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Anti-AIDS Activism in the 1980s and 1990s

> [M]isfortune is not the same thing as injustice. Death and illness are misfortunes. We are deeply upset over the prospect of a young man dying of incurable cancer, but we do not conceive it as a deep injustice which provokes a sense of outrage against a system productive of such misfortunes.
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> – Ralph H. Turner, "The Theme of Contemporary Social Movements," 1972[1]

> Oh, yeah?
>
> – Benita Roth, writing in the margins of the article above, 1990

INTRODUCTION: ANTI-AIDS ACTIVISM AND INJUSTICE REDEFINED

The preceding epigraphs are drawn from the work of one of the most respected and influential sociologists of the twentieth century – that would be the late Ralph Turner – and a snarky UCLA graduate student – that would be me. Juxtaposed, they show how much activism around questions of health and disease has shifted over the past several decades. Writing in 1972, Dr. Turner captured the general view that illnesses like cancer were equal-opportunity diseases. Very few of those suffering from cancer would have attributed the cause of that cancer to negligence by others, and therefore the means of generating the moral outrage that would turn misfortune to injustice was lacking.[2] But moral outrage around health issues was just around the corner. By the end of the 1970s, the feminist women's health movement was in full

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[1] Turner, Ralph. 1972. "The Theme of Contemporary Social Movements," pp. 586–599 in *Sociology, Students, and Society*, edited by Jerome Rabow. Pacific Palisades, CA: Goodyear Publishing Company.

[2] I'm indebted to Dolores Trevizo for making the point that an injustice frame requires the alleged malfeasance of others. Cancer, especially, was seen as the product of a repressed personality and therefore self-inflicted: see Sontag (1988).

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swing, challenging sexist health practices, doctors' paternalistic authority over women, inequalities in healthcare delivery, and prevailing standards in resource allocation for research. Views on what caused disease and who was responsible for health changed, and the feminist health movement spilled over (Meyer and Whittier 1994), spawning other movements that worked to pave the way for a large-scale democratization of the culture of medical treatment and research.[3]

One of the movements that spilled over, buoyed by the questioning spirit of feminist women's health activism, was the direct action anti-AIDS movement of the 1980s and 1990s. This book is about the life and death of an organization that was part of that movement, the AIDS Coalition to Unleash Power, Los Angeles, or ACT UP/LA.[4] ACT UP/LA was founded on December 4, 1987, when activists in Los Angeles called a "town meeting" for people who wanted to take direct action to fight AIDS.[5] The organization lasted for about ten years, ending sometime in 1997, when its three remaining members voted it out of existence.[6] ACT UP/LA's peak period of activism lasted from early 1989 to mid-1992, when it held weekly meetings attended regularly by eighty to one hundred people and sometimes twice that number. The group kept an office open until the mid-1990s, a bank account open beyond its final days, and maintained a network of contacts through an online listserve after it dissolved.

When I wrote my "Oh yeah?" comment in the margins of Turner's article, I myself was participating in ACT UP/LA, so I knew that the deaths of young men prompted outrage. Generating that outrage against the AIDS epidemic took effort and time. The first reactions of the lesbian and gay communities of Los Angeles, New York, San Francisco, and other American cities to the appearance of what came to be called AIDS was the widespread organizing of community-based social services for the sick.[7] In 1981, Gay Men's Health Crisis (GMHC) formed in New York City; in 1982, the organization that began as the

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[3] On the women's health movement, see Sandra Morgen (2002); on the democratization of health research in the United States, see Steven Epstein (2009); on the spillover effects of the feminist health movement *and* AIDS activism on the anti-breast cancer movement see Klawiter (2008).

[4] I use "ACT UP/LA" throughout this book when writing about the Los Angeles group, as opposed to the generic "ACT UP" which has come to mean ACT UP/NY (see Brier 2009, note 1, p. 242). In using "ACT UP/LA," I follow the group's most common spelling of its name because there are variations in how the acronym is spelled in the group's documents; I preserve those variations when citing from documents.

[5] ACT UP/LA, "A Very Brief History of ACT UP/Los Angeles." Author's collection.

