Grassroots Activism, Civil Society Mobilization, and the Politics of the Global HIV/AIDS Epidemic

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Although it is widely recognized that grassroots activism and civil society mobilization have played a major role in the global response to HIV and AIDS, the evolving nature of this response over the 30-year history of the epidemic has received relatively little attention or analysis. In part, this is because of the exceptionally wide range of social and cultural contexts in which the epidemic emerged and in which the civil society response to it was therefore created and constructed over time. These settings range from the gay communities of most major urban centers in the industrialized West to other at-risk populations, such as sex workers, people who inject drugs, and non-gay-identified men who have sex with men, to the wide range of poor and marginalized communities around the world that soon came to be disproportionately affected by the global epidemic. While it is important to recognize the diversity of activist responses to the epidemic, it is also important to highlight the commonalities among them in various settings, as well as to understand how these responses in turn have contributed to a transnational movement toward a global HIV/AIDS policy response.

With this in mind, it is possible to identify at least three historical phases of activism and civil society mobilization in the face of HIV and AIDS. First, from the very early years of the epidemic to roughly the early to mid-1990s, an initial phase of relatively intense activist mobilization took place to combat severe social stigma, denial, and inaction on the part of governments and public health officials. Then,
from roughly the mid-1990s to the mid-2000s, a growing transnational activist movement took shape around issues of treatment access and health equity; this movement played a critical role in shaping a global commitment to HIV treatment and service scale-up. Finally, from the mid-2000s to the present, the global activist movement has become fragmented, as some sectors of civil society have engaged in the implementation of treatment access and scale-up, while others have focused on a range of more localized struggles related to specific population groups and policy issues.

This article emphasizes the key role that civil society organizations and activist initiatives have played in the development of both government and intergovernmental agency responses to the epidemic. It highlights the central role played by these organizations in building the consensus that treatment access must be extended to all those infected with HIV, whether they live in resource-rich or resource-poor parts of the world. It also raises concerns about the recent fragmentation (and potential burn-out) of many activist initiatives and the difficulty of sustaining civil society responses in an era of ongoing financial crises and sharply constrained resources. Lastly, it also emphasizes the need for the independent, critical analysis, and continued monitoring of HIV/AIDS programs that activist and civil society organizations have consistently provided through the history of the epidemic, especially given the recent scale-up of these programs and services in the past decade.

Responding to Crisis: The Role of Early AIDS Activism

Grassroots activists and affected communities played a key role in shaping initial social and political responses to the epidemic around the world. In almost every community and country that has confronted HIV, there was an initial tendency toward denial on the part of governments and broader society about the threats posed by the epidemic. Grassroots activists from communities directly affected by the epidemic were almost universally the first to respond, providing home care when no adequate services were forthcoming from the formal healthcare delivery system, developing prevention education even before significant scientific knowledge was available about the causes of the emerging epidemic, and serving as the front line of defense against human rights abuses that almost everywhere accompanied the stigma associated with HIV and AIDS. Activists and civil society organizations were also the first social actors to exert meaningful political pressure on governments to take action in response to the epidemic. Almost immediately, a growing range of community-based activist organizations began to form, both to lobby governments for more effective services and to begin to provide these services when the state failed to act.¹

The early history of AIDS activism is perhaps best known for the involvement
of gay communities in the United States and other industrialized Western nations. AIDS emerged on the heels of the 1970s’ struggles for gay liberation, and gay communities had already begun to establish community-based health and social services to substitute for those that mainstream agencies failed to effectively provide. In cities across these countries, such community-based service providers quickly became the first line of defense against the epidemic. A rapidly growing gay press also became the first important source of information about the mysterious new fatal disease and provided a way for early activists to shock gay communities into action. Key nonprofit AIDS-service organizations such as the Gay Men’s Health Crisis in New York City, the AIDS Project Los Angeles, and the San Francisco AIDS Foundation were all founded in 1982. Combining community-based prevention efforts with a range of voluntary home-based care services and engaged political mobilization and pressure, they quickly came to serve as models for other similar organizations in cities around the United States and in other Western countries.2

