In low- and middle-income countries, the HIV/AIDS epidemic continues to spread among the most vulnerable groups, notably the poor and women (with vulnerability defined as “the extent to which individuals are capable of making and effecting free and informed decisions about their life”2(44)).3,4 The global cumulative prevalence of HIV-infected people is 33.2 million persons. Countries of sub-Saharan Africa are particularly affected, with an HIV seroprevalence of 18% among young adults in some countries.5 Where there are weak health care systems, control of the epidemic remains an unsolved issue.5

In Brazil, the HIV seroprevalence among young adults is estimated at 0.65%, and AIDS mortality has decreased significantly since 1997, when highly active antiretroviral therapy became available for free.6 The Brazilian federal and local (state and municipal) AIDS programs are considered to be a model for low- and middle-income countries because they have developed a close cooperation between government, health services, and nongovernmental organization (NGO) actors (persons or groups involved in the formulation and implementation of policies and programs). The Ministry of Health defined ambitious prevention policies and provided free access to antiretroviral treatment.7–13

Implemented at 3 levels—federal, state, and municipal—the AIDS programs have been developed within the Brazilian universal health system (Sistema Unico de Saude), impelled by the sanitariat movement.14–16 This movement involved physicians, public health workers, and politicians who in the 1980s advocated and then implemented this new health system, which is based on prevention and free access to care. Programs have been established in 27 states and more than 400 municipalities. In these states and municipalities, several HIV/AIDS facilities have been implemented, including voluntary counseling and testing centers, specialized assistance services for ambulatory care, and hospital services.17 Many NGOs, whether AIDS-specific (AIDS NGOs) or generalist, are involved in service provision and policy-making.18

During the past decade, the Brazilian epidemic has changed.19–21 Initially, the epidemic affected mainly urban men of middle and upper classes in the southeastern part of the country. Thereafter, it affected more and more the poor19–21 and women22,23 and diffused throughout the country. The national AIDS program has also been confronted with the rising cost of antiretroviral drugs, making the sustainability of the existing programs questionable.24,25 These changes require strategic evolution of the current AIDS policies.

To address these new trends, Brazil has, among recent initiatives, decentralized the handling of AIDS policies through incentivos (incentives), financial incentives allocated to states and municipalities that develop AIDS programs appropriate for the local epidemiological situation and integrated into the local health system. Within the incentives policy framework, states and municipalities define their action plan yearly. Such plans are adopted by state or municipal health councils, composed equally of health care professionals, end-users, and local government representatives.

The responses to these new trends in the HIV/AIDS epidemic have been studied by focusing on national AIDS policies, ignoring what happens at subnational levels.7–13 Moreover, very few published articles have adopted a political science stance and public policy analysis to identify what happens at the front line, to assess how different actors cooperate, and to assess what consequences their cooperation induces for prevention of HIV infection, care of the patient, and sustainability of AIDS programs.

We studied how decentralized approaches to the HIV/AIDS epidemic in Brazil addressed the new trends of the epidemic, highlighting

**Objectives.** We investigated involvement and cooperation patterns of local Brazilian AIDS program actors and the consequences of these patterns for program implementation and sustainability.

**Methods.** We performed a public policy analysis (documentary analysis, direct observation, semistructured interviews of health service and nongovernmental organization [NGO] actors) in 5 towns in 2 states, SãO Paulo and Pará.

**Results.** Patterns suggested 3 models. In model 1, local government, NGOs, and primary health care services were involved in AIDS programs with satisfactory response to new epidemiological trends but a risk that HIV/AIDS would become low priority. In model 2, mainly because of NGO activism, HIV/AIDS remained an exceptional issue, with limited responses to new epidemiological trends and program sustainability undermined by political instability. In model 3, involvement of public agencies and NGOs was limited, with inadequate response to epidemiological trends and poor mobilization threatening program sustainability.

**Conclusions.** Within a common national AIDS policy framework, the degree of involvement and cooperation between public and NGO actors deeply impacts population coverage and program sustainability. Specific processes are required to maintain actor mobilization without isolating AIDS programs. (Am J Public Health. 2009;99:1108–1115. doi:10.2105/AJPH.2008.138123)
positive effects and difficulties, and make recommendations for Brazilian policymakers and to other low- and middle-income countries.

METHODS

We conducted our field study primarily in 5 municipalities of 2 states with very different health and socioeconomic characteristics (Table 1). (Details are available as a supplement to the online version of this article at http://www.ajph.org.)

