

US: At a Time of Emergency, ACT UP Refused to Be Bystanders

Monday 12 July 2021, by [PRESS Alex N.](#), [SCHULMAN Sarah](#) (Date first published: 24 June 2021).

Sarah Schulman's *Let the Record Show* tells the story of one of the most compelling and successful social movements of the past century, ACT UP. We talked to Schulman about the "New York Crimes," the messy joy of political commitment, and how ACT UP changed history.

On July 3, 1981, the *New York Times* ran an article headlined "[Rare Cancer Seen in 41 Homosexuals](#)." For many people, this was the first they'd heard of what we now know as acquired immunodeficiency syndrome (AIDS). With startling rapidity, the illness would decimate entire communities, the gay community foremost among them. To wit: my dad lived in the New York area at the time. He read that article out loud to his two roommates, both of whom were gay. It was the first that either had heard of the illness. Within months, both had passed away from it.

In 1987, New Yorkers formed the AIDS Coalition to Unleash Power, better known by its acronym, ACT UP. After years of triage and loss caused by a plague that the government, helmed by Ronald Reagan, was utterly uninterested in combating, ACT UP members resolved to fight back, forcing changes that no one had been willing to offer them. Recall that, at the time, "gay-bashing" was a frequent occurrence, and the state — police in particular — was part of the problem. Sodomy laws were still on the books, and there were no protections against being fired or denied housing because of one's sexual orientation.

Enter ACT UP. The group's unifying principle? Direct action to end the AIDS crisis.

Sarah Schulman's latest book, [Let the Record Show: A Political History of ACT UP New York, 1987-1993](#), chronicles the organization's first six years. In that period, the activists, many of them living with AIDS, won victories against the state, the media, and the medical profession (and the Catholic Church and the city of New York and the health insurance industry — the list goes on). Schulman was present for much of this action and knew many of the participants, and her book is based on interviews with them conducted under the banner of the [ACT UP Oral History project](#), an undertaking coordinated by Schulman and Jim Hubbard.

I spoke to Schulman about the "New York Crimes," the messy joy of political commitment, and how ACT UP changed history. The transcript has been edited for length and clarity.

ANP | In *Let the Record Show*, you write that you want people to use the book to learn from the past to better organize in the present. Tell me about your aim in writing this book.

SS | It isn't nostalgia. It's almost impossible to find out what a movement like ACT UP did, what the strategies and the tactics were, because ACT UP didn't even theorize itself. People thought that what they and their friends did was ACT UP, so nobody had an organizational overview.

But ACT UP was amazingly successful considering everything, and I thought it'd be helpful for

people to see some of the successful moves and some of the problems, to be able to think critically about them.

ANP | What one thinks about ACT UP's success is tied to one's view of how change happens. As you write, "Unfortunately, most people do not participate in making change. My perception is that the fate of a society is determined by very small groups of people. Only tiny vanguards actually take the actions necessary, and even fewer do this with a commitment to being effective."

You mention "great leaps," surges, or waves, and that history's structure can't be forced. But ACT UP appeared at a moment when there was an opening, and the participants changed history.

SS | I think change really happens in the counterculture that surrounds movements. For a movement to be able to change the way other people feel about themselves, it needs to have a certain charisma to it. ACT UP changed the way queer people and people with AIDS thought about themselves, and the way they were seen. But it affected people globally, way beyond how many people joined ACT UP.

Very few people are willing to make the step to be in opposition to the apparatus of power, because we're ambitious. That's why I talk about the expression "no business as usual." To get into no business as usual, it means giving up certain ideas about yourself in relationship to power.

However, within the group of people who are willing to do that, most are not effective. There's a subgroup of people who actually can think about solutions, conceptualize a way forward, see the steps that need to be taken, and then implement them. For some reason, ACT UP attracted those people. That was one of the questions that I had: what do they have in common?

ANP | You write that the answer is "in cases of emergency, these were not bystanders." It's something in their character, rather than rooted in shared experiences. This is a question I sometimes find myself asking about collective projects on the Left: why do people commit?

SS | It was a state of emergency. Life and death are very high stakes. There are some movements right now that are facing life-and-death stakes.

Take the Palestine solidarity movement: that's a movement that needs to be as effective as it can be. They welcome everybody, including people who are not welcome in other movements. And they've changed strategies many times. They're desperate, and they need change. When BDS was introduced, that was a huge strategic shift. They were willing to try something completely different.

