



R E S E A R C H R E P O R T

**“I Will Fight to My Last Breath”:**

**Barriers to AIDS Treatment for Children in China**

**Asia Catalyst | April 2009**

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在一个家庭里有许多的孩子在玩，有的看电视，有的在跳，还有的在捉小虫子，有的在睡觉，有的在做饭，有的在洗澡，院子里有果树。松树和池里的小鱼有乌龟，天山飞着大雁和小鸟，地上长的有花和小草，他们生活的太好了。

我的爸爸妈妈一直在给我自信，他们对我说不要太小看自己，如果有 一口气就要活下去，如果家里有一分钱就要先给你看病。

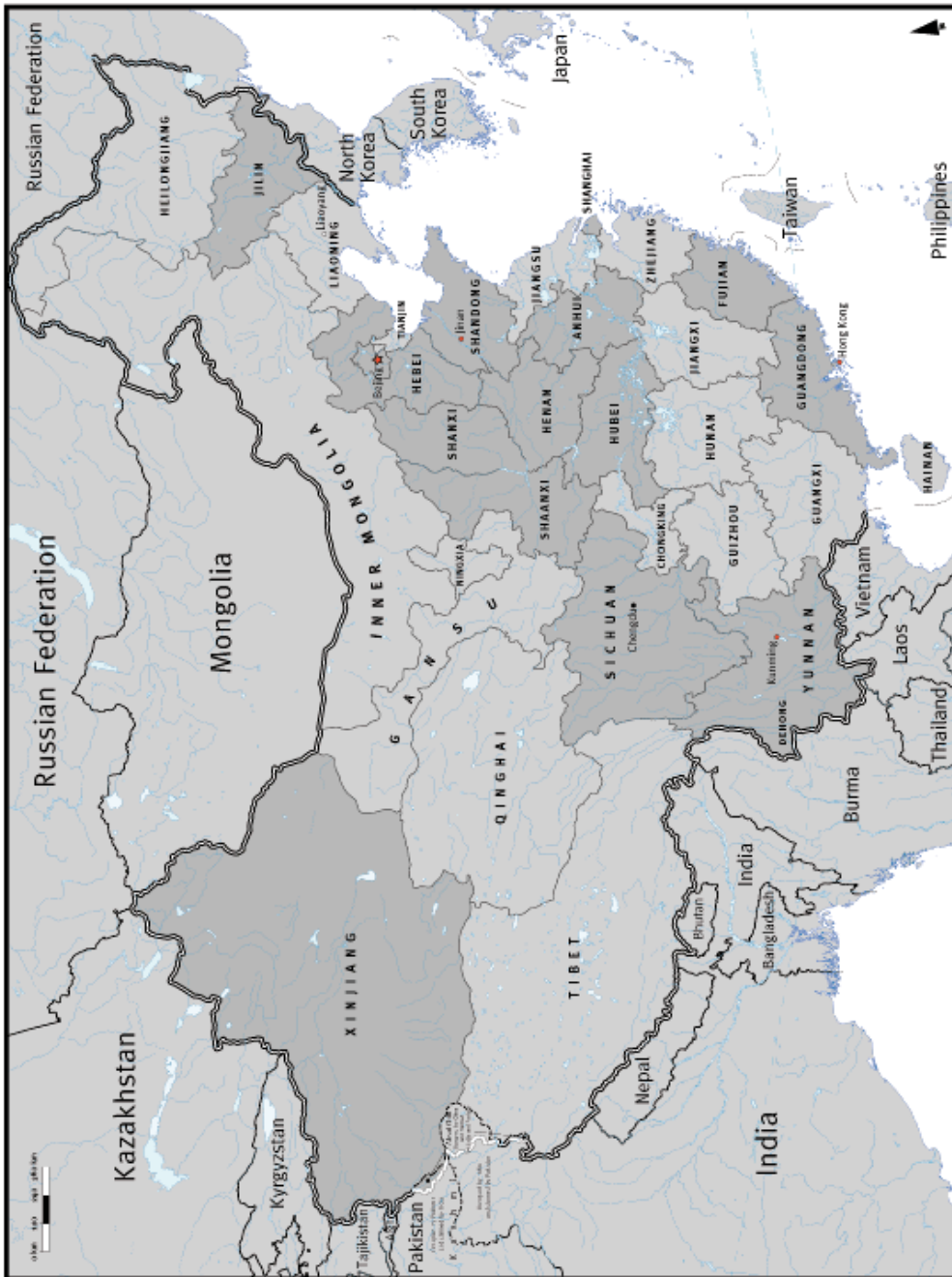
Inside a house, there are some children playing. Some are watching TV, some are skipping, and some are catching little bugs. Some are sleeping, some are making food, and some are bathing. There are fruit trees in the courtyard. There are small fish and turtles in the pond. Geese and little birds are flying in the sky, and flowers and grass are growing on the ground. Their lives are wonderful.

My mother and father have always given me faith. They tell me not to look down on myself. They say that I should fight to my last breath, and that they will treat my illness until their last penny is gone.

Xiao Liu, 1996–2009

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**MAP OF THE PEOPLE'S REPUBLIC OF CHINA**

## I. EXECUTIVE SUMMARY

In recent years, China has taken steps to expand AIDS treatment around the country, but the state still faces challenges in ensuring it reaches the people who need it. Though the government has committed to providing free AIDS treatment to children, Asia Catalyst's field research in China shows that in practice, significant barriers still limit children's access to this treatment. Thousands of HIV-positive children may not be receiving the medicines they need to survive.

The challenges are many, in part because China's AIDS epidemic has hit hardest at impoverished rural regions where health services are weak. The state AIDS treatment program provides some pediatric medicines supplied by an international donor, but not all children can obtain these, and many take adult medications that can cause serious side effects. In interviews, families and AIDS advocates also spoke of the urgent need for second-line AIDS treatment for children who had developed resistance to the first line of AIDS drugs; these expensive medicines are also not covered by the state program. Local hospitals pass on many treatment-related costs—everything from rubber gloves, to treatment for opportunistic infections—to families. These high costs force many families to make terrible sacrifices. One boy told Asia Catalyst how his parents had gone deeply into debt and sold everything they owned to pay for his treatment, and said that his sister had given up her own schooling in order to work and earn money for his care. Six months later, the family ran out of funds, and the boy passed away.

While the state has trained many doctors to treat children with HIV/AIDS, there are not enough of them. Families in Henan and Yunnan, two epicenters of China's AIDS epidemic, spoke of rural doctors who failed to recognize its symptoms, and of hospitals that turned away HIV-positive patients out of unfounded fear of contagion. Despite efforts by China's leaders to promote tolerance, discrimination and stigma are still widespread: several children said they had been told to leave their schools, and that other children and family members had cut off contact with them. Because of the devastating effect that discrimination can have on the whole family, and their lack of financial resources to pay for medical care, some parents are reluctant to even test their children for the AIDS virus.

The cumulative effect of all these challenges can be overwhelming for children and their parents. Some children interviewed by Asia Catalyst showed signs of severe depression and withdrawal. A few were abandoned by their overwhelmed families; in one case, parents left their HIV-positive teenager laying at a hospital door. Counseling and support are largely unavailable to help young people, and their families, to cope with the burden of growing up HIV-positive.

In December 2007, President Hu Jintao said, "AIDS prevention and control is an international problem. The Chinese government has paid special attention to the issue, always provided the greatest care to HIV-positive people and AIDS patients, and has earnestly fulfilled promises to curb the spread of the illness." China has made progress in the fight against AIDS; but the voices of children in this report call on China and international supporters to expand their efforts.

## II. POLICY RECOMMENDATIONS

### **Treatment Access**

A recent amendment to China's patent law gives the state expansive authority to issue compulsory licenses for urgently-needed medicines. The Chinese government should issue compulsory licenses to facilitate immediate domestic production of second-line AIDS treatment.

The U.S. government should end its policy of penalizing countries such as Thailand that issue compulsory licenses to address the AIDS epidemic.

The Chinese government should 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. The state should execute a transparent and adequate monitoring system to ensure that monetary allocations for AIDS treatment and care are reaching children with the greatest need. The state should publicly report the estimated number of children estimated to be HIV-positive and the number currently receiving treatment.

The families of HIV-positive children face high costs associated with AIDS treatment, and many cannot afford to pay for their care. The Ministry of Health should set a target date by which it will expand the "Four Free, One Care" program to include free treatment for opportunistic infections and all related costs for the treatment of people with HIV/AIDS. The National Center for AIDS/STD Control and Prevention (NCAIDS) should advocate with the Ministry of Health for expansion of the Four Free, One Care program.

In areas where pediatric HIV is more common, training focused on pediatric HIV/AIDS diagnosis, treatment, and care should be made more widely available by NCAIDS and the Ministry of Health. Health care workers should be encouraged to share information on successful AIDS treatment and care strategies.

It is a positive development that NGOs now provide care to many families affected by AIDS, and advocate for their treatment. The state should make it easier for these NGOs to register. It should provide direct funding to small, grassroots AIDS NGOs that can reach families in remote regions and children of injection drug users and sex workers.

The government should include independent and grassroots Chinese NGOs in the policy-making process, and consult regularly with patients' rights groups.

Provision of adequate funding at the local level should include building additional hospitals and clinics, training village doctors, and mobilizing traveling medical teams to more remote areas so that children living with HIV/AIDS have access to adequate health services.

