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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 incalculable 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

¹ Human Rights Watch interview with Zhang, Beijing, 2002.

² Yuan Ye and Li Nu'er, "AIDS prevention better than no cure: China's 'Last' Chance?", PANOS London, January 20, 1997, www.aegis.com/news/panos/1997/PS970101.html, July 29, 2003.

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").

⁵ China's 2003 application to the Global Fund to Fight AIDS, Tuberculosis and Malaria draws on earlier statements by the Chinese Ministry of Health to estimate that ten million Chinese citizens will have HIV/AIDS by 2010 (Country Coordinating Mechanism, *2003 Proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria*, June 20, 2003, Section III, p. 13); the U.S. National Intelligence Council estimates 15 million people living with HIV/AIDS in China by 2010 (National Intelligence Council, *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India and China*, September 2002, p. 4). Given the absence of accurate information about HIV infection rates in China, all such estimates are provisional at best.

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),⁶ have long suspected: Henan was just one of seven central Chinese provinces where similar blood collection practices fuelled the spread of HIV/AIDS.⁷ The sheer percentages cited in these documents indicate potentially larger HIV prevalence in China than the state has yet acknowledged.⁸ 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.⁹ 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.¹⁰

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 children¹¹ may be orphaned by HIV/AIDS by 2010;¹² 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.¹³ Many school-age

⁶ UNAIDS, *HIV/AIDS: China's Titanic Peril*, June 2002; p. 26.

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.

¹⁰ Bates Gill, Jennifer Chang and Sarah Palmer, "China's HIV Crisis," *Foreign Affairs*, March/April 2002; Wan Yanhai, "Mai xue chuanbo aizibing he guojia jimi [The transmission of AIDS through blood sales and national secrets]," Aizhi Action Project press release, December 28, 2002; Reporters Sans Frontieres, *China: Foreign and Chinese journalists banned from investigating the AIDS epidemic in Henan province*, report, Paris, November 13, 2001.

¹¹ In this report, the word "children" refers to anyone under the age of eighteen. The U.N. Convention on the Rights of the Child, ratified by China on April 1, 1992, defines a child as "every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier" (Article 1). U.N. Convention on the Rights of the Child, G.A. res. 44/25, annex 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/4/49 (1989).

¹² CCM, *2003 Proposal to the Global Fund*, June 2003, "Section III", p. 12.

¹³ Li Dan, "The situation of Chinese AIDS orphans," http://www.chinaaidsorphans.org/en_version/intro/intro.htm, retrieved June 21, 2003; and Chung To, presentation at Columbia University East Asian Institute, November 13, 2002. AIDS activist Wan Yanhai estimates up to two million people living with HIV/AIDS in Henan, most of them parents (Ciny Sui, Agence France Presse, "Chinese NGO that probed village AIDS deaths evicted," July 3, 2002, <http://www.globalpolicy.org/ngos/role/globalact/state/2002/0703china.htm>, retrieved July 31, 2003). Again, the actual infection rates are unclear.

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.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.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.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

¹⁴ State Council, Methods for Forced Detoxification [*Qiangzhi jiedu banfa*], January 12, 1995, article 6.

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: *Aizibing jiance guanli ruogan guiding* [Certain Number of Regulations on AIDS supervision and management], State Council, January 14, 1988, articles 5 and 8; *Dalianshi aizibing jiance guanli guiding* [Regulations for Dalian city AIDS supervision and management], article 7; *Beijingshi shishi aizibing jiancede guanli guiding* [Regulations for Beijing city AIDS supervision and management], article 8; *Shanghaishi aizibing fangzhi banfa* [Shanghai city methods of AIDS prevention], article 15; and *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.

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."¹⁷

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."¹⁸ 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.¹⁹ 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.²⁰ 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

¹⁷ Human Rights Watch interview with Han, Kunming, Yunnan, 2002.

¹⁸ CNN News, "China: Harsh punishment in SARS fight," May 16, 2003, <http://www.cnn.com/2003/HEALTH/05/15/sars>, retrieved July 31, 2003.

¹⁹ Mure Dickie, "Stringent new rules on AIDS proposed by China," *Financial Times*, August 15, 2003.

²⁰ State Council Office Document 2001-40, Ministry of Health Communicable Disease Control Division, China's Action Plan for Reducing and Preventing the Spread of HIV/AIDS (2001 - 2005), English translation, June 2001, <http://www.usembassy-china.org.cn/sandt/AIDS-actionplantranslation.htm>, retrieved July 31, 2003.

HIV/AIDS, such as Suzhou.²¹ 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.²² 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.²³

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.²⁴ 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:

²¹ AFP, "China-AIDS: Chinese city passes law to protect rights of AIDS patients," October 16, 2002.

²² People's Daily, "Marriage marks change in attitude to AIDS victims," August 4, 2003.

²³ CCM, *2003 Proposal to the Global Fund*, June 2003, p. 35.

²⁴ Chris Buckley, "AIDS-afflicted villagers say Chinese police attacked them," *New York Times*, July 8, 2003; Human Rights Watch, "China: Police violence against HIV-positive protestors escalates; Henan authorities deepen AIDS cover-up," July 9, 2003.

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.

²⁵ Martin Feckler, "China Must Curb AIDS Spread", Associated Press, October 14, 2002.

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 Xinxu 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 chubanshe, 2003).

¹³² Human Rights Watch interview with Loretta Wong, deputy chief executive of AIDS Concern, Hong Kong, 2002.

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

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).

¹³⁴ Sophie Beach, "Running in Place", August 2001, http://www.cpj.org/Briefings/2001/China_aug01/China_aug01.html, retrieved on February 28, 2003.

¹³⁵ Wan Yanhai, "National secrets and AIDS transmission via blood-selling."

¹³⁶ Reporters Sans Frontieres, *China: Foreign and Chinese journalists banned from investigating the AIDS epidemic in Henan province*, report, Paris, November 13, 2001.

¹³⁷ Reporters Sans Frontieres, *China: Foreign and Chinese journalists banned...*

¹³⁸ David Murphy, "A Nightmare in the Making," *Far Eastern Economic Review*, August 15, 2002, pp. 30-33; p. 31.

