



A Testing Challenge

**The Experience of Lesotho's Universal
HIV Counseling and Testing Campaign**

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I. Executive Summary

Experts estimate that fewer than 2 in 10 people in sub-Saharan Africa know their HIV status. Even fewer know the HIV status of their partner. Not knowing your—or your partner’s—HIV status can have devastating consequences. It puts millions of people who have HIV at risk of premature death by delaying initiation of treatment and unknowingly exposing others to the virus. Those who are found to be HIV-negative need the knowledge to continue to protect themselves against HIV infection. Ignorance of HIV status is particularly problematic for sero-discordant couples—people in relationships where one person is HIV-infected while the other is not—where, according to some studies, a significant percentage of new infections in sub-Saharan Africa occurs.

There is broad international consensus that HIV testing must be expanded urgently so that more people can protect their health, but the question of how to do this has been the subject of heated debate. As treatment has become more available in resource-constrained settings, some medical and public health officials have argued that the scale of the epidemic in high prevalence regions such as southern and eastern Africa requires a more aggressive response, in which certain human rights protections should be suspended or restricted for the benefit of the greater good. These officials have pitted a “rights-based” approach against a “public health” approach.

Good public health and human rights practices generally go hand-in-hand, though: The right to make a decision based on informed consent is not only protected by human rights law, but is also crucial from a public health perspective, as it enables people to act on the knowledge they obtain through the test; confidentiality, another aspect of the right to health and privacy, is also crucial for maintaining public trust in the health care system.

One of the new HIV counseling and testing approaches that has proliferated across sub-Saharan Africa in the last few years is large scale community-based testing. In contrast to provider-initiated testing in healthcare settings, this type of testing has

received little attention or scrutiny. By bringing HIV testing into communities, these testing programs seek to reach people who are unlikely to access voluntary testing and counseling services and who are not in touch with the healthcare system. While these programs have real potential, their impact may be limited if they result in, or contribute to—intentionally or unintentionally—violations of basic human rights. To date, no international guidelines exist to help countries implement this testing model in a way that both contributes to public health goals and is respectful of human rights.

Lesotho, a country of about 1.9 million people with the third highest HIV prevalence in the world and a severely overstretched healthcare system, is one of the countries implementing this testing model. With the encouragement of the World Health Organization (WHO), it developed a highly ambitious community-based HIV testing program in 2005 in which thousands of lay counselors from villages all over the country were to offer HIV counseling and testing to everyone twelve years and older. The “Know Your Status” (KYS) testing campaign, as it was called, which was launched on December 1, 2005, planned to offer 1.3 million people an HIV test within two years.¹ The then-Director of WHO’s HIV/AIDS program lauded the campaign as a model for other high prevalence countries to follow, with the potential to dramatically reduce HIV prevalence.²

By harnessing the potential of community-based lay counselors, the campaign sought to overcome a major hurdle to expanding HIV testing that is characteristic not just to Lesotho but to many other high-prevalence countries: the healthcare system’s crippling capacity problems and inability to reach those who are the least likely to seek HIV-testing or be in contact with the healthcare system, including those who live in remote locations. The campaign’s approach to expanding testing, though, also posed considerable challenges to Lesotho’s overstretched healthcare system. How would it ensure proper training and oversight of such a large number of lay

¹ Operational Plan, p.9, states that 1.8 million people will be tested over the course of the KYS campaign. However, subsequent official documents consistently cite 1.3 million as the target.

² Sam Lister, “AIDS test for whole nation,” *Times of London*, November 29, 2005, quotes Dr. Jim Yong Kim, on the eve of the campaign’s launch, telling journalists that every country with a prevalence of more than 10 percent should implement such a campaign.

counselors? How would it ensure that the campaign did not merely test people but also inspired people to change their sexual behaviors and linked those testing positive to care, support, and treatment?

The unprecedented scope and ambition of the program, combined with the lack of capacity of Lesotho's healthcare system meant that there was a real risk that the KYS campaign would fail to enable people to act on the knowledge of their status and to respect and protect the basic human rights of those that it was targeting. Infringements on rights could arise through testing without informed consent, failure to provide the information individuals needed to make an informed decision on an HIV test, breaches in confidentiality, and ineffective accountability mechanisms. The under capacitated health system meant that there was also a risk of poor access to prevention, care and treatment services.

The campaign's Operational Plan, a detailed 48-page plan of action, recognized these various risks and challenges. It stated:

While filled with promise for helping Basotho [the people of Lesotho], the "Know Your Status" campaign may also yield damaging effects—unintentional or intentional—to the people of Lesotho.³

Yet, the Operational Plan expressed confidence that the campaign would overcome these challenges and would—ultimately—significantly contribute to HIV prevention efforts, help enroll many more people into care and treatment, and reduce stigma.

The plan addressed most of the risks and challenges in detail. It indicated that all testing should be voluntary and that test results should be confidential. It called for proper training and supervision of lay counselors. It also described quality control, monitoring and evaluation, and independent oversight mechanisms that were to be put in place. Finally, it stressed the key importance of expanding care and treatment in parallel to the campaign, invoking the Ministry of Health's intention to make antiretroviral drugs available at all local healthcare clinics.

³ Operational Plan, p. 12.

Human Rights Watch and the AIDS and Rights Alliance for Southern Africa (ARASA) jointly conducted research in Lesotho in October 2007 and February 2008 to examine how well the principles and protections identified in the operational plan were implemented in the roll-out of the KYS campaign. We conducted dozens of interviews with key informants, including KYS staff, counselors, healthcare workers and others, as well as some KYS clients, in five towns and ten villages in five districts of Lesotho.

We focused our research on five aspects of the country's HIV counseling and testing campaign with direct relevance to international human rights principles and public health norms and standards. We examined: 1) informed consent and counseling; 2) confidentiality; 3) linkages between HIV testing and prevention, care and treatment services; 4) accountability mechanisms; and 5) the adequacy of the policy and legal framework for protecting the rights of people living with HIV.

Our research in Lesotho revealed both positive and negative aspects of the KYS campaign. On the positive side, we found no evidence of involuntary testing and heard only a few allegations of breaches of confidentiality. We also found that some efforts were made to ensure that testing was linked to HIV treatment and care services, and that there was a great commitment among counselors to bringing HIV counseling and testing to communities. On the negative side, we found a failure to ensure that the human rights safeguards included in the Operational Plan were properly implemented in practice, which resulted in the campaign failing to intervene when it became clear that many counselors in Mafeteng district were ill-equipped to conduct HIV counseling and testing. There was a clear disconnect between the planning on paper and the capacity to implement what was planned. All those involved in the planning of the campaign, the Lesotho government, and the WHO, bear responsibility for not recognizing this disconnect and responding to it from the outset. The KYS campaign's implementation was fraught with problems, resulting in poor training and supervision of counselors; poor linkages, at times, to other services after testing; and insufficient mechanisms to ensure respect for human rights and the accountability of government efforts. In places where the campaign was conducted most intensively, human rights protections, as well as the integrity of the counseling and testing provided, seemed most endangered. Human rights

protections should be an integral part of any testing campaign, not an optional element that can be added or left out depending on availability of resources.

To be sure, many of the KYS counselors we interviewed were deeply committed to the concept of bringing HIV education and testing into communities. Many told us of hours-long walks to remote villages to speak to villagers about HIV and AIDS. Others explained to us how they went beyond the call of duty to accommodate the concerns of their clients by inviting them to their own homes to test or returning to their homes repeatedly to counsel clients testing positive. We also encountered nurses at local healthcare centers who had invested considerable time and energy—on top of their already grueling schedules—in training and supervising KYS counselors, and offering people who tested not just referrals but integrated HIV-related health services.

The KYS campaign, though, has not been the quick-fix that policy makers had hoped for. From day one, the campaign was in trouble. While the Operational Plan had provided a detailed script for a highly disciplined and systematic testing campaign, in practice KYS' overall implementation was chaotic, uneven, lackluster, and fraught with problems. Many of the elements of the campaign that the Operational Plan described—a media campaign, quality assurance, monitoring and oversight for potential abuses—were either never implemented or implemented only after a long delay. Although by late August 2007—21 months after its launch—the campaign had trained about 3,590 lay people—of the 7,200 planned—in many parts of the country, it failed to meet its targets by wide margins.⁴ While HIV testing at healthcare clinics increased significantly, by late August 2007, fewer than 25,000 people had been tested through KYS, just 2% of the 1.3 million target that had been set for the end of 2007.⁵ An April 2008 press release by WHO in Lesotho stated that “while only 50,000 people in Lesotho knew their status in 2004, by the end of 2007, over 240,000

⁴ World Health Organization, “Progress report on Know Your Status HIV counseling and testing Campaign,” August 30, 2007, on file with ARASA and Human Rights Watch, p.8.

⁵ *Ibid.*, p.8 states that in total, by late June 2007, just under 200,000 people had been tested for HIV in Lesotho, the overwhelming majority at healthcare centers. In its submission to the UN General Assembly Special Session on AIDS in 2008, the government stated that around 160,000 people had been tested through the KYS campaign in 2007—again the vast majority of these people were tested at health centers and other venues. National AIDS Commission of Lesotho, “Lesotho UNGASS Country Report for the year January 2006-December 2007,” 2008, http://data.unaids.org/pub/Report/2008/lesotho_2008_country_progress_report_en.pdf (accessed October 20, 2008), p. 7. We have not been able to obtain the final number of people tested by KYS counselors during the KYS campaign.

Basotho tested for HIV” and that 30 percent of HIV tests were conducted in community-based settings.⁶ However, it does not estimate how many people had actually been tested by KYS counselors.

In response to the sluggish performance of KYS, the government organized a three-week long intensive testing drive in Mafeteng district in August 2007. As part of the drive, KYS program managers sent 318 counselors into villages in Mafeteng district to conduct HIV counseling and testing. This resulted in more people being tested than in any other three-week period during the two-year campaign—13,342, with 1,468 (11%) testing positive.⁷ Our research found that in its eagerness to test as many people as possible, the KYS campaign sent dozens of KYS counselors who had never received any practical training into villages; some had never even seen a test kit before. The lack of adequate training poses a clear risk of violations of informed consent and confidentiality.

Indeed, we found that counseling provided by KYS counselors was often substandard, raising concern about whether people’s consent to test—or their decision not to test—was actually informed. In some cases, women did not get tested because they were not permitted to consent or felt that they could not consent without their husband’s permission. Although we did not document specific cases of breaches of confidentiality, the KYS counselors we interviewed had varying degrees of understanding of the importance of confidentiality and attitudes towards it. Several nurses from Mafeteng district complained that the influx of KYS referrals after the drive had caused real strains on their clinics and laboratories, as well as on their ability to ensure linkages between testing and care. We were told that KYS had not coordinated with local clinics or labs to ensure that the healthcare system in Mafeteng district could absorb the considerable influx of people testing positive and although the Operational Plan stated that people who tested negative would be referred to prevention services, this has not happened in practice. In other parts of

⁶ World Health Organization/Lesotho press release, “‘Know Your Status’ HIV Campaign Receives Praise for the Achievements Accomplished in Lesotho,” 4 April 2008. (http://www.afro.who.int/country_offices_press/2008/pr20080404.html, accessed November 7, 2008).

⁷ *Ibid.*, p.10.

the country, it appears health clinics were able to absorb new patients referred by KYS because the pace of KYS testing was very low.

Lack of accountability mechanisms also meant, according to several supervisors and nurses interviewed by Human Rights Watch, that multiple individuals were wrongly told that they were HIV-infected because counselors did not know how to operate or read test kits. Some of these cases came to light when laboratory technicians became suspicious that immune level tests came back showing no abnormality and decided to retest the blood samples for HIV. It is not known how many such cases went unnoticed. Although the Operational Plan provided for various mechanisms, such as supervision for counselors, quality assurance procedures and internal and outside monitoring, aimed at ensuring that the government could detect problems caused by the KYS campaign and intervene when needed, most of these accountability measures were not actually implemented. Quality assurance procedures aimed at ensuring that the results of rapid tests were accurate were not followed, leaving the KYS campaign with no way of identifying problems with either batches of test kits or their administration by counselors. The KYS campaign has also failed to put in place a system to track uptake of referrals to healthcare centers for follow-up services. It thus had no way of signaling a problem should uptake of referrals be unacceptably low.

The Operational Plan called for the establishment of various KYS and independent monitoring mechanisms to collect information on the implementation of the campaign and potential problems it caused. However, as of October 2007, two months before the KYS campaign was supposed to end, these mechanisms were not functional. The independent monitoring mechanisms that were supposed to collect information about potential problems related to breaches of consent, confidentiality, the quality of counseling and testing, potential post-disclosure problems for women, or problems with linkages to treatment, were never even created. The authorities failed to seize the important opportunity KYS offered to engage civil society networks of people living with HIV and support groups, in providing oversight over the campaign. As a result, people were deprived of an accessible mechanism to raise potential concerns about the KYS campaign.