## **Discrimination**

The Ministry of Justice should provide affordable and accessible legal aid to people with HIV/AIDS in each province so that they can protect and enjoy their rights under Chinese law.

The Ministry of Justice should create mechanisms to enable people living with HIV/AIDS to preserve their confidentiality when filing suit, and should penalize courts that violate these protections.

The Ministry of Justice should issue an order compelling Henan courts to accept cases that pertain to HIV/AIDS.

The Ministry of Education should establish non-discrimination guidelines for schools and provide science-based training to teachers and school staff on the needs of children with HIV/AIDS.

China should fully implement its own National Action Plan on HIV/AIDS by taking further steps to expand access to information on HIV/AIDS, especially for children. Children should have access to basic information on HIV transmission and AIDS appropriate to their age level. It is especially important for them to learn that HIV is not spread by casual contact.

Yunnan Province should publish statistics indicating the number, if any, of health facilities that have been held accountable for discrimination under Yunnan's HIV/AIDS regulations.

## **Mental health**

To guarantee a child's right to participate in making decisions that affect her/his life, health care workers should inform children with HIV of their status. The state should provide affordable and accessible long-term psychological counseling for children with HIV/AIDS.

## **Testing**

China should conform to the WHO guidelines on early infant HIV diagnosis and treatment so that infants can be identified and receive appropriate ARV treatment as early as possible.

China should also offer better protections of confidentiality, as well as make available non-judgmental counseling and information, and clear procedures for informed consent, to encourage voluntary testing.

### III. INTRODUCTION

While conducting research in Beijing in summer of 2008, Asia Catalyst researchers met Xiao Liu, a fourteen-year-old boy living with HIV/AIDS. By that time, his illness was advanced, and Xiao Liu was no longer the round, smiling boy in the pictures that his father showed to researchers. His frame had shrunken, and Xiao Liu needed help to get dressed. He had to pause to rest after walking a few steps.

Like hundreds—perhaps, thousands—of other Chinese children, Xiao Liu contracted the virus from a blood transfusion he received as an infant at a state hospital in Henan Province. Because doctors were unfamiliar with the epidemic, and because tests for infants are not widely available in China, he was not diagnosed until he was eight years old. After that, Xiao Liu’s friends would no longer play with him. His relatives disowned his immediate family. His teacher said that he was not allowed to return to school.

At the time, pediatric formulations of antiretroviral medicines (ARVs) were not available in China. The adult formulations of AIDS medicines had a devastating impact on Xiao Liu. He contracted ascites, a condition in which excess fluid builds up in the space between the abdomen and the abdominal organs. The ascites caused Xiao Liu’s belly to swell so much that his father couldn’t even carry him on his back to hospital visits, as he had in the past. Other medical problems caused Xiao Liu to lose weight and become frequently tired.

Asia Catalyst met Xiao Liu in the summer of 2008, during the height of the excitement surrounding the Beijing Olympics, when an international supporter helped his father to bring Xiao Liu to Beijing for medical care. Xiao Liu posed for photographs in front of an Olympics display on Tiananmen Square, proudly waving a Chinese flag. He told Asia Catalyst how much he loved riding his bike to explore new places, and drew a picture of a happy family in a house surrounded by trees, rivers and birds. His condition improved, but by the end of the summer his father had to bring the boy back to Henan Province because they had run out of money for treatment.<sup>1</sup> Six months later, Xiao Liu’s parents were burying their only son.

Xiao Liu’s case is tragic, but it is not unusual. Asia Catalyst’s research has identified a series of barriers to treatment access for children living with HIV/AIDS in China, many of whom may die before even learning that they are HIV-positive. While China is not a wealthy country, it does have the capacity to address the needs of children living with HIV/AIDS. In recent years, China has taken important steps toward ensuring that these children get the care they need, passing new policies and laying the foundation for a national AIDS care program. China could expand existing programs to ensure that the lives of children like Xiao Liu are not cut short.

The report begins with a brief overview of the AIDS epidemic in China, a discussion of China’s obligations under international law, and a description of the research methodology, before turning to the research findings.



## **A. BACKGROUND: HIV/AIDS IN CHINA**

The official estimate made by the World Health Organization of the number of HIV-positive people in China is 700,000.<sup>2</sup> The Ministry of Health puts the number of reported AIDS cases between 80,000 and 90,000.<sup>3</sup> Recent research indicates that sexual transmission of HIV is on the rise.<sup>4</sup> Chinese children are vulnerable to HIV through mother-to-child transmission and through unsafe hospital blood donations. As discussed further in the findings below, the Chinese government and WHO indicate there may be 9,000 or 10,000 HIV-positive children in China.

Gaps in testing and surveillance have led some to question the validity of official estimates of HIV in China, and to suggest that the true number of HIV-positive persons may be much higher.<sup>5</sup> Discrimination, stigma, and an unwillingness to recognize AIDS by local officials who fear it will reduce investment or cause social problems in their regions sometimes leads to the downplaying of local prevalence and incidence of HIV/AIDS [*see Sidebar: "AIDS in Henan"*].

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### **AIDS IN HENAN**

In the early 1990s, local Chinese health authorities established commercial blood collection centers, and urged farmers to sell their blood.<sup>1</sup> The donated blood was put through a process of "blood fractionation," a separating of the more valuable elements using a centrifuge, and then reinjected back into donors in an effort to reduce the likelihood of donors becoming anemic and reduce the time before they could donate again. This reinjection process facilitated the spread of HIV to villages across central China.<sup>1</sup>

Central authorities have since acknowledged that most of China's provinces suffered from problems with HIV infection through blood sales.<sup>1</sup> However, Henan Province has been the focus of international and domestic attention for a number of reasons, including the extent of the epidemic there, the province's proximity Beijing, the provincial government's refusal to accept the severity of the problem, and local authorities' sometimes heavy-handed response to local AIDS advocates.<sup>1</sup>

The actual number of people infected with HIV in Henan and nationwide remains a politically sensitive question, in part because of local authorities' role in the 1990s disaster. In 2006, China's Ministry of Health, UNAIDS, and CDC estimated that there were approximately 25,036 people living with HIV/AIDS in Henan.<sup>1</sup> However, activists in Henan have consistently charged that the true number of people living with HIV/AIDS in Henan is far higher than the official estimates.<sup>1</sup> For example, Dr. Gao Yaojie, a prominent HIV/AIDS advocate, has estimated that a million people are living with HIV/AIDS in the province.<sup>1</sup>

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HIV/AIDS was first identified in the border regions of China in 1985, and Yunnan Province, the field site for this report, has been one epicenter of the epidemic, due to the traffic in drugs across the borders from Southeast Asia. In the 1990s, thousands of people in the central plains areas were also infected with HIV due to unsafe blood collection practices. Today, every Chinese province has reported cases.<sup>6</sup> Sexual transmission is now the most common source of new infections in China.<sup>7</sup> Mother-to-child transmission is also a growing problem, discussed in more detail below.

In 2003, in response to the AIDS crisis, China launched an ambitious treatment program: Four Free, One Care. The “One Care” refers to economic assistance to households affected by HIV/AIDS in selected areas, while the “Four Free” are services offered to all people living with HIV:

- Free antiretroviral drugs (ARVs)
- Free voluntary testing and counseling
- Free medications to HIV-infected pregnant women to prevent mother-to-child transmission
- Free schooling for children orphaned by AIDS.<sup>8</sup>

As of October 2007, roughly 40,000 adults had received ARV treatment through government programs.<sup>9</sup> The Chinese government has also enacted policies specifically for children affected by AIDS: building “Sunshine Homes,” orphanages for children in Henan Province; and later shifting to a “Sunshine Families” program, in which orphans are placed with foster families in their communities.<sup>10</sup> The central government has also decreed that all children orphaned by AIDS receive free health care, education, and other support, but acknowledges that implementation of this commitment has varied from one region to the next.<sup>11</sup>

As part of this effort, Chinese authorities have acknowledged that the Prevention of Mother-to-Child Transmission (PMTCT) is an important first step towards preventing HIV in children.<sup>12</sup> The government started PMTCT programs in 2003 in high-prevalence areas of Henan.<sup>13</sup> Since then, the program has expanded through the joint efforts of the Ministry of Health and the National Center for Women and Children. The program provides testing, counseling, medical and nutritional support, and infant testing.<sup>14</sup> With these measures, the National Center for Women and Children’s Health says that it has been able to reduce infant rates of HIV infection in target populations by sixty to ninety percent.<sup>15</sup>

However, implementation remains incomplete. In 2008, only 300 of 2,000 Chinese counties participated in the program.<sup>16</sup> Expanding the program, especially in high-prevalence areas, is critical to reducing future HIV infections among children.

## **B. CHINA’S OBLIGATIONS UNDER INTERNATIONAL LAW**

China’s constitution states that citizens have the right to material assistance from the state when they are “old, ill, or disabled.”<sup>17</sup> In regard to treatment access for children, China has also signed and ratified two key international treaties: the International Covenant on Economic, Social and Cultural Rights (ICESCR), ratified in 2001; and the Convention on the Rights of the Child (CRC), ratified in 1992.<sup>18</sup> These two treaties lay out clear obligations to States parties in relation to the right to health.

