

# The AIDS Quilt Text(ile)<sup>1</sup> Now: Tensions Between Memorialization and Activism

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## Introductions

I sat surrounded by loss. And beauty. The austere and reverent mood in the stone building that had once been a Roman Catholic Church was infectious. Outside, in York's cobblestone snickleways, the sun was shining and maple leaves were turning golden reds and English autumnal oranges. Inside, in the bowels of the old church, the air had a slight chill. It was not surprising to feel cold in this place as mortar and granite memorials formed the foundation of the whole building; testimonials to many centuries' dead made up the church's cobblestone floor. Stained glass windows depicted biblical scenes of judgment and redemption. Melancholy cherub facades and ancient Celtic coats of arms decorated the uneven walls.

York City Council had converted the old church into a cafe and meeting place, now known as the Spurriergate Community Centre. I was in Spurriergate Centre because the local HIV/AIDS service organization I volunteered with (North Yorkshire AIDS Action) was sponsoring a display of panels of the United Kingdom AIDS

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<sup>1</sup> I was inspired by and am borrowing this term from Judy Elsley's essay "The Rhetoric of the NAMES Project AIDS Quilt: Reading the Text(ile)." I am also indebted to Heather Davidson, Jonathan Dollimore, Chris Oakenfull, Alan Sinfield, and Hugh Stevens for reading this essay at various stages. A Killam Postdoctoral Fellowship enabled me to revise the essay for publication.

Memorial Quilt in the building.<sup>2</sup> I found myself sitting in this old church—a testimony to ideals and individuals in itself—one Friday morning, handing out pamphlets about the UK NAMES Project and answering visitors' general HIV/AIDS-related questions. It should have been a relaxing and interactive stint of volunteering. However, I had a difficult time keeping my composure. As someone who has been involved in AIDS work for nearly a decade, on both sides of the Atlantic, I should have been more resilient to the emotional power of the AIDS Quilt. Seeing the panels, hanging from five hundred year old rafters, however, I was overcome with grief and sadness for people I had never met or known. I temporarily lost my ability to see the UK AIDS Quilt as a whole or, for that matter, as activist. All I felt that autumn morning was sadness; I was mourning people whose only connection to me was being affected, in some way, by HIV/AIDS.

I am undertaking a reading of the memorial and, more specifically, my complex reaction to it in this essay, because the AIDS Quilt has been the text that has brought me to the tensions of my own activist aesthetic.<sup>3</sup> I found out that autumn morning in

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<sup>2</sup> The September 2001 exhibition was organized by Chris Oakenfull, a former member of the UK AIDS Quilt organization and, at the time of the Spurriergate display, the Volunteer Coordinator at North Yorkshire AIDS Action.

<sup>3</sup> As I have written elsewhere (see particularly Davidson 2003), my understanding of the term "activist aesthetic" comes partly from Steven Kruger's work on representations of AIDS. In the final chapter of his groundbreaking *AIDS Narratives: Gender and Sexuality, Fiction and Science*, Kruger subtitles his last section "Toward an Activist Aesthetic?" (294). He describes how in Sarah Schulman's 1990 novel *People in Trouble*, a narrative tension arises between the characters' political organizing and "the artist's claim that art in and of itself does political work" (298). Kruger says, "*People in Trouble* also does political work, and not just in helping its readers 'decide to take action.' As Schulman's novel itself repeatedly suggests, language, representation, and narrative do matter" (300). Kruger argues that Schulman's novel is both art imitating life and life imitating art, as it becomes a self-reflexive exploration of art's potential to make a political difference in the HIV/AIDS crisis. He comes to the conclusion that

Novels like Schulman's intervene in the broader discourses of AIDS, suggest how such discourses often do discredit to the realities of people's lives, and find other language, other narratives that might allow those realities to be differently represented and understood. Such work in rethinking AIDS, while it does not stand in for other, more direct political work, is a necessary way of responding to a health crisis still largely understood in (homophobic, racist, sexist) terms that continue to block an honest and open public discourse on sex

Spurriergate Centre that—as a reader, a scholar, and a human being—I have a need to mourn the people I read, write about, cite, and analyze. This need sometimes seems irreconcilable with my activist impetus to transform loss into empowering motivation. As an HIV organization board member and HIV educator, I try to redirect AIDS-related grief into knowledge, encouraging people to become educated, to take care of our sexual health, and, ideally, to change some of the socio-economic and political inequities that contribute to HIV's increasing global spread. Somehow, in this most recent experience of being near the AIDS Quilt, something in my earlier optimistic thinking about the Quilt's purpose and "work" changed: I felt a sense of sadness and horror about HIV/AIDS that I had not felt in years. While I had spent my time writing, teaching, and interpreting literary and artistic responses to the cultural trauma of AIDS, I had not allowed myself to experience many of my feelings about HIV/AIDS. Even while I could still appreciate and admire the craftsmanship, skill, love, respect, and, indeed, activism that went into each panel, on this autumn morning I could not reconcile the ugliness of death that lay beneath the AIDS Quilt's beauty.

