

# “Only Your Calamity”

## The Beginnings of Activism by and for People With AIDS

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The invention of AIDS activism came soon after the AIDS epidemic emerged in gay communities in the United States in the early 1980s. AIDS activism by and for people with AIDS, distinct from gay activism responding to the threat of AIDS on the behalf of the whole community, started as a way of resisting the phenomenon of social death. Social death, in which people are considered “as good as dead” and denied roles in community life, posed a unique threat to people with AIDS. An organized political response to AIDS began among gay men with AIDS in San Francisco, California, and New York, New York, formalized in a foundational document later called the Denver Principles. The ideas and language of these first people with AIDS influenced later AIDS activism movements. They also help to illustrate the importance of considering an epidemic from the point of view of people with the disease. (*Am J Public Health*. 2013;103:1788–1798. doi:10.2105/AJPH.2013.301381)

**ALMOST SINCE THE BEGINNING** of the AIDS epidemic, people living with HIV/AIDS have demanded involvement in local, domestic, and international public health policymaking. More recently, a series of declarations signed by world governments affirm the principle of their participation, if not always the practice.<sup>1</sup> People living with HIV/AIDS and their allies have created health activist movements, both local and global, a number of which have persuaded governments and societies to change their responses to the AIDS epidemic.

This global movement emerged originally from the politics of urban gay communities in North

America in the early 1980s. Gay men living with a disease of unknown etiology and sobering mortality faced not only a threat to their health, and the stigma that soon accompanied it, but a phenomenon sociologists in other settings have described as “social death.” Undiagnosed gay men also faced the stigma of the disease, and gay community political leaders soon began trying to combat the problem of stigma on behalf of the whole community. But only people with AIDS faced the problem of social death, and that challenge caused gay men with AIDS to see their agenda as distinct from that of the gay men around them. In the process, they

invented the idea of AIDS activism by and for people with AIDS.

Physiological death is the process by which the delivery of oxygen to the body stops and the body’s organs cease to function. Historically, social death has most often followed physiological death, with the social aspect of death marked by rites like funerals and wakes. But if other people consider someone essentially dead, or “as good as dead,” this creates social death in advance of biological death.<sup>2</sup> Medieval funeral rituals for people with the disease then known as leprosy (now Hansen’s disease) created and enforced the social death of the afflicted person, while also mourning it.<sup>3</sup> Families’ relationships to relatives with dementia sometimes offer a modern equivalent.<sup>4</sup> More subtly, when others make people with life-threatening illness into objects of pity, define their social existence by their predicted death, and ignore other aspects of their personhood, they create the conditions for social death that occurs before biological death.

Much has been written about stigma in the HIV research literature. Social death is not the same as stigma, which can be described in political terms as a mechanism of social control with the effect of enforcing social order.<sup>5</sup> More narrowly, stigma is created by a collectively held belief that a given attribute “spoils” a person.<sup>6</sup> If stigma means that a person is viewed as “not quite human,” social death means that a person is viewed as “not quite alive.” Social death is a specific response to either the occurrence or the anticipation of death. Before biological death takes place, social death may sometimes be imposed on a person thought to be dying; at other times, dying people themselves might create it.<sup>7</sup> Some cultures simply avoid discussion of life-threatening illness as a means of preventing social death.<sup>8</sup> Premature social death can be hastened by institutionalization, poverty, or stigma, which can push the socially dead into “zones of social abandonment”—physically segregated spaces in which the socially dead await their biological deaths.<sup>9</sup>

Although social death and stigma are distinct, the two can become tightly intertwined. Specifically, if living people are so despised as to be wished dead, the prediction of their death is not met with what death scholars describe as “anticipatory grief,” but rather with anticipatory relief. But the distinction between stigma and social death is important, and now more than ever in the era of effective treatment. If a community believes that HIV is a mark of death, people living with HIV/AIDS will be at risk for social death. On the other hand, if HIV infection is a survivable mark of sin, stigma may still attach to the diagnosis,

distinct from the isolation that comes from the anticipation of death. A sex worker on an effective antiretroviral regimen occupies a different position in her community than someone irrevocably marked for death—still precarious, but distinct.