The ICESCR provides for “the right of everyone to the enjoyment of the highest attainable standard

of physical and mental health.”<sup>19</sup> States parties to the ICESCR have obligations of immediate effect—to take steps towards realizing the rights equally and without discrimination. The framers of the ICESCR recognized that developing countries face special challenges in ensuring adequate access to health, social services, and other services, however. Thus, instead of requiring all States parties to immediately realize all rights in the ICESCR, the treaty obligates a State party to “progressively realize” the rights laid out in the Covenant “to the maximum of its available resources.”

At the same time, the Committee on Economic, Social and Cultural Rights (“the Committee”), the body charged with overseeing the implementation of the Covenant, has emphasized that these steps must be taken within a reasonably short time after entry into force of the Covenant, with a view toward “mov[ing] as expeditiously and effectively as possible towards that goal.”<sup>20</sup> Moreover, the Committee establishes a minimum core obligation to “ensure the satisfaction of, at the very least, minimum essential levels of each of the rights.”<sup>21</sup> Therefore, lack of resources does not by itself discharge obligations under the Covenant.

The Covenant includes obligations on States parties to provide international assistance and cooperation to enable developing countries to implement the rights in the Covenant.

The Committee has specifically considered the right to health and the particular challenges that developing countries face, writing that “for millions of people throughout the world, the full enjoyment of the right to health still remains a distant goal.”<sup>22</sup> However, the Committee emphasizes that even where States have serious resource constraints, there are steps that States are obligated to undertake in order to protect the right to health.

Specifically, the Committee has identified core obligations for States parties. These include providing essential drugs defined under the WHO Action Programme on Essential Drugs, and adopting and implementing a national public health strategy and plan of action.<sup>23</sup> These explicit obligations clarify that States should be taking steps toward fulfilling the right to health. As the WHO also notes, “It is important to distinguish the inability from the unwillingness of a State Party to comply with its right to health obligations.”<sup>24</sup>

The Convention on the Rights of the Child also states “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.”<sup>25</sup> The Committee on the Rights of the Child’s General Comment 3 on HIV/AIDS outlines the detailed obligations States parties have toward children living with HIV/AIDS: including obligations of non-discrimination, and the rights to child-sensitive health services, HIV counseling and testing, and comprehensive treatment and care.

As this report will show, rights protection and the rule of law are integral to ensuring that China and the world survive the HIV/AIDS pandemic. As the UN General Assembly said in its 2006 declaration on HIV/AIDS, “full realization of all human rights and fundamental freedoms for all is

an essential element in the global response to the HIV/AIDS pandemic.”<sup>26</sup>

### **C. METHODOLOGY**

This report draws on field research conducted by Asia Catalyst from May to August 2008 in China, and additional follow-up through March 2009. In Beijing, two graduate researchers interviewed staff at two agencies affiliated with the government, NCAIDS and the National Center for Women and Children’s Health, as well as fifteen domestic Chinese nongovernmental organizations (NGOs) and international experts at the UN and at international NGOs. They traveled to Harbin to attend a conference of AIDS NGOs, and participated in AIDS meetings in Beijing. One researcher traveled to four different field sites in Yunnan Province over a one-month period to interview six children, ten families, six doctors, and eleven local NGOs. In some cases, the same families were interviewed several times, or engaged in correspondence after the interviews.

Heightened security measures during the 2008 Beijing Olympics created serious obstacles to the research and made travel to Henan Province, an epicenter of the epidemic, impossible. An Asia Catalyst researcher did correspond with Henan NGO workers, parents, and children through email and phone calls. One researcher also interviewed two Henan families with HIV-positive children who traveled to Beijing for treatment, and interviewed a doctor treating HIV-positive children from Henan in the same hospital.

In addition to formal interviews, researchers engaged in participant observation, and visited hospitals, frontline NGO offices, and family homes to learn about the context in which children live with HIV/AIDS.

All interviews with children and their parents or guardians were conducted in Chinese and were recorded. When interviewing children, special measures were taken to ensure that children were comfortable with the environment. These included allowing them to choose where the interview would take place, engaging in information exchange and game playing before the formal interview began, and encouraging the children to play with and become comfortable with the recording equipment before the interview.

All participants were informed that a written report would be published with information garnered from their interviews. Both the children themselves and their guardians or parents consented to being quoted. To protect the identities of those interviewed, and because of the continuing political sensitivities surrounding HIV/AIDS, pseudonyms are used throughout unless otherwise noted. For the same reasons, some locations and precise dates of interviews are also withheld.

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#### **YUNNAN: AIDS ON THE BORDERS**

Yunnan, a province on China’s borders with Southeast Asia, has the highest number cumulative reported cases of HIV among Chinese provinces, and is often considered one of the epicenters of China’s epidemic.<sup>27</sup>

HIV/AIDS first entered China along the drug trafficking routes from Southeast Asia's "Golden Triangle."<sup>28</sup> HIV was first detected in intravenous drug users in Yunnan in 1989, and they are still the most severely affected in the province.<sup>29</sup> However, the epidemic in Yunnan has increasingly begun to affect other population groups, such as female sex workers and pregnant women.<sup>30</sup> HIV prevalence among women in Yunnan has increased disproportionately in the last decade.<sup>31</sup>

Yunnan's government is considered more open in its attempts to address HIV/AIDS, more willing to work with outside organizations, and allows more honest reporting of the issue, than other provincial governments.<sup>32</sup> As international organizations began to work on AIDS in China in the last decade, many of them located their first projects in Yunnan.<sup>33</sup> However, stigmatization, discrimination, and arbitrary detention of drug users in detoxification centers, all remain problems.<sup>34</sup>

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## **IV. RESEARCH FINDINGS**

Asia Catalyst has identified a range of obstacles to treatment access for children living with HIV/AIDS in China. They include the following:

- Gaps in the Four Free, One Care treatment program which families cannot afford to fill on their own
- Poorly-trained medical workers
- Geographic barriers to health care facilities
- Discrimination by hospitals and schools
- Problems with access to testing
- Limited access to psychological support services for HIV-positive children who suffer trauma, abandonment and discrimination

### **A. GAPS IN THE TREATMENT PROGRAM**

Families and experts interviewed by Asia Catalyst raised concerns about gaps in the government's Four Free, One Care treatment program. These include the lack of adequate access to pediatric formulations, of second-line ARV treatment, and of coverage of many hospital costs, including the opportunistic infections to which people with HIV/AIDS are vulnerable.

#### *Access to pediatric formulations*

Due to their smaller body mass and ongoing physical development, children need medications that are specifically formulated for them. Without treatment access, seventy-five percent of children with HIV die before the age of five.<sup>35</sup> According to the WHO, ARV treatment should be given to children in a once-daily, "fixed dose combination," in the form of scored tablets that are easily broken into pieces. For infants and children who are very young, syrup or other liquid forms may be necessary.<sup>36</sup> Unfortunately, as noted by MSF, "children [are] an afterthought when it comes to producing appropriate formulations of medicines."<sup>37</sup> Because the number of children living with HIV/AIDS is often under-reported, pharmaceutical companies do not have a strong profit incentive

to produce affordable pediatric ARV medications. Thus, the cost of pediatric AIDS medicines is considerably higher than the cost of those for adults.<sup>38</sup>

China provides brand-name and generic versions of some AIDS medications through its Four Free, One Care program.<sup>39</sup> The only drugs manufactured in China, however, are nevirapine (NVP), zidovudine (ZDV), didanosine (ddI), stavudine (d4T), and indinavir (IDV); others must be imported from international pharmaceutical companies.<sup>40</sup> In response to the urgent need for and high cost of pediatric medications, after a high-profile visit to China by President Bill Clinton in 2003, the Clinton HIV/AIDS Initiative established a relationship with the Chinese government.<sup>41</sup> In 2005, the Clinton Foundation began to assist the government in obtaining donations of pediatric drugs, and the state began providing them to children in Henan, and later gradually to other regions as well.<sup>42</sup>

It is difficult to pin down how many children are currently receiving this treatment. Like many countries, the Chinese government does not publish an official estimate of the number of children living with HIV/AIDS, though government figures indicated that there were 9,000 cases of mother-to-child transmission of HIV in 2005 alone.<sup>43</sup> This would not include children who became HIV-positive through hospital blood transfusions or other causes, nor does it include the number of cases of mother-to-child transmission in other years. Connie Osborne, a senior advisor on HIV/AIDS at the WHO in Beijing, estimates that there may be 10,000 children living with HIV in China today, and this number appears to be conservative.<sup>44</sup>

The number of children receiving ARV treatment is far less. In 2007, the Chinese government reported that a total of 805 children were receiving ARV treatment.<sup>45</sup> There are no reports from the Clinton Foundation of the number of children receiving treatment through its program.<sup>46</sup> Sources who had attended conference presentations by the Ministry of Health told *Asia Catalyst* that they had heard in the presentation that the Chinese government and Clinton Foundation are currently providing ARV treatment to 1,100 children.<sup>47</sup> If this number is correct, it implies that at least 8,000 children in China may not be receiving the ARV treatment they need to survive.

