

Civil Society, Political Mobilization, and the Impact of HIV Scale-Up on Health Systems in Brazil

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Abstract: This article examines the role of civil society in shaping HIV and AIDS policies and programs in Brazil. It focuses on the historical context of the redemocratization of Brazilian society during the 1980s, when the initial response to the epidemic took shape, and emphasizes the role of social movements linked to the progressive Catholic Church, the sanitary reform movement in public health, and the emerging gay rights movement in the early response to the epidemic in Brazil. It highlights the broad-based civil society coalition that took shape over the course of the 1990s and the political alliances that were built up shortly after the 1996 International AIDS Conference in Vancouver, Canada, to pass legislation guaranteeing the right to access to antiretroviral treatment. It emphasizes the continued importance of civil society organizations—in particular, AIDS-related nongovernmental organizations—and leading AIDS activists in exerting continued pressure to guarantee the sustainability of treatment access and the impact that action focused on HIV and AIDS has had on the Brazilian public health system more broadly, particularly through strengthening health infrastructures and providing a model for health-related social mobilization.

Key Words: activism, Brazil, civil society, health systems, HIV/AIDS, social movements

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The Brazilian response to HIV and AIDS has been widely acknowledged to be among the most effective in the world.^{1,2} This success has been associated, more than anything else, with the Brazilian government's pioneering decision in 1996 to make antiretroviral therapy (ART) universally available.³ Evidence has mounted during the past decade

suggesting that the HIV epidemic has not only reached a plateau but may also have begun to decrease, thanks to an aggressive public health response.^{4,5} The frequently highlighted role of civil society in shaping the Brazilian response to HIV and AIDS has been defined by researchers and politicians alike as one of the key ingredients of Brazil's relative success.⁶ This brief article highlights 3 important ways in which the representatives and organizations of civil society have contributed to the response to HIV and AIDS in Brazil, ways that help to explain not only the relative effectiveness of the country's National AIDS Program but also the relatively positive impact of AIDS-related activities on the broader Brazilian health system:

- The historical roots of this response during a period of political redemocratization.
- The broad-based coalition of social movements that came together in seeking to respond to HIV and AIDS.
- The ways in which the implementation of progressive policies and programs in response to HIV and AIDS has contributed to broader attempts at social control and standards of accountability in relation to the Brazilian health system more generally.

Although there is no easy recipe for translating these successes to other countries or contexts facing epidemics of their own, much can be learned from analyzing the Brazilian experience that might help us think more effectively about the challenges in other settings.

One of the key historical factors to remember in analyzing the early Brazilian response to HIV is the fact that it coincided with the return to civilian democracy after nearly 20 years of military authoritarian rule.⁷ Consequently, early mobilization around the emerging epidemic took place in a context of unprecedented mobilization of civil society around a whole range of social and political issues. Voluntary organizations flourished and the creation of mechanisms aimed at guaranteeing the protection of civil rights and at ensuring citizens' active participation in governmental decision-making became one of the highest priorities in public life, culminating in 1988 with the promulgation of a new "democratic" constitution. The initial response to HIV and AIDS in Brazil was very much a part of this milieu. For example, in the state of São Paulo, where the major impact of the epidemic was felt early in the 1980s, politicians linked to the progressive Catholic Church (which had played a key role in resisting the military dictatorship) were quickly elected to office after the return of democratic elections at the state level, and leading figures from the sanitary reform movement in public health were appointed the state Secretariat of Health. A new openness to popular

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political demands meant that the São Paulo Health Secretariat moved quickly when approached in 1983 by a group of gay activists concerned about the emerging epidemic, establishing the first governmental AIDS program in the Americas. By 1985, when the Brazilian Ministry of Health began to mobilize in response to HIV and AIDS, state-level programs largely modeled on São Paulo's experience had already been established in 11 of Brazil's 27 states and federal districts.⁸ During this same time, from new nongovernmental organizations across Brazil's major cities, a dynamic response began to emerge that brought together public health researchers and practitioners, social workers, and members of affected communities to provide community-based care, develop prevention programs, and advocate for more effective governmental policies.⁹ AIDS activists, together with representatives of the broader sanitary reform movement, would play an important role in the public debates leading up to the drafting of the new constitution in 1988, which articulated the legal basis for universal access to health care services, the principle of integration between treatment and preventive public health programs, and the principle of "social control" of health care policies and programs through citizen representation on health councils at every level of government—all of which would come to have significant implications for the elaboration and implementation of HIV/AIDS-related policies and programs over the next 20 years.¹⁰

