: "IV-users who choose to act contrary to the law may be acting contrary to an unjust law."78

⁷⁶ David Black, quoted in Illingworth, Patricia. AIDS and the Good Society. New York and London: Routledge, 1990, 77.

⁷⁷ Ibid., 82.

⁷⁸ Ibid., 83.

CHAPTER 3

ACT UP AND IDENTITY INVERSION

If my speech tonight doesn't scare the shit out of you, we're in real trouble. If what you're hearing doesn't rouse you to anger, fury, rage, and action, gay men will have no future here on earth. How long does it take before you get angry and fight back?⁷⁹

- Playwright/activist Larry Kramer, in a fiery 1987 speech at the Gay and Lesbian Community Center in New York, a speech which many claim signalled the birth of ACT UP.

The AIDS Coalition To Unleash Power (ACT UP) was founded in 1987 in New York City by a small group of gay men who were concerned about the frightening number of homosexuals who were dying of AIDS.⁸⁰ Defining itself as a militant "direct action" group, ACT UP soon became the self-proclaimed voice of people living with — and

⁷⁹ Kramer, Reports from the holocaust, 128.

⁸⁰ I discuss the founding of Canada's only longstanding ACT UP chapter, in Montreal, in a later section. For a comprehensive discussion of the Canadian activist response to AIDS, see the excellent chapter by David M. Rayside and Evert A. Lindquist, "Canada: Community Activism, Federalism, and the New Politics of Disease," in Daniel Kirp and Ronald Bayer, eds. AIDS in the Industrialized Democracies: Passions, Politics, and Policies, Montreal and Kingston: McGill-Queen's University Press, 1992. In it the authors chart the rise of government-funded and independent advocacy groups, and discuss the problems peculiar to AIDS activism in the Canadian context, including federalism and shared political powers over health matters. The authors point to an increasing danger that the Canadian activists' efforts to mobilize governments to act may in fact backfire: "Governments at all three jurisdictional levels in Canada have created distinctive administrative units to respond to AIDS, acknowledging that this epidemic poses special issues and dilemmas. But there are now signs that officials in established health bureaucracies would like to reclaim AIDS, absorbing it into their routines." (Lindquist and Rayside 1992: 93)

dying from — AIDS. Journalist Donna Minkowitz, a former member of ACT UP who has written extensively on the group and on AIDS in general, explains how the AIDS crisis gave birth to a group that recognized organizational structure as inherently political:

The entire group decided on every action to be done in ACT UP's name. For people born in a country where political passivity is imbibed along with mother's milk, this degree of participation was like eating political spinach. No wonder the federal health bureaucracy quaked when this massive empowerment-machine rolled toward it.⁸¹

While it had organized several demonstrations at the local level in major American cities — including its dramatically staged "die-ins" in which members draw police-style, chalk outlines around each other's "dead" bodies — it was in 1989 that the group made its first international splash. At the International Conference on AIDS in Montreal, ACT UP members heckled speakers, disrupted proceedings, and generally made a nuisance of themselves. Such a nuisance, in fact, that they could not be ignored by the thousands of journalists who converged on Montreal for the conference. As one reporter from *The Economist* wrote of ACT UP's presence at the conference: "No other medical or scientific conference has seen anything quite like this well-informed consumer lobby. Researchers presenting data from drug

⁸¹ Minkowitz, Donna. "ACT UP at a Crossroads." The Village Voice, Vol. XXXV, no. 23, 5 June 1990, p. 18.

trials found their results discussed by the guinea-pigs. Scientists describing new treatments found themselves questioned by people whose lives depend on the answers."82

What is striking about ACT UP, according to Gamson, is its apparent ability to reinvent itself, and to reclaim symbols that are used to oppress gay men, generally, and people with AIDS, specifically. He reminds us, for example, that ACT UP's main emblem, a pink triangle, was once a Nazi emblem for homosexuals: "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."83

Drawing on the writings of French theorist Michel Foucault,

Gamson asserts that ACT UP is responding to a historical shift toward
a form of domination in which power is maintained through a
normalizing process, where all behaviour that is non-conforming is
deemed punishable. Gamson places his analysis within a larger

^{82&}quot;On the AIDS barricades," The Economist, 30 June 1990, p. 79.

⁸³ Gamson, Josh, "Silence, Death and the Invisible Enemy: AIDS Activism and Social Movement Newness," Social Problems 36, no. 4 (October 1989): 361. For a conflicting view of ACT UP's use of the pink triangle, see Stuart Marshall, "The Contemporary Political Use of Gay History: The Third Reich," a paper delivered at How Do I Look? Queer Film and Video Conference, NYC, 1989.

discussion of the phenomenon of new social movements (NSMs).

NSMs are not necessarily "new" in the strictest sense of the word. The issues to which these movements are devoted — health, sexual identity, and the environment, to name a few — have been with us for years. They, however, are given a different emphasis and sense of urgency within these social movements. The values shared by NSMs are identified as "autonomy and identity ... and opposition to manipulation, control, dependence, bureaucratization, regulation, etc."

etc."84 NSMs, says Claus Offe, operate in the language of absolutes:

(NSMs) relate to other political actors and opponents not in terms of negotiations, compromise, reform, improvement or gradual progress to be brought about by organizational pressures and tactics, but, rather, in terms of sharp antinomies such as yes/no, them/us, the desirable and the tolerable, victory or defeat, now or never, etc. Such a logic of thresholds, obviously, hardly allows for practices of political exchange or gradualist tactics.⁸⁵

While much of the above is true of ACT UP — especially so in the case of its fierce campaigns against the Catholic Church's refusal to allow safe sex information in its schools — the organization also pursues some of the goals to which Offe might say it should be vehemently opposed. Although it decries government interference in

⁸⁴ Offe, Claus. "New Social Movements: Challenging the Boundaries of Institutional Politics." Social Research 52, no. 4 (Winter 1985): 829.

⁸⁵ Ibid., 830.

matters of sexual expression on the one hand, it also has lobbied vigorously for increased state intervention, especially in seeking the U.S. government's assistance in lowering the price of AZT, on which a British-based pharmaceutical giant retains the exclusive patent.

As Calhoun explains, the idea of NSMs is troubling for what it excludes (movements that do not fit the mold) and what it obscures (identity politics): "Without much theoretical rationale, it groups together what seem to the researchers relatively 'attractive' movements, vaguely on the left, but leaves out such other contemporary movements as the new religious right and fundamentalism..." (I discuss the similarities between ACT UP's tactics and those of the militant anti-abortion group, Operation Rescue, in a later section.)

Gamson dismisses the argument that ACT UP is an NSM of the first order, believing that this is too confining a category. While ACT UP is not without its list of well-defined enemies — pharmaceutical corporations, in particular, and the medical establishment, in general — the group, according to Gamson, is also forced to confront an enemy that is "invisible, abstract, disembodied, ubiquitous: it is the

⁸⁶ Calhoun, Craig. "Social Theory and the Politics of Identity." in Calhoun, Craig, ed. Social Theory and the Politics of Identity, Oxford UK and Cambridge USA: Blackwell Publishers, 1994, 22.

very process of normalization through labelling in which everyone except one's own community of the de-normalized (and its supporters) is involved."87

In other words, ACT UP has responded, in the name of people with AIDS, to the very categorizations of normalization upon which it is placed. Gamson sees in this ACT UP's potential as an effective pressure group and agent of social change.

But as Epstein warns, there is a danger inherent in reclaiming the symbols that are used to stigmatize a given group. By engaging in flashy demonstrations, which often involve explicit expressions of sexuality, ACT UP may be, in fact, reinforcing the identity of the homosexual which it and the gay movement have fought so hard to resist: "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 a peculiar consequence of the homosexual lifestyle."88 Gamson explains that this is not the fault of AIDS activists, but rather of the process of domination to which social movements must respond. This, however, appears an

⁸⁷ Gamson, Josh. "Silence, Death and the Invisible Enemy: AIDS Activism and Social Movement Newness." 357.

⁸⁸ Epstein, Steven. "Gay politics," 48.

inadequate response to our predicament. The reclamation of which Gamson speaks appears only to be beneficial or empowering to the group itself. The damage inflicted on the "outside" image of the homosexual as a disease carrier, it could be argued, may outweigh any of the benefits derived from flashy demonstrations or pressure tactics.

Conservative commentator Michael Fumento, while, albeit indirectly, applauding the efforts of ACT UP, believes that AIDS activists have attempted to rewrite the AIDS narrative to accommodate and strengthen their own identity as gay males:

Homosexuals have learned to use their victim status as a powerful lobbying tool. By the late 1980s, the pink triangle was used like an American Express platinum card, as a means of getting special privileges available only to the bearer. AIDS victims began the 1980s by asking to be treated no worse than victims of other fatal diseases. But within a few years they were demanding funding and other treatment far superior to that received by sufferers of any other disease.⁸⁹

Fumento appears to be suggesting that PWAs revel in their illness, that they believe themselves to be the only sick people on earth. Perhaps, however, his reactionary view should be understood as a response to the militant tone of activist rhetoric, rather than a blanket condemnation of all PWAs. He also disputes the claim made

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⁸⁹ Fumento, Michael. *The Myth of Heterosexual AIDS*. New York: Basic Books Inc., 1990, 329-330.

by many an AIDS activist that it is wrong to treat people with AIDS any differently from victims of other diseases. In fact, he says, activists for people with AIDS do want to be treated differently, and are intent on seeing that AIDS research and prevention is pursued at the expense of other, life-threatening diseases: "If AIDS victims want to be treated as well as victims of other diseases, that is their right. But they have no right to be treated any better, either. There is no national guilt for AIDS, and there is no excuse for condescending to AIDS activists as if there were."

Needless to say, Fumento has been vilified in the press and by academics in the AIDS field. Journalist Donna Minkowitz, a former member of ACT UP, lashed out at Fumento for caving in to his obviously conservative agenda and to the false belief that AIDS is an epidemic of media hype: "I'd like to believe that, wouldn't you? But the third largest killer of men and women in New York isn't media hype." of men and women in New York isn't media hype."

Still, despite some of its apparent mean-spiritedness, Fumento's observations testify to the power of illness, how it can transform a "sick" person from a passive patient to an active political participant.

⁹⁰ Ibid., 331.

⁹¹ Minkowitz, Donna. "Death Sentences: Michael Fumento's Weird Science." The Village Voice, Vol. XXXV, no. 5, 30 January 1990, p. 61.

For as more people become infected, people who are HIV positive need not live out their final days in painful isolation. They can find comfort, and a sense of identity or community, in the protective shell of AIDS patient activism.

ACT UP's brand of patient activism, however, seems to belie Parsons's notion of illness, which emphasized that health and illness are individual states of the mind and body. As Gerhardt points out, Parsons rejected the idea that illness could reside in collectivities. Parsons was attempting to demonstrate that a society or whole races could not be sick, but that does not stop him from characterizing illness, from a strict sociological perspective, as an aspect of deviant behaviour. In essence, illness here is viewed as a less-direct form of political action:

Illness, in so far as it is motivated, is a form of deviant behaviour, and, as such, may be subjected to a standard sociological analysis of deviance. Compared with other types of non-conformist behaviour, sickness characteristically entails passive withdrawal from normal activities and responsibilities. As such, it should be distinguished from active rebellion against the normal social expectations, and from the types of deviance characterized by compulsive conformity. For it is an escape from the pressures of ordinary life.⁹²

⁹² Parsons and Fox, quoted in Gerhardt, Uta. *Ideas about Illness: An Intellectual and Political History of Medical Sociology*. London: Macmillan Education Ltd., 1989, 9.

Lupton explains that Parsons's sick-role model is inapplicable to AIDS because his model rests on the false assumption that the patient is not blamed for his or her illness. According to Parsons's model, once the "sick" person seeks help from a physician, he or she is no longer regarded as deviant. However, she argues, people with AIDS continue to be viewed as deviant "because they have allowed themselves to fall ill; they have ignored the moral proscriptions of society and are paying the consequences... (D)eviance is not abrogated by entering the sick role."93

PWAs, the majority of whom identify as homosexuals, it would seem, might be labeled deviant on two counts: as gay men, they are members of a community which engages in deviant or "unnatural" sexual behaviour; and as PWAs, they find in the deviance of illness a ground upon which to articulate their demands.

Also, it should be noted that PWAs also fail Parsons's other litmus test: after seeking medical help, the ill are expected to follow their doctor's directions, investing their faith and trust in the expertise of the physician. The short history of AIDS activism,

⁹³ Lupton, Deborah. Medicine as Culture: Illness, Disease and the Body in Western Societies. London, Thousand Oaks, New Delhi: Sage Publications, 1994, 89.

however, illustrates that PWAs have vigorously resisted any attempts to crumble under an omniscient medical authority. Witness, for example, the rise in non-traditional methods of therapy which have not been sanctioned by medical professionals, such as homeopathy, acupuncture, and urine therapy. (ACT UP alone has an alternative and holistic subcommittee, which advocates a natural approach to the treatment of HIV/AIDS and fights discrimination against holistic therapies by insurance companies and the medical establishment.) Such actions should not be viewed merely as the desperate actions of a group in pursuit of the elusive magic bullet; they remain a powerful symbol of the community's belief that "traditional" medicine is but a tool of the dominant class aimed at keeping the "sick" in their oppressive place in society. "The alternative treatment movement," Erni explains, "is a form of political resistance that, through adopting a self-empowerment model of community, challenges the hyperrationalized form of technology held sacred by many mainstream scientists."94

As Singer notes in her examination of hospitalization and AIDS, patient activism has produced an important resistance to the isolation imposed by illness and by the institution of the Hospital, the latter

⁹⁴ Erni, John Nguyet. Unstable Frontiers: Technomedicine and the Cultural Politics of "Curing" AIDS. Minneapolis and London: University of Minnesota Press, 1994, 57.

being "a form of power to which subjugated bodies give their informed consent, because they have no other choice." The Hospital, she says, should be understood in all of its metaphorical manifestations. It is not so much a physical place, but rather a process exercised by a number of institutions in which the interrogated subject comes to expect intrusions upon his or her privacy. The AIDS narrative has emerged to challenge this notion of the "patient" patient who quietly awaits the word from the good doctor: "The tragedy of AIDS has given way to a resistance that does not cast itself within the imaginary of faith, optimism, and hope — it is a resistance cast in the language of demand." Of

Despite her obvious support of ACT UP's demand-centered brand of political action, Minkowitz acknowledged several years ago that the organization's future was on shaky ground. The organization, she explains, continues to experience growing pains as it tries to cope with, and reflect, the many competing identities present within the AIDS activist movement: "New pressures and opportunities stemming from ACT UP's surge in size and media attention have left this group

⁹⁵ Singer, Linda. Erotic Welfare: Sexual Theory and Politics in the Age of Epidemic. London: Routledge, 1993, 103.

⁹⁶ Ibid., 106.

— so brilliant at incorporating differences — struggling to contain its political divisions." Some activists working within ACT UP argue that the organization's "freewheeling structure," which Minkowitz says has been one of its saving graces and has allowed the organization to accommodate a wide range of concerns, should be centralized, and that it should more closely resemble a "traditional" interest group.