By the middle of the 1980s, affected communities in countries around the world had begun to respond to the epidemic, in part modeling their responses off of those of gay communities in the global North, but in part adapting to the local shape and circumstances of the epidemic as it took root in other contexts. In Brazil, the first nongovernmental AIDS organization, GAPA-São Paulo (the AIDS Prevention and Support Group-São Paulo), was founded in 1985, followed by ABIA (the Brazilian Interdisciplinary AIDS Association) in 1986 and a host of other similar organizations across the country over the next three to five years. While many of these organizations counted on the participation of members of Brazilian gay and lesbian communities, they also drew participants from front line health care providers and the sanitary reform movement led by progressive public health practitioners concerned with the relationship between social inequality and disease, from Catholic base communities and the liberation theology movement within the Catholic Church, and from other key social actors driven by a range of social and political concerns raised by the epidemic.3 Similar (and similarly-influenced) organizations sprang up in countries around Latin America—Corporación Chilena de la Prevención del SIDA (the Chilean Corporation for the Prevention of AIDS) in Chile; Acción Ciudadana Contra el SIDA (Citizens Action Against AIDS) and the Liga Colombiana de Lucha Contra el SIDA (Colombian League Against AIDS) in Colombia, and Colectivo Sol (the Sun Collective) and Letra S (the Letter S) in Mexico, to mention just a few.4 In

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Uganda, The AIDS Support Organization (TASO) was created in 1987 to provide psychological and social support to those infected with HIV or suffering from AIDS, as well as to their family members, and to mobilize to resist stigma, discrimination, and ignorance. (TASO would go on to serve as a model for community-based care and support and would inspire similar organizations across sub-Saharan Africa.)

In other countries and regions, existing organizations that had been created for other purposes but that found themselves in the eye of the storm as the HIV epidemic emerged also reoriented their work to take on significant AIDS-related activities. In many parts of Africa, for example, family planning and reproductive health organizations quickly became involved in AIDS-related work, as in the case of the Family Life Association in Swaziland. In Thailand, EMPOWER (Education Means Empowerment of Women Engaged in Recreation), created in 1985, began to develop AIDS-related projects and programs by 1988 and played a key role in mobilizing Thai women involved in the entertainment industry and in commercial sex work. In Haiti, the Centre de Promotion des Femmes Ouvrières (the Center for the Promotion of Women Factory Workers) began to develop programs to educate women factory workers about HIV and collaborated with international partners to develop programs for female sex workers.

By the mid- to late 1980s, organizations committed to activism and advocacy around HIV-related issues had emerged across the world. In both the global North and global South, they had begun to play key roles in responding to the epidemic. In most parts of the world, nongovernmental organizations (NGOs) working on HIV and AIDS were actually established before official government programs were put in place. Indeed, in many parts of the world, political pressure applied by activists and AIDS NGOs was the major force that pushed governments to overcome their deeply rooted denial about the epidemic and to develop formal public health programs in response to it. It is impossible to overstate just how important grassroots pressure was—not only in the industrialized countries in North America and Western Europe, but also in more resource-poor settings in Africa, Asia, Latin America, and the Caribbean—in the push for recognition of the challenges posed by the epidemic and for protection of the rights of those affected by it. This is not to say that this patchwork quilt of individuals and organizations that had come to the fore in building such a response was well integrated or unified in terms of its approaches to the epidemic. On the contrary, it was a movement marked by a number of important tensions that would play out over time with significant consequences for the effectiveness of the global response to the epidemic.

During this initial phase of the response to the epidemic, disagreement over whether to focus on service provision or political pressure was a source of tension
in countries and communities throughout the world. While the earliest activist responses to the epidemic often included both of these dimensions—provision of care to members of affected communities and political outrage and critique of the official denial and omission that made such care-giving necessary—very early on in the response to the epidemic, as activists began to organize themselves into community-based, nongovernmental organizations, this distinction began to take on increasing importance. Some believed that caring for the ill and providing a growing range of social services that the state failed to provide was central to their mission and, in some ways, the highest demonstration of solidarity. Others thought that political critique and pressure were more urgent. Indeed, an implicit division of labor emerged within gay communities in the United States and Western European countries, NGOs in Latin American countries, organizations representing affected communities in various Asian countries, and community-based responses across Africa. A tension between AIDS service organizations (ASOs) and what were perceived to be more politicized advocacy groups was one of the early characteristics of the civil society response to the epidemic and has continued to be visible up to the present.