However, several AIDS advocates and health care providers interviewed for this report cast doubt on even the putative 1,100 number. They suggested that in fact far fewer children are actually receiving the necessary treatment.<sup>48</sup>

Because the demand for treatment far outstrips the supply, some doctors are therefore forced to put children on adult medications.<sup>49</sup> The adult tablets must be physically broken into smaller doses for children. This can be inexact and can result in skewed doses, leading to sometimes severe side effects—especially if doctors are untrained in the complexities of managing combination therapy and treating side effects. Several children interviewed for this report described suffering severe side effects.<sup>50</sup> [*For more information on the medicines interviewees were taking and potential side effects, see Appendix II.*] Xing Lu, a child with HIV from Henan, said,

My leg doesn't feel like itself, my arm won't move on its own. I still get fevers and I become lightheaded. I get headaches, my neck is sore and heavy, I am in pain in every inch of my body. There is not a single part of me that feels okay.<sup>51</sup>

Bao Ling, an AIDS advocate who has worked with over one hundred HIV-positive people in Yunnan Province, notes that because of side effects: "Some people just give up on [taking AIDS medications]."<sup>52</sup> Two other frontline AIDS workers concurred that children often stop taking their medications if side effects are severe.<sup>53</sup> But if patients take their treatment sporadically or stop altogether, it can accelerate the time in which they will need to begin second-line treatment. And in China, second-line treatment is unavailable.

### *Second-line treatment*

Patients that have been on ARV treatment for some time normally develop resistance to it, and need "second-line" drugs that can cost more than ten times the cost of first-line drugs.<sup>54</sup> In places where treatment adherence is poor, the need for second-line treatment accelerates quickly. Many factors can lead to poor adherence to ARV treatment by children, including "the child's age, disease severity, availability and degree of social support, and caregiver illness," as well as other factors documented in this report, such as poorly-trained doctors and the high cost of hospital visits.<sup>55</sup> A study following over eighty HIV-positive children in China from 2005 to 2006 found that due to poor adherence, a disproportionately high number of children were already resistant to first-line medicines.<sup>56</sup>

Since that time, the need for second-line drugs in both children and adults has only become more urgent. In November 2008, Chinese AIDS activists who spoke with Asia Catalyst estimated that twenty percent of the people with AIDS they knew needed second-line treatment.<sup>57</sup> Duan Jun, an AIDS activist from Henan, estimated that roughly forty percent of those he knew in Henan needed second-line drugs.<sup>58</sup> The government has also acknowledged that there is an urgent need for second-line treatment.<sup>59</sup>

Meng Lin, the director of a national network of people living with HIV/AIDS, says that this urgent need has created a black market for the medications smuggled in from countries where drugs are produced at low cost due to compulsory licensing there.<sup>60</sup> Asia Catalyst had unconfirmed reports that a few dozen children are receiving second-line treatment through international donations. But those without connections through the black market or to foreign groups face rapidly deteriorating health. AIDS worker Xiao Fan notes that in Henan,

ARV drugs are already ineffective, our CD4 counts have plummeted, and many people are already resistant to the first-line drug treatment. Second-line treatment is not free, so for many people the situation is not very optimistic.<sup>61</sup>

As the situation becomes desperate, Chinese AIDS activists are raising increasingly urgent concerns about the lack of second-line ARVs.<sup>62</sup> In March 2009, a group of leading AIDS

advocates in China issued a public resolution calling on the government to issue compulsory licenses for second-line treatment, as well as for medications for people with hepatitis and leukemia [for more on compulsory licensing, see Appendix I]. The increasingly urgent demands for treatment in Henan, where people are beginning to die of AIDS due to the lack of second-line treatment, has in turn led to an increased government crackdown on and harassment of advocates in Henan.<sup>63</sup>

The Chinese government is aware of the problem. Chang Fu, an official at the government agency NCAIDS, told Asia Catalyst that many of the children who were put on pediatric formulations as recently as 2005 are developing resistance, and many more will do so in the next two to five years.<sup>64</sup> Three experts speaking to Asia Catalyst off the record in December 2008 said that the government had promised privately to begin providing second-line drugs to a limited number of people with HIV/AIDS. Verifiable public commitments, however, have not been forthcoming.

#### *The high cost of treatment*

The cost of buying smuggled second-line medicines, treating side effects and paying for other hospital costs quickly adds up. A number of international organizations working on AIDS in China said that, despite the Four Free, One Care system, the high cost remains the main barrier to comprehensive treatment for children living with HIV/AIDS.<sup>65</sup>

In particular, several cited the high costs of treating opportunistic infection treatment as a significant problem.<sup>66</sup> Because of their weakened immune systems, people living with HIV/AIDS are vulnerable to infections of many kinds, which may lead to serious illness and eventually death. These vary from patient to patient, but commonly include fungal infections such as candidiasis, protozoal diseases such as toxoplasmosis, viral infections such as cytomegalovirus, bacterial infections such as tuberculosis and pneumonia, and HIV-specific malignancies such as lymphoma or Kaposi's sarcoma. If ARV treatment is interrupted for any reason, it becomes even more urgent to treat opportunistic infections.

Some opportunistic infections can be prevented with early treatment; the WHO recommends such treatment for infants and children.<sup>67</sup> The government has committed to providing treatment for opportunistic infections at a reduced price.<sup>68</sup> However, Dr. Yang, the head of the ARV treatment program at a public hospital in Yunnan, explains that while patients may apply for this coverage, only around thirty-seven percent of the applications are approved. For the others, "sometimes it may be cost prohibitive to bring (HIV-positive) kids in."<sup>69</sup>

Families who spoke to Asia Catalyst bore this out. After Gu Lan's brother died of AIDS, Gu Lan took in his HIV-positive niece and became her guardian. He told Asia Catalyst, "The child has tuberculosis and we have to pay for that medicine. It costs about thirty RMB (roughly US\$4.25), but she has to take it a few times a month. It's very difficult to pay for it."<sup>70</sup>

Xing Lu, a fourteen-year-old living with HIV/AIDS, agreed:



The ARVs are [free] from the hospital, but we have to buy all the other drugs. Liver medicine, anti-inflammatory medicine, immunity booster medication—none of this is free. These past few days, we have spent about 1,700 or 1,800 RMB (roughly US\$242–\$257) on medicine. When we come again next month, I don't know where we will get it from.<sup>71</sup>

Ken Legins from UNICEF reported that even when taking a free HIV test, patients were required to pay for the cotton balls, gloves, needles, and other small costs associated with the procedure.<sup>72</sup>

The average rural income in China in 2008 was US\$690.<sup>73</sup> In Yunnan Province, the average rural income the same year was 3,102 RMB (about US\$453).<sup>74</sup> For these families, a onetime trip to the doctor for an IV costing fifty RMB is a major expense. As Rui Na, the mother of an HIV-positive child, explains,

Some people are utterly unable to bring their children to the hospital [because of the cost]. They try to buy some of the medicines themselves, or do whatever they can on their own, and their children just die.<sup>75</sup>

Thus, some families face difficult choices. One parent said that he had been forced to discontinue treatment for his HIV-positive child because he could no longer afford the high hospital fees.<sup>76</sup> Other families reported selling a home, a business, or a car in order to pay for a child's treatment.<sup>77</sup> One boy wrote about how his older sister had to drop out of a coveted university position so that his parents' savings could be spent on his medical costs.<sup>78</sup> Xing Lu explains the toll her medical costs have taken on her family:

Before I had this sickness, it wasn't that my family had a lot of money, but we were about middle class. Now we are in debt everywhere . . . [and] it's very bad and shameful to have to borrow money. We don't have anything except for a place to live.<sup>79</sup>

Recently, the Chinese government has announced plans to implement sweeping policy reforms that will expand the health insurance program to more Chinese citizens.<sup>80</sup> Zhejiang Province has also taken steps to include previously uncovered treatment costs for HIV/AIDS in the provincial health insurance program.<sup>81</sup>

But for now, many aid workers and parents of children with HIV feel the frustration expressed by Li Yulan, the HIV-positive mother of an HIV-positive child:

The country says it will care for people living with HIV/AIDS, but talk is only talk. [Programs] exist, such as Four Free, One Care, but . . . the implementation still hasn't come through. It's only words on paper.<sup>82</sup>

### *International standards*

As outlined above, China is under international legal obligations to ensure that all children are able to access the highest available standard of health through China's ratification of the ICESCR and the CRC. The Committee on the Rights of the Child specifically stated that "obligations of States parties under the Convention [on the Rights of the Child] extend to ensuring that children have sustained and equal access to comprehensive treatment and care, including necessary HIV-related drugs, goods and services on a basis of non-discrimination."<sup>83</sup> Additionally, the Committee emphasizes that treatment access should include "related opportunistic infections and other conditions," and that "States parties should negotiate with the pharmaceutical industry in order to make the necessary medicines available at the lowest costs possible at the local level."<sup>84</sup>

Two children who spoke to Asia Catalyst were infected with HIV by state hospital blood transfusions, but have not received compensation from hospitals. The children described lengthy legal processes in an effort to win compensation for their infection with HIV, involving what they described as fraudulent court documents produced on the hospitals' behalf.<sup>85</sup> Xiao Liu's father was still petitioning the government to pay for his medical costs when Xiao Liu died, though local officials warned his family against pursuing legal action.<sup>86</sup> The courts in Henan refuse to accept any cases related to HIV/AIDS.<sup>87</sup> The Committee on Economic, Social and Cultural Rights's General Comment 14 on the Right to Health states that individuals whose rights have been violated should have "access to effective judicial or other appropriate remedies."<sup>88</sup> The International Covenant on Civil and Political Rights, which China has signed but not ratified, requires that remedies to personal violations must be heard and determined in a court of law.<sup>89</sup>

In addition, it is troubling that there is no public accounting of the number of children currently receiving ARV treatment through the government program. International donors and the Ministry of Health should all uphold international standards of transparency and accountability that would enable such claims to be independently evaluated.

