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# Art and Social Change: AIDS Activism in Philadelphia

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This paper (February 1997) was an early product of Petty's study of art and social change with a focus on the distinct and varied uses of art in AIDS education, community organizing, and direct action social change strategies. The research culminated in her PhD dissertation: *Divine Interventions: Art in the AIDS Epidemic* (2000), Mary Stuart Petty, University of Pennsylvania.

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# Art and Social Change: AIDS Activism in Philadelphia

## Abstract

This study examines the social and political aspects of the AIDS epidemic through the lens of local arts and culture in the city of Philadelphia, asking these questions:

- What are the social roles of arts production and cultural activities arising in response to the AIDS epidemic?
- Are the categories of AIDS politics, such as treatment activism and prevention activism, or distinctions among infected populations reflected in cultural production?
- Is the concept of a “day without art” relevant only to those who count as artists and to their affluent patrons?
- How have the changing demographics of the epidemic affected AIDS related arts and culture?
- Does art work to communicate to the public information about the AIDS epidemic?
- Can art mobilize people and institutions for social change?

As the study site, Philadelphia provides an opportunity to extend a social and cultural analysis of the AIDS epidemic to an urban area other than New York or San Francisco. And, while Philadelphia’s proximity to New York City affects all aspects of its relation to the AIDS epidemic (and to its entire arts and cultural scene), AIDS-related activism and culture are embedded in the city’s own history and politics and are certainly worthy of study on their own terms.

## Disciplines

Arts and Humanities | Civic and Community Engagement | Social Policy | Social Work | Sociology

## Comments

This paper (February 1997) was an early product of Petty's study of art and social change with a focus on the distinct and varied uses of art in AIDS education, community organizing, and direct action social change strategies. The research culminated in her PhD dissertation: *Divine Interventions: Art in the AIDS Epidemic* (2000), Mary Stuart Petty, University of Pennsylvania.



**Social Impact of  
the Arts Project**

**University of Pennsylvania  
School of Social Work**

**Working Paper #5**

**Art and Social Change: AIDS Activism in Philadelphia**

**Mary S. Petty**

**February 1997**

The syndrome that we now know as AIDS<sup>1</sup>, first diagnosed in men identified as gay, was introduced to the world's news consuming public as a "gay plague." This was not the first widespread representation of gay men in the late twentieth century: the long-standing Western association of homosexuality and artistic sensibility had been given concrete form in several biographies of "famous homosexuals" and, in a confusing form, in plays and films of the late 1970s and early 1980s.<sup>2</sup> By the mid-1980s, the idea that gay men contribute to culture could be a weapon against homophobia . . . or reattached to the idea that gay men's sensibilities are not only decadent but result in disease. Even a cursory glance at the *New York Times* obituaries after about 1987 uncovers stories of designers, gallery owners, actors, dancers and directors experiencing untimely deaths.<sup>3</sup>

The homophobic response to the linking of AIDS and art, via the gay artist, may have helped fuel the right-wing backlash against arts funding, as revealed by the dramatic withdrawal of National Endowment for the Arts' funding for several gay artists. But the elite, liberal members of the art world understood this connection differently. Artists and patrons who saw their world being devastated by a viral disease began using arts fundraising events to make significant donations to AIDS research and service organizations. Explicit expressions of the link between high arts production and the AIDS epidemic became evident in events such as "Day Without Art" and "Art Against AIDS." By the late 1980s, the social impact of AIDS was an increasingly common theme in theater and literature available to both elite and mass audiences. Photography and other visual arts captured images of the sick and dying while graphic artists generated designs—symbols of a new AIDS activism—which moved interchangeably between art catalogs and the streets.<sup>4</sup>

As the 1980s unfolded, accumulating epidemiological evidence indicated that AIDS was not related to identity or cultural class, but to specific practices, albeit ones that often suggest participation in specific social groups. Intravenous (IV) drug users and people of color of all regions and economic classes, but especially people in poor communities, were quickly overtaking middle class, white gay men—the "artists"

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<sup>1</sup>Acquired immune deficiency syndrome (AIDS)

<sup>2</sup>*La Cage au Folles, Victor/Victoria*, etc.

<sup>3</sup>Even though "AIDS-related" illnesses were not named as cause-of-death in obituaries until five years into the epidemic, AIDS-related deaths were easy to decode with the rapidly increasing appearance of young and middle-aged men dying from "pneumonia."

<sup>4</sup>For a description of the New York exhibit, "Let the Record Show," see Crimp, D. (1990). AIDS demographics. Seattle: Bay Press.

most publicly celebrated and mourned--as the central demographic group affected by the epidemic. It was soon clear that while high profile cultural events might be effective in memorializing and raising money for groups that benefited from the early, private sector AIDS service organizations, they would have little impact on the communities of poor people and people of color affected by HIV<sup>5</sup>.