A second key tension, which was in some ways and in some places linked to the first, emerged around whether to emphasize prevention or treatment (as well as care) in responding to the epidemic. Prevention was central to many of the early activist responses, and the very idea of safe sex (or safer sex) was developed not by public health professionals or health education specialists, but by community-based activists developing culturally meaningful education and prevention activities, first in gay communities and then over time in a range of other affected communities and populations. Also, the need for meaningful treatment options for people living with HIV almost immediately came to the fore in the work of AIDS activists around the world. The most extensively studied early activism related to HIV treatment took place in the United States, where groups like ACT UP burst onto the scene in the mid- to late 1980s with a primary focus on advocating for changes in the processes of scientific investigation, drug development, and regulatory procedures that would make it possible to more rapidly develop new treatment options. While work around prevention was often more likely to confront the limits of moral values and to raise serious problems for more conservative sectors of society, activism focusing on treatment issues was perhaps even more likely to enter into open confrontation with complacent governments and deeply rooted commercial interests; in some settings, such as the United States, activists in the treatment movement were therefore especially likely to view it as the most radical wing of the HIV/AIDS movement.

Finally, this initial phase of the response to the epidemic was marked by an ongoing friction between some of the more well-to-do populations and communities affected
by HIV—particularly white gay men—and other, more marginalized populations affected by the epidemic, such as racial and ethnic minorities, women, people who inject drugs, and the poor. The more narrow focus of determined treatment activists in the global North intent on changing the system to gain access to life-saving medications often came into conflict with a broader set of concerns about the structural conditions that place more marginalized populations at increased vulnerability and limit the meaningfulness of many existing treatment options for members of these populations. Without access to housing or health care, new options for HIV treatment could hardly be seen to benefit many of those most affected by the epidemic. By the late 1980s, as awareness of these structural limitations increased across the world, a new set of intra-organizational conflicts emerged. In New York City, for example, ACT UP and what would come to be known as Housing Works quickly split around these issues, fragmenting into a number of diverse splinter groups.11

These tensions pointed to an even greater underlying split in the emerging movement between the multiple and diverse groups affected in various ways by the epidemic (e.g., gay, bisexual and other men who have sex with men; female and male commercial sex workers; people who inject drugs; women; heterosexual men; people from communities of color; and members of numerous ethnic minorities) and individuals with the virus in their blood—all those living with HIV or AIDS, no matter what their other affiliations, situations, or identities. In a global social context that for a number of decades had seen the rise of identity-based politics and social movements, this split between people living with HIV and those who may have been affected but were nonetheless uninfected created a powerful divide that may have been one of the major limiting factors in the development of a more broad-based social movement aimed at responding to the global AIDS epidemic. Although important efforts to overcome such divisions were undertaken—particularly in the global South, in countries such as Brazil, where a commitment to solidarity was quite consciously articulated as a way of countering a narrow a focus on identity—the fragmented nature of the social groups affected by HIV/AIDS around the world led less to a unified political movement than to a range of loosely interconnected affected communities struggling to build a broader movement.12

Progress was nonetheless made. As early as 1986, the Global Network of People Living with HIV/AIDS (GNP+) was founded to represent the unique needs of people living with HIV in communities around the world. The Society for Women and AIDS in Africa was founded in 1990 as a kind of federation of grassroots African organizations working on gender and women’s issues in relation to the epidemic and providing women’s leadership in response to AIDS at the community, regional, and international levels. Also in 1990, with support from the World Health Orga-
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nization’s Global Program on AIDS (WHO/GPA), civil society representatives and leading AIDS activists from around the world organized a meeting in Vienna and took the first steps toward creating a global network of AIDS-related NGOs that would ultimately result in the founding of the International Council of AIDS Service Organizations (ICASO) in 1991, with regional networks (AFRICASO, APCASO, LACCASO, NACASO, EUROCASO) in nearly all of the major regions of the world. Shortly thereafter, in 1992, the International Community of Women Living with HIV/AIDS was created as an international network run by and for HIV-positive women.

