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wufengshi@cuhk.edu.hk.

### **SOCIAL ACTIVISM IN HIV/AIDS PREVENTION IN CHINA**

Even though AIDS is a young disease in China, and the Chinese government was reluctant to face it for a long time, a recognizable societal and activist community surrounding this issue is emerging. Like the conservation case, this community is composed of a variety of actors, ranging from individual activists, professionals, NGOs, organizations led by people living with HIV/AIDS (PLWHA), rural community-based groups, to university student associations.

Key individual activists in this field include Dr. Gao Yaojie, Dr. Gui Xi'en, and Wan Yanhai, who became symbolic faces of China's bottom-up activism against AIDS. It is simply impossible to include every expert who has contributed to the rise of AIDS activism, especially some leading medical professionals (e.g., Dr. Zeng Yi, on the Board of the State AIDS Committee), who many times sheltered or spoke up for AIDS activists. Nevertheless, this research does its best to point out those who have played a crucial role in *linking* the activist group with the public, the government, or the international community. As of the end of 2004, and in spite of political obstacles and social stigma, there are about 17 registered (or engaged in the registration process) independent voluntary organizations (including six PLWHA groups) that are actively working on AIDS related issues. They implement relief, public education, and prevention projects, and advocate for policy changes. In addition, with

support from international and Chinese NGOs, many voluntary villager associations and university student associations are being formed. A few environmental NGOs and religious philanthropic organizations are also expanding their working plan to include AIDS prevention and advocacy activities. Due to the central government's attitude and policy change on AIDS prevention, a number of AIDS Care Centers and AIDS Patients Associations have been established by local CDCs, especially in the 128 focused counties.<sup>1</sup> And, these centers and associations are becoming new seeds and potential sources of inspiration for local activism surrounding AIDS. They are alike the newly established environmental GONGOs in the previous case of nature conservation. Their impact could be significant in the future, but it is still too early to make conclusion about. Table 4.4 below gives an overview of the various social groups and individuals that will be discussed in detail as the essential components of the AIDS prevention civil society.<sup>2</sup>

**Table 4.4. An overview of AIDS activists and social groups**

<b>Type</b>	<b>Main actors</b>
Individual activists and professionals	doctors, professors, journalists and other professionals
Institutionalized NGOs (and NGOs-to-be)	PLWHA groups, exclusively AIDS NGOs, gay community groups, hemophilia associations, women's groups, and a few non-AIDS focused NGOs
Rural community-based groups	Voluntarily established in some villages of rural China
University student groups	Most are in Beijing, and others are spreading in 10 provinces

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<sup>1</sup> Actual names of these centers and associations vary across locations, e.g., Home of Care and Love, but, in general, they are meant to provide some type of counseling, assistance, and training to AIDS affected population. They are physically situated within the local CDC office building, and formally operated by CDC staff. It is not unusual now for these centers to implement peer-training, and invite PLWHAs to be part of the regular staff team. They are usually formally staffed by doctors, medical professionals, and local governmental officials, and informally operated by local HIV+ patients and activists.

<sup>2</sup> Special thanks to Mr. Odilon Couzin, founder of the China AIDS Info. for sharing valuable data from the forthcoming Directory of Groups Working on HIV/AIDS in China, a project funded by the Ford Foundation.

## **Pioneers of AIDS Activism**

### ***Dr. Gao Yaojie***

Dr. Gao, a retired leading gynecologist in Henan, was drawn into AIDS work at the age of 70. A female patient was brought to her for her expert opinion on the uncommonly colored infections in her in early 1996. She had a suspicion of HIV related illness, and a blood test was ordered afterwards. After the case was confirmed, she was very puzzled by why this normal rural woman could ever be infected with HIV, and later found out that she got the infected via blood transmission during a surgery one year before. This incident of blood contamination struck Dr. Gao, and she decided to learn more about HIV and AIDS. When she realized that public education of AIDS had been skewed by only emphasizing sexual transmission, and completely omitting the possibility of direct blood contamination, she felt compelled to disseminate the correct information as soon as possible. By November that year, she had edited and printed 12,000 copies of AIDS education handouts. On the World AIDS Day, 1996, she and some helpers set off to public transportation centers. In three days, they went to all five long-distance bus stations in Zhengzhou city, and distributed over 800 handouts in person. At that time, Dr. Gao's sole intention was to increase public awareness of AIDS prevention. Never could she have imagined the death toll of AIDS patients in rural Henan that she would learn of one year later. When I met her in April 2004, she told me that: "I ran into this politics of AIDS totally by chance. I am a doctor, and all I knew at the beginning was that there were lots of patients in need of my help."

Since 1997, this elderly lady, with bonded feet, has visited thousands of HIV/AIDS patients from hundreds of villages in rural Henan. She sometimes goes under the cover of

giving free medical check-ups of women's health, yet hands out basic medicines (e.g., antibiotics, cold medicines) to alleviate patient's pain and illness. In more recent years, because the issue became more politically sensitive, many times she had to sneak into the villages to speak to patients, and "escape" from local police or authority's harassment. She is supporting over 160 children orphaned by AIDS patients, and is in close contact with many of them. In 2004, she finished a new book, called "Ten Thousand Letters", which selected 200 out of the 10,000 private letters from HIV/AIDS patients who seek counseling, anonymous people who are at high risk, students who are curious, and activists who are willing to help.