¹³⁹ *Beijing Aizhi Action Project 2002 Annual Report*, December 22, 2002,

<http://www.stanford.edu/~hcchang/annualreport2002/revised%20eng%20translation.htm>, retrieved June 13, 2003.

¹⁴⁰ In Chinese, *fanyizhan* or anti-epidemic station; the term is now officially translated as "center for disease control."

¹⁴¹ Melinda Liu, "The Blood Ties That Bind," *Newsweek*, October 29, 2002; pp. 58-61; p. 61.

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).

¹⁴³ Francis Markus, radio report, BBC News East Asia Today, December 30, 2002 and Odilon Couzin, "AIDS in China," radio report, *PRI's The World*, November 29, 2002.

¹⁴⁴ Human Rights Watch interview with Yu, Yunnan, 2002.

¹⁴⁵ Agence France Presse, "Villagers dying of AIDS make desperate appeal for help," May 30, 2001.

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.

¹⁴⁸ Lu Yiyi and Kathy Attawell, *Review of Primary Stakeholder Participation and NGO Involvement*, Beijing: UK-China HIV/AIDS Prevention and Care Project, November 2002, p. 15.

¹⁴⁹ *Regulations for Registration and Management of Social Organizations*, State Council order no. 250, published September 25, 1998, article 7.

¹⁵⁰ Human Rights Watch correspondence with Marina S., NGO worker, October 2002.

¹⁵¹ Lu and Attawell, *Review of Primary Stakeholder Participation and NGO Involvement*, p. 9.

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.

¹⁵³ John Gittings, "AIDS: China's state secret," *London Guardian Weekly*, January 7, 2003.

¹⁵⁴ Agence France Presse, "Chinese village dying of AIDS neglected and left to rot," March 20, 2001.

¹⁵⁵ Agence France Presse, "Sufferers held over HIV-drug demand," *South China Morning Post*, December 3, 2001.

¹⁵⁶ Elisabeth Rosenthal, "Spread of AIDS in rural China ignites protests," *New York Times*, December 11, 2001.

¹⁵⁷ James Kynge, "Chinese AIDS sufferers stage mass protest," *London Financial Times*, November 22, 2001.

¹⁵⁸ Tom Plate, "Ignorance fuelling China's AIDS pandemic," *South China Morning Post*, December 3, 2001.

¹⁵⁹ Pierre Haski, "La colère des contaminés de la misère du Henan monte à Pékin," *Liberation*, June 5, 2002.

¹⁶⁰ Agence France-Presse, "China to organize national conference on AIDS," October 1, 2001.

¹⁶¹ Philip P. Pan, "As China faces crisis, people with HIV are kept largely invisible: Beijing fears losing 'control of the message,'" *Washington Post Foreign Service*, November 20, 2001 and Reuters, "China's AIDS victims to seek help at national conference," November 11, 2001.

¹⁶² Agence France Presse, "Hundreds of police storm 'AIDS village' in China, arrest 13 farmers," July 3, 2003.

to the Henan epidemic.¹⁶³ 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."¹⁶⁴ The Chi Heng Foundation, based in Hong Kong, offers semi-underground AIDS education to male sex workers in Guangdong parks, brothels, and saunas.¹⁶⁵ 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.¹⁶⁶

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.¹⁶⁷ 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.¹⁶⁸ 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."¹⁶⁹ Article 21 of the ICCPR guarantees the right to peaceful assembly.¹⁷⁰ Article 22 guarantees the right to freedom of association with others.¹⁷¹

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."¹⁷² 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)."¹⁷³ General Comment

¹⁶³ Gao Yaojie, "My AIDS prevention journey."

¹⁶⁴ Tim McGirk and Susan Jakes, "Stalking a Killer," *Time Asia*, September 30, 2002.

¹⁶⁵ Chung To, presentation at Columbia University East Asian Institute, November 13, 2002.

¹⁶⁶ TRP reporting form, The Global Fund to Fight AIDS, Tuberculosis and Malaria, November 6, 2002.

¹⁶⁷ Universal Declaration of Human Rights, adopted and proclaimed by United Nations General Assembly resolution 217 A (III) on December 10 1948.

¹⁶⁸ International Covenant on Civil and Political Rights, G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976. China signed the ICCPR in October 1998.

Article 18 of the Vienna Convention on the Law of Treaties provides that signatory states are "obliged to refrain from acts which would defeat the object and purpose of a treaty."

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).

¹⁷² Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, "HIV/AIDS and Human Rights International Guidelines," paragraph 2.

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."¹⁷⁴

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."¹⁷⁵ 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,¹⁷⁶ 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."¹⁷⁷ 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".¹⁷⁸ 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.¹⁷⁹ 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."¹⁸⁰ 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.¹⁸¹

¹⁷⁴ Committee on Economic, Social and Cultural Rights, General Comment No. 14 (2000): "The right to the highest attainable standard of health", paragraph 11.

Regulations for Registration and Management of Social Organizations, State Council order no. 250, published September 25, 1998.

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

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

¹⁷⁸ Gunilla Riska, *NGOs in the GMS: Involvement Related to Poverty Alleviation and Watershed Management: Yunnan, China*, Regional Environmental Technical Assistance 5771: Poverty Reduction and Environmental Management in Remote Greater Mekong Subregion (GMS) Watersheds Project (Phase I), 1999. www.mekonginfo.org, retrieved March 1, 2003.

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

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

¹⁸¹ Commission on Human Rights, "The Protection of Human Rights in the Context of Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS)," Resolution 1995/44, adopted without a vote, March 3, 1995.

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.¹⁸⁸ It adds: "Those patients with STDs who have not been cured are for this reason not permitted to continue to work." 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,¹⁸⁹ 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 fang-zhi guanli tiaoli* [Chengdu City Regulations for the Prevention and Management of STIs and AIDS], passed at 17th meeting of the Chengdu City 13th People's Congress, October 27, 2000, ratified at the 12th meeting of the Sichuan Congress, Nov. 30, 2000, and *Jilin sheng xingbing fang-zhi guanli tiaoli* [Jilin province regulations for the prevention of sexually transmitted diseases], ratified at the eleventh meeting of the 7th Jilin party congress, November 7, 1992, article 9.

