

## Introduction

One day, when historians write the social history of AIDS, the mobilization beyond the medical field, driven by volunteer organizations, will undoubtedly be its most striking feature. And in industrialized Western countries . . . , the contribution of (chiefly male) homo- and bisexuals to that struggle will be a key chapter. (Pollak 1991a, 81)

As he wrote these lines in the early 1990s in a discussion of the French case, sociologist Michael Pollak was bearing witness to a thriving grassroots movement that would peak a few years later. In the article in question, however, Pollak painted a less-than-idyllic picture of the situation, as indicated by the title, “Constitution, diversification et échec de la généralisation d’une grande cause: Le cas de la lutte contre le Sida” (Creation, diversification and failure of the spread of a great cause: The case of the fight against AIDS). The main reason for the “failure” he diagnosed lay in then-recent divisions introduced by the emergence of a “new generation” of organizations that through “the designation of a political opponent and the definition of an ‘AIDS community’ . . . made themselves spokespersons for all who bear the mark of AIDS” and “assumed the right to represent this particular group” (87). According to Pollak, in addition to their assertive stance on homosexuality and HIV status, these newcomers were characterized by the implementation of a “distinctly political radicalization” (86), expressing a feeling of “guilt” that the designation of various enemies was meant to alleviate, using forms of action that Pollak considered questionable.

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In a book published three years earlier, Pollak had written: “If denouncing injustice entails using rhetoric aimed at convincing and mobilizing other people in order to unite them in protest so that the violence of their exposure matches the violence of which they are a victim, in the case of AIDS these paths of denunciation appear to be closed: indeed, the double stigma of homosexuality and the virus condemns the majority to silence and to the solitary management of their identity and its risks” (1988, 17). The changes that had in the meantime occurred in the field of community AIDS organizations thus led him to revise his conclusions by the beginning of the 1990s. Emphasizing a climate of violence that came to a head with an attempt to handcuff the head of the Agence française de lutte contre le sida (AFLS), the French AIDS agency, by Act Up activists during a conference Pollak co-organized (see Chapter 6),<sup>1</sup> the sociologist warned of dangers of radicalization likely to cause the decline of the “formidable engagement” of the previous years. As he died of AIDS himself the following year, Pollak was unable to follow the evolution of the movement and assess the pertinence of the alarm he had sounded in one of his last articles.

Reading this text a posteriori illustrates how difficult it is for social scientists to produce spontaneous analyses of a still-evolving phenomenon. It is now clear that the feared decline in engagement did not happen as Pollak had imagined it would. On the contrary, Act Up, which was still fairly small when he wrote his 1991 article (although 14 percent of gays active in French AIDS groups were already members, according to Pollak’s own article), would rise to prominence the following year, as France’s “tainted blood scandal” gave it unprecedented media exposure and a degree of recognition. Act Up then became an increasingly prominent player, leading it to nurture ongoing relationships with other organizations (which were also growing) but also with public institutions and authorities, culminating in the mid-1990s. Even though in its early years, various pundits argued that the American model could not work in the French context, Act Up–Paris remained for nearly twenty years one of the leading AIDS organizations in France and the most successful Act Up franchise outside the United States.

**T**he political, social, and media approach of AIDS as an exception, which lasted for years, gradually ended through a “normalization” process that had been described in the literature since the early 1990s (Kirp and Bayer 1992), but especially since 1996, with the introduction of new treatments that went on to have a crucial impact on the epidemiological evolution of AIDS in Europe (Rosenbrock et al. 2000). This phenomenon raises a question that keeps resurfacing: Is AIDS not a disease like any other?

Certainly, the fight against AIDS has taken some distinctive forms in France, particularly regarding the relations between the AIDS movement

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and the political realm (Pinell et al. 2002). In the history of epidemics and the fight against disease in France, social protest is a new development.

Social mobilization surrounding disease can be divided historically into three stages before the appearance of AIDS (Pinell 1997). The first, in the nineteenth century, was the era of charity. In the late nineteenth and early twentieth centuries, the fight against disease became part of the fight against social scourges. Then the “leagues” against tuberculosis, syphilis, alcoholism, and cancer appeared (Pinell [1992] 2002). This approach was characterized by the considerable distance between the ill and those concerned for them: socialites, physicians, public figures, and so on. The third stage involved a greater diversity of rationales and groups, with the rise of fundraising and aid for research, care facilities, and support groups influenced by the development of self-help in the United States in the 1970s. Even before the 1980s, there were patient groups whose characteristics and aims prefigured those of the later AIDS organizations. The first such groups appeared in the first half of the twentieth century, but the phenomenon really took off only in the 1960s and 1970s. This form of mobilization fit with the new economy of therapeutic relations brought about by chronic diseases and concerns numerous conditions, often chronic or degenerative, including tuberculosis, diabetes, hemophilia, multiple sclerosis, myopathy, cystic fibrosis, and cancer. These groups, which mainly interacted with the medical world, were structured around two central orientations: first, they encouraged the individual management of the disease, even to the point of acquiring scientific and technical knowledge rivaling that of physicians; second, they promoted the elaboration of a collective identity around the shared experience of the disease.