ANP | Let's talk about ACT UP's accomplishments. What were its biggest successes in the years your book is concerned with?

SS | They're very substantial in the six years I cover. ACT UP forced a redirection of how medications were researched. ACT UP forced the Food and Drug Administration to make experimental drugs available when they had not yet been approved. ACT UP forced the CDC to change the definition of AIDS so women could qualify for benefits and experimental drug trials.

ACT UP made needle exchange legal in New York. ACT UP removed the preexisting-condition exclusion for people with HIV from a number of forms of private insurance, which made hundreds of thousands of people eligible. ACT UP stopped the Catholic Church from inhibiting the distribution of condoms, and ACT UP started Housing Works for homeless people with AIDS.

But it also changed the way that people with AIDS saw themselves and were represented in

mainstream media.

ANP | Part of the explanation for those successes has to do with ACT UP's political lineages: people entered the organization with experience from other activism. Movements are so often counterposed, but there's always overlap.

ACT UP had people from the labor movement, the black freedom movement, the feminist movement, Latin American anti-fascist movements. Much as, in recent years, there's overlap among labor, Occupy Wall Street, the movement against police violence, and the Bernie Sanders presidential campaigns.

SS | We have to start with why there was an autonomous gay movement in the first place. It's not because gay people had a separatist politics; it's because gay people were kicked out of the Left.

The Communist Party expelled gay people. The Civil Rights Movement famously sidelined Bayard Rustin. The feminist movement had many lesbian purges, more than have been documented. We were forced into an autonomous gay movement because nobody else wanted us.

It's historicized as a discrete movement, but it's not — not only were there the influences that I laid out, but a lot of queer people were in other movements where they were closeted. There was Jeff Gates in ACT UP who died of AIDS, but he was in the Nicaraguan Revolution. Emily Hobson's book goes into this. We tend to think of the gay movement as something separate, but it's not.

Then there's the generational influence. I was born in the fifties, and most people in ACT UP were born in the forties, fifties, and sixties. As gay kids — which was a concept that did not exist, people deny that, that children were queer, but we were — there was no idea of gay community or gay movement.

But black resistance was evident. You'd see it on television or in *Life* magazine, or *Jet* magazine, or some people's families were involved in it. Black people standing up to the police, doing creative direct action like sitting in at segregated lunch counters, doing nonviolent civil disobedience.

ACT UP people internalized that, even though we never discussed it. When I was researching the book I reread Dr. King's "Letter from Birmingham Jail," where he lays out his view of direct action, and it is exactly what ACT UP did. Clearly, people had internalized these strategies and there was some kind of identification with them. That's a second way that there was an influence of other movements.

The third way is that the Monday night meetings were about three hundred to seven hundred people. If you look at the footage, or watch [United in Anger](#), you can see it's mostly white gay men. But those same people, when they left that meeting, were working with all kinds of movements and organizations. They were working with needle exchange, with incarcerated people with HIV, with women with HIV, with homeless people. There was mixing and reaching and connecting and impacting and being influenced by communities that were not predominantly white gay men.

Those are three realms in which ACT UP heavily engaged other movements.

ANP | You're laying out the importance of community, and in the book, you critique the most well-known representations of AIDS resistance for not depicting the role of community. The focus in these works is more often on a lone gay man and a heroic straight person who helps him.

SS | I'm arguing that those works were mainstream and highly rewarded because of the content that

they presented. I talk about *Philadelphia*, which won an Oscar, but another example is *Dallas Buyers Club*, where the guy is straight, even though the Buyers Club people were not straight.

These works have received Pulitzer Prizes and Oscars, and they were so rewarded because of the values that they present. If they had been accurate and depicted the profound abandonment of people with AIDS by their families, and the fact that it was only queer people and people with AIDS who united with each other and forced society to change against their will, the works would not have been rewarded.

In my book [Stagestruck](#), there's a section where I look at works that came out the same year as *Rent* and represented entirely opposed points of view, and they were completely marginalized. The point of view is what made those works get called brilliant, but they were highly inaccurate.

ANP | Another narrative you criticize is that the plague has been survived, that AIDS is defeated. In reality, AIDS is far from over. As you write in a note at the start of the book, thousands of people in the United States still die of AIDS each year. Globally, according to UNAIDS, there were around 690,000 deaths from AIDS in 2018.

