

# HIV/AIDS POLICY IN Senegal



## A Civil Society Perspective

*A series of reports on HIV/AIDS policy in  
Nicaragua, Senegal, Ukraine, the United States, and Vietnam*

**PUBLIC HEALTH WATCH**



**OPEN SOCIETY INSTITUTE**  
Public Health Program



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*Daouda Diouf, ENDA Santé*

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*Front cover (clockwise from left)* Luke Wolagiewicz, WPN: support group for people living with HIV/AIDS, Ukraine; Associated Press: a center caring for abandoned children living with HIV/AIDS, Vietnam; Donna DeCesare: 16-year-old living with HIV, and his mother, Central America.

*Back cover (top to bottom)* Associated Press: lab assistant tests blood for HIV, Senegal; Associated Press: coordinator with ACLU National Prison Project talks with people in the HIV/AIDS Housing Unit at Mississippi State Penitentiary.

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# Preface

In June 2001, at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), 189 national governments agreed to the Declaration of Commitment on HIV/AIDS. The document commits governments to improve their responses to their domestic AIDS epidemics and sets targets for AIDS-related financing, policy, and programming.

The Declaration also stipulates that governments conduct periodic reviews to assess progress on realizing their UNGASS commitments. In recognition of the crucial role civil society plays in the response to HIV/AIDS, the Declaration calls on governments to include civil society, particularly people living with HIV/AIDS, in the review process.

Established by the Open Society Institute in 2004, Public Health Watch supports independent monitoring of governmental compliance with the UNGASS Declaration and other regional and international commitments on HIV/AIDS. Public Health Watch aims to promote informed civil society engagement in policymaking on HIV/AIDS and tuberculosis (TB)—two closely linked diseases that lead to millions of preventable deaths annually. Toward this end, Public Health Watch also supports civil society monitoring of TB and TB/HIV policies, examining compliance with the Amsterdam Declaration to Stop TB and the World Health Organization’s Interim Policy on Collaborative TB/HIV Activities.

The Public Health Watch methodology incorporates multiple opportunities for dialogue and exchange with a broad range of policy actors during report preparation. Researchers convene an advisory group of national HIV/AIDS and TB experts, activists, and policy actors. They prepare draft reports on the basis of input from the advisory group, desktop and field research, interviews and site visits. Researchers then organize in-country roundtable meetings to invite feedback and critiques from policymakers, academics, government officials, representatives of affected communities, and other key stakeholders. Finally, Public Health Watch supports researchers in conducting targeted advocacy at the domestic and international levels around their report findings and recommendations.

For the HIV/AIDS Monitoring Project, Public Health Watch civil society partners in Nicaragua, Senegal, Ukraine, the United States, and Vietnam have prepared assessments of national HIV/AIDS policies based on a standardized questionnaire, which facilitates structured review of governmental compliance with key elements of the UNGASS Declaration.

To access the reports of the HIV/AIDS Monitoring Project and to learn more about Public Health Watch, including the TB Monitoring Project and the TB/HIV Monitoring and Advocacy Project, please visit: [www.publichealthwatch.info](http://www.publichealthwatch.info).



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## Public Health Program

The Open Society Institute's Public Health Program promotes health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with local, national, and international civil society organizations to foster greater civil society engagement in public health policy and practice, to combat the social marginalization and stigma that lead to poor health, and to facilitate access to health information.

[www.soros.org/initiatives/health](http://www.soros.org/initiatives/health)

## Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

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## Abbreviations

AIDS:	Acquired Immune Deficiency Syndrome
ANCS:	Alliance Nationale Contre le SIDA
ARV:	Antiretroviral
CFA:	Communauté Financière Africaine
CNLS:	Conseil National de Lutte contre le SIDA (National AIDS Council)
CTA:	Centre de Traitement Ambulatoire (Ambulatory Treatment Center)
ENDA:	Environnement et Développement du Tiers Monde
FHI:	Family Health International
GIPA:	Greater Involvement of People with HIV/AIDS
HIV:	Human Immunodeficiency Virus
IEC:	Information, Education, and Communication
M&E:	Monitoring and Evaluation
NGO:	Nongovernmental Organization
PLWHA:	People Living with HIV/AIDS
PMTCT:	Prevention of Mother-to-Child Transmission
PNA:	Senegal National Pharmacy
RSU:	Regional Support Unit
STIs:	Sexually Transmitted Infections
TB:	Tuberculosis
UNDP:	United Nations Development Programme
UNGASS:	United Nations General Assembly Special Session
VCT:	Voluntary Counseling and Testing
WHO:	World Health Organization

# Executive Summary

Senegal serves as a model among African countries in its control of HIV/AIDS. For the past two decades, its HIV-prevalence rate has been below 1 percent, a success that can be attributed to the country's timely response to the crisis. In the mid-1980s, when HIV/AIDS first emerged as a threat, the Senegalese government established Programme National de Lutte contre le SIDA (National AIDS Program). In December 2001, the program was restructured as the Conseil National de Lutte contre le SIDA (National AIDS Council or CNLS) to facilitate a better coordinated, multisectoral response. The CNLS adopted measures to prevent the spread of HIV/AIDS, promoting condom use, instituting a sentinel surveillance system, and increasing the number of voluntary counselling and testing sites. In addition, it strengthened several longstanding health policies—such as the priority to ensure blood safety and required registration and health checkups for sex workers—to minimize the risk of HIV transmission.

More than 20 years into the epidemic, however, many stakeholders believe that the government has made inadequate efforts to target high-risk groups; update national strategies according to emerging priorities, such as the increasing feminization of AIDS; and provide quality services for people living with HIV/AIDS. Interventions aimed at the general population have helped to raise awareness about HIV/AIDS, but these prevention efforts have failed to result in measurable behavioral change. Groups that are particularly vulnerable to HIV—men who have sex with men, mobile and cross-border populations, young people, and women—have been neglected. Furthermore, although legal sex workers have access to routine health care, unregistered sex workers do not, and they are persecuted by law enforcement agencies, which drives these individuals further underground and makes outreach difficult.

Efforts to fight stigma and discrimination have not been wholly successful, either. People living with HIV/AIDS reportedly continue to face discrimination in all aspects of their lives—within their families and communities, in the workplace, and in health care settings—and have no legal protection or means of redress.

Senegal has demonstrated leadership on treatment issues, however. It was the first sub-Saharan African country to establish an antiretroviral (ARV) treatment program in 1998 and is one of the few African countries that provide free ARV treatment. Access to treatment remains limited largely to those living in Dakar and other urban centers. Of the approximately 5,900 people receiving treatment today, nearly two-thirds live in Dakar. While ARV treatment is free, diagnoses and treatments for opportunistic infections require fees, presenting a barrier to access. For those living in rural areas, transportation costs to urban treatment centers further limit access. The government has yet to provide sufficient financial assistance to people living with HIV/AIDS and their families.

The stark geographical disparity in access to treatment can be attributed to the lack of a health care infrastructure and an adequate number of trained staff and also to the strict regulations on ARV delivery. Until recently, these regulations stipulated that only doctors can prescribe ARVs, but rural clinics are often only staffed with nurses. The disparity in access holds true for other services, too. For example, the number of voluntary counseling and testing (VCT) sites has increased in recent years, although not in rural areas.

Because of the health care infrastructure, patient care and support are also available, for the most part, only in urban areas. Nongovernmental organizations (NGOs) have recently become involved in providing care and support, forms of medical treatment traditionally within the domain of doctors and nurses. These organizations' extensive, "on-the-ground" knowledge of the needs of people living with HIV/AIDS may, in fact, make them better suited than health care providers to deliver these services. However, given the low national HIV-prevalence rate and continuing HIV/AIDS-related stigma, relatively few people openly seek care and support services and, as a result, many NGOs do not have a large base of people to serve. Only large national NGOs, most of which are based in the capital city, have access to large numbers of people living with HIV/AIDS and have formed partnerships with hospitals to provide care for them.

The government also has yet to integrate services effectively. HIV testing is often not provided in the context of a comprehensive program of treatment and care, which, some activists contend, keeps people from getting tested. HIV/AIDS and tuberculosis (TB) programs also continue to be managed separately, despite the close and deadly link between the two diseases and evidence that the incidence of TB/HIV coinfection is on the rise.

Senegal has a single, national, monitoring and evaluation (M&E) system, but it is not effectively decentralized. In addition, there are no mechanisms to support the analysis of data at the local and regional levels, which limits the ownership of information and fails to build local capacity. Several NGO representatives have noted that M&E indicators only account for government projects, the majority of which are funded by multilateral donors, rather than capturing information from the entire national response, including qualitative and quantitative data collected by civil society. The current M&E system is also not an effective tool for collecting information on marginalized, high-risk groups, such as sex workers and men who have sex with men—information that is critical in order to control the spread of HIV.

Many stakeholders point to a need for training seminars to ensure that all actors understand the M&E system, including methods for data collection and analysis, so the information can guide their work. For example, the process of preparing the 2005 United Nations General Assembly Special Session (UNGASS) national progress report revealed the need for the improved technical capacity of government M&E staff in order to more effectively consult with a wide range of stakeholders, and the need for civil society to gain greater

understanding of national and international monitoring processes, in order to participate in them, in a more meaningful way.