It is really because of her continuous writing and speaking frankly about the patients she has seen that the story of the blood scandal and AIDS villages in Henan finally appeared in newspapers, websites, TV programs, and later caught the attention of foreign media and international organizations.<sup>3</sup> By the end of 2004, she has edited, printed and distributed 19 issues of the AIDS Basics and Prevention Newsletter, around 10,000 copies of each issue. She has also written two books on AIDS and STDs, and over 300,000 copies of them have been distributed to various education institutions, hospitals, and more impressively, individual readers—all from her apartment.<sup>4</sup> More recently, at the age of almost 80, she has not only accepted numerous newspapers and TV programs to her home for interviews, but

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<sup>3</sup> Many overseas Chinese first paid attention to China's AIDS epidemic by reading Rosenthau's reports in New York Times in October 2000. In fact, it was through Dr. Gao that Rosenthau got chance to see some patients in person.

<sup>4</sup> Gao, Yaojie. 1997. *AIDS/HIV/STDs Prevention and Treatment*. 1<sup>st</sup> ed. Zhengzhou: Henan Science and Technology Press. 2003. *Unknown Stories: Popular Edition for AIDS and STDs Prevention and Treatment*. China Farmers Press.

has also taken trains and traveled to Beijing, Shanghai and Nanjing to give public talks.<sup>5</sup> As the AIDS epidemic in Henan has become more exposed, it has attracted numerous activists, journalists, researchers, and NGOs coming to Henan to collect information, distribute relief goods, and coordinate AIDS support work. Dr. Gao's two-bedroom apartment in Zhengzhou has literally turned into a transit-station for all of these people who want to learn about and help with the AIDS situation in Henan.

In a way, Dr. Gao became the face of AIDS activism in China and the voice outside the government. Within the international AIDS community, Dr. Gao's impressive work has won wide recognition and much respect. She was awarded the Jonathan Mann Award of Health and Human Rights from the Global Health Council in 2001, and the Lameng Magasasa Prize for Public Service (known as the Nobel Prize of Asia) in 2003. News of these awards greatly inspired and encouraged other Chinese AIDS activists and groups. On Dec. 18<sup>th</sup>, the Vice Premier, and Minister of Health, Mdm. Wu Yi and Dr. Gao had a private meeting in Henan. Chinese AIDS activists took this event as a significant signal of central government's attitude change. The Chinese Central TV (known as CCTV), the main propaganda instrument of the central government, named her as one of the "Figures who Moved China" for 2003, together with Dr. Zhong Nanshan, who became nationally known during the SARS crisis. After this "public promotion" of Dr. Gao by CCTV, most activists felt a fundamental relief of political pressure on AIDS related voluntary work.

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<sup>5</sup> On 2003 World AIDS Day, Dr. Gao gave a speech at Tsinghua University, Beijing. In Feb. 2004, Dr. Gao was invited to Nanjing University. She spent a week in Shanghai in late March 2004. During that week, she gave four public speeches at universities and at Shanghai AIDS Legal Research Center, in addition to multiple media interviews. During these few months, she alone, in a way, generated a momentum of AIDS awareness in China.

*Dr. Gui Xi'en*

Like Dr. Gao, Dr. Gui Xi'en from Wuhan Central-South Hospital, Hubei province, is another pioneer in AIDS prevention in China, who started helping Henan AIDS patients in the late 1990s.<sup>6</sup> Unlike Dr. Gao, he has always been low-key, and remained silent with regard to governmental policies. But, it is because of this cautiousness that he has been able to offer hundreds of HIV+ patients from Henan and neighboring provinces the access to testing and treatment. When I visited several villages in central and southern Henan in 2004, I met many HIV+ patients who referred to Dr. Gui as their life-saver.

Because blood tests for AIDS patients (e.g., CT4 cell level) are still not available in every hospital in China, Dr. Gui has also become the help-line for other medical professionals who see HIV+ patients. For example, the Xiangfan Clinic of MSF-Belgium has treated over 120 patients within 2 years, and all their blood samples were tested at Dr. Gui's lab.<sup>7</sup>

Dr. Gui has also conducted many research based on the cases he treated, the results of which, particularly those on mother-child transmission, and the vulnerability of women to HIV, have provided useful data and evidence for the AIDS activist community.<sup>8</sup> Particularly noteworthy as well is the actual number of farmers who were infected with HIV directly via

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<sup>6</sup> In November 1999, Dr. Gui took a trip with one of his medical students to a village in central Henan, because many farmers had died within a short period of time of "a strange disease" in this village. They took 155 people's blood samples back to the hospital laboratory, and found 96 of them were HIV positive. It is said that Dr. Gui, in his late 50s, burst into tears over the results. On that night, Dr. Gui decided to do his best to help these desperate farmers. Over the years, he has collected many villagers' blood samples for testing in person, and encouraged more to go to hospitals for VCT. (Interview with one of the patients treated by Dr. Gui in Henan, 22 April 2004.)

<sup>7</sup> Interviews with Xiangfan Clinic staff, 1 June 2004.

