LOCKED DOORS:
THE HUMAN RIGHTS OF PEOPLE LIVING WITH HIV/AIDS IN CHINA

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I. SUMMARY

People who are HIV-positive need emotional support. Many people, when they find out they are HIV positive, suffer very much and are very sad. They have many needs—psychological, medical, and legal—but many people just stay at home for years and years.1

Zhang, a person living with HIV and an AIDS activist

In 1985, a foreign tourist visiting southeast China became the first person in the country to be diagnosed with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS).2 Nearly two decades later, China faces what could be the largest AIDS epidemic in the world. Already, the virus has cut a devastating swath across the country, affecting at least 1.5 million men, women, and children. In fact, the numbers are probably much higher3—actual infection rates remain unclear in China, because local authorities have minimized the epidemic in order to protect external investment in local economies. During the 1990s, local authorities were also complicit in the transmission of HIV to hundreds of thousands or even millions of villagers through an unsanitary but highly profitable blood collection industry. Faced with such multiple local failures on the part of provincial and county governments, Beijing’s reluctance to act decisively in the AIDS epidemic continues to cost lives and cause inescapable suffering to those living with the virus.

As AIDS activist Zhang points out, persons living with HIV in China have urgent needs for health care, legal aid, and community support. Instead, widespread discrimination by state and private actors, and the lack of redress, are forcing many people with HIV/AIDS4 to live like fugitives. Their voices in this report, some of teenagers, tell of not only the horror of facing a painful and certain death, but also of facing that death alone, in squalor, with no one to bring them food or change their sheets, fearful to even show their faces to neighbors because of the risk of eviction. Having been fired from jobs, evicted by landlords, or worst of all, refused care by hospitals because of their HIV status, some try to mask their pain and despair with drugs—which in turn can hasten the spread of the virus to others. Stigma and discrimination are clearly fuelling the epidemic in China. As these voices tell us, China’s leaders must take concerted action immediately, or HIV/AIDS will destroy the lives of millions more.5

China has the capacity to combat AIDS. Despite a severely damaged national public health system and discriminatory hospital practices, some individual doctors and nurses have made extraordinary efforts to care for people with HIV. Behind the scenes, some senior policy makers are pressing Beijing to issue increasingly

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1 Human Rights Watch interview with Zhang, Beijing, 2002.
3 Chinese officials acknowledge 1 million people living with HIV/AIDS in China, while the Joint U.N. Programme on HIV/AIDS (U.N.AIDS) estimates between 800,000 and 1.5 million people. However, in China’s 2003 application to the Global Fund to Fight AIDS, Tuberculosis and Malaria, the state reports HIV prevalence rates among rural blood donors ranging from 4-40% across seven provinces with a combined total population of 420 million; and in all seven provinces, blood donation was a common source of supplemental income for farmers and their families (Country Coordinating Mechanism, 2003 Proposal to the Global Fund, Section III, p. 13). Without further information about this survey, these percentages cannot be evaluated, but they suggest potentially higher national infection rates than have previously been admitted.
4 English-language writing about HIV/AIDS commonly uses the phrase “people living with HIV/AIDS,” for which there is no precise or neutral Chinese translation. Frequently used terms in Chinese are aizibing bingren ("AIDS patient"—literally, "person sick with AIDS illness"), ganranzhe ("infected one"), aizibing huanzhe ("AIDS sufferer") and bingyou ("illness friend" or, more loosely, “AIDS comrade”).
progressive-sounding statements on the epidemic and to undertake serious legal reform. A handful of small-scale pilot projects on the borders, the products of collaboration between some concerned Chinese officials and international nongovernmental organizations (NGOs), show what could be done. Yet in practice, Beijing has thus far done remarkably little. While the outbreak of severe acute respiratory syndrome (SARS) in 2003 led, after a fitful start, to the full mobilization of the state to bring that deadly disease under control, the more widespread and dangerous HIV/AIDS epidemic has been treated as a lesser priority. One obvious reason for the differences in China’s treatment of AIDS and SARS is economic: SARS, an airborne disease, directly threatened the health of foreign visitors and had a visible impact on China’s trade and tourist industry. Another is the official discourse surrounding the virus, which links it with people considered “expendable” in China’s march toward modernization: injection drug users, sex workers, men who have sex with men, and ethnic minorities.

Thus many people living with HIV/AIDS in China live in a health care vacuum without hospital care, antiretroviral drugs, or counseling. In Yunnan, Human Rights Watch discovered that the door to a hospital AIDS ward was actually closed and padlocked.

This locked door may in fact be emblematic of the experience of being HIV-positive in China, which is like encountering a series of locked doors. On revealing their status (or having it revealed for them), persons living with HIV/AIDS may find themselves rejected by their families and friends, cast out of their homes, and unable to find or keep employment. If they turn to hospitals to seek assistance, some find they are refused care, and many are unable to afford care even when it is accessible. There are few NGOs that offer care or other services to people living with HIV/AIDS in China. Those individuals who dare to identify themselves to others as HIV-positive and who try to band together to form their own support groups face repression and censorship. Unable to afford medicines and lacking access to basic information about what works, some people with HIV even band together in secret to hold their own drug trials, experimenting with unregulated remedies sold by street peddlers in back alleys, in a desperate attempt to stave off the virus.

These persons are suffering without resources, treatment, health care, and support services, but their suffering is not inevitable. The state, with the support of international agencies, donors and NGOs, could address these issues in China as they have in other countries.

Locked Doors highlights the importance of protecting the rights of people living with HIV/AIDS and those at risk of contracting the disease in order to combat the epidemic. It draws on fieldwork in Yunnan province, Beijing, and Hong Kong, as well as archival research, to document human rights issues related to China’s HIV/AIDS epidemic. Rights abuses documented in this report include:

- the spread of HIV through unsafe state-run blood collection centers in the 1990s; the government’s failure to provide treatment or compensation to the overwhelming majority of those who acquired HIV directly or indirectly through those blood sales; and Beijing’s failure to prosecute responsible local officials;
- restrictions on freedom of expression, assembly, association and the right to information of those living with HIV/AIDS and persons seeking to help them;
- arbitrary detention of injection drug users;
- discrimination based on HIV status by state actors, including government hospitals, clinics and government employees;
- mandatory HIV testing in state facilities and violations of patient confidentiality; and
- lack of access to treatment and other issues in China’s under-funded and problem-ridden health care system.

Though the basic facts are now widely known, Beijing continues to abet the local cover-up of one of the world’s greatest HIV/AIDS scandals: the spread of HIV through unsafe blood collection practices to rural blood donors. In Henan province in the 1990s, perhaps one million people were infected with HIV through shoddy practices at blood collection centers run by the local health department as well as illegal, underground blood collection centers.
Infections occurred when the blood remaining after extraction of the plasma was combined and reinjected into the original donors. The motive of local officials was financial: they were trying to take advantage of the highly profitable global demand for blood plasma. Journalists, doctors, and AIDS activists who subsequently tried to reveal the truth were harassed, expelled from the province, or detained and interrogated by police.

Chinese government documents now reveal what many, including the Joint United Nations Programme on HIV/AIDS (UNAIDS), have long suspected: Henan was just one of seven central Chinese provinces where similar blood collection practices fuelled the spread of HIV/AIDS. The sheer percentages cited in these documents indicate potentially larger HIV prevalence in China than the state has yet acknowledged. In spite of the massive human toll, the national government has ignored calls for an independent investigation, compensation, and treatment for all the victims. To date no government official has been prosecuted for the scandal. This impunity for local officials’ cover-up of the AIDS epidemic is one cause of the lack of accurate epidemiological information nationwide, and likely led directly to similar cover-ups in the SARS epidemic.

Perhaps to avoid responsibility, perhaps as part of the government’s longstanding policy of censorship, which includes the suppression of “bad” news that otherwise might cause social unrest, the state has tried to control media coverage of the AIDS epidemic. While the state now permits positive stories about government AIDS programs, and some critical stories occasionally appear in the Chinese press, other journalists who write stories unflattering to state actors have been fired or intimidated into self-censorship.

Stigma, fear and discrimination have been common around the world in the HIV/AIDS epidemic, but in many other places — including Hong Kong — people suffering the ravages of AIDS can form independent support groups and lobby for reforms, such as antidiscrimination laws and access to treatment. With few exceptions, this is not allowed in China.

China also estimates that 260,000 children may be orphaned by HIV/AIDS by 2010; although, again, these numbers are contested — AIDS activists and NGO workers in Henan estimate that as many as a million children in that province alone are or will become orphans as a result of the blood collection disaster. Many school-age

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7 China’s 2003 application to the Global Fund cites “7 central provinces” and “56 counties” where the blood collection scandal “significantly affected” local populations (Country Coordinating Mechanism, 2003 Proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria, June 20, 2003, p. 14).
8 See footnote 3.
9 In a promising reversal of previous policy, senior health officials announced plans to produce new rules outlining the legal responsibility of local officials to treat people with HIV/AIDS and to prevent cover-up of the epidemic. However, it is not clear if these rules, once passed, would have the status of health department policy or of national law. Mure Dickie, “Stringent new rules on AIDS proposed by China,” Financial Times, August 15, 2003.
AIDS orphans were forced out of school because they could no longer afford school fees, or because they must work and care for sick parents.

Mistreatment of and misguided policies towards injection drug users have exacerbated the problem. In response to an epidemic of drug use in impoverished border regions, police officers regularly sweep the streets of “social undesirables,” such as people suspected of drug use. Public security officials have the authority to consign a suspected user without trial to a prison-like forced detoxification center.\textsuperscript{14} Psychological and moral education in the centers is militarized, consisting of rote repetition of slogans, marching in formation, and repetitive drills. Former detainees and NGO workers familiar with the centers report overcrowding, poor sanitation, and inadequate medical care. In many, detainees are required to work without pay, producing goods sold by the prison. Detainees are tested for HIV without their knowledge and, perhaps most disturbing, without being informed of the results and given appropriate counseling on care, treatment, and prevention. This means that while the state is aware that a person is HIV-positive, the infected person is not; upon release he has no reason to seek necessary medical treatment or to alter his behavior (such as the sharing of needles or use of condoms).

Chinese national law and local regulations permit mandatory testing of many categories of people, in contradiction of international standards prohibiting non-consensual medical procedures.\textsuperscript{15} Employees at hospitals also admit they routinely test for HIV without the consent of those tested. NGO workers and others report that state facilities sometimes inform employers and family members of a person’s HIV status, increasing the person’s vulnerability to discrimination, and making many others less likely to test for HIV voluntarily.\textsuperscript{16}

There have been a number of successful lawsuits by individuals against hospitals for illnesses acquired because of contaminated blood supplies, yet many hospitals remain unwilling to accept responsibility for the safety of their blood supplies. Some now require patients to sign waivers releasing the hospital from liability in case of the transmission of HIV or other diseases.

People living with HIV/AIDS also face many forms of discrimination in their daily lives. Perhaps most perverse is that some people with HIV/AIDS report being refused admission to hospitals by health care workers because of their HIV-positive status. Some were refused after unknowingly testing positive for HIV; others were refused categorically when hospitals actually locked their HIV/AIDS wards and barred all HIV-positive persons.

Other discriminatory measures are part of Chinese law. While national laws on marriage have recently been reformed, local regulations in many regions still allow authorities to refuse permission to marry to those with HIV/AIDS. People living with HIV/AIDS also face the threat of eviction by their families or villages or, in cities, by their landlords or neighbors. As there is no legal protection or recourse for victims of discrimination, these unredressed acts of discrimination also add to the stigma associated with AIDS. The fact that Chinese laws permit quarantine for testing or treatment also serves to reinforce the social stigma surrounding HIV/AIDS. Such

\textsuperscript{14} State Council, Methods for Forced Detoxification [\textit{Qiangzhi jiedu banfa}], January 12, 1995, article 6.

\textsuperscript{15} Both national and local regulations require mandatory testing for various groups, including foreigners, sex workers, drug users, prisoners, and those “suspected of” having HIV/AIDS. These include: \textit{Aizibing jiance guanli de ruogan guiding} [Certain Number of Regulations on AIDS supervision and management], State Council, January 14, 1988, articles 5 and 8; \textit{Dali ershi aizibing jiance guanli guiding} [Regulations for Dalian city AIDS supervision and management], article 7; \textit{Beijingshi shishi aizibing jiance guanli guiding} [Regulations for Beijing city AIDS supervision and management], article 8; \textit{Shanghai aizibing fangzhi banfa} [Shanghai city methods of AIDS prevention], article 15; and \textit{Sichuansheng yufang kongzhi xingbing aizibing tiaoli} [Regulations for Sichuan province prevention and control of STDs and AIDS], articles 1, 2, 16, and 17. According to the UN Committee on Economic, Cultural and Social Rights, in its General Comment 14 on “The right to the highest attainable standard of health,” August 11, 2000, persons are entitled to control of one's health and body, including the right to be free from interference, such as to be free from non-consensual medical treatment and experimentation. Paragraph 8.

\textsuperscript{16} Guideline 3 of the “U.N. Human Rights and HIV/AIDS International Guidelines” recommends that “in order to maximize prevention and care, public health legislation should ensure, whenever possible, that pre- and post-test counselling be provided in all cases.”
laws effectively disseminate inaccurate information about the virus – that is, the idea that HIV can be transmitted through casual contact.

In the decades after the 1949 revolution, China made enormous strides in public health. The national health care system was a central benefit of the Communist Party’s cradle to grave protection of workers as part of its “iron rice bowl” employment policy. The dismantling of this system during the transition to a market economy has limited access to health care generally. It has had serious implications for both prevention and treatment of persons living with HIV/AIDS, whether for opportunistic infections or for provision of antiretroviral drugs. The spiraling cost of doctor’s examinations, hospital beds, diagnostic tests, and drugs, and the profit-driven nature of these services, has made appropriate medical care inaccessible to most people with HIV/AIDS. Weaknesses in the public health care system have driven many living with the disease into an unpredictable world of backstreet clinics and unregulated, experimental remedies.

The combined effect of all these forms of public and private stigma and discrimination is to drive many people living with HIV/AIDS underground. Some flee from place to place with the constant threat of exposure as “carriers” of the “plague.” Unable to gain access to state services because they lack city residence permits, they are barely able to scrape together the means to purchase the vials of remedies sold by unscrupulous doctors and even street hucksters to “cure AIDS” until, finally, they huddle alone on their beds in rented rooms to wait for death.

“They call, they get tested, and they hide,” said Han, who runs a small-scale, local counseling service. “The life of an AIDS sufferer ... is a very lonely one.”

While the current picture is bleak, China does have the capacity to change its approach to HIV/AIDS, a capacity it began to display during some moments of the SARS epidemic in 2003. Given China’s high degree of control over state-run media, the country could combat social stigma and coordinate a national response to HIV/AIDS. China's government regularly demonstrates its ability get its message out about other topics, such as the banned religious group Falun Gong, its one-child policy, or its policy on SARS.

The SARS epidemic has shown both the old face of the Chinese political system, and a potentially new face. Beijing’s dark side was exemplified by its initial cover-up of the epidemic, and by its knee-jerk resorting to draconian measures developed during the AIDS epidemic, such as the jailing of “intentional transmitters.” But by firing the Minister of Health, the mayor of Beijing, and more than 100 health officials for covering up and under-reporting SARS infection rates, China has established new standards of public accountability. Recent statements that the Ministry of Health is drafting regulations to mandate accountability for officials who cover-up HIV/AIDS are very promising, provided they have the status of law and are strictly enforced. The challenge for China is to maintain and apply these standards to those who have been complicit in the spread of HIV, those who have covered up the AIDS epidemic, and to state actors who discriminate against people with HIV/AIDS.

Some national policies show sensitivity to the rights of people affected by HIV/AIDS, such as the national HIV/AIDS action plan. The principles expressed in these policies could be codified in law and enforced by an independent equal rights commission, as they are in Hong Kong. Some areas of the country have already developed pilot projects and local regulations that respect and protect some key rights of people affected by

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17 Human Rights Watch interview with Han, Kunming, Yunnan, 2002.
HIV/AIDS, such as Suzhou. These could serve as models for larger projects in areas with even larger numbers of people with HIV/AIDS. Officials in some areas, such as Yunnan, have shown more tolerance for independent NGO activity on HIV/AIDS. This could be emulated in other regions of the country, as could some of Yunnan’s successful pilot programs. People living with HIV/AIDS in Hong Kong also point out that Hong Kong’s positive experiences with subsidized treatment, its vibrant NGO community, and its antidiscrimination ordinance could be studied in mainland China. Hong Kong AIDS NGOs have initiated pilot projects on the mainland, which could be expanded.

There have been some small signs of change in China’s discriminatory local regulations. In September 2002 the city of Suzhou passed regulations barring discrimination based on HIV status. In June 2003 Sichuan province began considering regulations that would reverse earlier discriminatory laws and permit people living with HIV/AIDS to marry. In August 2003 Chinese media publicized the marriage of two people with HIV/AIDS in Sichuan. Individual, high-profile marriages such as this one could be translated into systemic change in Sichuan and elsewhere.

Another hopeful sign is China’s 2003 application to the Global Fund to Fight AIDS, Tuberculosis and Malaria (or “the Global Fund”), which acknowledges some facts for the first time. In the application, China’s government admits the spread of HIV through unsafe blood collection centers in seven provinces, including Henan. The application admits that it is “not uncommon” for hospitals to turn away AIDS patients. It states that “stigma has hampered the social and political response” to HIV/AIDS.

Perhaps most important, as an implicit statement that the provision of better medical care is in China’s national interest, the application states that a government survey shows that catastrophic illness, such as AIDS, is a major cause of poverty in China. The application states several times that the hardest-hit areas are rural and poor with a weak infrastructure and health care system, asserting

One of the major challenges in assuring the service delivery of HIV/AIDS care and treatment in a rural setting is the dysfunctional state of the existing rural health service across China, especially in those poor areas.

China has asked the Global Fund to support a plan to bring care and treatment, including antiretroviral drugs, to 50,000 persons living with HIV/AIDS across the seven provinces. The move also signals a potential growing openness by Chinese leaders to proposals for universal care and treatment for people with AIDS.

It is unclear if the Global Fund application represents a new and more enlightened view of the HIV/AIDS problem by Beijing, the views of a minority in China’s public health system, or mere rhetoric in a grant proposal. The test will be whether China ends its discriminatory laws and practices, tolerates public discussion and debate on the subject of HIV/AIDS, allows independent support and advocacy groups to form, provides treatment and compensation to blood scandal victims, and treats HIV/AIDS as a genuine public health crisis requiring a serious and coordinated response, rather than an embarrassment to hide. Moreover, official corruption is a serious hindrance to effective delivery of funds and care to rural persons affected by HIV/AIDS. In Henan, allegations of misuse of funds intended for AIDS care has led to a number of protests and demonstrations. The grant proposal fails to propose how to address this problem.

In October 2002 U.N. Secretary-General Kofi Annan made a visit to China, where he issued a plea for action against the AIDS epidemic. Speaking at Zhejiang University, Annan said:

There is no time to lose if China is to prevent a massive further spread of HIV/AIDS. China is facing a decisive moment.25

Much time has already been lost since Annan’s plea. It is time for the Chinese government to make the fight against AIDS a central and unambiguous plank of public policy, one that embraces people living with HIV/AIDS as victims of an illness rather than the objects of public scorn. The full weight of the Chinese public health system, from public education campaigns to appropriate treatment, must be activated, for the sake of sufferers and of Chinese society as a whole.

As one Hong Kong resident living with HIV/AIDS observed, China has far greater economic resources today than it did when the first case of HIV/AIDS was diagnosed in 1985. New cities, such as Shenzhen, have sprung up in the midst of rice fields. Beijing has become a global metropolis. Kunming, where research for this report was done, has transformed itself from a sleepy backwater into a bustling cluster of new hotels and businesses, its streets clogged with daily traffic jams. China’s economic wealth is greater than ever before. With or without assistance from the Global Fund, this emerging political and economic superpower is capable of doing more.

Since 2002 China’s leaders have emphasized the need for the international community to assist in the fight against AIDS. Another great resource in the fight has been left untapped by China: the expertise and leadership of people living with HIV. In other countries, people living with HIV/AIDS have been great allies and often leaders in the struggle against the epidemic. Instead of driving them underground, the state should guarantee their basic rights so that they can come forward and help to lead the fight against HIV/AIDS.

II. RESEARCH METHODS

Human Rights Watch conducted field research for this report in Yunnan, Beijing, and Hong Kong for a total of five and a half weeks in 2002 and 2003. Human Rights Watch researchers visited offices and interviewed representatives of thirteen NGOs and GONGOs (government-organized NGOs), two U.N. agencies, two hospitals, two religious centers, and two drug detoxification centers. Seven people living with HIV/AIDS agreed to be interviewed, and Human Rights Watch also interviewed twenty-three NGO workers, police officials, social workers, and health workers. The six male and one female HIV-positive interviewee ranged in age from late teens to late fifties and came from Hebei, Fujian, Yunnan, and Hong Kong.

Interviews were conducted in settings that were as private as possible. In almost all cases, interviews were conducted in Modern Standard Mandarin; in two cases where dialectal differences were significant, NGO workers assisted with translation. In addition, Human Rights Watch collected information from Chinese and English-language news accounts, NGO reports, scholarly journals, archives in Hong Kong and the U.S., and the Internet.

In an effort to understand these human rights issues in their broader social and cultural context, researchers visited and conducted participant observation in public and private places, ranging from urban hospitals to village homes. To supplement formal interviews, researchers held informal interviews and conversations with former drug users, entrepreneurs, students, religious leaders, government officials, farmers, researchers, and educators on the topics of AIDS and related social questions.

The scope of this study is necessarily limited by the information accessible to Human Rights Watch given the research constraints discussed below. In particular, it does not deal in depth with such important issues as violations of the rights of children, of women, of male and female sex workers, or of men who have sex with men in the HIV/AIDS epidemic. It is hoped that this report will prompt more field research into human rights and HIV/AIDS by Chinese and international researchers working in China.

Security concerns and restrictions on research

China may be increasingly open to international NGOs working on AIDS, but it remains closed to Chinese and international human rights organizations. Over the years, Human Rights Watch has received many reports of the detention and interrogation of Chinese activists and scholars because of their contact with international human rights organizations: for instance, in 2003 a copy of the indictment against Liaoning labor activists Yao Fuxin and Xiao Yunliang obtained by Human Rights Watch showed that the charges of state subversion against these two labor activists were based in part on their contacts with independent Hong Kong-based human rights groups, officially termed didui zuzhi (hostile organizations) by the Liaoning prosecutor’s office. International scholars who publish materials on subjects deemed sensitive by the government have been refused visas to China.

Moreover, Chinese scholars who travel abroad to teach or participate in scholarly conferences are often questioned by police on their return to China, as in the case of some scholars who reported such interviews after

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26 Events unfold rapidly in China. The information contained in this report is current as of August 21, 2003.
27 Participant observation is a qualitative social science research method that requires immersion in the research site. Everett C. Hughes calls it “the observation of people in situ; finding them where they are, staying with them in some role which, while acceptable to them, will allow both intimate observations of certain parts of their behavior, and reporting it in ways useful to social science but not harmful to those observed” (“Introduction: the place of fieldwork in social science,” in Buford H. Junker, ed., Field Work: An Introduction to the Social Sciences, Chicago, University of Chicago Press, 1960; p. v). By contrast, quantitative research methods such as questionnaires are useful for gathering larger amounts of information that are easier to compare across research sites, but these more superficial tools can also distort the data. For an excellent discussion, see Bruce Jackson, Fieldwork(Urbana and Chicago, University of Illinois Press, 1987).
their return from a scholarly conference in Thailand, and of a professor who was questioned when he returned to Xi’an after teaching at Yale University.\(^30\)

The situation of Chinese AIDS activists, especially those who worked to reveal the facts about the Henan blood scandal, is further evidence that HIV/AIDS is considered sensitive by the Chinese government. In 2002, Chinese AIDS activist Wan Yanhai was detained, allegedly for circulating “state secrets” to journalists, academics and human rights organizations about the Henan scandal. Several other Chinese AIDS activists have reported to Human Rights Watch that they believe they are followed by the police and that their mail, electronic mail and telephone communications are under surveillance. The importance of preserving security for people living with HIV/AIDS and AIDS activists was a major concern for Human Rights Watch in its research in China.

Because of the above concerns, Human Rights Watch researchers did not request interviews with government officials while in China, but did write to China’s representatives in New York to request an interview (appendix). The embassy did not respond. In Hong Kong, a Human Rights Watch researcher interviewed the chairperson of the Equal Opportunities Commission.

Also because of these concerns and due to the sensitive position of international NGOs in China, this report omits the names of all interviewees, including the names of international and local NGOs and their staff. Identifying characteristics of interviewees have been omitted or altered, as have precise dates and locations of field research. Only AIDS workers in Hong Kong gave permission for the use of their names. Human Rights Watch looks forward to the day when international human rights groups can work openly with all our colleagues in China.

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III. BACKGROUND

Exact figures are difficult to arrive at because government at local levels are very reticent to report on actual cases, a situation compounded by individuals who are reluctant to come forward because of discrimination.

Qi Xiaoqiu, director of China’s Department of Disease Control

For many years, the Ministry of Health claimed that only a few thousand persons were infected with HIV, though these numbers were widely contradicted by public health experts inside China and abroad. Though actual numbers remain unclear, as discussed below, UNAIDS estimates that at least 1.5 million people are living with HIV/AIDS in China, and there are quite likely many more.

There are many reasons for the confusion, including the underdeveloped Chinese public health “surveillance” system, which frequently does not provide the full picture of a disease; and cover-ups of the HIV/AIDS epidemic by the Ministry of Health and local authorities, who feared their cities or regions would lose external investment if the full extent of the problem were known, or that they would be punished by superiors for failing to prevent the spread of the disease.

There has been a long, internal fight within the Chinese government and its public health agencies over actual HIV prevalence and the importance of publishing accurate figures. One focus of this argument has been the question of whether to publish the number of confirmed cases reported by the Ministry of Health, or to rely on estimates generated by public health officials and official epidemiologists. For example, as of June 1998 China’s 31 provinces, municipalities, and autonomous regions had reported just 10,676 cases of HIV transmission, only 301 cases of full-blown AIDS, and 174 deaths. In September 2000 the Ministry of Health reported that there were just 20,711 confirmed, registered cases of people with AIDS. These numbers were not a credible reflection of the extent of the problem. By insisting on recognizing only the number of confirmed cases—creating the impression of a relatively small problem by recognizing only a small fraction of the total—the Chinese government seemed to be burying its head in the sand, perhaps hoping that the problem would miraculously go away.

But others in China’s public health system were already sounding the alarm. As early as November 1998 the Chinese “National Medium-and Long-Term Strategic Plan for HIV/AIDS Prevention and Control (1998-2010),” jointly drafted by the Ministry of Health, the State Development Planning Commission, the Ministry of Science and Technology, and the Ministry of Finance, stated that “the actual number of HIV infections in China might exceed 1.2 million by the year 2000.” This report asked China’s local governments to “implement its recommendations in a conscientious manner” and described AIDS as:

a major disease, which is a high priority for disease control in China ... Every region and every sector must formulate their own plans and strategies to implement according to this strategic plan according to specific local situations, and to incorporate them into their overall socio-economic development programs. The high priority given to HIV/AIDS prevention and control should be manifested through strong leadership and by implementing various plans and strategies in order to achieve the objectives and tasks of the Chinese national strategic plan in time.