This problem is exacerbated by the various interests within ACT UP, including activists who believe treatment issues should be a priority, activists for women with AIDS, drug users, and minority groups. Each interest group is assured a voice within ACT UP, and has formed a sub-committee to press for its demands, yet each member is united in anger over what is perceived as ACT UP's white, middle-class, gay male agenda. This perception, says Minkowitz, still plagues the organization.

In their article, "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines," ACT UP members Catherine Saalfield and Ray Navarro explain how women and people of colour within ACT UP have begun to form their own coalitions and to forge their own style of participation in order to advance their own particular agendas. Gay

⁹⁷ Minkowitz. "ACT UP at a Crossroads," p. 19.

⁹⁸ Minkowitz, "ACT UP at a Crossroads," p. 22.

men of colour, for example, have had to combat the dominant perception that they are more sexist than white men and more prone to drug addiction. While applauded for their AIDS activism, women within the AIDS movement have consistently fought the belief that the AIDS crisis does not belong to them: "The women of ACT UP ... are trying to crack open the world in which women live and allow themselves the space to change what doesn't work."

Unfortunately, Navarro and Saalfield fail to provide a necessary, critical examination of race and gender on the frontlines, as the title of their article promises. The tone of the article wrongly suggests that racism and sexism are not present within the ACT UP fold, but only confined to the outside world. The authors do, however, raise at least one compelling question: does participation in ACT UP activism invariably preclude the closeting of other identities? Must a gay man of colour check his racial identity at the door to devote all of his energies to AIDS activism? Similarly, must a female member of ACT UP shed her feminist skin to pursue the AIDS cause? In other words, must one identity take precedence over another? As the authors state, lesbians and gay men who are involved in activism have long been

⁹⁹ Saalfield, Catherine, and Ray Navarro. "Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines," in Diana Fuss. *Inside/Out: Lesbian Theories*, *Gay Theories*. New York and London: Routledge, 1991, 359.

asked to downplay or ignore their sexual identity: "Because of the price queers pay for political work which demands the privileging of race, gender, or class over sexual preference, we are now at great pains to make ACT UP work for us." 100

If the internal divisions over coalition-building, racism and sexism weren't enough, ACT UP is also forced to confront and contain a growing tide of resentment by angry gay men and lesbians "who want less and less to define their politics in terms of the struggle against AIDS. They are loath to define their queer experience in terms of the annihilation of an earlier generation." 101 ACT UP's brand of coalition politics, Robin Hardy suggests, demands that homosexuals cast aside their identities for the greater good of AIDS activism; it fails to acknowledge the possible harm of such a move to the gay community.

Characteristic of much of the press attention paid to ACT UP,

Celia Farber, a journalist who has written extensively on AIDS-related issues for *Spin*, an American music magazine, paints ACT UP as an organization on the brink. A recent article by Farber highlighted a

¹⁰⁰ Saaifield and Navarro, 354.

¹⁰¹ Hardy, Robin. "Die Harder: AIDS Activism is Abandoning Gay Men." The Village Voice, Vol. XXXVI, no. 27, 2 July 1991, p. 34.

controversy involving members of ACT UP San Francisco who disrupted an AIDS fund-raiser for a local AIDS organization that featured speeches by ACT UP founder Larry Kramer and Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases. After blowing whistles and hurling insults at Fauci, a near riot broke out at the event.

The local AIDS organization, Project Inform, the activists claim, "has become so entrenched with authoritarian, establishment, old-boy network views on AIDS that it has betrayed the community." 102 ACT UP members also objected to Kramer's apparent hobnobbing with the official AIDS establishment. This accusation of "selling out", however, is not new. ACT UP has long been faced with this dilemma: should it work outside the Establishment to effect change or forge alliances with the decision makers? As one ACT UP protester told *Spin*: "When our leaders start making friends with the people that (sic) are murdering us, then where does that leave us? It leaves us looking for another set of leaders ... AIDS activism took a nose-dive when Larry Kramer stopped calling Anthony Fauci a murderer and started calling him Tony." 103

¹⁰² Farber, Celia, "AIDS: Words From the Front." Spin 11, no. 6 (September 1995): p. 103.

ACT UP's identity crisis has, in effect, led the push to create a hierarchy, which many members vehemently oppose for several reasons. As one member explained of his opposition to the centralization campaign, top-down organizations are in more danger of being infiltrated than bottom-up ones: "No one can infiltrate chaos. People can only manipulate order." 104

To understand the AIDS activists' refusal to toe the Establishment line, it is necessary to examine the medical community's previous attitudes toward homosexuality. As Stuart Marshall explains, the revolt which we are witnessing cannot be divorced from this history; for centuries, the homosexual lifestyle was viewed as a medical condition, not as an acceptable way of life. Only 20 years ago, Marshall reminds us, did lesbian and gay activists win the fight to strike homosexuality from the American Psychiatric Association's list of mental diseases:

The medicalisation of homosexuality — a transition from notions of sin within ecclesiastical law to notions of sickness and deviancy within criminal law — is part of a general process of the medicalisation of deviancy which was to result in the proliferation of new social identities, a whole set of new species of human beings, many of which were to be witnessed and catalogued in the evidence of photography. 105

¹⁰³ Farber, pp. 103-104.

¹⁰⁴ Minkowitz, "ACT UP at a Crossroads," p. 22.

Medical photography, says Marshall, was able to stamp a human face on the deviant categorization, whether the offending subject was a prostitute, criminal or pervert. What was once confined to the pages of medical literature finally began to burs, with visual meaning. In order to achieve this "representative" image, the medical photographer need only zero in on the subject's distinguishing feature— "the physiological peculiarity which spoke in a visual language the hidden pathological secrets of the photographed subjects and allowed them to be accurately detected." 106

Foucault contends the medical establishment began to view homosexuality as a disorder following the release of an unsympathetic article in 1870 by physician Karl Westphal, who regarded homosexuality as "a form of moral insanity due to congenital reversal of sexual feeling." ¹⁰⁷ The identity of the homosexual, Foucault maintains, was totalizing: "Nothing that went into his total composition was unaffected by his sexuality. It was everywhere present in him: at the root of all his actions because it was their

¹⁰⁵ Marshall, Stuart. "Picturing Deviancy," in Boffin, Tessa and Sunil Gupta, eds. Ecstatic Antibodies: Resisting the AIDS Mythology. London: Rivers Oram Press, 1990, 25.

¹⁰⁶ Ibid., 26.

¹⁰⁷ Bullough, Vern L. and Bonnie. Sin, Sickness, and Sanity: A History of Sexual Attitudes. New York and London: Garland Publishing Inc., 1977, 204.

insidious and indefinitely active principle; written immodestly on his face and body because it was a secret that always gave itself away." ¹⁰⁸ Ironically, this view of homosexuality as an almost inescapable pathology — "a kind of interior androgyny, a hermaphroditism of the soul" ¹⁰⁹ — signalled the long-awaited birth of homosexuality as a recognized form of sexuality.

For many AIDS activists and gay men, the attempts by public health "experts" to combat AIDS were seen as old wine in new bottles, a return to and grim reminder of days past. Lynch's remarks are illustrative of this fear: "Gays are once again allowing the medical profession to define, restrict, pathologise us. What used to be a psychiatric pathology is now an infectious one." 110

¹⁰⁸ Foucault, Michel. *The History of Sexuality*, Vol. 1, tr. Robert Hurley, New York: Vintage Books, 1990, 43.

¹⁰⁹ Ibid., 43.

¹¹⁰ Michael Lynch quoted in Marshall, "Picturing Deviancy," 31.

CHAPTER 4

CIVIL DISOBEDIENCE AND THE POLITICAL ACTOR

Writing on the subject in the 1960s, Hannah Arendt argued that while civil disobedience is known and practiced worldwide, it is profoundly American in origin and substance. No other country and no other language, she noted, *had* a word for civil disobedience. In the United States, she says, there existed "a constitutional niche for civil disobedience," formed in large measure by the American revolution, which carried with it a concept of law that was never articulated fully.

In defining this peculiar American phenomenon, she lays out three detailed criteria, as expressed by Jennifer Ring:

(1) Civil disobedience must take place in the light of day, publicly rather than secretly (which distinguishes it from criminal lawbreaking); (2) civil disobedience calls for a group rather than individual endeavor (which distinguishes it from conscientious objection); and (3) civil disobedience aims at overturning a specific aspect of public life rather than the political system (which distinguishes it from revolution). 112

We should pause here to examine these criteria in closer detail and to ask whether AIDS activism satisfies Arendt's conception of civil

¹¹¹ Arendt, Hannah. "Civil Disobedience" in Arendt, Crises of the Republic. New York: Harcourt Brace Jovanovich, Inc., 1969, 83.

¹¹² Ring, Jennifer. "The Pariah as Hero: Hannah Arendt's Political Actor." *Political Theory* 19, no. 3 (August 1991): 449.

disobedience. The first criterion is certainly true of ACT UP; the organization almost always stages public events for the world to see. It is, after all, media savvy. Arendt, however, may be incorrect to characterize secret actions as being synonymous with criminal lawbreaking, for certain events, such as obstructing traffic, even if committed in the light of day, are punishable crimes.

Second, ACT UP's "actions", I would argue, do reflect a group "endeavor." In fact, seronegative members of ACT UP are counselled to inform police officers, if asked, that they are HIV positive, all in the interest of group solidarity. Recent political divisions over representation within ACT UP, and the splintering within the group along linguistic (Hispanics, in the case of the United States), racial, and gender lines suggest that individual concerns often clash with the group's overall mission.

Third, there may be some disagreement in the activist camp regarding the underlying goals of civil disobedience. Arendt, while treating the subject of civil disobedience with a degree of seriousness, seems to undermine the ability of its adherents to overturn the political system. AIDS activists may overstate their point, or exaggerate their importance, but it is clear that they are attempting to overturn more than a "specific aspect of public life." The fight against AIDS is not concerned solely with speedy access to clinical trials or

freedom from discrimination; it is a revolt against the Establishment, the "invisible enemy." 113

The private/public distinction raised by Arendt is especially relevant in the context of the gay and lesbian movement, which has fought consistently on the belief that what takes place between consenting adults is a private matter that should not be subject to state control. (Former Prime Minister Pierre Elliot Trudeau echoed these sentiments when he proclaimed that the state had no place in the nation's bedrooms.) The recent controversy surrounding the U.S.-based National Man-Boy Love Association (NAMBLA), which some have denounced as a front for gay pedophiles and counts among its members celebrated American novelist Allen Ginsberg, has blurred this private/public distinction and has, perhaps, harnied the gay lobby, reinforcing perceptions of gay men as child molesters.

Therefore, ACT UP's brand of political activism fails to fit neatly into the compartments laid out by Arendt. It does, however, reflect the spirit of civil disobedience elaborated by Arendt.

Childress introduces a further distinction, between indirect and direct forms of civil disobedience, citing the work of Mahatma Gandhi,

¹¹³ This phrase is borrowed from Josh Gamson's remarkable essay, "Silence, Death and the Invisible Enemy: AIDS Activism and Social Movement 'Newness," Social Problems 36, no. 4 (October 1989): 351-367.

the self-proclaimed father of non-violent resistance, to clarify his point:

Aggressive, assertive or offensive civil disobedience is non-violent, wilful disobedience of laws of the State whose breach does not involve moral turpitude and which is undertaken as a symbol of revolt against the State ...Defensive civil disobedience, on the other hand, is involuntary or reluctant non-violent disobedience of such laws as are in themselves bad and obedience to which would be inconsistent with one's self-respect or human dignity.¹¹⁴

For example, when Thoreau, who is credited with introducing the term "civil disobedience" into our political vocabulary, refused to pay a state poll tax to protest slavery, the Mexican war, and maltreatment of Native Americans, he was engaging in a form of indirect resistance. Thoreau was not questioning the validity of the poll tax law, but rather the injustice of other government practices.

Similarly, AIDS activists, while sometimes united in anger over a specific city ordinance or government policy decision, generally "violate just laws to protest other unjust or inequitable social policies and practices, such as inadequate provision of health care." This indirect form of resistance is what confounds scholars of civil

¹¹⁴ M.K. Gandhi. Non-Violent Resistance, Bharatan Kumarappa, ed. New York: Schocken Books, 1961, 175.

¹¹⁵ Campbell, Courtney S. "Ethics and Militant AIDS Activism," in Reamer, Frederic G., ed. AIDS & Ethics. New York: Columbia University Press, 1991, 172.

disobedience. As Kateb explains, acts of *direct* civil disobedience are much simpler to justify. The defiance of a law or policy "whose content is clearly criminal" is a morally justified action. What, however, constitutes a "clearly criminal" law or policy, and, conversely, a "clearly criminal" response or action? His use of the word "clearly" presumes that we understand to which type of crime he is referring.

A more troubling question to ponder, says Kateb, "is not the harm done by, say, those who trespass, but the readiness to believe that for vague reasons one can break some law or other without defaulting on the general obligation to be law-abiding in a representative democracy." Kateb is quick to point out that only if it could be demonstrated that such a democracy is in fact unrepresentative or undemocratic could such an attitude towards disobedience be deemed acceptable. The moral justifications advanced by AIDS activists appear to crumble under such an argument. It could be argued, for example, that activists, much as other citizens, can lobby their representatives for more action on the AIDS front and have the right to run for political office if they wish to effect change. Their

¹¹⁶ Kateb, George. Hannah Arendt: Politics, Conscience, Evil. New Jersey: Rowman and Allanheld, 1983, 143.

efforts may be unsuccessful, but Kateb might be inclined to argue that such are the limits of democracy: participation in politics entails both loss and victory. The system may not always work in your favour, but that doesn't mean it is not working.

By examining the patterns of justification used by AIDS activists along five moral criteria — just cause, last resort, reasonable expectation of success, proportionality, and limitation — Campbell brings his views on AIDS and ethics into sharper focus. It is important to note here that the author, while stating at the outset that the militant tactics adopted by AIDS activists cannot be understood without an appreciation for the government and societal neglect perceived by PWAs, applies a rigorous analysis to the issue at hand, believing that "AIDS activists who engage in civil disobedience thereby bear a burden of justification for their actions ..." 118

For the sake of this work, I will deal solely with the first criterion, as it informs the four remaining criteria. Campbell asks whether activists are correct to appeal to the concept of "just cause" in explaining the use of civil disobedience to rectify societal wrongs. While he says it could be argued that given the history of neglect, the rights of PWAs to health care generally and to drugs specifically have

118 Campbell, "Ethics and Militant AIDS Activism," 157-158.

been denied, Campbell warns that the danger posed by such an argument is that it appears to make a singular exception for PWAs. The fact is, Campbell reminds us, there is no guaranteed right to health care in the U.S. While the latter may be correct in the case of the United States, how would Campbell apply his point to the case of Canada, where universal health care is, arguably, perceived a natural right of citizens?

Arendt maintains that governments should deal with civil disobedients as they do with pressure groups. That is, they should be permitted, through their representatives, to influence decision-makers. This, she says, would make them a force to be reckoned with, not solely on days in which they organize demonstrations to garner media attention and a forum in which to press for their demands. Similarly, civil rights leader Martin Luther King suggests that the purpose of direct action is to force an issue onto the agenda:
"Nonviolent direct action seeks to create such a crisis and establish such creative tensions that a community that has constantly refused to negotiate is forced to confront the issue..."

