

GOVERNING AND REPRESENTING HIV/AIDS IN CHINA: A REVIEW AND AN INTRODUCTION

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ABSTRACT

This introductory essay provides a thematic framework for, and critical review of, the key issues and debates in HIV governance as well as its representation in the public sphere in the Chinese context. It discusses the current state and characteristics of the epidemic. In particular, it analyses the evolution of HIV/AIDS governance and its representation through two broad approaches: "AIDS work" and "AIDS talk." AIDS work is done by a multitude of agents at three different levels: the state at the macro-level; U.N. agencies, INGOs and foreign governments at the meso-level; and civil society at the micro-level. AIDS talk includes "telling AIDS" in Chinese HIV/AIDS media, "recording AIDS" by independent documentary filmmakers, "fighting AIDS" by HIV carriers, and "righting AIDS" by HIV/AIDS activists who are not HIV carriers. From public health campaigns and media education programs in the official media, to individual initiatives asserting rights and community endeavours for self-help—all agents utilise both old and new media and communication technologies to voice their concerns as well as to get their voices heard. This in turn impacts on China's AIDS work. "AIDS work" and "AIDS talk" illustrate the two interrelated areas of governance and representation in the Chinese HIV/AIDS regime. The present issue brings together original articles from diverse disciplinary areas to engage in a timely dialogue on how HIV/AIDS is represented and governed in China and how such representations and techniques of governance are constructive of the relations of power and agency in the context of HIV/AIDS.

Keywords: HIV/AIDS governance, representations, AIDS work, AIDS talk

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INTRODUCTION

With the largest percentage of infected population in the Asia-Pacific, China has ramped up its HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) campaign and governance and scaled up its engagement with the global health regime. These developments have also been accompanied by an increasing amount of research on HIV/AIDS in China arising from various disciplines: public health (see for example Wu et al. 2007), social policy (see for example Kaufman, Kleinman and Saich 2007), HIV media and health communication (Li et al. 2005; Hood 2011a), international relations (Hague 2008; Chan 2010), sociology (Jun and Worth 2010), political science (Schwartz and Shieh 2009) and many more. Apart from manuscripts, books and academic journal articles, there is also a growing body of reports commissioned by government and international non-governmental organisations (INGOs) examining and assessing HIV/AIDS prevention, education, treatment and care initiatives in China. The most well-known report "HIV/AIDS: China's Titanic Peril" (2001) by the U.N. Theme Group on HIV/AIDS in China triggered off a series of policy changes from the Chinese government. In the years since 2001, an increasing amount of money, personnel and research has been invested in HIV/AIDS programs, initiated by central and local governments, INGOs, foreign governments, academia and the private sector. Questions, debates, and critiques have arisen in response to China's HIV governance. A sense of urgency is imbued in these publications (in both English and Chinese) on how to improve China's HIV/AIDS governance in the context of a global AIDS regime and people's knowledge of and engagement with HIV/AIDS prevention, care, education and expectations of social tolerance.

HIV/AIDS is a social, economic and ethical problem of enormous magnitude. Its governance involves the state and the nonstate, national and transnational actors. Good governance is characterised at all levels by "full constituent **participation**, the rule of law, transparency, responsive to the community, consensus building, equity, effectiveness, accountability and vision" (Hsu et al. 2002: 4, original emphasis). These factors are interrelated and may take different forms in various local situations. The present issue of *International Journal of Asia-Pacific Studies* (IJAPS) addresses some of the key areas, as well as its representation in the public sphere, in the Chinese context. It contributes to the growing scholarship on HIV/AIDS in China by focusing on two key issues in the HIV situation: governance and representation. It brings together original articles from diverse disciplinary areas (e.g., political science, international relations, legal studies, sociology and media studies) to engage in a timely dialogue on how HIV/AIDS is represented and governed in China and how such representations and techniques of governance are illustrative of the relations of power and

agency in the context of HIV/AIDS. The present article discusses the evolution of HIV/AIDS governance and representation in China. It provides a critical review of China's responses to and governance of the epidemic since 1985. It examines what I call "AIDS work" and "AIDS talk" to illustrate the interrelated areas of governance and representation in the Chinese HIV/AIDS regime. HIV and AIDS, when used separately rather than jointly as in HIV/AIDS, refer to the different medical stages and situations of people living with HIV (asymptomatic stage) and people living with AIDS (symptomatic or disease stage, often with opportunistic infections) respectively.