Thus, as celebrity performances and well publicized events called attention to the devastating impact of AIDS on the arts and entertainment world, less visible projects emerged in more ethnically, socially, or politically defined community organizations. Like their more publicized high art analogues, these smaller, often unrecognized AIDS-related art projects and cultural events also interpreted the epidemic, memorialized the dead, documented the lives of those affected by HIV, and even changed social conditions for individuals and groups in poorer or less culturally elite communities.

## **Philadelphia Case Study**

### **Research questions**

This study examines the social and political aspects of the AIDS epidemic through the lens of local arts and culture in the city of Philadelphia, asking these questions:

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- Are the categories of AIDS politics, such as treatment activism and prevention activism, or distinctions among infected populations reflected in cultural production?
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- How have the changing demographics of the epidemic affected AIDS-related arts and culture?
- Does art work to communicate to the public information about the AIDS epidemic?
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As the study site, Philadelphia provides an opportunity to extend a social and cultural analysis of the AIDS epidemic to an urban area other than New York or San Francisco. And, while Philadelphia’s proximity to New York City affects all aspects of its relation to the AIDS epidemic (and to its entire arts and cultural scene),<sup>6</sup> AIDS-related activism and culture are

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<sup>5</sup> Human immunodeficiency virus

<sup>6</sup> A phenomenon which could be called “queer migration,” lesbians and gay men migrate to

embedded in the city's own history and politics and are certainly worthy of study on their own terms.

### **Methods of inquiry**

This working paper reflects upon the context and framework of an ongoing study and discusses parts of the data collected up to this point. The study employs three data collection methods: archival research, participatory observation and interviews. Data collection based on these methods is underway and will continue as the study progresses.

#### ***Archival research***

I began this work by examining the archives in the library of one of the city's largest AIDS service organizations, the AIDS Information Network. Holdings include several collections of national, mainstream media accounts of the epidemic which date back to the early 1980s. Two gay and lesbian newspapers have given extensive coverage to local AIDS politics. Many local groups and service organizations have produced newsletters that are also housed in the library's archives. The descriptive framework, background on the AIDS epidemic, and research questions were developed, in part, through this study of the archives.

#### ***Participatory observation***

During the fall of 1996, I began participatory observation at relevant public events. I joined the AIDS Coalition to Unleash Power (ACT UP) Philadelphia, attended a meeting of the Working Fund Committee (Day Without Art) and participated in AIDS-related cultural events. I also visited Taller Puertorriqueno, a community arts center, where collaborative arts/AIDS education projects have been undertaken since 1988.

The role of ACT UP in AIDS activism is an important focus of this study. Its practices are particularly important to consider because cultural activism and extensive use of graphic and performance art are integral parts of its direct action strategy for social change.<sup>7</sup> The reported demise (or transition, depending on who is reporting) of the group also makes it an important place to examine the effects of historical change in the course of AIDS activism and

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New York City in search of gay community. Accessibility to New York arts and culture is especially easy for those living in Philadelphia, an hour and a half away by train.

<sup>7</sup> See D. Crimp. AIDS cultural activism arose in relation to the cultural politics of postmodern art (1960s and 70s), which had rejected institutional museum art and had embraced appropriation and mass production as legitimate art forms and vehicles for social change. From its inception, ACT UP worked in coalition with artists' collectives and affinity groups—so much so that many of the graphics of groups such as Gran Fury are popularly attributed to ACT UP.

in the history of the epidemic. After learning that ACT UP Philadelphia continues (in the ACT UP tradition) to hold Monday night public meetings, I thought that joining the group would not only contribute important data to the study, but would also be an effective way to learn about AIDS politics and activism in Philadelphia.<sup>8</sup>

ACT UP membership means that I regularly attend meetings, go to some task oriented working meetings and help with various activities. I also participate in actions and demonstrations. For the most part, those ACT UP participants who have extensive knowledge of AIDS issues and activist experience, as well as those who work full time in AIDS service organizations or advocacy groups, provide substantial leadership for the group. As a participant/researcher, I limit my role to that of a novice member and play a minor role in decision-making. I do supportive work and participate in working parties and the implementation of actions. When I take photographs for data collection, I contribute these to the group.

### ***Interviews***

The interview material represented in this paper is based informal communications with people involved in the various projects. The next phase of data collection will include structured and formal interviews with a set of key informants.

## **Art and AIDS in the City**

### **Imagining the city<sup>9</sup>**

The merging of “arts world” and epidemic imagines the city as a place where communities of affiliation link people through identification with disease, political and social disenfranchisement, and culture. A postmodern view of the latter twentieth century imagines an urban landscape full of abandoned-looking spaces, once densely populated by working, dream-pursuing Americans, now inhabited by those who are left behind: an “underclass” of the unemployed and marginalized, the disabled, criminal, elderly and poor.

