

ACT UP, Racism, and the Question of How To Use History

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My reflections on this 25th anniversary of ACT UP's founding were spurred by a comment made to me recently that indicated that ACT UP's memory and legacy are haunted by the perception that it was racist. I do not know how widespread that perception is—my sense, anecdotally, is that it circulates in some younger activist circles—but regardless, it behooves us to take it and the question of racism in ACT UP seriously, especially if we care about the politics of remembering activist histories and the political potentialities that emerge, or don't, from how we do so. I had been invited to a student-run course in ethnic and critical race studies to speak about ACT UP during their unit on queer liberation. The comment came from a politically engaged queer student who expressed surprise and relief following my remarks: a friend of hers had wondered why the class was talking about ACT UP given that it was “a racist organization.” The claim did not surprise me—I had heard it before—but I was struck by this student's palpable anxiety about even discussing ACT UP and subsequent relief that it might be OK to do so. In this essay, I consider the claim that ACT UP was a racist organization.¹ In addition to the question of historical accuracy, I explore what is generated and what foreclosed by the claim itself, thinking more broadly about the potentialities that histories of activism can but don't always provide. Throughout, I analyze how racism functioned within ACT UP, seen from the perspective of a white participant in, and subsequent researcher of, the movement. A broad interest in the emotional states that course through activist scenes—often submerged and unacknowledged but nevertheless forceful and with effects—also motivates this essay. In particular, I'm curious about why a current activist might be wary of discussing ACT UP and what that wariness can tell us about the possibilities and perils of activist remembrance.

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The Claim and Its Moral Demand

When people describe ACT UP as a racist organization, they probably mean some combination of the following:

1. ACT UP was made up of privileged white gay men who cared primarily about people with AIDS like themselves and neglected the needs of other populations with AIDS;
2. ACT UP was a majority-white organization and, as such, an alienating place for many people of color, but even more, white participants at times disregarded and in other ways oppressed participants of color;
3. ACT UP tackled some of the racist dimensions of the AIDS epidemic but in ways that usurped the role of AIDS activists of color.

While these suppositions hold some truth, they produce a distorted picture of ACT UP. Rather than enhancing our understanding of how racism actually functioned within the movement, the claim that ACT UP was a racist organization paints a totalizing picture that treats racist occurrences and dynamics within the organization as definitive of the organization as a whole, neglecting features and actions of ACT UP that afford a more multifaceted understanding. The claim also problematically suggests that a majority-white activist organization in a white supremacist society like our own might be free of racism; such a perspective not only misunderstands the extent of the problem posed by racism, it also leads to a moralistic rather than political approach to anti-racist struggle that tends toward reproach and shaming rather than analysis, critique, and dialogue.² I also take issue with the implicit moral demand of the claim which I read as follows:

ACT UP was a racist organization *and therefore* you shouldn't value its direct-action AIDS activism, hold it up as an affirmative example, or try to learn positive lessons from the movement but instead should only and always be critical of ACT UP; to do otherwise would be to ignore, and even align yourself with, racism.

I worry about the hazards that attach to that demand: the dismissiveness and purism that it encourages and its embrace of a facile assertion rather than curiosity about how racism actually functioned within ACT UP. I also question its moralistic approach to history. More useful for social change activists would be an analytical and political approach that looks to the past both to understand it and to find tools to reconfigure the present and future: instead of condemning or praising people's past behavior, such an approach inquires into the conditions of possibility for that behavior, investigating the prevailing context with its specific constraints, openings, power relations, and dynamics, while simultaneously plumbing that past for ways of moving forward in the current moment. With a futural and political rather than a reproachful intention, this approach to and use of history acknowledges the past's ongoing and as-yet-unrealized potentialities. The claim that ACT UP was a racist organization and the implicit moral demand that it entails not only shut down critical analysis of ACT UP's historical importance but also foreclose exploration of

ACT UP as full of potential which activists might learn from today. I propose a different approach to the question of ACT UP and racism.

ACT UP and Racism

An alternative starting point for considering racism and ACT UP is to recognize, as the claim fails to do, that racism is pervasive in our society and likely present to some degree in any majority-white activist organization. The task, then, is to explore the specific ways that racism functioned in ACT UP, what the struggles within the organization around racism were like, how the organization fought racism, and what we can learn from ACT UP's experiences with racism.