The invention of AIDS activism by and for people living with HIV/AIDS started with the problem of social death, and also from a related tension in the response to AIDS. If the dangers of a medical threat are understated, a community may not mobilize to respond to it. But if mortality becomes the defining feature of a diagnosis, the people with the diagnosis risk social death before biological death. This was part of the social and political environment that caused gay men with AIDS to organize as people with AIDS, rather than acting only as gay men within broader gay community responses to AIDS. Although their initial political activity all took place within the gay community, it eventually influenced the political concepts and tactics of people living with HIV/AIDS around the world, many of whom later faced similar challenges in their own communities.

The movement of people with AIDS had its formal foundational moment at a 1983 conference in Denver, Colorado, with a manifesto later known as the Denver Principles. Described later as “the Magna Carta of AIDS activism,”<sup>10</sup> the Denver Principles called for a new relationship between people with AIDS, their health care providers, and the society around them.<sup>11</sup> Bobbi Campbell, from San Francisco, California, and Michael Callen, from New York, New York, were the de facto leaders of the small group of gay men with AIDS at the conference, and the

two men wrote the document. The influence of their ideas emerged later in advocacy by people living with HIV/AIDS around the world,<sup>12</sup> first in formal associations of people with AIDS and then by people living with HIV/AIDS in roles within broader AIDS activist movements.

### BOBBI CAMPBELL: MAKING THE NEW DISEASE VISIBLE

In the 1970s, a new kind of public gay community had emerged in and around the Castro District in San Francisco.<sup>13</sup> In 1975, a nurse named Bobbi Campbell moved from Seattle,

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Washington, got a job in a hospital near the Castro, and immersed himself in the political and social life of the community. By 1981, he had enrolled in the nurse practitioner training program at the University of California, San Francisco, intending to focus on health care for the lesbian and gay community.<sup>14</sup>

His opportunity to promote health in that community came sooner than he expected, and at an unexpected personal cost. On October 8, 1981, four months after the medical literature’s first description of a new syndrome of immune deficiency in young gay men, Marcus Conant, a dermatologist who would soon become a leader in responding to the new disease, diagnosed Bobbi Campbell with Kaposi’s sarcoma (KS).<sup>15</sup>

For Campbell, who a fellow nurse later described as “politically astute, . . . a mover and shaker,”<sup>16</sup> KS was not only a personal challenge but also a professional and political opportunity. By December, he started writing articles in the *San Francisco Sentinel*, a local gay newspaper, about his experience of what was then often called “gay cancer.” He put pictures of his KS lesions in the window of a Castro District pharmacy,<sup>17</sup> urging men with similar lesions to seek medical attention.

He also immediately saw social and political implications of his condition. As he explained in his second *Sentinel* article, “I had to come to terms with a cancer diagnosis in 1981—a crisis topped only by coming to terms with my homosexuality in 1970.” He continued:

The adjustment process in these two situations was similar. I had to acknowledge to myself that I really was in a particular situation, that I had not chosen to be there, but I could choose what I would do in response, and I especially could decide how public or private I wanted to be.

Gayness, like a cancer diagnosis, is socially stigmatized, and it can be concealed or divulged.

. . . If it never occurred to you that a cancer diagnosis is a ticket to minority status, think again. People have lost their jobs, their homes, their friends, and their lives because of others’ reactions to their illness.<sup>18</sup>

As an experienced inpatient nurse, he had almost certainly witnessed many pre-AIDS variations on the theme. Now as a patient, he started recruiting his “KS brothers”<sup>19</sup> in the KS clinic’s waiting room, for what was then called a “gay cancer” support group. The clinic’s head nurse later recalled his approach:

Bobbi Campbell . . . had started to make himself available at the clinic and say, “I want to meet the patients.” This was not seen as a friendly gesture by the physicians. They thought he was a little off the wall. They also thought he was kind of out of control. I think somebody called him hysterical. He was a flamboyant gay man. . . . But he was also very, very serious.<sup>20</sup>

Campbell and his KS brothers already understood that their disease was not simply “cancer.” But the Shanti Project, which sponsored their support group, had been started before AIDS to support people with cancer. San Francisco’s AIDS doctors’ early focus was on cancer.<sup>21</sup> And even if cancer was frightening, its precedent was useful to Dan Turner, one of Campbell’s early recruits:

My diagnosis was of cancer, not AIDS. . . . I remember thinking in the back of my mind, “Well, some people beat cancer. Maybe I will. . . .” Cancer was the worst thing anybody could say to you before AIDS. And I told myself that’s what I had—cancer. And the stories of people getting over cancer were a little core of hope.<sup>22</sup>

