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Anarchism and AIDS Activism

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1991

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This is a shortened version of the article Anarchism and AIDS Activism by Liz Highleyman that was first printed in the Anarchist newspaper *Love and Rage* in its June/July 1991 issue.

The text as presented here comes from the zine of the same name that was most likely distributed in Minneapolis at 2nd annual Love and Rage Organizing Conference in 1991. To read the original article and to see other anarchist writings from that time visit [<libcom.org/article/love-rage-vol-2-no-6-junejuly-1991>](http://libcom.org/article/love-rage-vol-2-no-6-junejuly-1991) to get a pdf of that issue.

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1991

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rently profit-based capitalist economy. These changes necessarily imply an alteration of the underlying power structure of society. Reform is not enough. Making revolutionary change happen will require the combined efforts of all people who are currently disenfranchised and who stand to gain by widespread change. Anarchist activists are an important part of this movement and making links between anarchist activists and progressive health care activists is an important task.

In "Positive," Rosa von Praunhelm's film about AIDS, it is mentioned how tragic it is that the AIDS epidemic has forced the affected communities to fend for themselves and come up with their own strategies to deal with the crisis. I feel the contrary is true. This process is highly empowering and is laying the groundwork for long-term change. Existing institutions can sometimes be relied on for short-term bandaid measures that help a small proportion of those in need, and in our desperation it is often tempting to accept these crumbs. At the same time we should never lose sight of the bigger picture; the AIDS crisis and the broader health care crisis are deep-rooted, long-term societal problems and it is important to seek comprehensive, long-term solutions. The government is too often more concerned with perpetuating its own power than it is with meeting the needs of those it claims to serve. What the state gives, it can also take away. In order to achieve a non-hierarchical, self-sufficient, cooperative society built upon anarchist values and focused on human needs and desires, it is vital that we find ways, individually and collectively, to develop solutions that do.

nation and oppression, and who have less faith in the political and medical establishment and less to lose by challenging it.

AIDS activists have been known to claim that if AIDS had struck wealthy straight white men, there would already be a cure. This is not evident when one looks at a typical malady of white male executives (such as heart disease). The men in power have not been moved to challenge the system (for example by demanding more research, speeding up the release of drugs, breaking pharmaceutical company monopolies, and providing more care and resources for the sick), even when they themselves are affected. Perhaps this is because they trust and feel invested in (and are often a part of) the government, the medical establishment, and the health care corporations: It seems that the powerful would rather die than challenge the system that keeps them in power. It is no surprise that it is the disenfranchised groups that are demanding drastic change.

The AIDS activist movement is among the largest social change movements today, and may become one of the broadest. As time goes on and the epidemic shows no signs of abating, activists are increasingly realizing how deep the roots of the AIDS crisis go. Activists are expanding their focus to include others in addition to the gay, largely white and middle-class men that started the movement. Addressing homophobia has always been an integral part of AIDS activism, since the fear and hatred of gay people has contributed to the apathy and hateful policies surrounding AIDS. It is ever more evident that sexism, racism, and classism are co-factors in the epidemic as well, and must be confronted and dealt with both within activist groups and in society at large. AIDS activists are also taking part in the fight against social service cuts, and in the anti-war movement, realizing that the focus on war and the military buildup allows the government to divert attention away from domestic issues, and consumes a huge amount of resources that would be better spent elsewhere. Defeating AIDS and improving people's overall quality of life will require major changes in the health care industry. In the political system, and in the cur-

AIDS is one of the most pressing social crises we face today, and it is important for anarchists to respond to it. If we hope to convince people of the value of anarchism, we should have concrete strategies for dealing with pressing social concerns.

Under our present system, it sometimes seems as if the government is the only entity with the money, resources, and power to make a dent in the AIDS epidemic. At the same time, we realize that the state is often not an ally, and may in fact be one of the greatest impediments to our fight against AIDS.