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### **CHINA'S HEALTH INSURANCE SYSTEM**

Since the 1980s, privatization and the decentralization of the health care system has caused the health system to fragment, widening the disparities between rural areas and cities, richer coastal regions and poorer western regions.

Under the current system, the central government accounts for only thirty percent of budgetary expenditures on health care. The other seventy percent is distributed among provinces, prefectures/municipalities, counties, and townships. As a consequence, the system assigns heavy expenditure responsibilities to lower level governments for health care expenditures.<sup>90</sup> China does not have a uniform system designed to ensure that local governments can finance the minimum level of services for which they are responsible, so the quantity and quality of services differs across localities. Different localities receive different resources for health and limited resources are distributed to poor areas.<sup>91</sup> Thus, rural poor

not only have access to fewer services than urban residents, but they also need to pay for a greater share of the cost of those services out of their own pockets.

Since government spending for preventive public health services is low, public health providers are forced to raise their own revenue. As a result, hospitals tend to spend in a way that generates income. Since patients have to pay for medical service by item, medical facilities provide excessive medical services, increasing the country's medical costs and wasting health resources.<sup>92</sup> This system has led to an over-emphasis on specialized services and expensive medicines for those who are able to pay, while the poor do not have access to basic services.<sup>93</sup> The uneven distribution and waste of public resources have had direct consequences: first, health services become inaccessible to the general population and their costs become a catalyst for people falling into poverty; and second, since patients pay for medical service by item, medical facilities tend to provide excessive medical services and health workers extensively rely on users' fees.

According to current estimates, around seventy percent of the Chinese population lacks health insurance.<sup>94</sup> A children's organization in Yunnan Province reported that some families are unable to register for health insurance because they cannot pay the ten RMB [about US\$1.40] registration fee per family member.<sup>95</sup> Additionally, under the health insurance system, medication costs must be advanced by the patient and reimbursed later. Several aid workers in Yunnan and Beijing agreed that if a family does not have the money upfront, their child may go without care.<sup>96</sup> Though injection drug users represent forty-two percent of HIV-positive people in China, one drug user reported being refused when she requested health insurance, and a Yunnan service provider said he had heard of other similar cases.<sup>97</sup> If former injection drug users have children, the practice of denying a drug user health insurance may affect the children as well.<sup>98</sup>

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## **B. WEAKNESSES IN RURAL HEALTH CARE**

AIDS care for children is complex. In most countries, only a few doctors are adequately trained to provide it.<sup>99</sup> Given its size and complexity, China faces unique challenges in ensuring that there are an adequate number of health care facilities to reach children in rural regions.<sup>100</sup>

When the Four Free, One Care program launched in 2003, Zhang Fujie, the program director, estimated to a reporter that there were fewer than one hundred doctors in China capable of properly administering AIDS drugs.<sup>101</sup> China has made efforts to expand this number, but while NCAIDS works with the Ministry of Health to train doctors in AIDS care, Chang Fu, an NCAIDS official, admitted, "In China, not all hospitals and doctors understand AIDS."<sup>102</sup> All of the organizations that spoke to Asia Catalyst, including UNICEF and the WHO, agreed.<sup>103</sup>

One child from Henan described a lengthy process she went through with local doctors who did not recognize the symptoms, and who repeatedly told her to go home whenever she came in with a fever:

[The doctor] said, "It must be a mistake. Don't worry, go home." Near the end of the year, my mother looked at me and saw how everything was wrong, how my face was all discolored. We went back to the hospital and said we wouldn't leave. But the doctor gave us an order to leave

the hospital so we had no choice.... Finally I went to Xi'an [where I was diagnosed with HIV].<sup>104</sup>

Dr. Yang, the head of ARV treatment in a hospital in Yunnan Province, says, "Most doctors... will just treat children for their cold and won't test them for HIV/AIDS."<sup>105</sup>

Due to the rapid changes in the immune system during the progress of the HIV virus, frequent check-ups are necessary. But this does not appear to be common practice in China. An AIDS NGO worker in Yunnan said that when it came to treatment for opportunistic infections, "[Our clients] really just decide for themselves what to do and when to do it."<sup>106</sup> A twelve-year-old with HIV said that she only visits the doctor when she is sick and does not receive check ups in the interim.<sup>107</sup>

Children who live in remote rural regions, which are some of the areas hardest-hit by the AIDS epidemic, may not be able to get to health care facilities for check-ups at all. While some hospitals refund travel costs, frontline AIDS worker Hai Bao notes, "Sometimes children won't have the money in advance" to pay for bus fare to the hospital.<sup>108</sup> Hu Jin said that children's weakened physical states make the commute over rough rural roads physically challenging, and many tell her that "they are too weak to access services."<sup>109</sup> Often, doctors cannot get in touch with patients by phone to check on their condition, because, says one, "They don't have phones, so you have no way of reaching them."<sup>110</sup>

#### *International standards*

China should take steps to ensure that trained doctors or medical workers are widely available in regions of with high HIV prevalence. Paragraph 36 of General Comment 14 on the Right to Health, which elaborates on State Parties' obligations under the ICESCR, 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."<sup>111</sup>

Because of their economic dependence and weak physical states, children living with HIV may need extra accommodations to enable them to access treatment. International human rights law mandates that health care facilities be geographically accessible. Article 12(b) of the General Comment on the Right to Health recommends that "[h]ealth facilities, goods and services...be within safe physical reach for all sections of the population, especially...children," a recommendation also endorsed by the Committee on the Rights of the Child in its General Comment on HIV/AIDS and children's rights.<sup>112</sup>

In its most recent periodic review of China's implementation of the ICESCR, the Committee on Economic, Social and Cultural Rights urged China to "undertake effective measures to improve the delivery of health services in rural areas and ethnic minority regions, inter alia, by allocating adequate and increased resources."<sup>113</sup> In its periodic review of China in 2005, the Committee on the Rights of the Child reiterated previous concerns on access to health care for children "with

regard to existing disparities...between rural and urban areas, eastern and western provinces.”<sup>114</sup>

### **C. DISCRIMINATION AND TREATMENT ACCESS**

The stigma surrounding HIV/AIDS is widespread and pervasive in China. Adults living with HIV told Asia Catalyst about of losing jobs because of their HIV status, and abandonment of pregnant wives by their spouses.<sup>115</sup> One HIV-positive woman said that when she went to a police station to report a sexual assault, police told her to wrap their pen in tissue paper before she could use it.<sup>116</sup> Children are not exempt. Children, families, and AIDS workers all told Asia Catalyst that children face refusal of care by hospitals and expulsion from schools.<sup>117</sup>

That discrimination against people with HIV/AIDS is widespread has been reiterated recently by Premier Wen Jiabao, who urged the country, “through campaign and education...to enable the whole society to treat people with HIV/AIDS appropriately, to provide more care to them, and to reduce stigma and discrimination against them.”<sup>118</sup> A 2003 Human Rights Watch report in 2003 documented hospital discrimination in hospitals against people with AIDS in Yunnan Province in some detail; in 2006, Yunnan passed detailed regulations prohibiting discrimination against people with AIDS.<sup>119</sup> It appears, however, that hospitals in China, including in Yunnan, continue to refuse access to children with HIV/AIDS.

Mary Su, a project manager of for an international AIDS service organization in Yunnan, confirmed that discrimination in treatment programs is a problem there.<sup>120</sup> Su described the case of an HIV-positive client who needed extensive surgery, and who was told by the hospital that the only way he could receive treatment would be to pay for all new equipment for the procedures.<sup>121</sup> A child in Henan told Asia Catalyst that she had been turned away from hospitals when she sought medication for her fevers and colds. She said the doctors told her,

Go away, we don't have anything we can do for you. Go away!<sup>122</sup>

Bao Ling, an AIDS worker in a rural region of Yunnan Province, reports, “The hospitals that do not specialize in infectious diseases will tell [HIV-positive] people, ‘Go away! We don't want you here, go to another hospital,’” rather than assisting the patient.<sup>123</sup>

As noted above, one reason for this behavior may be the strong financial disincentives for hospitals in taking on patients with HIV/AIDS. Zhang Fujie et. al. note:

While local governments are mandated to support medical care for HIV/AIDS patients, funding is inadequate and many patients have insufficient resources to afford the recommended care and treatment. This financial structure serves as a disincentive for physicians to treat HIV/AIDS patients. Moreover, it discourages local governments from identifying and treating HIV/AIDS patients; the more patients they identify, the more expenditures they have.<sup>124</sup>

HIV-positive children may also face harassment or be refused access to school, violating their right to an education and heightening their isolation. A 2008 UNAIDS survey found that many people in China think that HIV-positive school-aged children should not be allowed attend school.<sup>125</sup> Bao Ling, the Yunnan AIDS worker, described cases told of teachers forcing HIV-positive children to sit across the classroom from other students.<sup>126</sup> Xiao Liu wrote in a journal entry he showed to Asia Catalyst:

I can't go to school. All the students in the school are afraid of me, and from the beginning they would not play with me. The teacher told me the school doesn't want me to attend.<sup>127</sup>

In addition to discrimination, students face stigmatizing attitudes from peers that can interfere with their adherence to a strict HIV/AIDS treatment regimen. ARV treatment may consist of three or four doses a day, administered at the same time each day. A break in treatment can exacerbate drug resistance and leave children vulnerable to opportunistic infections. But many children appear to be ignorant of how HIV is transmitted—including, most disturbingly, children who are HIV-positive themselves. And children who face stigma among peers say they are reluctant to take their medications at school.