Although Lesotho has made considerable progress in recent years in adopting a legal and policy framework that protects the rights of people living with HIV, major gaps remain. In 2006, Lesotho adopted a landmark law granting women legal capacity, which means that women can now own property, maintain bank accounts, and make their own decisions about medical procedures. The law is an important first step toward breaking the almost complete dependence of women on their male partners, which had made them vulnerable to human rights abuses ranging from property grabbing to domestic violence. Yet, Lesotho still does not have a law on domestic violence, meaning that women remain extremely vulnerable to violence from male partners when disclosing their HIV status. Lesotho's laws protect employees with HIV and AIDS in the private but not the public sector. The country is in the process of adopting a new law on HIV and AIDS, but the draft legislation does not fully protect the rights of people living with HIV and AIDS, reduce vulnerability, or provide protection from infection.

Community-based testing campaigns have real potential. They offer a real chance to reach out to populations that are otherwise unlikely to test, but they also entail risks that must be addressed head-on through the implementation of robust human rights safeguards. While such safeguards were part of the plan for Lesotho's KYS campaign, they were not implemented. The government of Lesotho and international organizations such as WHO and UNAIDS can and must learn important lessons from the KYS campaign. These campaigns need careful planning, sufficient funding, good training, ample coordination, proper oversight, and the involvement of civil society which can play a critical role in ensuring accountability and reporting potential human rights abuses. Without these elements, these programs risk failing to achieve their ambitious goals—as happened in Lesotho—or worse, damaging the cause they were intended to serve.

II. Recommendations

Although the Know Your Status campaign was supposed to end in late 2007, the government of Lesotho has decided to integrate it into the Ministry of Health and Social Welfare and continue the campaign, as part of a broad scale up of HIV testing approaches, including the implementation of a problematic new mandatory testing policy for pregnant women in healthcare settings.⁸

It is very important that HIV testing be expanded to reach the entire population of Lesotho. However, for such efforts to be successful, greater attention to the principles of informed consent, confidentiality, linkages to services and support, accountability, and improved policy must be instituted. Going forward, the government of Lesotho and its partners should recognize that in order to ensure HIV testing services are a part of comprehensive prevention and treatment approach, they will need to secure the resources and implement the oversight necessary to expand quality HIV counseling and testing in a way that respects rights, reduces the vulnerability of those who test negative and protects the rights of those testing positive.

To the Government of Lesotho

- Provide counselors with additional training and guidance on **informed consent and confidentiality**. A particular concern should be addressing women and minors prevented from consenting to or declining tests, and providing training to address sero-discordant couples and testing and counseling of couples.
- **Strengthen general preparation and support offered to KYS counselors**. The training curriculum needs considerable revision; a way needs to be found to provide meaningful field training and to ensure adequate supervision without overburdening existing health structures; counselors must be provided with

⁸ At the end of the two year campaign, the government of Lesotho, the World Health Organization and the United States government conducted an evaluation of the campaign. The findings of this review are expected to be announced in late 2008.

- adequate tools, such as counseling check lists and ID cards, to consistently provide good services, and should be paid incentives as promised.
- **Ensure linkages to HIV-related services.** People should be referred to post test services whatever their test result. People who test negative must receive the knowledge and skills to avoid infection and be able to protect themselves. Those who test positive must have effective access to care and treatment, including to TB services. Treatment should become available at all healthcare centers as soon as possible.
 - Put in place workable **supervision and quality control** mechanisms that are capable of identifying problems in a timely fashion and allow redress for individuals who feel that their rights have been violated.
 - As a matter of priority, put in place **independent oversight mechanisms** to collect any potential complaints about problems with confidentiality, consent, linkages to other health services, and abuse based on HIV status. Civil society groups should play a key role in these mechanisms.
 - Adopt **laws and policies** that protect people who test positive against stigma and discrimination and enable people who are negative to remain so. In particular, laws recognizing women and children's right to inheritance and laws against domestic violence, property grabbing and discrimination in all work places, need to be adopted.
 - Ensure that **no mandatory testing** takes place in antenatal settings. Testing of pregnant women must include specific consent to be tested.

To WHO/UNAIDS

- As more and more countries in sub-Saharan Africa and other parts of the world experiment with different types of community-based HIV counseling and testing programs, there is a critical need for WHO and UNAIDS to learn from the experience of the Lesotho KYS program and to provide countries with detailed guidance on how such programs can be implemented while respecting and protecting human rights based on the recommendations addressed here to the government of Lesotho.
- In addition to providing guidance on community-based testing models, support the development of multiple venues of HIV testing to ensure that people can choose those services that they feel will best protect their rights.

To Donors to HIV Counseling and Testing Programs

- Support a review of various community-based HIV counseling and testing initiatives in sub-Saharan Africa and elsewhere in order to identify both best and worst practices and develop the evidence base for community-based testing programs.

III. Methodology

This report is based on information collected during field visits to Lesotho in October, 2007 and February, 2008. Over the course of a total of four weeks in the field, Luyanda Ngonyama, the advocacy coordinator of the AIDS and Rights Alliance for Southern Africa (ARASA), and Diederik Lohman, a senior researcher for Human Rights Watch, conducted detailed interviews with key informants, including twenty-nine KYS counselors, five staff members of the KYS campaign office in Maseru, five KYS district managers, two KYS district logistics officers, twenty-six nurses, doctors and other health workers at a dozen clinics and hospitals, eighteen representatives of NGOs and support groups for people living with HIV and AIDS, as well as representatives of the World Health Organization (WHO), United Nations Development Program (UNDP), UNAIDS, and the embassy of the U.S.. We also interviewed eleven people who were tested through KYS. Before the interview, we told interviewees of the purpose of the interview, explained what issues would be covered, and asked if they wanted to proceed. We did not offer or provide any incentives.

We conducted the interviews in five cities and ten villages in five districts of Lesotho. We chose these towns and villages based on information suggesting that the KYS campaign had been active there; we did not conduct research in villages and towns where there was little or no KYS activity. We conducted semi-structured interviews in private where possible. The interviews covered a broad range of topics, including selection and training of counselors; outreach and testing work in communities; informed consent, confidentiality and pre and post-test counseling; supervision mechanisms, quality control, and independent oversight; and linkages to prevention, care and treatment. Most interviews were conducted at healthcare centers or at the homes of KYS clients and counselors. We identified interviewees through KYS staff, staff at healthcare centers and hospitals, support groups, and NGOs. The KYS counselors were mostly women, aged between 30 and 50. KYS clients were also mostly women, ranging in age from their twenties to eighties. The interviews were conducted either in English or in Sesotho with the help of an interpreter.

Locating KYS clients was a considerable challenge. We relied mostly on KYS counselors to help us identify and approach people who had tested through KYS. In such cases, the counselors would approach persons individually and explain that we would like to interview them about their experiences with KYS. If an individual agreed, the counselor would introduce him or her to us, we would explain our work, again assure the consent of the individual, and then conduct the interview in private. The small number of KYS clients and the selection of KYS clients by counselors likely resulted in a biased sample of individuals who had more positive experiences and represents a significant limitation of our investigation.

In this report, we withhold the names of most of our interlocutors. Many of the people we interviewed were HIV-positive and agreed to speak to us on condition that their identities remain confidential. Others did not want to be seen as publicly criticizing the KYS campaign. Many noted that the government was highly sensitive to any negative assessments of the KYS campaign and that some government officials had made it clear that criticism was not appreciated.

All documents cited in the report are either publicly available or on file with ARASA and Human Rights Watch.

IV. Human Rights and HIV Counseling and Testing

Experts estimate that fewer than two in ten people in sub-Saharan Africa know their HIV status.⁹ Even fewer know the HIV status of their partner. Not knowing your—or your partners’—HIV status can have devastating consequences. It puts millions of people who have HIV at risk of premature death by delaying initiation of treatment and unknowingly exposing others to the virus. Those who are found to be HIV negative need the knowledge to continue to protect themselves against HIV infection. Ignorance of HIV status is particularly problematic for sero-discordant couples—people in relationships where one person is HIV-infected while the other is not—where, according to some studies, a significant percentage of new infections in sub-Saharan Africa occurs.¹⁰

There is broad international consensus that HIV testing must be expanded urgently so that more people can protect their health, but the question of how to do this has been the subject of heated debate.¹¹ Some have argued for introducing mandatory testing;¹² others have advocated for routine offer of HIV tests to patients at healthcare facilities;¹³ yet others have called for dramatic expansion of traditional voluntary counseling and testing (VCT) services or massive community based testing

⁹ See presentation by Kevin de Cock, then HIV/AIDS director at the World Health Organization, on provider-initiated testing and counseling in healthcare facilities at the 2007 AIDS conference in Sidney, Australia www.ias2007.org/PAG/ppt/TUSY201.ppt (accessed on July 18, 2008) slides 5 and 6. See also Lesotho Ministry of Health and Social Welfare, STI, HIV and AIDS Directorate and Partners, “‘Know Your Status’ Campaign Operational Plan 2006-7,” on file with ARASA and Human Rights Watch, p. 2, which estimates that 12 percent of women and 9 percent of men know their HIV status.

¹⁰ See S. Allen, et al., “Effect of serotesting with counseling on condom use and seroconversion among HIV-discordant couples in Africa,” *BMJ*, vol. 304 (1992a), p.1605-1609; and S. Allen, et al., “Confidential HIV testing and condom promotion in Africa: impact on HIV and gonorrhoea rates,” *JAMA*, vol. 268 (23), 1992b, p. 3338-3343.

¹¹ For a detailed discussion of the debates, see Open Society Institute Public Health Program, “Increasing Access to HIV Testing and Counseling while Respecting Human Rights,” August 2007, p. 20-30.

¹² See for example R. Holbrooke and R. Furman, “A global battle’s missing weapon,” *The New York Times*, February 10, 2004; “Clinton stirs debate with backing for mandatory HIV testing,” *Financial Times*, 2006. London: FT.com, 25 April. Available at <http://www.ft.com/cms/s/0485c2ec-d3f8-11da-b2f3-0000779e2340.html> (accessed on 29 September 2006).

¹³ Ibid. See also K.M. De Cock, D. Mbori-Ngacha, and E. Marum, “Shadow on the continent: Public health and HIV/AIDS in Africa in the 21st century.” *The Lancet*, vol. 360, 2002, p.67-72.

campaigns. Some have called for comprehensive programs that scale up both healthcare and community-based testing, allowing individuals a choice of venue.¹⁴

In these debates, the role of human rights has sometimes been challenged. Since the 1980s, human rights principles such as informed consent, counseling—providing people with information that allows them to make informed decisions about their health and medical treatment, and confidentiality, have played an important role in the response to HIV and AIDS. Because HIV/AIDS disproportionately affected populations who were already marginalized and created deep social stigma, there was a broad consensus among public health and AIDS activists that public health approaches which did not respect rights would be counterproductive and drive people away from information, care and support, and that a rights-based approach would be more effective in achieving public health goals.

As treatment has become more available in resource-constrained settings, some medical and public health officials have argued that the scale of the epidemic in high prevalence regions such as southern and eastern Africa requires a more aggressive response, in which human rights can be suspended or restricted for the benefit of the greater good. The emphasis on informed consent and counseling, they have said, has led to “widespread avoidance of discussion of testing.”¹⁵ They have argued that a new philosophy, based on “public health and social justice,” is needed to produce a “rapid and substantial effect on the African epidemic and to limit its devastation.”¹⁶

In their calls to expand HIV testing, these officials have created a false dichotomy, pitting a “rights-based” approach against a “public health” approach. One official went so far as to claim that the “human rights/AIDS exceptionalism approach is

¹⁴ The limited availability of HIV testing can result in a de facto violation of the principle of consent. True consent requires that if an individual declines a procedure that has no negative consequences. However, an individual who declines an HIV test because of fears of associated human rights violations and has no other venues for getting tested available, faces undeniable negative consequences. This person may therefore find himself forced by circumstance to accept the test even though he would rather decline it. Countries should strive to offer multiple venues for HIV testing.

¹⁵ K.M. De Cock, D. Mbori-Ngacha, and E. Marum, “Shadow on the continent: Public health and HIV/AIDS in Africa in the 21st century,” p. 68.

¹⁶ Ibid.

promoting an African Holocaust”¹⁷ and suggested that human rights advocates had a “tolerance of preventable death.”¹⁸

Such charges are based on an inaccurate understanding of human rights as an inflexible concept that is only concerned with individual rights and not the public interest. Human rights, in fact, have at their core a commitment to finding the appropriate balance between the rights of individuals and the interests of the community. Thus, certain restrictions on individual rights, such as informed consent, may be permissible in order to meet a pressing public need. But these restrictions must contribute to meeting that need and be no more restrictive than necessary.¹⁹ Furthermore, good public health and human rights practices generally go hand-in-hand: the right to make a decision based on informed consent is protected by human rights law, but is also crucial from a public health perspective, as it enables people to act on the knowledge they obtain through the test; confidentiality is an aspect of the right to health and privacy, but is also crucial for maintaining public trust in the healthcare system.