A second important aspect of civil society's contributions to Brazil's response to HIV and AIDS has been the unusually broad base of engaged social movement support mobilized around HIV-related and AIDS-related issues. The AIDS movement that took shape in the 1980s brought together at least 3 seemingly unlikely partners: the progressive Catholic Church and the liberation theology/base community movement; the sanitary reform movement; and the nascent gay liberation movement. During the 1990s, this initial coalition of actors from civil society and social movements succeeded in reaching out to other social groups and organizations, broadening its political base further still by building bridges to the feminist and women's health movements, the black movement, the popular health movement, and other emerging health-related movements among what have been described as the various "users" of the Brazilian health system, including people living with other conditions such as diabetes, drug addiction, and mental health conditions.¹¹ The increasingly broad base of support made it possible to pass legislation aimed at guaranteeing universal access to ART less than 6 months after the 1996 announcement, at the International Conference on AIDS in Vancouver, Canada, of early successes with such medications.¹² Equally important, the broad support provided the concrete mechanism to monitor the legislation's effective implementation and to sustain political support for treatment access independent of the significant associated costs. It was the widely supported AIDS movement that monitored availability of medications through local health posts and the scale-up of necessary equipment and health system infrastructure to ensure the existence of conditions for successfully implementing HIV treatment access across the country—and that denounced failure to meet these conditions when it occurred.¹³

Brazil's program of universal access to ART has impacted the Brazilian health system more generally in complex ways, among others by significantly effecting improvement to some aspects of the physical and technological infrastructure and to aspects of human resources, such as training and capacity building.¹⁴ Yet it is probably in relation to civil society's capacity to monitor and advocate around health-related issues that the most important and potentially long-lasting effect of HIV and AIDS on the Brazilian health system has been felt. Just as AIDS activists and nongovernmental AIDS advocacy organizations played a crucial role in ensuring the inclusion of health care as "a right of all and a duty of the state" in the 1988 constitution, the broad support that coalesced around the AIDS movement during the 1990s played a key role in implementing participatory Health Councils at municipal, state, and federal levels.¹⁵ The interaction between governmental AIDS programs and civil organizations focusing on HIV and AIDS (and typically referred to as AIDS nongovernmental organizations) became an important model for implementing "social control" over the health system more broadly, and the strategies employed to ensure active social and political engagement by civil organizations in relation to the development of HIV and AIDS policies and programs have increasingly been extended in seeking to guarantee wider health system reform and democratization.

Although many recent debates about how to most effectively strengthen global public health programs have revolved around the need to prioritize among specific diseases (such as HIV, tuberculosis, or malaria) rather than to focus on strengthening health systems in their entirety,^{16,17} one of the key lessons of recent Brazilian history is that framing the options in this way is fundamentally incorrect. On the contrary, just as Brazilian experience over the past decade undermined earlier assumptions about the need to invest in prevention as opposed to treatment in the field of HIV, the history of the mobilization of civil society in response to HIV and AIDS in Brazil suggests that strengthening a country's response to the epidemic can in fact have important consequences for its entire health system. In Brazil, this has been the case not only because of significant investments in health system infrastructure needed to effectively respond to HIV and AIDS but also, and perhaps even more importantly, because the energy and commitment of AIDS activism and mobilization of civil society associated with the HIV epidemic has spilled over in important ways to contribute to citizen involvement and greater social control of health care. The active engagement of communities and involvement of citizens in mobilizing around policy debates and monitoring health care programs' implementation are among the greatest legacies of the sanitary reform movement in Brazil.¹⁸ The civilians and civilian organizations that have led the response to HIV and AIDS in Brazil have played a key role in extending this legacy and in contributing to its impact on the Brazilian health system. It is easy to overlook this broader social process if we focus too narrowly on health institutions and programs. A wider focus on the social and political processes that shape the field of public health makes it clear that at least in Brazil, the response to HIV and AIDS and efforts to strengthen a participatory health system have existed in a kind of synergistic or feedback relationship. Although there is no easy

way to transfer Brazilian experiences to other countries, they certainly embody important lessons that may be relevant when considering the most effective ways to proceed in other very different settings and circumstances.

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