Based on the research and consultations conducted for this report, the following are the recommended strategies by which the government of Senegal can strengthen the national response to HIV/AIDS:

- Urgently develop a more comprehensive epidemiological surveillance system to determine the accurate rate of HIV/AIDS prevalence and incidence, particularly in rural areas. Utilize the epidemiological data to guide the national response to HIV/AIDS and to develop appropriate programming, inclusive of cross-border initiatives.
- Collaborate with civil society organizations to adopt innovative approaches to more effectively target populations at high risk for HIV and those vulnerable to the impact of HIV/AIDS in order to provide prevention, treatment, and care services, including by reformulating prevention messages, offering care and support to all sex workers, and providing orphans and other vulnerable children with comprehensive care.
- Improve access to, and the quality of, treatment, care, and support services, including by effectively decentralizing treatment and care services to rural areas; expanding the package of quality care offered to people living with HIV/AIDS to include food and transportation vouchers; integrating TB and HIV/AIDS programs to address coinfection; and promoting and facilitating greater involvement of the private sector and civil society in the provision of care and support activities.
- Increase the capacity and accountability of the health sector, including by expanding training opportunities; providing additional support to expand laboratory capacity; and increasing capacity building so that civil society organizations can provide a full continuum of prevention, treatment, care, and support services in collaboration with the public sector.
- Strengthen the role of the CNLS by securing financial support for the CNLS and its staff and ensuring that the CNLS focuses on the coordination and supervision of prevention, care, and support programs, rather than their implementation.
- Address the issue of stigma and discrimination, including by adopting the draft HIV/AIDS law, which guarantees the rights and dignity of people living with HIV/AIDS; developing programs about and strategies for reducing stigma and mitigating the impact of HIV/AIDS; and ensuring the involvement of a wide range of civil society stakeholders.

# Background

Senegal is one of the most stable democracies in Africa. It has a population of nearly 12 million people, the majority of whom are concentrated on the Atlantic coast and in regions of central Senegal, where the country's largest crop, the groundnut, is cultivated. In the late 1980s and early 1990s, Senegal enjoyed one of the most significant industrial booms in Africa, and in the past decade it has experienced steady economic growth. Despite these facts, more than one-third of its population lives below the national poverty line.<sup>1</sup>

The HIV-prevalence rate in Senegal is 0.9 percent, and approximately 61,000 people are living with HIV/AIDS.<sup>2,3</sup> The increasing feminization of the epidemic is evident in the differing prevalence rates between men and women: 0.4 percent and 0.9 percent, respectively.<sup>4</sup> Prevalence rates are estimated to be significantly higher among high-risk groups, such as sex workers (19 to 29 percent) and men who have sex with men (22 percent).<sup>5</sup> Regions marked by sociopolitical strife also tend to have higher HIV-prevalence rates. For example, in Kolda and Ziguinchor in the south, the Casamance conflict has led to a breakdown of the health care system, increased poverty, and mass migration of local populations. Those two areas have recorded HIV-prevalence rates of 2.8 percent and 2.3 percent, respectively. The disproportionate impact on women is also more marked in these regions. The prevalence rate is 0.8 percent among men and 3.4 percent among women.<sup>6</sup> Unless HIV/AIDS can be effectively prevented and controlled, by 2010 the national prevalence rate is projected to more than double, reaching 2.2 percent.<sup>7</sup>

Several factors have contributed to Senegal's success in maintaining a low HIV-prevalence rate. Since the 1970s, Senegal has made a safe blood supply a priority and has also required sex workers to register and to have quarterly checkups. These efforts have helped reduce the risk of HIV transmission through blood transfusions and through sexual contact with legal sex workers.

Despite Senegal's contained HIV/AIDS epidemic, the national response has not sufficiently targeted high-risk populations, such as men who have sex with men, unregistered sex workers, partners of sex workers, migrant workers, orphans and other vulnerable children, and rural populations. Because a low prevalence rate may be perceived as an indicator of successful HIV control, the government has found it more politically palatable to emphasize the low overall HIV-prevalence rate than to draw attention to the relatively high prevalence among certain groups. Although legal sex workers have access to treatment for sexually transmitted infections (STIs), HIV education, and other services, unregistered sex workers, who represent approximately 80 percent of the country's sex workers, lack access to similar care.<sup>8</sup> NGOs have recently started to raise the government's awareness about the need to address the incidence of HIV among high-risk groups, and, as a result, the

2007–2011 National Strategic Plan gives priority to the delivery of HIV/AIDS services to these often-marginalized populations. The means of implementation remains uncertain, however, and there is a need for more social and anthropological research into vulnerability factors to better understand the needs of these groups.

The government's health-sector budget allocation has increased steadily in recent years, from 23 billion CFA (Communauté Financière Africaine) francs in 2000 to nearly 44 billion CFA francs in 2005 (approximately \$46 million to \$88 million at about 500 CFA francs to 1 U.S. dollar).<sup>9</sup> The government's expenditure on health care as a percentage of total gross domestic product (GDP) is still only 2.1 percent.<sup>10</sup> Statistics suggest that the primary health care system must make greater strides to reduce mortality and morbidity among women and children. Currently, the mortality rate of children under five years old is 137 per 1,000; maternal mortality is 560 per 100,000 live births.<sup>11</sup>

## Political Commitment

*Strong leadership at all levels of society is essential for an effective response to the epidemic.*

—UNGASS Declaration of Commitment on HIV/AIDS,  
preamble to “Leadership”

Senegalese officials have joined other African leaders to affirm their commitment to the fight against HIV/AIDS in the international arena, participating in both the special summit in Abuja on HIV/AIDS and TB in April 2001 and in the United Nations General Assembly Special Session on HIV/AIDS in June 2001. The government has also demonstrated its commitment to control HIV/AIDS at the domestic level. In 1998, Senegal became the first sub-Saharan African country to establish an ARV treatment program: Initiative Senegalaise d'Acces aux ARV (Senegalese Initiative on Access to ARVs, or ISAARV).<sup>12</sup> Today, Senegal is one of few African countries that provide ARVs free of charge.

HIV/AIDS is integrated into the development programs and the poverty reduction programs supported by the United Nations Development Programme (UNDP), the World Bank, and other donors, in recognition of the fact that the control of HIV/AIDS is integral to the efforts to reduce poverty and develop peace, security, and political stability.<sup>13</sup> In keeping with the United Nations Millennium Development Goals, the Senegalese government has pledged to fight against poverty, hunger, and illiteracy and also to halt and reverse the spread of epidemics such as HIV/AIDS by 2015.<sup>14</sup> Since the onset of the HIV/AIDS epidemic, Senegal has collaborated with a range of international organizations and donors,

such as UNDP, the World Health Organization (WHO), and the United States Agency for International Development. In 1986, donors helped the government design the national HIV/AIDS program, which emphasized the importance of blood safety and the training of health care workers and which also supported the increased participation of civil society in implementing HIV/AIDS policies.

Although the government has been proactive in some aspects of HIV/AIDS control—the provision of ARV treatment, the insurance of blood safety, the prevention of mother-to-child transmission (PMTCT), and the decentralization of HIV testing sites—it has not demonstrated sufficient leadership and initiative in others. For example, the government does not provide adequate support to people living with HIV/AIDS, the majority of whom are poor and unemployed, or to orphans and other vulnerable children. HIV/AIDS and TB programs have not yet been effectively integrated to address the danger of TB/HIV coinfection, even though some studies indicate that HIV prevalence among TB patients exceeds 15 percent.<sup>15</sup> There is also a lack of support for marginalized groups, such as unregistered sex workers and men who have sex with men. Environment et Développement du Tiers Monde (ENDA) is the only NGO that works with unregistered sex workers, but it is only able to reach about 10 percent of the total estimated number in the country.<sup>16</sup> Two other NGOs and the Ministry of Health target men who have sex with men, but together they only reach approximately 300 people.<sup>17</sup>

In addition, Senegal has yet to adopt a legal framework that protects the rights and dignity of people living with HIV/AIDS. There have been numerous consultative meetings, and a draft law on HIV/AIDS was finalized in mid-2006, but it has not been adopted by parliament. Because of the stigmatization of people living with HIV/AIDS, many parliamentarians fear that an AIDS law would be politically unpopular. Despite the advocacy efforts of civil society organizations to push forward the law, there is a lack of collective urgency among policymakers. AIDS activists believe that the government must adopt the proposed AIDS law without delay and then immediately launch a mass campaign to educate judges, law enforcement agents, employers, and affected individuals about the rights of people living with HIV/AIDS.

In the meantime, stigma and discrimination create serious obstacles to implementing programs to control HIV/AIDS. Services can only reach people who are known to be HIV-positive or who seek care. People who are living with HIV/AIDS often take measures to keep their status secret, even to family members, so they often lack basic support, such as assistance with transportation and proper nutrition. They may be reluctant to join associations for people living with HIV/AIDS and may refuse home visits because they fear their neighbors will start asking questions.