However, these words were contradicted by the government’s simultaneous failure to report accurate numbers or to provide resources to local governments and public health systems too poor and ill-equipped to cope with the problem.

The past two years have seen a slow revelation of more realistic numbers from Chinese authorities, though the full picture still has not emerged in official statements. In December 2001 the government began to publish estimates, suggesting there were 600,000 people living with HIV/AIDS.\(^\text{35}\) That same month it revised its estimate to 800,000.\(^\text{36}\) The decision to use estimates reflected the seriousness with which at least some officials were beginning to see the HIV/AIDS epidemic. In December 2002 the Ministry of Health acknowledged one million people living with HIV/AIDS.\(^\text{37}\)

Other experts have put the number of cases in China higher by varying amounts. A UNAIDS report in China in 2002 estimated as many as 1.5 million people living with HIV/AIDS.\(^\text{38}\) In September 2002 a report by the U.S. National Intelligence Council forecasted that China would have 10-15 million AIDS cases by 2010.\(^\text{39}\) Though the data is not clear, injection drug users in the western border regions and farmers in Henan and other central provinces who became infected after donating blood probably make up the majority of persons living with HIV/AIDS in China.

China’s efforts to limit information about the disastrous spread of HIV through government-run blood collection centers in the pursuit of revenue from the sale of blood plasma during the 1990s has contributed to the confusion about numbers. Some NGO workers and doctors familiar with conditions in Henan province have estimated that there are at least one million HIV-positive people in that province alone. China’s application to the Global Fund for AIDS acknowledged that six other provinces had similar blood collection disasters and that the officially reported numbers of people living with HIV/AIDS in these seven provinces were probably low.\(^\text{40}\)

China’s upward revision of its estimate in 2002 was one sign of a gradual acknowledgment in the Chinese government of the epidemic, as was a new policy announced during the SARS epidemic of holding officials responsible for under-reporting of infection rates. As with many other aspects of China’s changing AIDS policy, it is not clear to how much political will exists to address the problem or to what degree the central government will or can enforce its policies and require accountability.

One measure of a government’s commitment to deal with a problem is the amount of money it spends to address it. Unfortunately, understanding how much China spends, both at the national and the provincial levels, on HIV/AIDS treatment and prevention is even more difficult than determining the number of people living with HIV/AIDS. Chinese government budgets are notoriously opaque and unreliable. It is also unclear whether funds allocated are actually spent on the intended subject. Corruption is a major and widely acknowledged problem.

China’s reported gross domestic product in 2002 was RMB 10.2 trillion (about U.S.$123.2 billion).\(^\text{41}\) How much does the government spend annually on AIDS programs? It is difficult to say for sure, but there are some indications. In May 2003 Dr. Yiming Shao of China’s National Center for AIDS Prevention and Control stated that the national budget for HIV/AIDS has continually increased during the past two years, and is currently over RMB 100 million (U.S.$12.08 million), with provincial governments additionally contributing RMB 500 million (U.S.$60.41 million). “Over eighty percent of the national budget [for AIDS programs] goes to rural areas,” he

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\(^{38}\) UNAIDS, HIV/AIDS: China’s Titanic Peril, June 2002; p. 11.


said, adding that the national government had recently added RMB 1 billion (U.S.$120.9 million) in additional funding to be allocated to western regions “to strengthen blood banks and public health infrastructure.”

The following presents a brief overview of the recent history of the epidemic in China, the once-strong, now greatly deteriorated national health care system, the gradual opening towards this once-taboo epidemic in the past three years, and persistent problems with social stigma attaching to AIDS.

**Brief history of HIV/AIDS in the People’s Republic of China**

An introductory section to China’s 2003 application to the Global Fund states that “the epidemic in China is in fact not unitary and consists of a number of overlapping epidemics.” China’s HIV/AIDS epidemic may roughly be conceived of in three phases: 1) the 1980s; 2) the early 1990s; and 3) the late 1990s-early 2000s.

In the first phase during the 1980s, the first persons to be diagnosed with HIV in China were foreigners, overseas Chinese visitors, and Chinese who had traveled overseas. Thus, the earliest responses to the disease focused on the control of foreigners and targeted the navy and customs department as important participants in AIDS prevention and control measures. These attitudes still prevail: local regulations in Shanghai require that work units and individuals report all those suspected of having AIDS to the local health bureau, “including foreigners, overseas Chinese, Hong Kong residents, Macao residents, and Taiwan residents.”

The concept of AIDS as a foreign disease brought into China from the west began to take hold during this period, stigmatizing sufferers as a particular social group different than the average Chinese citizen. Many of the same homophobic, anti-drug user, and xenophobic attitudes seen in other parts of the world in response to the outbreak of HIV/AIDS began to form in China. During this period, it appears that the number of people with HIV in China was small.

During the early 1990s, groups of injection drug users in Yunnan Province (Dehong Dai Autonomous Prefecture, a largely Dai [Tai] ethnic minority region on the Burmese border) began to test positive for HIV. Burma is a major source of heroin and opium for the rest of the world. The growing prevalence of HIV in areas dominated by ethnic minorities only bolstered the impression of many in China that AIDS was a problem for stigmatized tribal peoples, and that it was linked to moral corruption and “backwardness.” Because of centuries of imperial relationships with the western ethnic minorities, many believe that ethnic minorities are morally “loose” and sexually promiscuous. Dehong quickly became the epicenter of the epidemic for the nation, and the trade in drugs among farmers and other rural people spread the virus north along the impoverished western belt of China.

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44 *Shanghai shi aizibing fangzhi banfa* (Shanghai city AIDS prevention methods), Shanghai People’s Government document no. 64, Dec. 30, 1998, article 25.

45 Dehong Dai Nationality Autonomous Prefecture is one of a number of ethnic “autonomous” regions established in China during the 1950s. The process of ethnic identification and categorization China undertook in the 1950s has been criticized by some social scientists, as has the practice of “autonomy.” For more on such regions including Dehong, see Stevan Harrell, ed., *Cultural Encounters on China’s Ethnic Frontiers* (Seattle: University of Washington, 1995).

46 Such testing was likely to have been conducted at forced detoxification centers.

Official statistics in China suggest that drug use is the dominant transmission route for HIV, with “most reports of new HIV infections (66.5%) related to the sharing of needles among injection drug users.”\footnote{UNAIDS, *HIV/AIDS: China’s Titanic Peril*, June 2002, p. 14. More recent government statements have estimated that the majority of all new HIV infections in China are a result of needle-sharing among injection drug users [China CCM, 2002 *Proposal to The Global Fund*, July 2002, “HIV/AIDS Situational Analysis in China” (attachment 4), p. 5]. Given Beijing’s continuing efforts to minimize the role of state-run and licensed blood collection centers in spreading HIV throughout central China and to minimize the extent of the catastrophe in these regions, such estimates should be regarded with skepticism.} The highest prevalence rates have been reported in Yunnan, Xinjiang, Guangxi, and Sichuan, all western provinces that lie on the drug route.\footnote{World Health Organization, *HIV/AIDS in Asia and the Pacific Region 2001*, www.wpro.who.int/pdf/sti/aids2001/complete.pdf, retrieved May 13, 2003, p. 42.} UNAIDS reports “prevalence rates higher than 70 percent among injecting drug users in areas such as Yili Prefecture in Xinjiang and Ruili County in Yunnan.”\footnote{UNAIDS, *Report on the global HIV/AIDS epidemic 2002*, July 2002, http://www.unaids.org/barcelona/presskit/report.html, retrieved September 10, 2002.} These statistics reflect the seriousness of the epidemic in these areas.

The third phase of the epidemic, from the late 1990s to the present, has three defining characteristics. First the disease increasingly affects the general population and not just populations traditionally perceived as high-risk, meaning that it can no longer be wished away as affecting only “others,” such as foreigners, ethnic minorities, or drug users. Second is the continuously unfolding blood scandal centered in Henan that has affected untold numbers of persons (see section G below for more on the blood scandal). Third, and perhaps most important, are the first signs that the national government is beginning to understand the severity of the epidemic and the imperative of action (see below). The first nationwide conferences on the subject have now been held, public education programs have been initiated, and the Chinese media now speaks relatively frequently on the subject. However, the government has still not addressed a myriad of problems, ranging from discrimination and the lack of patient confidentiality to the rights to form advocacy groups and gain access to treatment. Journalists and activists often do not know whether what they say and do will find favor—or land them in prison.

**China’s HIV/AIDS policy in the past five years**

In the past five years, China has begun to engage actively in legal and policy reform pertaining to HIV/AIDS. The first move by the State Council\footnote{The State Council (guowuyuan) is the highest administrative organ in China. It is directed by the premier, currently Wen Jiabao, and includes vice-premiers, state councillors, ministers in charge of ministries and commissions, the auditor-general and the secretary-general. The State Council directs and makes policy for the ministries under its authority. For more information, see *Facts and Figures: Structure of the State*, Foreign Language Press (Beijing: 1987).} was to craft two national strategic plans on the epidemic: the *Chinese National Medium- and Long-term Strategic Plan for HIV/AIDS Prevention and Control (1998-2010)*, and the *China Action Plan for Stopping and Controlling AIDS (2001-2005)*.

The goals of the first strategic plan were ambitious. They included such benchmarks as mandating that by 2002 HIV transmission through blood collection would be eliminated,\footnote{State Council, *China’s National Medium and Long-term Strategic Plan for HIV/AIDS Prevention and Control (1998-2010)*, State Council Document GF (1998) 38, November 12, 1998, English translation, p. 6.} that 85 percent of all health care professionals would receive training on STDs, and that “85% of the medical institutions at county or prefectural level and above would be capable of providing standardized diagnosis, treatment, and counseling.”\footnote{State Council, *China’s Medium and Long-term Strategic Plan*, p. 8.}

China has made some progress toward some of these goals, including pilot projects on HIV/AIDS education and prevention and reform and attempts to standardize the screening of blood. Others remain a distant dream; for instance, standardized training, treatment, and HIV/AIDS counseling are still undeveloped in most impoverished rural regions on the front lines of the epidemic. Funding remains insufficient, the health care infrastructure remains weak, and there is no national agency with the authority to enforce these recommendations.

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48 UNAIDS, *HIV/AIDS: China’s Titanic Peril*, June 2002, p. 14. More recent government statements have estimated that the majority of all new HIV infections in China are a result of needle-sharing among injection drug users [China CCM, 2002 *Proposal to The Global Fund*, July 2002, “HIV/AIDS Situational Analysis in China” (attachment 4), p. 5]. Given Beijing’s continuing efforts to minimize the role of state-run and licensed blood collection centers in spreading HIV throughout central China and to minimize the extent of the catastrophe in these regions, such estimates should be regarded with skepticism.


51 The State Council (guowuyuan) is the highest administrative organ in China. It is directed by the premier, currently Wen Jiabao, and includes vice-premiers, state councillors, ministers in charge of ministries and commissions, the auditor-general and the secretary-general. The State Council directs and makes policy for the ministries under its authority. For more information, see *Facts and Figures: Structure of the State*, Foreign Language Press (Beijing: 1987).


In other cases, the plan has not been implemented because it came into conflict with longstanding state practices that restrict civil rights. The first strategic plan made some important recommendations for the lifting of restrictions on civil society to permit this sector to grow from the grass roots:

All social bodies, voluntary organizations and the community should be mobilized and actively involved in HIV/AIDS prevention and control and they should be encouraged and supported to provide home-based care and psychological counseling service for people living with AIDS, and health education among high-risk populations. Insofar as possible, these organizations should be assisted in offering support to help HIV infected individuals and people living with AIDS and their families.54

Despite these recommendations by the State Council, implementation of these recommendations is under the control of local Communist Party authorities and police bureaus, who generally are reluctant to permit the expansion of civil society for fear that it will increase public scrutiny of officials, expose corruption, lead to increased demands on government, and perhaps even lead to civil unrest. China’s national laws on the registration of NGOs and its restrictions on freedom of expression, information, assembly, and association create numerous obstacles to the growth and involvement of community groups in AIDS policy.

China’s second strategic plan, the *China Action Plan for Stopping and Controlling AIDS (2001-2005)* revisited the ambitious goals set by the first. Notably, the second plan addressed in strong language and in some detail the blood contamination scandal centered in Henan although, curiously, without ever referring to the province by name or holding its officials directly accountable. Noting that “some headway” had been made against the AIDS epidemic, the second strategic plan includes some strong language indicating growing frustration among Beijing policymakers with the sluggish response of local governments, cautioning that “some local government leaders are not fully aware of the potential risk of an enlarged HIV epidemic, and the social and economic impact on society in China. Implementation of the ‘Plan’ develops at different rates, and the coordinating capacity for comprehensive HIV/STDs prevention must be improved.”55 This is strong self-criticism in China, but to those in local administrations who read statements by the State Council as signs of the prevailing winds in Beijing, the absence of any clear references to Henan by the central government was a sign that there would be no accountability for that scandal or for cover-ups.

As with the earlier plan, the second action plan combined ambitious goals with vague implementation strategies. It revised some of the goals of the first plan: while the first plan stated that 85 percent of all health professionals should have short-term training on STDs by 2002, the second plan said that 100 percent of all health professionals should have HIV/AIDS education by 2005.57 Many provisions were laudable but vague: the plan recommends the installation of automatic condom vending machines without specifying numbers or locations of such machines, and advocates for promotion of the use of clean needles without specifics about how this should be done.58 In addition, the plan set out a series of new goals for the monitoring of blood supplies, expanding insurance coverage, and conducting AIDS research.

But the plan is also heavy on morality and exhortation, such as with the vague recommendation to “strengthen the construction of socialist spiritual civilization” by cracking down on drug use, an ill which the government implies grows out of China’s contact with the morally corrupting forces of global capitalism.59 The risk of such language

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54 Ibid., p. 10.
58 Ibid., Action measure 3.
59 Ibid., Action measure 3. The term “socialist spiritual civilization” was first used by President Deng Xiaoping during China’s economic reforms in the 1980s, to emphasize the importance of holding onto Maoist principles and values despite
is that it increases the social stigma attaching to drug users, driving them underground, and making it difficult for state services to provide testing, treatment, and care to them.

While references are made in both plans to combating discrimination against people living with HIV/AIDS, there are no clear mechanisms for redress. While the second action plan recommends that the government increase and earmark special funding for AIDS programs, amounts are not specified and contributions by local governments are left to local discretion “according to the local need of HIV/AIDS prevention and control.” This undercuts the State Council’s explicitly stated concern about the sluggishness of local governments in tackling the AIDS epidemic.

In addition to the national strategic action plans, a number of laws and policies have been passed by the State Council which contradict both local laws and international human rights standards. Some of these laws are holdovers from an earlier period where China’s understanding of the AIDS epidemic was less sophisticated than it is now. The national epidemics law categorizes HIV/AIDS as a class B infectious disease, grouping it with viral hepatitis, amoebic dysentery, and syphilis, among others. Persons diagnosed with a class B disease are to be isolated for treatment for a period to be determined by medical experts, and the police can be used to enforce isolation if patients refuse to cooperate or attempt to flee before the isolation period is finished. As discussed in more detail in section B on discrimination, forcible restraint and detention not only violate the right of victims, but contribute to the stigmatization of people living with HIV/AIDS.

Unfortunately, there is as yet no national law that prohibits discrimination against people living with HIV/AIDS. There are a number of policies that have strongly recommended against discrimination of persons living with HIV/AIDS, such as the Certain Number of Regulations and the Medium-term plan. However, there are no legal mechanisms for the enforcement of these national policies.

National laws on HIV/AIDS have been copied almost verbatim by some municipal and provincial governments into local regulations, though local regulations often include additional provisions or restrictions. Two pieces of local legislation, however, that could serve as partial models for legal reform in other parts of the country are antidiscrimination laws recently passed in the city of Suzhou and in Hong Kong. Suzhou's regulations include provisions that protect persons with HIV/AIDS from discrimination. Hong Kong's Disability Discrimination Ordinance, while enacted in a different political system than that of mainland China, includes a number of examples of positive, clear language, and mechanisms for enforcement that merit further study by policymakers in mainland China.

increasing contact with the morally corrupting effects of global capitalism. The term was again actively promoted by Deng’s successor Jiang Zemin during the 2002 Sixteenth Communist Party Congress. The revised Constitution of the Chinese Communist Party, passed during that Congress, urges members to “inspire the Party members and the people with the Party’s basic line, patriotism, community spirit and socialist ideology, enhance their sense of national dignity, and their spirit of self-confidence and self-reliance, imbue the Party members with the lofty ideals of communism, resist corrosion by decadent capitalist and feudal ideas, and wipe out all social evils, so that our people will have lofty ideals, moral integrity, a good education and a strong sense of discipline” (Constitution of the Communist Party of China, in the Documents of the 16th National Congress of the Communist Party of China, Foreign Language Press (Beijing), 2002; p. 82).

According to the law, “Class B infectious diseases include: viral hepatitis, bacillary and amoebic dysentery, typhoid fever and paratyphoid fever, AIDS, lymph disease, syphilis, poliomyelitis, urticaria, whooping cough, diphtheria, epidemic cerebrospinal meningitis [NB: the law does not specify which type], scarlet fever, epidemic hemorrhagic fever, rabies, leptospirosis, brucellosis, anthrax, epidemic and endemic typhus, epidemic encephalitis B, black fever, malaria, dengue fever.” Zhonghua renmin gongheguo chuanranbing fangzhi fa [Law on the Prevention and Treatment of Infectious Diseases], ratified by the sixth meeting of the seventeenth people’s congress, Feb. 21, 1989, for implementation September 1, 1989, article 3.

Chuanranbing fangzhi fa [Law on the Prevention of Infectious Diseases], article 24 (1).

Certain number of regulations,article 21; and the Medium-term plan (1998-2010).
In 2002 Tsinghua University policy consultants in Beijing held a number of conferences to discuss possible policy changes on HIV/AIDS, and the United Nations funded a report on legal reform on HIV/AIDS issues by a prominent Chinese scholar. Senior Chinese economists are beginning to advocate for the reform of China’s public health system, noting the likely impact of the dysfunctional system on the country’s developing economy. Chinese scholars began to publicly endorse human rights protections in the AIDS epidemic; Beijing University Health Law professor Wang Yue recently noted in a government controlled newspaper, “It is an international trend to protect the human rights of people with AIDS and other sexually transmitted diseases.” The report was not published, and legal changes on the national level have yet to be implemented. International donors and NGOs, which have become an increasingly important force in China’s response to HIV/AIDS, could lobby for these changes to take place and for further human rights protections as part of their agreements with Chinese partners.

Many who work on AIDS in and outside of China believe that the past three years have shown the first real signs of commitment by Chinese authorities to fight the disease. But even optimists recognize that the government continues to send contradictory signals, calling into question its commitment. For instance, the growing number of international projects on AIDS in China, while indicating increasing openness on the subject, has not been matched by national funding and commitment to AIDS projects.

In the late 1990s-early 2000s, China began to collaborate with international programs on AIDS education and prevention. Many of these situated their offices in Yunnan province, a mountainous and ethnically diverse region known for attracting Chinese and international visitors for its combination of temperate weather and a developing sex tourism industry. Gambling parlors, the illegal market in Burmese gems, eroticized ethnic song and dance revues staged in hotels and restaurants, and sex tourism, have been key motors of development in these border towns. In 2000 a U.S. embassy report estimated that people living with HIV/AIDS in Yunnan, “largely intravenous drug users, [account] for fifty percent of all reported Chinese HIV infections.”

Since the beginning of the AIDS epidemic, Yunnan’s government has had a reputation for being relatively open in its willingness to confront the problem. The bulk of Yunnan’s paltry RMB 3 million (U.S.$362,437) allocated for AIDS education and care came from the provincial government in 2000. Yunnan is also unique in its success in attracting and cooperating with international NGOs on AIDS. As of 2002 an unusually large number of NGOs and agencies had offices in Yunnan working on HIV/AIDS: the Australian Red Cross, the Salvation Army, Daytop Village, Save the Children-UK, and Futures Group Europe. The Australian Red Cross, Salvation Army, and Yunnan Red Cross also jointly opened the country’s first AIDS information and counseling center, Home AIDS, in Kunming in 2002.

Most Chinese and international NGO workers interviewed for this report stated that Yunnan’s government was the most open in China to confronting AIDS. A number of the international NGOs that began pilot projects in Yunnan have begun expanding these to neighboring provinces.

68 Ibid.
69 Other agencies such as UNICEF and Health Unlimited did not have official offices in Yunnan but supported AIDS education programs in ethnic minority regions of the province. See http://unicef.org/eapro-hivaidscountries/China.htm, and www.healthunlimited.org/china/index.htm for more information.
However, while Yunnan is relatively open to assistance and discussing the problem, some officials continue to adopt a policy of denial. For example, in Dehong an internal memo circulated among prefectural officials forbade them to speak of AIDS with “outsiders” to avoid negative impacts on Dehong’s booming tourism industry.\textsuperscript{70} A U.S. Embassy report notes that, “In this case ‘outsiders’ were not limited to foreigners, but included Chinese officials and media from outside of Dehong prefecture as well.”\textsuperscript{71}

Ministry of Health officials in Beijing have expressed frustration with the intransigence of some provincial and local authorities. Zheng Xiwen of the national AIDS Prevention and Control Center wrote that:

Some government leaders do not understand the potential for the further spread of HIV and its consequences for China. A minority of leaders conceals the true situation and block measures to prevent HIV. Investment in HIV prevention is inadequate.\textsuperscript{72}

In November 2001 central authorities began to make some efforts to change the national approach to HIV/AIDS when China held its first major AIDS conference. The four-day conference featured an official pop song (“Red Silk Ribbon”), a new logo (a smiling condom with sunglasses), and a dimly-lit testimonial by an AIDS patient thanking the Chinese Communist Party and the Chinese government for their efforts to combat AIDS.\textsuperscript{73} The meeting also brought together international experts with Chinese experts and policymakers.

In 2001 the State Council established an AIDS/STD Control Coordinating Committee to implement its national action plans.\textsuperscript{74}

In conjunction with its conference in Barcelona in 2002, UNAIDS released a report on AIDS in China that succeeded in drawing international attention to the issue. The report pointed to a number of factors in China that could lead to an explosion in the infection rate in the near future if the government did not act quickly.\textsuperscript{75} Soon after, Zhang Yishan, Deputy Permanent Representative of China to the U.N. General Assembly, responded by calling for international assistance in China’s plans to combat the AIDS epidemic:

As a country with a huge population, China faces special difficulties in preventing and controlling HIV/AIDS. We would like to continue our cooperation with the countries and international agencies concerned in such areas as financing, developing prevention and treatment projects, lowering drug prices and further leveraging the advantage of traditional Chinese medicine in treatment in a bid to contribute to the fight against the epidemic in China and around the globe.\textsuperscript{76}

“World AIDS Day” on December 1, 2002, was the occasion for some of China’s most widespread and open media discussions of HIV/AIDS. In the weeks leading up to and following World AIDS Day many provincial newspapers, especially in hard-hit regions, published articles on AIDS, stressing stories where people living with HIV/AIDS were enjoying basic civil rights, such as the right to marry.\textsuperscript{77} State-owned and international press

\textsuperscript{71} U.S. Embassy, “AIDS in China: Yunnan Province Confronts HIV”.
\textsuperscript{74} CCM, \textit{2003 Proposal to the Global Fund}, June 2003, p. 15.
\textsuperscript{77} For instance, in Yunnan: “\textit{Kunmingren guanzhu Aizibing}” [Kunming residents pay attention to AIDS], (Kunming, \textit{Dushibiao}), December 2, 2002; “\textit{Wanren qianming yufang Aizibing}” [10,000 people sign petition on AIDS prevention],
announced the marriage of an HIV-positive couple. The event sparked a national debate, with the Ministry of Health weighing in favor of the right of people with HIV/AIDS to marry. “Waking Up,” China’s first play about HIV/AIDS, opened in Beijing. According to the state-run People’s Daily, “The play not only introduces scientific knowledge about AIDS, urging young people to abstain from sex or practice safe sex, but also explores ethical and moral issues and how HIV/AIDS patients are treated, urging more understanding of their plight.” A number of government spokespeople emphasized the importance of HIV/AIDS prevention work.

A week after World AIDS Day, China’s national television network CCTV2 aired a half-hour program featuring an interview with Li Jiaming, the author of the first memoir published by a Chinese person living with HIV/AIDS, The Final Battle (Zui houde xuanzhan). His face shrouded in shadows, Li talked frankly about his personal experiences of shame and fear after his infection with HIV by a commercial sex worker, and his feelings of isolation and loneliness because he felt he could not reveal his status to his family and friends. At the end of the interview, his interviewer warmly and politely thanked Mr. Li for sharing his experiences with viewers.

All of these signs indicated increasing commitment to fighting the epidemic at higher echelons of the Chinese government. However, in stark contrast with official calls for international assistance in fighting the AIDS epidemic, in September 2002 Wan Yanhai, a former Ministry of Health official turned AIDS activist, was detained and interrogated for a month. Wan had been chosen to receive a joint award from the Canadian HIV/AIDS Legal Network and Human Rights Watch. The Chinese government said that the detention was in response to Wan’s “crime of leaking state secrets”: Wan circulated via electronic mail an internal government report acknowledging government responsibility for the Henan blood-selling scandal. After an international outcry, including protests by AIDS and human rights activists in front of the Chinese consulates in New York and Paris, Wan was released.

Poverty and China’s health care system

In the early days of the People’s Republic, the socialist government built a subsidized national health care system that made China a model for many parts of the world, especially in its unusually low infant mortality rates. In an earlier era, the Chinese state committed itself to creating an accessible and affordable health care system to rural peoples, encouraging city-trained doctors to dedicate themselves to improving the lives of peasants. Chairman Mao Zedong spoke often of the need for better rural health care. Between 1965 and 1997, China built
formidable health care system targeting rural areas with many renowned successes. Chinese experts assert that the country’s infant mortality rate dropped from 200/1,000 live births to 32/1,000, and that average life expectancy increased from 35 to 71.\(^{86}\)

In the period of economic liberalization that began in the 1980s, this system was almost completely dismantled, resulting in the privatization of most services, tests, and treatments.

China’s response to public health crises such as the SARS and AIDS epidemics has been hampered by the weakened state of its national health care system. As Dr. Daniel Chin of the World Health Organization observed in a radio report on SARS and tuberculosis:

> The public health program in China is in a shambles. It’s underfunded, understaffed, and basically the poor, which have the most to benefit from public health because they can’t afford many of the treatments, are being left out of the picture.\(^{87}\)

China’s most recent application to the Global Fund reports that catastrophic illness is one of the major causes of poverty in China, and adds “HIV infection can be assumed to be a significant element of the burden of catastrophic illness in the seven project provinces.”\(^ {88}\) The disease has disproportionately affected poor, rural regions.