My encounter with the AIDS Quilt, in a Yorkshire church-turned-tearoom, has prompted me to question my own faith in the Quilt as an activist tool and to examine my position within AIDS discourse and AIDS activism in general. This is a realization that is not only painful, but frightening: I worry that if I examine the activist aesthetic of the AIDS Quilt, and my reactions to it, I could discover that I do not completely believe in the power of making, or writing, to repair what AIDS has broken. This essay embodies the hope that perhaps if I can stitch together words, like someone stitching together pieces of fabric for a memorial panel, I can make something that will be a meaningful statement in the "fight against" HIV/AIDS. I am aware that if I challenge the AIDS Quilt as a tool of activism, the whole lexicon and rubric that I have designed for myself through years of careful reading and writing may start to unravel like a worn-out corner of a patchwork. But this is a chance I am going to take, because I think questioning the tools we use to educate and activate

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and safer sex; a real commitment to the health not just of the uninfected but of those living now with HIV and AIDS; and effective health care and education for all. (301)

is crucial to these methods' relevance within the many shifting social dynamics of the AIDS pandemic.

Hence, this essay seeks to use personal experience to introduce, uncover and explore how the AIDS Quilt exhibits its activist tensions in a new era of cultural understandings and responses to the virus and syndrome. The AIDS Quilt has been read as a unique cultural artifact: both a memorial and an educational tool. Before this particular morning in York, my understanding of the AIDS Quilt came from reading essays and viewing panels on the NAMES Project website. Using the work of critics such as Douglas Crimp, Judy Elsley, Katie Hogan and Nancy Roth, and Luis Varela and Scott Lago, I have read the AIDS Quilt's sometimes unbearable representation of loss as a push in the direction of change and activism. I had viewed the tensions between loss and activism within the AIDS Quilt as not only reconcilable, but also as productive and cathartic. When I first started working in the HIV/AIDS field in 1997, the AIDS Quilt represented (to me) a positive, emotive, and artistic response to the darkness of HIV/AIDS. In just ten years since its 1987 display on Washington's Capitol Hill, the AIDS Quilt, also known as the NAMES Project, had grown from a grass-roots memorial made in an "empty market street storefront in [San Francisco's] Castro [district]" (Ruskin 9) to a worldwide phenomenon, with official chapters organized in thirty-five countries as diverse as Canada, England, Thailand, the United States and Zambia.<sup>4</sup> Readers may be familiar with some of the many unofficial revisions and imitations of the AIDS Quilt that exist as a testimony to its perceived power for change. For example, in York, England, the North Yorkshire AIDS Action Group created a large blue quilt covered in white Yorkshire roses (a symbol of the area), with each rose memorializing an unnamed person. In Northern Alberta, Canada, the Edmonton HIV Network revised the AIDS Quilt into a "Living Quilt": a quilted mountain-scene background onto which buttons are pinned indicating the number of years a person has been living with HIV/AIDS.

The AIDS Quilt began not only as a memorial to the dead, but also as a radical monument trying to expose and repair the cultural damage done by AIDS. On the official NAMES Project AIDS Quilt

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<sup>4</sup> Please see the NAMES Project Official website at <[www.aidsquilt.org](http://www.aidsquilt.org)> for information on the AIDS Quilt organization cited in this essay.

website, the organization's stated mission is "to use the AIDS Quilt to help bring an end to AIDS." This is a bold and potentially revolutionary claim, complicated by the reality that in the two-and-a-half decades since HIV/AIDS was first written about in the 6 June 1981 edition of *The San Francisco Chronicle* as simply "a pneumonia that strikes gay males" (4), much has changed in our perceptions and responses to the HIV/AIDS phenomenon. When the AIDS Memorial Quilt was first displayed on Washington's Capitol Hill in October 1987, twelve thousand AIDS cases had been reported in the USA since 1981 (Kinsella 361). The USA was the country most visibly affected by HIV/AIDS. In the present-day, the UN estimates that, at the end of 2001 (when the Spurriergate display was opened to York's public) at least forty million people were living with HIV/AIDS worldwide. The majority of these people are living and dying in Sub-Saharan African countries.<sup>5</sup> Furthermore, according to the UN's figures, there were five million new HIV-infections recorded around the globe in 2001, one-third of them were in people aged fifteen to twenty-four. Although the West is not as affected as other parts of the globe, there were still 75,000 new HIV-infections recorded in 2001 alone (45,000 in North America and 30,000 in Western Europe). To put these new infections in perspective: in 2001 nearly four times as many people became HIV-infected in North America alone, as compared to the total number of American people living with AIDS when the AIDS Quilt was first displayed in October 1987.

Political activism in the West has waned since 1996, as the sense of urgency surrounding AIDS has shifted; in the West AIDS is now widely perceived as something we have "lived through" and as "manageable." In the after-glow of post-protease optimism, the AIDS Quilt starts to look more and more like a memorial not only to individuals lost to AIDS, but to a different era of AIDS, a pre-protease age, when loss meant something different than it does today.<sup>6</sup> While

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<sup>5</sup> UN statistics can be found in the 2001 HIV/AIDS epidemic report available online at <[www.UNAIDS.org](http://www.UNAIDS.org)>.