<sup>8</sup> Gui, Xi'en. 2003. "A Survey of Children with HIV/AIDS in Highly Affected Villages". *Chinese Journal of Pediatrics*, 41(8): 586-589. 2003. "A Study on HIV Transmission within Family". *Chinese Journal of Epidemic*, 24 (5): 396. 2004. "A Survey on Mother-Child Transmission of HIV and TTV". *China Public Health*, 20 (5): 583-584.

blood transmission from the late 1980s to the mid-1990s. The official number is 260,000, but Dr. Gui's estimate is 700,000. His field research has shown that about 1.4 million people participated in blood selling/donation practices during this time period, and the HIV infection rate among them was as high as 50%.<sup>9</sup>

Even though they have adopted very different ways to raise public awareness of AIDS and to offer their generous help to the patients in rural Henan, Dr. Gao and Dr. Gui are aware of and pay great respect to each other's work. They often refer to each other in their public talks and writings. They are the leading figures of AIDS activism in the eyes of the public, and the state praises them to convince the public it supports such voluntary work. In Dec. 2003, Vice Premier, Mdm. Wu met with Dr. Gao in Henan, and in the following May, Premier Wen Jiabao visited Dr. Gui in Hubei.

### ***Wan Yanhai***

In contrast to Drs. Gao and Gui, Mr. Wan Yanhai has always been a very controversial figure inside and outside of the AIDS activist community because of his working style. He certainly is more of a professional activist than the two doctors. A graduate from a leading medical school in Beijing, Wan worked for the Institute for Health Education, part of the MoH system in early 1990s. His former colleague recalled that he was very vocal about gay rights, legalization of prostitution, and other progressive ideas related to sexual and reproductive health. He advocated for changes in China's public health education within the Institute, and was able to mobilize the entertainment community and participated in the opening of the first

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<sup>9</sup> Round-table on "AIDS in China", hosted by the Center for Strategic and International Studies, Washington, D.C., Nov. 16<sup>th</sup>, 2004.

gay bar in Beijing. Such acts were unorthodox and unacceptable at that time, and Wan was ordered to stop any further involvement on May 10<sup>th</sup>, 1993. The director of the Institute at that time was forced to retire in the following August because of his sympathy of Wan's activist work.<sup>10</sup>

Wan established the Aizhi Action Project (later registered as the Aizhixing Institute for Health Education) in March 1994, and in August he was forced to resign from his work. Wan then became a full-time activist advocating for policy changes (e.g., equal rights for gay, legalization of commercial sex) and public education of AIDS prevention. Aizhi organized discussions, public meetings, and street exhibitions, and became a center for information exchange and a gathering spot for concerned researchers. Professor Zhang Beichuan, one of the most known and respected Chinese scholars on gay issues in China, recalled Wan as the first one who “extended his help to my research from Beijing”, and “introduced me to the gay community at that time”.<sup>11</sup> Wan also followed individual cases of discrimination against gays, and provided moral support. He published *Aizhi Newsletters* to disseminate information among the gay community, and co-organized conferences with professors from the Social Science Academy to promote new laws to protect basic rights for gay people and commercial sex workers.

Since 1999, Wan started his investigation of the blood contamination scandal, and support to AIDS patients in Henan and other rural parts of China. Since 2001, his activism has become more focused on AIDS, blood security, medical ethics, and patients' rights issues. In early summer of 2002, a confidential report on the status of AIDS in Henan by the Henan

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<sup>10</sup> Interview with Wan's former colleagues, Beijing, July 8, 2004.

<sup>11</sup> Prof. Zhang Beichuan's congratulation letter to Aizhixing's 10<sup>th</sup> anniversary in April 2004.

provincial government was leaked to Wan, and he further distributed it to people concerned through a personal email. This was after the release of the UNAIDS “Titanic Report”, which for the first time challenged the official data on HIV/AIDS infections and the denial of blood contamination scandal. The report Wan distributed was the first time the Henan provincial government admitted to severe AIDS problems in the province, and documented the highly hit regions and estimated the number of people who participated in paid blood donation and the infection rate among them. Therefore, Wan was accused of leaking confidential governmental documents, and arrested on August 23, just three days before that year’s Barcelona World AIDS Conference. This incident immediately drew a wide range of criticism, petitions and demonstrations against the Chinese government from the international community.<sup>12</sup> For example, about 60 people from groups like Human Rights in China (overseas Chinese group), Health GAP (AIDS lobbyist group) and ACT UP (gay activist group) took part in the peaceful protest in front of the Chinese consulate in New York on 19 September 2002.<sup>13</sup> The Canadian HIV/AIDS Legal Network and Human Rights Watch selected Wan as the recipient of their annual award for 2002.<sup>14</sup>

After Wan was released in October, Yale University granted him the World Fellowship to study in the U.S. During this time period, Wan met with a number of international organizations and media. Since 2003, substantial amount of assistance has

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<sup>12</sup> “Amnesty concerned over missing China AIDS activist”, *Agence France Presse*, 31 August 2002. [Accessed through LexisNexis on 30 March 2005]

<sup>13</sup> “Protest in New York against detention of Chinese AIDS activist”, *Agence France Presse*, 19 September 2002. [Accessed through LexisNexis on 30 March 2005]

<sup>14</sup> The award ceremony was held on September 13, which Wan was absent.

became available to Wan, which made it possible for him to build up the new Aizhixing office in Beijing and to recruit full-time staff.