The seven hard-hit provinces selected by China for Global Fund support are all regions “below national average in terms of income” where rural populations sold blood in order to supplement household incomes.\(^ {89}\) The Global Fund application acknowledges that the seven central provinces have also been severely affected by “increasing unemployment, increases in rural to urban migration, reducing rates of retention in schools and a dramatic decline in the rural health care system” and the spread of HIV/AIDS has exacerbated the situation such that “poor households, through poverty, weak infrastructure and rural health system decline, are unable to access quality treatment and care, or information to prevent the further spread of HIV.”\(^ {90}\) While rural residents make up seventy percent of the country’s population, urban regions receive a disproportionate percentage of China’s total health care budget.\(^ {91}\)

The lack of funding for public health has meant that hospitals in impoverished rural regions pass many of their expenses on to patients, who do not have the means to pay for necessary services or drugs. Moreover, according to the Global Fund application, “The costs of care also mean that households need to use various coping mechanisms, including borrowing money, selling off assets and changing plans. This results in a lack of support for the elderly of the household, as well as children…. [HIV/AIDS] also acts as a push for members of the community to migrate to find work, possibly leading to further spread of the [virus].”\(^ {92}\)

Moreover, and perhaps most worrisome, the absence of large-scale care, of pre- and post-test counselling, and of prevention programs in these regions means that many people living with HIV/AIDS in central China are probably unknowing transmitters of the virus to spouses, infants, and others.


\(^{89}\) Ibid., p. 16.

\(^{90}\) Ibid., p. 17.


International law and the right to the highest attainable standard of health

China is a state party to the International Covenant on Economic, Social and Cultural Rights (ICESCR). Article 12 of the ICESCR provides that states parties “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” Necessary steps for achieving the full realization of the right to health include the “prevention, treatment and control” of epidemic and other diseases and the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.” China’s treatment of persons with HIV/AIDS must be considered within the obligations of the right to health.

Article 2 of the ICESCR requires that each state “undertakes to take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to the achieving progressively the full realization of [these] rights.” Because states have differing development and resources, the U.N. Committee on Economic, Social and Cultural Rights issued General Comment 14, which provides a framework through which the right to the highest attainable standard of health can be understood and given force.

General Comment 14 explains that the right to health is not understood as a “right to be healthy,” but rather as “the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health” such that all citizens are able to access comparable health facilities. It stipulates that the right to health includes guarantees of non-discrimination in access to health facilities and services and proscribes discrimination “on the grounds of race, colour, sex ... [or] health status (including HIV/AIDS).”

According to General Comment 14, the right to health must be progressively realized as economic and other conditions permit: “Such steps must be deliberate, concrete and targeted towards the full realization of the right to health.” Further, “progressive realization means that States parties have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of article 12.”

Such rights are also deemed to have a minimum core content, which in all cases the state must guarantee. According to paragraph 43 of General Comment 14, these core obligations include the provision of access to health facilities, the provision of essential drugs in accordance with World Health Organization (WHO) guidelines, and the implementation of national action plans with clear benchmarks and deadlines. Paragraph 44 also

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95 CESCR General Comment No. 14, paragraph 8 (emphasis in the original).

96 CESCR General Comment No. 14, paragraph 18.

97 CESCR General Comment No. 14, paragraph 30.

98 CESCR General Comment No. 14, paragraph 31.

99 CESCR General Comment No. 14, paragraphs 43-45.

100 CESCR General Comment No. 14, paragraph 43, states that states parties to the ICESCR are obligated:

(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; …

(d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;

(e) To ensure equitable distribution of all health facilities, goods and services;
specifies obligations to ensure reproductive health care, to take measures to prevent epidemics, to provide access to information about health problems, and to provide training for health personnel.\textsuperscript{101}

In the case of epidemics and public health emergencies, the General Comment specifies the “right to prevention, treatment and control of diseases” and states that this includes “the creation of a system of urgent medical care in cases of accidents, epidemics, and similar health hazards.”\textsuperscript{102} In ratifying the ICESCR, China undertook to establish systems that would provide health care to all in epidemics, including HIV/AIDS.

States should also be guided in their response to the AIDS epidemic by international guidelines and recommendations crafted by the United Nations. In 1996, UNAIDS and the U.N. High Commissioner for Human Rights created “The U.N. HIV/AIDS and Human Rights International Guidelines,” a set of guidelines outlining human rights recommendations for the fight against AIDS.\textsuperscript{103} These guidelines were endorsed by the U.N. Commission on Human Rights in 1997, of which China was a member.\textsuperscript{104}

The guidelines do not have the force of law, but reflect international experience with the AIDS epidemic and the role that basic human rights protections play in fighting AIDS. The twelve guidelines include recommendations for community participation in policy design, the reform of national public health laws to make them applicable to the AIDS epidemic, the strengthening of antidiscrimination laws to protect people with HIV and those in high-risk groups, the regulation of goods and services, the reform of criminal and correctional systems to ensure that they are not used to target high-risk groups, and the implementation of legal support services for people with HIV/AIDS.

In addition, the guidelines recommend the creation of enforcement and monitoring mechanisms “to guarantee the protection of HIV-related human rights,”\textsuperscript{105} and call on states, relevant programs, and agencies of the United Nations to assist in and ensure that these mechanisms are created. In 2002 the U.N. guidelines were revised to include recommendations that states guarantee access to anti-retroviral treatment.\textsuperscript{106}

\begin{itemize}
  \item [(f)] To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.
\end{itemize}

\textsuperscript{101} Paragraph 44 of CESCR General Comment No. 14 states that these obligations are of comparable priority to those in paragraph 43:

- (a) To ensure reproductive, maternal (pre-natal as well as post-natal) and child health care;…
- (c) To take measures to prevent, treat and control epidemic and endemic diseases;
- (d) To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;
- (e) To provide appropriate training for health personnel, including education on health and human rights.

\textsuperscript{102} CESCR General Comment No. 14, “The right to the highest attainable standard of health,” paragraph 16.


China should ensure that its public health policies and laws, including provincial and municipal regulations, are consistent with these guidelines, and should seek technical assistance from the U.N. and others with expertise in these subjects in order to implement them.

**Social stigma**

Chinese society is made up of many overlapping and powerful social networks, and the stigma associated with HIV/AIDS can be extremely isolating for persons living with the disease. Informal social connections, or *guanxi*, including extended family networks, networks of former schoolmates, and networks of fellow natives of the same village, are reinforced through exchanges of gifts and favors. *Guanxi* undergird a variety of public and private transactions in daily life and are an important factor in daily life. The economy of favors and indebtedness facilitates the individual’s access to employment, education, health care, investment capital, and many state services. It is usual for adults to continue to live with the extended family until they marry, and sometimes after marriage, enabling family members to share household costs, childcare responsibilities, and financial capital.

However, due to the tremendous stigma and shame surrounding HIV/AIDS, many HIV-positive persons find themselves rejected by their families or decide to leave home in order to hide the truth from family and friends. Some leave home not to protect themselves, but to protect their parents from stigmatization by the larger community. This marginalization in a densely-networked society like China launches AIDS sufferers into extreme social and psychological isolation at a time when they need support the most, and even curtails their ability to access employment, housing, and state services.

Partly because of the national failure to educate Chinese citizens about HIV/AIDS in the 1980s and 1990s, misunderstandings and ignorance about the disease are common (as they have been in many parts of the world where public education has been lacking or the government has failed to take the lead in insisting on nondiscrimination). A survey in January 2003 found that 17 percent of Chinese citizens had never heard of HIV/AIDS. 77 percent did not know that transmission could be prevented through the use of condoms. Many thought HIV could be transmitted through casual contact: 75 percent of those surveyed in four major cities said they would avoid a person who they knew had AIDS, and 88 percent of those surveyed in a rural region of Sichuan province said they would prefer that people living with HIV/AIDS not have interactions with other people. Some 63 percent of respondents in a Sichuan province study “had no clear understanding of differences between HIV and sexually transmitted diseases.” Such attitudes are prevalent even among China’s small educated elite: the *Beijing Morning Post* reported that a survey of Chinese university students found that more than half would refuse to eat a meal with an HIV-positive person.

Such taboos extend to the subject of sex itself and create obstacles for HIV/AIDS education programs. In 2002 the Guangdong Federation of Trade Unions distributed one million condoms to female migrant workers in the province, and was “blasted” by workers: “The move is an insult to migrant workers like us because by...
[distributing condoms] they are suggesting that we have a lot of casual sex,” said one female worker. She added, “Why don't they also tell the media that Guangdong people, both men and women, from all occupations, must also protect themselves?”

Persons living with HIV/AIDS in China and NGO workers told Human Rights Watch of personal experiences of stigmatization and rejection by families, friends, and coworkers. According to Han, a Chinese NGO worker, if a person is known to be HIV-positive:

Your family won’t eat with you, they give you food to eat apart from them, and they won’t have contact with you. Your friends ignore you. They are afraid of getting it from casual contact. If you pass them a cigarette, they won’t accept it.

In one case, a young woman in her twenties of Dalian was apparently killed by her father when he learned that she had HIV/AIDS. Her father, distraught because his other daughter was already seriously ill and the family had pinned their hopes on the success of this younger daughter, allegedly struck her in the head and killed her.

Families that do not reject their HIV-positive members may suffer stigma themselves. Some rural villages shun families when one family member is known to be HIV-positive, for instance by banning an uninfected relative from using the village bathhouse. In a Western news account, a person with HIV/AIDS described the experience of a family he knew whose daughter died of AIDS: “After her death, her family was not able to lead a normal life. People would not talk to them or contact them, out of fear. The shops refused to sell to them. Instead, overnight, the shopkeepers would leave what they wanted at their door, secretly.” A few interviewees told Human Rights Watch that in areas of Yunnan and Henan where HIV/AIDS is extremely common, villages may rally around and support sick neighbors. However, most interviewees agreed that this was an exceptional response in China.

Because of the fear of stigma and discrimination, it is common for people with HIV to hide their status from even close family members. “I don’t dare to tell my family,” said Ji, an HIV-positive former drug user from a rural town in Yunnan. Author Li Jiaming writes that he moved to another city in order to protect his family from the knowledge that he was HIV-positive:

Giving my mom a telephone call is a challenge every time. Before I pick up the telephone, I always practice a few times: ‘Hi, Mom, it’s me! Hi, Mom, it’s me!’ I do this until I think my voice sounds steady, and only then do I dial the number.

In Hong Kong, where discrimination appears to be less severe than in China, many HIV-positive persons remain closeted. “Most people are not willing to disclose their identity,” says Alice Chan, CEO of Hong Kong’s Society for AIDS Care. “Some patients request that the Society for AIDS Care not disclose their identity to their closest relatives, and Society for AIDS Care policy is to respect that. When we visit someone at home, we say we’re just a friend.”

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113 Human Rights Watch interview with Han, Kunming, Yunnan, 2002.
114 Zhao Anping, “Nu azibing huanzhe bei sha diaocha pilu xian wei ren zhi gushi,” Jiankang Shibao [Health Times], December 27, 2002.
117 Human Rights Watch interview with Ai, Jinghong, Yunnan, 2002; interview with Cao, Yunnan, 2002; interview with Tao, Yunnan, 2002.
118 Human Rights Watch interview with Ji, Kunming, Yunnan, 2002.
119 Li Jiaming, Zuihoude Xuanzhan [The Final Battle], (Tianjin: Tianjin Renmin chubanshe), p. 21.
120 Human Rights Watch interview with Alice Chan, Hong Kong, 2003.
Stigma creates an environment harmful to the prevention of the spread of HIV. At a time of extreme stress, people with HIV/AIDS are marginalized and driven underground, afraid to seek help or to participate in programs that might reveal their status to others. As Zhang, an AIDS activist in Beijing, put it:

> People who are HIV-positive need emotional support. Many people, when they find out they are HIV positive, suffer very much and are very sad. They have many needs—psychological, medical and legal—but many people just stay at home for years and years.\(^\text{121}\)

**Doubly Disadvantaged**

Drug users, particularly those perceived to be infect with HIV, may be doubly vulnerable to isolation and ostracism. NGO workers interviewed by Human Rights Watch noted that because of the social problems inflicted by drugs on rural communities, drug users are even more likely than people with HIV/AIDS to be forcibly expelled from their home towns.\(^\text{122}\) In June 2003 the plight of drug users in southwest China received international attention when a three-year-old girl starved to death in Chengdu after her mother, a drug user, was arrested by police. Though the mother asked police to contact the child’s aunt, the police failed to do so, and the child was left locked at home without food for eighteen days.\(^\text{123}\) After a national outcry about the incident, some police were punished.

Because of widespread discrimination against women in China, women lack equal access to health services and to education, and are likely to face difficulties in negotiating safer sex with HIV-positive male partners.\(^\text{124}\) Sex workers are also highly vulnerable for the same reasons, and are vulnerable to compulsory detention in reeducation centers and to police abuse.\(^\text{125}\) Rarely do HIV/AIDS education and prevention projects in China reach out to men who have sex with men, another group of stigmatized and marginalized Chinese citizens who are vulnerable in the epidemic.

In 2002 the Chinese Ministry of Health and national and local media and schools joined the U.N.-sponsored global “Live and Let Live” media campaign to promote acceptance of persons living with HIV/AIDS. All U.N. member states participated, so it is unclear what level of commitment China has to this kind of public education. This campaign may help to address some of the stigma described here, but as Zhang observes, other forms of support, including access to treatment, services and legal protections, are also needed.

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\(^{121}\) Human Rights Watch interview with Zhang, Beijing, 2002.

\(^{122}\) Human Rights Watch interview with Wu, Kunming, Yunnan, 2002; Human Rights Watch interview with Cao, Kunming, Yunnan, 2002.


Kong is a neatly dressed, soft-spoken man in his late thirties, with deep lines in his face and a warm smile. He is a painter, and his abstract works are jumbles of bright-colored elongated figures, grimacing demons, and laughing babies that seem to spill over the edges of the wooden frame. “This one is called ‘Paths and Roads’,” he says, pointing to one. “Some I have traveled on, and others I haven't been down yet.” He chain-smokes while he slowly talks, pausing to exhale and think between sentences.

I began to do AIDS work as a volunteer in my hometown, just because I was interested. One day I had this big idea, I thought it was a really good idea: why not start a home for AIDS patients? These people are often discriminated against, especially if they are drug users. They can't find any kind of work. Because their friends and family reject them, they can't buy medication, they have no income. Many people have died in front of me, and no one else dared to care for them or help them. I set up a home, and found a small piece of land so they could grow some vegetables, raise some animals, and taught them to make crafts, such as clothes, to sell in a store. About ten AIDS patients participated.

I applied for funding from an international foundation, and I got the grant, and asked the local government to support [the project]. In the beginning they agreed. But after I had already set the place up, the money still hadn't come, and I didn't know where it went. The foundation gave the money to the [local] health bureau, and they just kept the funds. The health bureau gave us a few thousand yuan for rent, but the rest of the money never came. When I asked at the health bureau, they said, “We don't need you to manage this, we'll take care of it ourselves.” But they never did anything.

Because I was trying to raise funding, I did some reports about this work, including a VCD\(^\text{127}\) that explained what I was doing and why it was important to help AIDS patients. Thus my identity became public. This had a major effect on me. My mother, father, elder and younger sisters, and friends all feared me. They wouldn't eat with me. They took my clothes and belongings and threw them out the front door.

No one dared to help me. In my own town, everyone knew who I was. I became a living symbol of AIDS. When I went anywhere, it was as if AIDS came into that place because I brought it there. Even other infected people would not be seen with me, because if other people saw them with me they would guess that something was up.

I left that place, I was hurt and suffering. I moved up to Kunming, and I sought comfort in drugs.

After this interview, Kong returned to his hometown to visit his family over the Spring Festival holiday and disappeared. He was later reported to be in detention in his hometown on drug-related charges.

\(^{126}\) Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

\(^{127}\) Video cassette disk, a popular technology for watching videos in China and much of East and Southeast Asia that resembles a DVD.
IV. HUMAN RIGHTS AND HIV/AIDS IN CHINA

A. Violations of freedom of expression, information, association, and assembly

The rights to freedom of expression, association, and assembly are often described as core rights since they have proven to be fundamental to the exercise and realization of other rights. Without the ability to voice complaints, meet with others with similar interests or experiences, gain access to official information, and join together in peaceful assembly, it is often impossible to advocate for respect or the protection of other rights, such as the right to nondiscrimination or the right to the highest attainable standard of health.

International experience with the HIV/AIDS pandemic over the past two decades has shown that the ability to share and access information (central to freedom of expression) has been absolutely essential to respect for the rights of and improvements in treatment for those with the virus or disease as well as to any successful prevention program. Some of the most effective leadership in response to the crisis in many parts of the world has emerged from the ranks of people living with HIV/AIDS, their families, friends, and partners.

In China, each of these rights is regularly violated. At times the government has permitted media openness, criticism, and grass-roots organizing, but at other times it has arbitrarily censored information and clamped down on grass-roots organizations, demonstrations, and the speech of individuals. 128

One hopeful sign in recent years has been the degree to which Chinese media has increased its coverage of AIDS. As might be expected in a country with a state-controlled media, certain kinds of stories, such as those praising local government policies or programs, are always welcomed by the government. Increasingly, local papers cover positive news stories in which people living with HIV/AIDS exercise basic rights, as in the case of the HIV-positive woman who was married in Beijing.129 Local newspapers have also reported the success of AIDS information campaigns and events organized to mark World AIDS Day.130

The rapid growth of the Internet in China has been a boon to many people with HIV, who can now gather hard-to-find information on the epidemic and connect anonymously with a broader community. One such website first posted author Li Jiaming’s widely read essays about his experiences living with HIV. These were later published in the book The Final Battle,131 and Li Jiaming himself appeared on state television several times in the weeks prior to and following World AIDS Day 2002.

The website and electronic newsletter produced by Aizhi Action have become important resources for information about Henan, and about the rights of people with HIV/AIDS. Some Internet information about AIDS has been censored: the Hong Kong NGO, AIDS Concern, which has provided technical support and training on AIDS projects in the mainland, reported that its site is sometimes blocked in China,132 and indeed it was found to be inaccessible at several computers in hotels and Internet cafes in Yunnan and Beijing that were tested during this research.

The Chinese government has a long history of censorship and restrictions on freedom of expression in the press, restrictions that often play out in apparently arbitrary ways. While there has been some relaxation in the reporting of AIDS stories, stories that could put national or local government in a bad light continue to be sporadically censored. Either because of direct censorship or self-censorship by editors and journalists, there was no media

128 Historically, the government has sometimes invited openness only to punish those who spoke out, as with the Cultural Revolution. See for instance Thomas Robinson, ed., The Cultural Revolution in China (Berkeley: University of California Press, 1971).
129 Song Raosong, “Aizinu zhaodao fangzi” [AIDS woman finds house], (Kunming: Yunnan Xinxi Bao), November 24, 2002.
130 “Sicheng Kunmingren zhixiao Aizibing” [Four cities and Kunming residents learn about AIDS], (Kunming, Dushishibao), December 2, 2002.
131 Li Jiaming, Zuihoude Xuanzhan [The Final Battle] (Tianjin: Tianjin renmin chuban she, 2003).
coverage prior to or after World AIDS Day of the Henan blood collection scandal—not even a single mention could be found. As Bates Gill, Jennifer Chang and Sarah Palmer note:

> Although there has been more official media coverage, the scandals of rural blood collection or the more general breakdown of China’s health care system are rarely mentioned. Some investigative reporting by the quasi-independent Nanfang Zhoumou [Southern Weekend] has revealed the abuses of blood collection schemes in Henan, but the newspaper’s publishers have been pressured by provincial authorities to cut back on their coverage.\(^{133}\)

The editors and journalists at Southern Weekend were fired by management in April 2001, in a move many perceived as tied to its lively and open reporting on Chinese social problems such as HIV/AIDS.\(^{134}\) Henan is a particularly sensitive subject, as AIDS activist Wan Yanhai writes:

> From 1995 on, after our national government became aware that a large number of those selling blood were becoming infected with the AIDS virus, the governmental attitude toward this was to be secretive or to speak only in whispers. Reporters and experts who tried to bring the truth to light were repressed.\(^{135}\)

With few exceptions, foreign media correspondents based in Beijing and Chinese reporters have not been allowed to go to Henan.\(^{136}\) China’s Foreign Minister has consistently refused permits for international media to travel to Henan. Two German journalists were detained and interrogated by police when they went to Henan without permits.\(^{137}\) Two reporters from the state-controlled television station China Central Television were arrested after filming in a Henan village, and a Beijing student, Li Dan, who filmed a documentary in Henan, was interrogated by police.\(^{138}\) Reporter Zhang Jicheng, who reported on the AIDS epidemic in Henan’s Wenlou village, was reportedly fired from his job at Henan Media as a result.\(^{139}\)

Many journalists know the limits of what can and cannot be said on a sensitive topic, but these limits also appear to change from one day to the next. Given the threat of arrest or censorship, and because inter-provincial rivalry for national and international investment creates intense pressure to portray the home province in a positive light, some local journalists writing negative stories about AIDS publish their articles in other provinces.

While China has been unapologetic about its use of censorship in the AIDS epidemic, it has several times asserted a commitment to involving civil society. Encouraged by this message, enterprising individuals have entered the vacuum left by the state to organize grassroots NGOs that offer health care and residential services for people living with HIV/AIDS, and some have gotten local support. For instance, in a rural region outside of Kunming city, with the support of county officials and the local center for disease control,\(^{140}\) a group of people living with HIV/AIDS has established a collective residence in an old factory building they call the Sunflower Community.\(^{141}\)

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\(^{133}\) Bates Gill, Jennifer Chang and Sarah Palmer, “China’s HIV Crisis,” Foreign Affairs, March/April 2002. Beijing-based Aizhi Action Project reports that Southern Weekend has also been criticized “frequently” by the Central Propaganda Department for its AIDS reporting. See Aizhi Action Health Education Institute, Aizhi Newsletter: Special Issue on Thanksgiving for HIV/AIDS Awareness (Beijing, November 22, 2002).


\(^{135}\) Wan Yanhai, “National secrets and AIDS transmission via blood-selling.”


\(^{137}\) Reporters Sans Frontieres, China: Foreign and Chinese journalists banned...


\(^{140}\) In Chinese, fanyizhan or anti-epidemic station; the term is now officially translated as “center for disease control.”

In Henan, a small group of people living with HIV/AIDS has established a community library on the epidemic.\(^{142}\) Other informal collective residences for people living with HIV/AIDS seem to be springing up spontaneously in several Chinese cities.\(^{143}\)

However, restrictions on the freedom of association and assembly, as well as reports of corruption, chill initiatives from civil society. Local NGOs and individual activists in Yunnan point out that any funds raised from international donors for their local projects must be routed first through a state agency, which skims some or all of the grant money before disbursing it to the grantee (see case of Kong above). One reported that he is now reluctant to spend time applying for international funding.\(^{144}\) In Henan, HIV-positive villagers have alleged that some donations for local clinics have been embezzled by local authorities.\(^{145}\) NGO workers and local activists in Yunnan agreed that such things were common, though they were afraid to share specifics for fear of jeopardizing programs. “I know this happens, but I can’t tell you specifics, because those are also programs that are doing some good,” said Alex Z., a foreign NGO worker.\(^{146}\)

The state has encouraged the establishment of some AIDS-related organizations and associations in China. Most are not NGOs, but GONGOs (government-organized NGOs), and subject to direct government control.\(^{147}\) Some GONGOs have slightly more latitude than others from their supervising government bureaus and may be able to manipulate a variety of public and private positions to negotiate space for AIDS education and prevention programs. But most must answer to—in many cases employees are paid directly by and even live in—a government work unit (danwei).

Other mixed entities exist: as the United Kingdom’s Department for International Development (DFID) notes, for purposes of international fundraising, “it is not uncommon to find the phenomenon of ‘one organisation, two signboards,’ where a government agency presents itself as both a government organisation and an NGO.”\(^{148}\) Even ostensibly independent nongovernmental and social organizations must be affiliated with and supervised by a government department (for social organizations, a yewu zhuguan danwei, or “professional leading unit”).\(^{149}\)

One exception occurred in 2002, when, partially in response to international pressure and encouragement, the government officially recognized the “Mangrove Support Group,” a semi-underground network of people living with HIV/AIDS. Once registered and willing to accept government restrictions, the Mangrove Support Group opened a small office in a back hallway of the Beijing You’an Hospital to do AIDS prevention, education, and capacity-building programs.\(^{150}\)

When NGOs attempt to reach out to high-risk populations, police in some areas have targeted individuals who participate in their programs. A methadone project in Leshan, Sichuan funded by the China-UK AIDS project attracted the attention of the police, who staged a raid and arrested injection drug users who participated in the program.\(^{151}\) Similarly, an HIV prevention project targeting commercial sex workers (CSWs) in another region resulted in a police crackdown on the sex workers: “Subsequently the CSWs were dispersed and went

142 Aizhi Action Health Education Institute, *Aizhi Newsletter: Special Issue on Thanksgiving for China HIV/AIDS Awareness* (Beijing, November 22, 2002).
144 Human Rights Watch interview with Yu, Yunnan, 2002.
146 Human Rights Watch interview with Alex Z. in Kunming, Yunnan, 2002.
147 For more on Chinese NGOs and GONGOs, see China Development Brief, www.chinadevelopmentbrief.com. Material on the website includes translations of some of the NGO registration laws.
150 Human Rights Watch correspondence with Marina S., NGO worker, October 2002.
underground, and the effort invested by project staff in establishing contact and gaining the trust of these CSWs in this area was wasted.” 152 Though they are an officially registered organization, volunteers from Aizhi Action in Beijing report that in some areas of Henan they have sometimes been harassed or prevented from meeting with HIV-positive people. 153

HIV-infected farmers in Henan have organized a number of protests targeting government offices, calling for accountability for the blood collection scandal and demanding treatment. At times local authorities have met with demonstrators; at other times they have responded with repressive measures. When Henan villagers attempted to meet with county officials to request help for AIDS-stricken families in March 2001, three leaders were detained. 154 In November 2001 four demonstrators were confirmed by local authorities in Henan’s Shangcai county to have been arrested for protesting. 155 A month later, Sui county officials reportedly detained farmers with AIDS, as well as Chinese journalists who had come to interview them. “To them we are like bubbles,” commented one protestor. “They know if they turn away and ignore us, we will soon pop and be gone.” 156

At about the same time, a protest of several hundred villagers in Henan reportedly arose in response to the local government’s detention of a CCTV (China Central Television) camera crew trying to cover the epidemic. 157 In December 2001 finally beginning to despair of getting a response within the province, several groups of HIV-positive peasants traveled hundreds of miles to Beijing, carrying letters and petitions to the central government. 158 These pent-up frustrations erupted in another protest, when Henan protestors reportedly destroyed two official cars and held police officers for several hours. 159

In an effort to draw more attention to their plight and to call for government support and aid, in 2001 a group of Henan residents with HIV/AIDS went to Beijing in the hope of joining in the first national AIDS conference (mentioned above). “The meeting is open to the whole society because the fight against HIV/AIDS needs efforts from all people of the country,” said Dong Yongkun, secretary-general of the Chinese Association of STD/AIDS Prevention and Control. 160 In fact, people living with HIV/AIDS who traveled from Henan to Beijing to participate in the conference were not permitted to attend. 161

In May and June 2003, reports of protests and petitions by HIV-positive Henan protestors intensified, along with escalating accounts of arrests and abuse by police. In the worst reported incident in late June, hundreds of police raided Xiongqiao village after an unruly protest by HIV-positive villagers, smashing personal property, beating residents, and detaining thirteen. 162

Other prominent figures who have attempted to organize or advocate for the rights of people living with HIV/AIDS without the blessing of the state have faced harassment. Wan Yanhai was detained for a month. Retired doctor Gao Yaojie, who has been at the forefront of efforts to draw attention to the epidemic in Henan, was given an award by the national Ministry of Education but then not permitted by local authorities to go to Beijing to collect it. Gao says that local party officials have told her not to see journalists or draw more attention.