Racism in ACT UP

Some of the ways that racism manifested in ACT UP are familiar to anyone who has participated in a majority-white progressive activist group. Most generally, along with reflecting and replicating the racial divide in US society, the group's demographics likely made ACT UP a less-than-inviting environment for people of color. That may have been especially true in so far as some white participants vigorously resisted acknowledging their white privilege and how racism was exacerbating the AIDS epidemic. ACT UP/NY member Robert Vazquez-Pacheco remembers that when issues of race would come up, "everyone would just sort of like go into that stunned, 'Don't call me racist, don't call me racist' [mode]."³ As well, ACT UP/NY's first people of color caucus, the Majority Action Committee (MAC), formed in part because people of color found themselves combating racist views within ACT UP, including the perception that people of color were more likely to use drugs.⁴ In addition, ACT UP sometimes pursued its agenda without consulting appropriate AIDS organizations in black and Latino communities. In a memo in 1990, for example, MAC challenged ACT UP members who did an action that expressed "very legitimate opposition" to the nomination of Dr. Woody Myers, an African American, as New York's health commissioner, but "antagonized" communities of color in the process. "This could have been avoided easily by communicating with persons from MAC and other AIDS activists in communities of color."⁵

Racism was particularly pronounced in ACT UP's internal conflicts.⁶ Disagreements about how to fight AIDS existed from ACT UP's start, but they intensified and engulfed many ACT UP chapters in the early 1990s in large part because there seemed no end to the accelerating epidemic, many participants felt increasingly desperate, and a sense emerged that our activism might not be able to interrupt the dying. In that context, a scarcity mentality took hold: activism regarding issues of concern to one group of people with AIDS (PWAs) came to be seen as diverting activist energy and resources from other PWAs. Racism (and sexism and classism) shaped these dynamics, with harmful effects. Consider for example that although the movement's rhetoric and self-understanding articulated a commitment to fighting for *all* PWAs, some participants generalized from their particular experiences of AIDS and argued

that ACT UP should fight the epidemic from that perspective alone, effectively privileging the concerns of white, middle class, gay men over those of others with HIV/AIDS.

Important is the fact that in 1989–90, some ACT UP activists—primarily men in ACT UP/NY’s Treatment & Data Committee (T&D), many of whom were white and HIV-positive—gained access to top AIDS science researchers and government institutions against which ACT UP had protested. Such access introduced the possibility of getting AIDS treatments more quickly, and that changed some ACT UP members’ political calculus. Whereas initially activists had believed ACT UP should tackle both the scientific-medical and the political aspects of the crisis, including, for example, the question of unequal access to health care, some now believed the movement should focus solely on improving and expediting AIDS drug research, on getting “drugs into bodies.”⁷ Indeed, as ACT UP/Chicago member Jeff Edwards points out, pushing for new treatments became, for some, synonymous with “fighting AIDS.”⁸ Others in the movement questioned this narrowing of focus, worried that it would mean neglect of important issues like unequal access to health care (and thus to effective AIDS drugs) and would result in disadvantaged AIDS-affected populations falling through the cracks.

In this context, whenever participants interjected into the discussion topics like AIDS in communities of color or among women (disproportionately black and Latina), other participants began to ask “what does this have to do with AIDS?” and angrily accused people working on those issues of “getting off track.” Although as ACT UP/NY member Kendall Thomas recalls, and I would concur, discussions about various populations “were always raised about a very specific HIV/AIDS-related issue,” some heard them as non-AIDS-related.⁹ Thomas remembers discussions about HIV-positive women dying from infections that were not included in the Center for Disease Control’s definition of AIDS and about women being excluded from clinical drug trials. Although these topics are AIDS-related, Thomas believes that “what people were *hearing* was something that, because they arrogated to themselves the right to . . . draw the boundaries of the proper domain of AIDS, had nothing to do with AIDS” (my emphasis).¹⁰

The class dimensions of ACT UP’s internal conflicts become clear here. For many in T&D, their focus on AIDS treatments derived in part from their economic status: middle-class or wealthier, they often did not have to worry about things that were life-and-death issues for other PWAs, such as access to health care and housing. What they needed more than anything were medications. As a result their focus within ACT UP was on getting drugs tested and approved, and many experienced the felt urgencies of other ACT UP members—about, for example, the exclusion of women from drug trials—as either not about AIDS or as merely a diversion from T&D’s important work.