Because people living with HIV/AIDS have no legal recourse against stigma and discrimination, there are no formal complaints on record, despite reports of many incidents

in communities, hospitals, and workplaces. One person living with HIV confided, “We have to give up [formulating complaints] for fear that the media would seize the opportunity to reveal our HIV status to the general public.”<sup>18</sup>

Overall, the media has paid an inadequate amount of attention to the commitments the government has made at the regional and international levels to control HIV/AIDS. As a result, the public has little awareness of these commitments and no mechanism to hold the government accountable.

## Public Awareness

Information, education, and communication (IEC) efforts aimed at the general population of Senegal have resulted in nearly universal knowledge about HIV/AIDS. According to the 2005 *Demographic and Health Survey*, approximately 98 percent of those interviewed said they knew about or had heard of HIV/AIDS, and 78 percent of women and 82 percent of men could identify at least one method of preventing the transmission of HIV.<sup>19</sup> Among both men and women, the knowledge of ways to avoid HIV infection was related to levels of education and urbanization—in other words, an educated, urban resident is more likely to know how to prevent HIV infection than an uneducated, rural resident.

According to the survey, most young people are also well informed about HIV/AIDS. More than 94 percent of the men ages 15 to 19 and 99 percent of those ages 20 to 24 knew how to prevent sexual transmission of HIV.<sup>20</sup> The percentages are similarly high for young women in these same age groups.

The high level of awareness about HIV/AIDS among young people has failed to translate into safe behavior, however. Condom use is infrequent, especially among girls. A local NGO representative indicated that the infrequency of condom use among young people may be attributed to the inaccessibility of condoms.<sup>21</sup> When condoms are available for sale in pharmacies, they are expensive. Young people may be reluctant to go to health clinics for free or low-cost condoms. Infrequent condom use among girls also reflects the socioeconomic and cultural reality of gender inequality, as women lack the decision-making ability and sexual-negotiation powers to control condom use. Only about 5 percent of young women 15 to 24 years old indicated that they used a condom with a regular partner, compared to 43.3 percent of young men ages 15 to 19 and 50.8 percent of those 20 to 24.<sup>22</sup>

Women continue to face difficulty in negotiating condom use, even within marriage. In fact, a group of HIV-positive women participating in a self-support group confirmed that marriage was a risk factor for HIV for women; the majority of them had been infected by their husbands. One member added, “Sex workers are more protected than married women because they can better negotiate condom use.”<sup>23</sup>

Active networks of youth, women, and religious groups have played key roles in educating individuals and communities about HIV/AIDS, but the education and information efforts have mainly consisted of general prevention messages. These informal networks have not effectively reached marginalized groups, such as sex workers and men who have sex with men. They do not have experience in targeting marginalized groups with specific messages and may be uncomfortable reaching out to this population because of the often high level of associated stigma.

## Role of Civil Society

There are more than 3,000 civil society organizations involved in the HIV/AIDS response—from community-based groups to national level NGOs. These groups have been integral to Senegal's success in controlling HIV/AIDS, by disseminating information on HIV/AIDS, offering psychosocial support to people living with HIV/AIDS, and advocating for an innovative and efficient national response. In 2004, a group of five NGOs—known as l'Observatoire de la réponse au VIH/sida au Sénégal (Watchdog of the Response to HIV/AIDS in Senegal) or the Observatoire—drew attention to the weaknesses in the design and implementation of national HIV/AIDS policies.<sup>24</sup> In particular, the group pointed out the lack of social and financial support of people living with HIV/AIDS, especially those in marginalized populations. Little funding is allocated to sex workers and virtually none to men who have sex with men, despite epidemiological data that suggest these groups should have priority.

Civil society organizations have been increasingly active in policy formulation in recent years. For example, national NGOs, community-based organizations, women's groups, and people living with HIV/AIDS are included in the CNLS, the national HIV/AIDS coordination body, and the Global Fund Country Coordinating Mechanism. There are some concerns among activists, however, that civil society representatives in the CNLS are hand-picked by the government and do not fully reflect the diversity of civil society. Further, they are concerned that these representatives provide insufficient feedback to the larger group of constituents.<sup>25</sup>

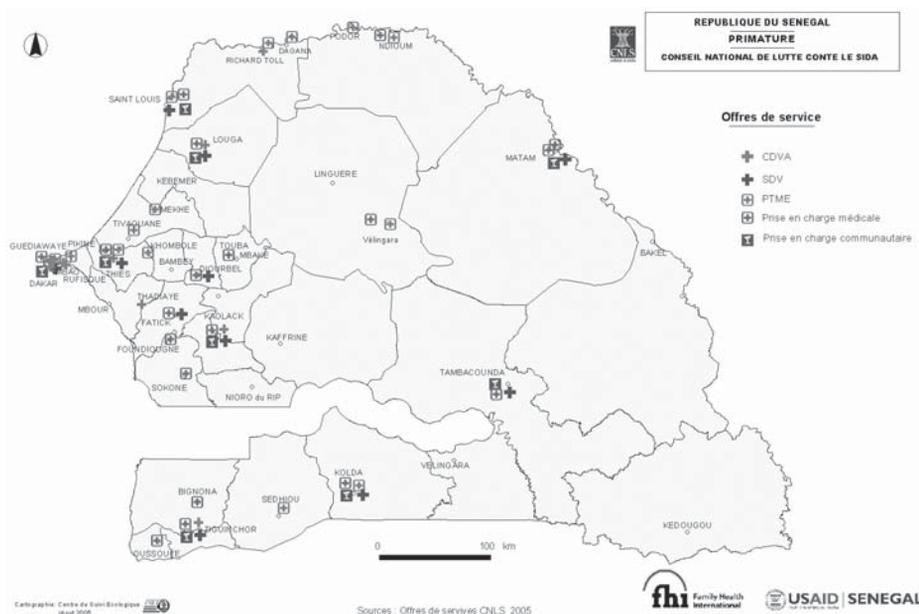
Due to pressure from a broad group of civil society organizations, the Global Fund established a parallel civil-society funding mechanism in April 2006. Alliance Nationale Contre le SIDA (ANCS), a national NGO, is now one of the Global Fund's principal funding recipients. ANCS is responsible for outreach to marginalized groups, orphans and other vulnerable children, and people living with HIV/AIDS. NGO funding has increased the involvement of civil society organizations, many of which fill gaps in the government's efforts to control HIV/AIDS. The largest program on orphans and vulnerable children is implemented by three NGOs: Hope for African Children Initiative, Society of Women against AIDS, and

Synergie pour l'Enfance. ENDA Santé manages the largest HIV testing and counselling program for unregistered sex workers.

In October 2005, the CNLS and civil society organizations together took stock of current interventions to determine priorities and to identify neglected areas. The results indicated a need to prioritize capacity building and to increase support for marginalized populations and people living with HIV/AIDS. Mapping identified geographical disparities in distribution of services (Figure 1).<sup>26</sup>

The map reveals a cluster of areas along the west coast and near the capital, Dakar, in which services are provided, indicating the need to improve access to services in other parts of the country. The World Bank has recently supported 622 community organizations and NGOs in the implementation of HIV/AIDS projects, giving priority in the selection criteria to the support of rural populations.<sup>27</sup> As the Observatoire explains, however, the support does not extend to any follow-up efforts, quality control mechanisms, or a technical assistance plan. Further, the one-time funding will likely not be renewed, so it does not foster a sustainable solution.<sup>28</sup>

**Figure 1.**  
**Geographical distribution of services**



The government has also solicited civil society contributions for the development of the 2007–2011 National Strategic Plan, which provides the national framework for all programs and activities to control HIV/AIDS. The involvement of civil society led to significant improvements in the 2007–2011 plan, as compared to the 2002–2006 plan. The new plan makes marginalized populations a higher priority. It also places greater emphasis on care and support activities for people living with HIV/AIDS and on programs that fight stigma and discrimination. Moreover, civil society organizations have officially been tasked with supporting the government in implementing these initiatives.

The inadequate capacity of these organizations may, however, limit their ability to expand their efforts beyond social mobilization and advocacy for quality services. Civil society organizations focus on the HIV/AIDS control efforts they have advocated and helped initiate, particularly those that ensure that marginalized groups have access to quality services. They have also been instrumental in widely promoting VCT. As the number of VCT sites and of people receiving ARV treatment increases, the need for other services, such as counseling, treatment literacy, and sustained social mobilization, also increases. Currently, the capacity of civil society organizations does not allow for a scale-up of these services, and the government has not elaborated on how it will build that capacity.

When the government considers strengthening the health care system, it considers only the public health sector, not the civil society organizations, which are vital in providing a full spectrum of health care services. Building the capacity of the health care sector requires simultaneously building the capacity of civil society organizations, so that comprehensive care will be accessible to all. Limited resources may hinder the government from directly investing in civil society organizations, but they do not hinder it from creating a supportive environment—for example, by emphasizing in the national plan the importance of building the capacity of civil society and by inviting donors to collaborate more closely with civil society organizations.