Perhaps in crossing some well-defined boundary, the view would inscribe other inhabitants: affluent consumers, sexual minorities, and artists who remain in the deteriorating city or migrate there because they desire

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<sup>8</sup> As an activist in Canada, I had been a participant in ACT UP demonstrations against government policies. Almost ten years later, ACTUP was being declared dead by many observers (for example, *A & U Magazine*), but ACT UP Philadelphia still existed.

<sup>9</sup> “Imagining communities” comes from Anderson, B. (1991). Imagined Communities: Reflections on the origin and spread of nationalism. London, New York: Verso Press.

proximity to culture and affiliation. On one side of the city, people live in warehouses; churches are now restaurants. On the other, social institutions have downsized or moved on; some people live on the street. Depending on one's perspective (inside or outside of the imaginary city), this view may be accompanied a demise of "social capital" and a discourse about the need to revitalize civic life and "communities." Although contemporary urban geography is far more complex<sup>10</sup>, this popular representation incorporates an explication of the AIDS epidemic—as confined to "inner cities," to queers/artists/drug addicts, and to people of color—and works to distance it from the "general population."

### **Imagining communities**

A loose grouping of activists, service providers and people living with HIV and AIDS (PWHAs)<sup>11</sup> form what may be called an "AIDS community." Support networks or communities of affiliation are often generated by contacts with service organizations, medical institutions, or by individuals' proximity to each other in relation to these. An AIDS community is a decidedly urban configuration,<sup>12</sup> although PWHAs are not exclusively urban dwellers; many who live in rural areas, suburban communities, or small towns often seek services and affiliations in a nearby city's "AIDS community."

The construction of a PWA community, as those who are HIV infected or diagnosed as having AIDS, suggests that infection with HIV levels other kinds of social and cultural differences, that the members of such a community hold in common some cultural identity.<sup>13</sup> In addition to common experiences of disease, people who are HIV-infected are likely to share a sense of oppression and social isolation.

Linked through common cultural interests, vocational pursuits, or a need for audiences, artists may also be bound together socially and ideologically, perceived by others as "unique" or "gifted." The popular conception of the "artist" is bohemian, odd, and inclined toward subversion. Large cities are magnets for aspiring artists as well as experienced and

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<sup>10</sup> See Stern, M.J., Social Impact of the Arts Project, Working Paper #3, Re-presenting the City: Arts, Culture, and Diversity in Philadelphia (February 1997).

<sup>11</sup> People living With HIV and AIDS (PWHAs)

<sup>12</sup> An extensive AIDS community in cyberspace as well as networks of activists, such as ACT UP, transcend local and nation boundaries.

<sup>13</sup> The idea of affiliation and identification around illness became popular during the 1970s self-help movement and was consolidated around the HIV epidemic in this notion of an "AIDS community."



accomplished ones.

### **AIDS: imagining the infected "other"**

The first cases of what we now know as AIDS appeared in the early 1980s. During the following decade and a half, the AIDS epidemic was constructed through epidemiological understandings of HIV: the categories of people who were infected and who carried this diagnosis, the modes of transmission, and the presumption of ultimate fatality after infection. AIDS diagnoses were most prevalent among homosexual men, followed by intravenous drug users and Haitians.<sup>14</sup> Although the boundaries of "risk" have, at various junctures, been enlarged to include (or narrowed to exclude) other categories of people, the demarcation of an "infected other" has endured. "AIDS information" marks the "general public" as "uninfected" and different from those in the "risk categories." They are presumed to be heterosexual, "normal," and are only at risk when they transgress or are lured into a world of the "infected." Periodically disseminated to this public, "AIDS information" either warns them about HIV "spreading to the heterosexual population" or lulls them into complacency.

Over the course of the epidemic, categories of the "infected" have fragmented and multiplied. The original "homosexual" category has dispersed into specific (explicit) categories of gender, sexual practices and lifestyles, and into (implicit) categories of social class, status and race. The presumably "heterosexual" public is introduced to the respectable (monogamous) gay lawyer, easily distinguishable from the young HIV-infected black man from the "underclass." The question of who to blame for the epidemic has become more complicated.

Media representations of AIDS (and AIDS "carriers") invite the "general public" to watch various knowledge communities debate the social problem of AIDS. This audience is imagined to be outside of the debates: as *not* HIV-infected, *not* directly affected by the virus, *not* the privileged holder of scientific knowledge and *not* the policy maker. Media representations, then, explicate the "AIDS problem" as that which is truly incomprehensible to the general public: scientific and legal discourse, and lifestyles of the sick and "deviant." The audience as "general public" can be persuaded, as the need arises, to be sympathetic to victims, to protect themselves, and to accede resources to fight the epidemic.<sup>15</sup> The public is portrayed, on the one hand, as innocent, unaware, and in need of protection. Yet, although removed from the front lines of the epidemic, the public is presumed capable of informing the

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<sup>14</sup> The category of Haitians was eventually dropped.