### ***Wang Shuping***

Wang Shuping is probably the first medical professional who became involved in the uncovering of the blood scandal in Henan. Dr. Wang used to be the chief physician of the Clinical Laboratory in Zhoukou Region Hospital in Henan.<sup>15</sup> In 1994, she started epidemiological research of Hepatitis and AIDS in the Zhoukou Region. In the summer of 1995, she found that out of over 400 blood samples, the HIV infection rate was 13%. By October, she submitted a report with the findings of her research to the local health authority.<sup>16</sup> Soon after that, Wang was told that she would not publish her report anywhere. Incidents of personal harassment followed. In Nov. 1996, a Party meeting was called by a provincial health official at the Zhoukou Regional Health Bureau, and local health officials were criticized for allowing Wang and her colleagues to research on AIDS. Wang's lab was soon closed down, and she had to leave her job. She brought the blood samples to Beijing and pursued support from the central health authorities. With the help of Zeng Yi, the leading scientist in HIV/AIDS in China and on Board of the National AIDS Commission, her research was preserved and acknowledged later.

### ***Zhang Jicheng***

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<sup>15</sup> Region is a level above County as administrative division in China. A Region sometimes can consist of as many as half dozen of counties.

<sup>16</sup> Wang's research showed an example of a local village of 1300 people. 900 blood samples were taken, excluding the old and the young, 300 of whom had donated blood before for compensation money. The HIV infection rate reached close to 50% among those who donated blood, and 20% among all the 900 samples.

A native of Henan, by chance Zhang Jicheng encountered two couples from the Wenlou village (now known as the most famous “AIDS village”) on a train ride in October 1999. After speaking with them about their “illness”, he decided to visit the village and conduct a thorough investigation. Shocked, as well as anguished, was Zhang; he believed he had found enough evidence to conclude that there were contaminated blood collection practices in Henan with dire results. He wrote an article based on his results, but it was blocked by his own newspaper; he went on and sent it to *Huaxi (China-West) Metropolitan News*, a daily paper in another province, Sichuan. On Jan. 18, 2000 it ran - “Strange Disease in a Henan Village Shocks Top Officials”. Only, When Henan officials learned of the *Huaxi* article they ordered the immediate firing of Zhang; only thanks to the protection from his editor did Zhang keep his job. To Zhang’s surprise, this story made it to the U.S. Embassy website within days, though the Chinese government turned a deaf ear to the stories in Henan. The Henan provincial government did its best to prevent more coverage of the AIDS outrage in the province. Attention from the central government was not called until October 2000, when The New York Times began in-depth reporting on Wenlou and AIDS villages in Henan.<sup>17</sup>

Like Liang Congjie, Liao Xiaoyi, and Wang Yongchen in the environmental field, Dr. Gao Yaojie, Dr. Gui Xi’en, and Wan Yanhai are *the* faces of China’s AIDS activism. However, the difference is that Dr. Gao and Gui remained working independently, instead of creating opportunities for more civil society participation in the movement. Both of them were particularly careful about not being affiliated with any organization, and had no intension of establishing their own. Despite his strong intention to be the leader of the activist

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<sup>17</sup> Cohen, Jon. “A Scoop of International Proportions”, *Science (Special Report on HIV/AIDS in Asia)*, Vol. 304, 25 June 2004.

community, and much effort made to organize networking events and conferences among all social groups, Wan did not become the unifying force among all AIDS activists and social organizations. On the contrary, sometimes, he is even the source of agony and distrust within the community. Wang Shuping and Zhang Jicheng are examples of the professionals that were mis-treated by state authorities when choosing to directly confront official lies. However, both retreated from the central stage of AIDS activism soon after their personal mischief. Compared with the conservation case, the AIDS prevention activism still lacks charismatic and practical leadership that can strengthen the interconnections within the community.

### **Professors, Lawyers and Researchers: The Second Frontier of AIDS Activism**

In November 2003, 22 members of the National Academy of Science and Academy of Engineering submitted a letter to the State Council concerning AIDS and spoke against the social stigma toward AIDS patients and encouraged immediate state intervention. In the letter, they even quoted a mission statement from the environmental movement to support their opinion.<sup>18</sup> As we learned from the environmental movement in China (and indeed from many experiences of other non-democratic regimes), during the process of social mobilization for policy changes such collective actions taken by scientific and intellectual communities can alarm the state authority.

In the case of AIDS prevention in China, many scientists and experts have virtually joined bottom-up activism by reporting accurate research findings and publishing true stories

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<sup>18</sup> Jin, Wei. 2004. pp258-260.

from the field. Additionally, there are many medical professionals, journalists, lawyers, and scholars who are activist-minded, and have provided support to bottom-up activism. Sometimes, they help to justify the stance of AIDS activists by raising similar opinions as the grassroots activists. Other times, they document grassroots activism, and convey it to a broader audience by publication, teaching, and public speech. They are sometimes the only communication channels between the activist community and the state. Their sympathy has occasionally resulted in the political tolerance of AIDS activists. University professors also often take part in the rise of social activism. By only publishing in academic journals or mobilizing within defined circles, they can sustain their activism a little bit better. With moral support from international community, they sometimes even can overcome political obstacles and maintain their activism work.

Professor **Zhang Beichuan**, chief physician of the Center of Sexual Health, Qingdao Medical College Hospital, became concerned with homosexuality related health and social issues in the early 1990s, and was among the main researchers and activists on the subject at the time. He contributed greatly to AIDS prevention within the gay community by publishing extensively on the topic and through direct involvement in the initiation of gay hotlines and self-help associations in most major cities in China. In 1998, with support from the Ford Foundation and the Berry & Martin Trust, Zhang and other colleagues established the Friends project in Qingdao to “promote scientific knowledge of sexuality, health and love”. In 2001, he was given the first Berry & Martin Award. Zhang’s work and research in gay issues and AIDS is now well accepted by the Chinese government and often used in forming policies.