¹⁸³ Two signs posted in women's showers, Peace Hotel, Beijing, 2002.

¹⁸⁴ *Shanghai shi aizibing fang-zhi 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 fang-zhi banfa*, article 26.

¹⁸⁶ *Aizibing jiance guanli ruogan guiding* [Certain Number of Regulations on AIDS supervision and management], State Council, January 14, 1988, article 6.

¹⁸⁷ *Shanghai shi aizibing fang-zhi banfa*, article 19.

¹⁸⁸ *Liaoyang shi xingbing fang-zhi 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.

this answer: "Go home and wait to die!" This patient's heart was so burdened that he killed himself a few days later.
Adam Li, quoted in *The Final Battle*¹⁹⁰

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

¹⁹⁰ Li, *Zuihou de xuanzhan*, p. 177.

¹⁹¹ Human Rights Watch interview with Ji, Kunming, Yunnan, 2002.

¹⁹² Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.

¹⁹³ Agence France-Presse, "AIDS villages out of limelight 'ignored'," November 5, 2001.

¹⁹⁴ Human Rights Watch interview with Zhang, Beijing, 2002.

¹⁹⁵ U.S. Embassy Beijing, "AIDS in China: Yunnan province confronts HIV," December 2000, <http://www.usembassy-china.org.cn/sandt/yunnanbarth.html>, retrieved June 16, 2003.

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."¹⁹⁷

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.¹⁹⁸ 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.¹⁹⁹

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."²⁰⁰ 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.²⁰¹

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."²⁰² 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."²⁰³ These grounds include "health status (including HIV/AIDS)."²⁰⁴

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

¹⁹⁷ Human Rights Watch interview with Jenny S., Kunming, Yunnan, 2002.

¹⁹⁸ Human Rights Watch interview with Mao, Hong Kong, 2003.

¹⁹⁹ CCM, *2003 Proposal to the Global Fund*, June 2003, "Goal and expected impact," p. 30.

²⁰⁰ Gao Yanfang, "A friend to people with AIDS", *China Today*, April 2002.

²⁰¹ Human Rights Watch interview with Tao, Ruili, Yunnan, 2002.

²⁰² International Covenant on Economic, Social and Cultural Rights, article 12 (d).

²⁰³ CESCR General Comment 14, "The right to the highest attainable standard of health", paragraph 12 (b).

²⁰⁴ CESCR General Comment 14, paragraph 18.

issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.²⁰⁵ 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.”²⁰⁶

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.”²⁰⁷

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.”²⁰⁸ 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.²⁰⁹

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.²¹⁰ 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.²¹¹ 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, 2002.²¹² 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.²¹³ In 2003 national media publicized the wedding of an HIV-positive

²⁰⁵ CESCR General Comment 14, paragraph 18, and UNHCHR and UNAIDS, “HIV/AIDS and Human Rights International Guidelines,” paragraph 10.

²⁰⁶ UNHCHR and UNAIDS, “HIV/AIDS and Human Rights International Guidelines,” paragraph 11; and Commission on Human Rights resolution 1997/33, “The protection of human rights in the context of HIV and AIDS,” paragraph 11.

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.

²¹¹ People’s Daily, “Southwest China province set to lift AIDS marriage ban,” June 2, 2003, www.english.peopledaily.com.cn/200306/02/eng20030602_117567.shtml, retrieved July 31, 2003.

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.

couple in Sichuan.²¹⁴ 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,²¹⁵ 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.²¹⁶

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).²¹⁷ 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.²¹⁸ 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.²¹⁹ Some children whose parents die of AIDS live alone because relatives are afraid to take them in.²²⁰ 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.²²¹

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 2010,²²² 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.²²³

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

²¹⁴ *China Daily*, "First HIV/AIDS couple to wed," August 4, 2002.

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.

²¹⁶ He Sheng, "Long Road Ahead in Fight Against AIDS," *China Daily*, August 21, 2000; translated into English and posted on www.usembassy-china.org.cn/sandt/hivartic.htm on July 1, 2001; retrieved June 4, 2003; John Pomfret, "The High cost of selling blood," *Washington Post*, January 11, 2001; "AIDS media star stirs up debate in China," *Asian Economic News*, December 9, 2002; Leta Hong Fincher, "AIDS crusader," *VOA News*, October 2001.

²¹⁷ Wan Yanhai, "Children in AIDS-affected families: A survey of two villages in Henan province, PRC," published by Aizhi Health Education Institute, April 2003.

²¹⁸ Aizhi Health Education Institute, "Children/orphans and HIV/AIDS in China," April 2003.

²¹⁹ Human Rights Watch interview with Cao, Kunming, Yunnan, 2002.

²²⁰ Li Xiaorong, "AIDS orphans in China: Stigma, neglect, and opportunity for better care," written statement submitted to the Congressional Executive Committee on China, October 21, 2002.

²²¹ Li Xiaorong, "AIDS orphans in China: Stigma, neglect, and opportunity for better care."

²²² CCM, *2003 Proposal to the Global Fund*, June 2003, "Section III: General information about the country setting," p. 12.

²²³ Agence France-Presse, "Look after my son, pleads AIDS mother," October 18, 2002; Nicholas D. Kristof, "China's deadly cover-up," *The New York Times*, November 29, 2002.

permanently deprived of his or her family environment," including "alternative care for such a child."²²⁴ The CRC and the ICESCR also guarantee the right to education, and prohibit discrimination in access to education.²²⁵

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.²²⁶

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.²²⁷

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."²²⁸ In Guangzhou, "a tiny, grass-roots-run care home for people with HIV/AIDS has been forced by landlords to move twice."²²⁹ 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.²³⁰

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.

²²⁴ Convention on the Rights of the Child, adopted November 20, 1989, G.A. Res. 44/25, U.N. Doc. A/RES/44/25, entered into force September 2, 1990; article 20. China ratified the CRC March 2, 1992.