152 Lu and Attawell, Review of Primary Stakeholder Participation ..., p. 10.
to the Henan epidemic. Other activists report that her home is under surveillance by local police and advised Human Rights Watch against visiting her for this reason.

As a result of all these restrictions, AIDS activists in China have learned to be security-conscious and circumspect, speaking elliptically or in veiled terms about state responsibility and human rights violations related to AIDS. In some rural areas, activists conduct “underground, door-to-door campaigns among high-risk groups, passing out condoms and safe-sex booklets like Avon ladies.” The Chi Heng Foundation, based in Hong Kong, offers semi-underground AIDS education to male sex workers in Guangdong parks, brothels, and saunas. To the degree that such projects remain low-profile and non-confrontational, local governments permit them to continue. But any attempt to hold governments, especially the Henan government, accountable for either HIV transmission or the ensuing cover-up, is believed to be asking for trouble.

Such restrictions are beginning to hamper China’s ability to cooperate with international partners or to raise international funds. China’s application to the Global Fund for AIDS was refused in 2002. The committee that recommended not funding the proposal listed as a key weakness the failure to plan or develop community participation.

China’s obligations are clear. As a member of the United Nations, China has promised to abide by the Universal Declaration of Human Rights, proclaimed by the U.N. General Assembly in 1948, which protects rights to free expression, assembly, and association. The provisions of the Universal Declaration are widely accepted as customary international law. China is a signatory to the International Covenant on Civil and Political Rights (ICCPR), which also provides for states to respect free expression, assembly, and association. Article 19 of the ICCPR stipulates the right to hold opinions, and to freedom of expression, a right that “shall include freedom to seek, receive and impart information and ideas of all kinds.” Article 21 of the ICCPR guarantees the right to peaceful assembly. Article 22 guarantees the right to freedom of association with others.

The U.N. “HIV/AIDS and Human Rights International Guidelines” endorse “community participation” as a means of addressing HIV/AIDS. According to the guidelines, “States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.” The same language appears in guideline 2 of the Commission on Human Rights resolution 1997/33, “The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS).”

163 Gao Yaojie, “My AIDS prevention journey.”
165 Chung To, presentation at Columbia University East Asian Institute, November 13, 2002.
169 International Covenant on Civil and Political Rights, article 19 (2).
170 International Covenant on Civil and Political Rights, article 21.
171 International Covenant on Civil and Political Rights, article 22 (1).
173 “States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.” Commission on Human Rights resolution 1997/33, “The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS)”, paragraph 2.
14 on article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) provides that “the participation of the population in all health-related decision-making at the community, national and international levels.”

Chinese NGO registration laws continue to limit the growth and activity of local NGOs. General Principle 3 of China’s Regulations for Registration and Management of Social Organizations requires that an organization have “more than 50 individual members or more than thirty institutional members or, if it has both individual and institutional members, a total of at least fifty.” As mentioned above, such organizations must be “led by” appropriate government departments. While article 1 of the regulations asserts Chinese citizens’ right to freedom of association, registration may be refused based on the purpose of the group: “If in the same administrative area there is already a social organization active in the same (xiangtong) or similar (xiangsi) area of work, there is no need for a new organization to be established.” This means that only one group is permitted in a specified geographic area; the group permitted is almost always controlled by local authorities. International human rights law allows for no such limitation on the numbers of permitted associations.

No specific Chinese legislation exists on the registration of international NGOs working on HIV/AIDS. Save the Children was the first to register in Yunnan, where it registered as a foreign enterprise through the Chamber of Industry and Commerce. However, as one international NGO observes, “New rules for NGOs are being prepared and there is a fear they may well mean tighter control than exists in the current legal vacuum.” Any unnecessary restrictions are likely to limit the growth of international assistance urgently needed in China’s fight against HIV/AIDS.

B. Discrimination against people living with HIV/AIDS

In December 2002 fifteen migrant workers were expelled from Liaoning province and sent back to their home in Jilin province because they were found to be HIV-positive. They were reportedly escorted to the airport by armed policemen to ensure that they left. This is one indication of the widespread problems with discrimination experienced by people living with HIV/AIDS in China.

Discrimination is prohibited by articles 2 and 26 of the ICCPR, which guarantees equal rights to all persons: “All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” At its fifty-third meeting in 1995, the U.N. Commission on Human Rights concluded that discrimination on the basis of AIDS or HIV status is prohibited in that it is covered by the term “or other status” in the ICCPR and other instruments.


176 Regulations for Registration and Management of Social Organizations, State Council order no. 250, article 1.

177 Regulations for Registration ..., article 13 (ii).


179 Human Rights Watch interview with Zhang, Beijing, 2002.

180 International Covenant on Civil and Political Rights, article 26.

People living with HIV/AIDS in China face a variety of types of discrimination in their daily lives. This section briefly explores discriminatory local legislation, discrimination in access to health care, in the granting of marriage permits, and discrimination by schools and residences.

Local legislation

In some regions of the country, discriminatory regulations have been enacted that effectively legalize discrimination by state and private actors against people living with HIV/AIDS. Regulations in Chengdu city and Jilin province forbid people with sexually transmitted diseases from using public swimming pools.\(^{182}\) A sign spotted in the pool and sauna area of an international hotel in Beijing also banned those with sexually transmitted illnesses.\(^{183}\)

Because early cases of HIV/AIDS were largely diagnosed among foreign visitors to China, many national and local laws on the prevention of HIV/AIDS revolve around the testing, detention, and expulsion of foreigners. For instance, the *Shanghai City Regulations on AIDS Prevention* require that all work units report persons suspected of being HIV-positive to the local Health department, “including foreigners, overseas Chinese, residents of Hong Kong Special Administrative Region, residents of the Macao region, and residents of the Taiwan region.”\(^{184}\) Those in the above categories who turn out to have HIV/AIDS must be reported to customs within twenty-four hours.\(^{185}\) According to national regulations, local health departments can recommend that the Public Security Bureau expel foreign residents with HIV/AIDS from the country.\(^{186}\)

Some HIV testing requirements are linked directly to discriminatory legal provisions. For instance, Shanghai requires that work units be notified of the identities of persons who test positive for HIV;\(^{187}\) while Liaoyang city's *Requirements for the Prevention and Management of Sexually Transmitted Diseases* requires that persons working in childcare, education, food service, hotel service, and others be tested for STDs. It adds: “Those patients with STDs who have not been cured are for this reason not permitted to continue to work.”\(^{188}\) While national policies, such as the *Certain Number of Regulations on the Supervision and Management of AIDS* and the *Methods for Management of Prevention of Sexually Transmitted Diseases* require health officials and others to preserve the confidentiality of those tested, local laws on testing conflict with and may take precedence in practice.

Health care

The attitude of [health care workers] can influence the spirit and mindset of an HIV-positive person for a very long time. I’ve heard of this before, it was an HIV-positive person who spoke of it. In their village, a person waiting for his HIV test results was given

\(^{182}\) *Chengdushi xingbing aizibing fangzhi guanli tiaoli* [Chengdu City Regulations for the Prevention and Management of STIs and AIDS], passed at 17\(^{th}\) meeting of the Chengdu City 13\(^{th}\) People’s Congress, October 27, 2000, ratified at the 12\(^{th}\) meeting of the Sichuan Congress, Nov. 30, 2000, and *Jilin sheng xingbing fangzhi guanli tiaoli* [Jilin province regulations for the prevention of sexually transmitted diseases], ratified at the eleventh meeting of the 7\(^{th}\) Jilin party congress, November 7, 1992, article 9.

\(^{183}\) Two signs posted in women’s showers, Peace Hotel, Beijing, 2002.

\(^{184}\) *Shanghai shi aizibing fangzhi banfa* [Shanghai City Methods of AIDS Prevention], Shanghai city people’s government document no. 64, Dec. 30, 1998, article 15 (“Targets of HIV testing”).

\(^{185}\) *Shanghai shi aizibing fangzhi banfa*, article 26.

\(^{186}\) *Aizibing jiance guanli de ruogan guiding* [Certain Number of Regulations on AIDS supervision and management], State Council, January 14, 1988, article 6.

\(^{187}\) *Shanghai shi aizibing fangzhi banfa*, article 19.

\(^{188}\) *Liaoyang shi xingbing fangzhi guanli tiaoli* [Liaoyang city requirements for the management of prevention of sexually transmitted diseases], ratified by the twenty-third meeting of the seventh Liaoyang province people’s congress, July 27, 1991; revised at the twenty-eighth meeting of the seventh Liaoyang province people’s congress, May 30, 1997; article 11.

\(^{189}\) *Certain number of regulations...*, article 21, and *Methods for Management of Prevention of Sexually Transmitted Diseases*, published by Ministry of Health, August 12, 1991, article 17.
A successful approach to containing the AIDS epidemic requires access to medical care for persons affected by AIDS. However, people living with HIV/AIDS and health care workers interviewed for this report in Yunnan and Beijing described discriminatory experiences in Chinese hospitals and clinics. Some reported being refused admission by health care workers based on their HIV status. In some cases the discrimination began after the patients tested positive for HIV without even knowing they had been tested, and without being counseled and officially notified of the test results. Reports and observation indicate that some hospitals have locked their HIV/AIDS wards and barred all persons living with HIV/AIDS from admission.

Ji explained to Human Rights Watch that he was refused admission to a hospital in Kunming because of his HIV status. Since this experience, Ji reports that he has telephoned several other hospitals in Kunming to see if they will accept him and has been refused:

I call up the hospitals first and tell them straight out that I’m positive. They won’t treat me.191

Alex Z., an NGO worker in Kunming, has heard of similar cases. In one case, a client was taken to a Kunming hospital after breaking her leg in a road accident.

The staff saw the track marks on her arm, gave her a mandatory HIV test, and then refused to treat her. They let her sit for a long time on the hospital bed with the bones sticking out her leg.192

Villagers living with HIV/AIDS in Suixian, Henan, have reported that “ignorant and fearful” staff at county hospitals and clinics have turned them away.193

Zhang, an AIDS activist in Beijing, said that many HIV-positive people he knows have been refused care based on their status.

If they are preparing to do surgery they test you, they can refuse you, and not tell you what the reason is. Many hospitals refuse to treat people, not just small hospitals but large ones as well. If you tell them you are positive they refuse you, and if you don’t tell them and they find out during a blood check, they will refuse you, and send you home to sit by yourself for years.194

These cases suggest discrimination by individual doctors, nurses, or administrators. In addition, some hospitals categorically refuse to accept any persons living with HIV/AIDS. A Human Rights Watch researcher visited a major hospital in Dehong Dai Autonomous Prefecture, historically the epicenter of the AIDS epidemic in China. As the entry point for much of China’s illegal narcotics trade, Dehong is one of the regions hit earliest and hardest by the HIV/AIDS epidemic.195 Employees at this hospital reported that those with full-blown AIDS were treated separately in the HIV/AIDS ward located at the rear of the hospital. However, they said, “No one is staying there right now.” The AIDS ward was locked up, with cots piled in the doorway and a locked chain barring the handles of the front door.196

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190 Li, Zuihoude xuanzhan, p. 177.
191 Human Rights Watch interview with Ji, Kunming, Yunnan, 2002.
192 Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.
194 Human Rights Watch interview with Zhang, Beijing, 2002.
196 Human Rights Watch visit to hospital in Dehong Dai Autonomous Prefecture, Yunnan, 2002.
International NGO workers who have visited numerous government hospitals in Yunnan report that this is common. One commented that she had been to many hospitals in Yunnan, but that because many hospitals closed their HIV/AIDS wards, “I have never once seen an HIV patient.”

A Chinese scholar with expertise on AIDS also confirmed that the locking of HIV/AIDS wards is “not unusual” because hospitals may fear that other paying patients will be “scared off” if they see people with HIV/AIDS going in and out. Strikingly, China’s 2003 proposal to the Global Fund openly admits to discrimination by state actors:

It is not uncommon that providers will turn away HIV/AIDS patients for fear that their facilities will be boycotted by other patients.

Given the stigmatization of HIV in China, a person with HIV/AIDS may only dare to confide his status to one person in his life: his doctor or nurse. A negative reaction by a health care worker can be especially devastating. On the other hand, where health care workers are sympathetic to the plight of AIDS patients, the doctor or nurse may take the place of absent family or friends, offering not just medical support, but also empathy and even companionship.

Some doctors and nurses have shown selfless dedication to their underserved clients. Author Li Jiaming writes of sharing meals with doctors and nurses in his hospital and of visiting the hospital just to chat with them. Newspapers and magazines sometimes feature articles praising such doctors, as with an article in China Today about Dr. Xu Lianzhi at Beijing’s You'an hospital, who said, “Patients consign their lives to us doctors, so our bounden duty is to help them. Any trace of loathing, reproach or discrimination will have a negative effect on the control of AIDS.” One health care worker interviewed in Yunnan said that when she retires from her fifty-year-long career, she plans to volunteer with AIDS patients.

The refusal of care by state hospitals and the closing and locking of HIV/AIDS wards is contrary to the right to nondiscrimination under article 2 of the ICESCR, which China has ratified, and of article 26 of the ICCPR. It also violates the right of everyone to the enjoyment of the highest attainable standard of health under article 12 of the ICESCR, which mandates that steps to be taken to guarantee that access “shall include those necessary for .... (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.” General Comment 14 to the ICESCR explains that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.” These grounds include “health status (including HIV/AIDS).

Guarantees of equal access to health care have been recognized by multilateral institutions as key to the fight against the AIDS epidemic. As will be discussed below, such measures, combined with educational efforts targeting healthcare workers, appear to have helped to minimize discrimination against people living with HIV/AIDS in Hong Kong. Where anti-epidemic stations, hospitals, and clinics on the mainland discriminate against patients on the basis of their HIV status, it is important that individuals and institutions be held accountable under local and national law, and that there be legal means by which individual patients can file complaints and seek redress for discrimination. Thus, the U.N. HIV/AIDS and Human Rights International Guidelines recommend that “government and the private sector develop codes of conduct regarding HIV/AIDS...
issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.”

Likewise, both documents use the same language in calling for states to “ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.”

**Marriage**

Chinese regulations that prohibit marriage on the basis of HIV status are in violation of the ICCPR’s provisions for nondiscrimination and the right to marriage. Article 23 of the ICCPR guarantees the right of “men and women of marriageable age to marry and to found a family.”

However, people living with HIV/AIDS who wish to marry may face national and local restrictions. The national Marriage Law prohibits marriage by “sufferers of diseases whom medical scholars consider should not marry.”

A recently revised version of the national Marriage Registration Regulations eases many restrictions on marriage permits including a mandatory health check-up. However, the revised regulations still refuse the right to a marriage permit for those infected with diseases “that medicine considers should not marry,” a vague provision that leaves the door open to abuse by discriminatory local authorities.

Using the language from the older national marriage law, local legislatures in a number of cities and provinces have enacted regulations forbidding the right to marry to people with sexually transmitted diseases including HIV. Having previously passed discriminatory legislation, in June 2003 authorities announced that Sichuan legislators were recommending changes to make marriage legal for people with HIV/AIDS. Several highly-publicized marriages of people living with HIV/AIDS in 2002 and 2003 indicated increasing official tolerance.

There have been some indications of a gradual shift toward revising these restrictive and discriminatory laws. A few provinces have permitted the registration of marriages between couples where one person was HIV-positive, as with the Guizhou antidiscrimination ordinance adopted on November 22, 2002.

On World AIDS Day, 2002, the national government invited a couple from Guizhou in which the woman was HIV-positive to Beijing for a public marriage ceremony, a move popularly seen as indication that policy changes could be underway. The news of the marriage was widely covered in Chinese popular press, although sometimes in ways that some Chinese AIDS activists described as stigmatizing.


207 International Covenant on Civil and Political Rights, article 23 (2).

208 Zhonghua renmin gongheguo hunyin fa [Marriage law], revised version ratified by the twenty-first conference of the Ninth National Party Congress, April 28, 2001, article 7 (2).

209 Hunyin dengji tiaoli [Marriage registration regulations], revised version passed by the sixteenth standing committee of the State Council on July 30, 2003, to be implemented October 1, 2003, article 6 (5).

210 See especially the marriage registration regulations for Zhejiang province, Xinjiang Uyghur autonomous prefecture, Tianjin city, and Shanghai city.


212 “Aizi nu lingdao jiehun zheng” [AIDS woman awarded marriage permit] (Kunming, Dushishibao, November 24, 2002). The article notes that the couple was warned by city government to take proper precautions to avoid transmitting the virus, and were told they “can even have their own child”.

213 Beijing’s Xinmin Weekly, in its November 25 to December 1 issue, featured a lurid cover with the banner: “I want to marry” (Wo yao jiehun), over a darkened photograph of a woman with a black stripe covering her eyes, bent over a man prostrate on a hospital bed with an IV tube going into his arm. AIDS activist Zhang objected to frequent references to the female partner as “AIDS woman” in this and other newspapers, and to the thinness of the black bars that are often used to cover the eyes of people living with HIV/AIDS in print photographs which, he said, made it relatively easy to recognize faces.
These individual cases are generally heartening, but they must be translated into legal reforms in local regulations.

**Treatment of minors**

Children are particularly vulnerable to both direct and indirect discrimination. Children who are HIV-positive or who have HIV-positive family members may be refused admission by schools. Song Pengfei, called “the Ryan White of China” by one American reporter, was infected with HIV at the age of sixteen after a blood transfusion during a botched surgical procedure at a hospital in Shanxi province. Song was expelled from his school in Shanxi, and neighboring residents demonstrated, called him and his parents offensive names, and hounded them out of their home town. The family now lives in a suburb of Beijing, and thanks in part to the considerable attention he has received from international media, Song is given antiretroviral treatment by an international foundation.

School fees pose a major barrier to children attending school in cases where a family member has HIV/AIDS, as the high cost of medical care makes it difficult for the family to afford the rising cost of school fees. In Henan’s Sui and Shangcai counties, tuition ranges from RMB 600-1000 (U.S.$75-120). National and local governments in China sometimes promise assistance for children affected by AIDS, but assistance is not always forthcoming in practice. In Henan’s Wenlou village, orphans were promised a tuition break but the program was discontinued after it received media coverage. In Yunnan, Cao described two children he knew who were orphaned by AIDS but have been unable to obtain long-promised government assistance to pay for school fees. Some children whose parents die of AIDS live alone because relatives are afraid to take them in. Many children affected by AIDS in Henan and Yunnan are forced to seek employment at an early age, in some cases as young as ten years old, in order to support ailing parents, younger siblings, and themselves.

In regions hardest hit by the epidemic, tens of thousands of children, if not more, may face catastrophic economic and social problems. A national survey estimates that 260,000 children may be orphaned by HIV/AIDS by 2010, though, as with other estimates, when the final total is tallied this estimate may prove to be low. Parents dying of AIDS who are unable to care for their children have in some cases decided to offer them up for adoption.

Two human rights instruments explicitly provide for the protection of children, especially of orphans, and for the right to freedom from discriminatory barriers to education. China has ratified the Convention on the Rights of the Child (CRC). Article 20 of the CRC ensures “special protection and assistance” for a child “temporarily or permanently deprived of his or her family environment.”

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215 Steve Friess, “AIDS in China: Voice of protest is heard, Authorities reluctantly face spread of disease,” USA Today, December 11, 2001. Ryan White was an American teenager who, as a hemophiliac, was infected with the AIDS virus during a botched surgery. White became a renowned AIDS activist and spokesperson against discrimination against people with HIV/AIDS. He died of complications related to AIDS in 1990 at the age of nineteen.
219 Human Rights Watch interview with Cao, Kunming, Yunnan, 2002.
221 Li Xiaorong, “AIDS orphans in China: Stigma, neglect, and opportunity for better care.”
permanently deprived of his or her family environment,” including “alternative care for such a child.” The CRC and the ICESCR also guarantee the right to education, and prohibit discrimination in access to education.

Townships and residences

People living with HIV/AIDS face the threat of eviction by their families or villages or, in cities, by their neighbors or landlords. Being forced from one’s home, a disaster in and of itself, can create a host of secondary problems. Freedom of movement is still not fully respected in China. One must obtain a household registration from local authorities to be a lawful resident in China. These are often refused, particularly in crowded urban areas, where many people with HIV/AIDS go to escape after they are forced out of their villages or towns by family members or landlords. This leaves such persons in a legal limbo, as many rights in China are dependent on a lawful household registration. Individuals without a valid household registration can face difficulties obtaining education, health care, employment, or state services of other kinds. Those without household registration are vulnerable to detention, high and excessive fines, and police abuse.

In urban areas, many people living with HIV/AIDS have reported problems with residence rights in private residence compounds. Zhang, the Beijing AIDS activist, said that a fellow activist he knows who has given a number of press interviews has been evicted from multiple residences once his neighbors recognize him as a person with AIDS:

His photograph was published in newspapers and on television. He has looked in many places for a place to live, and has been expelled from many places because his face is known. People see him on the news and he can’t find a place to live … This person has to walk around in disguise, wearing a scarf, hat and sunglasses. He’s living out in the suburbs because there he’s among rural people who rarely read the papers or watch television.

Many similar accounts have appeared in international media. In some urban areas of China, people living with HIV/AIDS whose status becomes publicly known may be “forced to flee from house to apartment, from neighborhood to neighborhood, evicted from every temporary residence they have managed to rent.” In Guangzhou, “a tiny, grass-roots-run care home for people with HIV/AIDS has been forced by landlords to move twice.” As growing numbers of people with HIV/AIDS begin to form similar grassroots collectives, they struggle to organize without revealing their status to neighbors. In a radio feature on AIDS in China, Odilon Couzin reported, “Adam Li started one of the first, and only, support groups for people living with HIV/AIDS in China … It’s still based out of his small apartment, and he keeps its very existence secret from the neighbors.” Li says,

They wouldn't let us stay, if they knew we had AIDS.

Kong, discussed above, faced a similar reaction: though the village did not formally evict him, constant harassment and rejection by neighbors and relatives, and the boycotting of his business by customers, ultimately made it impossible for him to continue to live and work in his home town. Local authorities did nothing to prevent this.

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Quarantine

One of the most disturbing forms of legal discrimination in China is the loophole permitting quarantine of people with HIV/AIDS during testing or for treatment. Because China currently classifies HIV/AIDS as a “Class B” epidemic, quarantines are allowed, and it is permissible to use the police to enforce quarantine under the same law.

National regulations on AIDS also rule that foreigners with HIV/AIDS may be quarantined for an indeterminate period before they are deported. Local regulations in, for instance, Jinan city, use similar language to permit quarantine during HIV-testing.

Unconfirmed reports of detention of people living with HIV/AIDS have circulated in China since the 1980s. Human Rights Watch interviewed one HIV-positive person who said he had been threatened with quarantine. Law, a Fujian native, took an HIV test as part of his application for a marriage license in Fujian. Asked if he had wanted to take the test, he responded bluntly, “Whether you consent or not, you’d better consent! [ni bu yuanyi ye yao yuanyi!]” He described what happened after he took the test:

Some places test fast—at the anti-epidemic station, they test pretty fast. When they told me on the third day that there were still no test results, I gave them some money [a bribe] and asked if they could manage this for me. They asked me, “Where did you go? Did you leave the country? Did you go to Southeast Asia, or Thailand, or some other place?” I said no, I had been at home the whole time, I didn’t have anyone to go traveling with.

The head doctor said I was HIV-positive. I said I didn’t know where I had gotten it from….I said, “I doubt your materials”…. [and then] my friend told me that in three days I would be detained. My friend said, “You’d better leave by the day after tomorrow, or on the third day they’ll grab you.” He had connections in the anti-epidemic station.

I didn’t wait around. I left that day. Let me tell you, labor camp in China is not like labor camp in other countries.

Law fled to Hong Kong, where he had friends who helped him to get a work permit. His fiancée remains in Fujian. Law asserted that he had heard that those who test positive for HIV in Fujian are quarantined in remote mountain hospitals until they or their families can pay for medical treatment. Lack of access meant that this allegation could not be verified. A person living with HIV/AIDS and an NGO worker in Hong Kong both reported hearing reports from Fujian of quarantines of people living with HIV/AIDS.

Experts and policymakers in China continue to raise the specter of quarantine and isolation for people with HIV/AIDS as a way to control the spread of the epidemic. At a Tsinghua University conference on AIDS legal reform in November 2002, such suggestions were raised again. Adam Li, founder of the Mangrove Support Group, spoke against the proposal:

231 Chuanranbing fangzhi fa [Law on Prevention of Infectious Diseases], article 14.
232 Aizibing jiance guanlide ruogan guiding [Certain number of regulations on the supervision and management of AIDS], article 23.
233 Jinan shi xingbing fangzhi tiaoli [Jinan city regulations for prevention of sexually transmitted diseases], ratified by the ninth meeting of the ninth provincial party congress, June 18, 1999.
236 Human Rights Watch interview with Harry, Hong Kong, 2003; interview with NGO worker who requested anonymity on this subject, Hong Kong, 2003.
I know that my testimony will represent the voices of other infected people. Although this is only a hearing about ideals, still I find it depressing. Many people think this way: “take all the infected persons and patients and leave them on an island until they are dead.” … We often hear of some legislature that has passed regulations to exclude infected persons. … [Such regulations] are threatening the majority of society.