There has been a tendency among some public health experts, misrepresenting the role of human rights, to promote HIV testing as an autonomous human right—a “right to know” your HIV status. Such an approach focuses too narrowly on HIV testing itself. The goal of HIV testing is not just learning your status, but being able to act on that information to protect your health. A narrowly construed “right to know” your status also appears to limit the responsibility of states to providing a test and the result. Instead, a “right to know” should be seen in the context of the broader right to health, which requires states to offer comprehensive HIV-related services that include not just HIV testing but also access to prevention information and services, access to treatment, and protection against abuse based on HIV status. This is the

¹⁷ Presentation by Kevin DeCock at the Eighth Conference on Retroviruses and Opportunistic Infections in 2001, <http://www.aidsmap.com/en/news/DFCCC398-592B-496A-AAFF-B681872F49C4.asp> (accessed October 3, 2008).

¹⁸ Transcript of interview with Kevin DeCock at the International AIDS Conference in Mexico, the Kaiser Family Foundation “XVII International AIDS Conference Newsmaker Interviews: Kevin De Cock, M.D.,” August 5, 2008, http://www.kaisernetwork.org/health_cast/uploaded_files/o8o5o8_ias_interview_decock_interview.pdf (accessed October 20, 2008).

¹⁹ For more detailed analysis see Ralf Jurgens, “Increasing Access to HIV Testing and Counseling While Respecting Human Rights,” *HIV/AIDS Policy Law Review*, vol. 12, 2007, p. 40-42.

approach that WHO and UNAIDS have taken in their guidance on provider-initiated testing and counseling in healthcare settings, but, regrettably, not in their 2002 policy brief on HIV testing and counseling.²⁰

One of the new HIV counseling and testing approaches that has proliferated across sub-Saharan Africa in the last few years is large scale community-based testing. In contrast to provider-initiated testing in healthcare settings, this type of testing has received little attention or scrutiny. By bringing HIV testing into communities, these testing programs seek to reach people who are unlikely to access voluntary testing and counseling services and who are not in touch with the healthcare system. While these programs have real potential, their impact may be limited if they result in, or contribute to—intentionally or unintentionally—violations of basic human rights. To date, no international guidelines exist to help countries implement this testing model in a way that both contributes to public health goals and is respectful of human rights.

Five aspects of the HIV counseling and testing campaign are particularly important from the perspective of international human rights principles and public health norms and standards. These are: 1) informed consent and counseling; 2) confidentiality; 3) linkages between HIV testing and prevention, care and treatment services; 4) accountability mechanisms; and 5) the adequacy of the policy and legal framework for protecting the rights of people living with HIV.

The right to make decisions about your personal life and your health based on informed consent is not only a bedrock principle of medical ethics, but is also an integral part of international human rights law.²¹ However, much of the debate on HIV

²⁰ World Health Organization, “The Right to Know: New Approaches to HIV Testing and Counseling,” WHO Fact Sheet, 2003, WHO/HIV/2003.08, http://www.searo.who.int/LinkFiles/Prevention_and_Control_Right_know_a4E.pdf (accessed October 20, 2008).

²¹ International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, arts. 7, 17 (1); Lesotho acceded to the ICCPR on September 9, 1992. International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force January 3, 1976, art. 12, Lesotho acceded to the ICESCR on September 9, 1992; Beijing Declaration and Platform for Action, Fourth World Conference on Women, 15 September 1995, A/CONF.177/20 (1995), art. 108(e); United

has focused on what exactly constitutes informed consent, what medical procedures require such consent, and how explicitly that consent must be given.²² In their guidance on provider-initiated HIV testing and counseling in healthcare settings, WHO and UNAIDS state that HIV testing must be performed with the informed consent of the individual concerned, but hold that the act of not declining a test when it is offered constitutes informed consent to the test.²³ Human Rights Watch believes that informed consent requires specific consent to an HIV test, not an absence of refusal.²⁴ Obtaining informed consent involves providing pre-test counseling of patients to convey information about the test and its potential benefits and risks.²⁵ Pre-test counseling not only allows the healthcare provider to ensure that the consent to test is informed, but also provides an opportunity to discuss sexual behavior and prevention with patients.

Confidentiality of personal—including medical—information is a fundamental principle of the human right to health and of medical ethics. Health care providers are obliged to respect the confidentiality of their patients' medical information.²⁶

Nations Educational, Scientific, and Cultural Organization (UNESCO), Universal Declaration on Bioethics and Human Rights, adopted October 2005, SHS/EST/05/CONF.204/3 REV, arts. 6 and 9.

²² For in depth discussion see Ralf Jurgens, "Increasing Access to HIV Testing and Counseling While Respecting Human Rights," *HIV AIDS Policy Law Review*, vol. 12, August 2007, p. 37-40.

²³ World Health Organization and UNAIDS, "Guidance on provider-initiated HIV testing and counselling in health facilities," May 2007, p. 9, 10, 36-39.

²⁴ Human Rights Watch, "Comments on WHO/UNAIDS draft, 'Guidance on Provider Initiated HIV Testing and Counseling in Health Facilities,'" Submission to WHO, January 2007, <http://hrw.org/pub/2007/hivaid/whwWhoGuidance.pdf> (accessed June 19, 2007).

²⁵ American Medical Association, "Informed Consent", March 7, 2005, <http://www.ama-assn.org/ama/pub/category/4608.html> (accessed December 26, 2006); Beijing Declaration, art. 108(e); Council of Europe, Convention on Human Rights and Biomedicine (CHBR), adopted April 1997, CETS No. 164, art.5; United Nations Educational, Scientific, and Cultural Organization (UNESCO), Universal Declaration on Bioethics and Human Rights (UDBHR), adopted October 2005, SHS/EST/05/CONF.204/3 REV, arts. 6 & 9.

²⁶ Art. 17(1) of the ICCPR states, "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation." According to Manfred Nowak in his treatise on the ICCPR, the right to privacy includes a right of intimacy, that is, "to *secrecy* from the public of private characteristics, actions or data." This intimacy is ensured by institutional protections, but also includes generally recognized obligations of confidentiality, such as that of physicians or priests. Moreover, "protection of intimacy goes beyond publication. Every invasion or even mere exploration of the intimacy sphere against the will of the person concerned may constitute unjustified interference" [emphasis in the original]. Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR Commentary* (Kehl am Rein: N.P. Engel, 1993), p. 296. The Committee on Economic, Social and Cultural Rights has held in General Comment 14, para. 12(c) that "All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e.

Although some have suggested that confidentiality is an imported “western concept” that has limited the understanding of the disease and has perpetuated stigma, the confidentiality of medical information is endorsed by WHO and UNAIDS, as well as the International Guidelines on HIV/AIDS and Human Rights.^{27 28} While the high prevalence of sero-discordance in couples underscores the importance of couples testing, the implementation of couples-based counseling and testing is complicated by multiple factors, including the wide variety in relationships between couples, the fact that labor migration separates couples often for extended periods of time, and the risk of post-test violence, particularly against women.²⁹

As discussed above, HIV testing should not be a stand-alone intervention that is limited to notification of sero-status. Rather, HIV testing programs should be integrated into broader efforts by states to offer comprehensive HIV-related health services. Thus, states that implement mass community-based testing programs must seek to expand other health services, such as the capacity of the healthcare system to provide prevention, care and treatment, simultaneously. These states also should ensure that mechanisms are in place, which enable them to learn of potential human rights abuses and other problems with the implementation in a timely manner so that corrective action can be taken when needed.³⁰ Finally, they must ensure that people who test positive are protected against potential violations of their rights. WHO and UNAIDS observed in their guidance on provider-initiated testing and counseling in healthcare settings that “at the same time as provider-initiated HIV testing and counselling is implemented, *equal efforts* [emphasis added] must be made to ensure that a supportive social, policy and legal framework is in place to

respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.”

²⁷ See, for example, Alan Brody, “In One Country, AIDS on the Rampage,” *New York Times*, August 12, 2006.

²⁸ OHCHR and UNAIDS, “International Guidelines on HIV/AIDS and Human Rights,” 2006, para. 120, http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf (accessed September 29, 2008).

²⁹ Suzanne Maman, “To Disclose or Not to Disclose: An Overview of Women’s HIV Serostatus Disclosure Experiences Globally,” in USAID/Synergy, *Women’s Experiences with HIV Serodisclosure in Africa: Implications for VCT and MTCT*, Meeting Report (Washington, DC: USAID, March 2004), p. 3.

³⁰ UN Committee on Economic, Social and Cultural Rights, “Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights,” General Comment No. 14, *The Right to the Highest Attainable Standard of Health*, E/C.12/2000/4 (2000), [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument) (accessed May 11, 2006), paras. 33 and 59.

maximize positive outcomes and minimize potential harms to patients.”³¹ This is true also for community-based testing programs.

³¹ WHO and UNAIDS, *Guidance on provider-initiated HIV testing and counseling in health facilities*, p. 32.

V. Background

Lesotho is a small country with a population of approximately 1.9 million.³² Over half the population lives on less than U.S. \$2 per day and average life expectancy is 42 years.³³ Poverty is most deeply entrenched in rural areas, where the population has experienced the gradual degradation of land, severe drought, and loss of human capital due to migration and disease. Lesotho's struggling economy is almost entirely dependent on South Africa, with tens of thousands of Basotho, as inhabitants of Lesotho are known, working in South Africa, often in the mines. Lesotho has one of the most serious HIV crises in the world: an estimated one-fifth of the adult population is believed to be infected. Although HIV prevalence among women at antenatal clinics in urban areas had jumped from about 5 percent in the early 1990s to around 35 percent by 2004, Lesotho's response to the HIV epidemic was slow. In 2004, Lesotho had only one facility in the country that was providing services to prevent mother-to-child transmission for pregnant women with HIV and a total of three VCT sites.³⁴ While the country adopted an HIV and AIDS policy in 2000 and a three-year strategic plan for combating the disease in 2003, by 2004 it had yet to develop guidelines on such crucial issues as HIV testing, prevention of mother-to-child-transmission, infant feeding, nutrition for people living with HIV, home-based care, orphan care, or TB and HIV.³⁵ The South Africa-based Human Sciences Research Council identified a lack of human resources and political will, government bureaucracy, institutional rivalry and duplication of efforts as factors in this slow response.³⁶

³² Lesotho Round 7 Grant Proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria, July 2007, http://www.theglobalfund.org/search/docs/7LSOH_1532_o_full.pdf (accessed October 29, 2008) p. 41.

³³ United Nations Development Program (UNDP), "Human Development Report 2007/2008," 2007, p.239, <http://hdrstats.undp.org/indicators/23.html> (accessed October 3, 2008).

³⁴ Nompumelelo Zungu-Dirwayi, et al., eds., "An Audit of HIV/AIDS Policies In Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe," *Human Sciences Research Council*, p. 51, <http://www.hsrbpress.ac.za/product.php?productid=1926&freedownload=1> (accessed July 21, 2008).

³⁵ *Ibid.*, p. 39.

³⁶ *Ibid.*, p. 40.

In recent years there has been notable progress in Lesotho's response, with high level government officials recognizing the threat of HIV and AIDS, and the healthcare system increasingly offering prevention and treatment services. In 2000, King Letsie III declared HIV and AIDS a national disaster.³⁷ In 2004, the prime minister, Pakalithi Mosisili announced a national testing campaign.

A number of international public health advocates, such as Stephen Lewis, the former UN envoy for HIV and AIDS in Africa; and Dr. Jim Yong Kim, the former director of the HIV department at the World Health Organization (WHO), began to speak out publicly about the disaster that was taking place in Lesotho. With the help of international humanitarian agencies and the donor community, Lesotho has rapidly expanded access to antiretroviral treatment.³⁸ While in 2003, only about 1,000 people were receiving ARV—only an estimated 3% of those in need—that number rose to more than 21,000 people—about 25% of those in need—by early 2008.³⁹ All hospitals in Lesotho now offer antiretroviral treatment to patients, and an increasing number of health centers now do so as well.

Despite the increased attention and resources, however, the HIV epidemic has posed enormous challenges for Lesotho's severely overstretched healthcare system. Nationwide there are fewer than 90 doctors, and many are non-nationals on short-term contracts.⁴⁰ Nurses are similarly in short supply. Only six of 171 health centers in

³⁷ Government of Lesotho, "National HIV and AIDS Policy," November 2006, http://www.aidsportal.org/Article_Details.aspx?id=4598&nex=67 (accessed October 20, 2008).