One eight-year-old boy who does not know his mother is HIV-positive stated that, if he found out a friend was HIV-positive,

I wouldn't play with him, because he could infect me.... You don't want to let [HIV-positive children] go to school, because they can give it to people.<sup>128</sup>

Another child with HIV told Asia Catalyst, "Kids in my class say that people with AIDS won't live for very long before dying."<sup>129</sup> Mei Li, a fourteen-year-old girl in Yunnan, admitted,

When [my friends and I] are eating things, they'll share their fruit, pears, and stuff like that. I don't want to be with them then, because I am afraid I will infect them.<sup>130</sup>

Chinese middle and high schools in rural areas of China are often run as boarding schools where children live together without much privacy. Mei Li reported that she was reluctant to take her medicine at boarding school because she lives in a dorm room and has no privacy.<sup>131</sup> Hai Bao, a worker at a support group for people living with HIV/AIDS in a province in southwest China, observed:

Kids are ashamed. They are afraid that people will see them taking the medicines, so they hide the pills or do not take them.<sup>132</sup>

#### *International standards*

Non-discrimination is a fundamental obligation under principle of international law, and is established in each numerous international human rights documents, including the Universal

Declaration of Human Rights (UDHR), International Covenant on Civil and Political Rights (ICCPR), the ICESCR, and the CRC.<sup>133</sup> Whereas states parties are required to “progressively realize” obligations under the ICESCR, the obligation to do so without discrimination is an obligation of immediate effect. In its review of China in 2005, the Committee on the Rights of the Child called on China to strengthen its efforts to eliminate AIDS-related discrimination against children.<sup>134</sup>

China’s constitution guarantees all citizens the right to an education.<sup>135</sup> A number of laws and policies require China to give children access to health care without discrimination. The PRC Law on the Prevention and Treatment of Infectious Diseases states:

The state and the community shall show concern about and help patients with infectious diseases, pathogen carriers and patients suspected of having infectious diseases, and make it possible for them to receive timely medical treatment. *No work units or individuals shall discriminate against patients with infectious diseases, pathogen carriers and patients suspected of having infectious diseases* (emphasis added).<sup>136</sup>

The law prohibits hospitals from refusing care to someone because the hospital lacks the capacity to treat that person: “A medical agency that does not have the capability needed for treatment shall transfer the patients and the copies of their medical records to a medical agency that has such capability.”<sup>137</sup> In addition, the 2006 AIDS Management Regulations prohibit discrimination against people living with HIV/AIDS.<sup>138</sup> Yunnan Province also has detailed regulations prohibiting discrimination against people with HIV/AIDS, and stipulates that health facilities that refuse access to care to people with HIV/AIDS face fines of between 5,000 and 10,000 RMB [roughly US\$730 to 1,460].<sup>139</sup>

Despite this framework, discrimination remains a problem in part because of enforcement: while Yunnan’s regulations are quite clear, it is not clear how many health care facilities have in fact been fined since the regulations were passed in 2006.

Additionally, accessing their legal rights is still a challenge for people with AIDS in China still face challenges accessing their legal rights. Legal aid is not widely available, and given their limited economic resources, a priority for people with HIV/AIDS may be paying for high treatment costs rather than hiring a lawyer. Asia Catalyst helped to launch China’s first legal aid center for people with HIV/AIDS in 2007, and has learned that people with HIV/AIDS are often reluctant to file suit for fear that their names and HIV-status will become public knowledge, exposing them and their families to further stigma and discrimination. In Henan, as mentioned above, courts refuse to accept any cases at all pertaining to HIV/AIDS.

China has obligations under international law to ensure that children have access to information about AIDS, information that which can save their own lives and , as well as making make it safe for their peers to take HIV/AIDS medications at school.<sup>140</sup> China has taken steps to promote AIDS

education in the schools, as outlined in a series of policies and programs.<sup>141</sup> However, according to a UNAIDS survey in 2008, only 8.5 percent of Chinese reported getting information about HIV/AIDS from school.<sup>142</sup> A recent WHO report found that ninety-two percent of youth in China believe that they are not at risk of HIV transmission.<sup>143</sup>

#### **D. TRAUMA, ABANDONMENT AND ISOLATION**

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 who seem all-powerful to a child, such as teachers and doctors. Many have also experienced the traumatic death of parents from AIDS or drug addiction.

Mei Li, a fifteen-year-old HIV-positive girl in Henan, saw her mother, father, and older brother die of AIDS. She described her last moments with her father:

They told me to go play in the millet [while they harvested], and my father collapsed on the ground. He told me to go back as fast as I could and tell my grandmother that he had passed out. I ran and ran, I ran till I was so tired, totally wiped out, but I really did not know what to say or what to do.<sup>144</sup>

By the time Mei Li returned to the field with help, her father was dead. Other children face the trauma of abandonment by parents. A doctor at a hospital in Beijing told Asia Catalyst of about a seventeen-year-old boy, too weak to even feed himself, who was left on the side of the road near the hospital entrance: “[His family] just said they couldn’t care for him anymore.”<sup>145</sup>

Two AIDS workers in Yunnan and Henan provinces shared similar stories of parents abandoning children who tested HIV-positive.<sup>146</sup> A twelve-year-old boy interviewed for this report was abandoned by his mother when he was only four, and left in the care of his grandparents.<sup>147</sup> Xue Fa says,

My mom is a drug user and now she has HIV. She makes me so angry. Every time I have a birthday she won’t get me any presents, even though she will buy them for other people on their birthdays.<sup>148</sup>

Xiao Liu’s father Liu Fang says that “families are in agony” because of the widespread stigma.<sup>149</sup> After learning of his HIV-positive status, Xiao Liu began to feel rejected by other children:

The illness has been a big blow to my friendships. Now, when I see my best friends from before, they hide from me. I don’t have any friends and it’s hit me very hard. It has also had a big impact on my family—my aunt’s family, my father’s friends. They are all afraid because I am sick.<sup>150</sup>



Other children described similar experiences.<sup>151</sup> As a result of the cumulative experiences, and the heavy burden of coping with their own illness, some children interviewed for this report exhibited signs of depression, hopelessness, and described thoughts of death. When Xiao Liu found out he was HIV-positive, he wrote, “my heart felt extremely sad, I thought I should just get death over with, because I was someone without hope. Living was pointless, and I didn’t want to cause pain and suffering to my family.”<sup>152</sup> An uncle said of his HIV-positive niece,

She doesn’t talk a lot, she just stays by herself. She won’t play with other children. She just cries.<sup>153</sup>

Another parent described keeping her HIV-positive child indoors out of fear that neighbors would not let their children play with her son, which would “break his spirit.”<sup>154</sup> A survey of over sixty HIV-positive adults in a Yunnan town found that when asked how they dealt with their illness, some said they do not mind it, “because they will die soon.”<sup>155</sup>

In addition to the psychological suffering caused by trauma and discrimination, this despair causes some children to stop taking their medications. Dr. Yang of Yunnan notes that the children she treats “are without hope. They drop out of school, they stop taking their medication, they don’t see the need to continue.”<sup>156</sup> Others engage in self-destructive behaviors, according to Frank Chow, of the Moon Family Education Consultancy in Henan, who suspects that some HIV-positive children who turn to sex work or drug use are committing “a kind of slow suicide.”<sup>157</sup>

Although researchers identified organizations that provide counseling services to children affected by AIDS, including the Moon Family Education Consultancy and Save the Children, services are inadequate to meet the need. National AIDS advocate Meng Lin notes that the standard price for counseling services in Beijing is several hundred RMB per session, far out of reach for most people with HIV/AIDS.<sup>158</sup>

#### *Chinese policy and international standards*

The ICESCR establishes that “The States Parties...recognize the right of everyone to the enjoyment of the highest attainable standard of physical and *mental* health” (emphasis added).<sup>159</sup> The General Comment of the Committee on Economic, Social and Cultural Rights on the Right to Health calls for “the promotion and support of the establishment of institutions providing counseling and mental health services, with due regard to equitable distribution throughout the country.”<sup>160</sup> In its periodic review of China, the Committee raised concerns about the lack of psychological treatment facilities.<sup>161</sup> The Committee on the Rights of the Child defines treatment and care as including “social, spiritual and psychological support.”<sup>162</sup>

Chinese policies also make reference to the need for counseling for people living with HIV/AIDS. The national AIDS action plan calls on health administrative levels to “strengthen the management of...psychological support” for people with HIV/AIDS.<sup>163</sup> Yunnan’s provincial policy calls on testing sites to include counseling for people with HIV/AIDS, though this is not specified as

long-term psychological care of the kind required for children.<sup>164</sup>

## E. TESTING

The most significant barrier to HIV treatment for children in China may be finding out that they are HIV-positive in the first place. Policies are in place in China that mandate the testing of any child with an HIV-positive parent.<sup>165</sup> However, implementation of these policies appears to be weak. Zhang Fujie, the head of China's AIDS treatment program, admitted to a reporter:

Definitely there are a lot of kids who haven't been found, and a lot of kids who died without knowing they had AIDS.<sup>166</sup>

According to Dr. Lao, the head of a hospital in Yunnan,

There may be more children who are infected with HIV/AIDS. If a child only lives until it is one month old and has never been tested, who knows if [the child died of] HIV/AIDS or something else.<sup>167</sup>

Ken Legins, who was chief of UNICEF'S HIV/AIDS Program in Beijing at the time of his interview, notes that the current average age of children receiving treatment for HIV/AIDS in China is nine years old, and says it indicates weaknesses in the testing system: "This shows [that] many kids are being missed. In Africa, [the average age is] between five and nine, and that's still too high."<sup>168</sup>

This problem is not unique to China. Dr. Connie Osborne, a senior advisor on HIV/AIDS in China for the World Health Organization, notes that at least forty percent of all HIV-positive children in the world die before the age of one and eighty percent die before age of five.<sup>169</sup>

Interviews by Asia Catalyst suggest several factors for why Chinese children with HIV/AIDS are not identified despite national policies mandating testing and free treatment. These include: the lack of tests for early infant diagnosis, reluctance by authorities to determine find out the number of HIV-positive children in their district, and disincentives for parents, ranging from lack of confidentiality of test results to lack of adequate information about the free treatment program. In some cases, parents may also be reluctant to face the truth.