Li also noted that even when a certain organization convening a conference on reforming policies to combat the AIDS epidemic invited an HIV-positive person to speak, it was on the condition that he not take meals together with other participants.237

The U.N. HIV/AIDS and Human Rights International Guidelines recommend that countries ensure that quarantining persons with AIDS is prohibited by law,238 reflecting policy guidelines that have been in force in the United States, Europe, and many other countries since the mid-1980s when it was clearly demonstrated that HIV is not transmitted by casual contact.239 Quarantines of persons living with HIV/AIDS also contravene the prohibition in the ICCPR against arbitrary detention.240

As Law’s testimony shows, the fear of quarantine helps to drive the disease underground, where it is more dangerous to sufferers and others. China should end its classification of HIV/AIDS as a Class B epidemic. Under guideline three of the U.N. HIV/AIDS and Human Rights International Guidelines, states are advised to “review and reform public health laws to ensure that ... their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.”241

International law and nondiscrimination

Nondiscrimination is a cornerstone of international human rights law. Article 7 of the Universal Declaration of Human Rights proclaims: “All are equal before the law and are entitled without any discrimination to equal protection of the law.”242 Article 2 of the ICESCR and article 2 of the ICCPR also state the rights of all persons to exercise their rights without discrimination.243 Antidiscrimination laws are also recommended by the U.N. HIV/AIDS and Human Rights International Guidelines, which recommends that states “enact or strengthen antidiscrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors... and provide for speedy and effective administrative and civil remedies.”244

Some Chinese national policies recommend nondiscrimination for people living with HIV/AIDS in workplaces, schools, and hospitals, such as the "Opinions on the management of persons infected with HIV and AIDS

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239 In the mid-1980s, Surgeon General of the United States C. Everett Koop emphasized this point in many communications. He was quoted in one account from the period as saying: "Quarantine has no role in the management of AIDS because AIDS is not spread by casual contact." See Joe Davidson, "Program to warn children on AIDS proposed by Koop," Wall Street Journal, October 23, 1986, p. 8. Early U.N. strategy documents on HIV/AIDS also emphasized this point, thanks in part to the influence of Jonathan Mann, the first director of the WHO Global Programme on AIDS, who especially underlined the lack of public health rationale for quarantining people living with HIV/AIDS. See, e.g., Mark Schoofs, "Body and soul: Human rights = public health--Remembering AIDS pioneer Jonathan Mann," Village Voice, September 9-15, 1998, pp. 3 ff.
240 International Covenant on Civil and Political Rights, article 9. Public health limitations on the right to be free from arbitrary detention must be carried out according to law and for an appropriate and narrowly defined purpose.
242 Universal Declaration of Human Rights, article 7.
243 ICESCR, article 2; ICCPR, article 2.
patients," but as policies, these lack any mechanisms for enforcement. Local laws, such as those discussed above in Chengdu and Jilin that explicitly discriminate against people living with HIV/AIDS are inconsistent with both Chinese national policy on AIDS and with international human rights law and should be reformed. Discriminatory practices by both state and private actors are preventing people with HIV/AIDS and their families from exercising fundamental rights to marry, to education, and to choose their places of residence. The right to marry, as discussed above, is guaranteed by article 23 of the ICCPR, and the right of individuals to choose their own residence is guaranteed by article 12 of the ICCPR. Article 13 of the ICESCR guarantees everyone the right to education.

Currently, people living with HIV/AIDS in China who experience discrimination by either public or private actors lack recourse. U.N. guideline 7 recommends that governments provide legal services to “educate people affected by HIV/AIDS about their rights, provide free legal services to enforce these rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.” We are aware of no such offices currently existing in China. Guideline 11 also recommends that states “ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights.” No such monitoring and enforcement mechanisms have been created; an Equal Opportunities Commission (as in Hong Kong—see below) or an ombudsman on HIV/AIDS and the rights of people living with HIV/AIDS could be such a mechanism.

C. Detention of injection drug users: the marginalization of persons at high risk

The government should help us and give us space, space in the cities and space in the countryside. They should not discriminate against us … But this is easy to say and hard to do. In the government, there are many selfish people who only think of their own personal profit. They see us as garbage, as something they have to get rid of to prevent their own loss of face.

Kong, drug user and person living with HIV/AIDS, Kunming, Yunnan, 2002

Persons at high risk of HIV infection in China, such as injection drug users, face stigma and harassment from officials, law enforcement agencies, and the wider society in China. In impoverished border regions of China police conduct regular “sweeps” of social undesirables, putting both drug users and sex workers in administrative detention centers, which differ little from prisons.

The campaign against crime and the wiping out of social evils, linked in national government rhetoric to the creation of a “socialist spiritual civilization,” fuels the fears and mistrust sex workers and drug users have of police, and by extension of other authorities, including government AIDS service providers. Such fears of stigmatization, expulsion, and detention discourage vulnerable persons from seeking information on and treatment for HIV/AIDS. The abuses detailed below against injection drug users deepen the social stigma and isolation of marginalized persons, and also make it unlikely that HIV/AIDS prevention or care services will be sought by them or offered in a respectful manner.

245 Guanyu dui aizibing bingdu ganranzhe he aizibing bingren de guanli yijian [Opinions on the management of persons infected with HIV and AIDS patients], published by Ministry of Health, April 20, 1999.
246 International Covenant on Civil and Political Rights, article 23.
247 International Covenant on Civil and Political Rights, article 12.
250 Ibid, paragraph 11.
Since the 1980s, the drug trafficking route that started in Yunnan has extended north along the impoverished and predominantly ethnic western provinces to Xinjiang, with HIV transmission following in its wake. Yunnan province is often called the epicenter of China’s AIDS epidemic because of the cross-border traffic in drugs. Chinese researchers have found that many drug users in Yunnan share needles. According to official figures, at least 72 percent of people living with HIV/AIDS in China are injection drug users, although this number cannot be relied upon as it does not take into account the unknown numbers of persons infected with HIV through unsafe blood collection centers.

Interviewees reported that stigmatization and expulsion from villages and townships of injection drug users is common in rural Yunnan. “Drug use is viewed as even worse than AIDS,” commented Wen, an NGO worker. Cao, another NGO worker, said that villages often expel injection drug users in Yunnan, taking over their land and denying their children household registration. “They just call this a village decision [cunhui minyuan]. The prefecture does not know what goes on in the villages and does not do anything,” says Cao. “Village rules can be harsh.” The resulting dislocation of injection drug users and their families forces them to become part of the “floating population” of migrants in larger cities, making it harder for them to access state services including health care and AIDS prevention programs, increasing their vulnerability to unsafe practices, and making them more likely to be detained in forced detoxification centers.

Human Rights Watch interviewed drug users, NGO workers, health care workers, and security officials with experience in a number of forced detoxification centers, and visited two detoxification centers, including China’s largest, the Kunming City Forced Detoxification Center [Kunming shi qiangzhi jiedu suo], colloquially known as Changpo. In 2000 China had 746 detoxification centers and 168 re-education centers. Yunnan currently has ninety-two such facilities. These range from small facilities in rural police stations to large centers like Changpo, which is designed to hold 2,000 detainees. The majority of detainees are men. Changpo security officials said they occasionally detain children.

Drug users are rounded up by local police, often as part of sweeps of “undesirables” before holidays or political meetings. According to Wu, an NGO worker, “On holidays such as Spring Festival or National Day, when there are big celebrations, people want to celebrate with their families.” Police round up drug users and others who might create disturbances. “The drug users try to hide at these times,” said Wu.

In accordance with the Methods of Forced Detoxification, a State Council policy that is enforced by police as if it has the force of law, the local police station can consign a drug user from three to six months to a forced detoxification center. The Methods of Forced Detoxification is implemented like other administrative measures, such as those authorizing forced reeducation through labor. While article 8 of the Decision of the Standing Committee of the National People’s Congress on the Prohibition against Narcotic Drugs mandates detention and forced labor instead of treatment for convicted drug users, the police sentence alleged injection drug users under the Methods of Forced Detoxification without trial or any other semblance of due process. Injection drug

254 Household registration, or hukou, is the system through which individuals register for all citizenship rights, including employment, education, residence and all state services. For a discussion of hukou and human rights issues of Chinese internal migrants without it, see Human Rights in China, Institutionalized Exclusion: The tenuous legal status of internal migrants in China’s major cities (New York: November 2002).
256 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
259 For more information on reeducation through labor, see “Reeducation through labor in China,” http://www.hrw.org/campaigns/china-98/laojiao.htm.
users thus face the choice of accepting treatment in detoxification centers without due process, or receiving China’s version of due process in a criminal trial that, where the verdict is guilty, is likely to mean no access to treatment.

Once arrested by police, detainees may be given the option of entering a voluntary detoxification center, which is sometimes a separate dormitory located on the same physical plant as the forced detoxification center, and in other cases a separate facility. It is unclear on what basis some are given this option and others are not. The term of detention may be renewed for up to a year with the approval of the county police who passed the original sentence. Detainees can apply to the court to have sentences overturned. In practice, however, this does not appear to happen often, and indeed would be difficult to arrange once a person is already in detention—because of ignorance of the law by detainees and lack of access to lawyers.

According to the *Methods of Forced Detoxification*, forced detoxification centers must provide programs of medical treatment, psychological treatment, legal education, and “moral education.” Medical treatment at Changpo consists of an herbal remedy called “626” that was manufactured, tested, and distributed by a pharmaceutical company located on the grounds of the forced detoxification center.

Psychological and moral education is militarized, consisting largely of rote repetition of slogans, marching in formation, and repetitive drills such as doing squats while shouting off numbers. In the women’s section of Changpo, Human Rights Watch observed women in groups of ten or fifteen, in some cases mixed with men, who were squatting and jumping up in order, shouting off numbers. In another area, new inmates shouted out official slogans and rules of the detoxification center. According to NGO worker Robin Y.:

> Injection drug users are required to repeat slogans such as “Drug use is bad, I am bad.”

Wen relays a similar experience:

> In the centers, the drug users follow orders like a soldier, better than a soldier. When I go to visit, the police ask them to greet us, and they do it with one voice. They also say, “The government is good.”

Longer-term detainees appeared to have some supervisory roles over newer arrivals, in what NGO worker Alex Z. described as “a cell boss system.” A foreign journalist described them as “Dickensian labor camps funded by local and provincial governments and run by corrupt guards.”

Kong, a former detainee interviewed in Yunnan, described poor and unsanitary conditions and overcrowding in several smaller rural detoxification centers where he had been detained at varying times in his life. At these facilities, “people slept everywhere, they filled up the floor,” Kong said.

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263 According to an information sheet on 626 distributed at the Kunming City Forced Detoxification Center, the medication consists of: “blood vine, small black medicine, hill full of fragrance, one cup fall over, bird that controls the rivers, and over twenty kinds of Chinese medicinal grasses and ethnic medicines.”
264 A brochure distributed by the forced detoxification center claims that 626 has a “100 percent drug addiction dropping efficacy proved by clinical observation.” If it was tested on the grounds of the forced detoxification center, it is not clear whether participants in these trials were asked for their consent before participating in medical research.
266 Human Rights Watch interview with Wen, Kunming, Yunnan, 2002.
267 Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.
NGO workers gave similar accounts based on numerous visits to facilities around the province. NGO worker Wu has visited dozens of forced detoxification centers in Yunnan and agreed that overcrowding is common. At one rural center, she said, a facility that was built to house 150 inmates had 200; another, built for ten inmates, had seventeen or eighteen. “There were not enough quilts,” said Wu. “Many people lay together on platforms, like the beds [kang] in northern China. Sanitation was very poor. Inmates slept near the toilets, their drinking water was near the toilets. There were not enough toilets, it was just a very large bucket.” Alex Z., who has visited five forced detoxification centers in Yunnan and Sichuan, estimated that each of these centers housed about fifty percent more people than the facilities had been designed for. In one Sichuan facility, he said, pigs shared quarters with detainees.

Conditions appeared to be only marginally better at larger facilities, where Kong recalled sleeping several to a bed. An official at Changpo said that during the Kunming International Flower Expo in 1999, an event that China promoted internationally and that prompted major infrastructure renovations in the city of Kunming, the population of inmates went up to 4,000 in a facility designed to accommodate two thousand. Xiao, an NGO worker, recalled the population of Changpo during the Flower Expo as closer to 5,700.

In smaller rural facilities run as part of local police stations, NGO workers who had visited dozens reported poor sanitation, lack of drinking water, and inadequate quantities and quality of food. Kong recalled that meat and other protein sources were given to detainees only once a week. At other times, “potatoes were cheap, so we ate potatoes for one or two months.”

The poor conditions of detention and hard labor requirements at some centers could endanger detainees with weakened immune systems. Detainees at forced detoxification centers engage in forced, unpaid labor. According to a former detainee:

Our behavior, our attitude, everything was forced.

A former detainee described doctors at detoxification centers as “despising” HIV-positive drug users:

There was no love or concern for us. They would give us the cheapest kind of medicine, just cold medicines or anything at all, regardless of what the illness was.

At the time of Human Rights Watch’s research, some Yunnan detoxification centers, including Changpo, permitted former drug users working with international NGOs to do HIV/AIDS educational programs with detainees.

In contrast to the poor and prison-like conditions in forced detoxification centers, those in some of the country’s voluntary detoxification centers resemble China’s two-star hotels. Inmates have access to a small gym, can play pool and sing karaoke, and go on organized hikes in the countryside. They pay higher fees for room and board (about U.S.$10 per day, a sum beyond the reach of ordinary Chinese). All of this is dependent on the ability to pay. Those who cannot pay cannot stay. However, while the voluntary detoxification centers may be more comfortable in some ways than the forced detoxification centers, the voluntary centers also require rapid detoxification without methadone, offer no counseling or treatment, no medical care for persons with HIV/AIDS,

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271 Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.
273 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
and no access to antiretroviral treatment. A small medical clinic on the grounds of a voluntary detoxification center visited by Human Rights Watch was clean and well-kept, but empty.278

**Changpo**

Changpo is considered to be something of a showplace for visitors. Changpo had several small clinics available for inspection by visitors: one had about twenty patients in beds, while another was empty.

All detainees in Changpo undergo mandatory testing for HIV and STDs as part of intake procedures. This information is turned over to the regional anti-epidemic stations as part of the state’s surveillance of HIV prevalence. The names of those tested are recorded by forced detoxification center employees along with their results, in contradiction with recommended U.N. guidelines on HIV surveillance.279 Most disturbing, individuals who test positive are not informed of the fact nor provided with counseling on treatment and prevention. And some who test positive are abruptly released by the center. One reason is that detoxification centers do not want to bear the cost of antiretroviral drugs.

At Changpo, detainees are required to perform unpaid labor. Human Rights Watch observed inmates in uniform, a few with shaved heads, racing across a floor with rags, ankle-deep in water, as an official stood over them shouting out orders. Dozens of women inmates were observed making ethnic-style batik cloth, and dozens of men were seen making fake gems, all of which are sold into markets patronized by Chinese and international tourists in Yunnan.280 The workshops were dark and poorly ventilated, and during a visit by Human Rights Watch, those working with chemicals had no protective equipment for their faces or eyes, and were working with their bare hands. Changpo officials said they plan to expand these workshops.281

In addition, Changpo has a large farm producing fresh produce, livestock, fish, and fruits, and all of the work for these is done by detainees. Its agricultural lands extend over 3,200 mu (about 213.50 acres). Changpo inmates raise over 50,000 chickens, producing twenty-one kilos of eggs per day, and over 1,000 pigs. In addition, they raise over 100 head of cattle, over 100 dogs for food and work, as well as deer, ostriches, ducks, over twenty varieties of fish, an orchard of 10,000 pear trees and 500 other trees. “All the meat we eat, we raise ourselves,” said Officer Shang, an official in Changpo.282 However, “wild cuisine” such as venison and ostrich meat can fetch high prices in Kunming’s fashionable tourist restaurants, so it would be surprising if these delicacies were fed to detainees.

Smaller rural forced detoxification centers also have farms on which detainees are compelled to work.283 Xiao reported that a “reeducation-through-labor” camp is attached to Changpo but is closed to visitors. He said that living conditions and the hard labor in this section are worse than those in the forced detoxification center.284 Detainees are never paid for their labor, but they are charged for room and board at the rate of RMB13 (U.S.$1.75) per day at Changpo,285 and about RMB 8 (U.S.$1) per day in some rural detoxification centers.286

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278 Human Rights Watch visit to Changpo, Yunnan, 2002.
280 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002. Officer Shang pointed out that the fake diamonds made by male inmates looked convincing because each has fifty-seven facets.
281 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
283 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
285 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
286 The officer said that the unpaid labor is done to defray the balance of the costs of housing detainees, but individual accounts of this amount are not kept.

Human Rights Watch
The detention of drug users and the kinds of treatment described here date back to the “moral reeducation” of sex workers and drug users conducted in the early days of the Revolution during the 1950s. At that time, moral rehabilitation of social undesirables was seen as part of larger projects aimed at creating model Chinese socialists. Today, the socialist project has been largely abandoned, but under the banner of creating a “socialist spiritual civilization” that eradicates social ills like drug abuse, the moral reeducation of marginalized people continues. Sex workers are, like injection drug users, detained in camps where they are compelled to chant slogans and rehabilitate themselves socially, all under the guidance of public security officials.

Officials at the largest forced detoxification centers are given training in the law, in administration, and in computers, but not in psychological counseling or treatment. At smaller rural detoxification facilities, detainees are simply supervised by police officers and nurses. No psychological counseling is offered at these centers, and medical care of detainees, including those with HIV/AIDS, appears to be minimal at best.

The official relapse rate of those detained in forced detoxification centers in China is 95 percent. NGO workers and others believed it could be even higher; one noted that some drug users avoid reincarceration by paying bribes to police officers. “Many people, when they come out of the forced detoxification centers, they find it very hard to accustom themselves to society,” concluded Kong. “Their heads are in a bad place because of the treatment in the detoxification centers, and they can’t find a way to fit in.”

The combined effect of this treatment, including the near criminalization of detention, the lack of due process, the dehumanizing conditions, the hostile and harsh treatment, and rote shouting and chanting of slogans, such as “I am bad,” and lack of control over basic medical information, is to dehumanize drug users. For former detainees, the overriding message is one of marginalization from mainstream society and distrust of those in authority. Those who had employment before their sudden arrest and detention are likely to have lost such employment, and are likely to face challenges in either finding new work or explaining their long absence. Even Changpo’s spokesman acknowledges that most drug users relapse because of stresses in their lives: “They need comfort, so they turn to drugs.”

China already has alternative models that could be the basis for a reevaluated and revamped approach to the treatment of drug use as a public health problem. One example is the Daytop Center in Kunming, a voluntary facility that trains peer educators to educate patients about HIV/AIDS, provides psychological support and counseling, and uses the “therapeutic community” model to establish support groups for former drug users. The Daytop Center also offers short courses of methadone to assist in detoxification.

As discussed below, China’s administrative detention of injection drug users is in conflict with several provisions of international law, particularly in its lack of respect for due process, the use of unpaid, forced labor, and the use of cruel, inhuman or degrading punishment. The absence of adequate medical care for HIV-positive detainees, and the use of mandatory testing, also raises rights issues.

The detention without trial of injection drug users is contrary to basic principles of international law. Article 9 of the ICCPR states that any person “deprived of his liberty by arrest or detention shall be entitled to take proceedings before a court, in order that that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful.” The human rights Committee has pointed out that this provision is “applicable to all deprivations of liberty, whether in criminal cases or in other cases such as, for

290 Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.
291 International Covenant on Civil and Political Rights, article 9 (4).
example, mental illness, vagrancy, drug addiction, educational purposes, immigration control, etc. According to a noted scholar: "An interference with personal liberty results only from the forceful detention of a person at a certain, narrowly bounded location, such as a prison or some other detention facility, a psychiatric facility, a reeducation, concentration or work camp, or a detoxification facility for alcoholics or drug addicts..." Article 14 of the ICCPR provides basic fair trial rights, including being charged with a criminal offense, having the right to a public hearing, and being presumed innocent until proven guilty. Those convicted of crimes should have the right to a review of the conviction "by a higher tribunal according to law." Similarly, the U.N. Body of Principles for the Protection of All Persons Under Any Form of Detention requires that persons "not be kept in detention without being given effective opportunity to be heard promptly by a judicial or other authority. A detained person shall have the right to defend himself or to be assisted by counsel as prescribed by law."

Local police hand down sentences against accused drug users in China without trial. Though such persons have the option of appealing their sentence, their lack of resources and of access to a lawyer while in detention poses significant and often insuperable obstacles. During Human Rights Watch’s visit to Changpo, several family members of detained drug users visited police officers to ask for the release of their relatives. The police did not inform those family members of their right to appeal sentences. Many detained drug users may not be aware that they have the right to appeal.

International law requires that persons in detention be kept in decent living conditions. Overcrowding, poor sanitation, poor water, and lack of sunlight and exercise violate international minimum standards. Poor conditions in prisons and other detention facilities are a serious concern throughout China.

Those who are at high risk of HIV and other illnesses, such as injection drug users, will suffer disproportionately in poor detention facilities. General Comment 14 to the ICSECR, which applies to those in state incarceration as well as to the general population, extends "not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health." Detention facilities are required under international law to provide medical treatment to inmates who are found to be ill. Thus, inmates at forced detoxification centers who test positive for HIV and those suffering from other ailments must be given proper medical care and treatment in conformity with the right to the highest attainable standard of health. Principle 9 of the Basic Principles for the Treatment of Prisoners requires that prisoners have “access to the health services available in the country without discrimination on the grounds of their legal situation.” Principle 24 of the Basic Principles for the Protection of All Persons under Any Form of Detention or Imprisonment states:

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292 Human Rights Committee, General Comment 8, Article 9 (Sixteenth session, 1982), Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1\Rev.1 at 8 (1994).
294 International Covenant on Civil and Political Rights, article 14 (1) and (2).
295 International Covenant on Civil and Political Rights, article 14 (5).
298 CESCR General Comment 14, “The right to the highest attainable standard of health,” paragraph 11.
299 ICESCR, article 12.
300 Basic Principles for the Treatment of Prisoners, article 9.
A proper medical examination shall be offered to a detained or imprisoned person as promptly as possible after his admission to the place of detention or imprisonment, and thereafter medical care and treatment shall be provided whenever necessary. This care and treatment shall be provided free of charge.301

The ICCPR also prohibits forced labor. Article 8 states that “no one shall be required to perform forced or compulsory labor.”302 While article 8 permits convicted criminals to be required to work as part of their punishment,303 detainees in forced detoxification centers have not been convicted of a crime in a court of law and should therefore be excluded from this provision. Moreover, international standards on the treatment of detainees demand that work undertaken be to their benefit. According to the Basic Principles for the Treatment of Prisoners:

Conditions shall be created enabling prisoners to undertake meaningful remunerated employment which will facilitate their reintegration into the country’s labor market and permit them to contribute to their own financial support and that of their families.304

China is a member of the International Labor Organization (ILO) and has ratified twenty of the 100 active ILO conventions on labor standards. In June 2002 China’s only legally-recognized trade union, the All-China Federation of Trade Unions, was elected to the Governing Body of the ILO.305 In 1998 the International Labor Conference approved a Declaration on Fundamental Principles and Rights at Work. Article 2 of the Declaration states that all members, even if they have not ratified the conventions in question, have an obligation as ILO members to realize fundamental rights in the conventions including the elimination of all forms of forced or compulsory labor.306 ILO Convention 29 defines forced labor as “all work or service which is exacted from any person under the menace of any penalty and for which the said person has not offered himself voluntarily.” Certain categories of persons are exempted from the ban on forced labor, but detainees are not among them. Regardless, even for those exempted from the ban on forced labor, according to article 12 of Convention 29, there is a 60 day limit per 12 months for compulsory labor.307

D. Mandatory testing and violations of confidentiality

In China, statistics on HIV/AIDS are compiled from “sentinel surveillance” sites that carry out HIV tests on persons in targeted groups once or twice a year. According to UNAIDS, such testing should “not aim at diagnosing individual HIV cases and is therefore carried out unlinked and anonymous.”308 Sentinel surveillance

302 International Covenant on Civil and Political Rights, article 8 (1).
303 ICCPR, article 8 (2).
304 Basic Principles for the Treatment of Prisoners, article 8.
306 "All Members, even if they have not ratified the Conventions in question, have an obligation arising from the very fact of membership in the Organization to respect, to promote and to realize, in good faith and in accordance with the Constitution, the principles concerning the fundamental rights which are the subject of those Conventions, namely:
(a) freedom of association and the effective recognition of the right to collective bargaining; (conventions 87 and 98)
(b) the elimination of all forms of forced or compulsory labor;
(conventions 29 and 105)
(c) the effective abolition of child labor; (conventions 100 and 111)
and
308 UNAIDS, HIV/AIDS: China’s Titanic Peril, June 2002, p. 12. In “unlinked” testing, the name of the person tested is never recorded with the test results. Instead, the person tested is randomly assigned a number.
of HIV involves the repeated HIV testing of a selected sample of persons from various locations. Outside of China, most such surveillance systems test blood taken for some other purpose—such as syphilis testing of pregnant women at antenatal care facilities—and the test is anonymous and “unlinked,” that is, it cannot be traced to the person who gave the blood.\(^{309}\) As of 2000 there were 101 sentinel sites documenting HIV prevalence among targeted population groups such as sexually transmitted infection clinic attendees, sex workers, injection drug users, long-distance truck drivers, and pregnant women.\(^{310}\)

However, given reports of abuses discussed here, it is not at all clear that information gathered in China is in fact unlinked or anonymous or that confidentiality is preserved. China’s 2003 proposal to the Global Fund acknowledges that confidentiality is violated in surveillance and diagnostic services.\(^{311}\) A joint report by the China Center for Disease Control (CDC) and U.S. CDC also acknowledges that testing programs require “greater attention to protecting patient confidentiality” in order to ensure “greater patient confidence in and acceptance of HIV testing.”\(^{312}\) The report also notes a troubling “lack of distinction at the clinic level between HIV testing for diagnostic purposes and HIV testing as part of the anonymous screening of a designated population for surveillance purposes.”\(^{313}\) In particular, the report notes, mandatory HIV testing of incarcerated drug users and sex workers “raises ethical concerns, particularly given the risks of discrimination and the lack of availability of treatment and medical follow-up.”\(^{314}\)

Employees at state facilities, including forced detoxification centers and hospitals, admit they routinely test for HIV without requesting consent of those tested. As described above, staff at Yunnan forced detoxification centers acknowledge that they conduct mandatory testing on all detainees in collaboration with the anti-epidemic station, and that such information is collected without consent, without informing those who test positive, and without counseling before or after testing.

Medical ethics in China are still strongly influenced by traditional practices surrounding openness and confidentiality.\(^{315}\) Doctors and nurses routinely shield patients from news about their medical condition, particularly when the diagnosis is a serious illness. Family members instead may be told bad news denied the patient. In addition, Western notions of confidentiality of personal medical information are not normally adhered to in China. Thus, information on patients gathered by a government hospital or clinic is openly available to other government agencies, even where the patient has not been informed of his or her condition.

These concerns of full disclosure and confidentiality pose especially serious problems for people with HIV/AIDS. When doctors, and then the individual’s family, withhold information about the illness, they virtually ensure that

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\(^{310}\) WHO, HIV/AIDS in Asia and the Pacific Region 2001, p. 42.


\(^{314}\) Ibid.

\(^{315}\) See M.C. Pang, “Protective truthfulness: the Chinese way of safeguarding patients in informed treatment decisions,” Journal of Medical Ethics, vol. 25, issue 3 247-253 (1999). According to Pang, “In the Chinese medical ethics tradition, refinement [xing] in skills and sincerity [cheng] in relating to patients are two cardinal virtues that health care professionals are required to possess. This notion of absolute sincerity carries a strong sense of parental protectiveness. The empirical findings reveal that most nurses are ambivalent about telling the truth to patients. Truth-telling would become an insincere act if a patient were to lose hope and confidence in life after learning of his or her disease. In this system of protective medical care, it is arguable as to whose interests are being protected: the patient, the family or the hospital. I would suggest that the interests of the hospital and the family members who legitimately represent the patient's interests are being honoured, but at the expense of the patient's right to know.”
the person with HIV will not seek treatment nor receive counseling, including on prevention of transmission. Violations of confidentiality and discrimination against people with HIV/AIDS can have tragic consequences beyond the illness, particularly in close-knit rural areas or where access to work, residency and health care are all linked to the government.