[6] As I discuss in Chapter 5, accounts of the end of ACT UP/LA differ. J. T. Anderson, Stephanie Boggs, and Peter Cashman, Interview with author, 1999; Jeff Scheurholz and Peter Jimenez, Interview with author, 2011.

[7] I use the terms "lesbian and gay" or "gay and lesbian" to denote what would now commonly be referred to as the "lesbian, gay, bisexual, and transgendered" (LGBT) community. I use the former terms because they were how the community referred to itself during the 1980s and 1990s. I consider this an imperfect solution to characterizing what was and is a diverse set of communities.

San Francisco Kaposi's Sarcoma Foundation and would eventually become the San Francisco AIDS Foundation had formed.[8] In October 1982, the information hotline that would become AIDS Project Los Angeles was set up by four "founders" who, along with a representative from the San Francisco Kaposi's Sarcoma Foundation, attended a meeting about what was then called Gay-Related Immunodeficiency Disease (GRID) at the Los Angeles Gay and Lesbian Community Services Center.[9]

These early community-based, service-oriented organizations were highly politicized responses by lesbians and gays to the sense "that public health entities were unlikely to address something considered a gay disease" (Brier 2009: 20). Organizing militant direct action against institutions seen as responsible for the AIDS crisis took a few years to coalesce as the pride of the community taking care of its own became rage at the continued unwillingness of the government to fight AIDS and at the homophobic backlash that ensued as the public became aware of the disease (Gould 2009; see Chapter 2). In March 1987, lesbian and gay activists in New York City formed the AIDS Coalition to Unleash Power/New York (ACT UP/NY). Although accounts of ACT UP/NY's founding vary, two things stand out. First, ACT UP/NY was not the first direct-action style protest group around AIDS that formed; second, the 300 or more "lesbians, gay men, and other sexual and gender outlaws" who attended the founding meeting of ACT UP/NY had the numbers and the desire to commit themselves to "the use of civil disobedience and direct action to fight the AIDS crisis" (Gould 2009: 131). ACT UP/NY became the largest, best known, and most widely emulated model for direct action anti-AIDS organizing. In particular, ACT UP/NY's appearance at the October 1987 March on Washington for Lesbian and Gay Rights left a strong impression on lesbians and gays from all over the United States who were fighting local battles for the resources to fight the epidemic.

One of the places where ACT UP/NY's model of militancy was catalytic was Los Angeles. ACT UP/LA arose in late 1987 because members of LA's lesbian and gay community were enraged by authorities who alternately ignored them and reviled them. The members of ACT UP/LA were extraordinarily ambitious. They addressed a wide variety of HIV/AIDS issues, matters of healthcare generally, and other political issues involving queer rights and human rights. Members worked on local matters – the establishment of the dedicated AIDS ward at the publicly run County/USC hospital, subsequent monitoring of the ward and of county-funded outpatient clinics – and they coordinated with other ACT UPs to mount national campaigns. A very partial list of issues that ACT UP/LA addressed include:

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[8] See http://www.gmhc.org/about-us); http://www.sfaf.org/about-us/; and Gould (2009).
[9] See http://www.apla.org/about/history.html and Kenney (2001).

- Challenging the Immigration and Naturalization Service's policy regarding the immigration of HIV-positive people to the United States
- Protesting the reluctance of the Catholic Church and then Archbishop of Los Angeles Roger Cardinal Mahony to endorse safe-sex practices and education
- Speaking out against the Federal Drug Administration's slowness in approving life-saving AIDS drugs
- Asking for more visibility and more recognition for women's AIDS issues, including the fact that women were affected by different opportunistic infections than were men and subsequently demanding that the Centers for Disease Control in Atlanta change definitions of AIDS to be more inclusive of female "people with AIDS" (PWAs)
- Raising awareness about consent issues for clinical trials
- Protesting prison conditions and the lack of care for prisoners with AIDS
- Arguing for universal healthcare and health insurance
- Promoting needle exchange programs and services for intravenous drug users
- Challenging discriminatory policies and individual acts of discrimination against HIV-positive people