AIDS activists often have a contradictory relationship with the state. ACT UP (The AIDS Coalition to Unleash Power) is known for its accusation that the government, by not doing enough, is committing genocide against people with AIDS and, by extension, against the populations that are most affected by the disease. Is the government, in fact, responsible for every death that it fails to prevent? Certainly if the state devoted unlimited resources and effort, many current diseases might have been eliminated, including diabetes and cancer as well as AIDS. Governments can "protect" us by instituting ever more strict regulations, but our freedom suffers as a result. A "blame-the-government" attitude can, unfortunately, allow us to deny individual and collective social responsibility and become dependent on the state. If it is true, as activists claim, that the government does not represent our best interests, it would be foolish to rely on it as a source of solutions.

Most anarchists acknowledge the value of people coming together to carry out various tasks. This is the basis of mutual aid: individuals sharing resources and skills for the benefit of everyone involved. The differences between a task-oriented organization and a government are based on their degree of power and control and on their overall purpose. Governments have the power to compel people to do what they command: task-oriented groups depend on voluntary participation. Governments have the proven tendency, whatever their initial purpose and stated aims, to evolve into entities whose primary function is to maintain their existence, per-

petuate dependence, and consolidate their power. Unfortunately, non-governmental “AIDS professionals” and their organizations are not immune to this tendency. It is often direct action, grass roots groups that must re-focus attention on the real needs of the people Involved.

Socialists claim that government exists to serve the people. and that It is therefore a proper role of activists to demand that the state do Its job.

This argument presupposes an idealistic belief that the government is basically well-intentioned. Anarchists generally believe that the state is not well-intentioned, and that it exists to serve a powerful elite. The first view (held by many liberals as well as socialists) claims that through educational, persuasion, and democratic process, we can convince the government to use its (that is our) resources to meet human needs. The opposite view claims that since government Is unwilling to use its (our) resources for what we feel is important, we would be better off putting the time, money (including taxes). and effort that we currently devote to petitioning, supporting, and evading the government Into alternative activities that meet our needs directly.

ACT UP and similar AIDS direct action groups follow an anarchist model In many ways, although their overall attitude toward the state ts ambiguous. For example, these groups are:

Decentralized — there is no formal leadership, either within or among chapters. ACT UP began in New York City In 1987, and has branched out to other cities and towns, evolving to meet the needs of local communities. There is not top-down agenda or methodology. Different groups use different strategies and tactics to achieve their goals. though they often network with each other and call upon others to support their projects.

Grass-roots based — different groups take on the issues that have the highest importance for the members and their local community. When members have differing priorities, subgroups may form to carry our various projects. ACT UP is known for bringing its mes-

activists will not reduce their efforts because other groups have not made similar efforts nor achieved the same success.

At the same time, AIDS activists are not demanding that attention and resources be given to AIDS at the expense of other pressing needs. That is a choice made by politicians who are more willing, for example, to rake funds away from cancer research to fund AIDS than to cut the military budget.

An increasing number of AIDS activists are joining with groups concerned with other health issues (such as women’s health activists working to combat cervical cancer and breast cancer, people concerned with reducing the high infant mortality rate in communities of color, and those working to develop more accessible and successful drug treatment programs), and are part of a growing movement to demand some type of universal health care regardless of financial or employment status.

Anarchists within this movement face difficult questions on the issue of national health care. We currently seem to be facing a choice between a state-supported Inclusive health care system or the continuation of the present system that benefits only the financially secure. A voluntary comprehensive, community-managed health care system would be ideal, but will require a great deal of time and resources to develop (as well as a basic change in the way people interpret the roles and responsibilities of the Individual, the community, and the government). and many lives are at risk in the meantime.

In the US, AIDS initially struck gay men, a relatively cohesive community that had considerable experience in political organizing: the group of all diabetics, for example, does not begin to have these characteristics. This community also had relatively high levels of education, skills, and resources, and was willing and able to give AIDS a high priority on its agenda. In addition to gay men, AIDS has most heavily allected other populations (communities of color, IV drug users, women) that have historically faced discrimi-

authoritarian and anti-elitist sentiment remains strong, are likely to resist such moves.