People living with HIV/AIDS, NGO workers, and AIDS activists interviewed for this report all said that they had personally experienced or knew of cases where mandatory HIV testing was done in hospitals without patient consent. Hospital workers appear to believe that this is in line with official policy. Hospital workers in Yunnan also acknowledge that they test incoming patients for HIV without their consent. Said Tao, a senior Yunnan hospital staffer:

People usually get tested at the hospital. Testing is not voluntary—they come in for something else, and we test their blood. We don’t ask their permission. We tell the patient and their family the results of the test, and we tell the family even if the patient does not wish to.\(^{316}\)

This is done, said Tao, so that the spouse of the HIV-positive person and her or his family members will take precautions.

Similarly, foreign NGO worker Alex Z. recalled talking with doctors in Xinjiang who reported that they tested patients without their consent and informed families of patients’ HIV status because they believed this to be mandated by national guidelines.\(^{317}\) People living with HIV/AIDS and NGO workers in Beijing, Hong Kong and Yunnan all reported that they knew of other cases where employees of anti-epidemic stations released information on the HIV status of persons to their families or employers without their permission. According to Cao, an NGO worker in Yunnan:

The policy is that testing is anonymous. In practice, they often release it. Someone will call the work unit and say “that person has AIDS”—and then the person gets fired.\(^{318}\)

In Beijing, AIDS activist Zhang said that among HIV-positive people he knew, “when people test positive, they are often not told, but their family or work units may be told.”\(^{319}\)

In other cases, while health care workers do not directly divulge test results, they may release them to people who do. For instance, the growing concerns about HIV/AIDS in Yunnan have led groups of people living in the same village to organize their own testing. In some of these villages, Cao recalled, community leaders organize the HIV tests for the group, gather up the information and distribute it back to all the individuals tested, with the result that the community leader knows the test results. Such results may not always be treated confidentially. In one such case, a community leader contacted the owner of a brothel where a sex worker had tested positive to inform the owner of her status. “He meant well,” said Cao. “He was saying to the brothel owner, ‘She’s sick, protect her, please don’t make her take so many clients, let her rest, don’t let her transmit it. She needs more care.’” As a result, though, the brothel owner expelled the sex worker and had her sent back to Burma. According to Cao, “We did not hear any word of her after that.”\(^{320}\)

The national *Regulations Concerning the Monitoring and Control of AIDS* contain articles that stipulate persons with HIV/AIDS, persons suspected of having HIV/AIDS, persons close to them, and “blood, blood products, virus strains, biological tissues, animal and other objects contaminated with HIV or with the possibility to spread HIV” as the “objects of monitoring and control of AIDS” and thus subject to mandatory testing.\(^{321}\) A legal reform

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\(^{316}\) Human Rights Watch interview with Tao, Ruili, Yunnan, 2002.
\(^{317}\) Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.
\(^{318}\) Human Rights Watch interview with Cao, Kunming, Yunnan, 2002.
\(^{319}\) Human Rights Watch interview with Zhang, Beijing, 2002.
\(^{320}\) Human Rights Watch interview with Cao, Kunming, Yunnan, 2002.
proposal sponsored by the United Nations Development Programme (UNDP) recommends revising these and other similar regulations to restrict mandatory tests to blood and organ donors.  

Some cities have regulations requiring mandatory testing for specific groups, with provisions permitting use of force. Beijing requires that the police compel sex workers and “those who may be transmitting AIDS” (you keneng chuanbo aizibingzhe) to undergo mandatory HIV testing, and that hospital workers send people they suspect of having HIV/AIDS to be tested at the anti-epidemic station. Shanghai requires mandatory testing of those who have close relationships with people living with HIV/AIDS, those “suspected of” (yiyi) having HIV/AIDS, those “suspected of” having sexually transmitted diseases, sex workers, injection drug users, those who have been in contact with infected blood, those applying to marry people from outside of the country, those who travel outside of the country, and any other people, animals or products that the city's health department request be tested.

The combination of mandatory testing and the lack of protections against discrimination for people living with HIV/AIDS may lead some people to avoid testing altogether. Because of the threat of discrimination, the lack of services for people with AIDS, and the unaffordability of antiretroviral treatment, the Daytop Center in Yunnan often counsels former drug users against HIV testing.

In their guidelines on surveillance testing for HIV/AIDS, UNAIDS and the World Health Organization (WHO) call anonymity “a basic premise of unlinked anonymous sentinel surveillance testing;” they urge caution in the collection of possibly identifying information during HIV surveillance. In the course of conducting surveillance testing and other research on HIV/AIDS, Guideline 5 of the U.N. HIV/AIDS and Human Rights International Guidelines calls upon states to “ensure privacy and confidentiality and ethics in research involving human subjects.” Guideline 3 of the same document states that apart from unlinked surveillance testing, “public health legislation should ensure that HIV testing of individuals should only be performed with the specific informed consent of that individual.” While Chinese national law and local regulations do permit mandatory testing of many categories of people, with the exception of unlinked and anonymous surveillance testing, non-consensual medical procedures are prohibited by the ICESCR under the General Comment on the right to the highest attainable standard of health.

Some policymakers in China are clearly concerned with privacy issues. Policy statements by the State Council and Ministry of Health have urged doctors or others to not inform family members or employers of an individual’s HIV status. However, the legal status of these statements is murky—they are policies and not law—and the vagueness of some of their language makes the policies difficult to enforce. Article 21 of the State Council’s Certain Number of Regulations on AIDS Supervision and Management states: “Work units and individuals may not discriminate against AIDS patients, those with HIV or their families. It is not permitted to

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323 Beijingshi shishi aizibing jiance guanlide guiding [Beijing City regulations for the implementation and supervision of AIDS testing], ratified by Beijing People’s Government, September 14, 1990, published by Health bureau, September 20, 1990, article 8.
324 Shanghaishi aizibing fangzhi banfa [Shanghai City methods for AIDS prevention], publication no. 64 of the Shanghai people’s government, December 30, 1998, article 15.
329 CESCR, General Comment no. 14, para. 8.
publicize or transmit the names, addresses or information about the situation. More generally, article 17 of the Ministry of Health’s *Methods of Prevention and Management of Sexually Transmitted Diseases* requires testing agencies to “strictly guard secrecy for sufferers.” And the *Opinions on the Management of Those Infected with HIV and AIDS Patients* recommends that those involved in the management or treatment of people with HIV/AIDS not release medical information to “unconcerned persons.”

330 *Aizibing jiance guanlide ruogan guiding* [Certain Number of Regulations on AIDS supervision and management], State Council, January 14, 1988, article 21.


332 *Guanyu dui aizibing bingdu ganranzhe he aizibing bingren de guanli yijian* [Opinions on the management of persons infected with HIV and AIDS patients], published by Ministry of Health, April 20, 1999, item 3 (1) (2).
Ji is in his late teens, stylish in a black turtleneck and grey slacks. As he tells his story he becomes increasingly unhappy.

I found out I was HIV-positive last summer. I felt ill, and I suspected that this might be what it was. At first I felt afraid, and feared getting the results. Then I got the result and it was positive, and I got the confirmation, also positive. I was very sad, I didn’t want to talk to anyone, very worried. I wanted to leave here, because even when good things happen, I couldn’t work up any joy. Later, [a counselor] talked to me and I began to have a lot of faith in her. She went with me to take the test, and they told her the results also. She gave me some suggestions that were helpful. When they told me the results, she said I would have a lot of time to prepare, and that I should try to have an active life so that I can live longer. I felt a lot of sadness, but I can’t get rid of the sadness by being sad, can I? So I have tried to change my thinking. Still, it’s better if my friends don’t know. I don’t dare to tell my family. I don’t know what they would say. They are not a supportive, cultured family. They are farmers, not city people, and their thinking is a bit feudalistic.

Someone, I don’t know who, told [one of my co-workers] that I was positive. I don’t know if someone told him, or if he just guessed. One time we all went out together to eat at a barbecue stand. I was eating my own bowl of rice and offered to share it with [the co-worker] and he shouted, “No! No!” [Bu yao! Bu yao!]

In hospitals, if they know you are positive, they won’t care for you. One time, before I got tested, I felt poorly, and I went for a check-up at the Pingan Hospital, a smaller hospital. I had not been tested yet, and they started to examine me. They did a blood test, and did they test for HIV? I don’t know. I slept on a bed there one night, and the doctor came to me late at night and found an excuse; he said that he did not dare to care for me because their treatment was not good enough. He said I should go to another hospital, maybe Number Three [a hospital known to treat AIDS patients].

I left and went to the anti-epidemic station to get tested, and then I found out I was HIV-positive...When I get sick, later, I might just leave here. I don’t want to take medicine. I’ll just go somewhere far away, a nice place, and wait to die.

It would be great if AIDS patients organized ourselves in China, but to organize, we need to know each other’s status. People are afraid to say. There are many HIV-positive people in China. If we were all active, we could unite, we could avoid discrimination. But as it is, if you know your own status, you do not dare to admit it in public.

It’s very lonely, and I need to be strong.

There is one more thing, but you have to promise not to laugh at me. I don’t think I got this from doing drugs. I didn’t do drugs very much, and usually I was injecting alone, not sharing a needle with other people. I think I may have gotten this another way...

Maybe two people who are positive could live together and take care of each other. Do you think something like this could happen?

333 Human Rights Watch interview with Ji, Kunming, Yunnan, 2002.
E. Hospital negligence and HIV transmission

Internal Chinese surveys have shown that a large percentage of the injections performed in rural health care facilities are unsafe. Reasons for this include generally unsafe medical practices, including the use of unsterilized syringes and the recycling of medical waste. In its application to the Global Fund, the China coordinating committee writes: “There is no estimation on the prevalence of nosocomial transmission of blood borne pathogens and attributions to it of different risk factors in China, but the evidence shows that unsafe injection, blood transfusion, delivery, and hazardous health care waste [are] strongly related to nosocomial transmission of HIV, and other pathogens.”

Yet despite the attention drawn to the problem of people living with HIV/AIDS who were infected through hospital negligence, and despite a number of successful regional lawsuits against hospitals, Chinese hospitals remain unwilling to accept responsibility for the safety of their blood supplies. State regulatory and law enforcement agencies have not held them accountable.

However, in the past two years, a number of lawsuits have broken new ground and held hospitals liable for damages for the transmission of HIV infected blood. In Hebei a court awarded RMB 362,042 (U.S.$45,255) to a family after the mother acquired HIV through a postpartum blood transfusion, including RMB100,000 (U.S.$12,255) for mental compensation and RMB 200,000 (U.S.$24,510) for her daughter’s medical treatment. In 2001, a Jiangsu court ordered a hospital to pay RMB 50,000 (U.S.$6,125) to a man whose wife contracted HIV from infected blood and passed the virus on to him and their daughter.

Some hospitals may be beginning to fight this legal trend: in another Hebei case, a family that sued the hospital for transmission of HIV to their child during a blood transfusion won substantial damages. But the hospital did not pay the damages, and instead countersued for nominal damages of RMB 1 (U.S.$0.15) and for restoration of damages. As discussed below, some hospitals now require patients to sign liability waivers.

It appears that the majority of HIV transmissions occur in rural communities. Uneducated rural residents have little contact with the law and may have little sense of how it works or what their rights are. Even in cases where no liability waivers are signed, such rural dwellers may not know how to seek redress or that it is even an option.

The success of these lawsuits in the absence of any other form of government monitoring or enforcement may have led to the increasingly common use of liability waivers for HIV transmission. According to Zhang, an activist with a wide network of contacts, several Beijing hospitals including the You'an hospital now require patients to sign contracts saying that the hospital will not be held liable if patients inadvertently are given HIV-positive blood. Similar “accident treatment covenants” were reportedly required of patients by Guangzhou hospitals. In April 2003 Chinese media reported the case of a Guangzhou patient who

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335 The term “nosocomial” refers to infections that take place in a hospital or other health facility.
337 Li, “Xiao Lide gushi” [Li Junior’s story], Zuihoude xuanzhan, p.172-3.
341 Human Rights Watch interview with Zhang, Beijing, 2002.
was required to sign liability waivers for HIV and other blood-borne viruses, and who was also informed by the hospital that there was a fifty percent risk of infection by blood transfusion.\textsuperscript{344}

The ICESCR places obligations on states to progressively achieve the right of everyone to the highest attainable standard of health. It specifically requires states to take steps to ensure "the prevention, treatment and control of epidemic, endemic, occupational and other diseases."\textsuperscript{345} The General Comment on article 12 explains that this requires the “appropriate training of doctors and other medical personnel, [and] the provision of a sufficient number of hospitals, clinics and other health-related facilities….States are also required to adopt measures against environmental and occupational health hazards and against any other threat as demonstrated by epidemiological data.”\textsuperscript{346} The General Comment also explains that upholding the right to health requires that “health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, \textit{inter alia}, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.”\textsuperscript{347}

In addition, the U.N. HIV/AIDS and Human Rights International Guidelines recommend that public health legislation “ensure that the blood/tissue/organ supply is free of HIV” and that public health law require the implementation of “universal infection control precautions in health-care and other settings involving exposure to blood and other bodily fluids.”\textsuperscript{348}

\textbf{F. Other problems in health care}

As the funding for China’s national health care system has decreased over the past twenty years, hospitals and clinics have increasingly passed on the costs for treatment and care to patients. For persons with HIV/AIDS, these include the costs of medical examinations, tests, hospitalization and treatment for opportunistic infections, as well as the high cost of antiretroviral (ARV) treatment.

In general, hospitals, clinics, and individual health care providers in hard-hit regions are now required to bring in user fees for a significant portion of their individual and institutional income: 40 percent of the income for county hospital doctors in Xinjiang now comes from fees for services provided.\textsuperscript{349} These fees can include the cost of a medical examination, costs for beds, tests, medical procedures, and prescriptions. For major surgery or serious illnesses, such as HIV/AIDS, families are required to make a substantial deposit to prove their ability to pay for the whole course of treatment and for room and board for the patient. Many people with HIV/AIDS may not be able to afford that deposit and are refused care on that basis.\textsuperscript{350} Instead, many turn to unregulated, experimental medicines sold in pharmacies or on the black market.

Staff members of international NGOs allege that hospitals require excessive numbers of examinations and diagnostic tests in order to generate income. China’s 2003 proposal to the Global Fund acknowledges that the poor financing of health services “create[s] incentives to overtreat and overcharge patients.”\textsuperscript{351} Speaking of tuberculosis, Dr. Daniel Chin of the World Health Organization in Beijing observed:

\begin{itemize}
\item \textsuperscript{345} International Covenant on Economic, Social and Cultural Rights, article 12.
\item \textsuperscript{346} CESCR General Comment 14, “The right to the highest attainable standard of health”, paragraph 36.
\item \textsuperscript{347} CESCR General Comment 14, paragraph 12 (d).
\item \textsuperscript{348} UNAIDS, “HIV/AIDS and Human Rights International Guidelines,” paragraph 28 (h) and (i).
\item \textsuperscript{349} Zhang Tuohong, “Report on Health Staff/Patient Interaction and Interpersonal Communication in Poor Area”, for UK Dept. of International Development, September 2002; page 12.
\item \textsuperscript{350} Human Rights Watch interview with AIDS activist Zhang, Beijing, 2002; interview with hospital worker Tao, Yunnan, 2002; interview with social worker Yang, Kunming, 2002; interview with Kong, Kunming, 2002.
\item \textsuperscript{351} CCM, \textit{2003 Proposal to the Global Fund}, June 2003, p. 19.
\end{itemize}
Hospitals clearly have an incentive to hospitalize patients as long as they can, to use expensive diagnostic tests, and even to use expensive drugs. This is the kind of warped incentive that is [sic] even in the public health system. They have to earn money, so they're not going to be going out and providing free treatment when they can be doing something else to get money.352

China’s 2003 proposal to the Global Fund actually suggests that some fees and procedures charged to people with HIV/AIDS in China may be discriminatory.353 In many countries with HIV/AIDS treatment services, antiretroviral treatment is considered to be called for when certain clinical indicators are present, including a low CD4 cell count (CD4 cells are white blood cells important to the human immune system) and HIV viral load (an indicator of the volume of the virus in the blood).354

Some people living with HIV/AIDS in impoverished Yunnan, who clearly cannot afford the cost of antiretroviral treatment, are reportedly given CD4 and viral load tests by their hospitals anyway.355 In Kunming, the CD4 test costs approximately RMB 400 (U.S.$48), and a viral load test costs about RMB 1500 (U.S.$181). NGO worker and medical doctor Alex Z. alleged the widespread use of diagnostic tests to raise funds for Chinese hospitals in Kunming. In addition, said Alex Z., in one Beijing hospital, “after testing positive (for HIV), people were made to stay in bed while they waited for results of mandatory CD4 and viral load tests.”356

If fees for medical exams and tests are prohibitive, then the high cost of antiretroviral (ARV) treatment places it completely beyond the reach of most people with HIV/AIDS. The cost of ARV treatment in China varies depending on the information source. In 2002 one official report had the annual cost of ARV treatment at about RMB 110,000 to 130,000 per year (about U.S.$13,460-15,900).357 Another put the annual cost of ARV treatment as RMB 82,000 (U.S.$9,907) in Beijing and RMB 104,000 (U.S.$12,565) in Guangzhou.358 These are roughly comparable to the cost of ARV in the United States.

In September 2002 Chinese health official Qi Xiaoqiu held a press conference in which he announced that China would be forced to break patents on Western AIDS drugs by early 2003 unless companies cut their prices. “We cannot afford to wait any longer,” he said.359 Three days later, the statement was retracted, and Qi promised that China would uphold intellectual property rights.360

In 2002 China began negotiating with large pharmaceutical companies, giving tariff exemptions for imported drugs, and encouraging production of generic medicines by domestic companies.361 Chinese ministries announced that two pharmaceutical companies were producing antiretroviral (ARV) medicines domestically. These included the Northeast Pharmaceutical Group, a Chinese domestic firm, which announced that it would manufacture ziduvodine (AZT) at one-tenth the price of imports. Northeast Pharmaceutical Group was already

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355 CD4 tests can be used for the management of opportunistic infections, though this does not appear to be the purpose here.
356 Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.
producing AZT for export.\textsuperscript{362} The second company was Shanghai Desano Biopharmaceutical Co Ltd. By the end of 2002, Xinhua, the official news agency, said that four drugs—zidovudine, didanosine, stavudine, and nevirapine—would be available in China soon and that the annual expense for each patient would be between 3,000-5,000 RMB (U.S.$360-$600).\textsuperscript{363} As of mid-2003 generic antiretroviral treatment in Beijing costs about RMB 470 (U.S. $47) per month.\textsuperscript{364}

Two small-scale pilot projects began providing treatment to persons with HIV/AIDS in Yunnan and Henan and are considered to be possible models for a nationwide treatment program.

In October 2002 the Aaron Diamond AIDS Research Center, run by renowned physician David Ho, launched a three-year study to provide 300 Yunnan residents with ARV treatment. The project is run jointly by researchers from the Aaron Diamond AIDS Research Center, Chinese Academy of Medical Sciences, and the Yunnan Provincial Center for Disease Prevention and Control. Participating patients are given Trizivir, a drug made by GlaxoSmithKline.\textsuperscript{365} The Yunnan provincial government announced that it would spend US$2.9 million to upgrade an AIDS laboratory in order to support the treatment program. The project imports drugs from outside of China, as Chinese firms only produce two of the three drugs required for this treatment program. Those selected for treatment are given regular medical exams for which they have to pay.\textsuperscript{366}

In January 2003 China announced plans to provide 3,000 Henan residents with ARV treatment as well. The domestically produced didanosine (DDI) and stavudine (D4T) were produced by Shanghai Desano, and were bought by the State Economic and Trade Commission.\textsuperscript{367} According to the South China Morning Post, the patent for DDI is held by Bristol-Myers Squibb Co., which said that Desano’s powder version of DDI did not violate Bristol-Myers’ patent, “which applies to the drug’s tablet form.”\textsuperscript{368} In July 2003 China announced that nearly 3,000 patients in Henan, 200 in Anhui, 420 in Hubei, and sixty-one in Sichuan were receiving ARV medicines. Some patients had reportedly stopped taking the medication because of serious side effects due to the poor quality of the powdered form of the drugs.\textsuperscript{369}

These are promising, if uncertain, developments. China is finally starting to put some national resources into treatment for people with HIV/AIDS. More work has to be done to establish clear criteria for acceptance into these programs and programmatic success. China has made no specific commitment of government funds to offer ARV treatment more broadly to HIV-infected persons.

As it stands, ARV treatment is only available to a wealthy elite. China’s official newspaper, the \textit{People’s Daily}, reported in 2002 that only two hundred Chinese people living with HIV/AIDS could afford regular treatment.\textsuperscript{370} Yang, a social worker in Kunming, comments that many of her clients, who have to contend with discrimination and stigma among their family and friends as well as difficulties in finding employment, find the “distressingly high” cost of treatment only “adds frost to the snow.”\textsuperscript{371}

\begin{footnotes}
\footnotetext{362}{Francis Markus, “China to get cheaper AIDS drug”, BBC, Aug. 16, 2002.}
\footnotetext{363}{Reuters, “China to Start AIDS Drug Mass-Production in January”, Dec 30, 2002.}
\footnotetext{364}{Human Rights Watch interview with Tang, New York, 2003.}
\footnotetext{367}{“Home-made AIDS drugs planned for Henan,” South China Morning Post, January 28, 2003.}
\footnotetext{368}{Martin Fackler, “Chinese company distributes anti-AIDS ‘cocktail,’” Associated Press, January 28, 2003.}
\footnotetext{369}{The drugs reportedly included domestically-produced versions of AZT, DDI, D4T and MVT, or in some cases the imported drugs Stocrin and Combivir. It is not clear whether patients given the drugs were warned in advance of possible side effects. AFP, “China starts offering free AIDS drugs but lacks doctors to administer them”, Jul 14, 2003. Human Rights Watch spoke with one foreign public health expert familiar with the program who raised concerns about the lack of training of medical staff who were distributing the drugs (Human Rights Watch interview with Bai, New York, 2003).}
\footnotetext{370}{People’s Daily Online, “Only 200 AIDS-sufferers Can Afford Regular Treatment.”}
\footnotetext{371}{Personal communication by Yang, e-mail, April 2003.}
\end{footnotes}
In November 2002 the Chinese state announced plans to reform the national health insurance system. In the past, like all government services, health insurance coverage was funneled through government work units, and the gradual dismantling of the work unit system during economic reforms has left a vacuum in access to social services, especially for rural peoples who do not work for large employers. AIDS activist Zhang reports that most private medical insurance plans in Beijing contain provisions that specifically exclude HIV/AIDS. Xiong Xianjun, head of the medical insurance division of the Ministry of Labour and Social Security, said that medical insurance policies for “serious conditions” ought to be interpreted to include HIV/AIDS, but that “AIDS patients and HIV carriers may still confront many difficulties when requesting additional medical insurance assistance due to prejudices and the misinterpretation of policies.”

According to newspaper reports, the revised national insurance plan, which will now collect funds from government agencies, employers, and employees, should cover HIV/AIDS (it is not clear whether this would include ARV). It will still mostly benefit city-dwellers, as rural residents must wait for implementation of a rural cooperative medical service in 2010. Under this system, the national government would put 10 RMB(about U.S.$1.50) into an account for each rural dweller per year, and ask local governments to add an additional 10 RMB annually. In practice, ten RMB would barely pay the cost of a single medical exam, let alone the cost of ARV treatment.

Weaknesses in the public health care system in the face of the HIV/AIDS epidemic have driven many living with HIV/AIDS into an unpredictable world of back street clinics and a booming market of incompletely regulated, experimental remedies.

Herbal medicines in China are a major industry, and have proven to be of real benefit to many who use them. As of 1997 there were 684 pharmaceutical factories producing over 4,000 medicines, and over 30,000 shops specializing in traditional Chinese medicines, which are sold over the counter without a prescription. National and local authorities have passed legislation on the registration of herbal extracts, and the State Administration of Traditional Chinese Medicine and Pharmacology is responsible for administering these. However, these medicines include experimental remedies for HIV that are apparently not adequately researched or regulated. Backstreet clinics have sprung up around Chinese cities and towns, offering services ranging from dentistry and breast enlargement to cures for syphilis and HIV/AIDS. Writes anthropologist Sandra Hyde:

[I]n almost every Chinese city one sees street posters advertising fly-by-night doctors who claim to be able to cure sexually transmitted diseases and AIDS, yet such cures are not openly discussed. In Jinghong, these posters are prominent only in the alleyways where locals venture; they are torn down where tourists are apt to view them.

In late 2002 Human Rights Watch researchers observed advertisements for private clinics and doctors of all types in local newspapers and in posters on the streets of large and small towns in Yunnan. Internet websites also market Chinese herbal remedies internationally, as with one that promises to “overcome, breakdown, kill and remove [the AIDS] virus.”

373 Human Rights Watch interview with Zhang, Beijing, 2002. Human Rights Watch attempted to contact insurance agencies in Beijing but was not able confirm this allegation.
374 Guo Nei, “Health reform...”
376 Zhang Feng, “Village health care to improve.”
Experimental remedies for a variety of ailments, including HIV, are marketed through similar advertisements, and are sold at pharmacies or by traveling salesmen. For instance, in Xincai, Henan, a private entrepreneur has been distributing an apparently unregistered liquid medication for HIV/AIDS. According to its label, this medicine, Aikang koufuye (Love Health Liquid for Oral Ingestion) is produced by the Beijing Kangderui Botanical Co., Ltd. The bottle did not list its contents, and had no registration marks or numbers. The treatment is free in the beginning, but will require fee payment later, according to a researcher who interviewed participating AIDS patients.

In some cases, government employees are reportedly distributing experimental remedies to people living with HIV/AIDS. In Henan province, as a result of grassroots pressure for government-subsidized HIV/AIDS treatment, individuals in certain counties have been issued government vouchers to subsidize the cost of the purchase of medicines of about RMB 100 (U.S.$12) per month. As this amount is not enough to pay for ARV treatment, it is reportedly being used for herbal and experimental remedies. One foreign researcher who managed to conduct interviews in Henan province learned that health care workers under pressure to show that the government program is beneficial were prescribing amoxycillin, a widely used antibiotic, painkillers, and what he called “random drugs” to people with vouchers. He reported that some doctors are “charging up to RMB 100 (U.S.$14) for drugs that might cost RMB 30 (U.S.$4) on the market, just to get the vouchers in.”

An NGO worker with field experience with the Henan AIDS epidemic confirmed this practice by health care workers under political pressure to show that the Henan HIV/AIDS epidemic was being addressed. For instance, anti-epidemic station officials in Xincai county have distributed a liquid to treat HIV/AIDS labeled Aibeike (loosely translatable as “ABC”) Biological Drink to HIV-positive residents in exchange for vouchers. Aibeike is manufactured in Zhengzhou by the Geruilin Healthcare Products Co., Ltd. A foreign researcher who interviewed villagers in Xincai and who obtained the bottle reports that it is registered as a foodstuff, not as a medication, and said that a number of villagers who ingested it reported side effects including facial swelling.

Some people living with HIV/AIDS have found Chinese herbal remedies to be effective in treating their symptoms. However, given the absence of adequate government regulation of herbal medicines and the urgency of their need, some have begun to organize their own informal drug trials, an extremely risky endeavor.