²²⁵ Convention on the Rights of the Child, articles 2(1), 2(2), 28(1); International Covenant on Economic, Social and Cultural Rights, articles 2(2), 13.

²²⁶ Human Rights in China, *Institutionalized Exclusion: The tenuous legal status of internal migrants in China's major cities* (New York, November 6, 2002).

²²⁷ Human Rights Watch interview with Zhang, Beijing, 2002.

²²⁸ Elisabeth Rosenthal, "Despite Law, China's HIV Patients Suffer Bias," *New York Times*, January 14, 2003.

²²⁹ Francis Markus, radio report, BBC World Service East Asia Today, December 30, 2002.

²³⁰ Odilon Couzin, "Denial in China," Background Briefing, Radio National, November 10, 2002.

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,²³¹ 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.²³² Local regulations in, for instance, Jinan city, use similar language to permit quarantine during HIV-testing.²³³

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!*]"²³⁴ 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.²³⁵

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.²³⁶

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 guanli 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.

²³⁴ Human Rights Watch interview with Law, Hong Kong, 2003.

²³⁵ Human Rights Watch interview with Law, Hong Kong, 2003.

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

²³⁷ Li Hujun, "AIDS Legislation Hearing: Ideal and reality" [*Aizi lifa tingzheng: mosi yu xianshi*], *Southern Weekend* [*Nanfang Zhoumo*], November 23, 2002.

²³⁸ United Nations HIV/AIDS and Human Rights International Guidelines, paragraph 28(d).

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.

²⁴¹ U.N., "HIV/AIDS and Human Rights International Guidelines," paragraph 3.

²⁴² Universal Declaration of Human Rights, article 7.

²⁴³ ICESCR, article 2; ICCPR, article 2.

²⁴⁴ U.N., "HIV/AIDS and Human Rights International Guidelines," paragraph 5.

patients," but as policies, these lack any mechanisms for enforcement.²⁴⁵ 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,²⁴⁶ and the right of individuals to choose their own residence is guaranteed by article 12 of the ICCPR.²⁴⁷ Article 13 of the ICESCR guarantees everyone the right to education.²⁴⁸

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."²⁴⁹ 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."²⁵⁰ 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,"²⁵¹ 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.

²⁴⁸ International Covenant on Economic, Social and Cultural Rights, article 13.

²⁴⁹ U.N., "HIV/AIDS and Human Rights International Guidelines," paragraph 7.

²⁵⁰ *Ibid.*, paragraph 11.

²⁵¹ National Congress of the Communist Party of China, Constitution of the Communist Party of China, Amended and adopted at the Sixteenth National Congress of the Communist Party of China on November 14, 2002. From *Documents of the Sixteenth National Congress of the Communist Party of China (2002)* (Beijing: Foreign Languages Press, 2002), p. 82. See p. 14 for a discussion of the term "socialist spiritual civilization."

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.²⁵² According to official figures, at least 72 percent of people living with HIV/AIDS in China are injection drug users,²⁵³ 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.²⁵⁴ "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.²⁵⁵ 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.²⁵⁶

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.²⁵⁷

In accordance with the *Methods of Forced Detoxification*,²⁵⁸ 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.²⁵⁹ 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,²⁶⁰ the police sentence alleged injection drug users under the *Methods of Forced Detoxification* without trial or any other semblance of due process. Injection drug

²⁵² CCM, *2003 Proposal to the Global Fund*, June 2003, p. 6.

²⁵³ National Center for HIV, STD and TB Prevention, Centers for Disease Control and Prevention, and U.S. Department of Health and Human Services; *Report of an HIV/AIDS Assessment in China*, July 30-August 10 and August 28-30, 2001, www.usembassy-china.org.cn/sandt/ptr/CDCAssessment_prt.htm, retrieved May 14, 2003.

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).

²⁵⁵ CCM, *2003 Proposal to the Global Fund*, June 2003, "HIV/AIDS situation analysis," p. 6.

²⁵⁶ Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.

²⁵⁷ Human Rights Watch interview with Wu, Kunming, Yunnan, 2002.

²⁵⁸ State Council, *Methods for Forced Detoxification* [*Qiangzhi jiedu banfa*], January 12, 1995.

²⁵⁹ For more information on reeducation through labor, see "Reeducation through labor in China,"

<http://www.hrw.org/campaigns/china-98/laojiao.htm>.

²⁶⁰ Human Rights Watch correspondence with Wang, legal expert, Beijing, 2003.

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.²⁶¹ 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."²⁶² Medical treatment at Changpo consists of an herbal remedy called "626"²⁶³ that was manufactured, tested, and distributed by a pharmaceutical company located on the grounds of the forced detoxification center.²⁶⁴

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."²⁶⁵

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."²⁶⁶

Longer-term detainees appeared to have some supervisory roles over newer arrivals, in what NGO worker Alex Z. described as "a cell boss system."²⁶⁷ A foreign journalist described them as "Dickensian labor camps funded by local and provincial governments and run by corrupt guards."²⁶⁸

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.²⁶⁹

²⁶¹ State Council, *Methods for Forced Detoxification* [*Qiangzhi jiedu banfa*], article 7.

²⁶² State Council, *Methods for Forced Detoxification*, article 2.

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.

²⁶⁵ Human Rights Watch interview with Robin Y., Kunming, Yunnan, 2002.

²⁶⁶ Human Rights Watch interview with Wen, Kunming, Yunnan, 2002.

²⁶⁷ Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.

²⁶⁸ Joshua Kurlantzick, "China's Drug Problem and Looming HIV Epidemic," *World Policy Journal*, Summer 2002, pp. 70-75; p. 74.

²⁶⁹ Human Rights Watch interview with Kong, 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."²⁷⁰ 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.²⁷¹

Conditions appeared to be only marginally better at larger facilities, where Kong recalled sleeping several to a bed.²⁷² 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.²⁷³ Xiao, an NGO worker, recalled the population of Changpo during the Flower Expo as closer to 5,700.²⁷⁴

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."²⁷⁵

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.²⁷⁶

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.²⁷⁷

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,

²⁷⁰ Human Rights Watch interview with Wu, Kunming, Yunnan, 2002.