 Already by the early 1990s, then, the initial architecture of a global AIDS activist movement was being built. Although it was highly fragile, and would continue to be so over time, it nonetheless provided an important set of transnational connections for activists and civil society representatives seeking to work beyond the limitations of local communities or national boundaries; it also constituted an important counterweight to emerging official programs sponsored by intergovernmental agencies, such as those of the United Nations system.

The Struggle for Treatment Access: A Second Wave of AIDS Activism in the 1990s

By the early to mid-1990s, as a result of the impressive grassroots activist responses and civil society organizing over the course of the previous decade, a number of truly remarkable accomplishments had been made. Not only had activist engagement managed to overcome much of the deeply rooted denial on the part of governments and communities around the world, but it had also helped push intergovernmental agencies and the intergovernmental system to begin to mount a meaningful response to the epidemic. Just as importantly, and in some ways even more surprisingly, diverse grassroots activists and organizations responding to the epidemic had managed to come together to construct a functioning global—or at least transnational—movement. While this movement was still riddled by the many divisions described above, it nonetheless created the foundation for a new wave of AIDS activism and civil society mobilization that, over the course of the 1990s, would in many ways move beyond the previous decade’s accomplishments—in terms of both global AIDS policy and the field of global health more broadly.

In the mid-1990s, new medical developments in HIV/AIDS treatment marked an important watershed for AIDS activism. Reports of the efficacy of combination antiretroviral therapy (ART), which made a major impact at the time of the 1996 International Conference on AIDS in Vancouver, Canada, reshaped the landscape in which activist work was carried out. The effect of this major change concerning the possibility for treatment of HIV infection, however, was twofold. On the one
hand, in many of the resource-rich countries of the global North, the availability of increasingly effective HIV treatment options contributed to a gradual reduction in the intensity of much AIDS activist work. On the other hand, particularly in the global South, and for at least some organizations and activists in the North, activist engagement took on a new urgency as the struggle to access medications that had become available in resource-rich countries but that were still out of reach for the vast majority of those living with HIV in the global South became a focus of global debates about equity and justice.\(^\text{13}\)

An important consequence of increasingly effective treatment options in the late 1990s and the 2000s was that many of those who had access to treatment found that they had little remaining incentive for activist involvement.

That grassroots activism in many parts of Western Europe and North America declined as antiretroviral treatment became available is perhaps not surprising. Much of the most effective activist mobilization in the late 1980s and the early 1990s had taken place around issues of drug trials and treatment development. Organizations like ACT UP had so effectively made their case and changed scientific research and drug development processes that after the results of this work became visible through the availability of effective new treatment options, at least some of the power that direct action had unleashed almost naturally began to dissipate. For many of the more privileged members of the AIDS activist community in resource-rich countries—relatively well-to-do white gay men and others whose social positions and resources made HIV a highly atypical interruption in their lives prior to the availability of effective treatment options—it was perhaps inevitable that some of the deeply felt urgency of responding to the epidemic would begin to recede once treatment became available and HIV infection became gradually transformed from an inevitably fatal illness into a chronic, but manageable, condition. ACT UP and other lesser-known direct action activist organizations had already splintered or disintegrated as a result of the divide between the more marginalized and impoverished populations and communities and the more well-to-do activists, whose social conditions made drug access an almost exclusive concern. An important consequence of increasingly effective treatment options in the late 1990s and the 2000s was that many of those who had access to treatment found that they had little remaining incentive for activist involvement. Once effective treatment became widely available, even those deeply enmeshed in the activism of the AIDS-service industry during the early 1990s began to channel their engagement less into direct action and activism than into the implementation of treatment programs and support services for
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less well-to-do populations. A gradual “normalization” of AIDS-related work took place, which tended to downplay the more politicized and confrontational activities that were so much a part of early AIDS activism in countries like the United States.