<sup>15</sup> The Chicago Tribune (April 26, 1987).

political process through representation, of having its wishes regarded through the production of laws and policies.

As the interstitial site of sexuality, health and morality discourses, the social problem of AIDS link problems of public health and medical knowledge with problems of morality and sexuality. Because HIV is "sexually transmitted" through "bodily fluids," AIDS becomes a "social disease." Social policy debates draw as evidence epidemiological assumptions, social beliefs and moral positions. Among the manufacturers of the debates are medical and social scientists, cultural and ethical critics, juridical authorities, and politicians who articulate the social and economic problems characteristic of the epidemic. Medical science produces knowledge such as "viral transmission through sexual contact and exposure to infected blood." Legislators pose and attempt to resolve conflicting public interests, forging policies and law. The virus is theorized and measured, its impact analyzed; experts argue about resource allocation and control measures.

## **Response to AIDS**

### **Activism**

The 1981 news reports of a previously unknown, infectious disease among gay men in San Francisco prompted a rapid response from an informal network of individuals and organizations known as the "gay community." Throughout the first decade of the epidemic, community-based AIDS organizations and groups proliferated and grew.<sup>16</sup> In contrast, existing health service organizations and public institutions initially failed to respond to the crisis, even when empirical evidence suggested rather straightforward policy initiatives which would have addressed the spread of infection.<sup>17</sup> Policy observer Ronald Bayer suggests that grassroots organizations and activist groups played an unprecedented role in policy agenda setting and change—so much so that they are the major source of information about the social organization of the epidemic.

AIDS-related organizations are usually defined by their focus (direct medical and social support services to individuals, research or education) and by their institutional structure (public agencies, private agencies, non-

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<sup>16</sup> In 1983, an estimated forty-five groups had formed in the US, and by 1990 there were over six hundred. See Bayer, R., & Kirp, D. L. (1992). The United States: At the center of the storm. In D. L. Kirp & R. Bayer (Eds.), AIDS in the industrialized democracies: Passions, politics, and policies, 7-48. New Brunswick, NJ: Rutgers.

<sup>17</sup> For example, targeted safe sex information, clean needles, etc. For an analysis of existing institutions' responses to the epidemic, see Perrow, C. & Guillen, M.F. (1990). The AIDS Disaster: the failure of organizations in New York and the nation. New Haven and London, Yale University Press.

governmental organizations, self-help groups, voluntary associations). Both the literature on organizational responses to AIDS and the literature on AIDS-related social movements draw distinctions between types of organizations and between organizational missions. Some AIDS-related community based organizations are understood to be altruistic, their primary goal being to offer support and assistance to individuals, not to challenge the status quo. Others are understood to be "activist" and to have an explicit social change mission.

Both in theory and in practice, these distinctions are ambiguous. The social construction and historical location of the AIDS epidemic politicizes altruistic support which, for some, can then be understood as activism. Some observers mark the appearance of ACT UP in 1987 as the advent of radical activism while others point to the early grassroots, community organizing in the gay community, including gay bars, as distinctly radical and activist.<sup>18</sup>

A retrospective mapping of the AIDS epidemic thus far—scientific discoveries, policies, politics, and changing demographics—brings us to the present, when the introduction of new pharmaceutical treatment strategies has generated a surge in publicity about the promises of life after HIV. While many activists and PWHAs are optimistic about these breakthroughs, they are also worried about limited access to treatments and about a media-fed perception that the epidemic is over.<sup>19</sup> At the same time that an increasing rate of infection is appearing in groups with poor access to health care—for example, women of color and their children, the funding cuts under “welfare reform” will severely limit medical treatment and research money. While they continue to pressure pharmaceutical corporations about drug pricing and accessibility, activists must now also contend with multi-level government policies that severely limit or reduce health care resources for poor people.

## **Arts and culture**

Literature, visual arts, and music—not only in their “high” forms but in myths and rituals—explicate as well as maintain the beliefs and practices of a society; they can also work to document social phenomena or to change social life. Artistic response to the AIDS epidemic has ranged from popular American films and major gallery exhibitions to local memorials for those

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<sup>18</sup> For a discussion and various accounts of the development of AIDS activism, see Patton, C. (1990). *Inventing AIDS*. London: Routledge.