Like Professor Zhang, Professor **Pan Suiming**, Director of the Institute of Sexuality and Gender Research at Renmin University, first created an electronic magazine *Miss* to document the lives of and social problems related to commercial sex workers. At one point he had to change the magazine's name to *Private Letters* to keep it in existence because of pressure from the government.<sup>19</sup> With financial and moral support from the Ford Foundation, the magazine has survived and been distributed among a wide range of readers. Recently, it resumed its original name.

In current China, university professors, researchers in government sponsored institutions, and leading professionals are often invited to be on advisory boards of the government. Through such dual status, some professionals have been able to provide some support to activists, pass on opinions from the activist community to policy-making circles, and communicate policy changes better back to activist groups. A good example in this case is Professor **Jing Jun**, Director of Center for AIDS Policy Research at the Tsinghua University. Co-sponsored by the Clinton Foundation and Aaron Diamond AIDS Research Center, Tsinghua University hosted the AIDS and SARS International Conference in November 2003. With the particular help by Jing, some HIV+ patients and activists had a chance to participate in the conference.

**Jin Wei**, a lecturer at China's Central Party School, started AIDS lectures (once every half year) for the Communist Party leaders since the end of 2001. She edited the *Handbook for Party Leaders on AIDS Prevention and Policies* (in Chinese) in 2003, which is still the main reference for governmental officials on the topic. She also conducted surveys on AIDS

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<sup>19</sup> When the word "miss" (*xiaojie*) is used in China, people know that the magazine is about commercial sex workers. While, "private letters" is more indirect, therefore less sensitive.

awareness among senior party officials from all provinces, and found that as many as 40% of the survey participants consider AIDS irrelevant to public policy. Since then, she has been very vocal on the urgency of AIDS education and the lack of awareness and political will of AIDS prevention among governmental officials. While remaining as a Central Party School lecturer, Jin has been in close contact with many AIDS activists including Dr. Gao Yaojie. She has accompanied Gao to investigate the AIDS situation and helped AIDS orphans in rural Henan and Shangdong.<sup>20</sup>

**Yang Shaogang**, Esq., serves as the leading legal expert for the Council of Shanghai Municipal Government. He initiated and became the leader of the AIDS Legal Research Center at Shanghai University. Due to his official affiliations and professional expertise, he was invited by the State AIDS Committee to provide advice on new AIDS related laws in April 2004. Before his meeting with Vice Premier Wu, he widely solicited opinions from the activist community.

There are many other important intellectuals and professionals that are worth noting: Xia Guomei, Director of the HIV/AIDS Policy Research Center in the Shanghai Academy of Social Sciences; Li Dun, professor of law, Tsinghua University; Zhang Konglai, professor of medical science, Peking Union Medical College, and Director of the AIDS Working Network (a Beijing based NGO); and Li Dongli, Associate Research Fellow at the China Population and Development Research Center. As I pointed out before, this group of activist-minded professionals is crucial for the development of social activism and civil society in that they are involved in activism, research and policy consultation at the same time, and consequently

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<sup>20</sup> Interviews in Beijing, summer 2004.

become the linkages between the state and civil society. They can be extremely helpful for the activist community in learning how to negotiate with the state. However, the journalist circle in the AIDS field is not as mobilized and connected with the activist community as in the conservation case. A large number of environmental journalists became activists, created their own NGOs, and utilized their communication skills and former connections within the media to organize public campaigns. This partially explains why activists in the AIDS field have organized very few media campaigns.

### **“Positive” AIDS Activists**

Some people knew of Song Pengfei years ago from reading his tragic story of being infected with HIV through a blood transfusion during a surgery when he was still a child. But most Chinese people learned about his name and courage more recently, when former U. S. president Bill Clinton accepted his challenging question, and hugged him at the Beijing AIDS-SARS Conference, Nov. 2003. On that day, Song challenged the Conference and its major celebrity speaker, Bill Clinton, with the fact that the whole PLWHA community was not represented. Up until today, Song is one of the very few faces of HIV/AIDS patients that the public has seen.

Like the impoverished minority farmers of the anti-dam movement in Southwest China, the community of people-living-with-HIV/AIDS has symbolic power in the AIDS movement. However, unlike those farmers, they are much more constrained in their activist work, public appearance, and even physical mobility due to social stigma and their own health condition. Despite such difficulties, some young and courageous “positive” people have taken up the task of erasing the mysterious and negative public view of HIV/AIDS

patient. They have established PLWHA support groups in three major cities, Beijing, Shanghai and Guangzhou, and their work has reached multiple provinces. In rural areas of Henan, Sichuan, Yunnan, and Guangxi provinces, where the epidemic has hit worst, some HIV+ farmers have also tried to form mutual-help groups, especially to take care of the children left behind by HIV/AIDS parents.

### *Urban PLWHA activism*

Due to their young age and energetic personality, Song Pengfei and Adam Li are the most liked PLWHA figures by the media. Song now has moved to Beijing with his father and is the Art Project Director of the Positive Art Workshop created by Jose Abad and Diana Valarezo at the hospice of You'an Hospital<sup>21</sup>. They organize exhibitions of artworks by PLWHA, design condom packaging for better public education of AIDS, and produce documentary films of the AIDS community.