While the global North witnessed a decline in activist engagement by at least some sectors of the AIDS activist movement in the wake of antiretroviral therapy (ART), for many civil society representatives and organizations in the global South, the news of new treatment successes had the opposite effect. Once it became apparent that effective treatment options would be available only to the wealthy few, even organizations in the South that had originally emerged primarily to provide care and support services, rather than direct political pressure, quickly mobilized around these obvious inequities. A new sense of political urgency began to grip the AIDS movement across the global South. In the North, for those activists and organizations that had prioritized broad social conditions and issues, this period brought a new focus on structural violence and solidarity (with the South). Both North and South of the equator, whatever other changes the development of ART may have unleashed, it also opened up the possibility for a new activist focus and cohesion around issues related to treatment access—as well as the emergence of a new generation of activists and activist organizations such as the Treatment Action Campaign (TAC) in South Africa, the Health GAP (Global Access Project) Coalition in the United States, and Médecins Sans Frontières, operating in a wide range of countries in the global South. In an era of growing economic globalization, but also increasing neoliberalism, the challenge for such organizations shifted in important ways from confronting official denial of AIDS as a global problem to contesting the conceptual and ethical paradigms that were taking shape in relation to the most effective ways of responding to the epidemic.14

The 1990s had also been a period of important and sometimes contradictory changes for global health governance, as powerful agencies like the World Bank increasingly challenged the World Health Organization (WHO) for primacy in responding to global health issues. The growing value placed on cost-benefit analyses of international health policies especially impacted global AIDS policy.15 In particular, the costs associated with treatment of HIV infection and AIDS led to a major emphasis on the perceived cost-effectiveness of investing in primary prevention. This position was taken up not only by the World Bank through its loans for HIV/AIDS prevention and control during the 1990s (which prohibited the use of funds for HIV treatment), but also by nearly all other intergovernmental agencies, such as the WHO, which sought to compete with the World Bank and maintain its relevance as the leading health agency in the intergovernmental system.16 For activists, the struggle for more enlightened global AIDS policies thus increasingly
became a struggle over values—a battle to convince the international agencies and the international system, as well as the governments of the global South that were so often constrained by the policies being articulated in the global North, of the fundamental importance of universal treatment access. In the face of the neoliberal cost-effectiveness arguments that increasingly dominated the global health policy agenda, it became a battle to convince the global system that "every life matters."  

The International AIDS Conferences, held every two years since 1994, provide a useful opportunity for taking the pulse of the field and monitoring key debates over policy and strategy. It is interesting to compare, for example, the 1996 conference in Vancouver with the 1998 conference in Geneva, the 2000 conference in Durban, and the 2002 conference in Barcelona to get a sense of how such debates were evolving. The 11th International AIDS Conference held in Vancouver in 1996 is best remembered internationally for reports of new scientific findings on the efficacy of antiretroviral combination therapy and advances in treatment that would soon be available to the very privileged. But it was also significant in that it highlighted the importance of social and economic inequalities—what many described as “structural violence,” such as poverty, racism, ethnic discrimination, and gender inequalities—in shaping the nature of the global HIV/AIDS epidemic. The irony of these contrasting points was lost on no one—least of all the activist community and even the scientific delegations from Southern countries participating in the conference. Indeed, the theme of “bridging the gap” was chosen for the 12th International Conference on AIDS in Geneva in 1998 precisely because of the perception of the profound gap that the availability of treatment options opened up between the rich and the poor worlds of the global North and the global South.