<sup>6</sup> In the summer of 1996, at the XIV International AIDS Conference in Vancouver, Canada, the family of retroviral drugs, including protease inhibitor drugs, were reported to have the potential to eradicate HIV, or at least make it undetectable, in the bloodstream of some patients. Since then the public perception of AIDS as a plague, as a death sentence, and even as a public health crisis has changed. While

the change in outlook brought about by medical advancements marked an important shift from the fatalistic to the optimistic for some living with HIV/AIDS, a new kind of silence has been imposed on AIDS discourse in the past eight years. Just as Western culture reached a point in our collective and public understandings of HIV/AIDS where people can increasingly talk about AIDS-related deaths without the terror of shame and ostracization negating our right to mourn, we slowly stopped talking about AIDS-related deaths all together, for fear that such talk would curb the hope and overly optimistic faith in the success of new drugs. While AIDS-related death rates have dropped in places where anti-retroviral drugs are available, HIV-infection rates continue to soar frighteningly in the West and around the world.

If the AIDS Quilt is to remain a viable way of memorializing, and, as the AIDS Quilt organizers post on their website, a potential tool of revolution, we need to ask the challenging and difficult question: how can the AIDS Quilt work as a tool of activism today? Furthermore, we need to ask: has the AIDS Quilt become a memorial not only to AIDS-related death, but also to a sense of political urgency in the West to end the AIDS crisis, in both the West and around the globe? HIV-infection rates are increasing around the world, in countries with very different levels of awareness, activist histories, funding for education and healthcare programs, and resources. In the December 2003 World AIDS Day on-line report from the United Nations, it is estimated that *"the global HIV/AIDS epidemic killed more than 3 million people in 2003, and an estimated 5 million acquired the human immunodeficiency virus (HIV)—bringing to 40 million the number of people living with the virus around the world."* Hence, perhaps it has become out-of-date or optimistically naïve to think that an artifact like the Quilt, however important it is as a memorial, could be enough to "end AIDS."

### Textile as Text

I take my first critical point of departure, in contemplation of the questions noted above, from one of two UK AIDS Quilt panels that

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anyone affected by HIV/AIDS knows that anti-retroviral drugs, including protease inhibitors, are not a cure for AIDS, in the words of Andrew Sullivan in his important and controversial essay "When Plagues End," anti-retroviral drugs do signal "something profound in the history of AIDS" (67).

stuck in my memory from the York Spurriergate Centre display. Imagine a panel the size of a grave, three feet by six feet, made of crisp white cotton. It does not have the sensual embellishments, personal details, or quilting artistry that many of the other panels exhibit. Against a plain cotton background read the following words in dark blue thread:

This panel was made for a Friend by a Friend.

The Parents do not want this panel shown anywhere.

The Stigma still exists—Until this changes this panel will remain covered.

A Red Ribbon is not enough.

The Quilt is not enough.

What will it take? Attitudes must change!

This piece of cotton cloth is carefully attached to the UK AIDS Quilt's background with safety pins and, on closer inspection, it becomes apparent that this textual panel is actually a sheet that covers another panel underneath, one we cannot see. The message on the viewable panel expresses what many of us feel, and probably what we are meant to feel, when we see the AIDS Quilt: if cultural attitudes about HIV/AIDS changed, then so too could the individual realities of living with, dying with, and surviving HIV/AIDS. This panel represents a fragility and contingency to the freedom to grieve AIDS-related loss, underscoring that such freedom is not available to us all, equally. This textual panel also draws attention to the fear that the Quilt may not be able to do what it positions itself as doing; that is, the Quilt may not be able to change the attitudes about HIV/AIDS *enough* to change the realities of HIV/AIDS. I am drawn to this self-reflexive panel because it embodies many of my own questions about the NAMES Project and about artistic representations of AIDS in general. This panel prompts us to attend to the tension between personal loss and political hope in the diverse day-to-day realities of the epidemic, and it speaks to the limitations of the AIDS Quilt as a political tool for change. For where does it leave us, as mourners and viewers, when a panel within the very artifact we are meant to invest with revolutionary potential states, "The Quilt is not enough. What will it take?" By covering the "real" panel underneath, this unique text says that, despite the AIDS Quilt's importance as a monument, it is not a symbol that, on its own, is "enough" to "end AIDS," as its organizers may still hope.