²⁷¹ Human Rights Watch interview with Alex Z., Kunming, Yunnan, 2002.

²⁷² Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

²⁷³ Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.

²⁷⁴ Human Rights Watch interview with Xiao, Kunming, Yunnan, 2002.

²⁷⁵ Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

²⁷⁶ Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

²⁷⁷ Human Rights Watch interview with Kong, 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

²⁷⁸ Human Rights Watch visit to Changpo, Yunnan, 2002.

²⁷⁹ See, e.g., UNAIDS, WHO, U.S. Agency for International Development, and the U.S. Centers for Disease Control, "Guidelines for Using HIV Testing Technologies in Surveillance: Selection, Evaluation, Implementation," Geneva, 2001, pp. 4-5. Available online at <http://www.unaids.org/publications/documents/epidemiology/surveillance/JC602-HIVSurvGuidel-E.pdf> (retrieved June 25, 2003).

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.

²⁸² Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002.

²⁸³ Human Rights Watch interview with Wu, Kunming, Yunnan, 2002.

²⁸⁴ Human Rights Watch interview with Xiao, Kunming, Yunnan, 2002.

²⁸⁵ Human Rights Watch interview with Officer Shang, Kunming, Yunnan, 2002. 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.

²⁸⁶ Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

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.²⁸⁷ NGO workers and others believed it could be even higher; one noted that some drug users avoid reincarceration by paying bribes to police officers.²⁸⁸ "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."²⁸⁹

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."²⁹⁰

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."²⁹¹ 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

²⁸⁷ CCM, *2003 Proposal to the Global Fund*, June 2003, "HIV/AIDS situation analysis," p. 6.

²⁸⁸ Human Rights Watch interview with Wen, Kunming, Yunnan, 2002.

²⁸⁹ Human Rights Watch interview with Kong, Kunming, Yunnan, 2002.

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.”²⁹² 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....”²⁹³ 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.²⁹⁴ Those convicted of crimes should have the right to a review of the conviction “by a higher tribunal according to law.”²⁹⁵ 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.”²⁹⁶

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.²⁹⁷

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.”²⁹⁸

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.²⁹⁹ 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.”³⁰⁰ Principle 24 of the Basic Principles for the Protection of All Persons under Any Form of Detention or Imprisonment states:

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).

²⁹³ Manfred Nowak, *U.N. Covenant on Civil and Political Rights: CCPR Commentary*, Arlington: N.P. Engel Publisher, 1993, p. 160.

²⁹⁴ International Covenant on Civil and Political Rights, article 14 (1) and (2).

²⁹⁵ International Covenant on Civil and Political Rights, article 14 (5).

²⁹⁶ Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, G.A. res. 43/173, annex, 43 U.N. GAOR Supp. (No. 49) at 298, U.N. Doc. A/43/49 (1988), principle 11 (1).

²⁹⁷ Human Rights Watch, *Anthems of Defeat: Crackdown in Hunan Province, 1989-92* (New York: 1992); Human Rights Watch, *Reeducation through labor in China*, 1998, www.hrw.org/campaigns/china-98/laojiao.htm; Amnesty International, *Torture: A growing scourge in China – time for action*, Feb. 12, 2001, www.amnesty.ca/stoptorture/chinareport.pdf, retrieved August 14, 2003; in Chinese, see Amnesty’s website for information on prison conditions, the use of torture and Chinese law at www.endtorture.org.

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

³⁰¹ Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment, G.A. res. 43/173, annex, 43 U.N. GAOR Supp. (No. 49) at 298, U.N. Doc. A/43/49 (1988), paragraph 24.

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.

³⁰⁵ International Labor Organization, Governing Body 284th Session, June 2002, posted at <http://www.ilo.org/public/english/standards/relm/gb/docs/gb284/index.htm>, retrieved August 14, 2003.

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

(d) the elimination of discrimination in respect of employment and occupation (conventions 138 and 181)." ILO Declaration on Fundamental Principles and Rights at Work, article 2, posted at <http://www.ilo.org/public/english/standards/decl/declaration/text/>, retrieved August 14, 2003.

³⁰⁷ ILO Convention 29, article 12, posted at <http://www.humanrightslebanon.org/Con29.htm>, retrieved August 14, 2003.

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

³⁰⁹ See, e.g., UNAIDS, WHO, U.S. Agency for International Development, and the U.S. Centers for Disease Control, “Guidelines for Using HIV Testing Technologies in Surveillance: Selection, Evaluation, Implementation,” Geneva, 2001, pp. 4-5. Available online at <http://www.unaids.org/publications/documents/epidemiology/surveillance/JC602-HIVSurvGuidel-E.pdf> (retrieved June 25, 2003).

³¹⁰ WHO, *HIV/AIDS in Asia and the Pacific Region 2001*, p. 42.

³¹¹ CCM, *2003 Proposal to the Global Fund*, June 2003, “HIV/AIDS Programme Capacity,” p. 19.

³¹² China CDC and U.S. CDC, “Joint HIV surveillance and laboratory assessment,” (Beijing, China and Atlanta, U.S.A., 2002), p. iv.

³¹³ China CDC and U.S. CDC, “Joint HIV surveillance,” p. 26.

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 [*jing*] 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

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.

³²¹ Human Rights Watch correspondence with Wang, legal expert, Beijing, 2003.

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.³²²

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.³²³ 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.³²⁴

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.³²⁵

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.³²⁶ 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.”³²⁷ 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.”³²⁸ 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.³²⁹

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

³²² Nick Young, “Chinese scholars call for AIDS rules based on respect for individual rights,” *Canadian HIV/AIDS Policy and Law Review* vol 7.2/3 (December 2002).

³²³ *Beijingshi shishi aizibing jiance guanli de 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.

³²⁵ “*Xiangmu jieshao zhiyi: Aizibing guanlian xiangmu* [Introduction to one of the programs: The AIDS care program,” *Fenghuang Niepan* [Phoenix Nirvana] no. 1 (Kunming: Daytop Center, 2002), p. 10.

³²⁶ UNAIDS and WHO Working Group on Global HIV/AIDS and STI Surveillance, “Guidelines for Second Generation HIV Surveillance: Second Generation Surveillance for HIV: The Next Decade,” 2000; p. 27.

