

June 23, 2009

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**Submission to the
Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest
Attainable Standard of Physical and Mental Health**

Re: Access to treatment for children living with HIV/AIDS in China

Children living with HIV/AIDS in China encounter significant barriers in accessing medicine and treatment they need to survive.

In particular, we wish to raise our concerns regarding the following issues preventing children living with HIV/AIDS in China from receiving adequate treatment:

- **The gaps in China’s “Four Free, One Cares” free treatment program**, including inadequate access to pediatric formulations, lack of access to second-line ARV treatment, and lack of any coverage for many other expensive medical costs, including treatment for opportunistic infections.
- **The lack of a functioning health care system in rural areas**, especially concerning a lack of adequately trained doctors and geographic impediments to children in rural areas receiving proper medical care.
- **Discrimination against and stigmatization of children living with HIV/AIDS**, which has led in many cases to refusal of treatment by hospitals and doctors.
- **The trauma, abandonment, and isolation experienced by children living with HIV/AIDS**, due to stigmatization, abandonment by family and friends, discrimination by schools, teachers, and doctors, compounded by the lack of affordable or accessible psychological counseling.

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- **Inadequate testing practices**, due to factors such as a lack of early infant diagnosis testing, disincentives for parents including a lack of confidentiality, and disincentives for local authorities to determine the true number of HIV positive children, have led to undiagnosed children who have not and will not receive treatment.

Under these circumstances, children's rights to life and health, as stipulated by the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of the Child (CRC) are under threat. China has signed and ratified both treaties (ICESCR, 2001; CRC, 1992), which lay out clear obligations to states parties in relation to the right to health.¹

Gaps in Treatment Programs

China's national "Four Free, One Cares" ARV treatment program guarantees ARV treatment free of charge to all people with HIV/AIDS. However, our research finds that there are major gaps in China's free treatment programs that directly impact children.

While it is difficult to pin down the exact number of HIV-positive children in China, as well as the exact number receiving pediatric treatment, it is clear that thousands of children in need are not receiving pediatric formulations. Although China does not publish official estimates of the number of children living with HIV/AIDS, we do know that:

- Government figures indicate that there were 9,000 cases of mother-to-child transmission in 2005 alone, a number that would not include children infected by mother-to-child transmission in other years or children infected through other circumstances, such as blood transfusions.²
- A senior advisor to the World Health Organization in Beijing told Asia Catalyst that there may be 10,000 children living with HIV in China.³
- The Chinese government reported in 2007 that only a total of 805 children were receiving ARV treatment.⁴

¹ The information presented here is based on field research in China from May to August 2008, and is also published in our report, *"I Will Fight to My Last Breath": Barriers to AIDS Treatment for Children in China* (April 2009).

² Ministry of Health, Joint United Nations Program on HIV/AIDS, and World Health Organization, "2005 Update on the HIV/AIDS Epidemic and Response in China," January 24, 2006,

http://data.unaids.org/publications/External-Documents/rp_2005chinaestimation_25jan06_en.pdf.

³ Connie Osborne, a senior advisor to the World Health Organization's on HIV-AIDS in China, Asia Catalyst interview, Beijing, China, August 2008.

⁴ State Council AIDS Working Committee Office and the United Nations Theme Group on AIDS, "UNGASS Country Progress Report P.R. China: Reporting Period January 2006-December 2007,"

January, 2008, p.i,

http://data.unaids.org/pub/Report/2008/china_2008_country_progress_report_en.pdf.

Even these conservative estimates imply that thousands of HIV-positive children in China are not receiving the treatment they need to survive, an estimate borne out by our interviews with Chinese AIDS advocates and health providers.⁵

China also urgently needs second-line AIDS drugs, which are unaffordable for people with AIDS in China, and which are not excluded from the government's AIDS treatment program. A 2005-6 study found a disproportionately high number of children in China already resistant to first-line medicines and in need of treatment.⁶ In 2008, Chinese AIDS activists who spoke with Asia Catalyst estimated that twenty to forty percent of the people with AIDS they knew needed second-line treatment.⁷

Above and beyond treatment access, many associated medical costs are not covered by the free treatment programs. The high cost of treatment for opportunistic infections are a particularly significant barrier to proper treatment.⁸ The Chinese government has committed to providing treatment for opportunistic infections at reduced price, but doctors and families told Asia Catalyst that a time-consuming application process was involved, that often applications were not approved, and that for many families, these necessary treatments remained cost-prohibitive.⁹ In many cases, these high costs, along with high medical fees that require families to pay for everything from tests to rubber gloves, lead to a stoppage in treatment – in some cases, after families have sold off everything they owned in order to meet a child's medical costs.