Among all "positive" AIDS activists, **Adam Li** (also known as Li Xiang) is the one with visible. He travels in between international conferences, and sits on the China's Country Coordinating Team of the Global Fund. And, his story has a little heroic flavor. Li is a hemophiliac and received tainted blood in the mid-1990s. After recovering from a major life-and-death illness, he quit his well-paid information technology job and decided to work for the people with a similar experience. The Mangrove Support Group was then created with major support from Beijing Ditan Hospital and international organizations (e.g., Ford Foundation, Marie Stopes China). The main goal was to set up connections and facilities in the rural areas of four provinces, i.e., Henan, Sichuan, Xinjiang and Guangdong, so that

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<sup>21</sup> You'an and Ditan are two leading hospitals specializing in treating infectious disease in China.

traveling medical personnel could provide free medical consultation for HIV+ farmers. Mangrove also helps the setting up of AIDS hotlines in various cities, trains HIV patients to do voluntary work, and publishes the *Hand in Hand* newsletter of AIDS education. At its peak, Mangrove had six full-time HIV+ staff. However, Li's health has gone through ups and downs, which impacted the sustainability of Mangrove.

The Chinese government has never publicized personal stories of any PLWHA who got infected through unsafe sex. PLWHA activists are fighting against so salient stigma that they even keep their activist work unknown to their families. Thomas and Li Jiaming are the two famous activists in this group. **Thomas** started an HIV/AIDS support group, China AIDS Care, in Guangzhou city in 2002. Within two years, more than 130 participants joined the group, and they expanded their outreach to the neighboring Guangxi province. Thomas' group currently provides generic ARV drugs to poor PLWHA, and coordinates home-care voluntary work to help homeless and rural PLWHA. In addition, they publish and distribute a monthly newsletter, *AIDS Care Bulletin*, to communicable disease hospitals and other communities of PLWHA around China, and maintain a website to inform and provide counseling on HIV/AIDS. More recently, Thomas has made more public appearances. He has delivered speeches to university students and medical professionals, and participated in the Bangkok World AIDS Conference and the UNAIDS Theme Group meetings in Beijing.

**Li Jiaming's** online novel *The Last Proclamation of War* which tells his own experience of dealing with HIV alarmed hundreds of urban white-collars of the danger of HIV; they are the main consumers of commercial sex in China. However, Li remained unknown except to a limited circle of friends and people concerned until a major decline of

his health in 2004. He now decided to quit his regular job and start a PLWHA support group full-time in Shanghai. He has named this group AIDS Sunshine and plans to publish a magazine for the PLWHA community.

### ***Rural PLWHA activism***

In rural areas, particularly in Henan, Sichuan, and Yunnan, where most internationally engaged AIDS programs are located, local farmer patients have been inspired to organize their own support groups. For example, in Shangcai county, the most “famous” AIDS-hit county in the eyes of the Chinese and world’s public, a few local villagers now see it is their responsibility to document the AIDS situation in their neighborhood, monitor the implementation of the AIDS compensation policy, keep the connection with AIDS activists in Beijing, and assist outside donors and volunteers who want to help.<sup>22</sup>

**Zhu Jinzhong** is the central figure of the story “52 kids 1 dad” which once caught much media attention.<sup>23</sup> Zhu was one of the hundreds of thousands of men and women who decided to sell blood for some extra money for their families in Henan. Both he and his wife tested HIV+ by 2001. He went to Beijing contagious disease hospitals for help, and became one of the first HIV patients who participated in official AIDS treatment lab tests. He encountered activists in Beijing like Wan Yanhai who informed him about AIDS and what he can do to help with other PLWHA. He decided to tell his story to newspapers and TV programs. More importantly, he decided to break the silence and challenge the discrimination in his village: he turned his house into a new home for all the orphans left behind by his

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<sup>22</sup> Interviews in Shangcai, April 2004.

<sup>23</sup> Many Chinese and international news media covered Zhu’s story, including CCTV and South China Morning Post.

neighbors who died of AIDS. With the generous help of Yang Jie (Taiwan Harmonious Association), Zhu opened his house to 20 children, and became their adopted father. This story soon was reported by multiple Chinese and international media, and support arrived from all fields of work. Employees of the CCTV alone donated 1 million RMB to him. Zhu was excited to expand his Home of Care and Love for more children. However, local authorities (county governments) became nervous and agonized with this kind of publicity. On Jan. 29, 2004, they shut down Zhu's Home of Care and Love, and drove away all the children. The county government received the donation from CCTV, and invested an extra 1.8 million RMB. They built up a special school for children orphaned by AIDS within 18 days, and took charge of all those kid who used to live with Zhu. Despite such pressure, Zhu continued lobbying for better care of AIDS orphans in his home village. After an exhausting trip to Beijing for 20 HIV+ children to get treatment, Zhu passed away on Jan. 15, 2005. His death was symbolic and caused much reflection within the AIDS community.