### *Diagnosis in early infancy*

As MSF states, "[D]etection of HIV infection in infants is crucial so that ARV therapy can be started as quickly as possible."<sup>170</sup> This has also been recommended by the Chinese Ministry of Health.<sup>171</sup> If an infant is found to be HIV-positive, the infant should be immediately assessed for ARV therapy and placed on an antibiotic, cotrimoxizole, to prevent opportunistic infections.<sup>172</sup> New advances in early infant diagnosis have produced a test of dried blood spots that can identify the virus in children as young as six weeks old. However, the program has yet to

receive full implementation in China.<sup>173</sup>

### *Official reluctance*

A second reason why many children may not be tested may be institutional reluctance among local authorities to confront the epidemic.<sup>174</sup> A number of organizations, such as the Mangrove Support Group, asserted that officials are reluctant to recognize the epidemic in their region because they would then be forced to take responsibility for addressing it.<sup>175</sup> As Mangrove Support Group director Li Xiang put it, officials “may have a good sense of the numbers [of children living with HIV in their districts], but they are unwilling to say anything until they have a solution to the problem.”<sup>176</sup>

### *Reluctant parents*

Some HIV-positive parents are reluctant to bring their children in for testing because they fear the stigma and discrimination that the family will face if the child tests positive, because they feel they will not have the support needed to deal with the situation, or because they are unaware of the free treatment program. Dr. Huang, a village doctor in a Yunnan town with high HIV prevalence, told Asia Catalyst that “no one has ever come in for voluntary testing.”<sup>177</sup> According to Li Xiang, “There isn’t enough belief in the system to get people to test kids. You need really good care to exist as an incentive for parents [before they will bring their children in to be tested].”<sup>178</sup>

One expert on HIV/AIDS in China mentioned that it was necessary to give personal information to the government to receive treatment, which many people living with HIV/AIDS are unwilling to do, because they do not trust that information will be kept confidential.<sup>179</sup> These concerns are justified. Employees at hospitals admit they routinely test for HIV without requesting consent of those tested; hospital employees and employees of testing stations then often share test results with family members, employers and other government agencies without the consent of the person tested.<sup>180</sup> People with HIV whose information is disclosed may then be fired from their jobs, evicted from their homes, and expelled from their villages.<sup>181</sup> In the words of one HIV-positive woman in Yunnan:

Usually, you don’t say you have HIV, you keep it a secret. But when you go to the hospital, the whole hospital knows you are infected.... [S]o I realized that confidentiality has two meanings, like there are quotation marks around it.<sup>182</sup>

Moreover, some parents appear unaware of the programs that are available to families with HIV-positive children. Two parents interviewed for this report did not know that China offers free treatment for HIV-positive children, even though they were HIV-positive themselves. As one HIV-positive mother said,

We haven’t [tested] our child. We don’t want to take him to get tested. We’re afraid that after the test...we wouldn’t be able to take him to see a doctor. We don’t know how to receive the support.<sup>183</sup>

According to frontline AIDS worker Bao Ling, of the over twenty children whose mothers she serves in her program for sex workers, only five have been tested for the virus. Most of the women tell her that they feel they would have no support, either emotionally or economically, to deal with the repercussions of a positive diagnosis.<sup>184</sup> Not knowing where to receive information and help is common: a survey of HIV-positive people done by NGO workers in another region found that only “sixty-three percent said they could access HIV information from hospitals and their village doctors.”<sup>185</sup> In a 2008 UNAIDS survey conducted in China, 26.3 percent of over 6,000 interviewees did not know where they could get an HIV/AIDS test.<sup>186</sup>

HIV-positive parents who have experienced the stigma themselves sometimes engage in denial about their children, postponing the test. Cheng Cheng, a thirty-two-year-old HIV-positive woman in Yunnan, explains that she does not want to test her three-year-old for HIV, “because we’re afraid that he’d be the same as us. We’d be heartbroken.”<sup>187</sup> Another mother notes, “There are certainly people who don’t know their own status or that of their children. If they don’t know, they don’t have to face it. They don’t want to...deal with reality.”<sup>188</sup>

None of the children interviewed for this report had been informed by a doctor that she or he had contracted HIV/AIDS. Many children learned by indirect means.<sup>189</sup> One Henan girl remembered,

Although my mother and [the doctors knew I was HIV-positive], no one said so. But inside the hospital I was suspicious. After they started the treatment in Beijing, I was taking antiviral drugs, and on the drug label it said ‘HIV.’ That’s when I knew.<sup>190</sup>

Such experiences reinforce a child’s sense of isolation, and the stigma surrounding the epidemic. Doctors who do not discuss a child’s HIV status with the child miss an opportunity to educate the child about HIV/AIDS and to prevent further transmission.

### *International standards*

The Committee on the Rights of the Child encourages states parties to “ensure that health services employ trained personnel who fully respect the rights of children...in offering them access to HIV-related information, voluntary counseling and testing, [and] knowledge of their HIV status.”<sup>191</sup> International donors can offer assistance to China to expand existing testing to include early infant diagnosis, and to develop counseling programs to accompany testing. The Ministry of Health should ensure that information about the Four Free, One Care program is made widely available.

China has recognized the need to protect the confidentiality of people living with HIV/AIDS.<sup>192</sup> Article 12 of China’s Infectious Disease Prevention and Control Act states, “Organizations who work for disease prevention and control and who provide health care are not permitted to disclose confidential information about individuals.”<sup>193</sup> However, Wang Xiaobin, an AIDS lawyer, explains, “The punishment for violating these regulations is really non-existent. [The regulations] are really just suggestions.”<sup>194</sup> Enforcing laws that protect confidentiality will help make it

possible for more families to come forward and be tested.

Due to inadequate provisions for confidentiality and the lack of protections against discrimination in China, Asia Catalyst does not endorse mandatory testing for HIV/AIDS.

The CRC establishes that parents or guardians have the primary responsibility to protect the “best interests of the child.”<sup>195</sup> Cultural interpretations of the “best interests of the child” may vary, but the CRC does protect children’s right to information, including information about her or his medical status. General Comment 3 states, “Information on the HIV status of children may not be disclosed to third parties, including parents, without the child’s consent.”<sup>196</sup> Explaining and discussing their HIV status with children empowers children to learn about and manage their health care; it can help to reduce feelings of isolation and fears of their own contagiousness.

## **CONCLUSION**

When Xiao Liu learned that he was HIV-positive, he said, “I felt shaky all over, as if I was about to die right then.” His parents gave him the strength to continue by telling him that they would spend every last penny to fight for his life, and they did just that. They took jobs at a spa giving massages so that they would be free to accompany him to hospitals. They borrowed money, and pursued a lawsuit against the hospital that infected him with HIV in the first place. His sister quit school and went to work to help pay for her brother’s medical expenses. When they had exhausted all their funds in a Beijing hospital, they took Xiao Liu home to Henan, where he died at the age of fourteen.

Across the city from his Beijing hospital bed, however, China was able to find US\$40 billion to spend on the 2008 Olympics, producing the most extravagant and costly Olympics the world has ever seen.<sup>197</sup> For a fraction of that cost, China could save the lives of children like Xiao Liu and others like him—reaching out to them to get them tested, providing them with legal protections and legal aid to ensure that they get hospital care and attend school, and providing the social and psychological support services necessary to enable their families to care for them. MSF has described children living with HIV/AIDS as “the silent victims of the HIV/AIDS pandemic.”<sup>198</sup> The voices of these children call on us to provide them with accessible, quality medical treatment.

Through programs such as Four Free, One Care, and by passing legislation such as the AIDS Prevention Law in 2004, the government has taken positive, meaningful steps in the worldwide fight against HIV/AIDS. More action must be taken before China fulfills its obligations to its youngest citizens.

## APPENDIX I: COMPULSORY LICENSING

China entered the WTO in 2001.<sup>199</sup> Under the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement, no party other than the patent holder can legally produce, sell, or import a drug in any of the WTO member countries for a minimum of twenty years after the drug's initial patent registration.<sup>200</sup> However, TRIPS does allow for certain “flexibilities,” including compulsory licensing, which is “when a government allows someone else to produce the patented product or process without the consent of the patent owner.”<sup>201</sup>

Countries are free to determine the grounds for using compulsory licenses. The TRIPS agreement outlines “reasonable commercial terms and conditions” of use: the country should attempt to negotiate a voluntary license with the patent holder, and should give the patent holder “adequate remuneration.”<sup>202</sup> The amount of remuneration should be determined through a legal process.