The AIDS activist movement now finds itself in the situation that anarchist organizations are likely to face as they grow and develop, and it is possible that the anarchist movement can learn some useful lessons from the way ACT UP and similar groups respond to this challenge. On one hand, it is exciting when the numbers of members increase, since it indicates awareness of the issues and admiration for the work the group has done. On the other hand, increased size can change the very character which has made the group successful. We can try to de-emphasize the importance given to the size of specific groups, and rather focus on developing and expanding the movement as a whole in a decentralized, grass roots manner.

AIDS and the “Big Picture”

People often claim that AIDS gets too much attention and resources in proportion to its occurrence. Other diseases like cancer and heart disease claim far more lives than AIDS in the US (40 million Americans have cardiovascular disease and 550,000 die of heart attacks each year); while an estimated 1.5 million are HIV positive and over 100,000 have died from AIDS. Why do AIDS activists selfishly demand so much?

Instead of asking why AIDS activists demand so much, perhaps we should ask why people concerned with other health issues are content with so little. Their attitude seems to be, “We have been dying quietly, so why don’t you shut up and do the same?” AIDS activists are asking instead, “How can you die quietly? Why aren’t you in the streets demanding what you need?” The success of AIDS activists is a testament to their effective organizing, persistence, and ability to find innovative ways to challenge the system. AIDS

sage to the streets and bringing wide exposure through the press, so that issues are brought before the public as a whole, not just the policy-makers.

Direct-action oriented — groups are committed to working outside the system, putting pressure on the government, corporations, and the medical establishment, doing direct outreach and education, and interfering with business as usual. Some groups have a component that works within the system as well, using the threat of direct action to get their demands met.

What AIDS Activists Do

Since their beginnings, ACT UP and related groups have had some notable successes. They have been instrumental in pushing AIDS drugs through the federal approval and regulation process more rapidly, and in getting more and better research done on promising treatments. ACT UP pressured Burroughs-Wellcome, the company that holds a monopoly on AZT (although it was developed at public expense) to lower its price from \$10,000 per year to a substantially lower rate. ACT UP has challenged state, church, and private officials who have blocked AIDS prevention efforts by prohibiting safer-sex information, sex education in the schools, and the distribution of condoms. ACT UP challenged the Immigration and Naturalization Service regulations that prevented HIV positive people from visiting or emigrating to the U.S. (ACT UP was joined in this effort by gay people, immigrants, and anarchist activists who oppose the INS for anti-statist reasons: while the INS regulations against gay and HIV positive people are pending repeal, regulations against anarchists are still in effect.)

AIDS activists have been on the forefront of safer-sex education. These efforts have been so successful that the rate of increase of HIV infection has declined among gay men. In our moralistic, sex-phobic society, activists have taken the lead in promoting the

kind of frank information and discussion that is necessary to motivate people to change risky behavior. The government, schools, and religious institutions are still resisting efforts to promote education about safer sex and safer drug injection and to make available informational resources, condoms, and clean needles. Since it is clear that establishment institutions cannot be relied on to strongly promote AIDS prevention, activists are working to develop outreach and education programs for heterosexual women and men, lesbians, sex workers and drug users similar to those that have been successful for gay men.

Grass roots activists have worked to improve health care delivery. Much of this work resembles and builds upon time-tested self-help strategies, like those developed by the women's self-help and underground abortion movements in the 1960's and 1970's. The AIDS activist/People with AIDS (PWA) movement aims to help people control their own bodies, and to empower them to take control of their own health care. Non-professional people are learning about the manifestations of HIV disease and challenging the medical establishment. PWAs are exploring new and alternative methods of treatment (like the women's health movement explored alternative methods of contraception and abortion), including traditional methods such as herbs and acupuncture; there is an emphasis on preventative care and use of controlled methods of health care delivery.