To understand how AIDS organizations stand out in this history, one must keep in mind their ties with movements that appeared in the wake of the events of May 1968, which marked an important break in France’s contemporary history. These included the Groupe d’information sur les prisons (GIP; Prison Information Group), founded by Michel Foucault and Daniel Defert in 1971, which was meant to provide a space for prisoners to express themselves. In the following decades, these movements acted as the voices of various marginalized groups, mixing a spokesperson’s role with advocacy.

**A**IDS differs from other diseases in another respect: In France, as in other industrialized countries, the epidemic spread largely within socially determined groups—the main two being gay men and intravenous drug users. It has often been rightly noted that the stigma attached to both groups gave AIDS particularly negative connotations and a strong symbolic charge. Initially, gay men were depicted as the only group affected, before public health officials constructed AIDS as a viral infection transmitted by “risky

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practices” and potentially affecting any individual exposed to the virus; later, AIDS became a great national cause of concern to the entire sexually active population. Roughly speaking, one might say that *stigmatization* of the most heavily hit groups was followed by *denial* of the epidemic’s selective spread.

In industrialized countries, the first decade after the advent of AIDS saw the construction of an epidemic with two speeds and two faces. In official discourse, the disease concerned the entire population in general, whereas in actual experience, the epidemic was limited to gay men and drug users. In both groups, the sudden appearance of the disease and of HIV was quick, massive, and devastating. But this is where the comparison stops. Gay men and drug users constitute groups that reflect epidemiological constructs but whose sociological reality is not self-evident. Epidemiology merely refers to the practice leading to transmission. Sociologically, the two groups differ in many ways, and this book focuses solely on gays. Here, I consider “gay” any person who defines himself as such; under this definition, homosexuality is neither a route of transmission of AIDS nor an essence but a social identity.<sup>2</sup>

The main thing I wish to underline here that makes AIDS an “extraordinary” disease is the differential experience of the epidemic and the ambiguous silence surrounding “gay AIDS.” While AIDS was initially constructed as a gay disease (the notorious “gay cancer”), much effort was then put into debunking that perception after the risk of a spread to the “general population” was envisioned. At the time, public health officials were caught in a double bind, wanting to limit the spread of the epidemic among gay men without stigmatizing them while also wanting to motivate others to protect themselves. The strategy they adopted emphasized that everyone was exposed, and for a long time, gays would be overlooked. At a time when the disease primarily ravaged gay men (and drug users), public discourse on AIDS stressed the scope of the threat and in the process overlooked the reality experienced by those who had already been hit hard, individually and collectively. Indeed, as some gays had taken up a communal lifestyle, the disease quickly became a collective event—even more so when screening tests appeared, making the presence of the virus among gays more visible. Daniel Defert, founder of the organization AIDES, wrote in 1990: “Currently, while heterosexuals are starting to gain awareness of the epidemic, they do not have this collective experience of the weight of loss or of HIV-positive status” (1990a, 62). This was the context in which Act Up–Paris was founded in 1989.

The silence that surrounded gay AIDS in the early stages of the epidemic was clearly an echo of past silence on the gay experience, to the extent that it appeared necessary to break those two silences at the same time to

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combat the disease effectively. As an interviewee pointed out in a film by U.S. activist Gregg Bordowitz (*Fast Trip, Long Drop* 1993), with AIDS, homosexuality became political, which also meant that with AIDS, homosexuality became *public*.

While gays were able to create various forms of social organization from the early twentieth century on, advocacy groups appeared only in the 1970s in France and in most other Western countries. In the wake of the civil rights movement and women's struggles in the United States and the events of May 1968 in France, groups of activists formed to claim the right to visibility and equality. The first decade of mobilization culminated in the repeal of discriminatory laws toward gays by François Mitterrand after his election as president of France in 1981—the very year when the first cases of AIDS were found in gay men in the United States.

In France, the change in political leadership resulted in weakening the activist factions that had until then been dominant. Instead, the 1980s saw the expansion of shared spaces, while the epidemic spread among “gays,” as homosexuals were now called. Many of them became involved in AIDS organizations whose representatives paradoxically chose to keep quiet about that dimension of the epidemic and the community that fought it. This applied to AIDES, the organization created by Michel Foucault's partner Daniel Defert after Foucault's death in 1984, even though by the end of the decade that group had the largest number of gay male members in France.

During the second half of the 1980s, as these organizations grew, they underwent a process of institutionalization. Concurrently, the AIDS struggle was transformed by a double process of generalization and fragmentation: having emerged onto the political field, AIDS became a mainstream cause; at the same time, multiple new organizations targeted specific populations.