SS | One of the book's scenes that moves me the most is when Mark Simpson, who was an artist in ACT UP, realized he was not going to survive and decided to take his own life. His friend, the filmmaker Tom Kalin, was with him while he committed suicide. He spent the weekend with him while he was swallowing pills.

Mark dies and Tom has to call his family and tell them, then he has to call the police so they can come and take the body. He's exhausted, and he's hauling himself home on Sunday and he grabs the Sunday *New York Times*. He gets upstairs to the kitchen table, opens the paper, and the cover story is by Andrew Sullivan. It's called "[When Plagues End](#)," and it's a claim that AIDS is over because Sullivan and his friends could get protease inhibitors.

The irony of this moment, how tragic it is — and it's not about whiteness, it's about being an elite, because Mark and Tom are white — the narcissism of thinking that the plague had ended because you could get protease inhibitors.

Look ahead to 2017, more than twenty years later, and Linda Villarosa, the black lesbian reporter for the *New York Times*, has a [cover story](#) where she shows that black gay men and the US South have a rate of HIV infection higher than any country in the world. In a sense, AIDS activists were able to defeat HIV but they couldn't defeat capitalism.

That's similar to what we're seeing with the COVID vaccine, that the treatments that exist are not made available because of the profit margin global pharma insists on. Fourteen hundred people died of AIDS in New York City two years ago. It's completely absurd, but it's because we don't have a logical or coherent health care system. People fall through the cracks or they get diagnosed at the emergency room when it's too late because they don't have health care.

ANP | The mainstream media's coverage of AIDS during the years your book is about was abysmal. ACT UP members would say the "New York Crimes." In 1989, there was a demo in front of *Times* publisher Punch Sulzberger's home and a march to the paper's offices. People said the newspaper ran "All the news that kills" and distributed leaflets asking why the paper was "rewriting the press releases of federal health organizations."

Not long before the demonstration, the *Times* had dismissed a federal study showing AIDS was being underreported. As the leaflet at that demo said, "This callous editorial assured its general

readership that AIDS will be over soon, once infected members of undesirable risk groups die off.”

SS | Gay people were not covered in corporate media. That’s why there was a network of underground newspapers, community-based feminist newspapers, and gay and lesbian newspapers. I started writing for them in the late ’70s. We wanted to find out what was happening with our community. The media was white and male, the private sector was white and male, and the government was white and male. And gay men who were inside that power apparatus were mostly in the closet.

The original depiction of people with AIDS in the media was emaciated people wasting away and dying, or people who are dangerous to you. When the media finally started covering AIDS, it divided people with AIDS into innocent victims and guilty victims. They actually used those words. An innocent victim was someone who had hemophilia, or had a blood transfusion, or a white heterosexual woman who had sex with a man who is secretly bisexual. A guilty victim was somebody who got AIDS through sex or needles. They were clear about that differentiation. So, the mainstream reporting was awful.

One of the people that I’m happy I included in the book is Donna Binder, who was a photojournalist. She describes how she would photograph ACT UP actions, bring the photos to photo editors, and they didn’t want them. They wanted the emaciated people. Only after ACT UP went into St Patrick’s Cathedral in December 1989 and disrupted mass did they start to understand that the photos that Donna was bringing them were photos of people with AIDS, but that these were people with AIDS who were fighting for their lives.

ANP | You show up in [United in Anger](#), the movie you did with Jim Hubbard, on the day of the St Patrick’s Cathedral action. You’re critiquing the tactics that were used. It’s a great moment because the book is also critical of approaches you disagree with —

SS | I want to disagree with you. We kept that scene in the movie to show me being wrong. History showed that I was wrong.

ACT UP was mostly Jewish and Catholic — it was pre-gentrification New York. But there was a substantial group of Protestants, and some of them were afraid of ACT UP coming across as an anti-Catholic movement. The Jews and the Catholics didn’t care about that.

So the compromise was that we would do a silent picket inside the church, and I went in to do that. But Michael Patrelis [famously](#) jumped on the pew and started screaming at the cardinal, “You’re killing us, you’re killing us!”

That went against what the group had decided, and it threw me. When I stumbled out of the church after all these people had been arrested and had a microphone put in front of me, I expressed that. But it turns out that what he did was right. It made the action much more powerful and was a turning point for ACT UP.

ANP | One critique you raise is when you question the effectiveness of an internal focus within movements. You write: “Women and/or POC ACT UP members did not waste their time trying to teach their white male comrades to be less sexist and racist.” Rather than focus on consciousness-raising among sexist or racist ACT UP members, the focus was on channeling resources to projects that aided women or people of color. That argument stands in contrast to how some of the Left currently approaches organizing.