<sup>19</sup> The new combination of drug treatments appears to have the potential to transform AIDS from a terminal illness to a chronic one, but annual cost is at least \$20,000 per person.

who have died. Rituals associated with religion, candlelight vigils, shrines and naming of the dead have become widely recognized cultural practices of the epidemic. Visual AIDS (“Red Ribbon campaign”) and the Names Project Foundation (AIDS Quilt), make explicit and directed conceptual links between the arts and the social impact of the epidemic. The Quilt, arising from American folk tradition, has come to be a global symbol of American cultural response to AIDS. These cultural symbols and events--such as display of the quilt or wearing of red ribbons--have received much public support; they often associate prominent, celebrity personalities with education and fundraising efforts, making the cause more "acceptable" to the general public.

The epidemic has also inspired a proliferation of literature, almost a new genre, in which HIV and the AIDS epidemic are themes. It has invoked artistic response from people, including those who are living with AIDS, who had never considered themselves to be "artists." Much of the artistic response to AIDS has grown out of the experiences of the people who are most affected.

Cultural activists have responded to the AIDS epidemic within the context of postmodern tendencies to merge art and politics. Groups such as Gran Fury, a New York collective of AIDS activists/artists, produce art for direct action campaigns. Douglas Crimp describes this cultural activism as an "engaged, activist aesthetic practice"—art becomes “horizontally” linked to everyday social life, facilitating or demanding a community response to a social crisis. At the same time, AIDS cultural activists understand that inadequate or nonexistent public funding for community-based AIDS organization or research necessitates “vertical” relationships (cultural elite providing charity to the “unfortunate”) to the art world as well.<sup>20</sup>

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<sup>20</sup> See Crimp, D. (1988). AIDS: cultural analysis/cultural activism. In D. Crimp (Ed.), AIDS: cultural analysis/cultural activism. Boston: MIT Press.

## **Discussion of Preliminary Data: Art and AIDS Activism**

### **ACT UP**

ACT UP New York arose in the spring of 1987, seven years into the AIDS epidemic. AIDS activist/playwright Larry Kramer appealed to a New York gay/lesbian activist audience to form a group devoted to direct action response to the AIDS crisis in New York. Activists and PWHAs saw that the energies of community-based AIDS service organizations were depleted by caring for people with AIDS and seeking funding for their programs, leaving little for social change struggles. Kramer and others believed that the Reagan administration's lack of response to the epidemic, New York City policies that ignored the extent of the crisis, and lack of access to drugs were conditions which called for direct action by people who could focus exclusively on calling the crisis to the attention of the public and pressuring governments to change policies.

The new AIDS Coalition to Unleash Power (ACT UP) became the direct action group that would collaborate with cultural activists and inject new energy into skillfully coordinated AIDS organizing. The work of visual/graphics artists/activists, most notably the "Silence=Death" graphic, had already begun to appear around New York City. Affinity groups sprung up rapidly in other cities and a network of activists began staging demonstrations and committing civil disobedience in an effort to mobilize for change.

### ***Activism***

ACT UP membership has changed over the decade of its existence, in part because many of its gay male members died. Present groups are more diverse and have increasingly attracted women and people of color. Some members say that there are now only three consistently active and viable affinity groups—New York, San Francisco (known as "Golden Gate") and Philadelphia, with Philadelphia being one of the more racially diverse groups. Information about existence and viability of ACT UP groups varies greatly depending on perspective and proximity to AIDS activism.<sup>21</sup>

Most ACT UP members identify themselves as treatment activists, and make distinctions between "treatment" and "prevention" activities. This distinction, articulated in the formation of ACT UP and in the activities of affinity groups, meant that ACT UP would purposefully focus on the needs of PWHAs, or as an ACT UP slogan said, "drugs into bodies." This position has not excluded advocacy for prevention policies, always an integral part of AIDS activism, but has strongly emphasized the treatment needs of those who are infected. In particular, treatment activists would fight against policies

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<sup>21</sup> The current issue of POZ, a glossy, consumer oriented magazine for PWHAs, declares that ACT UP Philadelphia is dead—this issue's cover story is about the 10-year anniversary of ACT UP's beginning.

based on the perception that the epidemic can be “contained” and that those who are already infected can just be written off. They take a vehement stand against the bifurcation of “innocent and guilty victims”—the treatment of gay men and drug users as being necessarily different from that of people who were infected through transfusions. Another slogan of ACT UP reads, “all people with AIDS are innocent.”

ACT UP Philadelphia holds advertised, public meetings every Monday night at a church in Center City and follows those by another night of working group meetings where plans and actions, decided upon at the weekly meetings, are carried out. The meetings are democratically facilitated while activities are informally directed by a core group of experienced activists, some of whom have AIDS-related day jobs. In the ACT UP tradition, committees work to stay apprised of the latest treatment developments, policy developments and government decisions at every level that affect PWHAs. This information is passed on to other members at regular meetings or at specific “teach-ins.”