The state of São Paulo is the most affluent, urbanized Brazilian state. It benefits from plentiful health care infrastructures, and its health indicators are the best among the Brazilian states. Major social disparities still exist, with a poor population concentrated in urbanized areas (favelas).27 The incidence of AIDS remains high (20.8 per 100,000), and the epidemic is spreading across the state.6

In São Paulo, we conducted the study in Guarulhos, a city with 1 million inhabitants and a suburb that includes a large poor population, and Ribeirão Preto, a city with 500,000 inhabitants and a rather affluent town in the interior that attracts many migrants.

The state of Pará (Amazonia) is sparsely populated, with a poor, rural population distributed over a large area. The health care infrastructure is deficient.26 The incidence of HIV/AIDS remains lower than that in São Paulo.6 Nevertheless, the epidemic is rapidly progressing. In this state, we conducted the study in Belem, the capital (1.2 million inhabitants); Ananindeua (500,000 inhabitants), part of the state’s principal agglomeration; and Santarém (300,000 inhabitants) located in the interior.

Data were collected in 2005 and 2006. We interviewed 76 public and nongovernmental operational actors in the AIDS programs and in the health care systems in a semidirected manner: 18 persons in each of 3 municipalities (Guarulhos, Ribeirão Preto, Belém) and 11 each in Santarém and Ananindeua. The persons we interviewed had identical professional roles in each case (details are available in the supplement to the online version of this article at http://www.ajph.org). We also used direct observation of the health care system and vulnerable groups.

We added a literature search (using terms “HIV,” “health policy,” “policy-making,” “nongovernmental organizations,” “prevention and control,” “delivery of health care,” and “Brazil”) in MEDLINE, BIREME, SCIELO, JSTOR, and GLOBAL HEALTH databases and in the available gray literature (open source material that can usually be obtained through specialized channels and may not enter normal channels or systems of publication, distribution, bibliographic control, or acquisition by book-sellers or subscription agents), for example, technical reports from government agencies or scientific research groups, working papers from research groups or committees, white papers, or preprints.

We analyzed the collected information with a systemic and strategic approach29 (details are available in the supplement to the online version of this article at http://www.ajph.org) that is highly effective for analyzing AIDS policies.29,30 Our approach was not limited to institutional actors but also focused on nongovernmental actors,30 who had been deeply involved in the Brazilian AIDS policy process and who had affected the whole health policy within the health councils.

The field data allowed us to define 3 models29 (details are available in the supplement to the online version of this article at http://www.ajph.org) according to the involvement and cooperation patterns of local actors, and the consequences of these cooperation patterns for the prevention of HIV infection, care of patients, and sustainability of programs.

The analysis refers to the notions of exceptionalism and normalization32,33 as defined by Rosenbrock et al.: HIV infections and the outbreak of AIDS attracted not only special attention in all the countries impacted but also led to a high degree of readiness to try out innovative processes as well as to institutionalize matters and disburse large amounts of money—AIDS became the exception from many rules in health policy, prevention and patient care.32

Normalization is a process in which a phenomenon that was previously considered as extraordinary loses this status and returns to the world of familiar and customary in terms of perception and action.33

RESULTS

Evidence collected by in-depth field studies in 5 cities of Brazil suggested that at least 3 different types of local approaches were at work in handling AIDS policies at the grassroots level. Table 2 presents the local actors involved in each model and their cooperative links. Table 3 outlines the effects that each of the 3 models had on prevention of HIV infection, care of patients, coverage, and sustainability of programs.

Model 1 describes the approach at work in the 2 towns of São Paulo state and in 1 town of Pará: exceptionalism, because of strong advocacy efforts of AIDS NGOs and their strong level of cooperation with the AIDS programs, has evolved to normalization as discrimination was lowered. This normalization facilitated close cooperation with primary health care services and the involvement of generalist NGOs, which resulted in the coverage of a large