PWAs and AIDS activists have started community health centers, volunteer service organizations, and buddy programs. Buyer's clubs have sprung up to provide access to drugs that are not available through the usual channels due to government regulation (some of these drugs can be obtained from other countries or produced in underground laboratories). Clubs allow PWA's to share and trade surplus medications, partially circumventing drug company monopolies. Initiatives have been developed to safely administer drugs such as Compound Q (a Chinese plant) which requires intravenous infusion. Volunteer medical workers risk losing their

more diverse groups became involved in AIDS activism, people began to claim that developing new and better drugs was not enough. PWA's have many pressing concerns that go beyond drugs, such as the need for housing and the problem of discrimination. Drugs are not enough if they are unavailable to the poor, the uninsured, women, children, people of color, IV drug users, and prisoners. People must have access to health care regardless of ability to pay.

Direct action groups often work best when they are small, the size of an affinity group or perhaps several affinity groups working together. Groups of this size let all members know one another, which is important in building trust and solidarity, as well as in maintaining security against infiltrators and provocateurs. Smaller groups allow everyone to give their input, and can work in a directly democratic way or by consensus. In contrast, larger groups may find it necessary to resort to representations, hierarchical structures, and rigid process rules. It would be valuable for anti-authoritarian political groups to develop genuinely democratic ways of working in large groups, but until these methods are developed and people are accustomed to them, it may be beneficial for groups to divide as they grow, with different groups focusing in different issues, while sharing an overall goal and working together when large numbers are effective. This allows members to do the work that needs to be done rather than arguing over priorities and process in huge group meetings. Unfortunately, some ACT UP chapters that have split up (such as ACT UP Portland, Oregon, and ACT UP/SF) have done so in an acrimonious way that has made it hard for the resulting smaller groups to work together. ACT UP/NY regularly has meetings attended by hundreds of people.

In March, Larry Kramer (the founder of ACT UP) distributed a letter calling for ACT UP to re-examine its goals and methods, suggesting that ACT UP should consider electing officers and establishing by-laws. Smaller and more cohesive chapters, in which anti-

ing the use of media by non-professionals. The government and corporations do not have an exclusive hold on the media, and it is important for activists to use these tools if they can further our goals. ACT UP has also been criticized for its faddish consumerism, with its ubiquitous ACT UP merchandise marketed to the tune of several thousand dollars, part of a million dollar annual operating budget (for ACT UP/NY alone).

A more serious criticism from the anarchist point of view is the tendency for some members of AIDS direct action groups to become “Insiders,” with access to high-level government and corporate decision makers.

Maintaining such access presents a real risk of cooptation, especially when the “Insiders” come to think of themselves as an elite and as more valuable than other members. The “insiders” cannot be allowed to forget that they have gained access only because they are backed by large numbers protesting in the streets. In the fight against AIDS, knowledge is indeed power. One of the strengths of the AIDS activist movement is that so many people without specialized education or medical training have learned so much about research and treatment. ACT UP and others have generally done a good job of disseminating information widely, but as groups become larger and the amount of information becomes greater, there is a tendency for knowledge to become concentrated in fewer hands; people tend to specialize and become “experts,” thus leaving some people in control of information, and increasing the risk that the “big picture” will be missed in favor of smaller details.

The explosive growth of the AIDS activist movement has presented serious issues for those concerned with maintaining decentralized, non-hierarchical structures. Some of the larger ACT UP chapters have faced divisions and splits when they have been unable to reconcile conflicting priorities. At its outset, ACT UP was a group of primarily gay white men with the specific goal of getting drugs into the bodies of people with AIDS. As the AIDS crisis worsened and spread to other segments of the population, and as

license for helping supply unapproved treatments, making these of sorts acts of civil disobedience as well as a direct health care provision. The devastatingly slow pace of federally sponsored research, and the overwhelming concentration of research on treatments that have drug company backing have led some activists to decide that they can do better themselves. Community Research Initiatives have been developed in several cities to carry out decentralized research based on the needs of PWAs. Because these initiatives are locally-based, they are more knowledgeable about and responsive to the needs of the diverse people they work with.