## Attitudes toward People Living with HIV/AIDS

*[Married women] often end up divorced when their status is disclosed, even if it's the husband who infected her. Men are often in denial and don't believe they are HIV-positive too.*

—A woman living with HIV/AIDS

Interviews with people living with HIV/AIDS and with members of marginalized groups reveal stigma and discrimination in all levels of society, including communities and social

and professional circles. The belief is widely held that HIV/AIDS is associated with promiscuity and is a divine punishment. This strong perception contributes to the difficulties that people living with HIV/AIDS have in revealing their HIV status, even to close relatives.

In one case, a woman living with HIV kept her status secret for 12 years because of her fear of rejection by her family.<sup>29</sup> She refused medical assistance because she feared her HIV status might be revealed and she subsequently died in childbirth. Unfortunately, fear of rejection by family members is not unfounded. As one interviewee explained, married women “often end up divorced when their status is disclosed, even if it’s the husband who infected her. Men are often in denial and don’t believe they are HIV-positive too.”<sup>30</sup>

Religious and traditional leaders often reinforce the belief that HIV is linked to sin and punishment, although a growing number of religious leaders promote acceptance and help raise awareness about HIV/AIDS and fight stigma and discrimination. A few Muslim leaders have met with other religious leaders to mobilize efforts to speak to communities about HIV/AIDS. Many have travelled to neighboring countries to speak about HIV prevention.<sup>31</sup> Given the great influence of religious leaders in Senegal, many AIDS experts believe they should be more vocal and more active in their efforts to discourage stigmatization.

The incidence of discrimination in health care settings has decreased considerably since the Ministry of Health initiated HIV training in medical and nursing schools. Violations still reportedly exist, however, including refusal of treatment and breach of confidentiality, although few are documented because people are afraid to report them.

According to a group of HIV-positive women, “when a pregnant woman who is HIV-positive goes to the hospital, her case is passed from nurse to nurse because no one wants to deal with an HIV-positive person.”<sup>32</sup> The stigma continues to plague HIV-positive women even after childbirth. “When HIV-positive women don’t breastfeed their babies, people talk and assume that it’s because she is sick.”<sup>33</sup> Some activists attribute these cases of stigma and discrimination to the fact that health care workers are overworked and dissatisfied, so they have pushed for incentives and improved conditions for health care personnel.<sup>34</sup>

Men who have sex with men face stigma and discrimination regardless of their HIV-status. “As soon as people learn that you are a man who has sex with men, the reaction of health staff becomes aggressive, and their derogatory looks discourage any attempt to solicit care,” one interviewee said. “Many doctors who refuse to treat us often do so in the name of religion, as they fear that a spell would be cast on them for having spoken to or touched us.”<sup>35</sup> Another man said, “[We] are seen as guilty. Being homosexual [is bad] and being HIV-positive only makes things worse. No one will visit you in hospitals. Family members don’t want to provide care and support.”<sup>36</sup> When one man died, no one wanted to bury him. Finally a local NGO paid for the funeral services. Due to the enormous stigma

against same-sex relationships, an overwhelming majority of men who have sex with men have relationships with women to conceal their sexual orientation.<sup>37</sup>

HIV/AIDS activists believe that civil society organizations must do more to reduce stigma and discrimination, starting at the community level, in order to ensure the long-term success of HIV/AIDS programs. “I believe that if we address stigma and discrimination, a lot can be overcome,” said an attendee at one conference. “In Uganda, for example, communities are very interactive and supportive, and this has helped them to control HIV/AIDS.”<sup>38</sup>

# HIV/AIDS Policy

*By 2003, ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 37

*It's like [the government is] holding up the flags of the World Bank and Global Fund rather than holding up the Senegalese flag.*

—Local NGO representative

By responding to the HIV/AIDS epidemic in a timely manner, Senegal has succeeded in maintaining an HIV-prevalence rate of less than 1 percent. To coordinate HIV/AIDS control efforts, the country established the Programme National de Lutte contre le SIDA (National AIDS Program) in 1986 under the Ministry of Health. In December 2001, the program evolved into the multisectoral CNLS, which reports directly to the prime minister and is supported by an executive secretariat. Its responsibilities include: defining national priorities; coordinating various government agencies and international HIV/AIDS partners in implementing the National Strategic Plan; and establishing a mechanism for monitoring and evaluation. The CNLS, which includes representatives from the government, civil society, the private sector, and people living with HIV/AIDS, is supposed to convene every six months, although meetings have not been held regularly.

There has not been a formal evaluation of the effectiveness of the CNLS in coordinating across ministries and with international partners, but there appears to be little communication and sharing of information among the actors in the HIV/AIDS response.<sup>39</sup>

## Policy Administration, Financing, and Coordination

### Administration

The CNLS has primarily focused on coordinating projects funded by the World Bank and the Global Fund, rather than orchestrating a national response by, for example, providing a platform for coordinating and capitalizing on the contributions of all stakeholders—including NGOs, faith-based organizations, and community groups. One local NGO representative said, “It’s like they are holding up the flags of the World Bank and Global Fund rather than holding up the Senegalese flag.”<sup>40</sup> Because of the CNLS’s narrow focus on donor

activities, monitoring and evaluation data reflect only the contributions of these multilateral organizations.<sup>41</sup>

The CNLS executive secretariat is fully funded by the World Bank. The NGO watchdog group Observatoire has been critical of this fact, believing that this overreliance on a single donor jeopardizes the sustainability of the national response—particularly as the World Bank’s Multi-Country HIV/AIDS Program is scheduled to end in September 2007. The Observatoire contends that national institutions should be financed by the government, not by an outside donor, and particularly not by a single donor. The secretariat, whose contract expired in February 2007, is already being disassembled. The CNLS is negotiating with the government to assume financial responsibility for the secretariat, but continued support is uncertain.

The termination of the World Bank program will not only affect the CNLS secretariat, but also the regional, district, and local AIDS councils that support the CNLS.<sup>42</sup> The 11 regional coordinators who oversee the operations of these councils have already been fired. The HIV/AIDS response is not yet effectively decentralized, and regional and local officials acknowledge the need to improve the delivery of prevention, treatment, and support services. As one local official from Nganda explained, “People sometimes have to travel more than 100 kilometers to get to the nearest health center, which can take four to six hours each way. That’s why patients don’t return for follow-up visits or to get their test results. Care and support should not be based in a referral hospital, but in communities, so they’re more accessible for people.”<sup>43</sup> The firing of the regional coordinators and the discontinuation of financial support for regional councils may hinder the decentralization process.

The current national response also fails to consider local realities because the government does not have an accurate picture of the HIV/AIDS epidemic. As the Observatoire has noted, the sentinel surveillance sites are limited to urban centers within each region, so the extrapolation of epidemiological figures to represent the entire region may mask serious epidemics at local levels.<sup>44</sup> For example, post-conflict regions, such as Ziguinchor and Kolda in the south, need specific initiatives that address the risks associated with high levels of poverty and the increased presence of soldiers and displaced people. In the north, there are many migratory workers, who travel to other parts of Africa that have a high prevalence of HIV and then return home. Polygamy also occurs more frequently in this region than in the south. Measures are needed to address these high-risk factors and, particularly, their impact on women.

Despite the disadvantages, the World Bank’s imminent departure has forced regional councils to think more strategically about their HIV/AIDS plans. All regions now have integrated HIV/AIDS plans, designed according to local needs, which offer multiple donors the opportunity to coordinate their responses. The Global Fund, Family Health International (FHI), and other donors are prepared to implement programs based on these regional plans.

## Financing

The 2002–2006 National Strategic Plan was supported with a budget of 49 billion CFA francs (approximately \$98 million). Government contributions represented about 14 percent of the budget, and donors provided the bulk of support.<sup>45</sup> The Global Fund and the World Bank, the largest donors, contributed 6 and 38 percent of the total budget, respectively.<sup>46</sup>

The estimated budget for the 2007–2011 National Strategic Plan is approximately \$105 million. As of March 2007, Global Fund Round 6 and the FHI had committed about \$30 million to the plan. Government contributions will likely have to increase to fill the funding gap, particularly in light of the soon-to-be-discontinued financial support from the World Bank.

Activists acknowledge that Senegal cannot afford to finance an effective and comprehensive HIV/AIDS response without donor support. They do believe, however, that donor funding can be more strategically utilized to ensure sustainability—for example, by helping to build local capacity.<sup>47</sup>

Since 2006, when ANCS became one of principal recipients of the Global Fund grant, funding has increased for civil society groups to implement care and support activities for orphans and vulnerable children and people living with HIV/AIDS. Although the CNLS has control over major donor funds that support the National Strategic Plan and makes the information publicly available, it is unaware of other sources of funding, such as any direct financial support provided to local civil society organizations. Currently, there is neither a mechanism in place nor the technical capacity within the CNLS to track funding to non-governmental entities. Without this information, the CNLS cannot prepare or disseminate a complete financial report on AIDS control. Such a report could help improve national coordination and allow for more efficient identification of emerging priorities.