³²⁷ 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 5.

³²⁸ U.N., “HIV/AIDS and Human Rights International Guidelines,” guideline 3, paragraph 28(b).

³²⁹ CESCR, General Comment no. 14, para. 8

publicize or transmit the names, addresses or information about the situation."³³⁰ 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."³³¹ 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."³³²

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

³³¹ *Xingbing fangzhi guanli banfa* [Methods for prevention and management of sexually transmitted diseases], Ministry of Health, Aug. 12, 1991, article 17.

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).

"I'll just go away and wait to die"³³³

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.³³⁴ In its application to the Global Fund, the China coordinating committee writes: "There is no estimation on the prevalence of nosocomial³³⁵ 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."³³⁶

Yet despite the attention drawn to the problem of people living with HIV/AIDS who were infected through hospital negligence,³³⁷ 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.³³⁸ 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.³³⁹

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.³⁴⁰ 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.³⁴¹

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.³⁴² Similar "accident treatment covenants" (*yiliao shigu chuli tiaolie*) were reportedly required of patients by Guangzhou hospitals.³⁴³ In April 2003 Chinese media reported the case of a Guangzhou patient who

³³⁴ U.S. Embassy-Beijing, "Recent Chinese Reports on HIV/AIDS and Sexually Transmitted Diseases," July 1, 2001, www.usembassy-china.org.cn/english/sandt/hivartic.html, accessed October 1, 2002.

³³⁵ The term "nosocomial" refers to infections that take place in a hospital or other health facility.

³³⁶ CCM, 2003 Proposal to the Global Fund, June 2003, p. 62.

³³⁷ Li, "Xiao Lide gushi" [Li Junior's story], *Zuihoude xuanzhan*, p.172-3.

³³⁸ Agence France Presse, "Hospital ordered to pay HIV family," November 9, 2001.

³³⁹ Mark O'Neill, "Widower wins payout for AIDS-tainted blood", *South China Morning Post*, June 4 2001.

³⁴⁰ Human Rights Watch interview with Jack S., Beijing, 2002.

³⁴¹ Human Rights Watch interview with Zhang, Beijing, 2002.

³⁴² Human Rights Watch interview with Zhang, Beijing, 2002.

³⁴³ Boxun news, "Bingren shoushu jing yao qian 'Shuxue ran aizi bu guan yiyuan shi' tongyi shu" [Surgery patients unexpectedly required to sign "Blood donors with AIDS transmission won't involve the hospital" agreements], Boxun.com, posted September 13, 2002, accessed September 13, 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.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."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."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, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation."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."³⁴⁸

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.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.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."³⁵¹ Speaking of tuberculosis, Dr. Daniel Chin of the World Health Organization in Beijing observed:

³⁴⁴ "Infected with HIV by blood transfusion and hospital is not responsible? Authorities say details must be analyzed," China News Net, April 18, 2003, posted on <http://china-aids.org/english/News/News074.htm>, retrieved July 30, 2003.

³⁴⁵ International Covenant on Economic, Social and Cultural Rights, article 12.

³⁴⁶ CESCR General Comment 14, "The right to the highest attainable standard of health", paragraph 36.

³⁴⁷ CESCR General Comment 14, paragraph 12 (d).

³⁴⁸ UNAIDS, "HIV/AIDS and Human Rights International Guidelines," paragraph 28 (h) and (i).

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.

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.

³⁵¹ CCM, 2003 Proposal to the Global Fund, June 2003, p. 19.

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

³⁵² Richard Harris, "SARS highlights need to address TB," Morning Edition, National Public Radio, June 6, 2003.

³⁵³ CCM, *2003 Proposal to the Global Fund*, June 2003, "Goal and expected impact," p. 30.

³⁵⁴ Some scholars advocate for the use of less expensive measures to monitor treatment in developing countries, such as total lymphocyte count (TLC). See T. Flanigan, A. Mahajan, N. Kumarasamy, K. Mayer, C. Carpenter, and S. Solomon, "Total Lymphocyte Count (TLC) as a Surrogate for CD4 Count to Initiate and Monitor HAART in Resource-Limited Countries." Poster presentation, "Antiretroviral Chemotherapy in Resource Limited Settings," Ninth Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002.

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.

³⁵⁷ People's Daily Online, "Few AIDS Patients in China Can Afford Standard Treatment", September 17, 2002, http://english.peopledaily.com.cn/200209/17/eng20020917_103354.shtml. These numbers should be taken with a grain of salt: the same article claims that there are only 200,000 HIV-positive people in China.

³⁵⁸ CCM, *2003 Proposal to the Global Fund*, June 2003, "HIV/AIDS situation," p. 18.

³⁵⁹ BBC News, "China may break AIDS drug patents," September 6, 2002.

³⁶⁰ AP, "China denies plans to make AIDS drugs," September 9, 2002.

³⁶¹ People's Daily, "Chinese, US Scientists Launch AIDS Treatment Study in South China," Oct. 23, 2002, <http://english.peopledaily.com.cn>.

producing AZT for export.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).³⁶³ As of mid-2003 generic antiretroviral treatment in Beijing costs about RMB 470 (U.S. \$47) per month.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.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.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.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."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.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 *People's Daily*, reported in 2002 that only two hundred Chinese people living with HIV/AIDS could afford regular treatment.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."³⁷¹

³⁶² Francis Markus, "China to get cheaper AIDS drug", BBC, Aug. 16, 2002.

³⁶³ Reuters, "China to Start AIDS Drug Mass-Production in January", Dec 30, 2002.

³⁶⁴ Human Rights Watch interview with Tang, New York, 2003.

³⁶⁵ Trizivir consists of zidovudine, lamivudine and abacivir in a single pill that is taken twice daily. *People's Daily*, "Chinese, US Scientists Launch AIDS Treatment Study in South China," <http://english.peopledaily.com.cn>, Oct. 23, 2002.

³⁶⁶ Kaiser Daily HIV/AIDS report, October 22, 2002, www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=14165

³⁶⁷ "Home-made AIDS drugs planned for Henan," South China Morning Post, January 28, 2003.