Brainstorming is an important planning strategy in ACT UP meetings. Everyone present is encouraged to come up with ideas, inchoate and spontaneous, for an action, demonstration or zap. These uncensored ideas, often recollections of past ACT UP strategies, are recorded as multiple courses of action; only after everyone’s ideas have been heard does discussion and evaluation of ideas-as-proposals take place.

ACT UP takes on many aspects of the AIDS crisis and opposes many policy decisions at every level of government. Often demonstrations, zaps, and actions are organized hastily since ACT UP strategy is to respond swiftly and pointedly to critical situations like policy decisions or drug company practices. Sometimes these events come together well, perhaps due to the experience and commitment of activists involved. At other times, the events bear little resemblance to the slick, highly organized zaps (for example, the Wall Street demonstrations in New York or the storming of the Food and Drug Administration) which made ACT UP famous.

### ***Direct action strategies and the arts***

The observations for this study have focused on how ACT UP uses art—in particular, the symbols and strategies for conveying messages effectively. Brainstorming, used for getting ideas on the table for all manner of decisions about direct actions and ongoing strategies, often focuses on making activist art—props for demonstrations and zaps, slogans that will engage, images that will linger and multiply their force by attracting the media. Many meeting participants are aware of how this works and are quite skillful at making performances, images and words that will carry a message artfully. Thinking up slogans and chants seems to inspire and encourage the efforts of group members, despite the dire circumstances calling for these strategies.

The strength of an ACT UP slogan or graphic often lies in its clear and

poignant message. An appropriated media phrase or quote from a public official imposed on a striking visual image inspires questions that can then be addressed by activists. Probably the most notable, and one of the earliest, graphics associated with ACT UP is “Silence=Death” printed over a pink triangle. When the graphic first appeared, gay, lesbian and AIDS activists immediately recognized the symbol. Others would be compelled to ask and the message would be effectively disseminated, reinforced by mass distribution of the graphic on stickers, banners, posters, and T-shirts. An especially useful skill developed by ACT UP members was the making of “fake badges” and other credentials that allowed access to otherwise restricted meetings and offices.

***The Names Project/AIDS Quilt.*** At the time I entered the group, a demonstration (coordinated by the national network of ACT UP groups) was being planned in Washington DC at the same time that the AIDS quilt would be on display. The first demonstration would be against a pharmaceutical company lobbying organization and was aimed at drug pricing issues. The other was a march to the White House where the ashes of dead AIDS activists would be dispersed on the lawn as both a memorial action and one which symbolized opposition to federal policies.

The present direct action strategies of ACT UP frequently derive from a rich tradition of demonstrations and actions, many of which have been recorded on video tape. Action strategies emphasize making the point with clarity and the use of highly visible drama, graphics, and props. Prior to the Washington actions associated with an AIDS Quilt celebration (see below), a teach-in at the regular meeting included a video of an earlier demonstration which had employed similar tactics. Those who were new to ACT UP could be inspired and instructed about what to expect.

The reaction of treatment activists to the widely “celebrated” display of the quilt as a massive public event, while not discussed extensively at planning meetings, was embodied in the replication of Mother Jones’ saying: “honor the dead, fight like hell for the living.” While the Names Project organization and its national quilt display were not being targeted by the demonstration, concerns about the symbolism of a monumental display which, for some, implied disproportionate efforts toward memorializing the dead and concomitant lack of resources toward treating the infected living. The Names Project’s tradition of reading of the names of the dead allowed the prominent appearance of government officials who consistently fail to support important AIDS-related policies. Drug companies, for which the regard for the life-saving needs of PWHAs has often been secondary to profit motivation, were permitted to set up promotional booths alongside the quilt display.

***“Health Choices” demonstration.*** In November 1996, ACT UP planned a demonstration as part of an ongoing action to stop the state from imposing its Medicaid-managed care program (Health Choices) on people

with HIV until their special needs had been adequately addressed.<sup>22</sup> Brainstorming had generated the suggestion of tombstone shaped posters—a traditional ACT UP visual symbol of life-threatening policies—which would convey a message about the consequences of Health Choices for people with HIV as well as actions the federal government should take in order to remedy this situation. Later in the week, the working meeting was devoted to making the props and telephoning other community groups, individual supporters and the local press, to inform them about the demonstration. A cardboard coffin from the prop archives was repaired and called into service once again. Most of the slogans and messages produced by ACT UP ten years ago are still applicable and relevant, or at least easily adaptable to local contemporary issues—obviously, policies which cause the death of PWHAs remain an important theme. Other community groups and organizations, as well as individual supporters, were telephoned and told about the upcoming demonstration.