ACT UP/LA members were also involved with other progressive causes, such as Central American solidarity politics, abortion clinic defense, and, by the early 1990s, queer politics through the organization Queer Nation. In the words of the late Stephanie Boggs, one of ACT UP/LA's last members, "there were too many AIDS issues."[10]

ACT UP/LA members used a wide variety of tactics to address these issues: they "employ(ed) multiple mechanism of influence (including disruption, persuasion, and bargaining" as they contended with power (Andrews 2001: 75). Members lobbied elected officials and they wrote letters to those in power, but they also participated in disruptive "phone zaps" and "fax zaps," where members would deluge an official's office with endless calls or faxes. They protested by sitting in officials' offices; they held vigils, marches, and demonstrations at relevant sites. They distributed leaflets, but they also put up stickers and wheat-pasted posters on the walls of public spaces, defying laws about those activities. ACT UP/LA members appeared at gay and lesbian pride parades, staging die-ins at those events and in other spaces. They attended government meetings and participated on internal review boards at hospitals but were willing to disrupt those same meetings. As one might surmise by the variety of tactics used, some members of ACT UP/LA championed disruption and feared any form of cooperation with authority. Others were willing to "play ball" with authority. Still others were ready to be nice or nasty as the situation required.

What these lists of issues and tactics show is how wide a net ACT UP/LA cast in trying to capture energy to direct against the many-faceted AIDS crisis. ACT

[10] Interview with author, 1999.

UP/LA participants were for the most part lesbians and gay men whose politics were left-of-center or had been pushed left by the crisis. People came to the group out of concern and outrage over inaction regarding the crisis and over societal prejudice against those infected with HIV. This concern and outrage was often very personal because many members were themselves HIV-positive and had friends who had died of AIDS. Some ACT UP/LA members died in the course of their activism. The ambitious list of goals was accompanied by a set of great expectations about what the group could accomplish. While not all of their expectations were met, the ACT UP/LA members accomplished enough to change the landscape of AIDS funding, service provision, and awareness in Los Angeles. In the late 1980s and early 1990s, AIDS was a pandemic barely addressed by government, the medical establishment, and the social service sector, and every victory seemed hard-won and insufficient. At the same time, an "AIDS industry" was beginning to be built in both private and public settings as doctors, drug companies, not-for-profit groups, magazines, and media emerged in support of the AIDS community. As such, ACT UP/LA's effectiveness really depended on negotiating two related stances: (1) criticizing the shortcomings of institutions in fighting the AIDS crisis – the insufficient resources devoted to stopping AIDS, the lack of basic information about the virus, and the dearth of services for PWAs – and (2) insisting that these same institutions build new agencies and incorporate new spaces for dealing with the pandemic.

WHY STUDY ACT UP/LA?

I wish to make several interventions into the field of movement studies through examining ACT UP/LA's life and death. First, I wish to remedy the conflation of the ACT UPs, a broad and decentralized social movement, with ACT UP/NY, a conflation that misrepresents the widespread appeal and coalitional nature of direct action anti-AIDS activism in the 1980s and 1990s. Second, I make the case for greater attention to the politics of place in movement studies. Scholars have acknowledged the importance of studying the local movement field (Ray 1999) in order to understand activists' choices and organizational trajectories. I argue that the LA metropolitan area's structure of "segregated diversity" (Pulido 2006: 52), the County of Los Angeles' role in healthcare provision, and the local history of LGBT politics in Los Angeles affected ACT UP/LA's trajectory as a movement organization. Third, I argue that ACT UP/LA, like other ACT UPs, was an example and, in fact, an exemplar of progressive, multi-issue, anti-corporate, confrontational movements of the late twentieth century. Last, I argue that a feminist intersectional theoretical lens is essential for understanding the dynamics and trajectory of this social movement organization as members grappled with challenges to their intent to engage in democratic and coalitional politics. ACT UP/LA as an organization struggled with maintaining the coalitional solidarity that its members sought due to intractable social inequalities and increasing heterogeneity within the group. A feminist intersectional lens, which

examines the mutually reinforcing hierarchies of oppression that impact interaction, makes it possible to see those social cleavages as they emerged.