David Barr, a white HIV-positive member of ACT UP/NY, offers the following analysis of why the question “What does this have to do with AIDS?” resonated with many in ACT UP, particularly those who came to the movement because they had HIV/AIDS:

Most of them were white, middle-class. Most of them were men who had this sense of privilege, and all of a sudden they came up against a system that was saying, “We don’t care if you die . . .” In addition to the rage about the disease itself, their rage about that [societal abandonment] was really overwhelming, and you [could] see them go through, “How dare they not take care of me.” So when other people [in ACT UP] started broadening the agenda,¹¹ I think they felt like “Well, what does this have to do with *AIDS*, you know, what does this have to do with *me*?”¹² (my emphases)

Barr’s analysis corroborates Thomas’s: some people felt that if an issue had to do with *AIDS*, it had to do with *me*, and *only* if it had to do with *me* did it have to do with *AIDS*. Because issues of racism, sexism, and poverty in the *AIDS* epidemic did not establish that link for most of the HIV-positive, white, middle-class men in the group, those concerns seemed to some to be “not about *AIDS*.” Barr’s comments indicate that white, male, middle-class privilege often motivated the “What does this have to do with *AIDS*” question, significantly affecting the debates about the movement’s priorities.

Racism, sexism, and class privilege were not the only forces in play. As Barr indicates, also triggering that question about ACT UP’s direction and focus were gay men’s rage about society’s homophobic betrayal of them and their fear that ACT UP would abandon them too. Tim Miller recollects as well the role desperation played in ACT UP/Chicago’s internal conflicts:

I don’t think the HIV-positive people were trying to be difficult when they were saying, “We don’t have time to do prisoners with *AIDS*. We don’t have time to do women with *AIDS*.” . . . I think it was the *desperation*, you know? I really feel like people felt, and they were in fact correct, the clocks were ticking. And a lot of them died. I don’t think that they were trying to be anti-woman, or anti-black . . . That may be what people heard. But I don’t think that was the intention. (my emphasis)¹³

Both Barr and Miller usefully indicate how feelings of desperation among PWAs in ACT UP, along with fear of abandonment and betrayal, prompted some to argue that fighting the racist and sexist dimensions of the *AIDS* crisis would detract from *their* needs and from the battle they wanted, *needed*, the movement to engage. Barr notes that getting people who feared betrayal as well as death to see that focusing on those issues would not detract from *their* issues required addressing people’s fears, but “that process didn’t happen.”¹⁴ Indeed, the emotional dimensions of these conflicts—including feelings of betrayal on the other side as well—remained unaddressed, overlooked in a context where most read the difficulties as due to ideological and political differences alone.

In my analysis, then, this form of racism surfaced in part because of increasing feelings of desperation within the movement and a sense among some that they had been or would be betrayed by others in ACT UP. I offer that contextualization and argue that we need to recognize the force of such feeling states and their role in ACT UP’s internal conflicts not in order to diminish the role of racism but because I think it important to understand the conditions in which racism emerges and plays out, especially if we wish to pursue an anti-racist politic.

In any case, the evidence indicates that there were significant racist incidents and dynamics in ACT UP. They took a toll on many participants and harmed the movement as a whole. At the same time, the claim that ACT UP was racist misrepresents the organization, portraying it in a totalizing manner that ignores the struggles over racism that occurred in the movement. Indeed, as its internal conflicts emphatically demonstrate, the movement was never as monolithic as the claim that “ACT UP was a racist organization” suggests, but rather was characterized by racial, gender, and political heterogeneity. An exploration of some campaigns that ACT UP spearheaded further challenges the claim and indicates what we risk losing if we follow the moral demand that we disregard ACT UP due to its racism.

