

AIDS Orphans in China: Stigma, Neglect, and Opportunity for Better Care

**Written statement submitted to
Congressional-Executive Commission on China
Roundtable: "China's Children: Adoption, Orphanages, and Children with Disabilities"
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I would like to thank the Congressional-Executive Commission on China for the opportunity to submit this statement for its record on the "AIDS orphans" in Henan Province, China.

As a scholar trained in philosophy, my expertise is in ethical studies of human rights, particularly in the areas of women rights, reproductive health, and cultural values. During this initial year of my editorship at the journal *Humanity and Human Rights* (since February 2002), I have focused on human rights issues raised by China's responses to its HIV/AIDS epidemic. This focus is a response to the reports from China of a rapid spread of the virus through unsanitary practices during blood sales in Henan Province. I am fortunate to have worked with local doctors and health professionals as well as activists. They work closely with infected villagers and leaders of village committees in Henan and have documented the epidemic first-hand. Their courageous efforts have often been frustrated and they have personally been harassed by authorities. I see my work as part of their effort to raise awareness about the human rights and humanitarian aspects of the epidemic and to gain international assistance to victims. Through this involvement, I have taken on an academic interest in the issues and have followed events closely. Currently, I am working with my colleagues at the University of Maryland and a team of experts to propose a study of the ethical challenge of social stigma and HIV/AIDS in China. This statement is based upon research conducted for the proposed study.

1. Overview

The HIV/AIDS epidemic is one of the worst health catastrophes in contemporary China. The UNAIDS report, "HIV/AIDS: China's Titanic Peril," estimates that more than one million Chinese are living with HIV and the numbers could grow to 10 million by 2010; and that 100,000 people will develop AIDS every year. Between 100,000 and 120,000 people have died. The HIV/AIDS epidemic is related to plasma collection, intravenous drug use, sexually transmitted diseases (spread through prostitution, and both heterosexual and homosexual activities) and has hit particularly hard in the provinces of Henan, Yunnan, Xinjiang Uygur Autonomous Region, Guangxi Zhuang Autonomous Region, Anhui, Sichuan, Guangdong, Jiangxi, Shanghai and Beijing. Despite controversies over estimates, millions of children will be affected by the epidemic - becoming orphaned, for example - and infected with the virus. Until recently, the Chinese government had not publicly acknowledged the large number of persons living with HIV/AIDS in China and had systematically given lower estimates.

However, AIDS is more than a health catastrophe. The rapid spread of HIV/AIDS in China in the past 15 years is the result of persistent human rights violations. Lack of political accountability, corruption, censorship, and discriminatory policies against women, rural residents, migrant workers, homosexuals, and ethnic minorities, have fueled ignorance, prejudice, and fear. These conditions hinder efforts to prevent and manage this preventable and manageable disease.

The groups most negatively affected by this epidemic include those who are most vulnerable to human rights abuses in China: women, poor rural residents and ethnic minorities, homosexuals, migrant laborers, and their children, particularly the "AIDS orphans." AIDS orphans are those children who lost one or both parents to

AIDS and those whose parents are living with HIV/AIDS and can no longer care for their children. Most of these orphans are not themselves infected with HIV, but they suffer from extreme poverty, neglect, discrimination, and isolation. Many of them are forced out of schools. Many AIDS orphans languish in rural areas of Henan Province, where, according to the "AIDS doctor" Dr. Gao Yaojie, who treat the villagers, possibly one million people have been infected from unsanitary practices during commercial plasma collections.

In spite of some public statements about the need to care for children infected with the virus, there has been little government response due to insufficient political commitment, inadequate allocation of resources, and over-emphasis on HIV/AIDS as a medical (rather than social and political) condition. The lack of good governance (including participation in policy making by people living with HIV/AIDS - and affected communities as well as grassroots advocacy groups) and the absence of free flow of information, and awareness and preventive programs have all contributed to the suffering of AIDS orphans. The defunct health care system in rural China and the increasing costs in education for rural children have further worsened the plight of AIDS orphans.