³⁶⁸ Martin Fackler, "Chinese company distributes anti-AIDS 'cocktail'," Associated Press, January 28, 2003.

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).

³⁷⁰ *People's Daily Online*, "Only 200 AIDS-sufferers Can Afford Regular Treatment."

³⁷¹ Personal communication by Yang, e-mail, April 2003.

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.³⁷² AIDS activist Zhang reports that most private medical insurance plans in Beijing contain provisions that specifically exclude HIV/AIDS.³⁷³ 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."³⁷⁴

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 2010.³⁷⁵ 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.³⁷⁶ 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.³⁷⁷ 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.³⁷⁸

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."³⁷⁹

³⁷² Guo Nei, "Health reform eases cash burden," *China Daily*, December 16, 2002.

³⁷³ Human Rights Watch interview with Zhang, Beijing, 2002. Human Rights Watch attempted to contact insurance agencies in Beijing but was not able to confirm this allegation.

³⁷⁴ Guo Nei, "Health reform..."

³⁷⁵ Guo Nei, "Health reform..." and Zhang Feng, "Village health care to improve," *China Daily*, November 21, 2002.

³⁷⁶ Zhang Feng, "Village health care to improve."

³⁷⁷ State Administration of Traditional Chinese Medicine and Pharmacology, "Chinese Herbal Medicines," http://www.satcm.gov.cn/english_satcm/zhongyao.htm, retrieved on August 18, 2003.

³⁷⁸ Sandra Hyde, "Sex Tourism," *China Urban*, p151.

³⁷⁹ International Chinese Herbal Medicine Functional Research Center, "Introduction of our research center," <http://www.herbaid.com/e-index.htm>, retrieved August 18, 2003. The center requests volunteer "AIDS cases" for medical trials, noting however that "the patient must be still alive."

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 Xincui, 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.³⁸⁰ The treatment is free in the beginning, but will require fee payment later, according to a researcher who interviewed participating AIDS patients.³⁸¹

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."³⁸²

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.³⁸³ For instance, anti-epidemic station officials in Xincui 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 Xincui 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.³⁸⁴

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.³⁸⁵

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.³⁸⁶

³⁸⁰ Human Rights Watch interview with Jack S., Beijing, 2002. A Human Rights Watch researcher inspected the bottle.

³⁸¹ Ibid.

³⁸² Human Rights Watch interview with Jack S., Beijing, 2002.

³⁸³ Personal communication with NGO worker Cho, Hong Kong, 2003.

³⁸⁴ Human Rights Watch interview with Jack S., Beijing, 2002. The numbers on the 100 ml. bottle of *AiBeiKe* were: *zhizing biaojun* [implementation standard]: Q/ZGB001-2000, *pijin wenhao* [approval number]: [2000] 0154. A Human Rights Watch researcher inspected the bottle.

³⁸⁵ Li, *Zuihoude xuanzhan*, p. 19.

³⁸⁶ In the U.S., transfusion of untested blood supplies in the 1980s facilitated the spread of HIV: See Patricia D. Siplon, "Blood Policy in the Age of AIDS," in Patricia D. Siplon, *AIDS and the Policy Struggle in the United States* (Washington, D.C.: Georgetown University Press, 2002), pp. 42-66. For an excellent narrative account of the growth of a grass-roots movement in the U.S. that among other things pushed for accountability for safety of blood supplies, see Randy Shilts, *And*

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

the Band Played On: Politics, People and the AIDS Epidemic (New York: St. Martin's Press, 1987). In France, nearly 2,000 people were infected with HIV through blood transfusions, leading to prison sentences for high-ranking officials: see J.B. Brunet, "Contamination of blood by HIV in France: facts, controversies and impact on society," *Annual Conference of the Australasia Society of HIV Medicine*, vol. 5 no. 19, October 28-30, 1993. In Ireland, many women were infected with Hepatitis C via "Anti-D" immunoglobulin from the 1970s to 1990s: see "Tribunal report on outbreak of hepatitis C infection due to contaminated anti-D in Republic of Ireland sheds light on natural history of infection," *Eurosurveillance Weekly*, vol. 1 no. 4, 1997. For a recent case in India, see DH News Service, "HIV-infected blood sold to patient," *Deccan Herald*, April 23, 2003.

³⁸⁷ See especially Elisabeth Rosenthal's "Silent Plague" series in the *New York Times*: "Despite Law, China's H.I.V. Patients Suffer Bias", *New York Times*, January 14, 2003; "AIDS Scourge in Rural China Leaves Villages of Orphans", *New York Times*, August 25, 2002; "AIDS Patients in China Lack Effective Treatment", *New York Times*, November 12, 2001; "Blood and Tears: a Chinese Family's Ordeal in a Nation in Denial of AIDS", *New York Times*, September 16, 2001; "SILENT PLAGUE: A special report; Deadly Shadow Darkens Remote Chinese Village", *New York Times*, May 28, 2001; and "In Rural China, A Steep Price of Poverty: Dying of AIDS", *New York Times*, October 28, 2000.

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.]

³⁹⁰ Human Rights Watch interview with Cho, NGO worker, Hong Kong, 2003.

of injections were unsafe due to poor sterilization and other unsafe practices.³⁹¹ 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.³⁹²

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.³⁹³ "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.³⁹⁴

These and other charges were outlined in a widely-circulated essay by a pseudonymous AIDS activist, He Aifang.³⁹⁵ 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.³⁹⁶ She recalls:

³⁹¹ *Recent reports on HIV/AIDS and STDs in China*, July 1, 2001, usembassy-china.org.cn/english/sandt/hivartic.htm, retrieved February 12, 2002.