In paragraph 25 of General Comment No. 3 (2003), “HIV/AIDS and the Rights of the Child,” the Committee on the Rights of the Child stated that “obligations of States parties under the Convention extend to ensuring that children have sustained and equal access to comprehensive treatment and care, including necessary HIV-related drugs, goods and

⁵ Li Xiang, founder and director of Mangrove Support Network, a national network of PLWHA support groups, email communication with Asia Catalyst, March 1, 2009; Dr. Yang, director of ARV treatment at People's Hospital, Asia Catalyst interview, held in Yunnan, China, July 2008; Xiao Fan, Henan AIDS NGO Worker, Asia Catalyst interview, held in Beijing, China, August 2008.

⁶ Zhang, Fujie et al. 2007. “Chinese Pediatric Highly Active Antiretroviral Therapy Observational Cohort: A 1-Year Analysis of Clinical, Immunologic, and Virologic Outcomes, *Journal of Acquired Immune Deficiency Syndrome* 46, No. 5 (2007), pp. 594-598; p. 597.

⁷ Asia Catalyst interview with Meng Lin, executive director of Ark of Love, Tokyo, Japan, November 17, 2008; interview with Li Man, executive director of a Yunnan-based AIDS NGO, Beijing, November 8, 2008; Asia Catalyst interview with Duan Jun, Henan AIDS Activist, Beijing, November 7, 2008.

⁸ Li Ran, worker at international NGO, Asia Catalyst interview, Beijing, June 2008; Dr. Yang, head of ARV treatment at People's Hospital, Asia Catalyst interview, (city withheld), Yunnan, July 2008; Dr. Huang, chief doctor in a rural village, Asia Catalyst interview, Yunnan, July 2008; Calvin Xue, staffperson at Loving Source, Asia Catalyst interview, Beijing, August 2008; Mary Su, Regional Project Manager of an AIDS Service Organization, Asia Catalyst interview, Kunming, July 2008.

⁹ State Council Notice on Strengthening HIV/AIDS Prevention and Control, (III, IV) Issued on March 16, 2004; Dr. Yang, head of ARV treatment at People's Hospital, Asia Catalyst interview, (city withheld), Yunnan, July 2008, Gu Lan, uncle and caretaker of an HIV-positive girl, Asia Catalyst interview, via phone, Yunnan, July 2008, Xing Lu, HIV-positive girl, Asia Catalyst interview, held in Beijing, China, June 2008, Rui Na, HIV-positive mother of an untested child, Asia Catalyst interview, Yunnan, July 2008, Liu Fang, father of Xiao Liu, an HIV-positive child, Asia Catalyst interview, Beijing, China, August 2008.

services on a basis of non-discrimination,” and that treatment access should include “related opportunistic infections and other conditions.”¹⁰

Lack of Compensation for HIV Infection Through Hospital Blood Transfusions - Paragraph 59 of the CESCR General Comment No. 14 on the Right to the Highest Attainable Standard of Health asserts that “any person or group victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels” and that “all victims of such violations should be entitled to adequate reparation.”¹¹ As documented in Asia Catalyst’s report, *AIDS Blood Scandals: What China Can Learn from the World’s Mistakes* (2006), thousands of children have been infected with HIV due to unsafe blood transfusions at state hospitals. Most have received neither proper compensation from said hospitals or adequate opportunity to demand compensation.

Asia Catalyst interviewed some of these children and their families and lawyers. They described obstacles to exercising their right to sue for compensation, including Henan courts that refused to accept any cases relating to HIV/AIDS, and local officials who threatened family members with retribution.¹² One child we interviewed passed away while his family was still petitioning for compensation in order to pay for medical costs which they could not otherwise afford.¹³

Weaknesses in Rural Healthcare

The lack of central government funding for China’s weak healthcare infrastructure has had a catastrophic impact on children living with HIV/AIDS in rural regions.

Lack of medical professionals with adequate training -- HIV-positive children in some areas of China lack access to doctors with the proper training and experience to treat HIV and the resulting opportunistic infections. When the “Four Free, One Cares” program launched in 2003, the program director admitted to the press that fewer than one hundred doctors in China were capable of properly administering AIDS drugs.¹⁴ While efforts have since been made to address this issue, our research in the field indicates that many children living with HIV/AIDS still lack access to adequately trained doctors. Children told Asia Catalyst about misdiagnosis and other improper or inadequate treatment by local doctors.¹⁵ A Chinese official with NCAIDS told Asia Catalyst that many hospitals and doctors in

¹⁰ UN Committee on the Rights of the Child, “General Comment No. 3 (2003): HIV/AIDS and the Rights of the Child,” UN Doc. CRC/GC/2003/1, January 13-31, 2003

¹¹ UN Committee on Economic, Social, and Cultural Rights (CESCR), “General Comment 14 on the Right to the Highest Attainable Standard of Health,” UN Doc. E/C.12/2000/4 (2000).