Seeing this unique panel-over-a-panel forced me, as spectator, to acknowledge my desperate want to believe the AIDS Quilt's organizers ideal that the artifact can enact "enough" change to bring an "end to AIDS." However, when I found myself sympathizing with and understanding the panel maker's assertion that "the Quilt is not enough," I realized that I no longer believe any one object, memorial, or activist statement can "end AIDS." Perhaps HIV/AIDS is too complex, too intertwined with the make-up of our cultural norms and taboos, and too entangled with age-old cultural questions of desire, fear, and difference to "end." I have come to the conclusion, along with many others, that HIV/AIDS will only "end" once an effective vaccine against HIV is developed, made readily available around the globe, and subsidized to be affordable. This is not to say that medical intervention alone will be "enough" either; it too must be accompanied by cultural and social change. Educators, artists, and activists must continue to do everything we can to continue to challenge the cultural conditions and beliefs that precipitate HIV's spread, we must try to prevent HIV-infection through safer sex education and harm reduction efforts, and we must continue to fight for better services and treatment options for those with HIV and/or AIDS-related illness. The AIDS Quilt may be a tool that can be used to heighten awareness, but we must also ask how it fails to do so, in the hopes that we can better understand the nature of our past, present, and future responses to the changing HIV/AIDS phenomenon.

While the AIDS Quilt is an artifact of activism, it risks equating remembering with activism. In "*Ars Memoriandi: The Names Project AIDS Quilt*," Louis Varela and Scott Lago discuss journalist Michael Musto's suggestion, in a 1989 edition of *The Village Voice*, that the AIDS Quilt should come with a warning sticker that reads, "Don't Feel That By Crying Over This You've Really Done Something For AIDS" (173). Musto's statement may seem cynically harsh, but it is worth considering the impetus behind it. Part of the difficulty in analyzing the AIDS Quilt, and hence, part of its limitation as a tool of real political change, comes from its role as a memorial to individuals. It may be seen as insensitive to suggest that an AIDS Quilt panel should be something "more" than a personal reconstruction or testimony to a lost life, it may be insensitive to imply that this personal representation is not "enough." After all, in his influential essay "Mourning and Militancy (in the Homosexual Community over

AIDS)," Douglas Crimp asserts that the AIDS Quilt works so well as a tool of activism, precisely because "private identity is held up as monumental" in the memorial (7). People do not necessarily make Quilt panels to join or forge a larger political statement; they may do so as an act of remembrance or as a way of working through loss. The AIDS Quilt is a collection of personal reconstructions. It is perhaps a faulty logic that we expect personal memories of the dead, as represented in an individual Quilt panel, to become political just because the cause of death has been made political.

Tensions between the individual and the collective are difficult to resolve in many representations of AIDS. However, these tensions can encourage us to see AIDS differently, to challenge assumptions about the disease, and to question current modes of activism. The NAMES Project is a text, and a collection of texts, that exhibits this complicated dynamic: the Quilt memorializes individuals, but also joins individual bodies to one another, to make a collective body. As Cleve Jones has written in the epilogue to his 2001 biography, *Stitching a Revolution: The Making of an Activist*, "the Quilt is all about the connection between all these different people united in one particular challenge" (248). Everyone remembered in the Quilt has died of AIDS-related causes and this potentially connects them to one another and to the larger identity of a person with AIDS (PWA). The AIDS Quilt, in both its design and political intent, cannot escape the fact that it is both a monument to private identity and a collective body designed for political means.

As viewers of the AIDS Quilt, we must respect the integrity of the reconstructions of people as represented in the memorial. However, in appreciating individual experiences and memories, we must also interrogate how AIDS-related discrimination and HIV-related ignorance relate to public or collective perceptions of sexual, racial, gender and "Other" identities. We must enquire about the differing experiences of those living with HIV/AIDS, and why silence and stigma still surround prevention efforts, HIV-diagnosis, and AIDS-related illness and death. It is obvious to argue that the inequities of Western culture arise from ingrained power imbalances based on identity and difference. In the initial days of the HIV epidemic (historically referred to as GRID, ARC, AIDS, and in 1985, HIV), the long-standing cultural homophobic representations of men who have sex with men as deviant, ill, and threatening to the norms

of patriarchal culture dominated and shaped discourse on the virus and syndrome. Because of the work of gay / lesbian and AIDS activists / artists, this hate and violence has been exposed and has started to lessen, although it has by no means been eradicated (as the panel discussed above illustrates). Furthermore, although men who have sex with men have been the most visible people stigmatized by AIDS in the consciousness of popular culture, people who use intravenous drugs, people who sell their bodies for sex, people who live on "the streets," and people who are not white have also been targeted as "carriers" of HIV/AIDS. Increasingly, people from sub-Saharan African countries are facing HIV/AIDS-related discrimination in their day-to-day interactions and in the representations of the global AIDS epidemic in the West. Cultural stereotypes of difference both allow "mainstream populations" to believe AIDS is not "their problem" and create "risk groups" categories that allow certain people to remain more vulnerable to HIV exposure and infection and AIDS-related death. Part of the tension between individual and community in the AIDS Quilt reflects the fact that people are disproportionately affected by and discriminated against in the HIV/AIDS phenomenon.

### **The Memorialized**

Part of my grief-stricken reaction to seeing the AIDS Quilt in Spurriergate Centre came from the unbearable specificity of many of the panels and the intimacy I felt privileged to access as a viewer. However, the panel that I have discussed thus far covers up the details of a personal life and replaces those representations with a political message. When I viewed the textual panel, I entertained the idea that perhaps I am part of a culture or public that does not even deserve to see these memorials. Perhaps the privilege of seeing such personal and private representations and memories should only be granted to a culture that will no longer tolerate prejudice and will do "enough" to change medical, political, and cultural responses to HIV/AIDS.