The name “acquired immune deficiency syndrome” came in August 1982.<sup>23</sup> But in the gay community of San Francisco in the earlier months of 1982, the new syndrome was so mysterious and yet such an omnipresent focus of dread that many people simply referred to the disease as “It.” The Shanti “gay cancer” support group’s first communication with the lesbian and gay community noted that people around them had quickly begun to assume that the men with “It” were a distinct group cursed by their past behaviors, whose fates would not be shared by others. The group’s newspaper ad asked the community to stop stigmatizing the men

with the new syndrome:

Brothers and sisters, we understand . . . that by making us different, you protect yourself from “It.” However, despite our understanding of your need to see yourselves as different, we need to tell you that we are not.<sup>24</sup>

### MICHAEL CALLEN: THEORY AS “LIFE RAFT”

In 1982, New York musician Michael Callen received his own diagnosis of AIDS. He tried first to make sense of his situation with a reading list of medical journals, cultural theorists, and feminist critiques of the health care system.<sup>25</sup> He chose a particularly theory-oriented doctor for his health care. Joseph Sonnabend was an infectious diseases doctor in New York’s gay community, with a background in immunology research. He and a small group of his patients—including Callen, who made no secret of his prior active sex life, and Richard Berkowitz, a writer and sex worker—began to believe that the new syndrome was the result of immune overload from repeated sexual exposure to multiple pathogens.

This idea contained hope: if an overload of pathogens caused AIDS, people with AIDS might recover immune function by eliminating exposures. As Callen wrote later,

Whether or not Joe’s multifactorial theory of AIDS ultimately proves to be correct, discovering a different way of thinking about AIDS at such a crucial turning point in my life provided a framework for me to justify believing that I might survive my disease. It was a life raft that kept me afloat in a sea of doom and gloom.<sup>26</sup>

Sonnabend’s theories suggested that the disease was the

result of what Callen and Berkowitz started provocatively denouncing as “promiscuity.” Callen and Berkowitz, with Callen’s lover Richard Dworkin (who did not have AIDS), wrote an essay for the *New York Native* titled “We Know Who We Are: Two Gay Men Declare War on Promiscuity.” They wrote, “We are the gay men who are becoming the victims of AIDS.” And, they said:

We veterans of the circuit must accept that we have overloaded our immune systems with common viruses and other sexually transmitted infections. . . . But in the end, whichever theory you choose to believe [about the cause of AIDS], the obvious and immediate solution to the present crisis is the end of urban gay male promiscuity as we know it today.<sup>27</sup>

Callen and Berkowitz also started a support group called Gay Men With AIDS. In a Gay Men With AIDS advertisement addressing other men with AIDS, they wrote:

WE must care about ourselves; obviously, others—particularly those who advise mere moderation of promiscuous behavior—do not care about us [caps in original].<sup>28</sup>

Callen and Berkowitz’s talk of “promiscuity” won them a reputation among many in the gay community as moral crusaders, victims of internalized homophobia, or even as unwitting tools of a larger effort to remedicalize homosexuality—which only a few years earlier had been a psychiatric diagnosis.<sup>29</sup> But Callen and Berkowitz’s opponents usually missed that they were speaking first and foremost as people with AIDS, concerned about the survival and immunologic recovery of people with AIDS. In strictly biological terms, they thought

changing the community’s sexual ecology would save lives. In social terms, if the disease was survivable, people with AIDS would no longer be “as good as dead.” They were willing to stigmatize “promiscuity”—and to take on that stigma as their own—to survive both biologically and socially.

Both sets of men were trying to reframe their diagnosis, and their relationship to the community. The San Franciscans framed themselves as cancer patients, asked for tolerance, argued that the disease wasn’t their fault, and might not be fatal. The New Yorkers, by framing their illness as the result of ecological conditions favorable to pathogens, described how they had been part of the creation of that ecology, but also pointed back to the rest of the community for the same reason. In very different ways, the two sets of men were arguing that they had a survivable condition, for which they should be neither scapegoated nor mourned.

### NOT PERFORMING BEARS

In the broader gay community, Larry Kramer’s essay “1,112 and Counting”<sup>30</sup> embodied a turning point in AIDS rhetoric, and presaged a later era of AIDS politics. Kramer, a key founder of the New York service group Gay Men’s Health Crisis, had decided that social services and medical research would not suffice; the epidemic required a political response. The essay emphasized the death toll to come and indicted scores of targets inside and outside the gay community for their failures. Its last paragraphs as published in the original *New York Native* version contained a specific call to arms,

urging a campaign of civil disobedience. In San Francisco, the *Bay Area Reporter*, the most prominent of the three gay papers in town at the time, reprinted Kramer’s article. Perhaps in part because the last section mentioned specific New York–based plans, though, it didn’t republish the call to arms—only the despairing and furious words that preceded it.