2. The AIDS Orphans

Gao Yan, an 11-year-old boy, lived alone, in fear, isolation, and despair. At night, he curled up on the mud floor in the empty shack where his family once lived. The shack had no roof and parts of the walls were crumbling. He lived on handouts from neighbors. Donations I sent never seemed to reach him. Anything valuable in the house had been sold to pay for medical bills and food. His mother died of AIDS in December 2000 and his father died of the same disease in August 2001. Gao Yan and his 14-year-old sister, Gao Li, went to live with different relatives. But the relative soon threw Gao Yan out, citing financial burdens. His sister lived with a kinder relative in another village. Having dropped out of school to care for her sick parents, she managed to return to school, with help from the principal of a local school, who resisted pressure from other parents to force her to drop out. But students avoided her... (From "Save AIDS Orphans," by Dr. Gao Yaojie)

How many orphans like Gao Yan and Gao Li are there in Henan? In China? How many have dropped out of school? What do they live on? There has been little public information about them and little has been done to provide care and protection for them. In May 2002, a French TV station first made known China's AIDS orphans when its crew interviewed and filmed eight Henan villagers who had traveled to Beijing to petition the authorities. Two of them were children whose parents had died of AIDS. It was the first international exposure to the problem of China's AIDS orphans.

Individual health professionals and Chinese advocacy groups estimate that one million people are infected with HIV in Henan, contesting the UN estimates. A study by an advocacy group found that in Zhumadian prefecture's Shangcai County alone (population 1.3 million, with 1.2 million rural residents) at least 34,000 people have tested HIV positive and that there have been more than 3,000 reported AIDS-related deaths. In 80 (out of 510) villages in the county, each has more than 100 people who have tested positive or more than 10 AIDS-related deaths. In Houyang village, of Shangcai county, population 4,000, 160 people have died of AIDS in the past five years. At least nine prefectures/townships in the province have been hard hit. (Wan, September 2002)

Among the reported HIV/AIDS-related deaths in Henan, 80.7% are male, 18% female; 53.6% are between the age of 20-29. The men and women in their prime were more likely to travel to towns and cities to sell blood. The rate of infection among those who sold blood is between 45-50%. For rural families, this means that the family providers from the "sandwich generation" suffered the heaviest losses, leaving behind them infected spouses, elderly parents, and young children, with hardly any source of income and social support.

Since 1996, Dr. Gao visited more than one hundred villages in Henan, to assess the epidemic and provide information and care for more than 1,000 HIV-infected people who live in these villages. Dr. Gao received more than 5,000 letters from villagers. Dr. Gao found that the ratio between persons living with HIV/AIDS who are married with children and the orphans that will be left behind is approximately one and a half child for every one parent. In one elementary school located in a hard hit rural area, where the principal is committed to helping the orphans stay in school, Dr. Gao counted 19 AIDS orphans among the approximately 100 students in April 2001. Seven AIDS orphans graduated last year but 23 started school at the same time.

Among the more than 300 orphans whom Dr. Gao has helped, some live alone, because relatives and fellow villagers stayed away for fear of contracting the disease. Some live in the streets and survive by begging. Some of them, as young as 10, become caretakers for their sick parents and elderly grandparents. They tend to the families' farming land, or find work in coalmines and at construction sites. Some of the younger children have been sent to orphanages by their relatives.

One advocacy group found that at least 3,000 children in Shangcai County lost one or both parents; most of these children are now out of school due to financial reasons, discrimination, and social stigma. (Stigmatization is understood here as the social perception and treatment of those who are infected with and affected by HIV/AIDS as fundamentally different from, and less adequate, worthy, or fully human, than the rest of the population.) There will be up to one million affected children in Henan (calculated according to estimated numbers of infected parents). In one village, Houyang, the group identified 104 orphans. (In this village, 45 widows whose husbands died of AIDS are infected with HIV, 63 widowers whose wives died of AIDS are infected.) Eighty-two children among these orphans have been forced out of school. In another village, according to the UNAIDS report, "HIV/AIDS: China's Titanic Peril," more than 80% of the adults carry HIV, and 60% are already showing AIDS symptoms.

In most cases, children of HIV/AIDS parents were forced to leave school because other parents put pressure on schools for fear of their own children becoming infected. Ignorance is the fuel for social stigma and discrimination, yet ignorance about HIV/AIDS has to do with lack of societal openness about the disease, tight control of information in the media, and official attempts to cover up the epidemic.

3. Laws and Policies: Neglect and Discrimination

The Chinese government has now acknowledged the problem that China has to deal with the growing number of children who have tested HIV-positive and has stated its support for international and regional plans of action - for example, UN initiatives adopted at the World AIDS Conference in 2001 and the UN Special Conference on Children in 2002. However, the government has yet to take action to implement these conferences' urgent calls to care for children suffering from the consequences of HIV/AIDS. The UN AIDS Conference adopted the document, Global Crisis, Global Action (6/27/2002), which called for special assistance to children living with HIV/AIDS and AIDS orphans. The document urges governments to adopt and implement national policies and laws by 2005 to build and strengthen government, family and community capacity to provide support to AIDS orphans, guaranteeing their education, housing, health care and social services. It also calls upon governments to protect AIDS orphans and vulnerable children from all forms of abuse, violence, exploitation, and discrimination, and to work toward eliminating discrimination against HIV/AIDS orphans and children living with HIV/AIDS as well as the social stigma they face.