## Coordination with Donors

Although donors and government representatives sometimes consult to determine priorities, donors can and do exert influence over the design and implementation of HIV/AIDS policies. For example, from 2003 to 2005, the main focus of the CNLS was on general social mobilization and prevention. These efforts coincided with the World Bank's priorities, even though the National Strategic Plan had identified care and support for people living with HIV/AIDS as a priority and the epidemiological data pointed to a need to target high-risk groups. In part due to this mismatch in priorities, the World Bank project is not considered a success. Its emphasis on the general population did not make a significant impact on the concentrated HIV/AIDS epidemic. From the civil society perspective, the World Bank enforced inappropriate guidelines and failed to effectively target high-risk groups or foster

the involvement of civil society. The World Bank, on the other hand, blames Senegal's flawed implementation for the poor results.<sup>48</sup>

Many donors enforce their own mechanisms and procedures for project implementation. They also choose the regions they work in, without regard to gaps in coverage of services.<sup>49</sup> The government has not forced the donors to comply with the "Three Ones" principles, which coordinate efforts, and also has not asserted the need for providing support in neglected areas.<sup>50</sup> In addition, donors have their own management and reporting requirements, which can create imbalances in the amount of resources that projects receive. Projects funded by large donors receive disproportionate amounts of local staff time and attention, to the detriment of other projects. Some donors also impose tight restrictions on spending. For example, the World Bank's criteria on low maximums for each HIV/AIDS activity have constrained some NGOs from implementing prevention and care and support projects, and a number of organizations have declined World Bank funding because of these restrictions.<sup>51</sup>

Finally, international donors and organizations have set negative precedents by paying cash stipends of \$20 to \$50 to local stakeholders to attend meetings. Local NGOs now also have to pay to encourage action, although such payments are out of reach for many groups. Whereas local organizations had previously worked well with groups and within communities that participated on a voluntary basis, there now exists a culture of per diems. As one NGO representative explained, international organizations "come with big cars, big offices, and have disturbed the good work that used to be done before."<sup>52</sup>

## Prevention

*By 2003, establish national prevention targets, recognizing and addressing factors leading to the spread of the epidemic and increasing people's vulnerability, to reduce HIV incidence for those identifiable groups.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 48

*By 2005, ... increas[e] the availability of and provid[e] access for HIV-infected women and babies to effective treatment to reduce mother-to-child transmission of HIV.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 54

Senegal implemented a number of innovative HIV-prevention measures at an early stage in the epidemic, such as the bolstering of blood safety measures and the provision of health services to registered sex workers. The overall prevention policy, however, targets only the

general population and fails to effectively reach many groups at high risk of HIV infection. HIV/AIDS experts agree that prevention messages have become almost too routine and familiar. Although IEC messages have raised awareness about HIV/AIDS to near-universal levels, knowledge has not translated into changes in behavior.<sup>53</sup>

In addition, although the number of HIV testing sites has increased in recent years, the sites are inaccessible to many rural residents. Testing services are also not well integrated into a comprehensive package of care that includes treatment, which may prevent some people from seeking to discover their HIV status.

Unless prevention programs are improved to serve high-risk groups more effectively, address emerging priority areas such as the increasing feminization of the epidemic, and increase access to testing and other services, HIV prevalence rates in the generalized population are likely to rise.

## High-risk Populations

*[The feminization of AIDS] is related to power dynamics. We cannot make the mistake of addressing women without addressing the men, too, because they're part of the root cause behind this phenomenon.*

—Local HIV/AIDS activist

HIV is largely concentrated among high-risk groups in Senegal, the very population that the government's prevention programs neglect. A few NGOs have recently started interventions specifically for marginalized groups at high risk of HIV infection, such as men who have sex with men, unregistered sex workers, and orphans and vulnerable children, but current efforts are not sufficient to fill the gap.<sup>54</sup>

The government has, however, successfully provided HIV care to legal sex workers, linking prevention efforts, such as education and testing, with existing services for STIs. Since 1978, the Division for HIV/AIDS and STI Control of the Ministry of Health has provided STI diagnoses and treatment to registered sex workers with some success. Syphilis rates among sex workers have decreased from 20 to 15 percent.<sup>55</sup>

Although staff members in STI clinics are trained to provide medical care and treatment, they are not equipped to provide other services to sex workers—for example, social support and instruction in the use of condoms. As a result, sex workers, their clients, and the sexual partners of those clients continue to be at high risk for HIV infection.

Government efforts entirely neglect unregistered sex workers, who make up approximately 80 percent of all sex workers. These sex workers are often arrested and harassed by law enforcement agents, which makes them reluctant to seek prevention, care,

and support services. Because of these factors, this marginalized group is invisible to many stakeholders working in HIV/AIDS.

Men who have sex with men have also been largely ignored in the government's prevention policy. The 2007–2011 National Strategic Plan addresses the need for efforts to control STIs among men who have sex with men, but the quality and scope of implementation remain uncertain.

Men who have sex with men are often reluctant to test for HIV, both because of the unavailability of care and support services and because of their fear of rejection by their families. Social workers admit that existing prevention services for the general population must be adapted to meet the needs of men who have sex with men.<sup>56</sup> These men bear an enormous psychological burden, resulting from extreme stigmatization and from the pressure of leading double lives to conceal their sexual orientation. Some may need specialized psychosocial support.<sup>57</sup> AIDS experts advocate that mobile testing and counseling sites with flexible hours would be an effective alternative for those individuals—illegal sex workers and men who have sex with men—who may be reluctant to visit clinics for fear of stigmatization or rejection.

Women are disproportionately at risk of HIV infection—the prevalence rate is 0.9 percent among women and 0.4 percent among men.<sup>58</sup> Prevention interventions have not adapted to respond to this fact effectively, however. As one expert explained, “[The feminization of AIDS] is related to power dynamics. We cannot make the mistake of addressing women without addressing the men, too, because they're part of the root cause behind this phenomenon.”<sup>59</sup> An increase in the number of HIV infections among women means mother-to-child transmission is also on the rise. The current approach to mother-to-child transmission is highly medicalized, however, and does not address issues such as psychosocial support for women and the various social and familial implications.

Synergie pour l'Enfance has been implementing mother-to-child-transmission prevention services at the community level for several years. “Based on an evaluation of prevention of mother-to-child transmission programs, we determined that we can't do it without community involvement,” one representative said. “Instead of wives asking their husbands' permission to test for HIV, we should have husbands encouraging their wives to test. This will require a whole shift in the way of thinking, and for this we need to effect change at the community level.”<sup>60</sup>

## HIV Testing

In 2004, the government made free and confidential HIV testing available and made significant improvements in increasing access to testing at both governmental and non-governmental facilities. The government now offers testing through a network of 87

voluntary testing sites, which focus on medical care, and 14 VCT sites, which provide a more comprehensive package of care that includes counseling, psychosocial support, home visits, and follow-up services.<sup>61</sup>

To further improve access to free and confidential testing, there is a need for more laboratories, particularly in rural areas, and for more training to increase technical capacity—both of which require more resources. Laboratories now exist only in large cities, and people living in rural areas often have to travel long distances to get tested. As a result, fewer people test, which means many may not learn their HIV status early enough to benefit from ARV treatment. There is also a need for more social workers to staff mobile testing sites, which would make testing available to nonurban residents and to marginalized populations whose members may be reluctant to visit health centers.

Recently, NGOs and public health facilities have partnered to provide HIV testing in rural areas by setting up temporary sites in local schools, primary health clinics, and vans. The NGOs mobilize community members for testing, and the health facilities provide the technicians and laboratories. Although there is no documentation regarding the number of people who have been tested because of these efforts, many local organizations attest that access to testing has improved.

## **Linkage with Treatment and Other Services**

AIDS experts believe that, as part of the scale-up of HIV testing, there must be greater emphasis on and availability of comprehensive service providers—“one stop shops” that offer testing, counseling, psychosocial support, and ARV treatment—to encourage people to make use of all of these services. Increased access to testing may mean an increase in the number of people diagnosed with HIV, so the health system must be prepared to offer treatment and the full continuum of necessary services to all.

To date, however, both government and community actors have failed to fully integrate prevention, care, and treatment components into their programs. For example, many groups that provide prevention do not provide information about the location of treatment facilities. One explanation is that treatment is highly specialized and considered the domain of medical doctors. Community groups and NGOs have not had opportunities to work closely with hospitals, so they have focused on IEC and other interventions.

There have been isolated attempts to offer a more comprehensive package of care. The Centre de Traitement Ambulatoire (Ambulatory Treatment Center or CTA) in Dakar, an example of an effective partnership between an NGO and a large, public-referral hospital, provides patients with pre- and posttest counseling, psychosocial support, diagnostic tests, and treatment for AIDS and opportunistic infections.<sup>62</sup> Several international donors support the CTA, which is closely affiliated with a network of people living with HIV/AIDS

that conducts peer counseling and home visits. An on-site kitchen supplies free, nutritious meals to patients and teaches them the importance of eating well while on ARV treatment. This is, however, the only exemplary institution in Senegal. The government has replicated this model in Ziguinchor and Kolda, but on a much smaller scale. To widely replicate such partnerships would require more resources.