The overriding impression of activists who attended the 12th International AIDS Conference in Geneva, however, was that little had been done in the intervening years to close the global North-global South treatment access gap or to address this issue directly and forcefully. Between 1998 and 2000, when the 13th International AIDS Conference was held in Durban, South Africa (the first time it was held in the global South, the region of the world that had been most devastated by the epidemic), the energy of the transnational AIDS activist movement came to focus on treatment access more than any other single issue. Indeed, more than ever before, the divisions within the AIDS movement began to give way to a sense of common cause that was unprecedented in the response to the epidemic. While the first phase of AIDS activism had been built in many ways upon a foundation of identity politics, in the second wave, living with HIV seemed to provide a more “essential” basis for political organizing. A politics of solidarity with those infected with the virus began to take precedence over the politics of identity that had shaped the AIDS movement.
during the 1980s and early 1990s.

Over the course of the late 1990s, battles for treatment access played out in multiple arenas with varied results. Almost immediately after the International Conference in Vancouver, Brazilian activists and AIDS NGOs lobbied the Brazilian National AIDS Program and sympathetic members of the Brazilian Congress; together they succeeded, in less than a year, in passing and implementing legislation guaranteeing access to antiretroviral therapies for all Brazilian citizens who needed them. In 1998, with the creation of TAC in South Africa, a struggle that would last for a number of years began as the Pharmaceutical Manufacturers Association of South Africa (PMASA) sued the government of South Africa for violating patent laws. TAC ultimately filed an *amicus curiae* brief, which brought global attention and led the PMASA to withdraw its case. Later, when the South African government of Thabo Mbeki showed no sign of actually providing the generic medications that its victory would have allowed, TAC, working together with partners such as the AIDS Law Project and the Congress of South African Trade Unions (COSATU), redoubled its efforts.

A new battle, which would play itself out over a number of years, focused on pressuring the South African government to make access to antiretroviral treatment a major part of its national strategy for HIV/AIDS prevention and control. Following the 1998 creation of the Health Global Access Project (GAP) Coalition in the United States, TAC and Health GAP collaborated to make treatment access one of the major global health issues at the end of the millennium. Health GAP activists and their allies focused on the Clinton administration, hounding Vice President Al Gore every step of the way as he embarked on his own presidential campaign, until the administration finally began to let up on its consistent support for the international pharmaceutical industry and stopped pressuring the Brazilian and South African governments on “Big PhRMA’s” (Pharmaceutical Research and Manufacturers of America) behalf. By the early 2000s, treatment access campaigns had sprung up all around sub-Saharan Africa, in countries ranging from Ghana to Kenya to Tanzania, and regionally, through the Pan African Treatment Access Movement and other similar alliances. Activist organizations across Latin America had largely succeeded in pressuring their governments to follow Brazil’s lead, and organizations around Asia, such as the Thai AIDS Treatment Action Group and the Thai Network of People Living with HIV/AIDS, had waged successful battles and secured commitments from a number of Asian governments.

By the start of the new millennium, then, a broad-based and well-articulated coalition of organizations committed to the struggle for treatment access had waged a campaign to change US policy. The campaign succeeded in embarrassing the US
administration, and President Clinton had issued an executive order saying that the
US government would no longer threaten trade sanctions against African countries
seeking to procure cheaper drugs for HIV treatment. This coalition had also begun
to win over the majority of the major intergovernmental agencies involved in the
response to HIV/AIDS and had the largest US and European drug companies in
full retreat when they announced, in conjunction with WHO, UNAIDS, the World
Bank, UNICEF, and the United Nations Population Fund (UNFPA), a new plan to
cut prices for AIDS drugs in South Africa by 80 percent. The UN Commission on
Human Rights issued a resolution on “access to medication in the context of pan-
demics such as HIV/AIDS,” and in the lead-up to the first United Nations General
Assembly Special Session on HIV/AIDS, to be held at the UN in June of 2001, Kofi
Annan announced plans to create the Global Fund to Fight AIDS, Malaria, and
Tuberculosis and to raise $7–10 billion to support work that prioritized treatment
access and took a human rights-based approach to the epidemic. By November 2001,
at the World Trade Organization (WTO) Ministerial Meeting in Doha, Qatar, a new
declaration on TRIPS (Trade-Related aspects of Intellectual Property Rights), public
health, and “access to medicines for all” was adopted that formalized provisions for
exceptions to patent laws under the condition of a public health emergency and
that would have been unthinkable only a few years before or without the persistent
activist interventions that had been carried out since the late 1990s. By the time of
the 14th International Conference on AIDS, held in Barcelona in 2002, the ethical
and ideological battle had essentially been won. While there were still major doubts
about how to implement treatment roll-out in order to successfully guarantee access
to all people who need it around the world, the debate about whether or not universal
access is a moral obligation was essentially over.