Thoreau, on the other hand, was much more direct and activistminded in his characterization of and support for civil disobedience.

¹¹⁹ Washington, James M., ed. Testament of Hope: The Essential Writings of Martin Luther King. San Francisco: Harper and Row, 1986, 289-302.

He appears to have little patience for Arendt's diluted brand of civil disobedience, which is regarded as a temporary, last-ditch attempt to correct moral wrongs: "If governmental iniquity is of such a nature that it requires you to be the agent of injustice to another then I say break the law ... Law never made men a whit more just and, by means of their respect for it, even the well-disposed are made the agents of injustice." 120

Ronald Dworkin, a leading legal theorist, suggests in *Taking* Rights Seriously, that the manner in which governments deal with civil disobedience should be taken as a moral barometer of how governments treat and deal with dissent. Government, he says, "must dispense with the claim that citizens never have a right to break its law ...Any Government's harsh the atment of civil disobedience, or campaign against vocal protest, may therefore be thought to count against its sincerity." 121

One might rightly pose the question: does AIDS activism constitute a "true" form of civil disobedience, as elaborated by Arendt, Thoreau or Gandhi? After all, the laws that pertain directly to

¹²⁰ Thoreau quoted in Nathanson, Bernard. "Operation Rescue: Domestic Terrorism or Legitimate Civil Rights Protest?" *Hastings Center Report* 19, no. 6 (November/ December 1989): 28.

¹²¹ Dworkin, Ronald. Taking Rights Seriously. Cambridge, Massachusetts: Harvard U. 7 Press, 1977, 204.

HIV/AIDS — such as mandatory testing or quarantining — are unbreakable in any significant way since, and, if necessary, the state can compel compliance. For example, Spiers asks, "how would one publicly break a law that makes it a crime to knowingly expose another person to HIV ...by holding a press conference where bodily fluids are exchanged or contaminated needles shared?" 122 In fact, however, Spiers's comments may be a tad premature. Several legal cases are unfolding in North America in which PWAs have been charged with transmitting HIV to their "unsuspecting" partners. 123

Spiers, a founding member of ACT UP, justifies the use of civil disobedience — although he appears unclear about whether such action is possible given the nature of AIDS activism — by echoing Thoreau's call to arms. Invoking the specter of genocide, which has been used in the past by activists such as Larry Kramer, Spiers

¹²² Spiers, Herbert M. "AIDS and Civil Disobedience." Hastings Center Report 19, no. 6 (November/December 1989): 34.

Without End: A Shocking Story of Women and AIDS, Toronto: Alfred A. Knopf Canada, 1995, focuses exclusively on the sexual exploits of Charles Ssenyonga, an Ontario man who was charged under the Canadian Criminal Code with criminal negligence causing bodily harm and aggravated sexual assault. (This case is discussed further in a later section.) Recently in Florida, a prostitute pleaded guilty to aggravated battery on a person over 65 years of age, robbery and auto burglary stemming from an attack in 1994 on her 90-year-old client. Health officials now believe that the woman, Naomi Morrison, infected the man with HIV by biting his arm. She has been sentenced to 10 years in prison. It is not clear whether the recent revelation, if proven, will result in an even stiffer penalty.

charges that governments, through neglect, are breaking laws, including the Fourth and Fourteenth Amendments of the U.S.

Constitution, and the Declaration of Independence, which guarantees the right to life, liberty, and the pursuit of happiness: "Passive genocide, by means of neglect, is believed by many activists to be the correct characterization of governmental policy on AIDS." 124

In contrast, Operation Rescue has occupied the same moral ground to justify and excuse its unrelenting assault on abortion clinics and their clients. But, as Nathanson explains, Operation Rescue's brand of civil disobedience is unique in that it is staged on behalf of a "moiety that is not only mute but is quite literally invisible." The organization does derive some authority from the scriptures, but, unlike groups such as ACT UP, it does not speak on behalf of an entity. Of course, Operation Rescue would probably contend that this only amplifies the need for a group such as theirs, as the unborn have no one to speak on their behalf. ACT UP, it could be argued, might employ the same justification to describe its actions.

¹²⁴ Spiers, "AIDS and Civil Disobedience," 34.

¹²⁵ Nathanson, Bernard, "Operation Rescue: Domestic Terrorism or Legitimate Civil Rights Protest?": 29.

Gays, generally, and PWAs, specifically, they might contend, are attempting to render visible the invisible subjects of oppression.

Operation Rescue demonstrators who are arrested at clinics withhold their names from the police and the courts, using, if pressed, fictitious names such as Baby Jane Doe. As Nathanson observes, while this practice is commonly used by disobedients to deliberately deceive, Operation Rescue's resort to this tactic carries a rich, symbolic undertone:

The ideological underpinning of this practice is not only non-specific resistance to the legally constituted forces of a State they perceive as illegitimate in that it permits the practice of destroying unborn human life, but also that it aligns the Rescuers with the unborn victims, none of whom survived long enough to acquire names. 126

¹²⁶ Ibid., 31.

Violence as a Means to an End

If we turn to the issue of violence, AIDS activists, especially members of ACT UP, begin to appear on shaky ground. Some members of ACT UP have skirted the issue altogether, while others have defended the resort to violence. As Spiers notes, in recalling an ACT UP "action" in which violence was done to property: "If, in the end, violence does become a part of an already tragic situation, it is certain it will come as a political act born of desperation." 127

Attempting to clarify ACT UP's position on the use of violence, however, is exacerbated by the fact that ACT UP purports to be a non-hierarchical organization; its members do not always conform to a specific set of attitudes or beliefs. The objective is always clear—ending the AIDS crisis—but how to get there remains a hotly-contested point. ACT UP's Direct Action Guidelines, as elaborated by Navarro and Saalfield, do little to resolve the issue:

We cannot guarantee the safety of participants at our demonstrations ...We try to protect each other at demonstrations by setting up a support and advocacy structure that can react quickly if problems should arise or if arrests occur ...At our actions, demonstrators act according to the love and caring we have built for each other. Individual or group actions that endanger the physical well-being of other demonstrators should not be done. Generally, actions that might endanger the safety of others at the demonstration include ... actions that cause panic such

¹²⁷ Spiers, "AIDS and Civil Disobedience," 35.

as running and throwing rocks."128

As the authors suggest, the issue of civil disobedience and its logical but unfortunate corollary, violence, need to be examined closely by ACT UP, since violence may very likely threaten the livelihood of ACT UP's shock troops: "ACT UP members may have strong principles but the cops have nightsticks, handcuffs, and guns ... The body that lies down in a street gets carried away to a jail. And some of the bodies are already fighting HIV infection. These bodies do not benefit from police brutality in the streets." 129 It is no longer sufficient, they claim, to repeat the familiar refrain: that violence really lies in the hands of law enforcement officers.

Larry Kramer, the so-called "father of AIDS activism", has stated several times on record that he supports violence as a last-ditch measure to wake society from its deep slumber. When asked in a recent magazine interview where he draws the proverbial line, Kramer commented, "I wish to hell there were some people out there courageous and crazy enough to go out there and throw bombs or burn buildings, or put a mark on Jesse Helms, or whatever." 130 But

¹²⁸ Saalfield and Navarro, "Shocking Pink Praxis," 35

¹²⁹ Ibid., 357.

^{130 &}quot;DPN Interview: Larry Kramer," Diseased Pariah News, no. 9 (1994): 27.

Kramer, it should be stressed, does not speak for ACT UP, and many past and current members have denounced him as a chronic, impatient, and bitter complainer. 131

Drawing on the works of angry PWA/author David Wojnarowicz and American rap artists such as Ice-T, Judith Halberstam tackles the issue of violence from a postmodern perspective. While she does not advocate violence per se, she does support an "imagined violence, the violence that is native to what June Jordan calls ... a place of rage ... it is a location beyond thought, action, response, activism, protest, anger, terror, murder, and detestation."¹³²

The power or utility of violence lies not in its realization, but in its potential to inflict harm. Imagined violence, Halberstam says, is imagining resistance and rage; it is a counter-hegemonic weapon that need not be fired at the appropriate target, but need only operate in the realm of fantasy. A quote from Wojnarowicz demonstrates this form of violence: "I'm beginning to believe that one of the last frontiers left for the radical gesture is the imagination. At least in my

¹³¹ Among others, author David Feinberg has said in Queer and Loathing: Rants and Raves of a Raging AIDS Clone, New York: Viking Penguin, 1994: "Larry Kramer has this annoying habit of founding organizations and then renouncing them... Larry Kramer — the fag who cried wolf, Cassandra, the prophetess of doom — shrieks his diatribes into the wind, and no one listens." (Feinberg 1994: 13-15).

¹³² Halberstam, Judith. "Imagined Violence/Queer Violence: Representation, Rage, and Resistance." Social Text 37 (Winter 1993): 187-188.

ungoverned imagination I can fuck somebody without a rubber, or I can, in the privacy of my own skull, douse (Jesse) Helms with a bucket of gasoline and set his putrid ass on fire ..." 1.3.3 ln

Wojnarowicz's imagination, U.S. Senator Jesse Helms, a longtime foe of gays and AIDS activists, can be made to suffer for his incendiary views. The author here can freely vent his rage in the language of violence and resistance.

The postmodern pressure tactics exerted by groups like ACT UP, Halberstam posits, signal a new form of political response that exploits the dividing line between representation and reality. Witness, for example, the posters produced for ACT UP by artists' collectives such as Gran Fury. None of the images is pretty; in fact, many of them are brutally provocative. Tearing a page from ACT UP's school of activist graphics, Benetton's magazine, *Colors*, featured a full-page photo of former U.S. President Ronald Reagan covered in Kaposi's sarcoma lesions. Reagan "got AIDS" thanks to a computer imaging program. Alongside the photo ran an editorial announcing the former president's death from AIDS-related complications. Perhaps, this is the type of imagined violence to which Halberstam is referring — the magazine gave Reagan, long criticized for his inaction on AIDS in the

¹³³ Wojnarowicz, David. Close to the Knives: A Memoir of Disintegration. New York: Vintage Books, 1991, 120.

early stages of the epidemic and for his deliberate refusal to utter the word "AIDS", his due punishment. Metaphorically, and while the irony should not be lost here, the magazine "killed" him. Surprisingly, the prank, which was part of the magazine's special issue devoted to AIDS, sparked little controversy.

In her essay, Halberstam does not take a definitive stand against real violence, preferring instead to argue that the gulf between "real" and "imagined" no longer exists. Imagined violence, in her view, appears favourable because it is more promising politically. Real violence may be self-defeating, and, evidently, wins over few converts.

Imagined violence ... is the fantasy of unsanctioned eruptions of aggression from "the wrong people, of the wrong skin, the wrong sexuality, the wrong gender." We have to be able to imagine violence and our violence needs to be imaginable because the power of fantasy is not to represent but to destabilize the real. Imagined violence does not stop men from raping women but it might make a man think twice about whether a woman is going to blow him away. 134

The danger, of course, in subscribing to this view is the very possibility that the line will blur between real and imagined violence. With the important exception of writers such as Wojnarowicz, who can channel their rage through the seemingly "harmless" act of writing, what would we make of that person who is incapable of expressing "imagined violence" without, from time to time, acting out

¹³⁴ Halberstam, 199.

those murderous fantasies in the real? Also, what is the utility of continuing to threaten the use of violence, if that threat appears empty or unlikely? This is where I depart from Halberstam, for I would contend that the call to "imagined violence" depends heavily on the occasional eruption of real violence. Obvious parallels can be made with native groups in Canada, which have threatened violence in the past, but, in the case of Mohawks, only seemed to warrant serious government consideration when they carried out these threats at Oka, Que., in the summer of 1990.

Power and the Pariah

It is not a coincidence that a group of PWAs in Oakland, California has titled their magazine, *Diseased Pariah News (DPN)*. Formed in 1990, the quarterly publication constantly challenges the boundaries of taste with its blend of savage humour and personal invective. They got the name for the magazine from a cartoon that lampooned a decision by an American airline to refuse the passage of a PWA. The cartoon showed an airline clerk asking a passenger at the airline counter, "And would you like the smoking, non-smoking, or diseased pariah section?" 135 As editor Tom Shearer asked in the magazine's inaugural issue:

What's so damn funny about a pandemic devastating the world? Well, we have it and sometimes we find it amusing. After all, life itself kills everybody, and there's much about life that is purty darn funny, if you like humour. Besides, who wants to be serious all the time, even about fatal illness? ... We should warn you that our editorial policy does not include the concept that AIDS is a Wonderful Learning Opportunity and Spiritual Gift From Above. Or a punishment for our Previous Badness. Nor are we much interested in being icons of noble tragedy, brave and true, stiff upper lips gleaming under our oxygen hoses... We are not saints, nor devils, just a couple-o-guys who ran into a Danger Penis and caught something we don't like very much. And we HATE teddy bears. 136

¹³⁵ Shearer, Tom. "Welcome to our Brave New World." Diseased Pariah News, no. 1 (1990): 2.

¹³⁶ Shearer, 2. The idea that AIDS was a "Spiritual Gift From Above" is embodied in a passage by the late French author Hervé Guibert, one of Michel Fourault's closest personal friends, in *To the Friend Who Did Not Save My Life*,

While its editorial stance may appear objectionable and its content sometimes offensive, one should avoid dismissing *DPN* as the ravings of a group of angry HIV-positive men. It may not carry the journalistic weight of a magazine such as *Poz*, which features serious, professionally-crafted articles about issues affecting PWAs, but *DPN* is one example of the inversion of an infected identity. The magazine is itself an outgrowth of identity politics; it was, in fact, fashioned from the ashes of identity politics.

The editor of *Poz* may wish to proclaim that his magazine "puts AIDS directly in people's faces," but the face of AIDS presented by his magazine is an unblemished one. Like the fashion magazines that have been long criticized for creating and perpetuating false images of women, *Poz* creates and maintains a safe world in which PWAs are lesion-free. The identity of the PWA in *Poz* is that of consumer, as evidenced by the sheer volume of glossy, full-page advertisements peddling everything from life insurance to diet supplements. Contrast this with the back cover of one issue of *DPN*, which features a satirical

London and New York: High Risk Book and Serpent's Tail, 1994: "Jules had once said to me, at a time vihen he didn't believe we were infected, that AIDS was a marvelous disease. And it's true that I was discovering something sleek and dazzling in its hideousness, for though it was certainly an inexorable illness, it wasn't immediately catastrophic, it was an illness in stages, a very long flight of steps that led assuredly to death, but whose every step represented a unique apprenticeship. It was a disease that gave death time to live and its victims time to die, time to discover time, and in the end to discover life, so in a way those green monkeys of Africa had provided us with a brilliant modern invention." (Guibert 1990: 164)

ad for a lesion-riddled "AIDS Barbie." The crude caption below the picture reads: "Don't let AIDS Barbie waste away in an empty shoebox ... Let her spend her final days languishing in her very own Malibu Dream Hospice!" 137

Jennifer Ring, in an important article that examines Arendt's thoughts on political action, argues that much of the literature on Arendt overlooks the conception of the political actor as pariah, as "history's outsider." ¹³⁸ Judging from Ring's characterization, one might find interesting parallels between the pariah and the modernday AIDS activist:

Almost the inverse of the public activist, the pariah and particularly the "conscious pariah" is aware of himself as an outsider, aware of himself in history or at least aware of the way in which history has shaped his life. He does not anticipate recognition from a group of peers. But while he does not act *for* a community of equals, neither does he act as an individual. He acts instead *as* a member of a group of outsiders against the prevailing community. 139

Ring's comments are especially relevant in the case of PWAs who also identify as homosexuals. Volumes have been written on the exclusion of gays from history, and other attempts to discredit them,

¹³⁷ Diseased Pariah News, no. 9 (1994), quoted from back-page advertisement.