## Treatment

*By 2003, ... make every effort to provide progressively and in a sustainable manner, the highest attainable standard of treatment for HIV/AIDS, including the prevention and treatment of opportunistic infections, and effective use of quality-controlled antiretroviral therapy in a careful and monitored manner to improve adherence and effectiveness and reduce the risk of developing resistance.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 55

*By 2005, ... improve the capacity and working conditions of health care personnel, and the effectiveness of supply systems, financing plans and referral mechanisms required to provide access to affordable medicines, including antiretroviral drugs, diagnostics and related technologies.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 56

In 1998, when Senegal became the first sub-Saharan African country to establish an ARV program, fees for treatment were based on a sliding scale. Patients were selected based on economic and social criteria. As even minimum monthly costs proved to be significant barriers to access for many patients, many of whom lived below the poverty line, patient fees were reduced. The fees were eventually eliminated in 2003.<sup>63</sup> Senegal is one of few African countries that provide free ARV treatment. Although this free treatment is supposed to be available to any resident living with HIV/AIDS who meets the clinical criteria (based on a CD4 count test), not all those in need receive it.

In addition, other costs associated with treatment—for example, costs of transportation, diagnostic tests, treatment for opportunistic infections, and nutritional and other needs—all create barriers to treatment access. Because the health care sector lacks capacity, only about one-half of the patients on ARV treatment are regularly monitored to ensure patient compliance and efficacy of treatment.

The government exercises tight control over the procurement and distribution of ARVs, but system inefficiencies have led to drug shortages. The strict regulations regarding

ARV delivery also hinder rural residents from accessing treatment. Until recently, only doctors could prescribe ARVs, and many rural clinics were staffed only with nurses. There are now a few national NGOs that are approved to dispense ARVs, but these are primarily based in Dakar and other major cities, which does not improve accessibility in rural areas.

Although studies indicate that the rate of TB/HIV coinfection in Senegal is on the rise, ARV treatment is not well coordinated with TB treatment. Worldwide, TB is the most common and deadly opportunistic infection for people living with HIV/AIDS. National guidelines on TB/HIV integration have been in development for more than a year, but HIV/AIDS and TB are currently managed separately.

## Access to Treatment

*Unless the whole package of care is provided, it's not effective treatment.*

*We still ask people to pay fees for services when they're poor. If we want to guarantee access, we must make it free.*

—Person living with HIV/AIDS

As of February 2007, there were approximately 5,900 people on ARV treatment in Senegal, the majority of whom were in Dakar, clearly illustrating the regional disparity in access to treatment.<sup>64</sup> This same disparity exists in the number of physicians trained to prescribe ARVs in each region: 53 in Dakar compared to 26 in the rest of the country.<sup>65</sup> Because there are limited numbers of facilities and trained physicians qualified to dispense ARVs, rural residents must travel to access testing or ARV treatment, which presents restrictive costs—both in terms of time and money.

The Observatoire has noted that the low number of ARV provision sites is a serious barrier to treatment scale-up and it advocates that treatment be decentralized more effectively. One possible way to decentralize is by certifying those NGOs and community organizations that are already involved in providing care and support to people living with HIV/AIDS to provide treatment as well. Only a few organizations currently satisfy the stringent requirements to prescribe and dispense ARVs—although some NGOs believe they are better positioned than government facilities to access marginalized populations and to offer a more comprehensive package of care, which can include psychosocial support through counseling and support groups.<sup>66</sup> In addition, as demonstrated by the CTA model, hospitals and NGOs in partnership can strengthen and complement each other's work and help provide a full range of services. These partnerships should be encouraged and supported.

The financial burden of HIV care presents another barrier to access. HIV and CD4 count tests, ARV treatment, and treatment for TB are free, but the diagnostic tests and treatment for other opportunistic infections require fees.<sup>67</sup> For example, a simple blood test to

determine efficacy of treatment during a six-month checkup costs CFA 5,500 (about \$11).<sup>68</sup> AIDS patients also have specific nutritional, care, and support needs that require additional resources. As one person living with HIV/AIDS explained, “We should eat well, as the drugs we take have to be accompanied with nutritious food. Medical checkups and treatment of opportunistic infections are expensive, and the majority of [us] are poor.”<sup>69</sup> According to a representative from an organization of people living with HIV/AIDS, “Unless the whole package of care is provided, it’s not effective treatment. We still ask people to pay fees for services when they’re poor. If we want to guarantee access, we must make it free.”<sup>70</sup>

Due to the lack of disaggregated data from the ARV provision sites, it is difficult to determine whether marginalized, high-risk populations, such as sex workers and men who have sex with men, have equal access to treatment. Because these groups are not effectively receiving testing, counseling, or other HIV services, it is likely that they also have difficulty accessing treatment.

ARVs are not available in pediatric forms, a situation that presents a significant challenge in providing treatment to children. As is the case in many developing countries, in Senegal pediatric ARVs are more expensive than adult ARVs, difficult to procure, and subject to frequent drug shortages. The problem of effective treatment is exacerbated by the unreliable estimate of the number of children who are in need of treatment. Children are not widely tested. Testing of a child under the age of 18 requires parental consent, which can be difficult to obtain if, for example, the father is unaware of the mother’s HIV-positive status. Providing treatment for children also involves more than just providing drugs. They need comprehensive care—including psychosocial and nutritional support, school fees, and treatment for their parents—which requires greater financial and human resources.

## Need for Treatment Literacy

*Many people don't know what drugs they are taking ... and why they need to take them, so problems like side effects are not dealt with. People just stop taking the drugs.*

—Person living with HIV/AIDS

Approximately one-half of the people on ARV treatment are monitored on a regular basis to ensure their compliance with treatment and to evaluate the side effects and effectiveness of treatment.<sup>71</sup> At the CTA in Dakar, for example, patients must have checkups every six months.<sup>72</sup> The CTA is a unique case, however, and can afford to heavily subsidize these tests or offer them for free to patients who cannot afford to pay. As a result, it is better able to monitor its patients than other facilities with less flexible budgets.

AIDS activists emphasize the importance of treatment literacy—the education of patients about their treatment and possible side effects. As one activist explained, “Many people don’t know what drugs they are taking ... and why they need to take them, so problems like side effects are not dealt with. People just stop taking the drugs.”<sup>73</sup> It is also important to involve families and community caregivers so that they can adequately support patients.

The lack of capacity in the health care sector accounts for the low percentage of patients who receive ARVs and also the low percentage of those who receive follow-up treatment on a regular basis. Not only is there an insufficient number of medical and laboratory facilities, but health care workers report that they do not receive adequate training or support to deal with the HIV/AIDS epidemic.

At the recent annual review meeting coordinated by CNLS, many health care workers admitted that they were overwhelmed and lacked the incentive to take on additional work because they felt they were not adequately compensated for their time and effort.<sup>74,75</sup> To supplement their incomes, many doctors and nurses take jobs in the private sector, which means they have less time to spend with each patient. Many health care workers also expressed frustration at the poor working conditions and infrastructure of care services. Some send patients to other regions because they don’t have the capacity to treat them or the necessary equipment—for example, CD4 count machines.<sup>76</sup>

## Availability and Delivery of ARVs

*Without a continuous supply of drugs, we have problems helping people adhere to treatment, and there are problems of drug resistance.*

*—Person living with HIV/AIDS*

In Senegal, ARVs are distributed through the same channels as other essential drugs. The Senegal National Pharmacy (PNA) procures the drugs in the international market and distributes them to regional pharmacy agencies, which, in turn, allocate the drugs on the local level. This system is supposed to ensure that patients in every community have access to ARVs. An official from the Ministry of Health admitted, however, that it is a “challenge to supply stocks of ARVs in health centers and district hospitals.”<sup>77</sup> The procurement system—the purchase of ARVs in the international market, the transfer of money, and the distribution of drugs—takes time and can encounter delays.

The government tightly controls the system to avoid the potential diversion or trafficking of ARVs, which only the PNA has the authority to procure and distribute. Although there may be inefficiencies with the PNA, this rigid, centralized process may serve as a quality-control mechanism. It also presents the opportunity for integrating programs, for

example, for HIV/AIDS and TB. Improvements in the ARV-procurement system could benefit the systems for procuring drugs to treat other diseases.

The government recognizes the potential downsides of a too tightly controlled system, however, and is considering ways to improve the process. For example, since the PNA is a state monopoly, it may not have any incentive, in the absence of competition, to guarantee the lowest prices for drugs. The government distribution channels are also ineffective in reaching rural areas, a problem exacerbated by the fact that, until recently, only physicians could prescribe ARVs.

In June 2005, in order to improve the efficiency of the drug supply system, the CNLS created a pharmaceutical management bureau staffed by procurement specialists. The impact of the bureau was immediate. According to government accounts, there have been no drug shortages since January 2006, and the process of procurement and distribution to rural areas has improved.<sup>78</sup> The CNLS has also recently trained 43 biologists and 27 pharmacists in the management of ARVs and the treatment of opportunistic infections.