According to the WTO, there are certain conditions under which these steps would not need to be taken:

For “national emergencies,” “other circumstances of extreme urgency” or “public non-commercial use” (or “government use”) or anti-competitive practices, there is no need to try first for a voluntary license. It's the only instance when the TRIPS Agreement specifically links emergencies to compulsory licensing: the purpose is to say that the first step of negotiating a voluntary license can be bypassed in order to save time.<sup>203</sup>

But as Richard Elliott, the director of Canadian HIV/AIDS Legal Network, observes:

China would *not* be required to invoke any national emergency to make use of compulsory licensing. In fact, the Doha Declaration from Nov 2001 makes it very clear that WTO Members are free to determine for themselves the grounds upon which compulsory licensing may be used—nothing in TRIPS limits that to just situations such as emergencies. This, in fact, was a major point of contention in the negotiations that ultimately resulted in the August 30, 2003, decision on compulsory licensing for export/import to assist countries with insufficient pharma manufacturing capacity.<sup>204</sup>

China has applied patent protections on medicines since 1993. The U.S. has sanctioned countries, such as Thailand, that issued compulsory licenses for AIDS drugs. Perhaps due to the risk of repercussions from the U.S., China has not yet taken advantage of the provisions in TRIPS that would allow the state to apply compulsory licensing to AIDS drugs. However, an amendment to China's patent law in December 2008 “support(s) expansive authority for the state to issue licenses, without the approval of the patent holder, to anyone who is able to produce the product once given access to the patented technology.”<sup>205</sup> Without the risk of international trade repercussions, it is possible that China would be free to issue compulsory licenses for second-line AIDS treatment.

## APPENDIX II: CHILDREN'S THERAPY AND POSSIBLE SIDE EFFECTS

Asia Catalyst did not have access to medical information for the children whose cases are discussed in this report. In two cases, children knew which medications they were taking; these are outlined below, along with the possible side effects. Other children did not know what medications they were taking.

### 1. Xing Lu:

#### **Stavudine, 司他夫定**

##### **Side Effects:**

From AIDS Info, a website of the U.S. Department of Health and Human Services ([http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int\\_id=43](http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int_id=43))

Serious side effects of this medicine include burning, numbness, pain, or tingling in the hands, arms, feet, or legs; joint or muscle aches; nausea; severe stomach pain; fever; skin rash; or vomiting. Individuals should tell a doctor if they have any of these side effects. Other side effects may be less serious and may lessen or disappear with continued use of the medicine. Less serious side effects of this medicine include chills and fever, diarrhea, headache, loss of appetite or weight loss, mild stomach pain, shift in body fat location, trouble sleeping, or unusual tiredness or weakness.

#### **Lamivudine, 拉米夫定**

##### **Side Effects:**

From AIDS Info, [http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int\\_id=126](http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int_id=126)

Serious side effects of this medicine include severe abdominal or stomach pain, or feeling of fullness; nausea; tingling, burning, numbness, or pain in the hands, arms, feet, or legs; and vomiting. Individuals should tell a doctor if they have any of these side effects. Other side effects may not be serious and may lessen or disappear with continued use of the medicine. Less serious side effects of this medicine include canker sores; ear discharge or ear swelling; redness of skin; sores, ulcers, or white spots on lips, tongue, or inside the mouth; swollen and painful spots on neck, armpit, or groin; and unusually warm skin.

[Drugs.com \(http://www.drugs.com/cons/lamivudine.html\)](http://www.drugs.com/cons/lamivudine.html)

Lamivudine can cause serious side effects. In one study, children with advanced AIDS were more likely than children who were less ill to develop pancreatitis (inflammation of the pancreas) and peripheral neuropathy (a problem involving the nerves).

#### **Stocrin/Efavirenz, 施多宁**

##### **Side effects:**

AIDS Info, [http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int\\_id=269](http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int_id=269)

Serious side effects of efavirenz include abnormal thinking, confusion, depression, hallucinations, memory loss, paranoid thinking, and thoughts of suicide. Some individuals may develop a severe rash. Individuals should tell a doctor if they have any of these side effects.

Other side effects may not be serious and may lessen or disappear with continued use of the medicine. Less serious side effects of this medicine include nausea, diarrhea, sleep problems, abnormal dreams, headache, dizziness, impaired concentration, and changes in certain blood tests.

## **2. Xiao Liu:**

### **Stavudine (see above)**

#### **Didanosine**

##### **Interaction with Stavudine**

##### A warning from the U.S. FDA:

Lactic acidosis and severe hepatomegaly with steatosis, including fatal cases, have been reported with the use of nucleoside analogues alone or in combination, including didanosine (stavudine) and other antiretrovirals. Fatal lactic acidosis has been reported in pregnant women who received the combination of didanosine and stavudine with other antiretroviral agents.<sup>206</sup>

##### **Side effects**

##### AIDS Info,

[http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?MenuItem=Drugs&int\\_id=16](http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?MenuItem=Drugs&int_id=16)

Serious side effects of this medicine include inflammation of the pancreas, with symptoms of severe stomach pain, nausea, or vomiting; enlarged liver or lactic acidosis, with symptoms of feeling tired or weak, stomach discomfort, feeling cold, dizzy, or lightheaded, and slow or irregular heartbeat; nerve problems, with symptoms of pain or tingling in hands or feet; or vision problems such as blurred vision. Individuals should tell a doctor if they have any of these side effects. Other side effects may not be serious and may lessen or disappear with continued use of the medicine. Less serious side effects of this medicine include diarrhea, nausea, vomiting, headache, dizziness, anxiety, sleep problems, and skin rash. Individuals should tell a doctor if these side effects continue or are bothersome.

#### **Nevirapine**

##### **Side effects:**

##### An FDA Public Advisory warns:

Both clinically symptomatic and asymptomatic liver toxicity are observed with long term use of nevirapine in combination with other HIV drugs.<sup>207</sup>

AIDS Info, [http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int\\_id=116](http://www.aidsinfo.nih.gov/DrugsNew/DrugDetailNT.aspx?int_id=116)

Serious side effects of this medicine include severe skin rash, chills, fever, sore throat, or other flu-like symptoms. These symptoms may be signs of liver disease. Individuals should tell a doctor if they have any of these side effects. The manufacturer of nevirapine provides a medication guide to further explain the risks of liver disease. Other side effects may not be serious and may lessen or disappear with continued use of the medicine. Less serious side effects of this medicine include stomach pain, nausea, diarrhea, tiredness, and headache.



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## ABOUT ASIA CATALYST

Asia Catalyst partners with activists in Asia to inspire, create and launch innovative, self-sustaining programs and organizations that advance human rights, social justice and environmental protection. For more information, please see [www.asiacatalyst.org](http://www.asiacatalyst.org).

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## ENDNOTES

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<sup>2</sup> World Health Organization, “WHO Epidemiological Fact Sheet on HIV and AIDS,” July 2008, [http://www.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008\\_CN.pdf](http://www.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_CN.pdf).

<sup>3</sup> 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](http://data.unaids.org/pub/Report/2008/china_2008_country_progress_report_en.pdf).

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- <sup>14</sup> UNICEF, *Children and HIV/AIDS Factsheet*; see also Zhang Lu interview, August 2008.
- <sup>15</sup> Zhang Lu interview, August 2008.
- <sup>16</sup> *Ibid.*; Asia Catalyst interview with Ken Legins, (real name), Chief of HIV/AIDS Programme, UNICEF, held in Beijing, China, August 2008.
- <sup>17</sup> *Constitution of the People’s Republic of China*, article 45, adopted December 4, 1982; <http://english.peopledaily.com.cn/constitution/constitution.html>.
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- <sup>19</sup> ICESCR, Article 12.
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<sup>45</sup> *UNGASS Country Progress Report* p.i.

<sup>46</sup> The Clinton Foundation declined to speak on the record for this report, stating that the foundation's policy is not to participate in research projects.

<sup>47</sup> Connie Osborne interview, August 2008.

<sup>48</sup> 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

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<sup>49</sup> Dr. Yang interview, July 2008.

<sup>50</sup> Qing Bao, HIV-positive girl, Asia Catalyst interview, held in Yunnan, China, July 2008; Xiao Liu, HIV-positive boy (now deceased), Asia Catalyst interview, Beijing, July 2008.

<sup>51</sup> Xing Lu, HIV-positive girl, Asia Catalyst interview, held in Beijing, China, June 2008.

<sup>52</sup> Bao Ling, founder of Sweet Sky HIV-positive support group, Asia Catalyst interview, held in Yunnan, China, July 2008.

<sup>53</sup> Hai Bao, HIV-positive direct services AIDS worker, Asia Catalyst interview, held in Yunnan, China July 2008; Stacy Lu, Chief of Beijing Staff at an AIDS organization working in Henan Province, Asia Catalyst interview, held in Beijing, China, June 2008.

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<sup>60</sup> For more on compulsory licenses, see Appendix I. Meng Lin, Asia Catalyst interview, Beijing, China, May 2008.

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- <sup>70</sup> Gu Lan, uncle and caretaker of an HIV-positive girl, Asia Catalyst interview, via phone, Yunnan, July 2008.
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