Apart from bearing testimony to individual lives, the AIDS Quilt becomes personal or private in both its subject matter and its medium. Part of the importance of celebrating life in an AIDS memorial comes from the fact that cultural views of AIDS have historically implied that HIV/AIDS affects people who are not worth celebrating or remembering. As Judith Butler has infamously claimed in "Critically Queer":

there has been an insistent publicization and politicization of grief over those who have died from AIDS; the NAMES Project Quilt is exemplary, ritualizing and repeating the name itself as a way of publically avowing the limitless loss. Insofar as grief remains unspeakable, the rage over the loss can redouble by virtue of remaining unavowed. (236)

The AIDS Quilt can be read as responding to ACT UP's (AIDS Coalition to Unleash Power) 1987 claim that, in the AIDS epidemic, "SILENCE=DEATH": by naming and memorializing individuals whose lives may have been silenced in particular ways, the AIDS Quilt ensures that their deaths will not be silenced, and, hence, works against their loss being "unavowed." The subject matter of HIV/AIDS also makes the Quilt, at times, unbearably personal: HIV is acquired through the exchange of bodily fluids during sexual encounters, the sharing of syringes, and from mothers-to-babies during the birthing process and/or breastfeeding. These are all private acts that, with the exception of breast-feeding in designated spaces, are constituted as shocking when they occur in public. Centuries of laws and institutions have ensured that these activities or events have been compartmentalized, ostracized, and clinicalized so that their actual occurrence will remain invisible to the public eye. As well, although quilts may seem to be mundane every-day items, they are actually "private" objects. Quilts belong on a bed—a site where intensely personal experiences such as sex, childbirth, illness, and death take place. The AIDS Quilt can be read, then, as a mixed metaphor: it covers, like a blanket, the death of a person, and tries to recover, like a monument, a person lost to AIDS.

Despite its message of loss, the AIDS Quilt does not depict death. As a memorial born from activism, the AIDS Quilt celebrates the life of an individual person. Even though it signifies loss, seeing a panel is not about seeing death. I draw attention to this obvious point in an attempt to understand the anger of people like the Spurriergate panel maker or Musto writing in *The Village Voice* in 1989, and indeed, as a way of pinpointing my own frustration with the AIDS Quilt's positioning as a tool to "end AIDS." Just as cherub facades and ornate gravestones hide the decay and illness of the bodies they memorialize and cover, AIDS Quilt panels rarely present the violence and horror that AIDS does to the individual psyche and body. The NAMES Project is not, as David Wojnarowicz's narrator

envisions in *Close to the Knives*, a pile of corpses dumped on Capitol Hill. He writes:

I imagine what it would be like if, each time a lover, friend or stranger died of this disease, their friends, lovers or neighbours would take the dead body and drive with it in a car a hundred miles an hour to Washington D.C. and blast through the gates of the White House and come to a screeching halt before the entrance and dump their lifeless form on the front steps. It would be comforting to see those friends, neighbours, lovers and strangers mark time and place and history in such a public way. (122)

Wojnarowicz reacts to the disposability of certain people with AIDS by making those bodies literally disposable and disposing of them on the doorsteps of those making them so. This passage may also be read as a reaction to the AIDS Quilt organizers' revolutionary claims. The last sentence in this citation is particularly ironic as the memorial is praised precisely for "marking time, place, and [AIDS-related] history in such a public way." Wojnarowicz's alternative scenario suggests that the AIDS Quilt's covering of death, in order to present life, may occur at the expense of representing the gritty and painful experiences of AIDS. More specifically, Wojnarowicz's passage suggests that political leaders and those at the top of the "pyramids of power" (to borrow his phrase) must come face-to-face, or body-to-body, with the ugliness of AIDS-related death in order for any real change to happen. I may be wrong, but I do not believe Wojnarowicz expects any of his readers to actually undertake his narrator's alternative reality. Nor do I think he wants AIDS Quilt panels to represent lesion-covered, bacteria-laden, tube-punctured, violated, contaminated AIDS bodies. What Wojnarowicz does make us do is think differently about AIDS, culture, and, in the above-passage, how the AIDS Quilt operates as memorial and activist tool. However disturbing, there is a truth to what Wojnarowicz implies in the above citation from *Close To The Knives*: the AIDS Quilt hints at the brutality of HIV/AIDS by presenting loss and then quickly covers it up by celebrating life and memory.