In a letter to the *Bay Area Reporter*, Bobbi Campbell responded to Kramer’s essay. He agreed with Kramer’s rebuttal of the “promiscuity theory,” and with many of his criticisms of government and the politics of research. But he also disagreed:

Finally—the most telling point!—Kramer says, “I am sick of everyone in this community who tells me to stop creating a panic. . . .”

This is where Larry Kramer and I most fundamentally disagree. Panic causes us not to act, but to react—and not in a rational way. . . . I think that hysteria and panic are as deadly to our community as the disease themselves.<sup>31</sup>

Although Campbell may not have read it, part of the *New York Native* version of “1,112 and Counting” (but not the *Bay Area Reporter*’s version) also highlighted a subtle but important difference in their agendas. Kramer wrote:

Little of what I’ve written about here is likely to be rectified with the speed necessary to help the growing number of victims. But something worse will happen, and is already happening. Increasingly, we are being blamed for AIDS, for this epidemic; we are being called its perpetrators, through our blood, through our “promiscuity,” through just being the gay men so much of the rest of the world has learned to hate.<sup>32</sup>

Kramer's "we" was the gay community. He was deeply concerned with the fates of men with AIDS. But he was even more concerned about the welfare of the gay community as a whole. If AIDS was a mortal threat to the survival of the entire gay community—and it was—then the specific concerns of those marked for death became secondary. The primary issue for him was how the community as a whole would survive. He aimed for community-wide alarm by emphasizing the likely mortality of the new disease.

Kramer's urgency grew out of terrifying epidemiological projections about AIDS that later turned out to be, if anything, overly optimistic. But in 1982 and 1983, with little known about the disease, the men with AIDS who spoke publicly about the disease avoided fatalism. Campbell disagreed with Callen and Berkowitz about the etiology of AIDS, but like them, he viewed AIDS as potentially survivable. As Callen wrote in 1985, "Do not die because everyone tells you that all AIDS patients die. Don't let them take away your will to live and fight."<sup>33</sup>

This was not simply self-affirmation; many undiagnosed gay men at the time were clearly considering whether they would commit suicide if they received a diagnosis, and if so, at what point. In San Francisco, before "1,112 and Counting," the *Bay Area Reporter* had devoted fairly nominal coverage to the AIDS epidemic, and the exceptions were notable: in late 1982 and early 1983, the *Bay Area Reporter* had run two prominent front page stories describing men with AIDS who decided to end their lives, the first by withdrawing care when very ill and the

second by committing suicide after getting a diagnosis of cutaneous KS. Neither man was well-known within the community; the stories were only newsworthy as observations of responses to AIDS.<sup>34</sup> After printing the second story, *Bay Area Reporter* editor Paul Lorch stated frankly that he saw suicide as a reasonable response to an AIDS diagnosis.<sup>35</sup> After Kramer's essay, as Lorch and the *Reporter* began to devote more attention to AIDS, Lorch's editorials maintained this theme: he wrote that "Each man owns his body" and "the way he wants to die," including, perhaps, a "one way walk into the Pacific surf."<sup>36</sup>

Then, while casting doubt on the value of extra government funding, Lorch appeared to refer to the Shanti Project:

Already one crowd has demanded that the mayor come up with tens of thousands for an AIDS victims' house—or warehouse—as would be assumed under the aegis of a crew I wouldn't trust my sick goldfish to.<sup>37</sup>

Campbell and 21 other men with AIDS responded to this editorial, and his overall direction in AIDS coverage, with a letter criticizing Lorch's "sensational approach to reporting", and explaining that "too often . . . the issue of AIDS and the 'victims' themselves are pawns on someone's editorial, political, or monetary gameboard."<sup>38</sup>

Speaking to a rival paper about the letter, Bobbi Campbell and fellow group member Gary Walsh announced that they were forming a new group "for AIDS patients only." Walsh said,

It's time we stopped being so passive. This group of AIDS patients will be more political, more social than the Shanti Project's group, which is basically for counseling.