³⁸ For example, MSF is working in Scott Hospital area where, according to its website, more than 2,200 people have started ART in MSF-supported structures, <http://www.msf.org/msfinternational/countries/africa/lesotho/index.cfm> (accessed October 28, 2008). Ontario Hospital Association Africa provides assistance to the Tšepong Clinic in Leribe, where, according to the organization's website, more than half of all new patients are put on ARV therapy in Lesotho each month, http://www.ohafrica.ca/pages/wwd_success.html (accessed October 28, 2008). As of June 2008, according to email correspondence with the Clinton Foundation, they had provided treatment support for more than 2,500 children. Partners in Health has projects in a number of mountain villages, providing ARV to more than 1200 people, according to PIH's website <http://www.pih.org/where/Lesotho/Lesotho.html> (accessed October 28, 2008).

³⁹ Email communication with UNAIDS Lesotho, February 27, 2008; National AIDS Commission of Lesotho, "Lesotho UNGASS Country Report for the year January 2006-December 2007," 2008, http://data.unaids.org/pub/Report/2008/lesotho_2008_country_progress_report_en.pdf (accessed October 20, 2008), p.39.

⁴⁰ Medecins Sans Frontieres, "Confronting the health care worker crisis to expand access to HIV/AIDS treatment: MSF experience in southern Africa," May 2007, p. 11. http://www.doctorswithoutborders.org/publications/reports/2007/healthcare_worker_report_05-2007.pdf (accessed July 21, 2008).

the country have the minimum staffing required and from 1994 to 2004 the number of employed nurses fell by 15%, due to low salaries, excessive workload and HIV disease.⁴¹

The Know Your Status Campaign (KYS)

Inception of KYS

In 2004, the prime minister of Lesotho, Pakalithi Mosisili, announced a national HIV testing campaign, entitled the Know Your Status (KYS) campaign. HIV counseling and testing was the key to a robust response to the epidemic, he said, stating that knowing one's status would "help stop the pandemic from spreading to those who have not yet been infected at the same time as assisting those who are already infected to live longer, and better quality lives."⁴² Despite being initiated by the prime minister, the campaign never truly took off.⁴³

In 2005, Dr. Jim Yong Kim, then-director of the HIV/AIDS department at WHO, expressed an interest in the fledgling campaign. WHO became actively involved in the development of an operational plan for the campaign that sought to offer an HIV test to all Basotho of twelve years and older over the course of a two-year period. The Operational Plan that eventually came out of this process summarized a grand vision for the testing campaign, as the centerpiece of Lesotho's HIV strategy,

...serving as a key entry point to all three services [prevention, treatment, care and support]. In particular, counseling provides a critical opportunity for prevention education and behavior change support for all Basotho and referral to appropriate treatment and care services for those who are HIV positive.⁴⁴

⁴¹ Ibid.

⁴² "Lesotho PM has HIV test, urges others to follow," Reuters, March 8, 2004.

⁴³ Human Rights Watch and ARASA interviews with U.N. officials and healthcare workers.

⁴⁴ Operational Plan, p. 1.

It was anticipated that the campaign would bring people together behind the common goal of beating HIV,

The direct involvement of communities in Lesotho, including people living with HIV & AIDS, in planning and carrying out the Know Your Status campaign will help foster a sense of community ownership, which, in turn will impact on participation rates. By properly linking this with quality counseling and appropriate post-test services for both prevention and treatment, there is greater likelihood that the silence, denial and stigma that permeates the HIV epidemic in Lesotho will start to dissipate, thereby helping to normalize HIV & AIDS.⁴⁵

And, Operational Plan continues,

Combined with adequate prevention, treatment, care and support services, it is reasonable to expect that the HIV counseling and testing program will, over time, have a dramatic effect on the epidemic in Lesotho.⁴⁶

The concept of Lesotho's KYS campaign generated considerable excitement among some public health experts and advocates, as well as high expectations of impact.⁴⁷ On December 1, 2005, as the campaign was being launched, Dr. Kim of WHO expressed his expectations to The Times of London,

This will be a major step forward. If we have 80 or 90 percent uptake of testing, which we believe we can, it will be a hugely effective way of

⁴⁵ Operational Plan, p. 3.

⁴⁶ Operational Plan, p. 1.

⁴⁷ Former US President Bill Clinton was quoted in *the Ottawa Citizen*, July 13, 2006 as asserting that "all African countries should do the same" as Lesotho; In an interview with National Public Radio on December 1, 2005, Richard Holbrooke, CEO of the Global Business Coalition against HIV and AIDS on HIV/AIDS, Tuberculosis and Malaria called the KYS campaign the "most advanced in the world;" and in a March 2006 report following a trip to Lesotho and Swaziland, Stephen Lewis, then the UN special envoy for AIDS in Africa, said that the KYS campaign was "one of the most ambitious initiatives on the continent" and expressed confidence that the government would make it a success.

reducing the rise in HIV infection. It could have as important an impact as a moderately effective vaccine.⁴⁸

Dr. Kim also told the newspaper that the campaign would be a blueprint for other nations crippled by the disease and that similar universal testing programs should be considered for any country with infection rates above 10 percent.

The Operational Plan

The Operational Plan set out a detailed roadmap for the HIV testing campaign that included the development of various policy documents to guide the campaign, the selection and training of counselors, extensive outreach to popularize the KYS campaign, the scale up of other HIV-related services, and the roll-out of the testing campaign itself. In total, the Operational Plan sought to offer an HIV test to 1.8 million people (this was downgraded later to 1.3 million) by the end of 2007.⁴⁹ The plan also contained a detailed, itemized budget of about US\$12 million.

The driving force behind the KYS campaign was to be 7,200 healthcare workers: 3,600 lay counselors and 3,600 community health workers, to be selected from communities all over the country, including from existing village health workers. The lay counselors and community health workers were to be provided both formal and on-the-job training to conduct the counseling and testing and broader mobilization and education. The Operational Plan noted that with new testing technologies “[l]ay personnel can be easily trained to carry out the rapid test.” It did not, however, openly discuss the challenges of providing adequate pre and post-test counseling, which requires considerable knowledge of HIV as well as interpersonal skills that would allow a counselor to speak about sensitive topics such as sexual behavior, condom use, and power dynamics in sexual relationships.

⁴⁸ Sam Lister, “AIDS test for whole nation,” *Times of London*, November 29, 2005

⁴⁹ Operational Plan, p. 9. Subsequent documents, however, name 1.3 million people as the target, see for example World Health Organization, “Progress report on Know Your Status HIV counseling and testing Campaign, August 30, 2007,” by Dr Patrick Abok Okumu, p. 11, on file with ARASA and Human Rights Watch.

The counselors and health workers were to receive 100 Maloti (approximately U.S. \$16) per month for their work.⁵⁰ The counseling and testing was to be conducted according to a national HIV counseling and testing policy that was to be designed especially for the KYS campaign. Testing was to be voluntary and test results confidential. Counseling was to include pre and post-test counseling, safer sex counseling, and condom education and provision. After testing, people were to be referred to post-test services whether they were positive or negative.

The Operational Plan sought to ground the campaign in local communities. In the initial phase, the campaign was to reach out to community leaders, educate them about HIV and the importance of testing, and ensure their support for and ownership of the campaign. After that, each community was supposed to decide for itself whether it wanted testing to take place through door-to-door campaigning, through public gatherings, or provider-initiated testing at healthcare facilities. The plan also called for phased implementation of the campaign based upon the assessment of the preparedness of communities to provide post-test services, including treatment and psychosocial support.

The campaign's communications strategy was aimed at "building knowledge and changing attitudes and behaviors,"⁵¹ using both mass media and interpersonal communications. The campaign intended to include public service announcements on TV and radio, outreach to newspapers, and the production of various materials, such as posters and pamphlets, about HIV testing and the Know Your Status campaign.⁵² Mass education sessions were envisioned for every village in the country. Village chiefs would be asked to call traditional public gatherings, known as *pitsos*, that villagers, according to local tradition, are expected to attend. At these *pitsos*, counselors would provide information on HIV and AIDS and the importance of HIV testing.

⁵⁰ A total of almost 15.5 million Maloti (about U.S.\$2.5 million) was budgeted for such incentives over the two-year period. Operational Plan, p. 37 and 38.

⁵¹ Operational Plan, p. 7.

⁵² Operational Plan, p. 7.

Once a village was deemed ready, the testing campaign was to start. KYS counselors were to go from house to house to offer the HIV test or offer testing at *pitsos*. Counselors were to refer people who tested negative to “post-test prevention services to help them stay HIV uninfected.”⁵³ People who tested positive were to be referred to local clinics and to support groups. The Operational Plan had budgeted 1.5 million Maloti, or US\$240,000, to help train these groups and strengthen their capacity to provide care and support.⁵⁴

The quality of services would be monitored through: 1) supervision by local health personnel; 2) the establishment of a monitoring and evaluation system at various levels, and 3) the creation of independent oversight bodies. Nurses at health centers were to provide ongoing supervision to KYS counselors.⁵⁵ Every tenth rapid test was to be confirmed with a highly sensitive ELISA test to ensure the quality of the rapid test and these data would be centrally collected.⁵⁶ An internal monitoring and evaluation process would be developed to track the progress of the KYS campaign, and external monitoring committees would be established to monitor the campaign and report on any human rights problems that occurred during its implementation.⁵⁷

The campaign was to be led by a national staff of twelve. In each district, three dedicated staff were to be hired, including coordinators and logistics managers. Nurses at healthcare centers were to play a key role in selection, training, and day-to-day supervision of counselors.

While the Operational Plan acknowledged that the KYS campaign would create additional burdens for the health sector generally, the US\$12 million plan did not provide for increased funding to regular healthcare structures to expand their capacity to offer prevention, care and treatment services. Despite an entire chapter devoted to strengthening post-test services, almost no funding was committed to

⁵³ Operational Plan, p. 10.

⁵⁴ Operational Plan, p. 8.

⁵⁵ Operational Plan, p. 10.

⁵⁶ ELISA stands for Enzyme-Linked ImmunoSorbent Assay. Operational Plan, p. 10.

⁵⁷ Operational Plan, p. 11-12.

this crucial goal. The budget contained only a 3,000 Maloti (about U.S.\$500) expense line for one expert meeting on revising referral tools.

The Implementation of the KYS Campaign

On World AIDS Day, December 1, 2005, King Letsie III formally launched the KYS campaign, despite the fact that campaign funding had yet to be secured. Fraught with difficulties from day one, the detailed plans of the Operational Plan were abandoned almost immediately, corners were cut on implementation of the human rights protections, and the implementation of the campaign as a whole came to be characterized by constant improvisation and ad hoc decision making. The campaign faced four interconnected problems: an extremely ambitious campaign plan, lack of resources, poor management, and a lack of political commitment.

WHO, after being heavily involved in the drafting of the Operational Plan, limited its involvement in the implementation phase, dedicating a single staff person to the campaign in 2006 before finally adding a second in 2007. A number of public health specialists in Lesotho expressed concern to ARASA and Human Rights Watch that this report would single out the government of Lesotho for criticism over the flaws of the KYS campaign, whereas they felt that WHO had forced the campaign on the government but failed to provide it with the support needed to properly implement it.⁵⁸

A lack of resources hamstrung the campaign from the very beginning. The estimated cost of the campaign—about US\$6 million per year—was about three-quarters of the country's entire HIV/AIDS budget.⁵⁹ The campaign thus had to depend on outside funding, seconded staff and donated goods. It is not exactly clear why the campaign, which had caused much excitement in some public health circles, was unable to attract significant outside funding, but the campaign struggled with its finances right from the start. As one United Nations official said, "The first big challenge was that

⁵⁸ Human Rights Watch and ARASA interview with T.F. and D.A..

⁵⁹ Lesotho's report to the 2008 UN General Assembly Special Session on HIV and AIDS states that the government of Lesotho spent a total of US\$8.4 million on HIV and AIDS in fiscal year 2005/6 and US\$8 million in 2006/7. The vast majority of funding for the HIV/AIDS response in Lesotho comes from international donors.

there was a programmatic commitment to KYS but not a financial one. Starting in January 2006, there was no money [in the budget] for the campaign.”⁶⁰

An official with KYS said in October 2007, “KYS started without a budget. We only opened bank accounts six or seven months ago. We have only had cars and computers for several months.”⁶¹ Grant proposals to the Global Fund against AIDS, Tuberculosis and Malaria and to the Bill and Melinda Gates Foundation for core funding were apparently never submitted.

The Ministry of Health and Social Welfare of Lesotho seconded four staff to the KYS campaign and shifted some money from its budget to the KYS campaign, and UN agencies contributed some staff and technical support, but this was not nearly enough to fund all the activities that had been planned.⁶² By the time Human Rights Watch and ARASA conducted their research, the Global Fund had stepped in with some limited funding and in-kind support.⁶³

Another big problem was the slow pace at which the government acted once the campaign kicked off. A KYS campaign manager was only appointed in mid-2006, six months after the campaign was supposed to have started. The steering committee appears to have met for the first time only in September 2006, although it was supposed to play a key role in leading the campaign.⁶⁴

Once underway, poor communications, logistics and management plagued the programs’ efforts. KYS staff and nurses in the districts spoke of regular breakdowns

⁶⁰ Human Rights Watch and ARASA interview with UN official.