¹³⁸ Ring, "The Pariah as Hero,' 433.

¹³⁹ Ibid., 441.

whether by the medical community, which once asserted that homosexuality was a disease, or by law-makers, who enacted harsh sodomy laws, some of which were punishable by death. While many of these laws have been repealed and the medical community has recanted its previous denunciations, a belief persists in the gay and lesbian communities that their lifestyle choices have forced them onto the sidelines of history. Ring's reading of Arendt brings this into sharper focus, and helps to shed light on how, paradoxically, AIDS activists can work within a system of which they do not consider themselves a part, whether consciously or not.

Unlike political action in its general sense, conscious pariahdom, according to Ring, stresses the importance of both public and private concerns. The author takes this one step further, asserting that Arendt seeks to make public aspects of the outsider's private life. She does not, however, specify whether all private acts should be transferred to the public realm.

We are nonetheless left to ponder whether Arendt would have regarded AIDS activism as the true embodiment of political action, since it is, in many respects, rooted "in the individual's capacity to do the unexpected." Would Arendt have supported ACT UP's brand of

¹⁴⁰ Weeks, Jeffrey. Sexuality. New York and London: Routledge, 1986, 33.

civil disobedience, which has included members chaining themselves to the doors of government buildings and the offices of pharmaceutical firms, or opted for a form of AIDS activism that more closely resembles traditional interest-group lobbying? After all, Arendt did view civil disobedience as the logical consequence of years of disillusionment with the democratic process.

Civil disobedience, according to Jeffrey Isaac, was central to Arendt's model of action. Action, I would argue, also requires an appeal to identity. As Arendt herself notes, "Action without a name, a 'who' attached to it, is meaningless, whereas an art work retains its relevance whether or not we know the master's name." Her characterization of civil disobedience, however, hinges on a false hope that civil disobedients would find refuge in the legitimate political process, that they would not deem it necessary to resort to such acts to make their voices heard.

¹⁴¹ Ring, "The Pariah as Hero," 450.

¹⁴² Arendt, Hannah. *The Human Condition*. Chicago and London: The University of Chicago Press, 1953, 180-181.

CHAPTER 5

ANATOMY OF AN AIDS ACTIVIST

To say that there exists a textbook AIDS activist is tantamount to proclaiming that there is a composite portrait of the PWA. 14.1 The spectrum of sufferers is as diverse as society itself. Webster's New Encyclopedic Dictionary defines activism as "a doctrine or practice that emphasizes vigorous or energetic action (as a mass demonstration) for political ends." 144 While this definition appears well-suited to the forthcoming discussion, it also presumes that activism is defined solely in traditional terms. Indeed, one may call himself/herself an activist, yet, at the same time, eschew participation in loud, public spectacles. Jerald Breitman, the American PWA whom I interviewed,

¹⁴³ For a discussion of the issues surrounding HIV portraiture and the controversy over an exhibition of photographs of PWAs, see Jan Zita Grover, "Visible Lesions: Images of the PWA in America," in Miller, James, ed. Fluid Exchanges: Artists and Critics in the AIDS Crisis. Toronto/Buffalo/London: University of Toronto Press, 1992, pp. 23-53, and, by the same author, "OI: Opportunistic Identification, Open Identification in PWA Portraiture," in National Gallery of Australia. Don't Leave Me This Way: Art in the Age of AIDS. Melbourne, London and New York: Thames and Hudson, 1994, pp. 213-230. Of the exhbition at the Museum of Modern Art, ACT UP complained that the images presented were too negative: "We believe that the representation of People with AIDS (PWAs) affects not only how viewers will perceive PWAs outside the museum but, ultimately, crucial issues of AIDS funding, legislation, and education ... We demand the visibility of PWAs who are vibrant, angry, loving, sexy, beautiful, acting up and fighting back." (Quoted in Grover 1994: 220-221)

¹⁴⁴ Webster's New Encyclopedic Dictionary. New York: Black Dog & Leventhal Publishers, 1993, 11.

is one example of an activist who challenges this narrow conception of the activist.

One of the key questions I sought to answer, or at least discuss, in the course of these interviews, concerned the factors that compel PWAs to enter the political arena. And, conversely, what drives someone who is not personally stricken with HIV to become so passic nate about AIDS, and, in some cases, become a spokesperson for PWAs? One of the activists with whom I spoke said an AIDS activist's HIV status is irrelevant, and politely declined to disclose his status. "We all *have* AIDS (my emphasis)," he said in an interview. 145

Clinical psychologist Walt Odets, in his recently published book, In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS, explains partly why some gay men prefer the marker of disease to the marker of homosexuality:

Apparently, many gay men are finding it easier to be threatened by AIDS, to die of it, or to be guilty for not dying of it, than they have ever found being gay ... AIDS has given many gay men a disease that, in all its horror,

¹⁴⁵ Tim Dean, in "The Psychoanalysis of AIDS" (October 63, Winter 1993: 83-116), argues that "a psychoanalytic perspective on AIDS must begin by acknowledging that each of us is living with AIDS (emphasis in the original): we are all PWAs ... insofar as AIDS is structured, radically and precisely, as the unconscious real of the social field of contemporary America. AIDS is encountered not only as the discourse of the Other ir a return of the repressed that constitutes the repressed as such (the structure by which we understand a neurotic subject); it is encountered also in the real as a consequence of its wholesale repudiation by a society that refuses to admit a signifier for AIDS and is therefore analyzable according to the structure by which we understand a psychotic subject." (Dean 1993: 84-85)

can provide an easier identity than being homosexual. Having AIDS provides many men a life as medical patient that is more accepted and supported — both by larger society and by gay communities — than was ever the case when they were merely physically healthy homosexuals. 140

Unfortunately, however, Odets fails to illuminate the controversy over the presence of several uninfected men in the field of AIDS activism. He prefers, instead, to suggest that those gay men who are as yet uninfected are also marked with an identity:

Being gay and uninfected in America is an identity, not the absence of one, and it is often a profoundly troubled identity. The extended social impact of the epidemic within gay communities, the number of losses endured by uninfected survivors, difficult prospects for the future, and the divisions and conflicts between positive and negative men conspire to make being HIV-negative a complex identity and form of life. 147

Although he does not reflect specifically on the presence of uninfected people in the AIDS activist arena, his comments may help to explain why so many negative people (primarily, but not exclusively, gay men) continue to devote much of their political energy to AIDS activism. AIDS activism, for some seronegative gay men, provides a much-needed sense of belonging, an affinity with members of their community. Odets compares the situation with that of a

of AIDS. Durham: Duke University Press, 1995, 106.

family in which one child is, for the most part, ignored because he/she does not appear to need the parent's attention: "When the good child finally does express needs, his beleaguered parents become angered by what seems a betrayal. Uninfected men have become, in the haunted, beleaguered family of the gay and bisexual communities, something like the 'needless' child." 148

Aware that his argumen¹ may be misconstrued by some PWAs as a deliberate refusal to acknowledge their pain and trauma and exaggerate the suffering of those who are leading otherwise healthy lives, Odets devotes an entire chapter to his rationale for writing the book. In the communities of uninfected gay and bisexual males, he contends, we are witnessing a psychological epidemic. In the early stages of the AIDS epidemic, Odets explains, many uninfected men resisted voicing their survivor guilt, fearing that they would be castigated for acting selfishly or inappropriately, or resented by the infected members of their communities. Numerous psychological studies now reveal that seronegative gay men also suffer from anxiety or depression directly related to AIDS.149

¹⁴⁸ Ibid., 16.

¹⁴⁹ According to one study noted by the author, half of the uninfected gay men surveyed by psychologist Rachel Schochet said they had consulted counselling or psychotherapy in the previous year. (Odets 1993: 19)

In interviews with four activists in Montreal. Toronto, and the United States — two of whom are HIV-positive themselves — I posed many questions regarding the nature of their work. I discovered in the process that activism takes many forms. I also found that identity — as an AIDS activist, as a PWA, or both — while perhaps not a conscious preoccupation of the interviewees. is not a singularly-defining term: the identity of the AIDS activist or PWA is both punishing and liberating. What follows is a thumbnail sketch of four people who shared their thoughts on the past and future of AIDS activism.

Michael Hendricks

One of the longstanding members of ACT UP Montreal,
Hendricks, a native of New Jersey, came to Canada in 1968 and soon
after became a political activist. At the outset, he focused much of his
energy on securing the safe arrival of American draft dodgers to
Canada. Today, he is in an enviable position to reflect on the growth
and demise of ACT UP Montreal. For almost three years, he served as
ACT UP's media co-ordinator; in effect, he was the organization's
official voice. Since the collapse of ACT UP Montreal in late 1993, he
has severed all ties with AIDS activism ("It [the end of ACT UP] was so
depressing that I threw out all of the ACT UP files") and now works on
contract at the National Film Board of Canada. He still, however,
maintains an unpaid position as co-ordinateur generale of the Table
de Concertation des Lesbiennes et des Gais du Grand Montréal.

The local ACT UP chapter was born in the shadow of the Fifth International Conference on AIDS, which took place in Montreal in June 1989. A group of activists from ACT UP's founding chapter in New York City had planned, in painstaking detail, a full-scale assault on the Montreal conference, with the goal of making its presence felt at a conference it deemed was wrongfully excluding PWAs. They had co-operated with the Montreal Urban Community police, and assured

the officers that there would be no violence. Paul Dufort, the MUC police officer with whom the activists discussed their plans in detail, recalled in a telephone interview how well-organized they and the police were. Dufort organized an information session with an AIDS specialist at a local hospital to allow police officers to better understand the nature of HIV infection and to dispel some of the myths surrounding the transmission of HIV. Dufort and members of the MUC police union also travelled to Washington to meet with officers who had dealt with activists, albeit rather unsuccessfully, at a previous AIDS conference "We didn't want to take any chances," said Dufort, who is now Commanding Officer at Station 11 in the West Island of Montreal. "We were anticipating any problems that might arise." Fearing they might be infected, the Washington officers donned masks and gloves, which infuriated the local activists. "We learned from the mistakes made by the Washington authorities," Dufort added.

Dufort says the activists co-operated fully with police. "We even blocked off streets for them. They didn't go overboard. I think they were very militant but they had to be outrageous to get their point across."

150 Telephone interview with Paul Dufort, 21 August 1995. All other comments attributed to Dufort were gleaned from the same interview

Although relations between the police and the gay community have been strained in the past, mainly due to a "lack of communication and understanding on both sides," Dufort is hopeful that the situation will improve. "You need mutual respect. When you don't have that, there are going to be problems."

Less than a year after New York AIDS activists crashed the Montreal conference, under the watchful eye of MUC police, ACT UP's Montreal chapter was born. Hendricks recalled ACT UP Montreal's first days. "It was very difficult for us to adapt to hyper-democracy and political correctness. We were Trotskyists. We had no identity as gay people. I was never involved in identity politics. I wasn't politically gay. As a Marxist, you couldn't possibly see it (identity politics) as a venue for change. ACT UP, however, proved us wrong."

"We took an issue and organized it along identity lines and gave gay people a chance to act out. We had our own little parallel government. We did what we wanted to do."

True to Arendtian form, ACT UP members staged public acts of defiance, holding dramatically staged events, such as die-ins, to entice journalists and news photographers to attend. And, according to Hendricks, their tactics were an unqualified success. "We wanted to be on the front page. We learned how to manipulate the media. People (in ACT UP) fell in love with the lens."

When asked to explain why he chose to get involved rather than remain on the sidelines, as so many have done, Hendricks points to the evening he discovered one of his closest friends was seropositive. "Our friends were dying. I wanted to show that I cared. We really believed that by putting pressure on the government, there would be a cure (for AIDS). It was a social experience, too. ACT UP was a social statement. It was a fashion statement."

Hendricks cites several reasons for the local chapter's demise, including one particularly annoying member, who drove away any new members from the group's meetings. Also, he notes, too many of ACT UP's members were seronegative. Seropositives, not unlike homosexuals in Montreal, remained in the closet, refusing to lend their support to the movement.

But, according to Hendricks, one of the key reasons for the collapse of ACT UP was beyond its control. It occurred in the summer of 1990 when the police raided a private party, dubbed Sex Garage, at which several gays and lesbians were assaulted. "We knew that we had lost it (the momentum) and couldn't get it back."

AIDS, it seemed, had to be placed on the back burner, in order to allow time to organize anti-police demonstrations and to deal with the dozens of gays and lesbians who had scheduled court appearances at which they would have to respond to charges of obstruction, indecency, and the like. "Sex Garage gave us a double workload. It muddied the waters. Gay rights suddenly hijacked the AIDS agenda. We wore people out because they had two issues to fight. I'm sure it (the focus on gay rights) turned off many seropositives. They must have been saying, 'So what if we get the right to marry.' Unfortunately, we didn't see gay pride as a mechanism for (HIV) prevention. We do now."

As for ACT UP Montreal's successes, Hendricks points to the campaign to make available condoms in prisons and the creation of a commemorative park for deceased PWAs in Montreal's Gay Village. "We won little victories, but lost the big one." The "big one" refers to the organization's failure to assure free medication for people with AIDS. ACT UP sought to have PWAs covered under the government's *Malade sur pied* program, which guarantees free medicine to people with fatal diseases such as cancer. All too often, Hendricks said, PWAs had to quit their jobs to apply for welfare, which ensures access to free medication.

Although ACT UP fancies itself a broad-based organization, with sub-committees representing the interests of women, people of colour, and treatment activists, Hendricks reminds us that "it was really organized by homosexuals. Gays ran it and founded it. Homosexuality was the leitmotif that was holding us together."

But even within AIDS activist circles, Hendricks says, there remains a reluctance to reveal that one is seropositive. "We'll scream from the church-top that we're gay. But it's much harder to say we're negative because there is a fear that we are bragging that we're clean and free from infection, that we're separating the healthy from the sick."

"When I left ACT UP I said I wouldn't do it again until seropositives took the helm. It's not our battle. The identity is theirs."

Douglas Buckley-Couvrette

Douglas Buckley-Couvrette, executive director of CPAVIH (Comité des personnes atteintes du VIH du Quebec)¹⁵¹, is a former member of ACT UP Montreal. His first contact with AIDS came in 1985, when he discovered that one of his best friends was HIV positive. He remembers a particularly devastating trip to the hospital to visit the friend. "I walked in the room and there was an old man. It was like something out of a Boris Karloff movie. It scared the hell out of me. I thought that that person in the hospital bed was going to be me."