¹² Xiao Liu journal entry, August 2008; Xing Lu interview, June 2008.

¹³ Liu Fang interview, August 2008.

¹⁴ Cindy Sui, “China starts offering free AIDS drugs but lacks doctors to administer them,” *Agence France Presse*, July 15, 2003, available at: <http://www.aegis.com/news/afp/2003/AF030781.html>.

¹⁵ Xing Lu interview, June 2008, Bao Ling interview, July 2008.

China did not understand AIDS, a view that was borne out by domestic and international AIDS NGO staff with whom we spoke.¹⁶

Paragraph 36 of General Comment 14 on the Right to Health stipulates, “States have to ensure the appropriate training of doctors and other medical personnel, the provision of a sufficient number of hospitals, clinics and other health-related facilities...with due regard to equitable distribution.”¹⁷

Stigma and Discrimination -- Discrimination against and stigmatization of children living with HIV/AIDS has led in many cases to refusal of treatment by hospitals and doctors. Children, families, and AIDS workers all told Asia Catalyst that children face refusal of care by hospitals and expulsion from schools.¹⁸ Asia Catalyst heard reports of children being turned away from hospitals, or forced to pay for new equipment, as well as facing harassment at school or being refused entry altogether.¹⁹ This type of discrimination is a violation of nondiscriminatory clauses in the Universal Declaration of Human Rights (UDHR), International Covenant on Civil and Political Rights (ICCPR), the ICESCR, and the CRC.

Geographic Barriers -- Geographic impediments keep some HIV-positive children living in rural areas from accessing treatment. in violation of Article 12 of the ICESCR. Article 12(b) of the General Comment on the Right to Health states that “health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ... children, adolescents... and persons with HIV/AIDS.”²⁰

In the remote rural regions where many of China’s HIV-positive citizens live, many children may not be able to get to health care facilities at all. Some hospitals do refund travel costs, but one AIDS worker interviewed noted that families often lack the funds to pay travel costs in advance.²¹ An AIDS worker in Yunnan described the difficulties that

¹⁶ Asia Catalyst interview with NCAIDS official, Beijing, August 2008; Connie Osborne interview, August 2008; Asia Catalyst interview with Ken Legins, Chief of HIV/AIDS Programme, UNICEF, held in Beijing, China, August 2008. David Chang, program officer of an international health organization, Asia Catalyst interview, Beijing, June 2008; Kathy Li, community health project manager at an international organization, Asia Catalyst interview, Kunming, July 2008; Bao Ling, founder of Sweet Sky HIV-positive support group, Asia Catalyst interview, held in Yunnan, China, July 2008; Li Xiang interview, August 2008.

¹⁷ UN Committee on Economic, Social, and Cultural Rights (CESCR), “General Comment 14 on the Right to the Highest Attainable Standard of Health,” UN Doc. E/C.12/2000/4 (2000).

¹⁸ Bao Ling interview, July 2008, Xiao Fan, Henan AIDS NGO Worker, Asia Catalyst interview, Beijing, August 2008; Xiao Liu journal entry, August 2008, Xing Lu interview, June 2008.

¹⁹ Bao Ling interview, July 2008, Xiao Fan, Henan AIDS NGO Worker, Asia Catalyst interview, Beijing, August 2008; Xiao Liu journal entry, August 2008, Xing Lu interview, June 2008, Mary Su, regional project manager of an AIDS service organization, Asia Catalyst interview, Kunming, July 2008.

²⁰ UN Committee on Economic, Social, and Cultural Rights (CESCR), “General Comment 14 on the Right to the Highest Attainable Standard of Health,” UN Doc. E/C.12/2000/4 (2000).

²¹ Hai Bao, HIV-positive direct services AIDS worker, Asia Catalyst interview, Yunnan, July 2008.

children may have traveling the necessary distance over poor rural roads at all, due to their frailty.²²

Trauma, abandonment, and isolation

HIV-positive children experience trauma and feelings of isolation, which are often compounded by a lack of access to psychological counseling or other mental health services. Growing up with HIV imposes special burdens: Children must learn to cope with chronic illness, fear of death, rejection by family and friends, and discrimination by adults such as teachers and doctors. Many have also experienced the traumatic death of parents from AIDS or drug addiction. Doctors, AIDS workers, and children in both Beijing and Yunnan told Asia Catalyst stories of HIV-positive children being abandoned by their families.²³ Other children and families interviewed revealed severe depression in HIV-positive children.²⁴ In addition to the psychological trauma, Asia Catalyst also heard reports of this despair causing some children to stop taking their medications or engage in other self-destructive behavior.²⁵ While Chinese policies make reference to the need for counseling for people living with HIV/AIDS,²⁶ such counseling is widely unavailable, especially the type of long-term psychological care required for children.