⁶¹ Human Rights Watch and ARASA interview with KYS official M.M..

⁶² World Health Organization, “Progress report on Know Your Status HIV counseling and testing Campaign,” October, 2006, p.3, a copy of the report is on file with ARASA and Human Rights Watch.

⁶³ In the summer of 2007, when the campaign was already formally winding down, the Global Fund committed to paying incentives for 540 counselors for a number of years. The National AIDS Commission made a commitment to support a similar number of counselors.

⁶⁴ None of the documents ARASA and Human Rights Watch have obtained make any reference to a meeting of the Steering Committee before September 2006.

in communication with the central office, the lack of a functioning logistics system, and poor support from the central office for the needs of KYS counselors.⁶⁵

Unsurprisingly, the lack of funds had major consequences for the roll-out of the KYS campaign. When we visited in October 2007, the headquarters for the KYS campaign in Maseru did not have a phone or an Internet connection. Staff used their personal cell phones for communication. For many months, the campaign was unable to buy and distribute sufficient test kits. Some district KYS coordinators told us that they organized training seminars for counselors but never received money to pay the trainers their honorariums. Counselors were not paid their stipends because of a lack of money.

The Operational Plan described in detail the various policy documents that needed to be developed for the campaign and the key components of its implementation, but many elements were never implemented or implemented only partially, as a review of the Operational Plan reveals. These include:

- An **HIV counseling and testing policy** was to be developed that would guide all the counseling and testing done under KYS and would be distributed nationally among the population. By October 2007, two months before the KYS campaign was supposed to end, this document existed only in draft form and was still awaiting approval from the Ministry of Health.⁶⁶ Although we were told a popularized version existed, KYS could not provide us with a copy.
- The **communications strategy**, a central element of the campaign, was finalized only in mid-2007 and its implementation had barely started in October 2007. Various printed materials, such as leaflets and billboards, were just in the process of development, as were, according to a UN official, flipcharts that counselors could use while counseling and leaflets to leave

⁶⁵ One district manager said they personally drove to Maseru to pick up test kits because otherwise these would never arrive. Another district manager said questions and comments sometimes went unanswered for weeks or even months. A third said that they had repeatedly requested ID cards for the counselors and that these had been promised but had never actually arrived. Several people noted that morale among KYS staff was low as, in the words of one, “they are always criticized but nobody ever gives them any support.”- This interlocutor added that several KYS staff had resigned out of frustration in the last several months.

⁶⁶ A draft of the policy is on file with ARASA and Human Rights Watch.

- with clients.⁶⁷ Another UN official summed up: “The whole communications and social mobilization parts of the operational plan have not happened.”⁶⁸
- The Operational Plan recognized that before starting the counseling and testing campaign in specific communities, it needed to be established that they had the necessary services in place to do so responsibly. A tool was therefore to be developed to assess the **preparedness of communities**. However, this tool was apparently never developed. We were unable to obtain a copy of it in our meetings, and did not find anyone who had actually seen or used the tool. Similarly, a tool that was to help communities to decide what type of testing they preferred (door-to-door testing, testing at public gatherings, or at clinics) was never developed.
 - The Operational Plan envisioned increasing the **capacity of referral services**, including prevention services and support for people living with HIV. However, this does not appear to have happened. Although in late 2007 UNAIDS paid for a staff person in the KYS office to liaise with support groups (groups that support people living with HIV and AIDS, often consisting of people who are HIV positive), no capacity building for support groups, which remained weak, had occurred. KYS clients who test negative have not been receiving referrals to prevention services.
 - The Operational Plan emphasized the need for **quality control, internal monitoring and evaluation, and independent oversight**. However, as of October 2007 quality assurance procedures described in the plan were not being followed, internal monitoring and evaluation protocols had been developed but were not yet operational, and no independent oversight bodies had been set up. In 2008, KYS piloted quality assurance in two districts.

Despite the fact that these various crucial components of the KYS plan were either not implemented, or only partially implemented, training of counselors nonetheless started and counselors began to test for HIV. As one UN official aptly said:

⁶⁷ Human Rights Watch and ARASA interview with UN official.

⁶⁸ Human Rights Watch and ARASA interview with UN official.

“Everything has been done backwards. They’ve put the cart before the horse.”⁶⁹ As a result, the implementation of the testing campaign had little in common with the operational plan.

It is difficult to provide a brief but accurate overview of the KYS campaign as it took place because implementation varied between different districts of Lesotho, and between different areas in these districts. In some areas, selection and training of counselors began in July 2006; in others, it had yet to happen when we conducted our research in October 2007. In some areas, KYS counselors actively conducted outreach with HIV education, whereas in others they spent months working at local healthcare centers before eventually beginning their outreach work in the villages. In many places, very little happened at all. By the end of June 2007, only a little over 10,000 people had been tested through KYS, and by August 2007, only 25,000 people had been tested—far off the pace of 1.3 million tested, counseled and linked to care.⁷⁰ An April 2008 press release by WHO in Lesotho stated that “while only 50,000 people in Lesotho knew their status in 2004, by the end of 2007, over 240,000 Basotho tested for HIV” and that 30 percent of HIV tests were conducted in community-based settings.⁷¹ However, it does not estimate how many people had actually been tested by KYS counselors.

Selection and training of KYS counselors were both problematic. In the absence of clear selection criteria, many nurses selected KYS counselors—often existing village health workers, people living with HIV, or support group members—without any assessment of their ability or motivation, and sometimes volunteered people without asking for their consent. Training was conducted according to a slightly revised curriculum for home-based caregivers which several trainers told us was too broad; had insufficient focus on HIV counseling and testing; did not adequately address the challenges of community-based HIV testing; and contained material that was too

⁶⁹ Human Rights Watch and ARASA Interview with UN official.

⁷⁰ WHO, *Progress report on Know Your Status HIV counseling and testing Campaign*, August 30, 2007, p.11.

⁷¹ World Health Organization/Lesotho press release, “‘Know Your Status’ HIV Campaign Receives Praise for the Achievements Accomplished in Lesotho,” 4 April 2008. (http://www.afro.who.int/country_offices_press/2008/pr20080404.html, accessed November 7, 2008).

complex for lay people.⁷² Subsequent field training was often problematic because staff at health clinics did not have the capacity to give meaningful training to the dozens of counselors that were assigned to them.

⁷² Human Rights Watch and ARASA interview with NGO representative M.T. and nurse M.L.. A KYS official told us that they had not received any complaints about the training curriculum.

VI. Findings

The introduction of a mass HIV counseling and testing campaign using large numbers of lay people to offer health services that until recently were mostly performed by professional healthcare workers, raises a series of human rights challenges. Below, we examine these challenges from the perspective of the right to health. We focus specifically on KYS' approach to: 1) informed consent and counseling; 2) confidentiality; 3) linkages between HIV testing and prevention, care and treatment services; 4) accountability mechanisms; and 5) the adequacy of the policy and legal framework for protecting the rights of people living with HIV.

Informed Consent

Under medical ethics and international human rights law, HIV testing should be performed with the explicit, informed consent of the individual concerned.⁷³ Enabling a person to make an informed decision on an HIV test is not just a question of respecting human rights—it is also indispensable for achieving the public health goals that underlie HIV testing campaigns. Advocates of aggressive HIV testing campaigns frequently say that HIV testing is the gateway to HIV prevention and treatment services, but HIV testing campaigns can only play that role if they enable people who test to act on the knowledge they obtain. At the very least, people who test negative must be counseled on how to stay negative and be given the tools to do so. A person who tests positive should receive counseling and referrals that would help him or her gain access to prevention methods, care and treatment. Without adequate counseling, HIV testing will do little to benefit the individual or the public health.

⁷³ ICCPR, arts. 7, 17 (1); ICESCR art. 12; Beijing Declaration and Platform for Action, Fourth World Conference on Women, 15 September 1995, A/CONF.177/20 (1995), art. 108(e); ICESCR, General Comment No. 14; UN Committee on the Elimination of Discrimination against Women, General recommendation No. 24, women and health, (Twentieth session, 1999) paras. 22, 31(e); Committee on the Rights of the Child, “Adolescent health and development in the context of the Convention on the Rights of the Child,” General Comment No. 4, paras 29, 35 (b).

The KYS campaign entailed a risk of failing to respect the need for informed consent. After all, thousands of lay counselors with no previous experience doing HIV counseling and testing were to provide these services to the people of Lesotho. The key concerns were:

1. the possibility that counselors might pressure people into testing;
2. that people might feel obliged to test because counselors came to their homes;
3. that certain members of households—particularly women and children (anyone twelve years and older was to be offered an HIV test)—would be unable to make their own decision on whether to be tested; and
4. that consent would not be truly informed due to inadequate quality of the counseling provided.

The government of Lesotho and its partners have a duty to take steps to ensure respect for the principle of informed consent and the right to autonomy, and to protect people against possible violations. Thus, Lesotho had to make sure that informed consent was a guiding principle in the HIV testing campaign, that adequate steps were taken to minimize the risk of violations, and that lay counselors were sensitive to the voluntary nature of HIV testing and appropriately trained to provide adequate counseling and education.

The KYS Operational Plan fully embraced the principle of informed consent. It stated that,

HIV counseling and testing will never be mandatory.... Every person will therefore be tested of their own free will and their human rights will be fully respected. Those administering the test will receive training on how to obtain informed consent prior to testing and ensure client understanding.⁷⁴

⁷⁴ Operational Plan, p. 3.

It also held that the HIV counseling and testing should not be seen as a stand-alone intervention to simply “identify those individuals infected and calculate numbers,” but that it should be seen as an “entry point to appropriate post-test services designed to prevent further spread of the disease and provide treatment, care and support for those in need.”⁷⁵

However, the curriculum that was developed to train KYS counselors is completely inadequate in preparing them to obtain informed consent. The curriculum’s section on pre-test counseling fails to give an overview of the elements that need to be covered in pre-test counseling; contains no guidance on conducting risk assessments with clients; does not explain what constitutes an informed decision; and does not discuss the specific challenges involved in obtaining informed consent in house-to-house settings where multiple family members may be present at the same time.⁷⁶

Findings on Informed Consent

Our research found no evidence of involuntary testing practices, although we were unable to extensively address the question through interviews with individuals who had been tested by the KYS campaign and therefore cannot say the extent to which involuntary—or coercive—testing may be taking place. We did find that some people—primarily women who find themselves in de facto subordination to their husbands or partners in Lesotho’s patriarchal society—were unable to make their own decision to be tested and that the quality of the counseling sometimes raised the question of how informed the consent some people gave to testing really was. As most of the KYS counselors we interviewed had not counseled and tested any children, we were unable to examine testing related to children under 18 years.

No Evidence of Involuntary or Coercive Testing

Almost all of the several dozen KYS counselors we interviewed told us that they presented testing as a choice for clients. About a dozen KYS clients confirmed that

⁷⁵ Operational Plan, p. 2.

⁷⁶ Copies of the modules are on file with ARASA and Human Rights Watch.

counselors had made it clear to them that it was their choice to agree to or decline the HIV test.

One KYS counselor explained how she offers people the HIV test:

I tell them why it is important to test; that they should not necessarily expect a positive result but that it is important to know their status so they can take care of themselves. If positive, I tell them, they will know what to do—and what not—to prolong life. I tell them that the test is voluntary. If negative, I tell them that they should retest after three months. I tell them that they can test anywhere where they feel comfortable.⁷⁷

A client of the counselor confirmed her words. She said: “The counselor explained that the test was voluntary and that I can retest as often as I want. We were with some other lady when the counselors came. The counselor did pretest counseling together for both. The other lady didn’t want to test. I was tested by myself.”⁷⁸

Another KYS counselor described how she approaches people about testing:

I introduce myself, talk about the testing work, talk about truths and myths around HIV, and give clients the opportunity to ask questions. Then I ask the client whether they feel ready to test; if ready, I proceed with counseling and testing. If not, I see if we can talk more another day.⁷⁹

With one exception, counselors did not tell their clients that the government had started the KYS campaign and wanted people to test. The one counselor who did make this point to his clients, however, told us that he also emphasized that testing was a choice and not an obligation.⁸⁰

⁷⁷ Human Rights Watch and ARASA interview with KYS counselor S.M..

⁷⁸ Human Rights Watch and ARASA interview with KYS client T.M..

⁷⁹ Human Rights Watch and ARASA interview with KYS counselor N.T..

⁸⁰ Human Rights Watch and ARASA interview with KYS counselor M.P..

None of the KYS clients we interviewed said that they had been tested against their will. In fact, it was our impression, from speaking to counselors and KYS clients in five of the country's districts, that villagers generally felt comfortable declining an HIV test. This may in part be due to the fact that the counselors were not medical doctors or nurses, but ordinary villagers. However, it is difficult to draw any definitive conclusions because of our small sample size.