The Chinese government has also made a commitment to implement the document "2001-2010 East Asian-Pacific Region Commitments to Children" (the "Beijing Declaration," May 14-16, 2001), which was adopted at the Fifth East Asian and Pacific Region Ministerial Meeting in Beijing. But the Chinese government has yet to respond to this document's call to give priority to the problem of AIDS orphans. It states that the spread of HIV/AIDS, which threatens the welfare of children in this region, has created obstacles to promoting children's interest. It acknowledged that the number of children in need of special care has grown,

including girls, child laborers, children suffering from the impact of HIV/AIDS and other epidemics, children of ethnic minorities and migrants, and disabled, poor, or homeless children.

The PRC State Council's "Outline on Children's Development in the PRC (2001-2012)," called attention to the care of children infected with HIV/AIDS. It recognized the rising number of children living with HIV/AIDS. But it did not acknowledge the devastating impact on the welfare of children with HIV/AIDS parents, particularly the orphans.

Currently, existing government regulations on HIV/AIDS do not acknowledge nor provide guidelines regarding the care of AIDS orphans. In "PRC Mid and Long Term Plan for HIV/AIDS Prevention and Control (1998-2010)," "Guiding Opinions for the Management of People Infected with HIV and AIDS Patients" (1999), "Guiding Opinions for HIV/AIDS Education and Communication" (1998), and "PRC Plan of Action to Contain, Prevent, and Control HIV/AIDS" (2001-2005), children affected by the HIV/AIDS epidemic and AIDS orphans were not mentioned.

Although there is no specific provision protecting the equal right to education of children suffering from certain health conditions in the 1995 PRC Law on Education (3/12/1995), this law can be used to defend AIDS orphans' equal rights to education since it protects all Chinese citizens' equal opportunity for education "regardless of (minority) nationality, ethnicity, gender, occupation, and property situation." There is no clear indication in this law whether its provisions requiring the state to support the education of disabled persons can be applied to persons living with HIV/AIDS.

There is no provision in the PRC Law Protecting Under-aged Persons(9/4/1991)about the care of children affected by any health condition. There are no clear prohibitions against depriving children affected by HIV/AIDS of their rights to education, housing, and health care. But some articles in this law can be interpreted as relevant to the protection of HIV/AIDS children's right to education and to be free from discrimination. For example, this law requires that schools must respect under-age students' right to education; and schools should not arbitrarily expel these students, and should respect their dignity. And the PRC Guidelines on Children's Development (2001-2010) do not include AIDS orphans in its special protections for the enjoyment of these rights.

The root causes of ignorance, prejudice and stigma against people living with HIV/AIDS and their families, including children, can be traced to government policies and state laws. Existing laws and regulations governing government responses to health issues and HIV/AIDS in particular, contain provisions that are discriminatory and legitimize social stigma. For example, in the 1995 PRC Law on Maternal and Infant Health Care, articles 8 and 39 require the postponement of marriage and childbearing until couples infected with infectious and sexually transmitted disease, including HIV/AIDS, are treated. Including AIDS as among the infectious diseases contributes to stigmatization and discrimination against people living with HIV/AIDS. "Regulations Concerning the Monitoring and Control of AIDS" contains language (Article 2) requiring "monitoring and control" of "(1)AIDS patients; (2)persons infected with HIV; (3)suspected AIDS patients and people in close contact with the persons referred to in paragraphs (1) and (2)." Requiring monitoring and control of "persons" legitimizes draconian measures such as mandatory testing, isolation, and confined movements, and exacerbates social stigma and discrimination. In the same law, there are provisions (articles 15, 16 and 17) about the reporting of AIDS/HIV cases by law enforcement, judicial, medical and public health officials. Health professionals are required to report HIV/AIDS cases but are not required to keep names and other identifying information of patients confidential. Lack of protection of patient privacy reinforces stigma and discourages patients from seeking information and treatment.