CONFLATION AND HIDING THE COALITION NATURE OF DIRECT-ACTION ANTI-AIDS PROTEST

Although ACT UP/NY was the first and the largest ACT UP, it was not the only ACT UP of consequence. The conflation of ACT UP with ACT UP/NY minimizes the scope and appeal of militant anti-AIDS activism in the mid-1980s to early 1990s. Some scholars have written about ACT UP/NY without conflating it with the rest of the movement (Carroll 2015); others have moved beyond the conflation (see Gould 2009; Stockdill 2003) to look at other ACT UPs. But popular media still sees ACT UP/NY as constituting all of ACT UP. Mainstream media in the United States remains centered in New York City: a recent story in *New York* magazine, "Pictures from a Battlefield," depicted ACT UP/NY founders "then and now," without any sense that ACT UPs existed outside New York City.[11] ACT UP/NY is also the most "researchable" ACT UP.[12]

In terms of social movement theory, the conflation of ACT UP with ACT UP/NY leads away from important explorations of the coalitional nature of social movements. What does a more accurate picture of the anti-AIDS direct action movement tell us about the kinds of coalitions needed to do direct action protest? Conflating ACT UP with ACT UP/NY portrays the anti-AIDS direct action movement as the project of a singular, vanguard organization rather than an example of real *social movement*. The ACT UPs were a loosely bound coalition of activists who used direct action along with other forms of disruption – and other forms of more routine political action – to make claims on authorities at the local, national, and, at times, international levels. The network of ACT UPs was internally fractured and at times fragile, but members were nevertheless able to coordinate actions *and* retain a measure of control over their participation. My study of ACT UP/LA contributes to the literature about coalitions in social movements and makes three larger points. First, the very way we speak about movements – the civil rights movement, the labor movement, the feminist movement, the anti-AIDS movement – minimizes differences among coalition members and minimizes the different kinds of challenges that coalition members face. As Van Dyke and McCammon (2010: vii) note

[11] David France, March 25, 2012, accessed April 2, 2012 http://nymag.com/news/features/act-up-2012–4/.

[12] ACT UP/NY's files have been made accessible at the New York Public Library (see http://www.nypl.org/archives/894); the excellent ACT UP Oral History Project focuses chiefly on activists who were in ACT UP/NY (see http://www.actuporalhistory.org/). Two recent documentaries – David France's Academy Award-nominated "How to Survive a Plague" (http://surviveaplague.com/) and Jim Hubbard's "United in Anger" (http://www.unitedinanger.com/) also focus on ACT UP/NY, although both filmmakers show ACT UP/NY members acting in concert with participants from other ACT UPs to pull off demonstrations outside the city.

many, if not most, movements are amalgamations of movement organizations. Many researchers assume that movements are simply homogenous social entities … conceptualizing social movements as … coalitional networks allows us to grasp more fully the varied constituencies, ideological perspectives, identities and tactical preferences different groups bring to movement activism.

The ACT UPs as a movement were such a coalitional network. As I discuss at a number of points in this book, ACT UP/LA had a tenuous relationship with the variously named national networks of ACT UPs that coordinated national actions, and it fought with the national network over questions of democratic decision-making and the distribution of resources. Conflating the whole of the ACT UPs with one social movement organization hides exactly what Van Dyke and McCammon advise us to uncover – the complex coalitional dynamics of ACT UP as a social movement made up of a variety of constituencies.

In fact, a number of social movement scholars agree that speaking of the existence of a social movement in the singular is no more than a "grammatical convenience … in reality, movements are much sloppier affairs" (Meyer and Corrigall-Brown 2005: 329). Some scholars have put forward understandings of movements as networks; for them, social movements are unique political formations because they rest on the creation of a new network out of

formally independent actors who are embedded in specific local contexts (where "local" is meant in either a territorial or a social sense), bear specific identities, values, and orientations, and pursue specific goals and objectives, but who are at the same time linked through various forms of concrete cooperation and/or mutual recognition in a bond which extends beyond any specific protest action, campaign, etc. (Diani 2003: 301)

There is further recognition by scholars that the edges and borders of movements are often unclear. New networks of activists and new organizations are formed as individuals with multiple alliances shift their relationships with others, with issues, and with particular groups (Meyer and Whittier 1994; Roth 2008; Saunders 2007).