### **The Viewers**

Part of the AIDS Quilt's political importance relies on the fact that it is a spectacle. The NAMES Project website estimates that over

two million people see the AIDS Quilt every year. The AIDS Quilt is a striking, clever, and portable monument that can travel and be seen by many people in various places and contexts. I use the term "spectacle" to invoke Simon Watney's influential essay "The Spectacle of AIDS," published the same year as the first display of the AIDS Quilt on Capitol Hill. Watney identifies the conflict between truth and tabloid in AIDS-related knowledge; he awakens us to the problem that, despite scientific knowledge of HIV transmission and HIV/AIDS in general being widely available, news media and popular consciousness construct HIV transmission as originating from the gay male body.<sup>7</sup> Watney speaks about the highly visible ways the gay male body is presented as a source of fear and contagion, as a body with AIDS. He writes:

[i]n all its variant forms the spectacle of AIDS is carefully and elaborately stage-managed as a sensational didactic pageant, furnishing "us," the "general public," with further evidence of what "we" already "know" concerning the enormity of the dangers that surround us on all sides and at all times. It provides a purgative ritual in which we see the evildoers punished, while the national family unit—understood as the locus of "the social"—is cleansed and restored. (78)

The AIDS Quilt demonstrates another tension when we define it as "spectacle" as it both embodies and combats Watney's important understanding of "the spectacle of AIDS." The AIDS Quilt can be seen as an artifact that enables the "interpellated spectator [to assume s/he] already knows all he needs to know about . . . AIDS." On the other hand, the NAMES Project resists being a "spectacle," as defined by Watney, because it does not restore the "mainstream," "the locus of 'the social,'" and instead "cleans[es] and restore[s]" those who are seen to exist outside that mainstream. The AIDS Quilt challenges ideas of family and the social by using a domestic artifact (associated with frontier resilience) to memorialize so-called undesirables. The

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<sup>7</sup> Watney also writes: "The entire subject continues to be framed by a cultural agenda that is as medically misinformed as it is socially misleading and politically motivated" (72). He further notes: "Epidemiology is thus replaced by a moral etiology of disease that can only conceive homosexual desire within a medicalized metaphor of contagion" (73).

AIDS Quilt names and remembers people who are often seen as existing outside collective bodies of family, and even nation. The NAMES Project tries to change the common perception that representations of AIDS are "sensitive only to the values of the dominant familial truth of AIDS," by privileging individuality and, apart from size, complete autonomy in the content and message of each panel. The AIDS Quilt tries to undo the spectacle of AIDS as it has been conceived in Western media and popular consciousness by presenting "the public" with a different kind of spectacle.

The desperate hope that the AIDS Quilt will "end AIDS" comes not from the Quilt itself, the construction of it, nor even the display of it: it comes from what is expected and what happens after it is viewed. One of the tangible and immediate effects the AIDS Quilt can have is as a tool for fundraising. Cleve Jones told a San Francisco journalist in 1989 that people "come to the Quilt, and they cry, and then they empty their pockets, and then they sign up and get to work. We've seen that over and over" (Elsley 188). While I am sure Jones did not intend to sound cynical, his comments to the West Coast reporter could be read in the same vein as Musto's suggestion for a warning sticker to be slapped on the Quilt: it is not enough to cry, for crying does not mean that one has done anything except react, but crying can be a way to pull on heartstrings and encourage financial donations. Working in the HIV/AIDS field, I am the first to admit that money and fundraising are essential to battling HIV-infection. The money raised by the AIDS Quilt, and other public AIDS Awareness campaigns, is necessary in assisting other HIV organizations and the NAMES Project itself to provide services and education. It costs money and human labour to display the AIDS Quilt. However, when something positions itself as a spectacle, and specifically as a spectacle displayed to generate funds, it also risks becoming a commodity.

Indeed, apart from its important role as a catalyst for fundraising, the AIDS Quilt has also become, in some branches of the NAMES Project organization, such a commodity. During some exhibitions of the AIDS Quilt, viewers are not only asked to donate money to an organization sponsoring the display, but they are also "invited" to purchase AIDS Quilt "memorabilia." When the Online Store Catalogue enables anyone with internet access and a credit card to purchase a piece of the AIDS Quilt "experience," without even

having to view it, we lose what Marx would have identified as the social character of the AIDS Quilt's labour. Commodification takes away some of the power of the AIDS Quilt, its revolutionary potential, that is there when we are intimately engaged and faced with the labour, love, and loss in each panel. Furthermore, when we buy a NAMES Project baseball cap, jacket, keychain, or calendar, we lose the idea that someone laboured over a panel and instead concentrate on the purchased object itself. The sale of these objects not only commodifies the AIDS Quilt, but the objects themselves risk becoming material proof of a consumer's supposed conscientious political sensitivity to the AIDS phenomenon. To be blunt, these objects offer an easy way into AIDS consciousness: why should we look at the causes of poverty-related HIV-infection when we can just buy a t-shirt on-line? I do not want to demonize the individuals who purchase AIDS Quilt memorabilia, as wearing or owning these goods may connect individuals to the memorial in a proactive or cathartic way. However, the fact that these goods are available in the first place must be questioned. When the NAMES Project invites its viewers to become consumers, it compromises its position as a tool of activism. Like the memento identification cards available at The United States Holocaust Memorial Museum in Washington D.C., or recent sales of bricks and rubble in wake of terrorist attacks in New York City, caps and keychains with images of the AIDS Quilt risk becoming souvenirs of catastrophe. Such items encourage us to tour through calamity instead of engaging with it. The AIDS Quilt, and its accompanying industry of memorabilia, creates a situation where we can purge our guilt about our own AIDS-related apathy by becoming good consumers.