The creation of the Global Fund, followed by the joint UNAIDS and WHO 3 x 5
Program (which aimed to provide ART to 3 million people by 2005) and the United
States’ massive PEPFAR (the President’s Emergency Plan For AIDS Relief) Program
(which initially provided an authorization for $15 billion from 2003 to 2008, with
a primary focus on providing ART access in 15 priority countries primarily in sub-
Saharan Africa), initiated a phase of “scale-up” of HIV-related services, and ART in
particular, that would come to define the field of global health and the architecture
of global health governance in the early twenty-first century.22 None of these de-
velopments would have been imaginable even a decade earlier, and it is fair to say
that none of them would have happened without the transnational treatment access
movement that had been created by AIDS activists and civil society organizations
in the second wave of the activist response to the epidemic.
A Third Wave: AIDS Activism in the Wake of “Scale-Up”

By the early to mid-2000s, after the tide had turned in relation to treatment access and the process of scale-up, not only of treatment but of all HIV/AIDS-related services, had begun to move forward, the third wave or phase of AIDS activism seems to have begun. It is important to recognize, of course, that from an activist perspective, the very notion of “scale-up” is relative at best; the extent to which necessary access has actually been guaranteed globally is still limited. From this perspective, there is still much to be done in terms of advocating for broader access among poor and marginalized populations across the global South. There is also a strong sense, however, that the ideological battle has been won—that the majority of the organizations and institutions responsible for administering the global response to the epidemic fully recognize the necessity of access and that the key struggles now lie in implementation.

This changing landscape has led to a number of subtle shifts in the emphasis of activists and civil society institutions involved in the broader response to the epidemic. In particular, they have been playing a growing role in monitoring various activities associated with global scale-up, sometimes as advocates but more often in a technical capacity. Activists have increasingly been drawn into the labor force of important global initiatives. This is hardly new in and of itself. Since the earliest days of the formal response to the epidemic, activists have been involved in many of the most important “official” spaces charged with responding to AIDS. As early as the late 1980s, the WHO/GPA was well known for bringing in key staff members linked to a range of affected and normally marginalized populations and communities, including gay men, sex worker rights advocates, people living with HIV, and others who would not previously have been likely to operate within the institution in this capacity. As representatives of affected populations, these advisors possessed especially relevant technical expertise precisely because of who they were and where they came from. This tendency has increased over a number of decades, and it has been formalized in a number of ways—through the representation of NGOs on the board of UNAIDS, the hotly contested but nonetheless successful inclusion of affected communities in the formal processes and institutional spaces of events such as UNGASS (the United Nations General Assembly Special Session), and similar developments throughout the history of the epidemic.33 This involvement, however, has clearly reached a new level since the early 2000s, as the demands of an expanding field have increased and new spaces have opened up for active participation: for example, in the elaboration, review, and implementation of large-scale projects funded by agencies such as the World Bank, the Gates Foundation, and, in particular, the Global Fund.

In part, this growing involvement of activists and civil society representatives
in a range of new program activities and service provision functions has almost inevitably led to at least some decrease in more confrontational political activism, as activist energy (and technical expertise) has been incorporated into what some analysts came to describe as the growing global AIDS industry—a complex field of institutions and social actors that grew up around the epidemic to provide prevention, treatment and care services, to conduct biomedical and behavioral research related to HIV, and to develop new products and practices aimed at responding to the epidemic.\textsuperscript{24} While the direct action and political confrontation that characterized earlier periods of mobilization in response to the epidemic have not completely disappeared, they have certainly been reduced, in both frequency and intensity, and, in some ways, have been domesticated—brought into the carefully controlled spaces of the so-called Global Village (made up primarily of the booths of civil society organizations) at the biannual International AIDS Conference (standing in contrast with the treatment access street demonstrations held in conjunction with the Durban conference more than a decade ago).