When he moved to Montreal in 1988 from Ottawa, Buckley-Couvrette said he vowed he wouldn't have anything to do with AIDS. That soon changed as he found himself involved in the organizing of the AIDS memorial quilt. But it wasn't until 1990 that he got involved with ACT UP. "One of my friends said ACT UP needed legal advice on civil disobedience (Buckley-Couvrette had worked as a para-legal). I worked my way up to facilitator of ACT UP because I knew Robert's Rules of Order and I was bilingual."

¹⁵¹ Since the interview on 23 August 1995, Douglas Buckley-Couvrette has resigned his post at CPAVIH to accept work on the organizing committee of the XI International Conference on AIDS, which will be held from July 7-12, 1996 in Vancouver, British Columbia.

Buckley-Couvrette cannot pinpoint a defining movement at which he decided to devote most of his life to AIDS. "I don't know what happened," he said, pausing. "I converted my pain into anger." He adds that his arrest at the now-infamous Sex Garage party may have been the catalyst: "After that, I got really pissed off."

When asked repeatedly about his HIV status, Buckley-Couvrette replied: "It's none of your business. I don't think it's an issue any more. I don't think there's much of a difference any more (between being negative and positive)."

Buckley-Couvrette said he's not surprised that few HIV-positive people in Montreal are coming out to join the activist ranks. "This city has a big AIDS denial. AIDS is not talked about. People don't want to expose themselves to the stigmatization that goes along with it." For example, Buckley-Couvrette notes, at Toronto's AIDS memorial park, "you see the names of the dead. In Montreal, you don't see any names."

Much time, he notes, has been spent de-gaying AIDS. "Now we're spending a lot of our time re-gaying it. How does one do that? One turns into a gay rights activist."

The future of AIDS activism, he says, lies in finding common denominators, such as poverty, marginalization and human rights.

That's why, he says, groups such as AIDS Action Now! in Toronto have

joined forces with a host of other community groups, including those representing immigrants, people with disabilities, and women, to fight the recent social services cuts imposed by Ontario Premier Mike Harris's Progressive Conservative government. "I think coalitionbuilding is the only way we can resist the divide-and-conquer tactic. For example, the disability movement has been fighting discrimination for years. We're exchanging recipes, discovering what works and what doesn't."

While he is no longer a militant activist, Buckley-Couvrette says his ACT UP reputation as a rabble-rouser precedes him. "You know that when I say I'm gonna cause hell, I will. When you say ACT UP, the Health Minister shits his pants."

He cites as an example an instance at a recent Montreal conference on HIV when a group of activists, including members of ACT UP, decided, literally, to turn their backs to (former) Federal Health Minister Diane Marleau as she addressed the delegates. The next day's *Globe and Mail* said, 'ACT UP turns its back on Marleau.' That's why I say ACT UP still lives."

Buckley-Couvrette admits there are drawbacks to his "respectable" job, which he began in January 1995, becoming the organization's eighth executive director in two years. "I cannot be perceived as being too activist or radical. When you don't have any

government funding (as ACT UP did), you're free." On the other hand, he admits, "This is a very powerful position. This has legitimized my voice. When I call the Minister now or the head of a giant pharmaceutical company, they return my calls. I do get a great ego boost out of it."

"I want people to own their status, and have the freedom to do with it what one chooses to do. Owning the disease, that's a difficult concept for medical science to take." As for his own status, he says: "I don't need it (my HIV status). I'm just the mouthpiece."

While he acknowledges that there's a long road to hoe — for exa. ple, HIV-positive people still are not covered by the province's *Malade sur pied* program — Buckley-Couvrette is hopeful that the situation will soon improve. "There are no medals in activism. But I know what I've done. It's a great thing to effect social change."

Darien Taylor

Taylor, 38, is the founder of Voices of Positive Women, a provincial support group based in Toronto. She contracted HIV while teaching in Zimbabwe in the early 1980s. After learning about the death of a Zimbabwean writer with whom she had had a year-long relationship, Taylor suspected she had been exposed to the virus. "In the pit of my stomach, I knew he had AIDS and I was probably infected, too. But I didn't want to know," she told a Concordia University audience in early 1995. "...AIDS was something which was happening in gay communities in North America and other African countries like Uganda." ¹⁵²

She first became involved in AIDS activism by joining a local support group for HIV-positive women. Never ashamed of her status, Taylor says she wore it on her sleeve. "I have no secrecy about this in my life. I can just be who I am. It's just immensely liberating." 153

Before long, however, Taylor grew tired of the support group's lack of activism. "All the women were raising incredible issues for

¹⁵² Katz, Helena. "HIV educates a carrier." Concordia's Thursday Report, Vol. 19, no. 16, 16 February 1995, p. 5.

¹⁵³ Unless otherwise noted, the following quotes are taken from a lengthy telephone interview with Darien Taylor, 30 August 1995.

political action, but the group was enclosed." Taylor then moved her concern to AIDS Action Now!, a community-based activist group located in Toronto. "Activism just seemed so much more engaging. Support groups breed a lack of self-respect because you tend to complain all the time."

She says of her current job, with the provincial government's AIDS Committee of Toronto: "It's work. It's a place for politics, too, but it's a paycheque and you need that."

On the subject of identity, Taylor recalls her earlier involvement with Voices of Positive Women, which produced the first information brochures for women with HIV, set up support groups, created a fund to cover the costs of medication and advocated for women's access to clinical trials. "The group was made up entirely of positive women." Because, at that time, HIV-positive women didn't have an identity to speak of, it was necessary to close the doors to women who were HIV-negative. "It may sound very pure and doctrinaire, but during identity formation, you do have to close the doors. There were many people willing to gobble us up onto their agenda (including feminists)."

Taylor acknowledges that she has had serious difficulty attempting to define herself in relation to identity. Does she identify as a woman first, a HIV-positive person, or a woman with HIV? "My experience of having HIV has completely undermined my notions of

what I understand as my gender and my sexual orientation. I have an identity that is different from what we understand as woman or straight."

She is unequivocal in her defense of her role as an AIDS activist. "I do this because I'm selfish, not because I want wonderful things for the world. I'm thinking of me first." As for those who moan about the toll activism exacts on its practitioners, Taylor says, "It's burnout talk. It's like, 'get your boundaries in order.' I think it's very negative to start saying what we can and cannot do."

Returning to identity politics, Taylor explains how she views IIIV and its attendant culture. In her view, HIV/AIDS has fostered a culture which is shared by positive and negative people alike.

"I do think HIV is a culture. Living in that culture doesn't give people a reason to live. I think people have to rediscover the reason to keep on living. I'm really interested in HIV-negative people finding a reason to live."

While acknowledging that initially, she, like many others, became obsessed with her diet and "healthy" lifestyle, Taylor has since given that up. "It was really hard to live year after year with the wretchedness of HIV and give up things which gave me pleasure. Now I drink coffee, alcohol, stay up late and smoke." 154

Taylor does not oppose, however, the use of experimental drugs or clinical trials; in fact, she keeps a close watch of medical developments to isolate a "cure" for AIDS. In the meantime, she says, people with HIV/AIDS should start living. "I'd like to put out a common-sense message of living with HIV and counter all the propaganda which sees the enemy everywhere. I think people are crippled, immobilized and depressed by this message. We have such a long list of do's and don'ts. We left Grade 8 health class behind a long time ago."

She notes with a dose of sarcasm how patient activism is beginning to develop at a time when the powers-that-be are attempting to pull out the rug from under subsidized health care. "It's interesting that our empowerment has dovetailed with the cuts in health care (introduced by Ontario's Harris government) and the individualization of health care."

Although her primary duty now is devising health promotion programs for people with HIV/AIDS for the AIDS Committee of Toronto, Taylor says she has not shed her activist skin. "I'm still an activist. When I go into meetings, I still take a very hard-line, community view."

¹⁵⁴ Katz, "HIV educates a carrier," p. 5.

Jerald Breitman

The former head of professional relations at Burroughs

Wellcome (renamed Glaxo Wellcome following a recent takeover), the

pharmaceutical company that developed and manufactures the antiviral drug AZT, Breitman is an activist of a different ilk. He spoke with

me in person on September 28 in Montreal, where he was scheduled

to deliver the first installment, on HIV/AIDS issues in the workplace,

of Concordia University's community lecture series on HIV/AIDS.

Diagnosed with HIV in 1989, Breitman belies any notion of the "typical" AIDS activist. He does not participate in noisy demonstrations; he does not regularly denounce politicians, doctors or public health experts. In fact, some might even hasten to call him an activist. Most of the Illinois native's "activism" has been confined to the corporate world. He has fought vigorously for same-sex insurance benefits. (Ironically, the victory came too late for Breitman and his longtime companion, Steven.)

He is the first to admit that despite his employer's positive reaction to his HIV status, "a lack of certain policies at Wellcome have adversely affected my health." Steven, for instance, was not covered under Breitman's company health insurance policy. "We spent

thousands and thousands of dollars on legal fees to protect his (private) insurance. We shouldn't have had to do that."

Breitman broke his silence after three years, spending an entire day informing bosses and colleagues, one by one, that he was gay and HIV positive. "We (Steven and I) spent a whole evening just planning my disclosure strategy. It was a very carefully planned event. When you disclose something like that, it's not like you could come back the next day and say, 'Gee, I didn't really mean that.' It's an irrevocable decision. Once you've done it, you can't take it back."

"And then it wasn't really an issue. It really shouldn't have been an issue. People saw that I continued to come to work just like I always did. We agreed to disagree just like we always had. My HIV status or sexual orientation only became relevant when people had a need to pick my brain, because I had a unique viewpoint."

Unfortunately, the initial reaction from his lover's employer, a real estate company, was less than comforting. "When Steve disclosed his HIV status, his boss was so supportive, couldn't have been nicer. A few days later, his boss came to him and told him they wanted him (Steven) to leave the company. They said, 'it might scare off some of our customers. It's just a business risk that we don't want to run."

Steven, needless to say, came home devastated, but refused to resign.

The couple hired two high-powered lawyers, and held firmly that if the company wanted Steve to quit, they would have to fire him first, a decision the couple was prepared to turn into an ugly media event. Over the next year, Steve's boss had a change of heart and agreed to allow Steve to work as lorag as he possibly could. "In the end, they were fabulous. What does it show? It shows that you've got to educate people. HIV-in-the-workplace education is critical. It is nothing but fear and tack of information that drive people to do things they shouldn't do. And Steve educated them."

Breitman, who has worked in the pharmaceutical industry for most of his professional life, about 27 years, is symbolic of the "new" patient. He is extremely well-informed about HIV/AIDS, he keeps a painstaking log of his laboratory values (the log allows him or his doctor to chart the disease's progression), and can explain without hesitation and with medical precision the effects of the drugs he is currently taking.

"I believe that the HIV-positive patient is the new paradigm in health care. Health-care providers are going to have to become accustomed to lots of questions and understand that they're going to have an enormously well-informed patient base who will challenge the provider to stay ahead of the patient. That's the way it should be."

Asked how his friends reacted to his decision to join Burroughs Wellcome, long criticized by gay men and AIDS activists as AIDS profiteers, Breitman said it ran the gamut from positive support to angry derision. "I had people who would say to me, 'I don't know how you could work for that company.' And I would tell them that I stay there for the same reasons I stay in the Presbyterian church. Because I fundamentally believed in what the company was doing. And because I believe there are two ways to effect change: you can be on the outside and yell at people that they need to change, or you can be on the inside and help to effect change more directly."

He also admits he had selfish reasons for taking a job with Wellcome. "I thought I would be at the cutting edge of what was happening in HIV/AIDS research and that I could, through my presence, make a difference in how we dealt with people who were HIV positive or who had AIDS. I've never regretted it."

Direct-action groups like ACT UP, he says, provide a muchneeded voice for PWAs, but their hard-line tactics do not appeal to
everyone. "I don't shun it, but I don't embrace it, either. I think ACT
UP and the tactics that were used, were absolutely, incredibly
important. That needed to happen. We had to get in people's faces. We
had to shake up the American perspective about what was going on,

because they didn't care. And we had to show them, that whether they cared or not, we were there."

Breitman recalls that he and his colleagues were at a loss to understand the viciousness of ACT UP's past attacks against Burroughs Wellcome. "I remember sitting in a senior staff meeting one day after ACT UP had invaded Burroughs Wellcome's building (in North Carolina) and we were trying to figure out what to do. That was really a traumatic experience for the company. The company looked at it and said, 'We're the only ones out here really trying to help these people. We're the ones who are investing all this money in research. We have pulled out all the stops. We have denied or canceled lots of research initiatives to do the work that needs to be done in HIV/AIDS. And these people are coming down and acting like we're the enemy.' The company really didn't understand; it was a real culture shock."

Confrontation, ACT UP's modus operandi, "is a little bit like managing through fear," Breitman says. "Those are short-term motivators (sic). I don't believe that in the long run, that you can effect social change through that kind of behaviour. We don't need confrontation. There's more that can be accomplished by working in collaboration with society, by mainstreaming yourself into society, rather than standing on the sidelines and yelling and screaming."

That's not to suggest that Jerald or Steven have remained complacent. "With Steven we went though all the stages (of dying), and I may go through them yet myself. We went through the anger, denial, bargaining, acceptance. And one of the things I came to realize is that we talk a lot about the stages of dying (as elaborated in a landmark work by Elisabeth Kübler-Ross¹⁵⁵), and they happen, but they are not linear. We tend to present them as though you go through each of these stages and then you get to acceptance. Well, you go in and out of these stages. We go from anger to denial to bargaining, back to denial, back to bargaining, back to anger again. Steven was angry again about six months before he died. Part of the reason he was so angry was that we have friends who are HIV negative who think nothing of having 15 to 29 sexual encounters, most of them unprotected. This is something Steven and I never did. Steven would get angry that we were dying of this disease and people like that were continuing to put themselves at risk."

Breitman is no stranger to denial. Even when his health began to deteriorate and he was forced to take naps in the middle of his working day, he tried his best to keep his problems hidden from public view. "Here I was becoming symptomatic and I was simply

¹⁵⁵ See Kübler-Ross, Elisabeth. On Death and Dying. New York: Macmillan Publishing Co., 1969.

denying what was going on. I didn't want it to be true. When you spend as much time as I had spent in an industry, and build a department like I did this department, it's really hard to go in and say to somebody, 'I can't do this any more." Breitman said he and his superiors agreed that he should take a two-month medical leave of absence, but he knew otherwise. "It was just more denial. I didn't want to admit that I wasn't coming back."

Now on permanent disability leave, Breitman said he has chosen to devote the rest of his life to educating others about HIV/AIDS issues in the workplace. "I think for most of us, what's really important in life is to have made a difference, mostly for other people, but that's OK. We are taught that it is better to give than to receive." Apart from several speaking engagements, Breitman serves on the board of directors of the National Leadership Coalition on AIDS in the United States.

Breitman said he wants people to understand that HIV-positive people or people with AIDS do not look or act alike, and that they can live healthy, productive lives in a workplace that is sensitive to their needs. Steven, for one, baffled many of his doctors, who expected him to die much sooner than he did. Even on the morning he died, "other than the fact that he wasn't breathing, he looked the picture of health.

You would never have guessed that this man had been unable to walk, unable to sit up by himself for a full week."

Breitman prefers to compare Steven to a bumble bee.