Another man said, "This is the first time that we as a group have decided to get together and stand up on our own."<sup>39</sup>

In a letter in reply, Lorch was unmoved:

Like yourselves, I am impotent in the face of this onslaught. With respect to this community I have paid my dues—for over 10 years. For most of the names on your list, the only thing you have ever given to this Gay life is your calamity.<sup>40</sup>

He did not feel that the "calamity" of diagnosis offered the men with AIDS any particular credibility in speaking about AIDS. And he offered no apology.

In New York, Callen observed that while large community forums about AIDS generally featured various "experts" and gay community leaders, they often did not ask for the views of people with AIDS themselves. As Callen wrote later about this period:

But heaven forbid that a [person with AIDS] should express an opinion about etiology, about organizational structure, about service delivery, about the politics of AIDS! No, we were only permitted to participate in forums as performing bears brought in at the end to make them cry before the hat got passed.<sup>41</sup>

But neither the San Franciscans nor the New Yorkers aspired to become objects of pity, grief, or fundraising. If they could only inhabit the role of tragic victims, could only speak in the voice of "calamity," then they would find themselves closer to social death whether they spoke or remained silent. If, on the other hand, their experience gave them credibility in the larger discussion about how to respond to the disease, the fact of their diagnosis would actually make them more central,

more vital. Despite a real and constant threat to their biological survival, they would be just as socially alive as before—perhaps even more so.

### GAY MEN WITH AIDS, ORGANIZING AS PEOPLE WITH AIDS

San Francisco's men with AIDS acted politically for the first time in response to what they viewed as Lorch's nihilism and sensationalism, as well as his cynicism about the Shanti Project, an organization that supported them. But as Campbell explained a few weeks later, they viewed the *Bay Area Reporter* and Lorch as only one of a greater set of problems that had moved them to action.

For months we have struggled with illnesses, death, isolation and fear. During this time, doctors have defined us, politicians have defined us, and the media has defined us. . . . [S]ome . . . adopt a strident tone because they want to compel the complacent to realize how important AIDS really is. . . .

Unfortunately, this often results in sensationalizing AIDS and fostering panic and hysteria in the community. The community then reacts by attacking people with the disease.<sup>42</sup>

The men had already started planning a candlelight march “to honor the dead and support the living.” It took place on May 2, 1983, and evoked another candlelight march along the same route less than five years earlier, to memorialize Harvey Milk, the country's first openly gay elected official, and George Moscone, the city's mayor, after they were assassinated.<sup>43</sup>

The San Francisco 1983 candlelight march was joined by a parallel event in New York. In San Francisco, the memorial's

parallels to the Milk memorial implicitly suggested that men who had already died of AIDS had joined the community's honored dead. At the same time, the living people with AIDS marched in front, in the crowd's embrace. Their banner, “Fighting for Our Lives,” acknowledged a biological threat but refused to accept it as destiny. Later AIDS activists would fight for their lives by demanding access to treatment, not only for their own survival but also to emphasize that other people could go on living despite having HIV.<sup>44</sup>

In the gay and lesbian newspaper *Coming Up!* Chuck Morris, the former publisher of the *Sentinel*, highlighted the immediate political purpose:

I think the march is important because the more people see us—those of us with AIDS—in the flesh, the less they're going to fear us. . . . Hopefully, this march will humanize the AIDS crisis.<sup>45</sup>

The *New York Times* later told Morris's story:

Three years ago . . . Mr. Morris was publisher of [the *San Francisco Sentinel*]. . . . Now, he says, he has more than 30 active symptoms, has had three brain seizures in six months, is unable to work, and is abandoned by friends of years' standing. Twice he has been forced out of his apartments, both times while in the hospital.<sup>46</sup>

The second eviction, he said, took the form of a phone call from one of his roommates, who called to tell Morris that he would kill him if he moved back. He moved out. As he told the *New York Times*,

I was standing on Castro and 18th Street with a little plastic bag with all my possessions that I could grab, and all of a sudden the enormous horror of all

this hit me. . . . [H]ere I was, standing on the street, homeless and broke, and I had no idea where I was going to stay. It was the first time that I realized that this had caused my whole world to crumble around me.<sup>47</sup>