Second, much of the work that social movement scholars have written on coalitions has to do with how "grammatically convenient" movements affiliate (or don't) with other movements. In other words, scholars tend to focus on when and how individuals in organizations in different movements – defined as "different" on the basis of issues – come together in coalition across difference (see, among others, Agustin and Roth 2011; Beamish and Luebbers 2009; Dixon and Martin 2012; Ferree and Roth 1998; Krinsky and Reese 2006; Mayer et al. 2010; Meyer and Corrigall-Brown 2005; Mix and Cable 2006; Rose 1999; Roth 2010; Saunders 2013; Simmons and Harding 2009; Van Dyke 2003).[13] According to Meyer and Corrigall-Brown (2005: 327)

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[13] For a look at intramovement coalition formation – again with the movement defined by an issue as such – see Staggenborg (1986).

(t)he decision of social movement organizations to join a coalition is akin to the process whereby individuals join social movements, involving an assessment of costs, benefits, and identity. As the political context changes, the costs and benefits are assessed differently and, for this reason, actively engaged coalitions are difficult to sustain over a long period as circumstances change.

Thus, scholars generally agree then that heterogeneity among social movements – of issues, of constituency, of ideology – is a challenge for joint political action.

Third, I wish to broach the question of how heterogeneity or diversity within a social movement organization is also a challenge for actors. Unlike social movements, social movement organizations generally have perceivable outlines and boundaries – in fact boundary-making by members of an organization between themselves and the outside is a key way of mobilizing and establishing collective identity (Taylor and Whittier 1992). Within a social movement organization, members often struggle with negotiating common interests while battling structural inequalities among members that lead to division. To give just one example, Ostrander (1999: 640) has written about how, even in progressive organizations, members engage in active practices to try to prevent structural inequalities from impeding action, such that "gendered and racialized patterns may both be very much in evidence and, at the same time, be regularly and actively challenged" (Ostrander 1999: 640). Silke Roth, in her work on the Congress of Labor Union Women (CLUW), a "bridging organization" (Roth 2003) that sought alliances with other related movements, argued that CLUW needed to use conscious strategies to maintain a collective identity that was "sufficiently broad as well as meaningful to a diverse constituency" (Roth 2008: 215). In particular, Roth emphasized that CLUW's organizational structure provided a means of integrating diverse elements because the group followed the formal, federated, and representation structure of the American labor movement in mobilizing members.

Using a very different template but also relying on structure to manage heterogenous interests, ACT UP/LA and other ACT UPs declared themselves to be coalitions of individuals. The name "ACT UP" itself – "AIDS *Coalition* to Unleash Power – showed that participants intended the group to be diverse in its make-up. ACT UP/NY established a participatory democratic structure of having a general assembly – or "General Body" – make decisions while having committees devoted to members' diverse interests and, less easily, their diverse identities. ACT UP/LA emulated ACT UP/NY's structure of "General Body plus committees" and made participation the sole criterion of membership. ACT UP/LA's founding was, as I discuss in Chapter 2, based on a coming together of a variety of groups working against AIDS and for lesbian and gay rights, and its founders wanted to maintain the new group as a coalition of individuals united by the desire to actively fight AIDS. In practice, the ACT UP/LA's coalition of individuals was maintained by channeling members into committees but also by allowing for participation "only" in the General Body or

"only" at actions The structure that ACT UP/LA used came at a moment of heterogeneity within the larger lesbian and gay community, which had come to tolerate a great deal of diversity in organizing. By the late 1980s, the lesbian and gay movement, organized as it was around constituencies seeking changes in policy, seeking to celebrate identity, and looking for pleasure, had what Armstrong calls a "high tolerance for ambiguity," which helped foster cooperation among its constituencies (Armstrong 2002: 198). In this book, I show how ACT UP/LA's members negotiated the pressures of maintaining unity in the face of real structural differences among members.