Counselors consistently told us that a considerable percentage of the people they approached did not want to be counseled or tested.⁸¹ In interviews, we asked counselors to estimate what percentage of the people they approached agreed to or declined to being counseled and tested. These estimates varied considerably, with some saying that only about three or four in ten would agree to be counseled and tested and others saying the majority of people approached agreed to the test. KYS counselors and supervisors engaged in the Mafeteng drive observed that there was wide variation from village to village—one supervisor said that in most villages the majority of people were willing to test but that “in one village people shut their doors and windows whenever we came near.”⁸² The supervisor speculated that the chief might have called a meeting beforehand and warned people not to agree to counseling and testing. Most KYS counselors noted that many more women agreed to test than men.

While most KYS counselors said that they made it clear to clients that testing was voluntary, some officials were less careful. Several people also told us that village chiefs introducing public gatherings sometimes told villagers that they should get tested for HIV.⁸³ A counselor said that one day she noticed a vehicle promoting KYS saying that KYS counselors were going to test “everyone.”⁸⁴

At the 2008 International AIDS Conference in Mexico City, the Lesotho Minister of Health, Mphu Ramatlapeng, stated that it was national policy that all pregnant

⁸¹ No exact data exists as KYS did not ask counselors to track how many people declined to be counseled and tested.

⁸² Human Rights Watch and ARASA interview with Mafeteng drive supervisor K.S..

⁸³ Ibid.

⁸⁴ Human Rights Watch and ARASA interview with KYS counselor M.T..

women presenting at medical facilities would be tested for HIV but that people could “opt-out” of receiving the result. She further stated that those individuals who chose not to receive their result would be counseled to accept the result and that those continuing to decline the result would receive a visit from health personnel in their homes and further counseling. She cited the interests of the unborn child as the reason for this policy. A physician from Lesotho on the same panel as the Minister confirmed that mandatory HIV testing of pregnant women had become the government’s policy.

Particular Situation of Women

A second concern regarding consent was the fear that in Lesotho’s patriarchal society, male heads of households would make a decision—whether to consent or decline—for all other members of the family. Men have traditionally held overwhelming powers over women in Lesotho. Until the entry into force of the 2006 Legal Capacity for Married Persons Act, married women had no legal capacity. Although the law has significantly improved their legal status, traditional law and custom continue to limit their rights in areas such as property, inheritance, and contracts.⁸⁵ The 2004 Lesotho Demographic and Health Survey found that half of women who are married or living together with a partner not only do not make their own decisions about their health care, but are not even consulted on those decisions.⁸⁶

Our interviews with KYS counselors suggest that some women were indeed not—or did not feel—able to consent to being tested. Some counselors recounted situations in which male heads of household told them that they could not test anybody in the house, thus denying other members of the household their own choice. None of the counselors said that they had encountered situations where the male head of the household decided for other household members that they should test. Some counselors also said that women who were alone at home did not feel that they could agree to an HIV test without their husbands’ blessing.

⁸⁵ US State Department, Bureau of Democracy, Human Rights, and Labor, Country Reports on Human Rights Practices - 2007: Lesotho, " March 11, 2008, <http://www.state.gov/g/drl/rls/hrrpt/2007/100488.htm> (Accessed October 20, 2008).

⁸⁶ Lesotho Demographic and Health Survey 2004, November 2005, p. 41, http://www.measuredhs.com/pubs/pub_details.cfm?ID=563 (accessed October 28, 2008).

Counselors were unprepared to counsel couples together or provide post-test counseling to sero-discordant couples. One counselor said that she had encountered situations where some people in a household wanted to be tested but others did not.⁸⁷ She said: “Men are very reluctant to test. Sometimes they make the decision, and the women in the household can’t test. I just keep going back to such houses [hoping to encounter the women alone].” Another said that when the male in the household declined to test, most women did not want to be tested either, because of the fear that a positive result would lead to disharmony in the household.⁸⁸ A supervisor during the Mafeteng drive said that many women she had encountered declined to be tested because their husbands were not present, saying things like “I can’t do it, he’s not here.”⁸⁹

Lack of Couples’ Counseling

Couples’ counseling and testing has been shown to be an effective HIV prevention strategy and is particularly important given the high prevalence of sero-discordance in couples. It offers some clear benefits over individual counseling, facilitating partner disclosure and linkages to HIV prevention, care and treatment. But it also entails a risk of human rights abuses due to widespread inequality between men and women.

The KYS campaign did not make use of the potential of couples’ counseling, as KYS counselors did not receive the necessary training to do so. As a result, most KYS counselors conducted strictly individual HIV counseling and testing. For example, a supervisor during the Mafeteng drive said that when there were multiple family members at home, counselors would send all but one family member outside and counsel and test them one-by-one.⁹⁰ While done with the intention to protect the privacy and autonomy of these people, had training been adequate, more effective couples’ counseling could have been conducted, potentially increasing the impact of the campaign while ensuring the rights were protected.

⁸⁷ Human Rights Watch and ARASA interview with KYS counselor S.M..

⁸⁸ Human Rights Watch and ARASA interview with KYS counselor M.M..

⁸⁹ Human Rights Watch and ARASA interview with Mafeteng drive supervisor K.S..

⁹⁰ Human Rights Watch and ARASA interview with Mafeteng drive supervisor M.T..

KYS Campaign and Children

The age of consent to medical procedures in Lesotho is 12 years and the government included young people between the ages of 12 and 18 years old in the target group for the KYS campaign. The operational plan made no mention of any special procedures for obtaining informed consent from members of this group, evidently suggesting that they be treated exactly as adults. The module on HIV counseling and testing that was used to train KYS counselors contained no specific instructions on obtaining informed consent from minors between 12 and 17.

In many countries, HIV testing guidelines suggest that only under certain specific circumstances can individuals under 18 get tested without parental consent. For example, in Kenya, the HIV testing policy says that:

Young people under 18 who are married, pregnant, parents, engaged in behaviour that puts them at risk or are child sex workers should be considered ‘mature minors’ who can give consent for VCT, although the counsellor should make an independent assessment of the minor’s maturity to receive VCT services.⁹¹

For children not judged to be “mature minors,” or children under the age of fifteen, the Kenya guidelines recommend, “[T]esting of minors under 18 who are not mature minors, especially those under 15, should be done with the knowledge and participation of their parents or guardians.”⁹²

While these types of regulations discourage testing of children and adolescents who, for one reason or another, do not wish to speak to their parents about the test, they also are intended to protect children who may face added difficulties testing for HIV without familial support, or who are unable to assess the potential risks and benefits associated with testing. A child’s ability to consent to a test is even more difficult when the parent is present to exert influence on the child’s decision, to demand that the result be disclosed, or to inquire why a test has been refused. Children also have

⁹¹ Kenya National AIDS and STD Control Programme, “National guidelines for voluntary counseling and testing,” 2001, p.5.

⁹² Ibid.

very specific needs in terms of post-test counselling and access to care. Health services are often not youth-friendly and many adolescents avoid going to general health centres.

As most counselors we interviewed had tested few or no people in this age group, we were unable to document potential problems linked to this policy and to the lack of specific training, or to document what problems these failings led to in practice. Statistics suggest, however, that KYS counselors did counsel and test considerable numbers of people in the age group during the Mafeteng drive—2087 people between 12 and 19, 56 of whom tested positive (2.7%).⁹³ Lesotho needs to ensure that counselors who offer HIV testing to children between 12 and 17 years old have appropriate training and skills to do so.

Poor Quality Counseling Undermines Informed Decisions

In order to make an informed decision about an HIV test, a person needs adequate information. If counseling is poor, incomplete, or incorrect, this may result in a violation of the principle of informed consent.

The training course for KYS counselors did not identify the basic elements of pre-test counseling. The WHO and UNAIDS guidance on provider initiated HIV counseling and testing in healthcare settings, however, provides a minimum list of issues that must be discussed during pre-test counseling:

- The reasons why HIV counseling and testing is being recommended;
- The clinical and prevention benefits of testing and the potential risks, such as discrimination, abandonment or violence;
- The services that are available in the case of either an HIV-negative or an HIV-positive test result, including whether antiretroviral treatment is available;
- The fact that the test result will be treated confidentially and will not be shared with anyone;
- The fact that the patient has the right to decline the test;

⁹³ WHO, *Progress report on Know Your Status HIV counseling and testing Campaign*, August 30, 2007.

- In the event of an HIV-positive test result, encouragement of disclosure to other persons who may be at risk of exposure to HIV;
- An opportunity to ask the health care provider questions.⁹⁴

In our research we found considerable evidence of poor pre-test counseling practices. A number of supervisors during the Mafeteng drive told us that they had observed KYS counselors who provided very little pre-test counseling. One, for example, said that she observed a counselor proceeding straight to the HIV test when the client told her she knew what HIV and AIDS were.⁹⁵ It is hard to assess, however, how widespread this problem is. In interviews with Human Rights Watch and ARASA, KYS clients often had difficulty remembering exactly what KYS counselors had told them during pre-test counseling and, in any case, the limited number of KYS clients we were able to interview does not allow for broader conclusions to be drawn. All KYS counselors we interviewed insisted that they did not proceed straight to offering the test when clients said they knew about HIV, but went through the basics of HIV and AIDS with clients.

Yet, in our interviews with KYS counselors, we found clear indication that many did not adequately counsel their clients on the issues listed above, which is, perhaps, not surprisingly, given that the training module did not list them. We asked counselors to describe how they approached clients, and what issues they covered during pre-test counseling. Over and over, we found that counselors were unable to give us a run-down of the issues they covered in counseling sessions.

Confidentiality

Under international human rights treaties, states must ensure confidentiality of medical information. This means that information about a person's medical condition may not be arbitrarily disclosed to third persons without the specific consent of the individual concerned.⁹⁶

⁹⁴ WHO and UNAIDS, *Guidance on provider-initiated HIV testing and counseling in health facilities*, p. 37.

⁹⁵ Human Rights Watch and ARASA interview with Mafeteng drive supervisor K.S..

⁹⁶ Art. 17(1) of the ICCPR states, "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation." According to Manfred Nowak in his treatise on the ICCPR, the right to privacy includes a right of intimacy, that is, "to *secrecy* from the public of private characteristics, actions or

As with informed consent, the deployment of large numbers of lay counselors with limited training posed a risk of breaches of confidentiality. The KYS Operational Plan emphasizes that confidentiality will be guaranteed to all those who test through the campaign.⁹⁷ While the training module on general counseling for people living with HIV and AIDS gives considerable emphasis to the need for confidentiality, the section on pre and post-test counseling offers only fleeting references and does not provide counselors with any guidance on either the specific challenges of ensuring respect for confidentiality posed by the campaign, or on managing disclosure.

Findings on Confidentiality

We did not document any individual cases of breaches of confidentiality. In some of our interviews with KYS counselors, however, we found that some counselors did not fully appreciate the importance of confidentiality and might inadvertently disclose people's HIV status to others. Some nurses and patients we interviewed told us that they had come across cases of breaches of confidentiality.

A non-KYS lay counselor at one healthcare clinic told us that she had come across various breaches of confidentiality by KYS counselors.⁹⁸ She claimed that "counselors don't respect confidentiality. They talk to others about the results. Talk about it to family." A KYS counselor said that when he asked people why they did not want to test, some people said that the counselors were not trustworthy and disclosed people's status to others.⁹⁹

data." This intimacy is ensured by institutional protections, but also includes generally recognized obligations of confidentiality, such as that of physicians or priests. Moreover, "protection of intimacy goes beyond publication. Every invasion or even mere exploration of the intimacy sphere against the will of the person concerned may constitute unjustified interference" [emphasis in the original]. Manfred Nowak, *UN Covenant on Civil and Political Rights: CCPR Commentary* (Kehl am Rein: N.P. Engel, 1993), p. 296. The Committee on Economic, Social and Cultural Rights has held in General Comment 14, para. 12(c) that "All health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned."

⁹⁷ Operational Plan, p. 4.

⁹⁸ Human Rights Watch and ARASA interview with healthcare worker A.M..

⁹⁹ Human Rights Watch and ARASA interview with KYS counselor M.P..

Linkages to Other HIV-Related Health Services

The opportunity to learn one's HIV status is an important aspect of the realization of the right to health and anyone who wishes to learn their status should be able to. However, the right to know your status should not be viewed as an autonomous right—after all, there is little point in knowing your status if you cannot do anything with that knowledge. The right to health therefore requires that HIV testing services should be offered as part of a continuum of health care services. This continuum should include prevention, care and treatment services. People should have access to information and tools to protect themselves and others from HIV; to immune level testing, antibiotics to suppress or treat opportunistic infections, and antiretroviral drugs; and to support services to help them cope with the knowledge of their status.

The level at which these services should be made available will depend on the level of resources of the country in question. Yet, a country that undertakes an aggressive campaign to strongly encourage people to test for HIV needs to recognize that this brings with it the responsibility to proportionally offer the other services of the continuum of care. It would not be consistent with the right to health to strongly encourage people to test for HIV without offering them at least the basic package of prevention, care and treatment services. Thus, a country that undertakes an aggressive testing campaign should, as its efforts result in more people knowing their HIV status, expand the care, support and treatment services that are available to these people.