That month, the AIDS panic growing within the gay community was joined by a more generalized alarm from people outside it. A *Journal of the American Medical Association* report published in early May 1983 described cases of childhood AIDS, in which, the authors implied, the disease could have spread from household contact.<sup>48</sup> An editorial by Anthony Fauci acknowledged the possibility of mother-to-child transmission (demonstrated by another article in the same issue<sup>49</sup>), but also speculated, “If . . . non-sexual, non-blood-borne transmission is possible, the scope of the syndrome may be enormous.”<sup>50</sup> A wave of anxious media coverage followed.<sup>51</sup> In an uncertain time, fear was a rational response. But if fear spread, so too could social ostracism, violence, and other consequences of stigma, as well as formal or informal quarantine, which in an incurable disease could mean social death. For the men with AIDS, other people's fear was a dire threat.<sup>52</sup>

### NEW YORK AND SAN FRANCISCO MEET IN DENVER

By the time of the candlelight march, Campbell was planning to attend a conference of gay and lesbian health professionals, including a special satellite AIDS forum, in Denver. He wanted people with AIDS to be there.<sup>53</sup> Their new group, People With AIDS San Francisco, voted to send Campbell and Dan Turner as representatives, and they sent

word to men with AIDS in New York.

Turner and Callen later wrote, “As soon as the concept of PWAs [people with AIDS] representing themselves was proposed, the idea caught on like wildfire.”<sup>54</sup> Eight New Yorkers came to the meeting; three San Franciscans and two or three men from other cities also attended.<sup>55</sup> The men with AIDS attended conference workshops but also spent hours in their own caucus, each sharing their own experiences.<sup>56</sup> AIDS panic was close at hand: the hotel hosting the conference removed

all mention of the word “AIDS” from signs until conference-goers boycotted the hotel’s restaurants.<sup>57</sup>

Despite the bond of shared circumstances, the caucus of men with AIDS started with tension. By then, Callen and Berkowitz were well known not only for campaigning against “promiscuity” but also for their advocacy for the immune overload theory. Turner and Campbell worried that the New Yorkers would focus on “abstruse medical issues.”<sup>58</sup> The two groups of men differed on how to think about AIDS and how to treat it, but also in

personal style: Berkowitz later confessed to initial irritation from the San Franciscans’ habit of “hugging and holding one another and taking time for spiritual reflection.”<sup>59</sup> They also differed on how to think about sexuality. Like Callen and Berkowitz, Campbell had helped write a guide to safe sex. But for him, safe sex practices were a way of embracing sexuality, including anonymous sexual encounters and multiple partners.<sup>60</sup>

Nonetheless, by all the later accounts of men who were present, the New Yorkers and

## The Denver Principles

*Statement From the Advisory Committee of People With AIDS (1983)*

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”

### RECOMMENDATIONS FOR HEALTH CARE PROFESSIONALS

1. Come out, especially to their patients who have AIDS.
2. Always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatments and advice they give.
3. Get in touch with their feelings (e.g., fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually.
4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
5. Treat people with AIDS as a whole people, and address psychological issues as well as biophysical ones.
6. Address the question of sexuality in people with AIDS specifically, sensitively and with information about gay male sexuality in general, and the sexuality of people with AIDS in particular.

### RECOMMENDATIONS FOR ALL PEOPLE

1. Support & Membership in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

### RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the board of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential partners of their health status.

### RIGHTS OF PEOPLE WITH AIDS

1. To live as full and satisfying sexual and emotional lives as anyone else.
2. To receive quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status or race.
3. To obtain full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To ensure privacy and confidentiality of medical records, to receive human respect and the right to choose who their significant others are.
5. To die—and to LIVE—in dignity.

*Note.* The text of the Denver Principles has been reprinted in a number of places. I have taken this text from the *PWA Coalition Newslines* (July 1985):14. This version was reproduced by Michael Callen and has since become the standard. Its earliest appearance seems to have been in B. Campbell, “Second National AIDS Forum,” *San Francisco Sentinel* (June 23, 1983):4. Bobbi Campbell’s early reprinting of the text from the meeting is not identical to Callen’s, but the differences are slight.