Once informed of AIDS basics, patients in rural areas are as motivated as urban activists to increase public awareness of AIDS. They form support groups to help each other, advocate for better health services and treatment delivery, and pursue other activities to alleviate the impacts of AIDS. Thus, a number of farmers' AIDS support groups have emerged out of bilateral agency or international NGO's support work, and more recently, local CDC's AIDS programs. For example, the China-UK AIDS Project started working in Zizhong county, Sichuan province in February 2000. By the end of 2003, 60 PLWHA came out public, and 20 of them performed a play based on their own experiences. They were

received by the local society with great enthusiasm, and were invited to travel to neighboring province, Yunnan, to perform the play.<sup>24</sup>

*Activism among the “hidden population”: Drug users and sex workers*

PLWHA associations are the least developed among IDUs and CSWs for obvious reasons—social stigma and lack of direct support. On top of the discrimination against AIDS, drug users and prostitutes are still seen as criminals in most parts of China. Rehabilitation centers of drug addiction and commercial sex are operated by the public security department with rules similar to prisons. It is hard for AIDS programs to reach these two groups without notifying the public security sector. In most cases, international assistance cannot go directly to IDUs and CSWs, but to governmental agencies for secondary distribution. Despite such obstacles, innovative measures (e.g., peer-education) have been pushed forward by progressive international NGOs and bilateral programs. Consequently, activism among IDUs and CSWs is emerging.

In Kunming, Yunnan, a young woman (HIV+ and former IDU) from a rural township, Wei Ping, has been recruited as the PLWHA project coordinator at the Provincial Red Cross. As early as 1995, Wei was invited to AIDS peer-education sessions organized by the Australian Red Cross at Yimen township. She was then encouraged to form a support group among all young people with a similar situation as her. Wei and her friends now coordinate and help with many PLWHA groups in Kunming city and nine counties in Yunnan. Her passion is visual arts, and her dream is to teach HIV+ friends how to paint and create just as healthy people. As part of the China-UK Project in Liangshan, Sichuan province, peer-

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<sup>24</sup> Beijing Morning News, Dec. 1, 2003. Also interviews in Yunnan, Aug. 2004. Unfortunately, a few patients died before the performance could take place.

education was organized also among CSWs. In 2004, the AIDS Relief Fund for China started supporting one of the best students of this program to reach more young women and continue the momentum.

The PLWHA community is a potentially important activist group. Because they are bearers of the disease or victims of the blood policies, they are genuinely passionate about AIDS prevention. However, they are constrained by their own health condition and social stigma, and this adds some uncertainty to their social activism in the AIDS field.<sup>25</sup> Most the HIV+ activists introduced here use pseudo names in public and have not allowed any media to take pictures of them.

### **NGOs and University Student Groups: The New generation of AIDS Activism**

The emergence of institutionalized NGOs is a key indicator of the development of social mobilization and civil society. After the “Titanic Report” and Wan’s arrest in 2003, we have witnessed the rise of a new generation of AIDS-related NGOs and activists. This new generation includes social organizations from diverse backgrounds, ranging from PLWHA, gay community, women’s rights, environmental justice and medical professionals. (Table 4.5) Compared with the environmental civil society in China, the AIDS community is still limited in terms of number and geographic spread. Among the 21 NGOs surveyed in this study—who are the majority of the most well-known Chinese NGOs in the field—most are concentrated in Beijing, Shanghai, and Yunnan, where NGO activity in general is more active. (For all the organization names, see Appendix 4.3)

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<sup>25</sup> Among all the well-known activists introduced above, Zhu Jingzhong died on 13 January 2005. Both Adam Li and Li Jiaming became very ill since the end of 2004.

**Table 4.5. Breakdown of institutionalized AIDS-related NGOs/NGOs-to-be by organizational character (2004)**

Total	PLWHA-led	AIDS general	Gay	Women	Non-AIDS specific
21	6	6	3	3	3

Besides the activists mentioned before, the PLWHA activism community also consists of many hemophiliac associations. Many hemophilia patients became infected with HIV through contaminated blood and blood products. Activists of the Shanghai based Hemophilia Home of China have been advocating for governmental compensations for hemophilia-HIV patients. Due to their effort, 50 such patients in Shanghai have received compensations from the municipal government. However, in 2003, a hemophilia-HIV patient from Hunan traveled to Shanghai to pursue governmental compensations, but was rejected. According to Xu Zhenjun, an activist from Grassroots Community (a Shanghai based NGO), the hemophilia-HIV issue is becoming even more sensitive than the Henan blood scandal. Journalists have been banned to report on the issue, and there is little attention from the international community.<sup>26</sup>

Besides the Aizhixing Institute, a few policy advocacy oriented NGOs have emerged. The Beijing Loving Source for Education and Research is an example.<sup>27</sup> The chief founding member of this NGO, Hu Jia, is a veteran activist in a variety of social issues, including human rights. Due to Hu Jia's outspokenness on sensitive human rights and democracy topics, he has been arrested and home arrested multiple times since April 2004. However, the organization has survived, and the other main member, Zeng Jinyan, has created a Pen Pal

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<sup>26</sup> Interviewed in Shanghai, March 2004

<sup>27</sup> Multiple interviews with Hu Jia and Zeng Jinyan, founders of the Loving Source Institute, in Beijing, summer 2004. This organization was registered as a private company in May 2004, but meant to operate as a non-profit organization according to the organizational by-laws.

Club to connect college students with AIDS orphans in Henan. The number of volunteers participating in this Pen Pal Club increased from a dozen to over 80 within a year's time.