G. The Henan blood scandal and unsafe blood collection in China

One of the world’s most disastrous and preventable HIV/AIDS catastrophes has slowly unfolded in the past three years in the central province of Henan. There, hundreds of thousands, perhaps one million Chinese citizens were infected with HIV as the result of a profit-driven blood-selling scheme that involved many local officials. Attempts to cover-up the scandal continue, though the determined efforts of those infected, local activists, and local and foreign journalists have made sure that the truth of this calamity is slowly but surely being discovered. Blood scandals have plagued other countries, such as France, at various stages of the AIDS epidemic.

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381 Ibid.
383 Personal communication with NGO worker Cho, Hong Kong, 2003.
385 Li, Zuihuoude xuanzhan, p. 19.
In the summer of 2000, a number of regional Chinese newspapers began reporting that sales of blood in Henan villages had led to the widespread transmission of HIV. The blood sales were part of China’s effort to profit from the lucrative global trade in blood plasma. The injection of blood donors with contaminated blood products led to the widespread transmission of HIV. Soon after, reports began to appear in western media.387

In Henan, the local ministries of health in many regions inadvertently transmitted HIV to many villagers through a blood sales scheme motivated by the profitable trade in blood plasma. While the first transmissions were apparently inadvertent, it is unclear when local officials and businesspeople learned that people were being infected with tainted blood and how soon after they stopped the practice. Plasma is an important raw material for the production of a number of pharmaceutical products. Some proteins in blood plasma are used directly to increase blood coagulation in surgical procedures or in the treatment of immune disorders.388 The biotechnology industry has not succeeded in creating a synthetic version of human plasma, and the global demand for it is high. The Chinese biological products industry abetted by the government was well poised to profit from this demand, given its access to a huge supply of human plasma.

Local government health facilities organized and encouraged villagers to sell their blood. In North America and Western Europe, companies that collect blood for plasma generally use a technique that enables the plasma to be extracted and the remaining blood cells to be returned to the donor in one process, a technique that prevents anemia among plasma donors.389 In Henan, however, the blood of many villagers was collected and pooled, and the lucrative plasma was separated out for sale from the pooled blood. The remaining pooled blood cells were reinjected into the donors to prevent anemia and enable them to donate more often, some many days in a row. The combining of the blood of many villagers meant that if only a few were HIV-positive, the reinjecting would efficiently spread the disease to many. In addition, HIV was probably transmitted in some cases by use of contaminated equipment used in blood collection.390

In addition, because of the lack of knowledge about HIV/AIDS in China and the prevailing practice by medical professionals of reusing needles without taking proper sanitary precautions, unsafe injection practices were and remain widespread. In 1999 the Ministry of Health conducted a survey in Hubei province that found 88 percent


388 See http://www9.who.int/vaccines/Biologicals/Blood1.asp for WHO’s listing of the wide range of biological products derived from plasma. See also information on the history of industrial use of blood plasma at http://www.bloodbook.com/plasma-pool.html. [From JC: I saw one source on the web that estimated a $6.9 billion industry for one plasma-derived immunoglobulin protein alone, but I can’t find it now. You should be able to find something about the plasma industry that would give people a sense of what big business this is.]

389 See, e.g., the explanation of collection of blood from individual donors by a major plasma commercialization corporation in the United States, PlasmaCares, at www.plasmacares.com.]

of injections were unsafe due to poor sterilization and other unsafe practices. In 2001, a Chengdu newspaper reported that fourteen local hospitals had been found to be selling used medical waste to a broker. The waste included used disposable syringes, disposable transfusion equipment and disposable blood containers.

In some areas, provincial and local health officials encouraged and promoted the sale of blood by farmers. Some Henan health officials were personally involved in the development of the industry and they or their families may have personally profited from it.

As the Henan crisis has come to light, criticism by Chinese activists and in the press has largely focused on the director and employees of the provincial health bureau, who allegedly encouraged blood sales. “Our county’s health department and People’s Hospital each set up a blood station,” said an open letter by HIV-positive farmers in Henan:

On the walls were written, “Donating blood is glorious.” Propaganda material was filled with information on how donating blood would not harm the body.

These and other charges were outlined in a widely-circulated essay by a pseudonymous AIDS activist, He Aifang. According to He, in 1993 Liu Quanxi, director of the provincial health bureau, began to advocate for the development of blood collection stations that could sell plasma extracted from the blood of Henan’s people to larger biological products companies, arguing that the industry would economically benefit poor farmers. He alleges that Liu led delegations to the U.S. in 1993 and 1994 to market blood products, which he alleged were free of HIV. The writer alleged that Liu made capital investments in blood collection stations in Henan himself, and directed family members to set up six stations. In 1995-96, He said that medical workers began reporting that some former blood donors were HIV-positive. In 1996, Liu allegedly did his own study of HIV in Henan that showed a majority of persons tested were HIV-positive in regions including some where Liu’s family ran blood collection stations. Liu allegedly covered up the report and did not permit it to be published. At the same time, health department and Communist Party officials in Henan applied pressure on outspoken doctors who attempted to get the word out about Henan’s epidemic.

Henan provincial health officials closed the government-sponsored blood banks in the late 1990s, but many rural people had begun to rely on blood donations as a source of much needed supplemental income. To sell their blood, they turned to illegal blood banks, the so-called “blood heads” (xuetou), and these in turn expanded their business into other provinces. According to one AIDS activist who has interviewed farmers in Henan, some of these were no more than a cluster of cots hidden in the midst of fields.

In April 1996, Dr. Gao Yaojie, a Henan gynecologist, was conducting research on STDs and quack doctors advertising cures when she diagnosed a case of HIV/AIDS in Zhengzhou, Henan’s capital. She recalls:

392 ibid
395 He Aifang, Revealing the “Blood Wound”...
396 Ibid.
Ms. Ba was the first AIDS patient I ever saw. I was astonished to find that the contaminated blood had come from a blood bank. If [the] blood bank has been contaminated with HIV, there certainly must be more than one victim! This could only be the tip of the iceberg that appears above the water’s surface, I reflected as the thought pierced my heart. … From that day forward began my difficult and trying AIDS prevention journey.  

Dr. Gao succeeded in drawing national attention to the epidemic in Henan. In 2001 the national Ministry of Education gave her an award, but she was forbidden by local authorities to go to Beijing to collect it. Dr. Gao says that local party officials told her not to see journalists or draw more attention to the Henan epidemic. When the Global Health Council, a U.S.-based non-profit organization, awarded Dr. Gao the Jonathan Mann Award for Health and Human Rights, Henan officials refused to issue her a passport. Dr. Gao said that Liu Quanxi and health bureau officials blocked her passport application:

The health department sent people to the police department to get my passport application. They told the police I have political problems. A police officer told me this.

In 2002 Chinese activists reported to Human Rights Watch that Dr. Gao’s home was under surveillance by local police and advised Human Rights Watch against visiting her for this reason.

After spending years denying the full extent of the scandal and censoring local and foreign journalists and activists, the Chinese government now admits much of what is already known, though it is still not forthcoming with the full story. In 2001, the Vice Minister of Health admitted for the first time that illegal blood collection centers had facilitated the spread of HIV and that in some cases local government officials had been involved. However, the minister insisted that this ceased around 1996. He observed that Beijing faced obstacles in the fight against HIV/AIDS due to ignorance and obstructionism on the part of some local officials, noting that some villages with high rates of HIV infection had implored him to help them hide the problem because it could make it difficult for them to sell their products outside their villages. The minister observed:

The leaders and general public there [sic] do not fully realize the hidden dangers of a large scale epidemic of HIV/AIDS as well as the harm it may bring about to the local social development and general public in those places.

In a national HIV/AIDS action plan published in 2001, the State Council acknowledged that illegal blood collection and blood plasma collection stations had not been stopped “despite repeated prohibitions,” suggesting a more widespread problem in other provinces as well.

In 2002 a committee of Chinese government officials, NGO representatives, academics and pharmaceutical company representatives organized a Country Coordinating Mechanism (CCM), a body whose creation is required by the Global Fund in order to submit an application and coordinate any projects that may result from funding. The 2003 proposal to the Global Fund acknowledges that the scandal in Henan was the tip of an even larger iceberg. Six other Chinese provinces—Hebei, Hubei, Shandong, Shanxi, Shaanxi, and Anhui—

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398 Gao Yaojie, “My AIDS prevention journey.”
were also sites of blood tainting scandals.\textsuperscript{403} The seven provinces lie within the central belt of China where HIV transmission has resulted overwhelmingly from unsanitary blood plasma collection practices.

While the Global Fund proposal acknowledges only 250,000 persons infected with HIV in the seven provinces,\textsuperscript{404} it also cites infection rates that could contradict this estimate. Limited studies among blood donors have revealed HIV prevalence rates of 18-40 percent in Henan, 4-10 percent in Hebei, 25 percent in Hubei, 2-6 percent in Shandong, 15 percent in Anhui, 1.6-39 percent in Shanxi, and 1-5.5 percent in Shaanxi. In all but one of the seven provinces selected, blood plasma donors account for over 50 percent of all infections (range 50.1-89.1 percent).\textsuperscript{405} The combined population of the seven provinces is 420 million. Without full information about HIV surveillance it is difficult to estimate, but the percentages suggest possibly much higher numbers of people living with HIV/AIDS in the seven provinces.

Thus far, the state’s response has been limited. When reports of the scandal in Henan began to emerge, the Ministry of Health sent a team to Henan to investigate the HIV/AIDS epidemic. In 1998 Beijing issued a new regulation requiring closer supervision of and accountability for the management of blood donation centers by local and provincial authorities.\textsuperscript{406} The need to crack down on blood collection centers was discussed prominently in the country’s second national AIDS action plan.\textsuperscript{407} Cases where the police and health bureaus succeeded in closing blood collection centers were reported in some Chinese media, as in the closing of five blood collection stations in Chongqing, Sichuan.\textsuperscript{408} Beijing announced plans to phase out compulsory blood donation programs over three years in the city.\textsuperscript{409} However, even after the official centers were closed, illegal blood collection centers continued to thrive for several years, in part because farmers had come to rely on the income from blood sales.

The state has acknowledged a problem with HIV/AIDS in Wenlou village in Henan, the most widely-reported on “AIDS village” in Chinese media, and has established a clinic with some free medicines, but many other affected villages lack access to medical care.\textsuperscript{410} Journalists who have succeeded in visiting AIDS-stricken villages in Henan have described scenes of devastation, with farmers and their families wasting away in mud-brick houses, borrowing money from neighbors and family members in order to survive.\textsuperscript{411} Some parents, unable to find treatment for HIV-positive children in Henan, are forced to watch them waste away without treatment.\textsuperscript{412} Other Henan parents living with HIV/AIDS who find themselves unable to care for their uninfected children have made the decision to put them up for adoption.\textsuperscript{413}

In 2002 UNAIDS wrote that:

\textsuperscript{404} Ibid., p. 14.
\textsuperscript{405} Ibid., p. 13. Given the state’s consistent minimization of the blood scandal, these percentages are probably underestimates.
\textsuperscript{406} \textit{Xuezhan guanli banfa} [Methods for the management of blood stations], Health department publication no. 2, September 21, 1998.
\textsuperscript{408} \textit{Recent reports on HIV/AIDS and STDs in China...}
\textsuperscript{409} Raymond Li, “Compulsory blood donations to be phased out,” \textit{South China Morning Post}, November 5, 2001.
Many victims have already developed opportunistic diseases but often have little or no access to even the most basic treatment such as first-line antibiotics, let alone counseling, antiretroviral therapy, and hospital care.414

There have also been reports of corruption and embezzlement of funds earmarked for Henan’s AIDS catastrophe. One group of protestors alleged local government embezzlement of donations earmarked for AIDS care.415 Wan Yanhai, the AIDS activist detained in late 2002, says:

We are concerned that some Henan Province officials who made money for years selling blood will now have the chance to make fortunes for themselves on AIDS prevention. Will this happen? We will wait and see.416

To date, there have been no prosecutions of officials involved, though there have been arrests of “blood heads” and closings of blood collection centers. Amazingly, even after the public disclosure of the scandal, several key actors in the scandal were promoted to high-ranking positions. In 2003 Liu Quanxi was named to head a provincial committee on health, education and culture, and in the ceremony was publicly thanked for his “important contributions to the development of the province’s sanitation industry.”417 He Aifang’s essay alleges that other health officials who assisted Liu in the cover-up were promoted to higher-ranking positions.418 Chen Kuiyuan, secretary of the Henan branch of the Communist Party from 2000-02 during the cover-up of the epidemic, was named director of the Chinese Academy of Social Sciences, one of China’s premier research institutes.

Not discussed in He’s essay is another significant Henan figure now in a high-ranking national position. Li Changchun was deputy secretary of the Henan branch of the Communist Party from 1990-92 and secretary of the Henan branch of the Party in 1992-93, during the early stages of the blood scandal. In 2002 Li was named to a powerful position as a member of the Politburo Standing Committee of the Chinese Communist Party.419

In a very promising move, health ministry officials announced in August 2003 that they were drafting new rules to prevent local health officials covering up the spread of HIV/AIDS.420 Such regulations should be passed as law and stringently enforced.

Thus far, the lack of any government accountability for the events in Henan has made it clear to provincial-level authorities there and around the country that covering up epidemics is a sensible tactic to ensure political survival. This has had disastrous consequences for other public health emergencies in China, including SARS. Officials in Guangzhou and Shanghai insisted for months that there was no SARS epidemic, and later that it was under control, while the epidemic continued to spread.421 Henan officials continue to harass protestors and people living with HIV/AIDS who attempt to bring international attention to the plight of victims. After the World Health

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418 He Aifang, Revealing the “Blood Wound”...
419 People’s Daily, “Li Changchun—Politburo Standing Committee Member of CPC Central Committee,” November 15, 2002.
Organization (WHO) visited Henan to investigate SARS, the Chinese NGO Aizhi Action Project reported that Henan officials rounded up persons living with HIV/AIDS to hide them from the WHO, and that a woman with HIV/AIDS who attempted to protest this treatment was beaten by the police.422 In May and June 2003 journalists and AIDS activists reported escalating protests, arrests and police abuse of HIV-positive protestors calling for medical care and treatment in Henan.423

It is time for the Chinese government at the highest levels to launch a complete, independent and impartial investigation into the events in Henan and any other provinces where tainted blood was bought and sold with local government involvement.424 Any health officials determined to be involved or negligent should be removed from their positions and replaced with qualified public health professionals. Criminal investigations should result for those who knowingly or recklessly engaged in such commerce, and for officials who were complicit in crimes or acted to cover crimes up.

In addition, the government is obligated to provide adequate compensation and appropriate treatment to those persons who contracted HIV/AIDS as a result of government negligence or recklessness. In August, a government news organ admitted that sixty-seven persons in Sichuan province had contracted HIV as a result of the blood scandal in Henan.425 The sheer impossibility of separating direct victims from those persons who contracted HIV/AIDS indirectly as a result of the blood scandal necessitates an expansive notion of government obligation, rather than a narrow one.

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424 The State Council, under the direction of Premier Wen Jiabao, could establish a commission of inquiry into the blood scandal. The Chinese Communist Party should exert its influence to ensure this is done. The Discipline Inspection Commission of the Communist Party of China has conducted numerous investigations into official corruption and illegal medicine production in the past five years, and could also be involved in an investigation into the blood scandal.
425 “Sixty-seven residents of Gongmin Town have been diagnosed with HIV/AIDS, including 25 who later died of the disease. All of the infections directly or indirectly resulted from the illegal sale of blood in the early 1990s in Central China's Henan Province.” China Daily, “First HIV/AIDS couple to wed,” August 4, 2003.
In Hong Kong, the situation is a bit better than on the mainland. Here, the government helps us to buy medicine, and there are NGOs that support us. There are sports for AIDS [AIDS charity walks], and there are big posters, I have seen them on the train platforms. They even have hospitals, just for AIDS. We don't have anything like that on the mainland.\textsuperscript{426}

Law, an HIV-positive person from Fujian now living in Hong Kong

HIV prevalence rates in Hong Kong are estimated to be relatively low. In the second quarter of 2003, the AIDS Office of Hong Kong reported that 2,116 residents were HIV-positive in a population of approximately 6.8 million.\textsuperscript{427} While some problems remain in the treatment of people living with HIV/AIDS in Hong Kong—particularly with stigma and discrimination—people living with HIV/AIDS, medical professionals, and NGO workers in Hong Kong familiar with the situation on the mainland point to a number of differences in Hong Kong's approach that has made Hong Kong more successful in respecting the basic human rights of people with HIV/AIDS. These include the ready availability and affordability of treatment and care, the strength of Hong Kong’s NGO community, and the enforcement of a strong antidiscrimination ordinance by the Equal Opportunities Commission.

Jenny W., who runs an HIV/AIDS education program in Hong Kong, said that while most people living with HIV/AIDS do not feel safe enough to publicly identify themselves as HIV-positive, with the arrival of combination therapy, “it is possible for them to live longer, and there is no need to tell” others that they have HIV.\textsuperscript{428} Treatment for people living with HIV/AIDS, including ARV treatment, is subsidized for Hong Kong residents. The region's official HIV/AIDS unit at Queen Elizabeth hospital charges H.K.$60 (U.S.$7.80) for each consultation, with prescriptions costing H.K.$10 (U.S.$1.30) each.\textsuperscript{429} If hospitalization is required, rooms at Queen Elizabeth hospital cost about H.K.$100 (U.S.$12.80) per day.\textsuperscript{430} Those experiencing financial difficulties may apply for social security coverage. Hong Kong’s Queen Elizabeth hospital treats people living with HIV/AIDS, and most users and NGO workers interviewed reported a relatively high degree of satisfaction with health care workers at this AIDS unit.\textsuperscript{431}

Hong Kong’s relative wealth and greater commitment to public health makes treatment relatively more affordable than in China. Hong Kong’s health system as a whole is of an international standard. The importance of access to treatment for people living with HIV/AIDS cannot be overstated. Appropriate drugs and medical treatment save lives and greatly improve the quality of life for people with HIV/AIDS.

While treatment is a crucial component, people living with HIV/AIDS have a range of other needs, too. In Hong Kong people living with HIV/AIDS are able to obtain services from a number of NGOs and church groups, form their own support groups, gain access to all sorts of HIV/AIDS-related information, including state-held information, and participate actively in grassroots organizations. NGO staff report that they try to tailor their programs to the requests of people with HIV/AIDS. As an example, the Hong Kong AIDS Foundation (HKAF) runs educational programs in schools and workplaces, relying on about 300 volunteers and a pilot peer education

\textsuperscript{426} Human Rights Watch interview with Law, Hong Kong, 2003.
\textsuperscript{428} Human Rights Watch interview with Jenny W., Hong Kong, 2002.
\textsuperscript{429} Human Rights Watch correspondence with Loretta Wong, 2003; Human Rights Watch interview with Ma, Hong Kong, 2003.
\textsuperscript{430} Human Rights Watch correspondence with Loretta Wong, 2003.
\textsuperscript{431} Concerns about this treatment policy have also been raised. Loretta Wong of AIDS Concern notes, “The government provides health care services to those who have a Hong Kong ID card. Those who don't have to pay for the full cost. There are quite a number of people having AIDS (PHA) affected by the new policy, particularly HIV positive couples if the wife is from China” (Human Rights Watch correspondence with Loretta Wong, August 2003).
program in mainland China. HKAF also runs a discussion forum on the Internet where anonymous writers can post questions and have them answered by trained counselors. Two service workers provide individual counseling and run support groups for people living with HIV/AIDS, their families and partners, including a group for gay men.

To address problems with stigma, HKAF has developed some alternative strategies, says Barry Lee, Senior Service Officer:

> Because of Chinese cultural issues, people are reluctant to come for group work. So we organize interest classes, such as English language, computer training, and yoga. People are more relaxed, and then we do the group interventions afterwards.\(^{432}\)

Other HIV/AIDS NGOs offer a variety of services and educational programs. AIDS Concern has a well-known home soup delivery program and gives free transportation from home to clinic for people living with HIV/AIDS, and runs outreach programs in saunas and public toilets targeting men who have sex with men and sex workers.\(^{433}\) The Society for AIDS Care has a day center offering medical care, a computer center, a gym with volunteer personal trainers, physiotherapy, support groups, and a community kitchen.\(^{434}\)

NGOs like these offer an alternative support network in a society where stigma is often still a problem. In 1999 when a clinic for the treatment of people living with HIV/AIDS opened in Kowloon Bay, near the Richland Gardens housing project, community members organized protests. Some protestors blocked access to the clinic, hurled invective at patients and health care workers, and threw buckets of water at those trying to enter the clinic.

But in Hong Kong, unlike the mainland, victims have a forum for complaints. A group of patients from the Richland Gardens clinic lodged complaints with the Equal Opportunities Commission (EOC), which investigating the complaints, held hearings in the neighborhood, and ultimately filed lawsuits against some individuals in order to pressure them to apologize. Most of these efforts were successful in resolving the incidents, although NGO workers report that the “Richland Gardens episode” has left many people living with HIV/AIDS with lingering fears of stigma.\(^{435}\) The Society for AIDS Care, sensitive to fears of stigma among its clients in the period after the Richland Gardens protests, established its day center behind a car sales lot in the old Hong Kong airport.\(^{436}\) Alice Chan, the Society's CEO, remembers that the Richland Gardens protests were “a big deal,” and explains:

> With our location, we took that into consideration. This is a nice place, and once you know where it is, it's not hard to find, but it's quite remote ... Outside the door, we don't use the name. It just says 'fitness center' or 'activity center'. Even with the remote location, people living with HIV/AIDS feared that people would see them going in and out.\(^{437}\)

Treatment, care, and the input of NGOs and community groups are important, but in extreme situations, people living with HIV/AIDS in Hong Kong also have legal recourse. In 1997 the Equal Opportunities Commission was empowered to address complaints of discrimination by people living with HIV/AIDS by a Disability Discrimination Ordinance (DDO). The DDO guarantees the right of people living with HIV/AIDS to not be verbally or physically harassed, and protects rights to equal access to services, facilities, and equal opportunity in

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\(^{432}\) Human Rights Watch interview with Barry Lee, Hong Kong, 2002.

\(^{433}\) See the website of AIDS Concern, www.aidsconcern.org.hk (this site appears to be sometimes blocked in mainland China). See also AIDS Concern’s collection of anonymous narratives by Hong Kong people with AIDS and soup recipes collected from their home soup delivery service, *Feichang song tang renwu* [Extraordinary soup delivery mission], Hong Kong, 2001.

\(^{434}\) Human Rights Watch interview with Alice Chan, CEO, Society for AIDS Care, Hong Kong, 2002.


\(^{436}\) Human Rights Watch interview with Alice Chan, chief executive officer, The Society for AIDS Care, Hong Kong, 2003.

\(^{437}\) ibid.
employment. Brochures explaining the DDO in English and Chinese are available at NGO offices and at the Red Ribbon Centre, and include contact information for the Equal Opportunities Commission.

According to Anna Wu, chairperson of the EOC, the commission investigates all complaints of discrimination and attempts to settle problems through confidential conciliation. Wu explained:

[This is] a statutory process, and our officers stay in the room, but they have to be neutral, they are not directive. Our average rate of success with this is two out of three. We have the power of litigation, which we use to create a deterrent effect.438

The highest settlement to date, said Wu, has been for HK$1 million (U.S.$129,870), but other settlements have included training programs for discriminators, charity work, verbal apologies, “or even a basket of fruit to show respect to the complainant.”439

Most Hong Kong interviewees felt that the work done by the EOC had improved the situation, especially in addressing complaints stemming from the Richland Gardens protests. However, several raised concerns about the requirement for HIV-positive complainants to reveal their identity in the process of filing and conciliating disputes,440 and two said they saw the EOC as insufficiently aggressive.441 Some expressed concerns that the workings of the EOC has been hampered post-1997 by government fears of independent watchdog agencies, and an editorial in the South China Morning Post warned of rumors that the EOC would be dismantled, though not for its work on people with HIV/AIDS.442

Hong Kong residents still report some problems of HIV-related discrimination. The EOC and NGOs are working on addressing some of these issues, but additional legal reforms may be necessary. The problems with discrimination described by persons living with HIV/AIDS in Hong Kong largely fell into three categories: problems with individual health care workers, problems with cross-border marriages and relationships, and problems of mandatory testing and discrimination by employers.

Two interviewees reported experiences of verbal harassment by health care workers. In 2002 Ma saw an ear surgeon about persistent deafness in both ears. During a pre-surgery intake interview, the surgeon confronted Ma about his HIV status. After the first surgery on one ear had been completed, Ma saw the surgeon again at the Yaumatei Jockey Club's Ear, Eye, Nose and Throat Clinic for a follow-up meeting. At this meeting, the surgeon became confrontational and shouted at Ma for not being more forthcoming about being HIV-positive:

He started telling me about his wife and children, and said, “If by mistake I got infected by you, you might give my family trouble.” So I fought back. I said, “Whether or not I'm positive, you still have to provide care to me.” The doctor then started praising himself. He said, “I'm a good doctor! None of my colleagues would perform surgery on you, I'm the only one who was willing.” He indicated the three nurses who worked in his clinic. “None of them were willing to assist me to perform the surgery. They had to draw lots to choose, and that's how I got a nurse to assist me to perform the surgery.”

439 Ibid.
440 Human Rights Watch interview with Loretta Wong, deputy chief executive, AIDS Concern, Hong Kong, 2002; interview with Jenny W., Hong Kong, 2002; interview with Lili P., Hong Kong, 2003. Anna Wu, chairperson of the EOC, responds that in a recent court case the EOC was able to obtain a court order protecting the identity of the plaintiffs, and suggested that courts might consider this more generally for plaintiffs who were HIV-positive (Human Rights Watch interview with Anna Wu, Hong Kong, 2003).
441 Human Rights Watch interview with Lili P., Hong Kong, 2003; interview with Ma, Hong Kong, 2003.
442 “Watchdogs are meant to have teeth”, South China Morning Post, Feb. 11, 2003.
The surgery was only done on my left ear ... Because of this incident, I gave up on the right ear. I couldn’t accept that doctor's attitude, so I decided to give it up.443

Another person living with HIV/AIDS also reported experiences of verbal harassment by doctors.444

Anna Wu commented that such incidents could potentially be addressed by the EOC. “We have had incidents of that type [reported],” she said. “There was one man [who was HIV-positive] who needed surgery on his knee and it was postponed, from six months to twenty months. The conciliation was successful.”445

Many people living with HIV/AIDS are reluctant to file complaints because the procedure requires them to reveal their HIV-positive status. The EOC has managed in some cases to negotiate solutions to this through court orders protecting plaintiff identities, but may need a more systematic approach to guarding anonymity of HIV-positive complainants.