San Franciscans eventually found at least some common ground in their experiences, and camaraderie as a result of sharing them.<sup>61</sup> Callen later recalled,

Bobbi Campbell and I emerged as the two control queens. . . . Tremendous power was delegated to us by the other PWAs and we took it very seriously.<sup>62</sup>

Together, the two men side-stepped their enduring disagreements to create a consensus document—the Denver Principles.<sup>63</sup>

During the closing session, the men took the stage in two rows, with the first row of men holding People With AIDS San Francisco’s “Fighting for Our Lives” banner. They read their recommendations out loud, taking turns reading the points one by one. They finished, “We will die—and LIVE—in dignity.” They got a standing ovation from their audience of gay and lesbian health professionals. The *Gay Community News* in Boston, Massachusetts, described it as “the most moving and significant part of the conference.”<sup>64</sup>

### STARTING PAROCHIAL, BECOMING GLOBAL

The Denver Principles reflect their origin in a group of gay men with AIDS, without social or political connections to other groups of people with AIDS, making a set of recommendations to a group of mostly gay and lesbian health care providers. Given that, even at the time, people other than gay men had been diagnosed with the new illness, the document is sometimes parochial. On the other hand, the ideas of the Denver Principles were not simply the product of a moment in gay politics. They were distilled not only from the experiences of the men in the

group, but also from Campbell’s nursing education, Callen’s wide reading list and his unique relationship with his doctor, and, for both men, the ideas of the women’s health movement of the decade prior.<sup>65</sup>

Briefly summarized, the document rejects the victim role, asks clinicians to view themselves as subjective individuals, asserts a right to sexuality, demands freedom from discrimination and stigma, insists on central social and political roles in society’s response to AIDS, and emphasizes autonomy and dignity in research, medical care, and end-of-life decisions. By contrast, we can outline the natural history of modern social death as beginning when people become victims and patients, marked for biological death by medically defined diagnosis and prognosis; evolving as they are pushed out of the social world or leave it of their own accord; and made final when the body becomes the property of medicine and science until physiological death. The Denver Principles represent a point-by-point strategy of resistance to the concrete elements of that process.

As a trio of HIV-positive authors from Nigeria, Australia, and the United Kingdom explained in 2009,

The Denver Principles are simple, but their significance has been profound. They articulate the key challenges in the lives of those living with HIV and the role of people with HIV themselves in overcoming such challenges by refusing to be victims and demanding to be involved.<sup>66</sup>

The document was also the source of a linguistic shift in the epidemic. The San Franciscans’ recently deceased comrade Mark Feldman had written in January

1983 about rejecting the words “patient” and “victim.”<sup>67</sup> Feldman died in June, soon before the conference, and was represented in Denver by his lover, who did not have an AIDS diagnosis. Feldman’s feelings on the topic were integrated into the preamble of the document, which argued for the term “people with AIDS.” As the antibody test rather than the clinical diagnosis began to define the political identity, that widely used descriptor eventually evolved into several descendants, including “people living with HIV/AIDS” and “people living with HIV.”

### THE DENVER PRINCIPLES’ LEGACY IN ACTIVISM

People with AIDS initially organized not only because they wanted to survive biologically, but also because they did not want to spend their lives—however short or long—as exhibits in other people’s spectacles of grief, fear, anger, or nihilism.

The Denver Principles led to the creation of the National Association of People With AIDS (NAPWA) in the United States, and eventually to similar associations in a number of nations. But the legacy of the Denver Principles also had an important if less obvious influence in later, more confrontational forms of AIDS activism, when the separate agendas of defense of the broader community and the empowerment of people with AIDS were synthesized by later, larger, and more influential AIDS activist groups.

Kramer, Callen, and hundreds of others found themselves enacting that synthesis during the formation of the AIDS Coalition to Unleash Power (ACT UP) in New York in 1987. ACT UP became a



national movement in part from new chapters that followed, as well as from incorporating like-minded political groups that were emerging in other cities during the same time.<sup>68</sup> Kramer himself, like many gay men of the time, assumed he might be infected, but didn't have his HIV-positive status confirmed until 1988.<sup>69</sup> For him, AIDS was important because it affected the gay community as a whole—so the distinction between the diagnosed and the undiagnosed was less important. The political approach of the Denver Principles, by contrast, made diagnosis into a distinct political category and emphasized the unique voice of people with AIDS.

ACT UP succeeded in part because its constituency and its membership were larger and more broad than those of groups composed only of self-disclosing people with AIDS. The latter kind of groups were often more effective as mutual aid societies than as political forces in and of themselves. The Denver Principles' agenda meant claiming an active role in a conversation about AIDS, but did not necessarily establish where that conversation should lead.<sup>70</sup>

Still, the ideas of the Denver Principles ended up being fundamental to later AIDS activism. Early ACT UP meeting minutes reveal a disagreement between ACT UP and NAPWA about who should speak as "AIDS activists" at a larger gay and lesbian protest march—and whether that should be someone like Kramer, who did not have an AIDS diagnosis.<sup>71</sup> Members of the People With AIDS Coalition and the People With AIDS Health Group, groups based on the ideas of the Denver Principles, spoke on the ACT UP floor as representatives

of people with AIDS. The meeting notes make clear that they helped explain to ACT UP members why NAPWA might feel that people with AIDS should represent the politics of AIDS within this larger community event.