While it is impossible not to highlight the extent to which at least some activist energies seem to have been channeled into more official spaces and activities, it is also important to recognize that much significant political energy has nonetheless been maintained, even during this most recent period, in fighting against continued examples of idiosyncratic irrationality (such as the ongoing “denialism” of HIV as the cause of AIDS during the administration of Thabo Mbeki in South Africa and the irresponsible statements and policies of his minister of health).\textsuperscript{25} Activist energy has also been redirected in extremely important ways to new challenges that have emerged as the importance of treatment access has been officially recognized and scale-up of services has gradually been underway. Just one key example of this process is the continuing role of activists and their allies in a range of battles around intellectual property rights and access to lower-priced generic medications as central to containing the cost of HIV treatment in resource-poor countries.\textsuperscript{26} These issues were, of course, already central at the height of the campaign for treatment access in 2000 and 2001, as groups like Health GAP hounded Al Gore’s campaign to criticize the Clinton administration’s threatened aid and trade sanctions in defense of the US pharmaceutical industry; as TAC and COSATU fought lawsuits brought by the PMASA; and as AIDS activists from around the world sided with Brazil in defense of the complaint against it by the US government in the WTO. Such efforts have only grown in importance since 2001, in the wake of the WTO ministerial meeting in Doha, Qatar, and the adoption of the declaration on TRIPS, public health, and access to medicines for all.\textsuperscript{27} Over the course of the 2000s, a global network of AIDS and intellectual property rights activists served as watchdogs over Big PhRMA’s excesses,
educating local communities and people living with HIV about the complexities of intellectual property law and about the rights of countries within the negotiating and regulatory structure created by the WTO.

How activist engagement will continue to evolve in the future is an open question. The increasing incorporation of activist engagement and energy into the formal structures and institutions of the global response to HIV/AIDS is likely to continue. The difficulty of maintaining an ongoing political critique and independent political position is also likely to grow in the wake of the global financial crisis that emerged at the end of the 2000s. One of the key results of this financial crisis, together with changing patterns in donor priorities, has been an ongoing process of funding cutbacks. As development cooperation agencies have reorganized their programmatic priorities, support for civil society efforts, and, in particular, for more politicized approaches to the epidemic, have been the first thing to go. Donors with a more technical (and sometimes technocratic) approach, such as the Gates Foundation, have increasingly come to dominate the field, while others that once played an important role in supporting civil society monitoring and mobilization (such as the Ford Foundation, the MacArthur Foundation, or the Rockefeller Foundation) have reduced or even discontinued their work in this area. A growing shift away from policy monitoring and critical dialogue and towards more technical implementation support appears to be a key tendency at the beginning of the fourth decade of the epidemic.

While it is impossible to fully predict the ways in which these recent developments will affect the future of the AIDS activist movement, there is certainly reason for concern that they will lead to reduced support for advocacy and policy monitoring at a critical moment: when the scale-up of the global response to the epidemic has been most significant; when the large scale of health bureaucracies around the world, as well as of the intergovernmental system, has mobilized unprecedented resources; and when the need is greatest for ongoing monitoring and watchdog activities aimed at ensuring the effective implementation of the full range of services and programs that scale-up has made possible. In what is otherwise a somewhat somber scenario, however, there may be reason for some degree of optimism. In the now 30 year history of the civil society response to the epidemic, grassroots activists have managed to transform their movement into a transnational coalition capable of overcoming the resistance of some of the most powerful private interests in the world and creating an unprecedented level of mobilization of public institutions at both the national and intergovernmental level in ways that are unheard of in relation to any other global health issue. While the economic and policy challenges are significant, the persistence of the AIDS activist movement in seeking to transform the world’s response to the epidemic should give us at least some reason for hope about the future.
Notes

5. Altman, *Power and Community*.
7. Ibid.
8. Dennis Altman, *Power and Community*.
9. Ibid.
11. Ibid.

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