ACT UP Against Racism

Assertions that ACT UP was a racist organization ignore the anti-racist work of many within the organization, women and men of color and white women in particular but also many white gay men, and negate the tremendous impact their efforts had on the movement and on the AIDS crisis. These activists engaged in a multiyear campaign that forced the CDC to expand its definition of AIDS to include the infections that were killing women and poor people with HIV, a disproportionate number of whom were black and Latino/a. They successfully fought the exclusion of women from experimental drug trials.¹⁵ They fought for needle exchange programs, housing for PWAs, and medical treatment for prisoners with AIDS. They demonstrated for equal access to health care, placing the fight for national health insurance at the center of the fight against AIDS. They struggled with their ACT UP comrades to take on these crucial battles—all of which focused on the needs of poor and working class PWAs, disproportionately people of color—and to confront the racism within the organization. The totalizing claim that ACT UP was a racist organization effaces their work and the victories they secured.

This anti-racist activism was by no means without problems. Those of us who engaged in these struggles made mistakes that augmented rather than unraveled racism. Sometimes the organization’s anti-racism slipped into tokenism; sometimes white activists presumptuously “spoke for” people of color; sometimes white anti-racist activists failed to build genuine alliances with AIDS organizations in black and Latino communities; sometimes white anti-racist activists resisted acknowledging the blinders we white people wear. Such mistakes are not trivial, but they do not negate ACT UP’s anti-racist work. Rather than proving that ACT UP was a racist organization, they perhaps reveal just how entrenched racism is in our society and the importance of continuing to do anti-racist work. If we reject a notion of activism as working from a clear blueprint and instead recognize that it requires a high degree of improvisation and trial and error, then these mistakes can also be understood as opportunities for learning how to do it better next time.

Interviewed by *Spin* magazine in 1990, Keith Cylar, an African American member of ACT UP/NY, suggests the stakes involved in *how* we talk about an organization’s racism. He begins by asserting “ACT UP is a racist organization” and then

reconsiders, arguing for a more nuanced account that acknowledges the presence of racism in ACT UP as well as the important work ACT UP has done, including its anti-racist work. Refusing a notion of activism as morally pure, Cylar criticizes and praises simultaneously. Especially instructive is his suggestion about how to confront racist occurrences and dynamics within an organization.

I mean it's as racist as any other organization or institution. Any time you get a group of people together who happen to be white men, who happen to be gay, there is a certain amount of racism present. But I don't have a problem working with them or fighting with them. To simply label a group or person as racist doesn't work in 1990 anymore. You have to go one step further and say, "This is exactly what you did, this is why it's racist, and this is what you should do to correct it." We've done that in ACT UP and they're getting better. All of our flyers, for instance, are translated into Spanish now. And ACT UP was one of the first activist groups who said universal health care is a right. They were also the first to point out that people of color were not getting into clinical AIDS drug trials.¹⁶

Cylar does not ignore ACT UP's racism, but he contextualizes it and acknowledges ACT UP's anti-racist activism as well; he also offers active engagement—including confrontational arguments—rather than a purist and moralistic dismissiveness as the way to tackle racism in an organization. His critical appraisal also models how we might approach remembrance of activist histories.

Learning from Activist Histories

The claim that ACT UP was a racist organization moralizes that activist past rather than using it to inform contemporary struggles. Its implicit demand to disregard ACT UP seems anxious, as if discussing this flawed organization might contaminate and compromise one's own politics. An approach to activist history that instead expects imperfection, examines how mistakes come about, and studies past activist experiences with an eye toward how they could strengthen contemporary struggles to remake the world, might alleviate that anxiety and offers an alternative to what seems to me a damaging activist purism.

I wrote this essay because I think current progressive and left activists can learn from ACT UP's history and I worry that a moralistic approach to its past inhibits doing so. What might be learned from this investigation of how racism played out in the movement? It alerts us to how entrenched racism is in a white supremacist society but also to how a majority-white organization can engage in anti-racist activism, even if imperfectly; it reveals possible forms of racism in such efforts that, with greater awareness, might be directly addressed and diminished; it reminds that activist groups typically are neither all good nor all bad and that they sometimes mess up even as they simultaneously do amazing and vital work.