THE POLITICS OF PLACE: THE SIGNIFICANCE OF LOCAL FIELDS FOR ACTION

A second contribution I wish to make with this examination of ACT UP/LA, one that dovetails with the coalitional perspective on social movements advocated earlier, is to suggest that scholars pay attention to the politics of place in exploring the actions of social movement participants and the trajectory of organizations. Local histories and relationships among political actors condition social movement activism and mean that actors working in coalition but situated in different physical spaces face different challenges. In social movement studies, scholars have usefully referred to local contexts as social movement *fields*, following Raka Ray's (1999) term. In her work comparing the two different settings for Indian feminist organizing of Bombay and Calcutta, Ray defined "field" as "a structural, unequal, and socially constructed environment *within* which organizations are embedded and *to* which organizations and activists constantly respond" (1999: 6, emphasis in the original). In Ray's view, a field encompasses the other political players – movement organizations, political parties, and state structures – that social movement actors confront. Significantly, a field also has a prevailing political culture, that is, a way that actors make and respond to claims. Political culture can be understood as being both the routine ways that politics is done in a given context and the embodied understandings of politics based on the experience of the founders and joiners of organizations (Roth 2003; Whittier 1997). Ray's conception of activists confronting the local as well as the national helped to bring questions of regional variation to the front of analyses of movements, and the term "field" has been used in social movement studies in a variety of ways to signify the environment that social movement participants act in beyond the organization. Although Ray meant the field to include social movement actors and the political institutions to which they made claims, others, for example, Armstrong (2002), have used "field" to mean the social movement sector itself, specifically that of LGBT organizing in the city of San Francisco. In another comparative work on feminist organizing within a national framework,

Guenther (2010) examines how feminist organizations in different parts of "reunified" Germany constructed different agendas linked to local contexts and political cultures. She makes a particularly strong case for how local histories and local political opportunities shape the character of local feminist organizations.

Following Ray's original definition of a social movement field as an environment for social activism that includes institutions, social movement organizations, and a history of political culture, in this book, I examine how ACT UP/LA operated in a social movement field characterized by features specific to Los Angeles as a metropolitan area: (1) the city as a sprawling urban metroscape of "segregated diversity" (Pulido 2006: 52) and the way that public health institutions were distributed within that urban space and (2) the specific history of lesbian and gay activism, some of it militant, in the Los Angeles metro area. First, as any visitor would know, LA is a huge, sprawling metropolitan area. That sprawl is a relatively recent phenomenon, and the hollowing out of the urban core due to the growth of suburbs is a post-World War II phenomena. Suburbanization in Los Angeles further divided the metro area by race and class. Political geographer Laura Pulido (2006: 34) has noted that while LA's postwar development was triggered by "a tremendous population explosion" and by "massive economic development, particularly in the military and aerospace industries," it proceeded along lines of race and class. As defense companies turned Los Angeles into a "martial metropolis" (Loyd 2014: 7), the new jobs provided opportunities both for people of color – with interned Japanese Americans returning from camps with nothing and no choice but to find new places to live – and for internal white working-class migrants, but segregation deposited them in different neighborhoods,

The "incorporation movement" in LA County further ensured racial and class segregation:

Between 1940 and 1960, almost sixty cities incorporated in the metropolitan area. . . . . [Incorporation] established a geographic base for unequal opportunity, as incorporated cities were able to exert far more control over who lives, entered, and shopped in their communities . . . the reproduction of white privilege was predicated on distancing oneself from the poor and people of color. (Pulido 2006: 34)

These "minimal cities" (Davis 1990: 166) were able to keep the Other – however the Other was defined – out, and they foisted responsibility for municipal functions onto Los Angeles County. At roughly the same historical moment, the federal government passed the 1946 Hill-Burton Act, which allowed for the construction of new public hospitals, with specific provisions that allowed the hospitals to be placed in "underserved" areas. The Act allowed counties and municipalities to justify racial discrimination on the basis of creating geographical "service areas" with racially separate medical facilities. According to Loyd (2014: 38),