<table>
<thead>
<tr>
<th>TABLE 1—Demographic, Sociosanitary, and AIDS Epidemiological Indicators in São Paulo and Pará, Brazil: 2005–2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>São Paulo State</td>
</tr>
<tr>
<td>Population, millions</td>
</tr>
<tr>
<td>Urban population, %</td>
</tr>
<tr>
<td>Human development index &gt;0.850</td>
</tr>
<tr>
<td>Population living under the poverty threshold, %</td>
</tr>
<tr>
<td>Infant mortality rate per 1000 inhabitants</td>
</tr>
<tr>
<td>Number of medical doctors per 1000 inhabitants</td>
</tr>
<tr>
<td>AIDS incidence rate per 100,000 in 2006</td>
</tr>
<tr>
<td>AIDS-related deaths, 1980–2006</td>
</tr>
<tr>
<td>Cumulated total AIDS cases, 1980–2007</td>
</tr>
</tbody>
</table>

Sources: Pan American Health Organization,26 Brazilian Ministry of Health (http://www.aids.gov.br).
exceptionalism had no chance to emerge. The issue of HIV/AIDS was managed only by administrative actors. There were difficulties in trying to cover large parts of the poor population and in safeguarding the sustainability of any AIDS policy.

From Exceptionalism to Normalization and Integration

*Actors and patterns of cooperation in model 1.* In this approach, several major groups cooperated closely in implementing the AIDS policy in a context of little discrimination against persons living with HIV/AIDS. These groups included local, state, and municipal authorities; municipal and state AIDS programs; generalist and AIDS NGOs; and operational health units including voluntary counseling and testing centers and specialized assistance services for ambulatory care, hospital infectious disease departments, maternity units, and primary health care services.

State and municipal governments and state programs gave intensive support to the municipal AIDS programs so that the latter were considered reliable and relevant partners when program staff were negotiating with other actors. The NGOs, many of them well organized, maintained close partnerships with the staff of AIDS programs and with local government heads.

The profile of AIDS NGOs has evolved over the years. Although at the beginning they intensively lobbied local authorities, their demands were gradually met, to the point that, at the time of the study, AIDS program leaders sometimes criticized NGO activists for their lack of lobbying efforts. The activists allocated their attention to improving the way health care was operationally managed, an issue mainly discussed at the state level during periodic state AIDS NGO forums (meetings of NGOs with state AIDS program personnel).

In these towns, there was little public ostracism of HIV-seropositive persons, and the AIDS policy was originated by consensus and quickly legitimized by health councils. At the operational level, primary health care service units were strongly involved in the prevention of HIV/AIDS. Because of the public support,
these programs received the explicit political support that AIDS programs benefit from, with cooperative relationships among the actors.

Persons in the primary, secondary, and tertiary health care levels acted in a somewhat collective way. Public health physicians also helped to integrate HIV prevention, screening, and care. Because of their different cultures and methods of operation, field cooperation between primary health care services and NGOs remained unusual, impacting the rational coverage of the population.

Public health consequences, strengths and weaknesses of model 1. Local government support and the negotiation capacity of the AIDS programs facilitated the allocation of financial and human resources.

In the field of prevention, the fact that primary health care service structures were directly involved increased the coverage of the population, especially in areas of poverty. Several NGOs targeted specific vulnerable groups such as sex workers, or men who have sex with men. Other NGOs and religious charities were more open to wider segments of the population.

Thus, multiple groups were taking an active role in the prevention of HIV infection, relying on a wide variety of actions (male and female condoms, health education, and so on). Primary health care service and maternity units together ensured a rather efficient level of mother–child transmission prevention (more than 70% of pregnant women had access to testing and, if necessary, treatment).

Antiretroviral drugs and treatments for opportunistic infections were widely available, and care structures had been improved because of the focus of NGOs and public actors on antiretroviral drug availability and care provision. This focus may have delayed the onset of a local prevention policy targeting the new trends toward different populations. However, the response to these trends became fairly satisfactory.

After years of exceptionalism, the AIDS program was undergoing a process of normalization. Overall, this had a beneficial impact on the number of people served. However, there is a risk that the epidemic may be considered a rather banal phenomenon. The advocacy activities of AIDS NGOs often decline, and the population at large, many end-user representatives in health councils, primary health care service personnel, and decision-makers no longer consider the HIV/AIDS epidemic to be a priority, regardless of the size of a local epidemic.
Persistent Exceptionalism and Isolation

*Actors and patterns of cooperation in model 2.*

In the municipality described by model 2, discrimination against HIV-seropositive persons was more severe than in the municipalities described by model 1. Fewer actors were strongly involved in implementing the AIDS policy, but included state and municipal AIDS programs, AIDS NGOs, voluntary counseling and testing centers, and specialized assistance services for ambulatory care. They shared the same concern: to ensure that HIV/AIDS remained a priority despite scarce resources and the fact that other actors had different short-term priorities and agendas.