As people with AIDS become sick, they are at risk of losing their jobs or their homes. Homelessness is an increasingly common problem with PWAs, especially in large cities that have a widespread housing crisis. Some AIDS activists have taken up squatting as a means of securing housing. Unlike the typical demonstration, whose purpose is to call attention to an issue and get bureaucrats to act, squatting is a direct appropriation of a needed resource, which at the same time educates the community and puts pressure on the powers-that-be. ACT UP/Philadelphia got much community support when they took over an AIDS hospice that had lost its funding. ACT UP/Boston is currently exploring squatting to provide places for PWAs to live.

A large and ever increasing number of people have become infected with AIDS through IV drug use, by sharing or renting needles contaminated with blood that contains the HIV virus; In order to protect themselves, injection drug users must have access to sterile needles. The possession and non-prescription sale of needles and syringes is illegal in eleven states, including California and the Northeast: probably not coincidentally, these states are home to the cities with the highest incidence of AIDS. Several AIDS activist groups are doing clean needle distribution or exchange in opposition to the law. Among these are the National AIDS Brigade (started by former addict Jon Parker in New Haven, Connecticut in 1986). San Francisco’s Prevention Point (the nation’s largest). and

ACT UP groups in Boston (the IV league). New York and East Bay. Studies in Europe and the U.S. have shown that access to clean needles greatly reduces the spread of AIDS among Injection drug users, and does not lead to an increase in drug use. Drug users are often the target of police harassment, and face stiff sentences for needle possession; it is crucial to abolish laws that punish people for trying to protect themselves against AIDS. Ironically. In some cities, activist pressure has convinced the state to take over the funding and operation of needle exchange programs; state programs tend to exclude activists and are tailored to meet the needs of bureaucrats rather than drug users (for example, a pilot needle exchange program in New York City required drug users to come to a central facility located across the street from a police station). As is so often the case, we cannot depend on the government and must continue to develop community-based, user-controlled programs. In the U.S. AIDS disproportionately affects those outside the law. such as IV drug users, sex workers and prisoners. The state, as well as many private organizations, seems more concerned with preventing supposed moral sins than with preventing the spread of AIDS. Drug laws drive drug users underground and keep them away from sources of support and health care. Laws against prostitution subject sex workers to continual harassment by the police, and make them vulnerable to abuse from clients and pimps. Sex workers are often scapegoated as spreaders of AIDS, when In fact they are more at risk of getting AIDS themselves than they are of infecting a client. Police policies of confiscating condoms as evidence of prostitution, which makes sex workers less willing to carry them, are killing people, and must be abolished. Moralistic and legalist attitudes lead officials to deny that sex and drug use occurs in prison, despite clear evidence to the contrary. Prison populations have very high rates of HIV infection, and it is crucial that prisons allow Inmates to protect themselves by means of condoms and clean works.

ACT UP is known for its protest of the bureaucracy, red tape, and regulations of the Food and Drug Administration (FDA) and

other government agencies. Some activists believe that regulations should be done away with, and that people should be freed to make their own choices about their treatment. The ability to make such decisions depends on a level of knowledge, literacy, and access to information that many PWAs unfortunately do not have. Other activists have called for stricter regulation, especially for alternative treatments, to protect people from charlatans who seek to make a quick buck off sick people's desperation. In order to responsibly advocate a reduction in government regulation, we should develop ways to make information and options available in an accessible and understandable way so that people can truly make their own informed decisions about their health care.

The need for AIDS service is so pressing that it would be of great value if people with the necessary motivation, experience, and knowledge were allowed to put their skills to use without having to spend large amounts of time and money on formal medical education and licensing. PWA's and community activists who often have as much or more knowledge about AIDS care are risking prosecution for practicing medicine without a license. Reduction of regulations would also make it possible to use needed facilities without having to meet expensive and often unnecessarily stringent approval requirements.

An Anarchist Critique of AIDS Activism

While direct action AIDS activists may be anarchistic in method and attitude, ACT UP and similar groups can not be considered an anarchist ideal. Some anarchists have criticized ACT UP for becoming just another part of the spectacle. More than most direct action groups. ACT UP has been very successful in using media Images, and its way of doing so sometimes appears similar to the manipulative tactics of the state and corporations. At the same time, new and creative ways of using the media have been developed, includ-