Article 12 of the ICESCR explicitly states that the right to the highest attainable standard of health applies to mental as well as physical health. General Comment 14 paragraph 17 states the requirement for “the provision of equal and timely access to...mental health treatment and care” and in paragraph 22 explicitly requires that children and adolescents have access to mental health services.²⁷ In addition, The Committee on the Rights of the Child’s General Comment No. 3 (2003): HIV/AIDS and the rights of the child paragraph 25 defines treatment and care as including “social, spiritual and psychological support.”²⁸

Inadequate testing practices

The lack of early infant diagnosis testing in China, disincentives for parents including a lack of basic protections of confidentiality, combine with political factors that incentivize

²² Hu Jin, AIDS project officer at an international organization, Asia Catalyst interview, Kunming, July 2008.

²³ Dr. Zhang, doctor in HIV/AIDS wing of a Beijing Hospital, Asia Catalyst interview, Beijing, August 2008, Bao Ling interview, July 2008, Xue Fa, untested son of HIV-positive mother, Asia Catalyst interview, Yunnan, July 2008, Mei Li interview, July 2008; Xing Lu interview, June 2008.

²⁴ Xiao Liu journal entry, August 2008, Gu Lan, uncle and caretaker of an HIV-positive girl, Asia Catalyst interview, via phone, Yunnan, July 2008.

²⁵ Dr. Yang, head of ARV treatment at People’s Hospital, Asia Catalyst interview, Yunnan, July 2008.

²⁶ *China’s Action Plan (2006-2010) for Reducing and Preventing the Spread of HIV/AIDS*, paragraph 3.4.

²⁷ UN Committee on Economic, Social, and Cultural Rights (CESCR), “General Comment 14 on the Right to the Highest Attainable Standard of Health,” UN Doc. E/C.12/2000/4 (2000).

²⁸ UN Committee on the Rights of the Child, “General Comment No. 3 (2003): HIV/AIDS and the Rights of the Child,” UN Doc. CRC/GC/2003/1, January 13-31, 2003

the coverage of AIDS by local officials to create a weak testing system in China. As a result, many children remain undiagnosed and may never receive treatment.

The chief of UNICEF's HIV/AIDS program in China informed Asia Catalyst that the average age of a child receiving treatment was nine, indicating weakness in testing resulting in undiagnosed cases in younger children.²⁹ According to both domestic and international AIDS experts interviewed by Asia Catalyst, official reluctance to confront the scope of the AIDS epidemic, because it may reflect badly on the career prospects of local officials, may contribute to this problem.³⁰ In addition, health care providers, activists and families all reported to Asia Catalyst that some parents may be unwilling to have their children tested due to fears of discrimination, fears that results will not be kept confidential, or because they are unaware of available treatment programs.³¹ The head of China's AIDS treatment program has admitted to reporters that there are many children living with HIV/AIDS who have not been found and have died without ever being diagnosed.³²

Requested Actions

Asia Catalyst requests that you, in conjunction with other relevant UN human rights mechanisms, raise the above concerns with the Chinese government and urge China to take the following actions:

- Exercise China's right under WTO regulations to issue compulsory licenses to facilitate immediate domestic production of second-line and pediatric ARV treatment.
- Take effective measures to ensure that adequate funding is allotted at provincial and local levels for the provision of adequate health facilities throughout rural areas.
- Provide an estimated number of children who are living with HIV/AIDS, the number currently receiving treatment, and information on the process through which these numbers are gathered.
- Expand the "Four Free, One Care" program to include free treatment for opportunistic infections and all related costs for the treatment for those living with HIV/AIDS.
- Increase trainings for health care workers on pediatric HIV/AIDS diagnosis, treatment, and care.
- Encourage the work of NGOs who provide support to families affected by AIDS, by easing restrictions on civil society organizations, particularly in the area of registration.

²⁹ Ken Legins interview, August 2008.

³⁰ Ken Legins interview, August 2008, Li Xiang interview, June 2008.

³¹ Dr. Huang interview, July 2008, Li Xiang interview, August 2008, Dr. Zhao Yang, worker at domestic HIV/AIDS related NGO, Asia Catalyst interview, Beijing, June 2008, Bao Ling interview, July 2008, Cheng Cheng, HIV-positive mother, Asia Catalyst interview, held in Yunnan, China, July 2008.

³² National Population and Family Planning Commission of China, "Better Drugs Urgent for China to Combat AIDS," August 13, 2006, <http://www.nfpcc.gov.cn/en/en2006-08/news20060813.htm>.

We also request that you conduct a mission to China to investigate its compliance with international laws on the right to health, especially concerning the above issues.

We would welcome an opportunity to discuss these issues further and to answer any questions you may have regarding this letter.

Sincerely,

A handwritten signature in black ink, appearing to read "Sara Davis", with a stylized flourish at the end.

Sara L.M. Davis, Ph.D.
Executive Director