"Aerodynamically, a bumble fee can't fly. The wing span is inadequate to support the body. But nobody ever told the bumble bee. And it flies anyway. Steven was like the bumble bee. They told him he shouldn't be able to walk, but he just did it anyway. He had great internal strength, enormous courage."

CHAPTER 6

IDENTITY, OTHERNESS, AND BLAME: THE OTHER 'OTHERS'

Those that love are butchered and those who butcher are bronzed 150 - Montreal poet/PWA Ian Stephens, Diary of a Trademark

The placing of blame is a recurring theme in the popular AIDS discourse and has been the subject of countless books. AIDS has been blamed on everyone and everything from Africans to swine monkeys to one particularly "promiscuous" Quebec flight attendant. Blaming the Other for disease, according to Nelkin and Gilman, is a way to create social and psychological boundaries between the "sick" and the "healthy." For the individual, the placing of blame releases anxiety, and draws a fictitious dividing line between the self and the diseased. Throughout history, the dominant class has cast a wide net of blame into which those on the lower rungs of the sociocconomic ladder invariably fell. Methodist preachers in England connected the cholera epidemic of 1832 with drunkenness¹⁵⁷; tuberculosis, long identified as a disease of the poor, was tied to alcoholism. But as

¹⁵⁶ Stephens, Ian, "Diary of a Trademark," taken from the book of the same name, Ste. Anne de Bellevue: The Muses' Company, 1994, 23.

¹⁵⁷ Sontag, Susan. Illness as Metaphor and AIDS and its Metaphors. New York: Doubleday, 1988, 142.

Brandt observed in his comprehensive study of the history of venereal diseases, except for syphilis, which was blamed on American Indians and linked to sexual contagion, "no life-threatening illness has had the potential of AIDS to be so closely linked with sexuality and personal behaviour." 158

In an insightful essay, Richard Goldstein contends that AIDS carriers are marked both by their Otherness and the common humanity they are denied. Although they can infect anyone, he says, they themselves are infected because they are not just anyone, but, instead, members of one of society's constructed risk groups: "This paradox amplifies the fear and denial that always surround disease. AIDS is not just contagious; it's polluting. To catch this disease is to have your identity stolen; to be lowered, body and soul, into the pit of deviance." 159

Citing the example of Ryan White, an infected Indiana teenager whose case gained notoriety when he was taunted by schoolmates and members of his community, Goldstein asserts that even the so-called "innocent victims" 160 of AIDS must endure the wrath of bigots

¹⁵⁸ Allan Brandt quoted in Altman, Dennis. *AIDS and the New Puritanism*. London: Pluto Press, 1986, 14.

¹⁵⁹ Goldstein, Richard, "AIDS and the Social Contract," in Erica Carter and Simon Watney, eds. *Taking Liberties*. London: Serpent's Tail, 1989, 84.

and fearmongers, thereby dispelling any notion that there are innocent and guilty victims, or good and bad ways to contract HIV.

Goldstein suggests that the gay marker of AIDS is extended to identify all people with AIDS, regardless of the nature of their infection.

(White, a hemophiliac, contracted HIV through a blood transfusion.)

Of the medical response to his condition, White told an interviewer:

"They marked my folders ... They marked 'fag." As Goldstein explains,

Fag: the incarnation of whoredom, the servicer of upperclassmen's needs, the kindling in an inquisitional bonfire. All these connotations are stamped on the identity of anyone infected with HIV. This tendency of stigma to spread beyond its original boundaries is the real casually transmitted disease, and the hidden source of AIDS hysteria. 162

While it originates in the male homosexual, the category of the Other, as evidenced by White's treatment, is not his exclusive domain. This is especially noteworthy as it raises the notion of a floating identity, how one aspect of a person's identity in a given group can go

¹⁶⁰ In a characteristically angry attack, DPN bestowed its Golden Pariah Award on Kimberly Bergalis, whom the magazine dubbed "our nation's favorite innocent victim." The Florida woman is the first person believed to be infected with HIV by a dentist. The 1991 case sparked a flurry of media attention over whether medical professionals should be compelled to undergo mandatory testing for the presence of HIV: "I didn't do anything wrong! I'm innocent!" DPN quoted Bergalis as proclaiming to a Senate panel. (DPN, no. 5, 1992, p. 14)

¹⁶¹ Goldstein, Richard. "A Death in the Family." The Village Voice, 24 April 1990, p. 15.

on to pollute another, otherwise healthy identity. In other words, Goldstein is suggesting that the identity of, for example, a heterosexual woman with AIDS, can be fused with the identity of those who make up the majority of AIDS cases (gay men). The stereotypes that were once restricted to homosexuals are now extended to anyone who is associated with a disease that bears the gay marker. This solidifies my contention that identity is not a fixed marker; it is transferable, dynamic, molded and remolded. This also suggests that groups are indeed capable of altering or erasing these seemingly permanent markers, as ACT UP's experience has demonstrated.

It is difficult to determine which gay stereotypes are carried over to the illness camp. Philosopher Richard Mohr asserts that there are two groups of anti-gay stereotypes held by society: one revolves around gender identity, or the idea that gay men want to be, or look like, women, and that lesbians are women who want to be men. In common parlance, they translate into the "effeminate" gay male or the "butch" lesbian. Although derisive, these stereotypes, according to Mohr, generally view gay men and lesbians as "ridiculous." 163

¹⁶³ Mohr, Richard. Gay Ideas: Outing and Other Controversies. Boston: Beacon Press, 1992, 254.

The second set of stereotypes, which is especially relevant in the context of AIDS, views homosexuals, and gay men in particular, as a "pervasive, sinister, conspiratorial threat." The main stereotype to which he is referring demonizes the gay man as a child molester and/or sex-crazed maniac. This stereotype serves two functions: it reaffirms the sanctity of the traditional, nuclear family and, socially, it serves to normalize sexual conduct. Mohr warns that while laughable, we should not dismiss these stereotypes as products of a past, less tolerant society:

Stereotypes have a life beyond facts. Their origin lies in a culture's ideology — the general system of beliefs by which it lives — and they are sustained across generations by diverse cultural transmissions, hardly any of which, including slang and jokes, ever purport to have a scientific basis. Stereotypes, then, are not simply the products of bad science or of prescientific or ascientific generalizing from observation but are social constructions that perform central functions in maintaining society's conception of itself. 165

While gay men remain the object of much of the scorn directed at people with AIDS, the AIDS epidemic has also unleashed a current of anger against other so-called "risk groups," namely blacks, prostitutes and intravenous drug users. Much has been written about the identity struggles of blacks in relation to the U.S. civil rights

¹⁶⁴ Ibid.

¹⁶⁵ Ibid.

movement, but there remains a paucity of research on the identities of the other two groups listed above, especially in relation to AIDS.

For example, the Canadian Centre on Substance Abuse and the Addiction Research Foundation of Ontario estimate that there are about 100,000 injection drug users in Canada, a figure they warn is a conservative estimate. 166 Yet, if there were any reason to believe that there is strength in numbers, the experience of IV drug users indicates otherwise. IV drug users identify as such, yet they have not formed an identity around the behaviour in which they engage. This, however, has not stopped some researchers from attempting to construct stereotypes about this population. One such myth, according to Maia Szalavitz, a former heroin addict herself, is that needle-sharing among IV users is something of a cultural ritual, a charge Szalavitz vehemently denies. According to Szalavitz, another myth, which I would argue has been extended to promiscuous gay men, is that addicts don't care enough about their lives to protect themselves from AIDS. As Szalavitz explains, "While I was doing heroin, I didn't want to die; I wanted to live without pain. I told myself heroin was keeping me from suicide. AIDS did not offer such promise

¹⁶⁶ "Canadian Profile: Alcohol, Tobacco, and other Drugs," The Canadian Centre for Substance Abuse and the Addiction Research Foundation of Ontario, 1994, 171.

— only slow, painful, almost certain death." ¹⁶⁷ Graham Hart, in a discussion of HIV and the injecting drug user, is typical of the view Szalavitz attempts to discredit. He paints the subject (drug user) as a person teetering on the brink of self-destruction. Hart does not suggest that outreach programs should be abolished or that needle-exchange programs should be eliminated. Instead, he insists that it is foolhardy to assume that all IV drug users wish to alter their behaviour: "(M)any injecting drug users do not wish to receive treatment and are going to continue to inject." ¹⁶⁸

To their credit, many AIDS activists have fought a long, uphill battle to ensure that addicts, including those who are serving time behind bars 169, obtain access to needle exchange programs, which were first introduced in the Netherlands in 1984. In Canada alone, there are an estimated 235 needle exchange programs, many of them

¹⁶⁷ Szalavitz, Maia. "Point Counterpoint: Why IV Users Deserve Clean Needles." The Village Voice, Vol. XXXV, No. 13, 27 March 1990, p. 24.

¹⁶⁸ Hart, Graham, "HIV and the Injecting Drug User," in Aggleton, Peter, Graham Hart and Peter Davies, eds. AIDS: Social Representations, Social Practices, New York, Philadelphia, London: The Falmer Press, 1989, 170.

¹⁶⁹ This move has sparked a heated controversy, including charges by prison officials, here and south of the border, that providing bleach or needle exchange to inmates condones a behaviour that is supposed to be forbidden behind bars. The same charge was levelled at AIDS activists when they fought for, and won, the right to distribute condoms in federal prisons. For an overview of the Canadian response to HIV prevention in prisons, see, among others, Michael Orsini, "Brass Knuckles and Bleach," The Montreal Mirror, April 18-25, p. 7.

linked to other health services.¹⁷⁰ ACT UP's experience has shown that AIDS activists possess the moral determination to press an agenda on behalf of a group (IV drug users) which, for all intents and purposes, is invisible and silent in AIDS activist circles.

In an article on the cultural responses to AIDS, Richard Goldstein argues that gay men have used their artistic gifts as weapons in the fight against AIDS. Be it in film, painting or literature, the arts has allowed gay men to express their grief and build an identity and community around the unspeakable horror of AIDS. This is not the case, he laments, for other people who have been affected by AIDS:

No comparable process of self-expression exists among the other groups hit hardest by AIDS — IV drug users, their children, and their mostly black or Hispanic partners — in part because of the paralyzing impact of poverty and stigma among these groups, in part because there is no "community," perceived as such, to bind drug users together. In their isolation and secrecy, these people with AIDS are less visible than the middle-class white homosexuals whose plight has been so amply documented.¹⁷¹

¹⁷⁰ Quoted in Savoir Faire: HIV Prevention News, no. 1 (Summer 1994): 1. Published by the Canadian Public Health Association's AIDS Program.

¹⁷¹ Goldstein, Richard. "The Implicated and the Immune: Cultural Responses to AIDS," *The Milbank Quarterly* 68, Suppl. 2, (1990): 297-298.

The Prostitute as Political Subject

Prostitutes, while they do not represent a significant proportion of the infected community, merit careful attention because they have a long history of being blamed for society's ills, with AIDS being no exception. 172 Brandt notes that prostitutes became the subject of increasing suspicion during World War I. In the charged atmosphere of world war, venereal disease posed a serious threat to the livelihood of the troops. The only path to moral victory, it was believed, was to contain that threat, both literally and figuratively. (The belief that soldiers could remain chaste was rejected outright by the defenders of the "Keeping fit to fight" campaign.) As a result, some 30,000 American women, prostitutes, and women suspected of being prostitutes were rounded up and incarcerated in detention camps surrounded by barbed wire to control the rate of syphilis among army recruits. But, as Brandt observes, the incarceration caused no drop in the military's rate of infection, as its proponents had hoped and believed. The quarantining of women regarded as vessels of disease, however, was more than an unsuccessful or harsh response to a

¹⁷² John D'Emilio and Estelle B. Freedman provide a detailed, historical account of the concerted attacks on prostitutes in the U.S. in *Intimate Matters: A History of Sexuality in America*. New York: Harper and Row Publishers, 1988. Originally viewed as a necessary evil, as it allowed men to fulfill their insatiable sexual desires and spared their wives of unwanted sex and pregnancy, prostitution soon became regarded as a problem that demanded "social purity." (D'Emilio and Freedman 1988: 141)

crisis: "What began as an attempt to save the health and efficiency of the American fighting man was eventually transformed into a comprehensive program to rid the nation of vice, immorality and disease." 17'3

According to political scientist Shannon Bell, prostitute discourses have emerged in the last 20 years to lay claim to a new political terrain. These discourses — those of prostitutes' rights groups, WHISPER (Women Hurt in Systems of Prostitution Engaged in Revolt, and Prostitutes Anonymous — differ markedly, according to Bell, but are united in countering the hegemonic discourse on prostitution. They are discussed briefly here in an attempt to understand identities that, like gay and AIDS-associated identities, are situated within the explosive contours of sexuality.

Counter-discourses are formed when those identified as other begin to speak on their own behalf, to represent themselves, and thus to provide alternative mappings of their subject position and their specific territory in the social field. The shape of the other is determined, in large degree, by the shape of the dominant discourse. The dominant form of resistance is usually manifest as counter-identification whereby the other rejects and inverts in some way the identity constructed by the dominant discourse; yet it never goes beyond that to transgression, displacement, and dis-identification.¹⁷⁴

¹⁷³ Brandt, Allan. No Magic Bullet: A Social History of Venereal Diseases in the United States Since 1880. New York: Oxford University Press, 1987, 52.

¹⁷⁴ Bell, Shannon. Reading, Writing, and Rewriting the Prostitute Body. Bloomington and Indianapolis: Indiana University Press, 1994, 102.

First, prostitutes' rights groups are concerned with transforming the identity of the prostitute from that of a disease carrier to a responsible worker in the business of sex. WHISPER and Prostitutes Anonymous, on the other hand, paint the prostitute in a far more negative light, the former arguing that the prostitute will never be liberated until she escapes from the oppressive shackles of prostitution, and the latter viewing prostitution as a treatable addiction.

WHISPER is concerned primarily with the subject of identity, in so far as it seeks to liberate the prostitute from her "false" identity. As WHISPER founder Evelina Giobbe explains,

The process of "becoming" a prostitute entails the systematic destruction of a woman's beliefs, feelings, desires and values. Upon entering prostitution a woman typically acquires a new name, changes her appearance, and creates a fictitious past ... To be a prostitute is to be an object in the marketplace: a three-dimensional blank screen upon which men project and act out their sexual dominance. Thus the word "prostitute" does not imply a deeper identity; it is the absence of identity: the theft and subsequent abandonment of self. What remains is essential to the "job": the mouth, the genitals, anus, breasts ... and the label. 175

WHISPER rejects claims made by prostitutes' rights groups that prostitution should be regarded as an acceptable profession. It exists

¹⁷⁵ Giobbe, Evelina. "The Vox Fights," Vox (Winter 1991), p. 35, quoted in Bell, Reading, Writing, and Rewriting the Prostitute Body, 128.

to educate the public about the crippling effects of life as a prostitute, and acts as an advocate for women and girls who wish to leave the sex industry. 176

While much less politically-minded than the above-mentioned groups, Prostitutes Anonymous (PA), which takes its inspiration from 12-step programs such as Alcoholics Anonymous, concentrates on addiction and recovery. Although the group's literature states that it is non-judgmental, it should be stressed that it does urge its members to quit prostitution. Also, its reliance on the 12-step program seems to suggest that prostitutes are morally and spiritually bankrupt, that they desperately require divine intervention to set them on the proper moral course. This evidence refutes the claim made by Bell that the organization "does not treat prostitution as a disease or the prostitute as diseased; PA views a person's addiction to prostitution as a disease."177 The PA discourse, I would argue, views the prostitute as morally diseased but as potentially salvageable. The fact that the organization has not explicitly condemned the prostitute should not be taken as a priori acceptance of that lifestyle.

