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## 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 re-democratization 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, in order to pass legislation guaranteeing the right to antiretroviral treatment access. It emphasizes the continued importance of civil society organizations – in particular, AIDS-related NGOS – and leading AIDS activists in exerting continued pressure in order 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 more broadly.

### Keywords

activism; civil society; social movements; health systems; Brazil

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The Brazilian response to HIV and AIDS has been widely acknowledged to be among the most effective in the world.<sup>1,2</sup> This success has been associated, more than anything else, with the Brazilian government's pioneering decision in 1996 to make antiretroviral treatment universally available.<sup>3</sup> Evidence has mounted over the course of the past decade suggesting that the HIV epidemic has not only reached a plateau, but may have begun to decrease thanks to an aggressive public health response to the epidemic.<sup>4,5</sup> The role of civil society in shaping the Brazilian response to HIV and AIDS has frequently been highlighted, and has been defined by researchers and politicians alike as one of the key ingredients of Brazil's relative success.<sup>6</sup> This brief article highlights three important aspects of the ways in which civil society representatives and organizations have contributed to the response to HIV and AIDS in Brazil that help to explain not only the relative effectiveness of the country's National AIDS Program (NAP), but also the relatively positive impact of AIDS-related activities on the broader Brazilian health system: (1) the historical roots of this response during a period of political re-democratization; (2) the broad-based coalition of multiple social movements that came together in seeking to respond to HIV and AIDS; and (3) 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

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

One of the key historical factors that must be remembered in analyzing the early response to HIV in Brazil is the fact that it took place at the same time as the return to civilian democracy after nearly 20 years of military authoritarian rule.<sup>7</sup> Because of this, early mobilizing around a newly emerging epidemic took place in a context of unprecedented civil society mobilization around a 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 in the promulgation of a new "democratic" Constitution. The initial response to HIV and AIDS in Brazil was very much a part of this historical milieu. In the State of São Paulo, where the major impact of the epidemic was felt early in the 1980s, for example, politicians linked to the progressive Catholic Church (which had played a key role in resisting the military dictatorship) were quickly elected to office following 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 political demands meant that the São Paulo Health Secretariat moved quickly when approached in 1983 by a group of gay activists concerned about the newly 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.<sup>8</sup> During this same time, a dynamic response began to emerge on the part of newly formed non-governmental organizations across Brazil's major cities that brought together public health researchers and practitioners, social workers, and members of affected communities to provide community-based care, develop prevention program, and advocate for more effective governmental policies.<sup>9</sup> 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 and AIDS related policies and programs over the next two decades.<sup>10</sup>

A second key aspect of civil society's key contributions to Brazil's response to HIV and AIDS has been the unusually broad base of engaged social movement support that has been mobilized around HIV and AIDS-related issues. The AIDS movement that took shape in the 1980s brought together at least three seemingly unlikely social movement partners: the progressive Catholic Church and the liberation theology/base community movement; the sanitary reform movement; and the nascent gay liberation movement. Over the course of the 1990s, this initial coalition of civil society and social movement actors succeeded in reaching out to other social movements and in 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 nascent health-related movements among what have been described as the various "users" of the Brazilian health system, including people living with other health conditions such as diabetes, drug addiction and mental health conditions.<sup>11</sup> This increasingly broad base of support made it possible to pass legislation aimed at

guaranteeing universal access to antiretroviral treatment in less than six months following the announcement, at the International Conference on AIDS in Vancouver, Canada, in 1996, of early successes with such medications.<sup>12</sup> Equally important, it provided the concrete mechanism to monitor the effective implementation of this legislation, and to sustain political support for treatment access independent of the significant costs that would be associated with it. It was the broad-based AIDS movement that monitored availability of medications through local health posts, and the scale-up of necessary equipment and health system infrastructure, to ensure that conditions existed for successfully implementing HIV treatment access across the country – and that denounced failure to meet these conditions when it occurred.<sup>13</sup>

Brazil's program of universal antiretroviral treatment access has impacted on the Brazilian health system more generally in complex ways, including, among other things, significant improvement in some aspects of the physical and technological infrastructure as well as training and capacity-building in relation to human resources.<sup>14</sup> 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 non-governmental AIDS advocacy organizations played a crucial role in insuring the inclusion of health care as "a right of all and a duty of the state" in the 1988 Constitution, the broad-based coalitions that the AIDS movement established over the course of the 1990s played a key role in implementing participatory Health Councils at the municipal, state and federal levels.<sup>15</sup> The interaction between civil society organizations focusing on HIV and AIDS (and typically referred to as AIDS NGOS) and governmental AIDS programs 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 on the part of civil society organization in relation to the development of HIV and AIDS policies and programs have increasingly been extended in seeking to guarantee health system reform and democratization more broadly.

While many recent debates about how to most effectively strengthen global public health programs have revolved around the need to choose between prioritizing specific diseases (such as HIV, tuberculosis or malaria) as opposed to focusing on strengthening health systems more broadly,<sup>16,17</sup> one of the key lessons from 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 civil society mobilization 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 health system more broadly. In Brazil, this has been the case not only because of significant investments in the health system infrastructure that is needed to effectively respond to HIV and AIDS, but also, and perhaps even more importantly, because the energy and commitment of AIDS activism and civil society mobilization that has been associated with the HIV epidemic has spilled over in important ways to contribute to citizen involvement and greater social control in relation to health care more broadly. The active engagement of communities, the involvement of citizens in mobilizing around policy debates and in monitoring the implementation of health care programs, is one of the greatest legacies of the sanitary reform movement in Brazil.<sup>18</sup> The civil society actors and 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 more broadly. It is easy to overlook this broader social process if we focus our attention too narrowly on health institutions and programs, but a broader focus on the social and political processes that shape the field of public health makes it clear that at least in the case of Brazil the response to HIV and AIDS

and efforts to strengthen a participatory health system more broadly have existed in a kind of synergistic or feedback relationship. While there is no easy recipe by which experiences in Brazil can be transferred to other countries, there are certainly important lessons that can be learned which may be relevant in thinking about the most effective ways to proceed even in very different settings and circumstances.

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