On the day of the demonstration, we assembled on Washington Square and then marched across Independence National Historic Park to the Liberty Bell pavilion (often used in Philadelphia as a site for demonstrations). Demonstrators carried tombstone shaped foam core posters with slogans and messages directed to the federal Health Care Financing Administration (HCFA)<sup>23</sup>. The “delay enrollment” directive was later printed on pins worn in a meeting with representatives of HCFA. Various community organizers and several ACT UP members made speeches about the problems related to mandatory enrollment in Health Choices. These were followed by the performance of a “die in” –another ACT UP tradition used to symbolize any practice or policy which threatens the lives of people living with HIV.

***Day Without Art.*** In 1988, Philadelphia artists and AIDS activists organized a three-day, multidisciplinary arts event as a tribute to artists who had died and those who were living with HIV and AIDS. “Our Living Legacy” was probably one of the first of this type of observance to be held during the course of the epidemic. Some of these artists subsequently organized the Working Fund for Philadelphia Artists Living with HIV/ AIDS<sup>24</sup> and this group, collaborating with local cultural institutions, organized a local

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<sup>22</sup> The Health Choices plan results from multi-level policy planning and health care resource rationing. While the state legislated the plan, it was imposed through federal policies that limit state budgets for medical assistance plans.

<sup>23</sup> Health Care Financing Administration handles administration of federal health care programs. In the case of Medicaid programs, administered at the state level, the federal agency can grant state “waivers” which change the rules. The change from fee-for-service to managed care requires a waiver, and HCFA can grant or withdraw the waiver, depending on the state’s compliance with certain requirements.

<sup>24</sup> The Working Fund organizes Day Without Art events and also gives grants to artists living with HIV.



following of a tradition known as “Day Without Art.” Organizers describe the day as a tribute to the lost talents of artists who have died of AIDS, usually in the prime of their careers.<sup>25</sup>

The 1992 local filming production of Jonathan’s Demme’s *Philadelphia* coincided with World AIDS Day events. The Day Without Art tributes, as part of World AIDS Day, featured some of the celebrities associated with the film. The theme for “day without art” was symbolized by a graphic--“loss/life”--imposed on the image of a black umbrella over another image of a crossed out picture frame. Local cultural institutions, coordinated by the Philadelphia Museum of Art and the Working Fund, participated in the day’s events in a variety of ways including the draping of works of art and the exhibition of works with AIDS themes. Processions of people carrying black umbrellas walked from various museums in the city and arrived at a park in the city where there were performances and speeches by local politicians, activists and cultural leaders. The black umbrella was said to be, not only a symbol of society’s blindness to issues dealing with AIDS and HIV, but a symbol of hope and unity in the fight against AIDS.

**1996 World AIDS Day.** Prior to the 1996 World AIDS Day events, a member of the Working Fund Committee came to an ACT UP meeting to announce the Day Without Art events schedule and to determine what ACT UP’s role would be this year. Traditionally, ACT UP has performed the symbolic draping of the “LOVE” statue with a black shroud. During this and subsequent meetings, members discussed plans for the group’s role in 1996 events. Much of the discussion focused on the World AIDS Day 1996 theme, “One World, One Hope.” Members pointed out that the theme belied the reality of a global AIDS epidemic in which treatments for most infected people were completely inaccessible and in which even the basic necessities for prevention were unattainable. Therefore, many felt that ACT UP should appropriate the slogan, address its misleading representation, but in doing so, be careful not to trivialize the situation of more affluent people who are living with HIV. This led to suggestions of visuals of the globe and banners and script explicating facts about the global epidemic.

In an effort to bring new and critical focus to its actions at this event, ACT UP decided to forego the performance of draping the statue even though this tradition would be continued and performed by someone else. One member pointed out that for many people, Day Without Art is the only AIDS-related public event in which they participate annually, and that some use this time for grieving or memorializing people who have died. ACT UP should respect this function while, at the same time, focus on disseminating simple and direct messages about pressing AIDS issues. Some members were critical

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<sup>25</sup> Descriptions derived from study of Working Fund archives as well as conversations with several members.

of the purpose and promotion of the public event; for example, that it addresses the sensibilities of “Main Line” ladies, who are more concerned about the disappearance of art than about the AIDS crisis. ACT UP’s public presence at the event, however, would be collaborative and supportive.

The slogan, “Day Without Art” was critiqued in terms of its relevance to the AIDS crisis, in particular, the critical lack of access to treatment faced by poor people with HIV. Hence, “Day Without Health Care” was suggested as a slogan to use during the event. Clearly, for some participants, the survival issues of people living with HIV are somehow trivialized by a concern for “art,” which in this context seems a luxury. Although not stated explicitly, this anger appears to be directed at a particular kind of art, perhaps at the people who fear a loss of art more than the loss of life and health associated with the epidemic.