176 Ibid., 129.

177 Ibid, 133.

Which of these discourses, then, is best suited to a discussion of identity and AIDS activism? Certainly, the prostitutes' rights discourse, which aims to eradicate the shame that is often associated with working in the sex trade, is closely connected with positive identity formation. Is it fair, however, to portray all prostitutes as safe-sex professionals who have chosen this field of work of their own free will? Does it not ignore some of the critical issues, such as poverty and drug addiction, which "force" some women (and men) into a life of prostitution? Conversely, is WHISPER, with its purportedly "true" picture of prostitution, not exaggerating the case, seemingly suggesting that women who work as prostitutes do not possess the presence of mind to make decisions that affect their own bodies?

Regrettably, while offering a remarkable analysis of the prostitute as a new political subject, Bell fails to provide a detailed discussion of the identity of the prostitute in the age of AIDS. She prefers, instead, to embrace the trendy notion of the prostitute as the ultimate safe-sex professional, a view which is trumpeted by prostitutes' rights groups. Certainly, the low incidence of prostitute-to-client infection cited by Bell points to a widespread campaign of misinformation in the general population vis-à-vis prostitutes' sexual practices; it fails, however, to redress the long-standing connection between prostitutes and disease/dirt.

Inferiorization and the Other

In his study of inferiorization, sociologist Barry Adam presents a composite portrait of the Other as an inferiorized individual: "The inferiorized are (1) a 'problem,' (2) all alike, and (3) recognizable as such without exception." Adam extends this portrait, which was applied originally to Jews, to blacks and gay people. (Much to the anger of lesbian feminist academics, he does not distinguish gay men from lesbians.)

It is not surprising, according to Adam, that members of these inferiorized groups attempt to escape from their identity; what is puzzling, perhaps, in the light of this inferiorization, is that some, specifically gay men, would wish to cling to their identity. Adam compares this state of inferiorization to an iron cage from which its prisoners try to break free. They have two choices, or as Adam prefers to call them, "pseudochoices" 179: (1) they can accept the categorization that has been placed upon them and all the character traits specific to the inferiorized person, or (2) reject this portrait outright, or in part, by failing to recognize themselves in this portrait. In the case of gay

¹⁷⁸ Adam, Barry D. The Survival of Domination: Inferiorization and Everyday Life. New York: Elsevier, 1978, 43.

¹⁷⁹ Ibid., 90.

men, he says, the answer has been to hide in the closet, refusing to identify with the given group.

As Patton explains, "every person oppressed under a metaphorized 'identity' which both inscribes and regulates the 'self' understands the fragile safety of invisibility. Identity is visibility, a textual production, the condition of both community and annihilation." ¹⁸⁰

It is much more difficult, however, Adam continues, for blacks to reject their identity, since it remains a publicly visible marker. They can, for example, move out of a black ghetto into the white heartland of suburbia, but the inferiorized portrait accompanies them to their new place of residence.

Altman states that to be a Haitian or hemophiliac "is determined at birth, but being gay is an identity that is socially determined and involves personal choice." The author, however, ignores the possibility that one may suppress his or her identity, even if that identity is fixed at birth. If I, as a Haitian male living in Montreal, choose to move to a predominantly white neighborhood, I

¹⁸⁰ Patton, Cindy. *Inventing AIDS*. New York and London: Routledge, 1990, 129.

¹⁸¹ Altman, Dennis. AIDS and the New Puritanism. London: Pluto Press, 1986, 98.

am, in effect, rejecting my identity. I may still *identify* as a Haitian, but I have effectively, or perhaps symbolically, suppressed my identity. Similarly, a gay man who chooses to keep his homosexuality a secret in the workplace may be seen as rejecting his identity, but may still *identify*, in other settings, with gay men. In short, identity is not fixed or all-encompassing. It can be summoned or suppressed depending on the circumstances. It can be used, manipulated, denied, and celebrated, no matter its origin. Connolly was thus correct to ask the truly vexing question, "Must we truly have a true identity?" 182

Therefore, the distinction made by Altman, while generally correct, leaves a false impression that identities are permanent markers, especially in the case of members of visible minorities. While it is not my intention here to begin a stultifying "nature vs. nurture" debate, permit me to quickly address Altman's observation as it is crucial to any thoughtful discussion of identity in the age of AIDS. First, there has been considerable academic discussion regarding the physiological origins of homosexuality, so it does not suffice to state flatly that homosexuality is caused exclusively by social conditions. We might ask, for example, if and how the debate would shift if we were to discover that people are born gay or lesbian, that they have a

¹⁸² Connolly, William E. *Identity\Difference: Democratic Negotiations of Political Paradox.* Ithaca and London: Cornell University Press, 1991, 118.

"natural" sexual predisposition for people of the same sex? In other words, what if being gay were not someone's conscious choice, just as being black isn't? Some gay and lesbian writers have posed the same question, asking whether a medical breakthrough into the cause of homosexuality would signal the end of homophobia, because, if proven that homosexuality is genetically linked, society would be more tolerant or accepting of homosexuals. This is not the concern here. Rather, I am interested in emphasizing the weakness of an argument such as Altman's, which illuminates only the differences between, and not the similarities shared by, competing identities.

It is perhaps not a coincidence that black men and gay men share a stereotype of being wildly promiscuous. As Adam explains, white fascination with black sexuality persisted for many years, and rested on the belief that "many Negroes were literally wild beasts with uncontrollable sexual passions and criminal natures stamped by heredity." 183 Black men, it was also believed, had an almost natural propensity to rape women.

A recent case in Canada suggests that we have not evolved significantly from the earlier views of blacks as morally (read:

¹⁸³ Frederickson, George. The Black Image in the White Mind: The Debate on Afro-American Character and Destiny, 1817-1914. New York: Harper and Row Publishers (1971), 276, quoted in Adam, The Survival of Domination.

sexually) unrestrained. The case of Charles Ssenyonga, an Ontario shopkeeper who has become the subject of a recent book by Canadian author June Callwood, illustrates my contention. Ssenyonga, a native of Uganda, had been accused of knowingly spreading HIV to his sex partners. Estimates of the number of people infected by Ssenyonga vary, but Callwood reports that at least 20 women may have been infected by him. He died three and a half months after being brought to trial, just two weeks before the verdict would have been rendered in the case. Callwood is clearly disgusted with his behaviour, but instead lets Ssenyonga's "innocent victims" speak on her behalf: "He is a totally dishonest, promiscuous person. I'll bet he is still infecting women. He doesn't give a damn for anyone but Charles Ssenyonga." 184

Callwood, however, does not pass judgment on the behaviour of those women who engaged in seemingly carefree sex with him; they have already suffered enough and should not be stigmatized further, she might argue, calling to mind a similar argument that is employed by advocates of rape victims. The difference, in this case, is that these women *knowingly* engaged in sex with Ssenyonga. They may have been duped into believing that Ssenyonga was disease-free, but Callwood's argument denies that these women had any choice in the

¹⁸⁴ Callwood, June. "A Date with AIDS," Saturday Night, (March 1995): 57.

matter. Callwood says that most of his female partners agreed to have sex without a condom, and took his word when he said that he always practiced safe sex. The women, in this case, are portrayed as helpless victims who were unable to exert any control in the bedroom.

Callwood does not extend this same courtesy to the other victim, Ssenyonga himself. He is, after all, a criminal — a shrewd, sexobsessed African who preyed on defenseless women. All of this is not to suggest that Ssenyonga should be canonized, but rather to illustrate that, perhaps, there is more to this story than Callwood would have us believe. The author attempts to deflect any criticism that race was a factor in the subsequent flurry of media attention that greeted this case: "Public health officials and law-enforcement people moved to stop Ssenyonga because of his behaviour, not his colour. Ssenyonga was a scoundrel who happened to be black ..." 185

Despite her protestations to the contrary, the issue of race cannot be ignored here, especially since Africa has long been regarded as the birthplace of AIDS and the continent's inhabitants viewed as deliverers of disease. Mehboob Dada laments that even gay men, in an apparent attempt to divert attention from gays as the cause of AIDS, accept, uncritically, suggestions that AIDS originated in Africa:

¹⁸⁵ Callwood, June. Trial Without End: A Shocking Story of Women and AIDS. Toronto: Alfred A. Knopf Canada, 1995, vii.

"Fantasies about dirt, disease and sexual promiscuity come readily to the Western mind when thinking of Black people ... Racism, like AIDS, is not a selective disease." 180

Curiously, there is another case unfolding in Canada, similar to Ssenyonga's, this time involving a Newfoundland man, Raymond Mercer, who is believed to have infected a number of women in Conception Bay, Nfld. One wonders if the same degree of scorn will be heaped on this man, who is white. So far, it seems, there are no plans by Callwood to devote an entire book to his sexual exploits.

¹⁸⁶ Dada, Mehboob. "Race and the AIDS Agenda," in Boffin, Tessa and Sunil Gupta, eds. Ecstatic Antibodies: Resisting the AIDS Mythology. London: Rivers Oram Press, 1990, 87-92.

CHAPTER 7

THE IMPACT OF AIDS ACTIVISM

It is abundantly clear that activists have influenced the policymaking arena as regards AIDS. One of ACT UP's major targets for political action was, and for some activists, continues to be, Glaxo Wellcome (formerly Burroughs Wellcome), the British pharmaceutical giant that developed AZT, an anti-viral drug that slows the onset of AIDS symptoms. ACT UP demanded nothing less than the free availability of AZT to anyone who wished to undergo the treatment. Anything else, they argued, "would be genocide." 18/ To illustrate their anger, ACT UP activists staged noisy demonstrations on New York's Wail Street, occupied the New York Stock Exchange and raided the offices of Burroughs Wellcome, sealing themselves in the office by bolting steel plates to the door frame. The result? Burroughs Wellcome relented, announcing a 20-per-cent cut in the cost of AZT. While the announcement fell short of ACT UP's stated goal, the negative media attention paid Burroughs Wellcome appears to have influenced the company to rethink its public relations strategy. In 1992, the company launched Positive Action, an international

¹⁸⁷ Crimp, Douglas. AIDS: Cultural Analysis/Cultural Activism. Cambridge: The MIT Press, 1993, 117.

program of HIV and AIDS education. In a booklet explaining the program, Burroughs Wellcome boasts that it is the "first pharmaceutical company to take a truly comprehensive approach to the problem of HIV and AIDS; not just delivering treatments, but also making substantial commitments of time and money to education, care and community support." Is beyond the scope of this thesis to judge the morality of Burroughs Wellcome's actions. But even the ever-critical AIDS activists would have to agree, perhaps grudgingly, that the AIDS prevention programs funded by Burroughs Wellcome fill a much-needed void. Indeed, in the United States today, less anger has been directed towards the company.

On a general note, AIDS activists have helped to initiate a discussion of the issues surrounding sexuality, including homosexuality. While their defense of explicit, frank discussions of safe sex has angered many¹⁸⁹, many of the AIDS education programs

¹⁸⁸ Positive Action Around the World, The Wellcome Foundation Ltd., 1993, Foreword. One example closer to home of the firm's attempt to turn around its public image is its funding of the Concordia University HIV/AIDS Advisory Committee Community Lecture Series, which was inaugurated in 1994.

¹⁸⁹ The federal government withdrew its funding of *Tête a Queue*, a glossy comic book that used graphic pictures and explicit language to appeal to street youth vulnerable to HIV infection, after a furor erupted over the magazine s content. See Clyde H. Farnsworth, "In Canadian Comic Book, AIDS is the Villain," *New York Times*, 19 November 1991, p. A13. A similar controversy surfaced when a booklet titled *Doing It in the 90s*, a joint project of Health and Welfare Canada and the Canadian AIDS Society, was released. Several conservative-minded MPs

existed were it not for the groundwork laid by AIDS activists. You will note here that, so far, with the important exception of the drive to lower the price of AZT, the impact of AIDS activism has been felt mainly in that community of uninfected persons. It is difficult to gauge how many lives, for instance, have been saved by important interventions in the field of HIV prevention.

Of course, in the case of the lives of PWAs themselves, activists have enjoyed a modicum of success, and that too, depends on a loose definition of the term success. PWAs do appear to live longer, some as long as 12 years without symptoms, but since medical science has yet to isolate a "cure" for AIDS, despite billions of dollars of research into the problem, we should use the term cautiously.

As was noted earlier by two AIDS activists based in Montreal, not all of ACT UP Montreal's demands have been met, the most pressing case being the coverage of PWAs under the Quebec government's *Malade sur pied* program.

It can be argued, however, that ACT UP's influence has extended well beyond the confines of AIDS policy. Although he lashes out at the AIDS lobby in general for hoarding the lion's share of public money and media attention, journalist and author Claire Hoy credits

denounced it as "nothing more than a sex recipe for gay men." (The Gazette, 17 June 1994, p. B1).

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AIDS activists with giving breast-cancer advocates a context within which to press their demands. As one breast-cancer activist told *The New York Times* in 1991: "They showed us how to get through to the Government ... They took on an archaic system and turned it around while we are quietly dying." ¹⁹⁰ Or as Susan Love, founder of the National Breast Cancer Coalition, said of the AIDS lobby's influence on breast cancer activism: "Women started to see with the AIDS movement that here was a group of people who took it (power) into their own hands, who said, 'We're going to yell and scream until you give us enough research money and we start to solve this disease.' Women with breast cancer are now saying, 'Hey, we can do that too." ¹⁹¹

While one cannot dismiss the role of AIDS activism in the birth of the breast-cancer movement, it should too be stressed that this alone does not explain its rise. As Wachter states, the breast-cancer lobby owes much to the pioneering efforts of the feminist movement, which has been urging women for years to assume control of decisions that affect their bodies. 192 Similarly, the AIDS movement has

190 Gross, Jane. "Turning Disease Into Political Cause: First AIDS, and Now

Breast Cancer." The New York Times, 7 January 1991, p. A12.

¹⁹¹ Hoy, Claire. "The Politics of Breast Cancer," Saturday Night, (February 1995): 26.

benefited immeasurably from the countless men and women who have been fighting for gay rights since the 1960s.