It is always difficult to match up idealist views of an equitable world economy with the sad reality that money is necessary to survival. There is a painful reality that money, and specifically lack of money, is socially constructed and orchestrated to affect people differently. As AIDS continues to devastate economically disadvantaged nations around the globe, the connections between poverty and HIV-infection that have existed since the beginning of the epidemic are becoming undeniable. Stuart Hall's catchphrase "the West and the Rest" has become all too real in a present dominated by appalling "Third World" poverty, increasing HIV-infection rates and AIDS-related deaths among people in developing nations and

among economically disadvantaged people in developed nations, and in a world in the grips of unprecedented tactics of warfare targeting civilians. As cultural critics, we must continue to interrogate how all inequities—particularly economic ones—contribute to the HIV/AIDS phenomenon.

Two decades into the epidemic, AIDS remains a disease identified with “otherness” but the definitions of that otherness are shifting. For example, the African continent was once seen as the “birthplace” of AIDS and is now seen as the epicenter of an AIDS apocalypse. Specifically, “the black African woman” has become the most visible body with AIDS in the new millennium. In a December 29, 2002 article in *The New York Times*, United Nations Director Kofi Annan writes: “[a] United Nations report released last month shows that women now make up 50 percent of those infected with H.I.V. worldwide—and in Africa that figure is now 58 percent. Today, AIDS has a woman’s face.” While Western women may be perpetually represented in the role of caretaker, African women are presented as bodies ravaged by AIDS. Since the new millennium, Western media presents the image of a skeletal dark female body lying on a mat in a far-away shack to symbolize the current effects and dynamics of the HIV/AIDS pandemic. Similar to many early Western representations of the white gay man with AIDS,<sup>8</sup> the black African woman is presented as an exposed (often literally naked), voiceless body, passively waiting to die while the world stands by and watches. It is now unacceptable to construct the white gay male body as equaling AIDS, to borrow Watney’s terminology, as “spectacle.” Yet, the black African female body is presented in current media in similarly reductive ways to those early Western depictions of the white gay male with AIDS. When women are presented as caretaker or spectacle, the complicated reasons why we are at increased risk for HIV infection are silenced and our daily lives as individuals living and dying with HIV and AIDS are erased; instead of being represented as complex individuals, we become roles and bodies.<sup>9</sup>

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<sup>8</sup> For an excellent discussion of images of PWAs in the '80s, see Crimp 1992.

<sup>9</sup> How we remember those lost to AIDS and who does the remembering are questions about the AIDS Quilt that are tied to larger cultural questions about the construction and lived realities of gendered identities. I did not have the space in this

While the artifact of the Quilt cleverly domesticates AIDS and makes it a "household" issue, a patchwork quilt is also a Western artifact; hence, how can it do enough to represent the diverse and complicated experiences of AIDS in the new millennium? For example, is Cleve Jones justified in celebrating the NAMES Project's efforts to "encourage Quilt-making and Quilt displays in townships and rural areas across South Africa" (365)? Are there not more culturally meaningful symbols that could be used to foster memorializing and activism among such diverse groups as the Zulu, Xhosa, Ndebele, and Afrikaners? To be more specific, we must ask if the AIDS Quilt really can acknowledge the range of HIV/AIDS experiences or if it is an object already invested with certain cultural meanings that shape its reading and thereby direct its power, or revolutionary potential, to a certain public. Current representations of AIDS, including the NAMES Project, need to build on the work of the past and use current understandings of the globalized pandemic to see how certain patterns of representation and interpretation both hinder and help activist efforts.

### Conclusions, Or Re-reading the AIDS Quilt

There are many complicated problems in how the AIDS Quilt represents the HIV/AIDS phenomenon. Sometimes its presentation of loss overwhelms its political viability or potential for future revolution. However, ultimately, we must read the NAMES Project as a constructive response to tragedy, if we hope to understand both its past and its future. The piecing together, or act of making, displayed in the AIDS Quilt is moving and inspiring. The AIDS Quilt has the unique position of memorializing an event that is past, present, and future. While other memorials carry the message that their dead need not have died and that the event they remember should never happen again, the NAMES Project awakens its viewers to the fact that AIDS-related deaths should not have happened, should

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essay to engage in the debate concerning quilt makers' identities and gender. See Crimp's (1988) and Hogan and Roth's (1998) essays for two very different arguments about "women's work" and the AIDS Quilt. Also see Michelle Cliff's 1990 short story "Bodies of Water" in which quilts become a narrative site where AIDS, women's political resistance, and American history converge. I write about Cliff's story in my chapter in the 2004 book, *Spectral America: Phantoms and the Literary Imagination*.

not be happening, and can be prevented in the future. The AIDS Quilt, as an object and as a text, recognizes the present moment as a continuing state of crisis. The panel that most affected me at the Spurriergate display, asserting that "The AIDS Quilt is not enough," is a remarkable example of the freedom and diversity of expression in the NAMES Project. Very few monuments, carved in granite or erected as an obelisk, dare to question their own purpose. The AIDS Quilt can be a progressive and exciting tool of activism, not necessarily to "end AIDS," but to better understand it, which, ultimately, can change AIDS. The fact that someone can ask and explore multiple questions about the AIDS Quilt's integrity as a tool for activism is a fine example of the Quilt's revolutionary potential: surely if seeing the memorial has made me think and question and want to know more about AIDS, then it has served its purpose of raising awareness. On one level, the analysis within this short essay answers its own question of whether or not the AIDS Quilt is still a relevant tool of raising awareness simply by asking the question and working through a handful of issues facing current HIV/AIDS activism and prevention work.