Finally, immediately following Day Without Art events, ACT UP decided to launch a direct action against the government official in charge of public welfare (and involved in the implementation of Health Choices). Participants were encouraged to join the demonstration at the residence of the official. A large banner, reading “RAGE” and appropriating the artistic arrangement of “LOVE” from the famous sculpture, was draped across the front of the house. Local media coverage of the demonstration was ensured by the fact that the press were already present at the World AIDS Day event prior to the demonstration. Despite the differences in activist ideologies associated with “Day Without Art,” the events of December 1 were collaborative and achieved a substantial amount of public recognition.

### **Community arts and AIDS education**

The distinction between “guilty victims” and “innocent victims” of the AIDS epidemic is represented, to a certain extent, in the goals of many prevention campaigns. During the mid-1980s, when public fears of AIDS “spreading to the general population” (meaning heterosexual transmission), prevention goals were often framed in terms of these fears: how could heterosexuals protect themselves? Along with this trend went an implicit disregard for persons in the “high risk” groups, but also disregard for those who were already infected with HIV—indeed those who were “innocently” infected before AIDS and HIV were discovered.

“Treatment activists,” such as ACT UP groups, focused their efforts on those who were already infected or diagnosed as having AIDS, fighting against “containment” policies which some conservative politicians and leaders advocated and which, for some, could be considered prevention tactics. Treatment activists were also concerned with research and drug access and development. Prevention activists and most well-informed public health authorities focused on stopping the spread of HIV. Many prevention activities

focused on particular groups of people who were thought to be especially vulnerable to infection and in need of special education efforts. Of course, the work of many activist groups and service organizations addressed both prevention and treatment, and most individual activists would not limit their goals to one category or the other.

### ***Taller Puertorriqueno***

For some communities and marginalized groups whose rates of HIV infection and AIDS-related death were rapidly multiplying, distinctions between prevention and treatment activism did not make sense. Community specific education and cohesive organizing efforts were needed to address the AIDS crisis within distinct ethnic, racial and income groups. Taller Puertorriqueno, an arts center serving the North Philadelphia Latino/Puerto Rican community, has been involved in AIDS prevention education and advocacy for nearly ten years.<sup>26</sup>

In 1988 a Taller board member who was also an AIDS activist/artist, inspired by the Names Project quilt displayed that year in Washington DC, suggested that the center coordinate a quilt-making project. Local artists and AIDS educators would organize the quilt-making sessions with community members. The board member knew of a community woman whose son had recently died from an AIDS-related illness. Because the woman was unsure about how others would react to her situation, she had been afraid to continue going to her seniors' group at a local center. Part of the project's plan involved holding the quilt-making sessions at the seniors' center and supporting this woman's continuing participation there.

At the conclusion of the quilt-making project, the seniors spoke about the meaning of the quilt panels and how awareness of AIDS would contribute to saving the youth of their community. The following year, at a candlelight service held by Taller, community members of varying religious traditions and representing a range of ages and interests participated in what was described as a "coming together" around this crisis. The seniors' quilt-making project was followed by banner-making workshops with school kids and later by a poster-making project in the schools. Most recently, a banner-making project involved other community organizations as well as collaborating artists and AIDS educators. The results of this project are magnificent banners on display outside of the community centers and organizations.

Most of the quilt panels resulting from the original project have

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<sup>26</sup> Descriptions of these projects derive from conversations with Johnny Irizarry, director of the center, and from a videotaped documentary of the first project.

remained in the community rather than joining the Names Project national quilt. Community members and leaders of the project felt that the need to educate within the community warranted keeping them there and circulating them locally. As one participant pointed out, the quilt panels spoke directly and specifically to this community's grief and compassion, serving as visible and continuing reminders of the epidemic.

### **Continuing the Study of Art and Social Change**

The distinct and varied uses of art in AIDS education, community organizing, and in direct action social change strategies will continue to be the focus of this study. Through participatory observation, archival document searches, and interviews, I will pursue the questions that initially launched the study, adding to or modifying these as a result of data analyses.

The next phase of the study will involve a set of formal, structured interviews with a variety of key informants. Interviews with individuals who developed or worked on a project, such as Taller Puertorriqueno's AIDS quilt, will disclose community members' understanding of the need for memorial and other projects and their assessment of the potential effects within their communities. Interviews with individual artists who have adopted AIDS-related themes in their work or who contribute their skills to direct action campaigns will describe the ways in which artists understand their own art as a mechanism for social change. Finally, interviews with AIDS activists from a variety of groups throughout the city will uncover the ways in which those who do not primarily identify themselves as artists understand the role of art in a social change process.

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**Mary S. Petty**  
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