Embedding HIV counseling and testing into a broader spectrum of HIV-related services is not just a rights issue, it is also crucial for achieving the public health goals underlying expanded testing campaigns. Only if people who test have access to prevention, support, care and treatment services will a testing campaign be able to make a public health impact.

Findings on Linkages to Prevention Services

Research has repeatedly found that one-off HIV prevention interventions are unlikely to change people's behavior.¹⁰⁰ Thus, for the KYS campaign to be an effective tool in

¹⁰⁰ Operational Plan, p. 10.

HIV prevention, one of the goals set out in the Operational Plan, linkages and referrals to sustained HIV prevention—information and services, as well as structural interventions—were crucial.

According to an October 2006 progress report on the KYS campaign, the objective of strengthening post-test services was “almost attained.” The report stated that referral tools had been developed by the Ministry of Health and Social Welfare and that a stakeholders meeting had been called to revise the referral mechanism.¹⁰¹ It does not appear, however, that the post test service referral tools and databases were ever updated or distributed, and linkages to HIV prevention were apparently never implemented. Our research found that people who tested negative did not receive any referrals.

Our research found that there was little effort by counselors to help their clients devise strategies for staying negative and that in many cases no, or very few, condoms were provided to the client. Often, the lack of condom provision was due to their limited availability. We also found some evidence that post-test counseling for people who tested negative was often perfunctory. For example, several supervisors during the Mafeteng drive, as well as health center nurses, said that they had the strong impression that counseling for people who tested negative was almost non-existent.

We repeatedly found problems with condom provision. Most KYS counselors said that they had a limited supply of male condoms and that they had no female condoms at all. Some said that they had to go to the local clinic to pick up condoms because the KYS office was not offering any. While some counselors said that they always handed out condoms—even if in small numbers—many others said that they only offered condoms when people requested them. Some counselors said that they demonstrated condom use while others did not.

A UN official expressed concern that in the rush to scale-up treatment, the government was generally neglecting prevention—that no education on sexuality and

¹⁰¹ WHO, *Progress report on Know Your Status HIV counseling and testing Campaign*, October 2006, p 3.

HIV was taking in place in the schools, that too little was being done to discourage multiple concurrent sexual relations, and that too little condom promotion was taking place.¹⁰²

The KYS campaign could have been an important vehicle for HIV prevention in sero-discordant couples. However, counselors did not receive appropriate training in conducting couples counseling and were unable to counsel people on sero-discordance or help couples devise effective strategies to protect their health.

Linkages to Care and Treatment

Because of the lack of monitoring by the KYS program and the Ministry of Health, it is impossible to say what percentage of individuals testing positive sought care and treatment and what percentage received it. ARASA and Human Rights Watch did not receive any reports that KYS clients were denied ART treatment when they needed it or that they were placed on waiting lists. As noted above, the availability and accessibility of ART has increased considerably since 2005 and the number of people on ART is now about 21,000, up from 8,500 in 2005. The scale-up of treatment is ongoing, with more healthcare centers planning to offer ART and the patient load continuously increasing.

Despite this progress, it is unlikely that the healthcare system would have been able to absorb the numbers of new patients that the KYS campaign would have generated if it had tested people at anywhere near the pace envisioned by the Operational Plan. In interviews with ARASA and Human Rights Watch, staff at various ART centers said that, as it was, they were operating at or beyond capacity and that it would have been impossible to absorb considerably increased numbers of patients. Although nobody tracked the number of KYS referrals among current patients, several healthcare workers estimated that their numbers were low.

The Mafeteng testing drive, however, provided a preview of the kinds of problems that might have been. During the drive, 13,342 people were tested by KYS counselors of whom 1,468 people tested positive. Thus, on average about 80 people were

¹⁰² Human Rights Watch and ARASA interview with UN official.

referred to each of the 17 healthcare centers in Mafeteng district for immune system (CD4) testing, enrollment into HIV care, and possibly ART. Even allowing that some of these people may not have sought follow-up care, this is a considerable number for clinics that are staffed by one or two nurses at best.

Indeed, several nurses in Mafeteng district complained about the considerable increase in workload in the weeks of, and following, the drive. One nurse said: “Many people were coming in, too many.”¹⁰³ Another nurse estimated that her clinic had had about fifty people come in for follow-up services. She said, “The workload really increased after the Mafeteng drive. I did not have enough staff. I was taking blood for CD4 then had to provide antenatal care. It was too much.”¹⁰⁴ Her clinic has one nurse, one nurse assistant, and an HIV counselor who is not authorized to take blood. The nurse said that she had run short of containers for blood storage and had to turn some patients back.

These nurses and others told us that they were informed of the Mafeteng drive just a week before it started. One nurse said that she received no communication from KYS about the campaign. “KYS told the counselors to start the drive,” she said, “and I learned about it from the counselors.”¹⁰⁵ Hospital laboratories were similarly unprepared for the steep increase in demands for CD4 testing, and no preparation was made for individuals tested in villages far from health centers that offered ART. The Operational Plan made no reference to TB diagnosis and treatment, and no specific preparation was made for increased demand for TB treatment.

Problems with Post-Test Counseling

Post-test counseling is a crucial element of ensuring proper linkages between HIV testing and follow-up services. We found considerable evidence, however, that many KYS counselors do not properly counsel people who test positive, particularly with respect to partner disclosure.

¹⁰³ Human Rights Watch and ARASA interview with nurse N.M..

¹⁰⁴ Human Rights Watch and ARASA interview with nurse M.S..

¹⁰⁵ Human Rights Watch and ARASA interview with nurse M.L..

Various nurses and HIV counselors at healthcare clinics, as well as supervisors during the Mafeteng drive, told us that they had observed considerable problems with post-test counseling for people who tested positive. One nurse from a clinic in Mafeteng district, for example, said that she had instructed her staff to re-counsel all KYS referrals because of the considerable gaps in counseling.¹⁰⁶ A healthcare worker at a different healthcare center, which re-tests and re-counsels all KYS referrals, said that post-test counseling by KYS counselors was often limited to informing clients that they were HIV positive and needed to go to the clinic for a CD4 test, and giving them a referral form. She said: “Some people come in very scared and weren’t counseled at all.”¹⁰⁷

Many of the counselors noted that a considerable percentage of women—two or three out of ten by most estimates—expressed concern about disclosing their status to their partners. These women said they were afraid of their partners accusing them of sleeping around and bringing HIV into the household. They also feared harassment and discrimination, abandonment, or beatings. For example, one healthcare worker said,

Women are afraid to tell husbands. They fear beatings, insults. They worry that disclosure will destroy peace in the house. Some men may start calling them names, accuse them of sleeping around.¹⁰⁸

In response, most KYS counselors said that they told the women they should try to bring their husbands to them for couple’s counseling and testing or that they should talk to their partners about HIV and the importance of HIV-testing to convince them that they should get tested themselves. Few KYS counselors, though, said that they followed up with women after the post-test counseling to learn whether or not the women had in fact disclosed and what their experiences had been. While some KYS counselors referred such women to the local clinic or a support group, none referred them to support groups specifically able to address women’s rights and provide

¹⁰⁶ Human Rights Watch and ARASA interview with nurse N.M..

¹⁰⁷ Human Rights Watch and ARASA interview with healthcare worker F.S..

¹⁰⁸ Human Rights Watch and ARASA interview with healthcare worker L.M..

psycho-social counseling, legal advice, or other support to women at risk of domestic violence due to disclosure of their HIV status to their husbands or partners.

Linkages to Support

Despite plans to provide resources and training to support groups for people living with HIV, KYS has done little to enhance the capacity of support groups, or to ensure that individuals were routinely referred to these groups. Although materials exist—for example, the Lesotho Network of People Living with HIV and AIDS has produced a book with information on several hundred support groups throughout Lesotho—KYS has not used these materials or developed their own brochures or leaflets. In 2007, UNAIDS funded the Lesotho Network of People Living with HIV and AIDS (LENEPWHA) to hire and second someone to the KYS campaign to specifically work on linkages between KYS and support groups. At the time of our research, this person had just started her work with KYS, was visiting various support groups around the country and was developing hand-out materials for KYS counselors.

Accountability

States obligations under human rights law include not only the duty to *respect* human rights norms, but also to *protect* them.¹⁰⁹ In the context of the right to health, when new public health policies and programs are developed, states must show due diligence in preventing abuses from happening and ensuring that corrective action is taken as early as possible if they do happen. This is particularly so if the policies and programs have serious potentially negative human rights implications. For the KYS campaign, this meant that, apart from offering adequate training for lay counselors, proper supervisory arrangements and a monitoring system should have been put in place.

Supervision

The Operational Plan did not seek to set up a special supervisory system for the KYS campaign. With a minimal skeleton staff, the campaign did not have the capacity to provide meaningful supervision to the thousands of lay counselors who were to be

¹⁰⁹ General Comment 14 of the Committee on Economic, Social and Cultural Rights, para 33.

trained. Instead, it sought to strengthen the existing system “at the district and community levels.” This was to be achieved by revising health center supervisory checklists to include village supervision on HIV testing and counseling; orienting health center nurses in the community in such supervision (including the checklist); and supervising community HIV testing and counseling teams.¹¹⁰

In practice, supervision of KYS counselors rested almost completely with nurses and professional HIV counselors at local healthcare centers. Thus, in addition to selecting KYS counselors and providing them with training, these overworked healthcare workers were also tasked with providing supervision to an average of some 20 to 30 KYS counselors per clinic. It is hard to see how the authors of the KYS campaign had envisaged that understaffed and overburdened healthcare centers in Lesotho could offer meaningful supervision to such large numbers of counselors who were going to be offering counseling and testing in villages that were often several hours of travel away from the clinic.

While some officials with the KYS campaign insisted that functioning supervisory mechanisms were in place, most nurses we interviewed openly acknowledged that they did not have the capacity to provide meaningful supervision to counselors once they went into the villages, which is, perhaps, not surprising considering that providing meaningful supervision to several dozen counselors during attachment was a big challenge.¹¹¹ Also, it appears that the supervisory role nurses were supposed to play was never conveyed to them clearly. One nurse said, “Maybe I’m supposed to supervise counselors but I wasn’t told. [In any case,] I cannot go out there to work with them. I don’t have transport. I don’t have time. We’re only two nurses here.”¹¹²

¹¹⁰ Operational Plan, p. 10.

¹¹¹ One district campaign manager insisted that before counselors can go out alone, health care personnel go with them to make sure they do it well (KYS district manager H). A UN official said that professional HIV counselors at clinics had provided supervision to KYS counselors but acknowledged that supervision had been difficult at clinics that did not have a professional HIV counselor as nurses are overstretched. (UN official BF)

¹¹² Human Rights Watch and ARASA interview with nurse N.M..

Another nurse echoed those remarks, saying,

The counselors are out in villages most of the time. I'm not with them when they're out there. We do have meetings here twice a month. We just don't have enough staff. We do ART here, care for under-fives, antenatal care, tuberculosis, etc. I don't have enough people to do supervision in the field. ...we're short staffed, so short staffed.¹¹³

The majority of KYS counselors we interviewed said that there had essentially been no supervision once they went into the communities. They said that they had never been accompanied by nurses or professional HIV counselors on their work in the villages, and that their counseling and testing in the field had never been observed by an experienced counselor or healthcare worker.¹¹⁴

Supervision during the Mafeteng drive

During the Mafeteng drive, KYS arranged for supervisors to accompany its counselors in the field. Most of the supervisors we interviewed said that they had supervised a group of 12 to 15 KYS counselors. They had accompanied these counselors into the villages while they were going from house to house to offer HIV counseling and testing. The supervisors said that they had served a number of roles: they observed some HIV counseling and testing sessions by KYS counselors; were a resource for questions and problems; and led discussions with the group about issues encountered. Some also said that they compared used test strips against the forms counselors filled out.

Many of the supervisors encountered significant problems with counseling and testing. Several told us that most of the KYS counselors they oversaw had never seen test kits before; that they found significant discrepancies between test strips and the forms the counselors had filled out; or discovered that the counselors were unable to

¹¹³ Human Rights Watch and ARASA interview with nurse M.T..

¹¹⁴ There were some notable exceptions. For example, in one village the nurse had designated one day per week for KYS activity. On that day, she or the clinic's second nurse traveled together with the counselors to a specific set of villages that had picked and notified of the visit beforehand. In the villages, the nurses provided the counselors with support and supervision. Human Rights Watch Interview with nurse N.M..

properly counsel their clients. They described a variety of steps that they took when encountering such problems. Some said that they conducted impromptu refresher trainings; some went back to certain homes to re-test people because of doubts about test results; and some said they provided feedback on counseling to counselors after observing sessions. As such, the supervision system fulfilled a useful function.