In 1989, three journalists created Act Up–Paris, based on the namesake U.S. group founded in New York in 1987. Unlike other French AIDS organizations, Act Up did not aim to offer practical services to people affected by the disease; it strove to be their voice and represent their interests through openly political activism. From its earliest days, it clearly asserted its gay background and membership. Despite many hostile or skeptical reactions from those who perceived this import to be inappropriate to the French context, little by little Act Up went on to become a central player both in the AIDS movement and the gay movement and ended up becoming one of the most prominent protest groups in 1990s France.

This book examines the conditions and consequences of this success and sheds light on Act Up's defining feature of being the only French group to have sought and occupied a leading position both in the “social space of the fight against AIDS” and in the “field of homosexuality” (Pinell et al. 2002, 5, 9).<sup>3</sup>

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Act Up was created at a time when the situation of gays in France (as in many Western countries) was deeply transformed by the mass experience of the epidemic. As it took on the fight against AIDS while asserting its roots in the “gay community” when other organizations refused to consider the epidemic from that angle, Act Up made it possible to reconcile the experience of homosexuality and AIDS at individual and collective levels.

The conditions that made founding Act Up possible in Paris hinged on context, the skills of the actors involved, and their orientations. In the late 1980s, the French AIDS movement experienced large-scale transformations, particularly in the wake of the emergence of a public expression of the experience of HIV and of an opposition to the “dehomosexualization” of AIDS. Besides the fact that it contributed to both trends, Act Up stood out in the fight against AIDS by adopting a political approach to the epidemic and relying on forms of action and depictions of AIDS aimed at challenging predominant representations of the disease.

Having initially inherited a discourse formatted by the U.S. organization, Act Up gradually adapted to fit the French context, with the twin goals of imposing its conception of the epidemic and encouraging the populations it intended to defend and unite to become involved. It developed a full-fledged theory of AIDS, indirectly inspired by the writings of Michel Foucault, and undertook the construction and promotion of an identity for the HIV-positive gay man, intended to serve as a reference point.

These representation strategies would have had little chance of working if not for the public actions that were Act Up’s signature in the fight against AIDS and in collective mobilization against disease.<sup>4</sup> These interventions contributed vastly to making the group appear a central actor in the fight against AIDS, thanks in particular to their steadily growing media exposure in the early years.

In Act Up’s discourse and demonstrations, the question of death was prominent: the group’s entire rhetorical apparatus revolved around the lethal consequences of AIDS. From 1996 onward, the form of the epidemic changed considerably as new treatments appeared; faced with the redefinition of AIDS as a chronic disease, Act Up began rethinking its actions.

Act Up’s representation strategies, aimed both at controlling the social definition of the people or groups affected by the epidemic and at asserting its position in social spaces where it sought to be recognized as a legitimate actor, pertained to homosexuality just as much as they did to AIDS. Through its public actions, the organization helped shape the social definition not only of HIV-positive people but also of gays, whose situation would be deeply affected over the two decades that followed the creation of Act Up, due in large part to the reactions and mobilization elicited by the epidemic.

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By emphasizing the link between homosexuality and AIDS from its inception, Act Up not only came up against all the other AIDS organizations that denied the existence of such a connection; it also challenged most gay groups that were intent on keeping their cause and the fight against the epidemic distinct. Rather than assert a gay identity, Act Up claimed to defend a “gay point of view” on AIDS, which by analogy was also meant to be that of all minorities concerned.

During the second half of the 1990s, the social status of homosexuality made considerable progress, and demands for the recognition of gay couples, rooted in the fight against AIDS, ultimately led to the adoption of the *Pacte civil de solidarité* (PACS; Civil Solidarity Pact) that effectively legalized same-sex unions in France. These changes resulted in a degree of normalization of homosexuality but also in protests against it. This led Act Up to redirect its gay politics, both by joining in the fight for gay marriage and by speaking out on the question of AIDS prevention in the gay community. In the late 1990s, the new dividing lines between opposite and competing definitions of how gays should relate to AIDS were laid bare in a controversy between Act Up and two HIV-positive gay writers who wrote about unprotected sex. The conflict reflected the new stakes at the site of homosexuality, pertaining in particular to its normalization process and the opposition it attracted.

The period covered by this book ends as this controversy died out, in the mid-2000s. Subsequently, two new developments would again change the course of the history of the fight against AIDS and gay mobilization in France. The first was the recognition of the preventive value of antiretroviral treatments in late 2007, which had a major impact on the meaning and experience of HIV and the mobilization surrounding it. The second was the fight that led to the legalization of “marriage for all” in 2013. In this recent history, which remains to be written, Act Up has experienced a progressive decline, to the extent that it has become a second-tier, if not a minor, actor.