Health care workers and people living with HIV/AIDS in rural areas, however, report there are still problems with delivery of ARV drugs to rural areas. “We are always having drug shortages. ARVs are free, but there are problems with procurement. Sometimes we go for a month where there are no drugs available. This is not right. Without a continuous supply of drugs, we have problems helping people adhere to treatment, and there are problems of drug resistance.”<sup>79</sup>

## Link between HIV/AIDS and Tuberculosis

*HIV constitutes a favorable ground for the emergence of tuberculosis, and care and treatment of tuberculosis is an urgent issue among PLWHA. Also, care and treatment of TB patients facilitates access to PLWHA, hence the development of a joint HIV/AIDS integration strategy.*

—Khouidia Sow, MD, TB/HIV Unit, World Health Organization

The 2007–2011 National Strategic Plan stipulates that diagnosis and treatment for opportunistic infections should be an integral component of HIV/AIDS care. According to Khouidia Sow of the WHO, one of the first lessons for HIV/AIDS care providers is that “the initial symptoms of HIV are various opportunistic infections, which should be treated.”<sup>80</sup> Due to the lack of technical capacity in health centers, however, particularly in nonurban areas, the diagnosis and treatment for opportunistic infections are often insufficient. In addition, treatment for opportunistic infections, with the exception of TB, is not free, and many patients cannot afford to pay for the medicines they need.

TB is the most common opportunistic infection among people living with HIV/AIDS. According to recent surveillance, the HIV-prevalence rates among TB patients are 14.8 percent, 15.7 percent, and 1.7 percent in Dakar, Kaolack, and Thies, respectively.<sup>81</sup> One physician in Dakar estimates that out of 2,000 registered HIV-positive people in his facility, approximately 30 to 40 percent also have TB.<sup>82</sup> The WHO has provided technical assistance to the Ministry of Health to develop standards and protocols for TB/HIV integration, but the guidelines are still being developed, and a strategy document that designates specific roles, responsibilities, and objectives is yet to be adopted. The national TB program has changed directors several times in recent years, and the inconsistent leadership likely contributed to the delay in finalizing the TB/HIV guidelines.

As a result, TB and HIV/AIDS programs are managed in parallel by two independent departments. The respective administrators and program officials maintain authority over their own programs. Although it will require more comprehensive health system reform to fully integrate these programs, the separate departments can, at a minimum, coordinate more effectively so that patients can receive both HIV and TB diagnoses and treatment in one facility. For example, at the CTA in Dakar, every TB patient is encouraged to test for HIV and every HIV patient is encouraged to test for TB.<sup>83</sup> Other health care providers have also successfully implemented integrated care. According to Sow, “Doctors and nurses who have been trained under the AIDS program are offering care and treatment for TB. Similarly, in some health districts, health care providers often perform HIV tests on TB patients.”<sup>84</sup>

There are also opportunities to integrate TB and HIV/AIDS care at the community level. In some countries, community-based TB services, including directly observed therapy, have been successful in helping patients adhere to treatment, and have helped to extend the reach of overstretched clinics.<sup>85</sup> Collaboration between community-based TB and HIV/AIDS services could help bolster both efforts—training for TB care delivery can help build capacity of HIV/AIDS community care providers while mobilizing communities to care for patients can help strengthen civil society response to TB.

Unfortunately, the TB program in Senegal has had difficulty involving communities. As a telling indicator, Senegal’s Global Fund proposal for TB has been rejected each of the three times it has been submitted, including most recently for the Round 6 funding, in part because of lack of community involvement. TB control is highly medicalized in Senegal, as in many other countries, and community advocates have struggled to find ways to collaborate with hospitals and other treatment facilities. Strengthening civil society involvement in TB-control efforts may not only improve patient adherence to treatment and mobilize the community in response to TB/HIV, it may also help secure future funding.

The Global Fund proposal for TB also did not sufficiently address TB/HIV integration. In order for integration to occur at the implementation level, the proposal must include specific plans as to how it will happen. After the funding has been disbursed, there is little

incentive for programs to integrate and share resources. The Global Fund must emphasize the importance of integration of services for the treatment of TB, HIV/AIDS, and malaria by insisting that grant proposals are submitted jointly or in a fully coordinated manner.

## Care and Support

The majority of the care and support that people living with HIV/AIDS receive comes from their families and communities, NGOs, and associations of people living with HIV/AIDS. In addition to providing psychosocial care and support, the associations help to raise public awareness. They also advocate for access to treatment, care, and support services. In Senegal, there are now 13 associations of people living with HIV/AIDS, represented in all regions except Diourbel.

Although hospitals employ social workers and provide some care and support, their focus is still largely on medical issues and isolated treatment. NGOs, on the other hand, can provide more comprehensive and customized care, for example, by following up with patients and visiting them at home.<sup>86</sup> Only a relatively small number of NGOs are currently involved in care and support activities, however. The majority of NGOs are primarily focused on prevention and on building the capacity of their members and constituents (for example, by training peer educators).

As a result of French influence, the health care system in Senegal is focused on hospitals. Patient care and support traditionally have been regarded as medical interventions and outside the realm of community-based organizations. As a result, NGOs do not have much experience or expertise in providing home- and community-based care. Although many NGOs would like to take on care-related activities, such as improving treatment literacy, providing nutritional support, and monitoring side effects, few groups have been able to implement these programs due to lack of capacity and resources.

Further, due to the relatively low HIV-prevalence rate in Senegal, there are approximately 61,000 people living with HIV/AIDS, not all of whom require care and support services. Because some of these people are not open about their status, for fear of being stigmatized, the majority of local organizations simply do not know about or have access to many of the people who are living with HIV/AIDS. Only five or six large national NGOs that work closely with hospitals have access to a large number of people living with HIV/AIDS—and even for these organizations, collaboration with hospitals is a recent phenomenon.

As with access to treatment, there is a geographical disparity in access to care and support activities. One reason is that there is a greater concentration of NGOs in Dakar and on the west coast. Fewer services are available to rural populations, although they are

arguably more vulnerable to HIV and its impact because of various factors that put them at greater risk: poverty, political instability, cross-border migration, and traditional practices such as polygamy, female circumcision, and widow inheritance. Rural residents have reported serious shortfalls in care and support activities for people living with HIV/AIDS and their families. A representative from an organization of men who have sex with men based in Mbour (approximately 70 kilometers from Dakar) indicated that there are no counseling services available, even though it is one of the organization's priority needs.<sup>87</sup>

For its second round of funding, the World Bank has prioritized support for NGOs working in the underserved rural regions, but there are no plans to continue support for current activities and services when the program terminates. National NGOs are trying to decentralize their services to reach rural areas more effectively, but they do not have adequate resources or capacity to expand quickly without sacrificing the quality of the services they already provide.

AIDS care providers have noted a particular weakness in providing care and support to orphans and vulnerable children.<sup>88</sup> HIV-positive orphans face a double stigma: as an orphan and as a person living with HIV/AIDS. There are only a few NGOs equipped to address this issue, however. From the handful of NGOs that provide care and support, an even smaller subset focuses on orphans and vulnerable children.

In 2005, the government consulted with civil society to develop guidelines on treatment, care, and support that would strengthen the capacity of home- and community-based caregivers. These guidelines have not yet been widely disseminated, however. In the same year, the government also facilitated the training of 313 public-sector care providers in the practices of psychosocial support and counseling and 187 health workers in methods of ARV care and treatment.<sup>89</sup> Although this is a positive development, care providers in the nongovernmental sector and in communities need more training.

Civil society organizations have increasing responsibility in the response to HIV/AIDS, which includes providing care and support to people living with HIV and affected communities, fighting stigma and discrimination, and mobilizing people for testing. Civil society and the public sector must work together to provide a continuum of care. In order for the entire system to function, the government cannot neglect one sector in favor of another.