Municipal and state AIDS programs had poor cooperative links and were only slightly supported by municipal and state governments. AIDS NGOs were, thus, key partners for local programs. Together, they attempted to make the epidemic an exceptional civil and health problem demanding an exceptional public response. The activism of NGOs, supported by the national AIDS program and locally relayed by the media, was essential to maintain pressure on local authorities and health services.

Primary health care services appeared unwilling to become involved in the HIV/AIDS programs because of strong discrimination against people living with HIV/AIDS in the areas where the primary health care service facilities were located, hostility or indifference on the part of local government, and the fear of strong pressure from AIDS NGOs to obtain better care for HIV-infected persons in a
context of scarce human and financial resources.

Public health consequences, strengths and weaknesses of model 2. The prevention policy tended to target only some vulnerable groups. In turn, these groups formed NGOs focusing only on HIV/AIDS. They were the cornerstone of the prevention policy, through condom distribution and health education, because primary health care services participated little in prevention campaigns. Primary health care services only received stocks of condoms that health care workers and physicians working in these facilities considered insufficient and randomly distributed.

As a consequence, the population coverage was partial. Persistent strong discrimination also contributed to underdiagnosis of HIV infection, including among pregnant women.

Antiretroviral drugs were available, supplied by the federal authorities, but drugs for opportunistic infections, which were locally supplied, were often lacking. Finally, hospital care was sometimes delayed by a lack of beds. However, NGO activism helped to overcome these obstacles, through pressure via media and recourse to judicial proceedings based on the Brazilian constitution guaranteeing the right to health.

AIDS policies poorly fit the new epidemiological trends, owing to the weak involvement of primary health care services, the focus by AIDS NGOs on some vulnerable groups (men who have sex with men, sex workers), and the inadequate number and limited capacity of NGOs focusing on the poor or on women.

Programs described by this model were not progressing toward normalization but perpetuated exceptionalism, a temporal pattern in sharp contrast with that of model 1. The actors in the AIDS program were still mobilized, and this contributed to the sustainability of the programs. However, the exceptionalism also led to isolation of the AIDS program within the health care system and poor coverage of the population.

No Exceptionalism and An AIDS Program With No Alliances

Actors and patterns of cooperation in model 3. Where there was strong discrimination against people living with HIV/AIDS and in the absence of powerful AIDS NGOs, the actors were the municipal AIDS programs and the operational units (voluntary counseling and testing centers and specialized assistance services for ambulatory care). The development of the AIDS programs relied on public administrators and health care professionals.

Although they benefited from the incentivos policy, the AIDS programs remained closely dependent on the municipal authorities. Because of divergent priorities or political conflicts among authorities, the relationship between municipal and state programs oscillated between cooperation and defiance.

Preventive measures were mostly implemented by generalist NGOs who acted as service providers of municipal administrations, often limiting their activity to the distribution of condoms. Their agenda was not focused on HIV/AIDS, and their advocacy was very weak.

Despite various initiatives by the actors of the AIDS programs, primary health care services and maternity clinics were poorly involved in the policy.

Public health consequences, strengths and weaknesses of model 3. The absence of AIDS NGOs, the fragility of the AIDS program without the support of local authorities, and the lack of pressure by generalist NGOs explain why funding of AIDS programs at the local level was inadequate. Even if generalist NGOs provided the poor with some access to AIDS programs, the territorial coverage of the programs remained limited. The weak involvement of maternity clinics and primary health care services did not allow improvement of the access to care and prevention.

Antiretroviral drugs were fairly accessible, but the supply of drugs for opportunistic infections was irregular. The lack of physicians involved in the AIDS program led to delays in diagnosis and care.

Thus, the new trends of the HIV/AIDS epidemic were poorly addressed in the communities described by this model. In the absence of AIDS NGOs, the sustainability of the AIDS program was clearly threatened.

DISCUSSION

Table 4 summarizes the strengths and weaknesses of the HIV/AIDS programs we studied and provides recommendations for decision-makers.

The successful accomplishments of the Brazilian AIDS programs are obvious and the AIDS policies have positively affected the whole health system. These successes were at least partly because of the role of AIDS NGOs, the decentralization of programs, and the integration of the AIDS programs within the health system. However, our study highlights the local heterogeneity of AIDS programs within the national framework because of the varied degrees of discrimination against people living with HIV/AIDS, which sometimes differed from one municipality to another in the same state, the local health system capacities, and the local cooperation among health actors, on which our public policy research was focused.