This history also cautions against creating hierarchies of oppression. An investigation of ACT UP's internal conflicts which frequently pit one population affected by AIDS against another elucidates why and how ruptures in empathy and solidarity sometimes occur in activist contexts and points to the ways that movement

conflicts typically have emotional undercurrents which structure the very content and character of those conflicts. It may be that what underlies the claim that ACT UP was a racist organization is precisely a form of hierarchicalizing among progressives, seemingly suspicious about the very fact that ACT UP included many relatively class-, race-, and gender-privileged individuals, and was fighting for the lives of similarly situated individuals. Such a perspective not only fails to reckon with the depths of homophobia in this country—the US government and dominant society were indifferent at best to the deaths of hundreds of thousands of gay men—it also suggests that injustice that kills relatively privileged people is less weighty than injustice that kills the most disadvantaged. That may be an attempt to upend the more typical disregard for those on the bottom of society, but why not instead challenge such hierarchies altogether?

That question provides segue into my final point. I think one of the forceful if submerged affective states that courses through some progressive activist scenes is anxiety about being revealed as having “bad politics”: something you say or do will reveal how blinded by privilege you are, or that your politics are only superficially anti-racist, or that you are insufficiently aligned with the “most” oppressed.¹⁷ I think the totalizing claim that ACT UP was a racist organization and its implicit moral demand to dismiss the movement derive from and reinforce that sort of anxiety. My intervention here hopes to encourage curiosity and critical analysis instead, and a plumbing of ACT UP’s history for insights that can help us move forward today.

Notes

- [1] My reflections here are about ACT UP during its heyday, from 1987 through the mid-1990s. A few ACT UP chapters still exist and do vital work, but I think the claim about racism refers to ACT UP during its heyday.
- [2] For a similar contrast between moralistic and political approaches, see Wendy Brown, *States of Injury* (Princeton, NJ: Princeton University Press, 1995).
- [3] Robert Vazquez-Pacheco, “Interview conducted by ACT UP Oral History Project,” 2002: <http://www.actuporalhistory.org>.
- [4] Catherine Saalfeld and Ray Navarro, “Shocking Pink Praxis: Race and Gender on the ACT UP Frontlines,” *Inside/Out: Lesbian Theories, Gay Theories*, ed. Diana Fuss (New York: Routledge, 1991), 353.
- [5] ACT UP/NY Majority Actions Committee. “Memo to ACT UP; Issue: Cultural Sensitivity and Communication,” 1990. Primary Source Microfilm, Gay Rights Movement—Series 3: *ACT UP: The AIDS Coalition to Unleash Power*, reel 6, box 8, folder 5. Produced by Gale CENGAGE Learning.
- [6] Having explored ACT UP’s conflicts in detail elsewhere, I am relatively concise here. See *Moving Politics: Emotion and ACT UP’s Fight Against AIDS* (Chicago: University of Chicago Press, 2009).
- [7] The lore is that getting “drugs into bodies” was ACT UP/NY’s original mission, but the evidence indicates otherwise. See, for example, Mark Harrington, “Some Transitions in the History of AIDS Treatment Activism: From Therapeutic Utopianism to Pragmatic Praxis,” *Acting on AIDS: Sex, Drugs, and Politics*, ed. Joshua Oppenheimer and Helena Reckitt (London: Serpent’s Tail, 1997), 275.

- [8] Jeffrey Edwards, "AIDS, Race, and the Rise and Decline of a Militant Oppositional Lesbian and Gay Politics in the US," *New Political Science* 22 (2000): 495.
- [9] Kendall Thomas, Interview conducted by Deborah Gould (New York, September 11, 2002), personal ACT UP archive.
- [10] Thomas, Interview.
- [11] Again, the evidence counters this idea that ACT UP's *original* mission was solely to get "drugs into bodies;" still, many saw it that way and consequently felt ACT UP was veering. For elaboration, see Gould, *Moving Politics*, 351–53.
- [12] David Barr, Interview conducted by Deborah Gould (New York, September 11, 2002), personal ACT UP archive.
- [13] Tim Miller, Interview conducted by Deborah Gould (San Francisco, July 13, 1999), personal ACT UP archive.
- [14] Barr, Interview.
- [15] ACT UP/NY Women and AIDS Book Group, *Women, AIDS, and Activism* (Boston, MA: South End Press, 1990).
- [16] Quoted in Celia Farber, "AIDS: Words From the Front," *Spin* (October 1990), 73–75.
- [17] A more recent activist practice of establishing "ground rules" for discussion—including speaking in "I" statements and acknowledging that everyone makes mistakes—seems attuned to, and an effort to alleviate, such anxieties.

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