# Monitoring and Evaluation

*Conduct national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers, of progress achieved in realizing these commitments, identify problems and obstacles to achieving progress, and ensure wide dissemination of the results of these reviews.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 94

*By 2003, establish or strengthen effective monitoring systems ... for the promotion and protection of human rights of people living with HIV/AIDS.*

—UNGASS Declaration of Commitment on HIV/AIDS, Article 96

*[The national monitoring and evaluation (M&E) process] could be enriched to take into account the progress reports from the community level to help build capacity and to guide appropriate responses according to local needs.*

—Souleymane Anne, M&E officer, ENDA

Following the Three Ones principles, Senegal has adopted a single monitoring and evaluation (M&E) framework as part of its 2002–2006 National Strategic Plan.<sup>90</sup> The national M&E system includes indicators that measure process, results, and impact. These indicators are comprised of those included in the Global Fund objectives and the UNGASS Declaration of Commitment on HIV/AIDS. (See sample list of indicators below)

The M&E indicators only take into account data from projects implemented by CNLS, the majority of which are funded by the World Bank and the Global Fund. Some experts have criticized the narrow scope of the national process. “It could be enriched to take into account the progress reports from the community level to help build capacity and to guide appropriate response according to local needs,” said Souleymane Anne, an M&E officer at ENDA.<sup>91</sup> The Observatoire has stated that the national M&E, which does not capture data generated by civil society, should consider the entire national response, not just the government response.<sup>92</sup> The government criticizes civil society for not providing data on a regular basis, while civil society contends that they have no incentive to provide data because the information is not reflected in the final indicators or the quarterly national M&E reports. One NGO representative said, “Although we always send our data, we never receive feedback.”<sup>93</sup>

## Sample of Monitoring and Evaluation Indicators<sup>94</sup>

Indicators	Description
IND 1	Percentage of ministries that grant budgets for AIDS control
IND 2	Composite index of national policies
IND 3	Number of functional VCTs, according to the standards
IND 4	Percentage of regions covered by the PMTCT program
IND 5	Rate of acceptance of testing among targeted pregnant women
IND 6	Percentage of pregnant women infected with HIV who are receiving full ARV treatment to reduce the risk of mother-to-child transmission
IND 7	Percentage of persons reporting to the structures for STI diagnosis
IND 8	Number of patients receiving ARV treatment
IND 9	Percentage of PLWHA benefiting from follow-up psychosocial support
IND 10	Number of NGO subprojects and community-based subprojects funded as AIDS control activities
IND 11	Percentage of civil society subprojects funded and successfully implemented in accordance with the respective performance indicators set forth in the implementation manual
IND 12	Percentage of schools whose teachers have received training in HIV/AIDS
IND 13	Percentage of major enterprises /companies that have developed HIV-control policies
IND 14	Rate of condom use among boys ages 15 to 19, during their most recent sexual intercourse
IND 15	Percentage of young people ages 15 to 24 who have exact knowledge about ways of preventing sexual transmission of HIV and who reject the main erroneous ideas about transmission of the virus
IND 16	Percentage of young people ages 15 to 24 who declared using a condom during sexual intercourse with a casual partner
IND 17	Percentage of young people ages 15 to 24 who are infected with HIV
IND 18	Current ratio of education of orphans ages 10 to 14
IND 19	Percentage of infants who were born to infected mothers and are carrying the virus
IND 20	Prevalence rate

Civil society has advocated for more process-oriented, midterm indicators that, rather than focus exclusively on quantitative results, evaluate the activities of NGOs and community-based organizations—including the accessibility and quality of services. Civil society representatives have also emphasized the need for operational guidelines and training seminars to ensure that all actors in the M&E process understand the system, including the methods of data collection and analyses, so they can use the information to guide their work.

The M&E system encompasses the 11 regions of Senegal. The Regional Support Unit (RSU) supervises the regional AIDS committees in compiling and validating the monthly monitoring data from local committees. The RSU then sends the information to a central agency for analysis. There are no mechanisms in place to support the analysis of data at the local and regional levels, which limits the degree of ownership of the information and building of local capacity. The staff that handles the processing and analysis tasks are based in Dakar, which makes it difficult to mobilize technical support to address difficulties at the regional and local levels. Further, the epidemiological surveillance data are collected from urban centers and then generalized to apply to the entire region, which may misrepresent or fail to convey accurate local information.

In January 2005, CNLS conducted an assessment of the M&E system to identify the system's weaknesses. It found that data on marginalized groups, such as sex workers and men who have sex with men, were lacking. Although some donor-funded projects disaggregate information on these groups, there is no systematic way to collect information from other sources. As a result, organizations do not share practices or benefit from the experiences and lessons of others.<sup>95</sup> The *Demographic and Health Survey* does, however, conduct periodic behavioral surveillance of select target groups—such as young people, sex workers, uniformed men, and truck drivers—and provides information on how best to deliver prevention messages to these groups.

Other weaknesses in the M&E system include the lack of complete financial information. Because CNLS does not have access to information on the financial flows to civil society organizations, it is difficult to identify funding gaps and plan activities for subsequent years. The lack of technical M&E skills among CNLS staff also presents a challenge, particularly at the regional and district levels. More training will help ensure full and effective use of the tools.

The preparation of the UNGASS national progress report in 2005 illustrates the inability of the M&E staff to consult effectively with a wide range of stakeholders. Civil society groups were informed about the process, but, because the report was prepared within such a short period of time, they did not have the opportunity to comment or contribute in a meaningful way. They were sent a draft report only two days before it was submitted to the Joint United Nations Programme on HIV/AIDS. The general sentiment of civil society organizations concerning the UNGASS progress report was that it focused only on quantitative indicators and did not accurately reflect the state of the HIV/AIDS epidemic or the implementation of the UNGASS Declaration of Commitment. For example, the report did not address the accessibility and quality of testing and treatment; the lack of wide availability of care and support services for people living with HIV/AIDS, particularly for orphans and vulnerable children; or progress in reducing stigma.

# Recommendations

The following recommendations for the Senegalese government, based on research and consultations conducted for this report, specify strategies that will strengthen the national response to HIV/AIDS.

- Develop a more comprehensive epidemiological surveillance system to determine accurate and disaggregated rates of HIV/AIDS prevalence and incidence, particularly in rural areas, by focusing on the following:
  - HIV prevalence rates for marginalized and high-risk groups, such as men who have sex with men and both legal and unregistered sex workers
  - Geographical disparities in HIV/AIDS prevalence, to help assess the impact of migratory flows, poverty, sociocultural factors, and cross-border activities
  - The increasing degree of vulnerability of women to HIV infection, particularly young women of childbearing age, rural women, and those with low levels of education
- Utilize the epidemiological data to guide the national HIV/AIDS response and to develop appropriate programming, including cross-border initiatives.
- Collaborate with civil society organizations to adopt innovative approaches to HIV/AIDS prevention, care, and treatment services that effectively target populations at high risk for HIV infection and those who are vulnerable to the impact of HIV/AIDS by
  - reformulating prevention messages to target groups that are most vulnerable to HIV, such as women and girls, unregistered sex workers, and men who have sex with men;
  - offering care and support to all sex workers, including unregistered sex workers;
  - providing orphans and vulnerable children with comprehensive care that includes school fees, medical care, and recreational, psychosocial, and nutritional support;
  - articulating strategies for prisoners, mobile and cross-border populations, and informal sector workers.

- Improve access to and quality of treatment, care, and support services by
  - decentralizing treatment and care services to rural areas and ensure that services are located according to need, not solely in the capital and other urban areas;
  - expanding the package of quality care offered to people living with HIV/AIDS, including food and transportation vouchers and free diagnoses and treatments for all opportunistic infections;
  - integrating TB and HIV/AIDS programs to address TB/HIV coinfection;
  - promoting and facilitating greater involvement of the private sector and civil society through projects that build the capacity of civil society organizations and encourage hospitals and health care workers to collaborate with home- and community-based caregivers to offer more comprehensive care and support to people living with HIV/AIDS.
- Strengthen the capacity and accountability of the health care sector to ensure that it effectively addresses the HIV/AIDS epidemic by
  - building human capacity through additional training and increasing compensation for health care workers to improve retention;
  - allocating more funds to increase laboratory capacity;
  - training actors in all levels of the M&E system to improve data collection, analysis, and utilization of information;
  - increasing the capacity of civil society organizations to provide a full continuum of prevention, treatment, care, and support services in collaboration with the public sector.
- Guarantee the sustainability and coordination role of CNLS by
  - securing financial support for the CNLS and its staff, either by supporting it with funds from the national budget or from contributions by multiple donors;
  - ensuring that the CNLS focuses on coordination and supervision rather than implementation.

- Address stigma and discrimination by
  - adopting, as soon as possible, the draft HIV/AIDS law that guarantees the rights and dignity of people living with HIV/AIDS;
  - developing programs and strategies for reducing stigma and mitigating the impact of HIV/AIDS;
  - ensuring the involvement of a wide range of civil society stakeholders, through activities that mobilize religious leaders, empower associations of people living with HIV/AIDS to serve as positive role models, and provide incentives for hiring people living with HIV/AIDS in fulfilment of the Greater Involvement of People with HIV/AIDS (GIPA) principle.<sup>96</sup>

# Notes

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23. Interview with members of Aboya, a network of women living with HIV/AIDS, Dakar, Senegal, April 20, 2006.
24. The Observatoire includes African Consultants International (ACI); ENDA Santé; SIDA Service; Synergie pour l'Enfance; and Alliance National Contre le SIDA (ANCS).
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[We] acknowledg[e] the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects, and recogniz[e] that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic.

—UNGASS Declaration of Commitment  
on HIV/AIDS, Article 33

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Public Health Watch promotes informed civil society engagement in policymaking on tuberculosis and HIV/AIDS. The project's monitoring reports offer a civil society perspective on the extent to which government policies comply with international commitments such as the Amsterdam Declaration to Stop Tuberculosis and the Declaration of Commitment on HIV/AIDS—and on the extent to which those policies have been implemented. HIV/AIDS monitoring reports include assessments of policies in Nicaragua, Senegal, Ukraine, the United States, and Vietnam.