As HIV/AIDS is spreading to the general public, gay and women are identified as two most vulnerable populations. With support from the international community, particularly the Ford Foundation, the Berry & Martin Trust (UK) and Chi Heng Foundation (Hong Kong), gay rights movement activists in China (e.g., Zhang Beichuan, Wan Yanhai) have helped to establish hotlines and support-groups in almost all provincial capitals and major coastal cities. Recently, more international assistance has become available, and the Chinese government is more open to the gay issue. Consequently, many gay hotlines and support-groups have expanded and institutionalized their activism work. For example, the Beijing Gay Hotline became the Beijing Gender Institute, which has received many grants from international organizations to implement AIDS awareness projects within the gay community.<sup>28</sup>

“Women” was the theme for 2004 World AIDS Conference. In China, rural women are identified as a high-risk population due to the lack of access to health information and services. Women's rights is one of the most active issue area in civil society development in China. But, there are still not many women's rights NGOs working in health or AIDS. The three women's rights based NGOs included in this study are the earliest bottom-up initiatives in the AIDS field. They also perfectly illustrate the important role played by international NGOs in the development of Chinese social groups. The Women and Child Development Centre of Ruili was, in fact, initiated by Save the Children UK during its own comprehensive AIDS prevention project in the region. Both the Legal Assistance Center for Women and

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<sup>28</sup> Interview with Zhen Li, founding member of the Beijing Gay Hotline, in July 2004.

Children of Xishuangbanna in Yunnan and Qianxi Women's Health Association in Hebei were founded by activist-minded former local Women's Federations officials with substantial support from international foundations (e.g., the Ford Foundation and the Asia Foundation). During their grassroots, the Xishuangbanna group gradually found AIDS imperiling the lives of minority young women in the region. Starting from single case investigation, they have helped many individual patients and their families.<sup>29</sup> The Qianxi group has reached to over 200 villages and 10,000 rural women in the county, and provided health trainings for group leaders among these women since its establishment in 2002. In 2004, the AIDS Relief Fund for China (a U.S. private charity) gave the Qianxi a small grant to start their first training in HIV/AIDS prevention. With the support, the staff members created educational materials suitable for local women and innovative programs to overcome the social stigma of AIDS. Another American NGO, the Aixin Foundation, is currently helping to publicize their achievement and replicate their work in other parts of rural China.<sup>30</sup>

Besides the above NGOs, a few non-AIDS focused NGOs are switching gears and joining their colleagues to promote public awareness of AIDS, for they see the epidemic is not a simple medical matter, but involves many social justice issues. There are three environmental NGOs currently active in the AIDS field, all of which have developed a solid societal foundation and relatively a high level of self-capacity.

The importance of university student groups to China's civil society development was demonstrated by the conservation case in the case of conservation. The AIDS field also is

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<sup>29</sup> Interview with Long Sihai, Director of the Legal Assistance Center for Women and Children of Xishuangbanna, in Wuhan, 3 June 2004.

<sup>30</sup> Interviews and follow-ups with the Qianxi Women's Association from June 2004 to January 2005.

undergoing a rapid growth of university student groups since 2002. According to the survey conducted by the Loving Source Institute, by 2004 there were 24 university student groups engaged in AIDS awareness and care work.<sup>31</sup> Among these groups, ten are located in Beijing, and nine outside the three main cities (i.e., Beijing, Shanghai, Tianjing), spreading across Hubei, Jiangxi, Fujian, Guangdong, Anhui, Xinjiang, Jiangsu and other seven provinces.

Social activism in HIV/AIDS prevention and nature conservation presents some commonalities. Both started to emerge in the mid-1990s by a group of courageous activists, and have undergone political suppression from the government. Professionals are crucial to the development of both communities. With the growth of university student groups, both are energized and prepared to building on successes of the past. International NGOs have provided important support to Chinese activists and NGOs in both fields.

However, social groups as a whole have not developed as many and as strong networks among each other in the AIDS field as in the conservation field. Even though meetings, social gathering, and exchanges are becoming more frequent among AIDS activists and NGOs, major nation-wide coalitions, public campaigns, or movements have not occurred in this field yet. There are only some minimal signs of collective actions taken by activists in this field.

In April 2004, Aizhixing Institute received a call for help from some dying HIV+ patients in rural Henan. They complained about being cheated into AIDS clinical trials by the Beijing Ditan Hospital. Aizhixing first took the lead in investigating the issue, and was later

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<sup>31</sup> Special acknowledgement goes to Zeng Jinyan, Renmin University and Loving Source Institute, for sharing the information about university student groups working on AIDS related issues.

joined by many other activists and concerned professionals. In May, Lin Gu, an activist-minded journalist for the Xinhua News Agency wrote an article uncovering all related parties and politics, and the *Southern Weekend* featured the story on the front page. The Ditan Hospital eventually posted an announcement about the clinical trial on their official website. Even though the involved patients didn't get fair compensation, the symbolic success of the activist community was evident. In another case, when a farmer couple in Henan who used to help a Beijing based Chinese NGO to deliver relief goods was arrested by local police in August 2004, many AIDS activists in Beijing coordinated their resources to help them. Activists from No-HIV, a web-based activist group, printed and disseminated black postcards in Beijing to protest the incident. In January 2005, Zhu Jinzhong passed away, and the Loving Source Institute, who kept in close contact with this villager activist received tens of letters/emails of condolence from the AIDS activism community. Such incidents did generate momentum for AIDS social groups to communicate with each other, and build up mutual-trust. More importantly, like what is seen in the conservation field, by going through these emergent or politically sensitive events together, AIDS activists are learning together how to interact and negotiate with authorities. However, among other things, due to the lack of leadership and the low level of mobilization of the journalist circles, this learning process in the AIDS field has not proceeded as fast and recurrent as in the conservation field.