In her paper "AIDS and the Responsibility of the Writer," originally presented at the 1990 *Outwrite* conference in San Francisco, Sarah Schulman argued, "[t]here is no book that got any drug released, any drug trial opened, or any service provided. Reading a book may help someone decide to take action, but it is not the same thing as taking action" (rep. *My American History* 196-197). I have always agreed with Schulman's point that writing in itself does not replace the work of political demonstrations or fundraising for AIDS service organizations, or prevention education, but I do think that the creative work of writing, in itself, can be activist. A creative work, whether it is a NAMES Project memorial panel, a journalistic editorial, a song, a novel, or a painting can express the sometimes conflicting realities of AIDS activism in a way that day-to-day community work cannot afford to do, in a world of too few resources and too many overworked activists.

I would like to finish this personal essay by describing the second panel that most captured my imagination that autumn morning at Spurriergate Centre. This panel is not confrontational like the self-reflexive one that claims, "The AIDS Quilt is not enough." Rather, this one is a tribute panel to a writer named Joseph Beam. Beam

grew up in Philadelphia and worked as a writer and African American gay rights activist.<sup>10</sup> The UK AIDS Quilt panel to Beam is elaborate and visually stunning; it has a satin background of oranges and blues that surround a portrait photo of Beam. Underneath the photo, the panel maker has embroidered a letter, "Dear Joe," in gilded stitching. Arthur Law, a man living in Brighton, UK, created the panel to Beam despite never having met him. In his written explanation of the panel, which was displayed with the UK NAMES Project at Spurriergate, Law says that as a reader he felt so connected to Beam that he paid this tribute to him. The letter embroidered on the panel reads:

*Dear Joe,*

*I stumbled across your words when I felt like I was dying.  
You dared me to dream as you dared all of us to dream.*

*You gave me back my life. And I risked believing that I  
really could fly, that I really could be strong enough, that I  
would never be alone and that the power of our love really  
is invincible.*

*Your loss is an impenetrable silence.*

*Love, Arthur*

X

Remembering the beauty and hope in Arthur Law's panel to Joseph Beam, during my own process of creating this essay, I felt a slightly renewed faith in the AIDS Quilt's revolutionary potential. Arthur Law's panel reconfirmed my belief that creating, in this case, writing and quilting, have the power to change lives.

In seeing the AIDS Quilt, we bear testimony to loss in the hopes that the acts of remembering and naming the dead will allow us to move forward into a better future where HIV/AIDS is concerned. Just as there are many different panels in the AIDS Quilt, there are

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<sup>10</sup> Beam was the editor of a journal called *Black/Out* and published numerous articles and short stories. He worked at Giovanni's Room in Philadelphia, a major organizing space for gay and AIDS activism in the 1970s and 1980s. Beam is best known for editing a critically acclaimed anthology of black gay men's writings entitled *In the Life* (1986). He was collecting articles for a second anthology when he died of AIDS-related illnesses in 1989. Two of his colleagues, Dorothy Beam and Essex Hemphill, finished editing the anthology and published it as *Brother to Brother* in 1991. Biographical information about Joseph Beam is taken from the "Joseph Beam Papers" available on-line at the New York Public Library's Digital Library Collection. The collection number for the Joseph Beam Papers is Sc MG 455.

many different pieces in any understanding of HIV/AIDS. Individual narratives deserve to be heard even if they do not always “fit” together to make a cohesive statement or answer. Colour and contrast—diversity—are necessary to make a beautiful piece of art, whether it is a textile or a book. Representations of AIDS may have irresolvable tensions, but these tensions can be productive to enacting or even interpreting change. Part of the AIDS Quilt’s uniqueness as a memorial is its mutability: it can change and grow as long as people continue to make and add panels and continue to view it and respond. The NAMES Project’s inherent character of mutability must be used to address the changing nature of the HIV/AIDS epidemic. I will conclude that the AIDS Quilt can remain a relevant and potentially revolutionary tool in AIDS activism—if it is used as a way to generate HIV/AIDS education, and if it continues to uphold the individual life lived and lost as monumental. If the AIDS Quilt is positioned as something it is not—a commodity—or is given an insurmountable task—as a way to “end AIDS”—then its effectiveness as a political artifact will be compromised. The AIDS Quilt is, as the Spurriergate panel maker asserts, not “enough” in the fight against AIDS, but it can remain and continue to be an important artifact and historical document of our responses to HIV/AIDS.

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