It should be emphasized that, for the most part, breast-cancer advocates have eschewed ACT UP's radical street theatre, preferring instead to focus efforts on prevention and possible treatments or cures. That, however, has not stopped some radical elements in the movement from trying to imitate ACT UP. For example, a group of activists erected a billboard on a busy San Francisco street that read: "Thirty women dead from breast cancer every hour. Marked for death by the National Cancer Institute." 193 As a whole, breast-cancer activists have deliberately shied away from antagonizing government, which has won them tentative praise. Perhaps, however, this could be attributed to the movement's infancy. It may be too premature to

England Journal of Medicine 326, no. 2 (January 9, 1992): 131. Ironically, perhaps, women are again battling measures to control their bodies, this time in relation to AIDS. The controversy stems from a plan to screen expectant mothers for HIV. Although all pregnant women in the U.S. are tested for HIV, privacy laws prevent medical officials from informing them of the blood results unless the woman specifically requests the information. The issue is critical because it is believed that AZT, if taken early, can block the transmission of HIV from mother to child. For an overview of the American controversy, see Christine Gorman, "Moms, Kids and AIDS," Time, 4 July 1994, p. 54, and Kevin Sack, "Battle Lines Drawn Over Newborn H.I.V. Disclosure," The New York Times, 26 June 1994, p. 23. For a Canadian discussion of AIDS and reproductive issues, see, among others, an article by noted epidemiologist Catherine A. Hankins, "Women and HIV Infection and AIDS in Canada: Should we worry?" Canadian Medical Association Journal 143, Vol. 143, No. 11 (December 1990): 1171-1173.

¹⁹³ Gross, "Turning Disease into Political Cause," p. A12.

declare, with any certainty, that the breast cancer movement should be characterized as non-militant. The movement's course will be decided by other factors, such as the continued complacency of health officials coupled with a frightening rise in the number of breast cancer cases.

Several AIDS activists, many of them women, have successfully challenged gender-based assumptions about AIDS. They were fuelled, in large part, by an 1988 article in the U.S. fashion magazine Cosmopolitan, in which the author, physician Robert E. Gould, reassures women that they need not worry about contracting HIV. 194 Angered by the assumption that women were safe from infection and had nothing to fear, several women in the New York chapter of ACT UP responded loudly and decisively. They protested the offices of the magazine's New York publisher, urging the public to boycott the magazine, and distributed flyers that challenged many of the author's claims, point by point. The actions culminated with the release of a documentary video, Doctors, Liars, Women: AIDS Activists Say No to Cosmo, and a book, Women, AIDS, and Activism. Treichler explains in a much-overlooked article that the "action" against Cosmowas successful in overturning prevailing representations of the PWA: "We

¹⁹⁴ See Robert E. Gould. "Reassuring News About AIDS: A Doctor Tells Why You May Not Be at Risk." Cosmopolitan, Volume 204, Issue 1 (January 1988): 146+.

can say that for women, the effect of AIDS' longstanding identity as a 'gay disease' or a 'man's disease' is that the burden has been on them to prove their own significance — as spokespersons, as persons at risk, as objects worthy of scientific and medical inquiry, and as agents of social justice and political change." Defining AIDS as an epidemic that threatened men's and women's lives, the action against Cosmo connected women's health to the struggle against AIDS; any discussion of women's health issues such as breast cancer or domestic violence was incomplete without some attention paid to the issues surrounding AIDS. And finally, Treichler explains, the protest addressed three important dimensions of the problem of identity: "the identity of the epidemic itself, personal and collective identity, and the relation of identity to representation." 196

Arthur Frank, writing on his history of illness, says that AIDS activists have crystallized our understanding of what it means to be ill. First, he says, they insisted on the term "person with AIDS", rather than "AIDS victim." which, despite its unpopularity in conventional academic texts, is still used frequently in the media. There is some

¹⁹⁵ Treichler, Paula. "Beyond Cosmo: AIDS, Identity, and Inscriptions of Gender." Camera Obscura: A Journal of Ferninism and Film Theory 28, (January 1992): 51.

controversy over the use of this politically-correct term¹⁹⁷, which

Frank fails to acknowledge, but regardless, we should recognize the importance of this language shift. Not only does it restore the dignity of people who are ill, it paves the way to an understanding of the "sick" person as an active, as opposed to passive, participant in his/her health.

Frank also makes an important distinction between disease and illness, one which I would argue has been reinforced by the arrival of AIDS activism: "Illness is the experience of living through the disease. If disease talk measures the body, illness talk tells of the fear and frustration of being inside a body that is breaking down. Illness begins where medicine leaves off, where I recognize that what is happening to my body is not some set of measures." 198

At the very least, Frank appears to suggest, the experiences of PWAs have demonstrated to others with life-threatening diseases that it is safe to emerge from their imposed hiding, that they can resist the

¹⁹⁷ For an overview of the contested meanings of the language employed in the AIDS discourse, see, among others, Jan Zita Grover, "AIDS: Keywords" (pp. 17-30) in Crimp, Douglas, ed. AIDS: Cultural Analysis/Cultural Activism. Cambridge: The MIT Press, 1993, and Judith Wilson Ross, "Ethics and the Language of AIDS" (pp. 39-48) in Christine Pierce and Donald VanDeVeer, eds. AIDS: Ethics and Public Policy. Belmont, California: Wadsworth Publishing Company, 1988.

¹⁹⁸ Frank, Arthur W. At the Will of the Body: Reflections on Illness. Boston/New York/London: Houghton Mifflin Company, 1991, 13.

pain and stigma that often accompany illness: "To lose the sense of stigma, persons with cancer must come in from the margins and be visible ... Every attempt to hide cancer, every euphemism, every concealment, reconfirms that the stigma is real and deserved." Strangely, despite his belief that ill people should organize themselves, Frank rejects the idea that illness "should be lived as a fight." 200

While it is tempting to speak only in terms of its devastation, that is, of the thousands of lives cut short by a deadly disease and of the countless others who have been left to pick up the pieces, AIDS activism has also injected hope in a discourse drenched with doom. It has forced us to re-examine and refashion notions of what it means to be ill, to belong to a sexual or racial minority — to be human. More important, perhaps, it has shown others, especially those outside of the affected communities, that PWAs and their supporters possess the political determination to alter the political landscape. The question of identity and the pursuit of identity-based politics will continue to trouble us: identity informs and politicizes much of the AIDS discourse. Still, despite the wrenching questions posed by a politics of

¹⁹⁹ Ibid., 97.

²⁰⁰ Ibid., 83.

identity, without an injection of identity politics, AIDS activists run
the risk of losing sight of their pressing political agendas. Identity
serves as a constant reminder to AIDS activists that they must
vigorously assess and reassess their responses to AIDS in the light of
the growing heterogeneity of the publics they purport to represent.

Over the years AIDS activists have vented their anger at many, arguably deserving, targets, waging spirited battles against the dominant media²⁰¹, governments, and medical practitioners. What they may have neglected to examine, however, is the enemy within. They have denied their own thoughts and feelings for the greater good of crushing the enemy. As Crimp tells us, AIDS activists need be reminded that "violence is also self-inflicted." ²⁰²

AIDS in the 1980s, see Kinsella, James. Covering the Plague: AIDS and the American Media. New Brunswick and London: Rutgers University Press, 1989.

²⁰² Crimp, "Mourning and Militancy," 16.

CONCLUSION

The words of the late Michael Callen, who was quoted at the outset of this thesis, were indeed prophetic: identity in the age of AIDS is, or at least has become, a double-edged sword. Employing some of the characteristics of civil disobedience, the community of those who identify as people with AIDS has achieved remarkable success in mobilizing countries, and subsequently, the world, to join the fight against AIDS. This, however, has exacted a heavy price on their identity. Through their actions, they — I refer here specifically to activists associated with ACT UP — have reinforced the meanings attached to homosexuals by members of the medical establishment. This criticism, however, should not be construed as a call for the destabilization of an identity-based politics. Following Butler and reiterating an earlier argument, I would assert that those identities that continue to swirl around illness need to be articulated and rearticulated as a response to the political forces which attempt to silence these identities:

So what I'm calling for is not the surpassing of particularity, but rather a double movement: the insistence on identity and the subjection of identity-terms to a contestation in which the exclusionary procedures by which those identity-terms are produced are called into question. This seems to me to be the

necessary and contingent place of identity within a radical democratic culture. ^{20,3}

As I have attempted to demonstrate, illness can be effective as an identifier when the group in question contains some semblance of identity and a fertile political terrain upon which to articulate its demands. Nowhere is this more evident than in the contemporary gay liberation movement. Constructing an identity around illness is much more problematic, however, for those people who identify as members of less-cohesive social groups, namely prostitutes, blacks, and IV drug-users. Their struggles are no less real, only more difficult to resolve, as they are entangled in a complex web of oppression, from within and without, and remain the target of societal condemnation for their apparent role in the spread of AIDS.

Lest it be assumed that we are engaged solely in an academic argument over semantics, or that identity has had no impact on public health responses to AIDS. In fact, much of the tensions ACT UP and other AIDS activist groups have experienced can be traced to the pitfalls of identity politics. To speak of identity invariably presumes the existence of "true" identities, and, conversely, false ones. ACT UP is struggling, even in cities such as New York, where it has enjoyed some of its strongest support, to contain those divisions which

²⁰³ Butler, Judith, in "Discussion," October 61, "The Identity in Question: A Special Issue," (Summer 1992): 108.

threaten its future as a pressure group. Because it is regarded as one of the most outspoken advocates for people with AIDS, it is viewed as crucial that ACT UP attempt to present an accurate, representative picture of the PWA.

Gamson, for example, might be inclined to argue that the schisms present within the movement reflect the true face of the epidemic. Perhaps it is impossible, and consequently futile, to try to forge a single identity around illness, since there is no accurate portrait of the infected individual. Certainly, the evidence in North America suggests that AIDS is becoming a disease of black and white, rich and poor, male and female, straight and gay, not to mention the overwhelmingly heterosexual course of the epidemic in several countries throughout Africa and South East Asia. This, of course, poses a unique challenge to AIDS activism: it will become increasingly difficult as the disease's centre of gravity shifts from one identifiable social group (gay men) to society at large to build a sustainable coalition committed to fighting AIDS and its attendant cultural narrative, when there is little agreement on how to articulate the identities of widely disparate groups. In an ideal setting, a gay, HIVpositive AIDS activist would demonstrate the same amount of compassion in defending the rights of an infected intravenous drug user as he would in defending another gay man; he would understand that illness, not personal identity, is the common denominator upon which to respond to AIDS. The short history of the pandemic, however, illustrates that the response to AIDS is framed by who is doing the suffering. Women, for example, have experienced tremendous difficulty in trying to convince authorities that AIDS poses a unique challenge to their health. The situation has begun to turn around as public health officials are being forced to swallow several sobering statistics, including the fact that in New York City, "AIDS is the leading cause of death in women aged 25-54." ²⁰⁴ Moreover, the World Health Organization (WHO) estimates that by the year 2000, more than 13 million women worldwide will be infected with HIV. ²⁰⁵ In Latin America and the Caribbean, for example, in the last three years the male-female ratio of AIDS cases has increased from 6:1 to 3:1.

Darien Taylor and Douglas Buckley-Couvrette, two of the AIDS activists interviewed for this research, suggested that the future of AIDS activism lies in coalition-building, in establishing links with likeminded social groups, including anti-poverty and women's

²⁰⁴ Crimp, Douglas and Adam Rolston. *AIDS Demo Graphics*. Seattle: Bay Press, 1990, 39.

²⁰⁵ "AIDS: Images of the Epidemic." World Health Organization Publications, 1994, 3.

organizations. Such a goal, on the face of it, would appear laudable. It is, however, fraught with a host of uncertainties: will PWAs, for example, be assured a voice within the larger activist community, or will their voices be drowned out by a chorus of "traditional" lobbyists or protesters? Such a move also presumes that all non-AIDS activists are on the side of the angels, and ignores the possible homophobic backlash against AIDS activists by traditional, God-fearing activists. It is evident that other social groups which have toiled in relative obscurity for years can learn a great deal from AIDS activists, especially in devising foolproof methods to garner media attention. How AIDS activists can benefit from joining such a coalition, however, still remains unclear.

As Black Studies scholar bell hooks notes, there may be something to be gained from remaining in the space of marginality. This space, she says, is

...much more than a site of deprivation ...it is also the site of radical possibility, a space of resistance... As such, I was not speaking of a marginality one wishes to lose — to give up or surrender as part of moving into the center — but rather of a site one stays in, clings to even, because it nourishes one's capacity to resist. It offers to one the possibility of radical perspective from which to see and create, to imagine alternatives, new worlds. 2006

²⁰⁶ hooks, bell. Yearning: Race, Gender, and Cultural Politics. Boston: South End Press, 1990, 149-150.

Any wholesale attempt by AIDS activists to join the swelling ranks of angry interest groups runs the risk of weakening the political power they continue to derive from occupying this "space of radical openness." 207 Strength, in this case, to convert an old adage, may not be found in numbers. If AIDS activists opt to join a coalition, they will have to choose their allies carefully. For example, there is a strong, albeit controversial, tradition within ACT UP of working closely with feminist groups; in fact, many of the women (lesbians and heterosexuals) who have worked and continue to work with ACT UP, while often complaining bitterly of sexism within AIDS activist rar ks, have nonetheless enjoyed a fruitful collaboration with ACT UP.

Prior to joining any coalition, those groups on the AIDS frontlines must first address the serious, pressing question of underrepresentation of PWAs in organizations that purport to speak on PWAs' behalf. I do not mean to suggest here that all AIDS activists must be HIV-positive or have AIDS. A good starting point, however, would be to acknowledge that any organization representing the interests of PWAs or involved in AIDS lobbying should include in its fold members who are HIV positive. One example to be emulated is Quebec's CPAVIH, of which Buckley-Couvrette served as executive

²⁰⁷ Ibid., 149.

director; the organization's board of directors is made up entirely of people with HIV/AIDS.

The brief history of public health responses to AIDS indicates that many are eager to act; what they need to begin to do now is think, as well. They need to temper their notions of sexuality and group behaviour with what Weeks has called "moral pluralism" 208 — with the belief that sex is neither good nor bad, neither moral nor immoral. The overriding fear is that policy-makers know too much about AIDS and precious little about sexuality, and the identities that have formed around this notion and which continue to complicate otherwise earnest attempts to respond to AIDS.

The evidence suggests that we still have a lot to learn from and about sex, which Foucault once called "the explanation for everything ... our master key." 209 Just as feminism had to teach us that sex is not simply a means to an end (procreation), we may have to be reminded that AIDS is not an end in itself and that the affected communities are not the victims of divine retribution for the pursuit of a heinous lifestyle. Perhaps, unfortunately, this realization may only begin to figure into the collective imagination as the disease's centre of

²⁰⁸ Weeks, Jeffrey. Sexuality. New York and London: Routledge, 1986, 120.

²⁰⁹ Foucault, The History of Sexuality, 78.

gravity shifts from gay men to heterosexuals of all stripes, when the homosexual marker of disease is erased from the identity of the infected person.

As Douglas and Calvez note, attitudes to disease are often conditioned by the dominant class's expectations of contracting the illness: "So the fears of those working with AIDS victims that they will be segregated, marginalised and discriminated against, are not unreasonable. The conscience of the central community is not essentially compassionate to all the citizenry."²¹⁰ As for AIDS activists themselves, one of the greatest challenges is posed, perhaps ironically, by the nature of the disease itself: "Although activists have succeeded in demanding that the world take note of the urgency of the epidemic, the very urgency is what robs the movement daily of its best soldiers through burnout, illness, and death."²¹¹

²¹⁰ Douglas and Calvez, "The self as risk taker," 463.

²¹¹ Wachter, "AIDS, Activism, and the Politics of Health," 131.

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