A second problem is technically addressed by the DDO, but not effectively. A number of NGO workers expressed concerns with a loophole in the law that allows employers to require blood tests of employees as part of their annual mandatory medical examinations. Said Alice Chan of Society for AIDS Care, “Employers require an annual medical checkup, and many people don't know if they're testing for HIV and if that's why [the applicants are] turned away for jobs. Companies find an excuse.”446

“They can fire you and say it's for other causes,” agreed Barry Lee of the Hong Kong AIDS Foundation.447 Loretta Wong of AIDS Concern noted that migrant workers and domestic workers in Hong Kong are especially vulnerable: they can be compelled to be tested for HIV by their employers, and may then be fired if they test positive, leaving them with invalid visas. “The question arises, who owns the medical information?” notes Wong. “The employer says that they paid for the test, so they own the medical records.”448 According to the language of the Disability Discrimination Ordinance, however, while employers may require medical information such as whether the job applicant has an infectious disease, this specifically excludes HIV-positive status as a basis for firing an employee.449 Anna Wu of the EOC observes, “The law doesn’t forbid (employers) from asking everyone to go through medical tests. It is easy to manipulate it and reject the person.”450

The third problem raised by Hong Kong interviewees is a problem with China’s restrictive laws forbidding marriage and entry permits for HIV-positive persons. Because of this, cross-border couples may be split up because one member of the pair is HIV-positive. Loretta Wong reported a case where a man, a Hong Kong resident, became engaged to a Chinese mainland resident. Because they were in the mainland, the couple was required to test for HIV in order to acquire a marriage permit:

She was negative, he was positive, and he was kicked out. His family is still there. This was one to one and a half years ago, and she's pregnant. Because of the situation, the guy had to smuggle her to Hong Kong to have the baby, and she's an illegal immigrant here.451

443 Human Rights Watch interview with Ma, Hong Kong, 2003.
444 Lili P., a Hong Kong PLWHA, reported that a friend who stayed in Queen Mary hospital towards the end of his life was neglected by medical staff. In another case, Lili accompanied a friend who was mentally disabled to the emergency room and when the doctor learned of the patient's HIV status, "he dropped his pen and rushed off to wash his hands." Human Rights Watch interview with Lili P., Hong Kong, 2003.
446 Human Rights Watch interview with Alice Chan, Hong Kong, 2003.
449 Disability Discrimination Ordinance, chapter 487, section 61 (2).
450 Human Rights Watch interview with Anna Wu, Hong Kong, 2003.
In a similar case, said Ma:

> One Hong Kong citizen I know went to the mainland, got HIV there and was kicked out, forbidden to go back for the rest of his life. His wife is in China, and when he goes back he needs to go illegally. His wife lives in Guangzhou, and she can't come here.\(^{452}\)

Anna Wu of the EOC reported a formal complaint of discrimination by an HIV-positive mainland woman whose Hong Kong-resident husband also had HIV/AIDS. The woman tried to relocate to Hong Kong in order to care for her husband, and ultimately was only given a three-month visitor's permit. Said Wu, “Her permit did not allow her to work in Hong Kong, and we can not work on immigration because it is exempted from our law.”\(^{453}\)

Many people living with HIV/AIDS underscored the importance of having NGOs as intermediaries and advocates. Lili reports that she has drawn on the help of NGO staff in dealing with problems of discrimination and remembered that one staffer often threatened to file complaints with the EOC when negotiating with discriminatory funeral parlors or other facilities.\(^{454}\)

Hong Kong’s NGOs played a critical role in establishing the legal framework in the first place: the NGOs successfully mobilized a grassroots movement to push for the inclusion of antidiscrimination language on HIV/AIDS in the DDO—an effort that included peaceful marches and a quilt with squares sewn by people with HIV/AIDS which was used at teach-ins in neighborhood libraries.\(^{455}\) The experience of these NGOs contrasts with the sense of powerlessness of AIDS activists in mainland China. Asked about any plans for legal reform in Yunnan province, a Chinese NGO worker responded, “That's a matter for big officials, we can't do anything about that.”\(^{456}\)

Given the increasingly open borders between Hong Kong and mainland China, there are more opportunities for Hong Kong organizations to take their expertise with the HIV/AIDS epidemic into mainland China. At least three Hong Kong NGOs and civic organizations have initiated pilot projects on the mainland. Hong Kong AIDS Foundation and AIDS Concern have education, prevention and service projects in southern China, and AIDS Concern led some workshops for counselors in Kunming in 2002.\(^{457}\) The Hong Kong-based Chi Heng Foundation conducts AIDS education projects with male sex workers in southeast China, and provides scholarships to HIV-positive children and children affected by AIDS in selected towns in Henan province.\(^{458}\)

Some people living with HIV/AIDS in Hong Kong expressed concerns about their peers on the mainland, and a desire to help. Said one: “Me and my friends all support each other. You can't do that on the mainland.”\(^{459}\)

Asked if he has any suggestions for the Chinese government in how to better deal with the HIV/AIDS epidemic, Ma recommended freeing up NGOs in mainland China and allowing more to register, guaranteeing equal opportunity for people with HIV/AIDS, and doing more education and publicity about HIV/AIDS to reduce stigma and discrimination. He noted:

\(^{452}\) Human Rights Watch interview with Ma, Hong Kong, 2003.
\(^{453}\) Human Rights Watch interview with Anna Wu, chairperson of EOC, Hong Kong, 2003.
\(^{456}\) Human Rights Watch interview with Han, Kunming, Yunnan, 2002.
\(^{457}\) Human Rights Watch interview with Barry Lee, Senior Service Officer, Hong Kong AIDS Foundation, Hong Kong, 2002; and Loretta Wong, deputy chief executive, AIDS Concern, Hong Kong, 2002.
\(^{458}\) Chung To, presentation at Columbia University East Asian Institute, November 13, 2002.
\(^{459}\) Human Rights Watch interview with Harry Z., Hong Kong, 2003.
In the last thirty years or so, we can say that it had limited resources, so China couldn't do much about HIV. But nowadays, that’s not the case. Now we can't use that as an excuse to not do more.\endnote{460}

VI. POSITIVE PRACTICES IN MAINLAND CHINA

Credible reports from Chinese policymakers indicate that serious consideration is now being given to the review and reform of national and local laws and policies on HIV/AIDS. This development is welcome and should be actively encouraged by international donors and NGOs working on AIDS in China. International experts and donors should offer technical assistance to facilitate the enactment of laws that will help to combat human rights violations against people with HIV/AIDS and persons at high risk of being infected.

China has the capacity to improve its approach to education about HIV/AIDS and to improving the lives of people living with HIV/AIDS. This has already been demonstrated by a number of pilot projects in localities around the country (described below), and by the relatively successful example of Hong Kong. The following projects could be studied and evaluated for national implementation in China.

**Education and prevention**

Over the past five years, a number of Chinese associations, local authorities, NGOs, international donors, and multilateral agencies have developed education and prevention programs aimed at informing persons at high risk of HIV/AIDS about the epidemic and how it can be prevented.

Several cities and provinces have launched education and prevention projects and have begun distributing condoms. In 2002 the state family planning commission began distributing free condoms in four pilot areas, including Sichuan, Shandong, Henan and Gongzhuling.\endnote{461} In 2001, Anhui province announced a decade-long campaign for prevention and control of HIV/AIDS including publicity campaigns and increased medical services.\endnote{462} Shenzhen, a special economic development zone near Hong Kong that attracts large numbers of domestic migrants, launched a five-year publicity campaign on HIV/AIDS.\endnote{463} The city of Shanghai launched a fifteen-year project to prevent and control AIDS by stressing the importance of safe sex.\endnote{464}

Some NGOs and associations have established small-scale pilot AIDS education projects that target women, ethnic minorities, injection drug users, sex workers, and men who have sex with men. Many of these pilot projects have been concentrated in Yunnan province, both because it is an area of high HIV prevalence and because its provincial government is described by some international NGO workers as more tolerant than others. For instance, the Yunnan Reproductive Health Research Association is a professional association that brings together scholars, government officials, and NGO workers for research and pilot training projects in rural communities. It also runs a number of training workshops targeting women and girls on reproductive health issues, including HIV/AIDS. The workshops also address women’s empowerment, men’s responsibility and participation in reproductive health, traditional cultures, drug abuse issues, and provide services to migrating populations.\endnote{465} Save the Children-UK also runs two centers in minority prefectures of Yunnan that do training workshops targeting women, including sex workers.\endnote{466}

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\item[460] Human Rights Watch interview with Ma, Hong Kong, 2003.
\item[463] “AIDS-awareness drive as Shenzhen cases double,” *South China Morning Post*, October 31, 2001.
\item[464] “Municipal government vows to provide more financial support and prevent discrimination against patients,” *Xinhua*, December 3, 2001.
\item[465] Human Rights Watch interview, Kunming, Yunnan, 2002.
\item[466] Human Rights Watch interview, Kunming, Yunnan, 2002.
\end{footnotes}
Some U.N. agencies and NGOs have supported innovative education and prevention projects in ethnic minority languages that aim to draw on traditional educational practices to transmit HIV/AIDS information around the borderlands. UNICEF has conducted training workshops for Tai minority Buddhist monks in Yunnan who teach younger novices in Buddhist seminaries, and has funded the printing of posters and educational materials in the traditional Tai alphabet, an alphabet the state does not officially encourage Tais to use. UNESCO has supported the production of a radio soap opera about HIV/AIDS in the Tai language which is broadcast in northern Thailand and reportedly can be heard in nearby regions of Burma, Laos, Thailand and Yunnan. Health Unlimited also does transborder HIV/AIDS education projects in the Tai and Kachin minority languages, working in border areas of Yunnan and Burma.

The Sino-American Daytop Center, a non-profit voluntary facility staffed by Chinese workers and founded by the U.S.-based Daytop Center, offers an alternative treatment approach to the forced detoxification centers described above. The Daytop Center, a small residential facility based in Kunming, incorporates methadone, psychological counseling services, and the “therapeutic community” model in which patients talk about their experiences and give each other emotional support. Services at the Daytop Center include small, informal women’s and men’s support groups. The Daytop Center also houses an Injection Drug Users’ HIV/AIDS Prevention Peer Education Project, which offers individual counseling and a telephone hotline. Several pilot projects in Kunming run by the Australian Red Cross and others train former drug users to run HIV/AIDS workshops with other injection drug users housed in forced detoxification centers.

Fewer projects have targeted men who have sex with men. One is run by the Hong Kong-based Chi Heng Foundation. Chi Heng works with saunas and brothel owners to hold HIV/AIDS education projects and to distribute AIDS information, as well as doing one-on-one counseling and education with sex workers.

All these projects could be evaluated for possible expansion to a larger scale. Moreover, the Chinese government should use public education to promote HIV/AIDS awareness in ways that would reduce stigma and increase tolerance.

_Freedom of assembly_

The restrictions on freedom of assembly and association that have significantly constrained the work of AIDS NGOs in Henan and elsewhere have been loosened in Yunnan without, apparently, causing social unrest. In late 2002 NGOs and GONGOS in Yunnan were permitted to organize a spirited rally to promote understanding and support for persons living with HIV/AIDS, organized around the U.N.-promoted slogan, “Live and Let Live.” On a rainy afternoon the week before World AIDS Day, a few hundred students, NGO workers and volunteers rallied in Kunming’s Jinbi Square, including dozens of volunteers who participated in a city-wide bicycle ride to raise awareness of HIV/AIDS. Volunteers took to the stage to act out a skit about stigma and discrimination, while families of people living with HIV/AIDS, including small children, joined in writing messages and drawing pictures on a long banner on the ground that illustrated the principles of love and tolerance.

They were watched by a few dozen passersby, including rural migrants dressed in ragged clothes, some carrying infants on their backs in embroidered baby carriers, who stared in amazement at colorful signs and banners on the taboo topics of AIDS and sex. At one of a number of NGO information booths set up around the square, university students dressed in bright yellow t-shirts handed out free condoms and AIDS information brochures to passersby. While some responded with shock and embarrassment at the suggestion, others simply blushed, smiled, pocketed the condoms, and continued on their way.

469 Human Rights Watch interview, Kunming, Yunnan, 2002.
471 Chung To, presentation at Columbia University East Asian Institute, November 13, 2002.
“Mostly, we just get together and talk”\textsuperscript{473}

Ma is a Hong Kong resident in his mid-fifties, thin but energetic. As the conversation unfolds, he warms up, becoming enthusiastic and talkative. Though he speaks good Mandarin he prefers to speak his native Cantonese through a translator.

I found out I was HIV-positive in July 1997, the month when Hong Kong was handed back to China. During that time I had persistent diarrhea, and had been to private doctors a couple of times, but they couldn't stop it. One day I learned about HIV/AIDS in a newspaper. The piece in the paper described similar symptoms [to what I had], and diarrhea was one of them. I decided to take the blood tests. I got the test results and learned I was HIV-positive, and it was a big surprise. I couldn't take it at that moment. I found out that not only was I HIV-positive but my health situation was critical, and I was admitted to the hospital immediately.

I went to Queen Elizabeth hospital, and was sent into an isolated room. I felt discriminated against, but because I was sick I had no choice. I needed to be hospitalized. I was very satisfied with the care provided by the specialty AIDS clinic, but once I left the care of the specialists, in other departments I felt discriminated against in different ways. I was hospitalized about two months, and then discharged. After I was discharged I was in touch with welfare services, NGOs, and those who provide services are nice, very good at providing care, and I felt no discrimination.

I have no health insurance. I paid for my surgery out of my own pocket. But health care in Hong Kong is cheap, usually only HK$50-60 [U.S.$6.40-7.70] a day. People with AIDS in Hong Kong are the luckiest in an unlucky population.

In 1998 there was a PHA\textsuperscript{474} conference in Warsaw, and Loretta [Wong, of AIDS Concern] organized a group of people to go. I went to that conference. After that I gained confidence, and began helping my own life. Before that I had always thought I only had a few years of my life [left], I may as well just mess around. But in Warsaw, I saw many kinds of people all gathered together. Some had been fighting AIDS for ten to fifteen years, and had contributed a lot to their own countries. When I came back, I set up a support group for people with HIV/AIDS.

In the last three years, AIDS Concern has been guiding the group to grow. We started to plan our own activities. Most of the things we do now, we do by ourselves. We have open membership, and anyone is welcome as long as they are HIV positive. When it was first established, we had thirty to forty members, but people come and go. We don't keep records of who comes. Our last two activities were mostly trips outdoors in the Hong Kong area, and we visited Guangzhou and met some people with AIDS there. Mostly we just get together and talk.

This has been the period for me to grow up. I have a more confirmed life goal, and a better direction for the future, and… [Ma smiles] … that's all.

\textsuperscript{473} Human Rights Watch interview with Ma, Hong Kong, 2003.
\textsuperscript{474} People with HIV/AIDS.
VII. RECOMMENDATIONS

To the Chinese Government:

On the blood transmission scandal:

- Authorize a full, independent, and impartial investigation into the involvement of local authorities in the blood collection and transmission scandal in Anhui, Hebei, Shandong, Henan, Hubei, Shanxi, and Shaanxi provinces and any other parts of China where HIV-contaminated blood was bought and sold and used to infect large numbers of people. If this cannot be accomplished, the United Nations or other credible international body should be authorized to conduct such an investigation. The findings of such a report should be widely publicized, including on state television and radio and on official websites.

- Initiate criminal investigations into the blood collection and HIV transmission scandal. Criminal prosecutions should be initiated against those who knowingly or recklessly engaged in such commerce and against officials who were complicit or acted to cover it up. Prosecutors and investigators should be brought in from another province to ensure maximum public confidence in the integrity of the investigation.

- Take appropriate action, including dismissal, against any officials determined to have been responsible or negligent in the blood scandal or who were involved in the cover-up.

- The government should provide adequate compensation and appropriate treatment to those persons who contracted HIV/AIDS as a result of government negligence or recklessness. The sheer impossibility of separating those infected directly from those persons who contracted HIV/AIDS indirectly as a result of the blood scandal necessitates an expansive notion of government obligation, rather than a narrow one.

- Gather and publicly provide accurate figures on the numbers of persons infected with HIV through unsafe blood collection practices in Anhui, Hebei, Shandong, Henan, Hubei, Shanxi, and Shaanxi.

Freedom of Expression, Association and Assembly

- Uphold the fundamental rights to freedom of expression, assembly, and association by not interfering with free and critical speech on the subject of HIV/AIDS, granting access to non-confidential state-held information on the HIV/AIDS, permitting internet users access to Hong Kong-based and international websites with information on HIV/AIDS, permitting Chinese and international journalists to investigate and report on any and all aspects of the epidemic, and respecting the right to form independent associations and NGOs to work on HIV/AIDS-related matters.

- Revise the “Regulations for Registration and Management of Social Organizations” to permit groups applying for registration as “social organizations” to register with a minimal number of members. End registration restrictions that limit the number of social organizations in the same administrative area that are active in the same area of work.

Antidiscrimination

- Review the Disability Discrimination Ordinance of the Hong Kong Special Administrative Region, and other such laws and regulations in other countries, for language to incorporate into new national legislation protecting the rights of people living with HIV/AIDS against discrimination.

- Establish an independent commission, similar to the Equal Opportunities Commission in Hong Kong, to investigate and resolve complaints of discrimination on the basis of HIV status.

- End the arbitrary detention of injection drug users in forced detoxification centers without trial before a court of law and other due process protections.
Ensure that all forced detoxification centers meet international health standards. Convert forced detoxification centers into state-subsidized voluntary detoxification centers. Offer methadone or other substitution therapy, psychological counseling, and HIV/AIDS education and prevention programs.

Revise clause 8 of the Decision of the Standing Committee of the National People’s Congress on the Prohibition against Narcotic Drugs to make treatment for drug users voluntary, not compulsory, and to remove provisions requiring rehabilitation through labor for drug users.

Withdraw all laws and policies requiring forced detoxification.

Labor in detoxification centers should be voluntary and provide a reasonable wage.

Remove HIV/AIDS as a “Class B infectious disease” from the Law of the PRC on the Prevention and Treatment of Infectious Diseases and review all diseases within this provision for possible reclassification.

Require by law informed consent and doctor-patient confidentiality for those tested for HIV except for sentinel surveillance testing where the results are known only to the test administrators and used only for research purposes.

Require that anyone tested for HIV be informed promptly of the results and that appropriate counseling be offered before and after the test.

Establish legal clinics to provide both free and subsidized legal information and services to people living with HIV/AIDS.

Revise laws and policies on HIV/AIDS to limit mandatory testing to blood and organ donors. Aside from unlinked and anonymous sentinel surveillance, all other HIV testing should be based on informed consent.

Establish a new national training program for all health care workers on HIV/AIDS. Among the objectives should be the reduction of stigma and discrimination in the provision of health care, training on the disease, universal precautions, and best practices for treatment and prevention, training on confidentiality, and to ensure the competency of all health care providers.

To the Ministry of Health:

Establish provincial-level offices to coordinate education, prevention, treatment, and care programs on HIV/AIDS.

Closely monitor hospitals to ensure that HIV/AIDS wards are functioning, not locked and closed, and to ensure that hospitals accept as patients and treat people living with HIV/AIDS.

Establish minimum standards of training for health workers about HIV/AIDS, methods of transmission, universal precautions, appropriate treatment and care, and problems related to stigma and related subject. Work with international and Hong Kong non-governmental organizations on the content of training programs, which should include on-the-job monitoring and follow-up training.

Establish mechanisms of accountability for health workers. Retrain or discharge hospital, clinic, social services, and other government staff who discriminate or behave inappropriately towards people living with HIV/AIDS.

Establish city and county-level voluntary, free, drop-in “activity centers” for use by low-income people with HIV/AIDS where they can receive medical treatment, psychological counseling, cook and eat meals together, and gather for mutual support and assistance.

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475 Universal precautions are procedures for health workers that are designed to prevent the transmission of HIV and other bloodborne pathogens in the course of provision of health care or first aid. They are widely used in many countries and have reduced the need for isolation of patients with certain conditions. See U.S. Centers for Disease Control, "Guidelines for prevention of transmission of human immunodeficiency virus to health-care and public safety workers: A response to P.L. 100-607, the Health Omnibus Programs Extension Act of 1988," Morbidity and Mortality Weekly Review, vol. 38 (S-6), pp. 3-37, June 23, 1989. Available online at http://www.cdc.gov/mmwr/preview/mmwrhtml/00001450.htm (retrieved August 20, 2003)
To the National People’s Congress:

- Establish a “Committee on the Prevention, Treatment, and Care of HIV/AIDS” to provide oversight of legislation and implementation of laws in relation to HIV/AIDS to ensure that the human rights of people living with HIV/AIDS are promoted and protected.

To the government of the Hong Kong Special Administrative Region:

- Support the long-term viability of the Equal Opportunities Commission as an independent monitoring body. Ensure that the chairperson and members of the Equal Opportunities Commission are insulated from interference by the executive branch and political interference.
- Expand training programs of health workers on HIV/AIDS. Include universal precautions, legal standards on discrimination in such programs.
- To decrease stigma, suggest that information on HIV/AIDS be included in basic training programs related to workplace safety.
- Expand existing public education programs on HIV/AIDS. Include Hong Kong’s legal standards on discrimination in such programs.
- Instruct the Labor department to meet with Hong Kong AIDS NGOs to discuss the problem of discrimination by employers and measures that can be taken to prevent it.

To the Hong Kong Equal Opportunities Commission

- Work with courts to obtain court orders so that people living with HIV/AIDS can file complaints related to discrimination while protecting their identities. Publicize this option widely, including by working with AIDS NGOs.
- Communicate more closely with NGOs to identify possible cases of discrimination and assist people living with HIV/AIDS to file complaints.

To the United Nations, bilateral and multilateral donors, and international NGOs providing assistance or carrying out programs on HIV/AIDS in China

- As part of working agreements with Chinese partners, require independent monitoring of discrimination against people with HIV/AIDS, conditions in forced detoxification centers, mandatory HIV testing, and access to treatment in Henan and other provinces affected by the blood contamination scandal. Require community input by individuals, independent NGOs and associations of people with HIV/AIDS into the design of any AIDS-related programs funded by donors.
- Include an agreement to observe the principles set out in the U.N. HIV/AIDS and Human Rights International Guidelines, particularly those relating to discrimination and mandatory testing, in all written agreements with government agencies.
- Advocate for the reform of national, provincial, and local laws and regulations on AIDS that discriminate against people living with HIV/AIDS. When joint programs are planned, international NGOs and donors should request and review all local laws relevant to AIDS in the
administrative region they plan to serve. Ensure that the disbursal of funds is contingent on progress on legal reforms and practices that ensure the human rights of people living with HIV/AIDS.

- Advocate for the rights to freedom of expression, information, assembly, and association for people living with HIV/AIDS in China and organizations acting on their behalf.
- Emphasize programs related to treatment, counseling, and legal services, in addition to prevention.
- Support monitoring of local hospitals to ensure that HIV/AIDS wards are functioning, not locked and closed, and to ensure that hospitals accept as patients and treat people living with HIV/AIDS. Ensure that all hospital staff are trained in universal precautions. Where hospitals or clinics are reported or observed to refuse treatment to people living with HIV/AIDS, report this to the Ministry of Health, provincial governments, the Chinese Red Cross, the United Nations, other donors, and others who can act to address the problem.
- In all AIDS education and prevention programs, distribute Chinese translations of the U.N. HIV/AIDS and Human Rights International Guidelines, ICCPR, ICESCR, and other relevant international documents.
- Support technical assistance programs to assist the Chinese government to create legal clinics serving people living with HIV/AIDS.
- Work to bring down the cost of antiretroviral and other drugs for that prolong and greatly improve the quality of lives of people living with HIV/AIDS.
- The United Nations Special Rapporteur on Arbitrary Detention should visit forced detoxification centers in Yunnan province and other such sites in China.
VIII. ACKNOWLEDGMENTS

This report was researched and written by staff of the Asia Division in collaboration with the HIV/AIDS and Human Rights Program. Brad Adams, Asia division director; Joanne Csete, HIV/AIDS and Human Rights program director; Rory Mungoven, global advocacy director; Jim Ross, general counsel; Mickey Spiegel, China researcher; and Widney Brown, deputy program director, edited the report. Ami Evangelista, Liz Weiss, Andrea Holley, Veronica Matushaj, Fitzroy Hepkins and Jose Martinez provided production assistance.

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IX. APPENDIX

June 6, 2003

Mr. Yang Jiechi
Ambassador
Embassy of the People’s Republic of China
In the United States of America
2300 Connecticut Avenue, NW
Washington, DC 20008

Your Excellency:

Human Rights Watch conducts regular, systematic investigations of human rights abuses in some seventy countries around the world. As part of its ongoing work on HIV/AIDS, Human Rights Watch is currently conducting an investigation into a range of issues including HIV testing procedures, detention of injection drug users, access to hospital care and access to treatment for people living with HIV/AIDS in China.

Human Rights Watch has conducted previous investigations into human rights aspects of HIV/AIDS in the United States, India, Kazakhstan, Canada, Togo, Congo, Kenya, Zambia, and South Africa. Our work on HIV/AIDS has involved investigations in reference to children’s rights, access to information, police harassment of outreach workers and of drug users and sex workers, and rights of women. We publish reports and press releases in English, French, Russian, Spanish, Arabic and Chinese, both in print and on our website (www.hrw.org) and (www.hrw.org/chinese).

We plan to publish a report on the rights of people living with HIV/AIDS in China this summer. In order to fully and accurately reflect your government’s policies and practices, we would be grateful for your assistance in obtaining answers to the following questions from the appropriate officials within your government. We will incorporate your government’s responses in our published report.

1. What is China’s current annual budget for national, provincial, prefectural and local healthcare?
2. What percentage of this is allocated to treatment and care for people living with HIV/AIDS?
3. Are there current plans for review and reform of existing laws on HIV/AIDS? If so, what are they?
4. What is the policy of the government if it were discovered that a provincial official had under-reported HIV infection rates?
5. What is the existing law or policy on discrimination against people living with HIV/AIDS? How is it enforced?
6. What procedure exists for those who believe they have experienced discrimination and wish to seek redress?

I would like to be able to meet with you to discuss these questions, and your government’s response. In order to be able to reflect the information you provide in our report, we would appreciate having your response no later than July 6, 2003.

Sincerely yours,

Brad Adams
Executive Director
Asia Division
Human Rights Watch
Asia Division

Human Rights Watch is dedicated to protecting the human rights of people around the world.

We stand with victims and activists to bring offenders to justice, to prevent discrimination, to uphold political freedom and to protect people from inhumane conduct in wartime.

We investigate and expose human rights violations and hold abusers accountable.

We challenge governments and those holding power to end abusive practices and respect international human rights law.

We enlist the public and the international community to support the cause of human rights for all.

The staff includes Kenneth Roth, executive director; Michele Alexander, development director; Rory Mungoven, advocacy director; Carroll Bogert, associate director; Barbara Guglielmo, finance director; Lotte Leicht, Brussels office director; Steve Crawshaw, London office director; Maria Pignataro Nielsen, human resources director; Iain Levine, program director; Wilder Tayler, legal and policy director; and Joanna Weschler, United Nations representative. Jonathan Fanton is the chair of the board. Robert L. Bernstein is the founding chair.

Its Asia division was established in 1985 to monitor and promote the observance of internationally recognized human rights in Asia. Brad Adams is Executive Director; Sara Colm and Mickey Spiegel are Senior Researchers; Meg Davis, Ali Hasan, and Charmain Mohamed are researchers; Ami Evangelista and Liz Weiss are associates. Joanne Leedom-Ackerman is Chairperson of the advisory committee.

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