Their insistence on maintaining their distinct political identities within ACT UP was notable; ACT UP veteran Gregg Bordowitz later recalled that during that early phase,

[I]t was taboo to identify as a person with HIV within the group. It's hard to imagine, but you'd be sitting in this room and you would assume that most of the men in this room were positive or had lovers who were positive. But no one—I only remember Michael Callen and Griffin Gold were the two people who would announce that they were people with AIDS before they spoke.<sup>72</sup>

Callen and Gold were cofounders of New York's People With AIDS Coalition—a direct descendant of the Denver Principles.

Nonetheless, although many people within ACT UP thought of it primarily as a gay and lesbian social movement (and indeed, it is still framed as such in a recent scholarly account by a former ACT UP activist<sup>73</sup>), the earlier ideas of self-empowerment of people with AIDS eventually became a fundamental part of ACT UP's politics. As the HIV-negative ACT UP veteran Jim Eigo later put it:

[W]hat we had to articulate was first, the whole idea that people with AIDS, or people with HIV, had a right to make decisions about their lives, their treatment, how they were treated at every stage of their disease and through every government organization they had to deal with.<sup>74</sup>

That broader idea of the empowerment of people with

AIDS, most often without reference to that idea's distinct political history, ultimately became the basis of ACT UP's political credibility. When ACT UP and its members gained the power to influence research, drug approval, and other aspects of AIDS policy, that power was built on the legitimacy of its claims to represent people with AIDS.<sup>75</sup>

Later, the Treatment Action Campaign (TAC) in South Africa ended up using a similar synthesis of broad mobilization and the narrower notion of the empowerment of people with AIDS. TAC was founded by Zackie Achmat, an activist living with HIV, and some of his friends and political allies. Originally a project of South Africa's National Association of People With AIDS (another Denver Principles descendant), it evolved into what might be described as a militant trade union for HIV-positive people, and as the most successful of a number of social movements that demanded that the post-apartheid government do more for the poor.<sup>76</sup>

Like ACT UP, the Treatment Action Campaign drew on the expertise and energy of a broader constituency. Like ACT UP, it also had a larger community defense agenda, in TAC's case by demanding economic and health justice for impoverished Black people. But its legitimacy depended on its ability to enlist and represent people living with HIV/AIDS. Because of that legitimacy, TAC succeeded in pressuring the government to make antiretrovirals available in the South African public sector health system.

The legacy of the People With AIDS agenda in the United States includes changes in clinical research, drug development, and

the regulation of medicines. Once effective treatment became available—partly as a result of these changes—the global legacy of the People With AIDS agenda was to persistently reduce seemingly complex policy debates to their simple essence: should people living with HIV die of a treatable disease to support other competing priorities? Because activists helped simplify and then answer the myriad forms of that question, millions of people lived who otherwise would have died.<sup>77</sup>

Public health practitioners are trained to think from the point of view of defending communities, rather than from that of individuals with a disease. Indeed, many of us would recognize in ourselves the impulse to, as Campbell put it, "adopt a strident tone . . . to compel the complacent to realize how important [the problem] really is."<sup>42</sup> But the risk of social death is not simply an ethical peril. It is also a practical challenge: if a diagnosis puts people at risk for social death, that risk becomes a powerful incentive to avoid diagnosis. By contrast, the earliest AIDS activists offered an affirmative strategy of responding directly to a health threat while resisting social death.

The first people with AIDS did not deny the seriousness of their disease. But if the threat of death became the defining feature of their existence, social death would soon follow. By organizing themselves, and then organizing their communities around them, the earliest AIDS activists remained important and, ultimately, honored people within their communities. Their ideas and actions, and those of the activist movements they inspired, helped to eventually make AIDS a fact of life rather than a synonym for death. ■

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language of "promiscuity" or its rebuttals; and the second recommendation for health care providers appears to be a gentle assertion of Callen's concerns about etiology, while the third likely reflects Campbell's own approach to how to be a clinician, and would have been the sort of instruction a progressive nursing educator might have given at the time.

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