SS | People with AIDS didn’t have time for that. ACT UP had to be effective. Anything that was

bureaucratic or not geared towards getting drugs released, or getting insurance access, or getting housing, didn't make sense. Plus, while that bureaucratic way of doing things did have a history on the Marxist left, community-based activist movements didn't really have that approach yet.

If you were working on the campaign to get women with AIDS benefits and drugs, and ACT UP had an art auction that made \$650,000, you would use that money to bring women with HIV so they could testify at hearings in Washington DC, or to pay for their travel and hotels so that they could go to demonstrations.

When the Latino caucus realized that people with AIDS in Puerto Rico needed help, they used the money from ACT UP to fly to Puerto Rico. Nobody asked them to raise the money because there were people in ACT UP that had elite relationships and they could raise it.

Don't forget: you can spend your whole life trying to change one person and fail.

ANP | I think of the phenomenon you're arguing against as a focus on language rather than action.

SS | There is a lot of focus on trying to force language right now. But when I look back, I cannot find any movement that tried to force a homogeneity of analysis and of strategy and actually succeeded. The model is a Leninism where you have the Central Committee deciding what the line is, putting that out in the paper, and then the members read the paper and stick to the line.

But that doesn't work. What works is radical democracy and big-tent politics, where people are encouraged and empowered to act effectively from wherever they sit with a bottom line of a principle of unity. In ACT UP, the principle of unity was: direct action to end the AIDS crisis.

ANP | The book has a fidelity to showing the messy truth of the movement, including how weird ACT UP's structure was.

SS | And how weird the people were! People acted out all over the place. There's so much messiness in ACT UP. It isn't only Michael screaming in the church. There's people stealing money, people who OD'd and died, people who pretended they were HIV positive when they weren't.

It was not respectability politics, for the most part, because it was a movement of humans, and ACT UP allowed people to be that way. No one was thrown out or threatened with being shunned or excluded. We didn't have a supremacy ideology about ourselves.

When you're oppressed to the point that you have no rights, you're dying, and your families have rejected you, you're not in a position to decide that you're superior to other people and you're going to throw them out because they're not clean or pure enough. It's a concept of community. Community is not a curated event. Community is an open door.

ANP | With acknowledgement of the weirdness also comes frankness about joy. ACT UP was of course structured by loss and death — you write of a "landscape of disappearance and apparition." But there is also elation. ACT UP members talk about flirting during meetings, about dancing and sex and sharing a life with one another.

That sense of the joy that comes with commitment to a collective project is often missing from movement histories. While organizing can certainly be a slog, some of my most fulfilling moments have come when I was all-in on a collective project. Some of the people you organize with become your best friends, but even the ones you don't like, you can respect. Why do you think it's important to show that joy?

SS | Don't forget that this is a time when most gay people are in the closet. People who come out into so much oppression are people who have an investment in their sexuality.

The dominant culture of AIDS was sexually punitive. When safe sex was first invented by Joe Sonnabend and Mike Callen and Richard Berkowitz, it got conflated with a moralistic punitive argument that "promiscuity" was what caused AIDS. But that wasn't true: if you used condoms, it didn't matter how many people you had sex with.

So there was an effort to control people, and ACT UP represented what would now be called a "sex positive" alternative to that. The people I interviewed for the most part said that for the first few years of ACT UP, everybody used condoms. It was a love fest — in a way, it was very hippie-ish. And people were young. When AIDS was first observed, I was twenty-three. People wanted to have fun, and they did have fun.

Movements that try to guilt trip you and are a burden aren't going to succeed. That's why Emma Goldman said, "If I can't dance, it's not my revolution." Movements need to enhance the lives of the participants, and ACT UP did that.

Sarah Schulman is a novelist, playwright, screenwriter, nonfiction writer, and AIDS historian. Her twentieth book is *Let the Record Show: A Political History of ACT UP New York, 1987-1993*.

Alex N. Press is a staff writer at *Jacobin*. Her writing has appeared in the *Washington Post*, *Vox*, the *Nation*, and *n+1*, among other places.

[Click here](#) to subscribe to ESSF newsletters in English and/or French.

P.S.

Jacobin Magazine

<https://www.jacobinmag.com/2021/06/sarah-schulman-interview-act-up>