From the legal and policy point of view, the Chinese government, in order to honor its public commitment to care for HIV/AIDS affected and infected children, should take a number of steps, including:

- To elevate the HIV/AIDS campaign to the highest level of political commitment and broaden the narrow focus on HIV/AIDS as a "medical condition," to include programs responding to this epidemic as a social, economic, and political challenge and as a matter of human rights protection - including protections from stigmatization and discrimination against people living with HIV/AIDS, their families and AIDS orphans, and safeguards for their basic social and economic rights.
- To end the segregated rural-urban healthcare system and take into consideration in its rural health care reform process the many needs of people living with HIV/AIDS - including those of AIDS orphans. The government should promote primary care and home-based care for people living with HIV/AIDS, state-subsidized and community-based care of AIDS orphans, and protection for their families.
- To integrate into broad political and legal reforms efforts to promote societal openness, access to information, and involvement of people living with HIV/AIDS and civil society groups. Their involvement in policymaking and efforts to develop effective measures is crucial. The government should end legal impunity for local officials and investigate official responsibility in promoting illegal profit-making plasma collection and management of blood in the 1990s.
- To amend existing PRC laws, regulations and policies governing prevention and management of health conditions, particularly those relevant to prevention, treatment and care of HIV/AIDS patients and children, so as to prohibit policy stigmatization and legal discrimination against people living with HIV/AIDS and people infected with sexually transmitted diseases, to protect their privacy, and to care for children infected and affected by the disease. The government should also eliminate legal provisions that effectively exacerbate ignorance, fear, and stigmatization, resulting in discriminatory treatment of people living with HIV/AIDS and their families.
- To conduct thorough investigations to identify rural areas stricken by HIV/AIDS in Henan and other provinces. Most farmers do not recognize HIV/AIDS themselves and few have easy access to doctors and hospitals. To map the full extent of the epidemic's scope, government agencies need to identify the areas where plasma was collected in the late 1980s and 1990s to be sold to drug manufacturers. In these areas, health authorities should provide HIV testing to determine the scope of the epidemic and provide prevention information and treatment.
- To allocate sufficient resources to assist children affected and infected by this epidemic, particularly those whose families are devastated by the epidemic in poverty-stricken rural areas. The government should help keep HIV-affected and infected children in school by waiving tuition and fees, securing jobs for and income for people living with HIV/AIDS, promoting multi-layered (state, community, and home-based) care for people living with HIV/AIDS and AIDS orphans.

Social assistance to AIDS orphans has been too little and impeded by government regulations. Chinese advocacy groups and concerned journalists have tried to connect families to domestic and international charity organizations. But they have been harassed, monitored, and warned to stay away by officials and security agencies. Dr. Gao has helped the orphans with her own retirement savings and has channeled individual donations to the children's relatives. However, Dr. Gao is under pressure to stay away from any organized group efforts. Moreover, one activist group, the Beijing AIZHI Action Project, was outlawed in July and its coordinator, Dr. Wan Yanhai, was detained for one month at the end of the summer in 2002, though the group has now been allowed to register as a for-profit entity, under a new name.

In some villages, local government only very recently allowed distribution of donation from charities to AIDS orphans. In Houyang village, Henan, for example, 21 orphans got about \$12 each from a charity through arrangement made by the county government. In at least one village, Wenlou, in Shangcai County, local officials asked schools to reduce or exempt tuition for children with HIV/AIDS parents. But villagers report that the tuition break stopped after the story was reported in the press.

Since the Chinese government acknowledged in September 2002 that one million people in China are HIV-infected, a number of programs have been announced, including the granting of licenses to Chinese drug companies to produce generic anti-AIDS drugs, which would significantly reduce the costs, and a plan by the Henan Provincial government to invest millions of dollars in distributing free drugs to AIDS-stricken villagers. These are welcome steps. But the orphans and orphans-to-be still need care and support from the state and society. While drugs may help sustain life, sick farmers may not be able to care for their families. Combating social stigma and securing basic rights for people living with HIV/AIDS and their families require concerted efforts much broader in their scope than free drug treatment for AIDS patients.

4. Recommendations

What could the U.S. Administration and Congress do to improve the care for the AIDS orphans in China? The experts who testified on the AIDS epidemic in China at the September 2002 roundtable held by CECC staffers have offered excellent suggestions. I will add only a few thoughts: First, the Commission should urge U.S. government leaders, through visiting congressional delegations and high-level talks, to communicate concerns about AIDS orphans and propose constructive ways to facilitate positive changes.

Second, the U.S. government should specifically direct its aid to China to support governmental and non-governmental efforts to care for people living with HIV/AIDS and their families, and programs designed to mitigate social stigma and prejudice. The U.S. government should also make a commitment to support UN programs aimed at these public health objectives.

For more fundamental changes, Congress and the Administration should support international efforts and efforts within the Chinese society (such as those that are being made by grassroots advocacy groups and independent-minded scholars and health professionals) to address the HIV/AIDS epidemic and its consequences. As discussed above, the current legal framework and policies have proved to have little or adverse effect on the prevention, care, and treatment of people living with HIV/AIDS and their families.

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