³⁹² *ibid*

³⁹³ He Aifang, *Revealing the "Blood Wound" of the Spread of HIV/AIDS in Henan Province*, November 28, 2000, www.usembassy-china.org.cn/english/sandt/henan-hiv.htm, retrieved Feb. 12, 2002; Wan Yanhai, *Jiankang bao: Henan renmin jiankangde zhexiubu* [The Health Times: The fig leaf over the health of the people of Henan], January 30, 2001, <http://www.aizhi.org/news/jkb2.htm>, retrieved June 18, 2003; Zhongguo zhengfu he shehui dui aizibingde fanying [The negative response of China's government and society to AIDS], <http://www.aizhi.org/shyx/aidsreaction.txt>, retrieved June 18, 2003; *Recent reports on HIV/AIDS and STDs in China*, July 1, 2001, www.usembassy-china.org.cn/english/sandt/hivartic.htm, retrieved Feb. 12, 2002; Elisabeth Rosenthal, "Deadly shadow of AIDS darkens remote Chinese village," *The New York Times*, DATE 2001; Odilon Couzin, "Background Briefing: Denial in China," ABC Radio National, October 11, 2002.

³⁹⁴ Agence France Presse, "Chinese village dying of AIDS neglected and left to rot," March 20, 2001.

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.³⁹⁷

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.³⁹⁸ 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.³⁹⁹

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.⁴⁰⁰ 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.⁴⁰¹

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.⁴⁰²

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—

³⁹⁷ Gao Yaojie, "My 'AIDS Prevention' Journey", May 1, 2001, http://iso.hrichina.org:8151/iso/article.adp?article_id=613&subcategory_id=10, retrieved May 21, 2002.

³⁹⁸ Gao Yaojie, "My AIDS prevention journey."

³⁹⁹ Agence France Presse, "Doctor fighting for Chinese AIDS victims banned from going to U.S.," May 29, 2001.

⁴⁰⁰ DPA, "Illegal blood trading fueling HIV infections, China admits," August 23, 2001.

⁴⁰¹ Reuters, "China admits 'very serious' AIDS epidemic," August 23, 2001.

⁴⁰² *Unofficial Translation of June 25 China AIDS Action Plan: China's Action Plan for Reducing and Preventing the Spread of AIDS, 2001-2005*, State Council Office document no. 2001-40, translated into English and posted on www.usembassy-china.org.cn/english/sandt, retrieved October 1, 2002.

—were also sites of blood tainting scandals.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,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).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.⁴⁰⁶ The need to crack down on blood collection centers was discussed prominently in the country's second national AIDS action plan.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.⁴⁰⁸ Beijing announced plans to phase out compulsory blood donation programs over three years in the city.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.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.⁴¹¹ Some parents, unable to find treatment for HIV-positive children in Henan, are forced to watch them waste away without treatment.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.⁴¹³

In 2002 UNAIDS wrote that:

⁴⁰³ CCM, *2003 Proposal to the Global Fund*, June 2003, p. 13.

⁴⁰⁴ *Ibid.*, p. 14.

⁴⁰⁵ *Ibid.*, p. 13. Given the state's consistent minimization of the blood scandal, these percentages are probably underestimates.

⁴⁰⁶ *Xue-zhan guanli banfa* [Methods for the management of blood stations], Health department publication no. 2, September 21, 1998.

⁴⁰⁷ 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. 1.

⁴⁰⁸ *Recent reports on HIV/AIDS and STDs in China...*

⁴⁰⁹ Raymond Li, "Compulsory blood donations to be phased out," *South China Morning Post*, November 5, 2001.

⁴¹⁰ Elisabeth Rosenthal, "Spread of AIDS in rural China ignites protests," *The New York Times*, December 11, 2001.

⁴¹¹ Steve Friess, "Enter the Dragon," *POZ*, December 2001,

www.poz.com/archive/december2001/inside/enterthedragon.html, retrieved August 7, 2002; Odilon Couzin, "Background briefing: Denial in China," Australian Broadcasting Corporation Radio National, October 11, 2002.

⁴¹² Peter S. Goodman, "In China, AIDS crisis is at the mercy of global commerce," *Washington Post*, December 5, 2002; Elisabeth Rosenthal, "AIDS patients in China lack effective treatment," *The New York Times*, November 12, 2001.

⁴¹³ Agence France-Presse, "Look after my son, pleads AIDS mother," October 18, 2002; Nicholas D. Kristof, "China's deadly cover-up," *The New York Times*, November 29, 2002.

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

⁴¹⁴ UNAIDS, *HIV/AIDS: China's Titanic Peril*, June 2002, p. 17.

⁴¹⁵ Agence France Presse, "Villagers Dying of AIDS Make Desperate Appeal for Help," Beijing, May 30, 2001.

⁴¹⁶ Wan Yanhai, "Mai xue chuanbo aizibing he guojia jimi [The transmission of AIDS through blood sales and national secrets]," Aizhi Action Project press release, December 28, 2002.

⁴¹⁷ Henan province health department, "Ma Jianzhong ren Henan weishengting dangzu shuji, tingzhang. Liu Quanxi ren sheng renda jiaokewen wei gongzuoweiyuan hui fuzhuren [Ma Jianzhong becomes Henan health department Party secretary, department director. Liu Quanxi becomes deputy director of the provincial people's congress education, science and culture health work committee.]," press release, February 21, 2003.

⁴¹⁸ He Aifang, *Revealing the "Blood Wound"*...

⁴¹⁹ *People's Daily*, "Li Changchun—Politburo Standing Committee Member of CPC Central Committee," November 15, 2002.

⁴²⁰ Mure Dickie, "Stringent new rules on AIDS proposed by China," *Financial Times*, August 15, 2003.

⁴²¹ Leu Sieu Ying and Bill Savadove, "WHO says mainland officials continue to hinder investigation", *South China Morning Post*, April 1, 2003; "China's efforts lead to decreasing SARS cases," *People's Daily*, April 3, 2003, <http://english.peopledaily.com.cn>, retrieved April 3, 2003.

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.

⁴²² Hu Jia, "AIDS yu SARS: Shijie weisheng zuzhi kaocha Henan aizibing cunzhuang jilu [AIDS and SARS: Record of the World Health Organization investigation in Henan and an AIDS village crackdown]," electronic mail, May 26, 2002.

⁴²³ Human Rights Watch, "China: Police violence against HIV-positive protestors escalates," July 9, 2003, <http://www.hrw.org/press/2003/07/china070903.htm>,

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.