Yet, the supervisory system also had its limitations. One supervisor noted that it was “difficult to monitor the work. There were two supervisors for 22 counselors who were supposed to cover more than 30 villages.”¹¹⁵ Another supervisor said that there was such a need for additional help at the healthcare center where her counselors were working, that she spent much of her time at the clinic counseling and testing women who were seeking antenatal care.¹¹⁶ Several supervisors also said that the KYS leadership did not truly listen to the problems that supervisors were identifying, or take steps to address them.

Quality Assurance, Monitoring and Evaluation

An important element of accountability is ensuring properly functioning quality assurance, monitoring and evaluation systems. As part of quality assurance, the Operational Plan proposed that counselors would take a dried blood sample from every tenth person they tested and bring that sample to the healthcare clinic for testing. This system would allow the authorities to both identify potentially defective or unreliable batches of test kits but also flag potential problems with counselors. However, this procedure was never implemented. None of the counselors we interviewed said that they had ever taken a dry blood sample. Officials with KYS and the World Health Organization confirmed that no quality assurance testing had been done. One WHO official acknowledged that no quality assurance was being done at the time, but said that a task team on quality assurance had been formed and was setting up a decentralized quality assurance system. As of this writing, quality assurance procedures were being implemented in two of Lesotho’s ten districts.

¹¹⁵ Human Rights Watch and ARASA interview with Mafeteng drive supervisor J.T..

¹¹⁶ Human Rights Watch and ARASA interview with Mafeteng drive supervisor P.M..

As a result of the lack of quality assurance, the KYS campaign has no way of collecting information on the reliability of either the test kits used or the administration of those kits by KYS counselors. While some false positives may be discovered when a KYS client comes to the clinic and his or her CD4 count turns out to be suspiciously high—which, we found, has happened several times—this is not the case with people who test negative. Unless these people heed KYS counselors’ advice to retest after three months, the likelihood that such false negatives are discovered is very small. Underscoring the importance of quality assurance mechanisms, there have been several reports of reliability problems with rapid tests.¹¹⁷

The Operational Plan also envisioned an internal monitoring and evaluation process. This included the development of a database; training of staff for data collection, entry and analysis; and the production of monthly reports. It would, according to the Operational Plan, “be crucial to understanding whether or not the Know Your Status campaign is on the ‘right track’ while it is being implemented and the impact it has had (or not) when it ends.”¹¹⁸

A WHO official said that the monitoring and evaluation database had been developed.¹¹⁹ She said that people had been trained, that it had been used in Mafeteng, and that it would now be evaluated.

Independent Oversight

The independent oversight mechanism was to specifically monitor respect for human rights principles. According to the Operational Plan, independent monitoring committees would be created at the national, district and community levels that would “monitor the roll-out of the campaign and report any grievance or

¹¹⁷ See Rong-Gong Lin II and Juliet Chung, “More Sites Drop Oral HIV Test; A spate of false positives prompts health centers in New York and California to halt use of the product as federal agencies begin inquiries,” *Los Angeles Times*, December 20, 2005; “DOH HIV/AIDS Administration to Review Testing in Response to Reports of Increased ‘False Positives’ in New York City, San Francisco,” *US Fed News*, December 19, 2005; “Orasure Technologies Investigates Problems with HIV Test,” *FDAnews Device Daily Bulletin*, December 22, 2005; see also “HIV Testing: Rationale for Changing Recommendations,” *HIV Testing*, vol. 15 (1) March 2007.

¹¹⁸ Operational Plan, p. 11.

¹¹⁹ Human Rights Watch and ARASA interview with UN official.

violations.”¹²⁰ These committees were to consist of representatives of people living with HIV and AIDS, businesses, churches, youth groups, and women’s organizations. The national committee would also operate a telephone hotline for complaints. The national committee was to collect information from the district and community level committees and produce reports at least twice a year to the National AIDS Commission.

Although a UN official said that the national oversight committee had been set up, it was not functional.¹²¹ The district and community committees had never been created. As a result, KYS clients lacked any KYS-specific avenues of complaint when problems with KYS occurred. They could potentially go to local support groups but these played no formal role in the KYS campaign, their local clinics did not have any specific mechanisms to receive KYS-related complaints, and in any case, KYS clients were not advised of the possibility to complain.

Not only has the failure to set up these monitoring, evaluation and oversight mechanisms led to a dearth of information about the implementation of the KYS campaign and potential violations of human rights associated with it, it was also an important missed opportunity to engage and strengthen civil society in Lesotho. While the Operational Plan identified networks of people living with HIV, support groups and civil society as important resources for ensuring that the KYS campaign did not lead to human rights abuses—and had budgeted some funds for training of these groups—in the end they were denied the opportunity to play a meaningful role in oversight. Support groups, positive networks and other civil society organizations in Lesotho should play a key role in formulating HIV-related policy, providing services, and ensuring accountability.

Protections for People Living with HIV and AIDS

In their guidance on provider-initiated HIV testing and counseling in healthcare facilities, WHO and UNAIDS state that, as such testing and counseling is implemented, “equal efforts must be made to ensure that a supportive social, policy

¹²⁰ Operational Plan, p. 12.

¹²¹ Human Rights Watch and ARASA interview with UN official.

and legal framework is in place to maximize positive outcomes and minimize potential harms to patients.”¹²² A human rights based approach also requires that such efforts be undertaken when rolling out universal HIV counseling and testing strategies.

The KYS campaign envisioned encouraging hundreds of thousands of Basotho to test for HIV and, if targets had been met and people had tested positive at about Lesotho’s prevalence rate, this would have led to tens of thousands of people learning that they were HIV positive. It would be unacceptable if these people were to find, when encountering discrimination or other negative consequences of their HIV status, that they did not enjoy adequate protection under the law, or had no access to effective remedies. It was therefore particularly urgent for Lesotho to ensure that all people living with HIV and AIDS were protected by law against discrimination and other negative human rights consequences, such as abandonment by family, property grabbing, domestic violence, or discrimination in the workplace or in healthcare facilities.

The 2006 National HIV and AIDS Policy and the accompanying National HIV and AIDS Strategic Plan for 2006-2011, which outline the government’s response to HIV and AIDS, identifies the development of a minimum package of legislation to safeguard the rights of people living with HIV and AIDS, and of girls, women and other vulnerable groups, and to create a legal and policy environment that reduces vulnerability to HIV and AIDS.¹²³ Both the Policy and the Strategic Plan recognize basic human rights principles. Indeed, a number of important steps have been taken in recent years to this effect, but much still remains to be done.

Protection against Discrimination in the Work Place

The Labor Code, as amended in 2006, prohibits pre-employment testing and testing during employment, ensures confidentiality and non-disclosure, and prohibits

¹²² WHO and UNAIDS, *Guidance on provider-initiated HIV testing and counseling in health facilities*, p. 32.

¹²³ National AIDS Commission, Lesotho, “Lesotho National HIV and AIDS Policy 2006,” November 2005, http://www.aidsportal.org/Article_Details.aspx?id=4598&nex=67 (accessed October 28, 2008); National AIDS Commission, Lesotho, “National HIV and AIDS Strategic Plan (2006-2011),” November 2006, <http://www.safaids.net/?q=node/439> (accessed October 28, 2008).

discrimination in employment.¹²⁴ It is broad and follows human rights principles, providing protection to employees who are living with or presumed to be living with HIV or AIDS. However, the Labor Code only applies to private employers and state-owned corporations, not civil servants. As the government of Lesotho is one of the biggest employers in the country, it is important that similar provisions ensuring non-discrimination at the workplace apply also to civil servants. A draft HIV and AIDS Bill appears to ban discrimination in both the public and private sectors but this bill has not been finalized yet.¹²⁵

Women's Rights

Lesotho has recently taken a number of important steps toward expanding the rights of women. These steps also provide women living with HIV and AIDS significant protections against abuse. Until 2006, common law provisions deprived married women of legal capacity. A married woman could not undergo medical surgery without the consent of her husband; sign a contract; get a bank loan; or institute legal proceedings in her name. In 2006, Lesotho adopted a new Legal Capacity of Married Persons Act that granted women legal capacity and removed the overwhelming legal power husband had over their wives.¹²⁶

The 2003 Sexual Offences Act recognized for the first time the crime of marital rape, enabling women to refuse sex with their spouse.¹²⁷ In 2003, a special police unit on children and gender-based violence was created, which works closely with women's rights groups to disseminate information about gender based violence to communities all over Lesotho.¹²⁸ However, no specific legislation on domestic violence exists to date and a women's rights activist told us that she did not think parliament could be persuaded to adopt such a bill in the near future.¹²⁹ While no

¹²⁴ Labour Code (Amendment) Act, No. 5 of 2006.

¹²⁵ Art. 18 of draft bill, on file with Human Rights Watch.

¹²⁶ Legal Capacity of Married Persons Act, No. 9 of 2006.

¹²⁷ Sexual Offences Act, No. 3 of 2003.

¹²⁸ Human Rights Watch and ARASA interview with Mabulai Mohasi of FIDA.

¹²⁹ Human Rights Watch and ARASA interview with Me Polo of FIDA.

dependable statistics are available, domestic violence against women is believed to be widespread.¹³⁰

Although these laws have greatly improved women's legal position, the new legislation has done little so far to improve the position women have in the family in practice. Many men continue to see their wives as their property. A women's rights activist, for example, told us that at public gatherings where she spoke about violence against women and marital rape men would sometimes speak out indignantly, saying that since they paid a dowry for their wives they should be able to have sex with them whenever they wanted.¹³¹

Protection of Property

The Inheritance Act of Lesotho dates back to 1873 and is based on customary practices, which discriminate against women.¹³²

Unfortunately, the draft HIV & AIDS Bill is silent on the issue of inheritance. Lesotho is a party to the Convention on the Elimination of Discrimination against Women (CEDAW),¹³³ which is clear about the specific obligations to safeguard women's right to equal enjoyment of property rights, including in areas of inheritance. CEDAW requires states to take appropriate measures to accord the same rights to men and women "in respect of the ownership, acquisition, management, administration, enjoyment and disposition of property."¹³⁴ General Recommendation 21 of the CEDAW Committee specifically addresses inheritance, reminding states that, "There are many countries where the law and practice concerning inheritance and property result in serious discrimination against women.... Such provisions contravene the

¹³⁰ See US State Department, Bureau of Democracy, Human Rights, and Labor, Country Reports on Human Rights Practices - 2007: Lesotho, " March 11, 2008, <http://www.state.gov/g/drl/rls/hrrpt/2007/100488.htm> (Accessed October 20, 2008).

¹³¹ Human Rights Watch and ARASA interview with Mabulai Mohasi of FIDA.

¹³² Inheritance Act, No. 26 of 1873.

¹³³ Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), G.A. res. 34/180, U.N. Doc. A/34/46, entered into force September 3, 1981. Lesotho ratified CEDAW on August 22, 1995.

¹³⁴ Article 16 (1) (h).

Convention and should be abolished.”¹³⁵ The Inheritance Act and draft HIV and AIDS Bill should be amended to grant women and children inheritance rights in line with Lesotho’s international obligations under CEDAW and the Convention on the Rights of the Child, and to outlaw property grabbing,¹³⁶ the unlawful appropriation of property by relatives of the deceased (usually the husband).

¹³⁵ UN Committee on the Elimination of Discrimination against Women, General Recommendation 21, Equality in Marriage and Family Relations, (13th session, 1994), para. 35.

¹³⁶ The Committee on the Rights of the Child called on Lesotho “strengthen urgently its efforts to ensure full implementation of the principle of non-discrimination... to give particular attention to ending discrimination against girls and women .. in legislation, customary law and in practice” Consideration of Reports Submitted by States Parties Under Article 44 of the Convention: Concluding Observations of the Committee on the Rights of the Child, Lesotho, CRC/C/15/Add.147, February 21, 2001, para. 26. Lesotho ratified the Convention on the Rights of the Child on March 10, 1992.

VII. Conclusion

The opportunity to learn one's HIV status is an important aspect of the realization of the right to health. However, the right to know your status should not simply be viewed as an autonomous right. States must offer HIV testing services as part of a continuum of health care services. While expanding access to HIV counseling and testing should be a key priority for all high prevalence countries, testing should be expanded not on its own but as part of a broader effort to scale up HIV-related healthcare and other services.

Community-based testing campaigns have real potential. They offer a real chance to reach out to populations that are otherwise unlikely to test. However, Lesotho's KYS campaign shows that mass community-based HIV counseling and testing campaigns do not offer the quick fix for the HIV pandemic that some public health and other officials appear to have believed they would. International organizations such as WHO and UNAIDS can and must learn important lessons from the KYS campaign. These campaigns need careful planning, sufficient funding, good training, ample coordination, proper oversight, and the involvement of civil society, which can play a critical role in ensuring accountability and reporting potential human rights abuses. Without these elements, these programs risk failing to achieve their ambitious goals—as happened in Lesotho—or, worse, damaging the cause they were intended to serve.

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