Nongovernmental organizations, notably AIDS NGOs, appeared to be essential to ensure a strong mobilization in the initial phases of programs. In their absence, the implementation and sustainability of AIDS programs were very difficult. The NGOs also had an impact on territorial coverage and sustainability of the programs, both of which differed according to their local activities and patterns of cooperation with other actors. The programs described by model 1 showed the risk of “institutionalization” of AIDS NGOs with the loss of their advocacy role and its consequences for sustainability. Programs in model 2 highlighted the risk of isolation of the AIDS actors within the local health system as a consequence of exceptionalism and its negative impact on the coverage of poor populations.

The decentralization process, which had many positive effects on AIDS policies, may also undermine political mobilization and hinder the functioning of local programs where there is strong discrimination with weak actors involved in AIDS policy (model 3) and poor support from local authorities (models 2 and 3). The decentralization may also foster over-normalization because of local redefinition of health priorities, notably when primary health care services are involved in the AIDS policy (model 1).

Cooperation of actors involved in AIDS policy with other operational health actors is difficult. In the programs of model 1, this cooperation allowed coverage of large numbers of the poor population, but it might jeopardize the long-term sustainability of the
programs. In the programs of models 2 and 3, this cooperation was weak or absent, and this negatively affected service provision and the care of the HIV patient.

Finally, in each model, a major issue is to ensure both coverage of the poor population and the sustainability of the program.

Recommendations

At least 3 recommendations may be made for the programs described by all models. First, direct federal funding for NGOs should be maintained because it helps to ensure their independence from local authorities. Second, cooperation between operational public actors should be enhanced by the involvement of infectious disease physicians in the primary health care service units. Similarly, local cooperation between AIDS NGOs and primary health care services could be developed under the supervision of AIDS programs. Finally, AIDS NGOs should be encouraged by financial means to focus on new vulnerable groups.

In the programs described by model 1, the normalisation process allowed an efficient integration among actors involved in the prevention of HIV infection and care of AIDS patients. But the activism of NGOs should be sustained to maintain pressure on local political authorities so that they maintain their support of HIV-infected persons. The focus of information campaigns on community leaders and representatives of end-users in health councils seemed to be important as they played a role in overnormalization.

In the programs described by model 2, for operational health units such as primary health care services, involvement in AIDS programs has a cost (additional workload, pressure from AIDS NGOs) but may also have benefits in terms of resources, education, and research. To foster the involvement of these units, it would be useful to ensure that they will receive benefits, as they will have to support the cost.

In the programs described by model 3, strong generalist NGOs may favorably affect the AIDS programs if they help inexperienced groups organize themselves to create AIDS NGOs and cooperate more closely with health professionals.

Conclusions

Few published articles have considered the transferability of the Brazilian AIDS program to other countries.12,13,37,38 They have pointed out some specific aspects of the Brazilian response affecting this transferability: the strengths of the public health system; the mobilization of civil society, which played a major role in the development and sustainability of AIDS programs; the role of the sanitarist movement; and a specific sexual culture, as analyzed by Parker et al.39

Our study leads to complementary conclusions. Our study of Brazilian AIDS programs focused on actors and patterns of cooperation that were at work in the AIDS programs of nearly all countries. We described the dynamic of decentralization within AIDS programs that face new epidemiological trends and, in some parts of the country, rather severe discrimination and relative scarcity of human and financial resources as in many other emerging and developing countries. Such countries may benefit from similar analysis to better adapt their AIDS programs to the local context and take advantage of the successful Brazilian experience.

We hope that our models of local responses and recommendations will help strengthen HIV/AIDS programs in Brazil and other low- and middle-income countries.

Acknowledgments

This research was funded by Agence Nationale de Recherche sur le Sida et la Ménopause Endocrinologique (Acquis (SIDA; project Agence Nationale de Recherche sur la SIDA 12105), SIDACTION, and Institut de Médecine et d’Épidémiologie Appliquée.

We acknowledge Xavier Lescure, Marie Boisvert, and Mahinda-Gamini Sirivardhana.

Human Participant Protection

The project was approved by the ethics committee of the Rio de Janeiro State University and by the Brazilian committee of research ethics.

References