THE BIG PICTURE

It may be useful at this point to review the current state of affairs in the Chinese HIV/AIDS regime by providing a "big picture" before moving on to the details. The history of HIV/AIDS in China has been well documented. Equally so are the Chinese government responses to the epidemic. Since the first HIV/AIDS case was found in 1985, HIV/AIDS cases have grown and spread rapidly throughout China. By 1998 HIV-positive persons were present in all 31 provinces and municipalities of China. HIV/AIDS has evolved from a disease of "the Other"—foreigners, minorities, and the rural, peripheral, disadvantaged and vulnerable groups of people—to an epidemic that threatens the general populace. The transmission patterns have also expanded from foreign origins (foreigners living in China and Chinese returning from overseas) to iatrogenic transmission; from injecting drug users (IDUs) in Yunnan and along major drug trafficking routes to commercial sex workers (CSWs); from former plasma donors (FPDs) in central China to men who have sex with men (MSM) in urban areas; and from non-commercial sexual contact to mother-to-child transmission. As of the end of 2010, the Ministry of Health estimated that approximately 740,000 persons, or 0.57% of the whole population, may be infected (BBC 2011). Figure 1 illustrates the growth of HIV/AIDS in the last 25 years. Despite many doubts about the veracity of the official statistics, it is recognised that HIV/AIDS has spread from at-risk groups and vulnerable areas to the general population, a dispersal demarcated by three lines of geographic concentration: the Southwest→Northwest line (Yunnan, Sichuan, Xinjiang), the central plateau (Henan, Anhui), and the Southwest→Southeast line (Guangdong, Guangxi). These three lines represent three major transmission routes: illicit drugs, blood and sex.

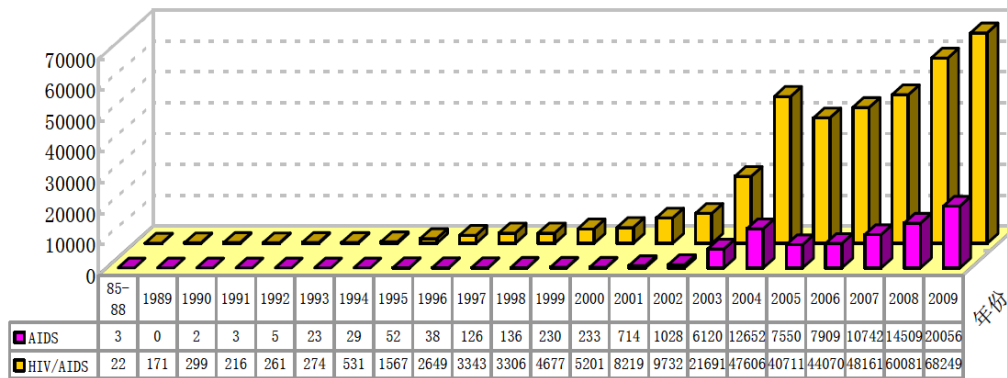


Figure 1: HIV/AIDS in China 1985–2009 (MOH 2010: 11).

Since the first case among IDUs was found in Yunnan along the China-Myanmar border in 1989, HIV has spread to nearby cities and provinces and all the way to Xinjiang. Xinjiang is home to more than 60,000 people living with HIV/AIDS (PLWHA), almost 10% of the total HIV infections in China even though the region's population is only 1% of China's overall population. The HIV infection rate in Xinjiang is 0.13%, the second highest among all Chinese provinces and autonomous regions (Henan province being the highest), compared to the national average of 0.05% (www.aiziwang.com/zdt_052.html). Located along two of the world's largest heroin and opium drug trafficking routes, the Golden Triangle and the Golden Crescent (see Figure 2; also see Anna Hayes' contribution in this issue), Xinjiang has one of the largest groups of infected IDUs. In recent years, sexual transmission in Xinjiang and Yunnan has increased dramatically. However IDUs remain the largest group affected by HIV in both areas.



Figure 2: Drug trafficking routes in China (http://www.stratfor.com/memberships/106391/analysis/chinas_attempt_narcotics_crackdown).

Innovative programs targeting HIV in these border regions have been carried out among IDUs by governmental, non-governmental and international organisations in Yunnan and Guangxi, where scientists, health officials and foreign aid concerns have congregated (for example Hyde 2007). Similar programs have also been piloted and carried out in Xinjiang. Unlike the Southwestern provinces, HIV/AIDS in Xinjiang has more serious implications for China's health security, ethnic relations and regional stability. Anna Hayes's article "HIV/AIDS in Xinjiang: A Serious 'Ill' in an 'Autonomous' Region" considers the socio-graphic history of the HIV/AIDS epidemic in Xinjiang and how it is intertwined with political discontent and ethnic tensions in the region. The Xinjiang minority nationalities' unfulfilled goals of real autonomy within the Chinese state, coupled with discontent over losing out to Han Chinese in economic development and missing out in terms of political and economic development in their own homelands have fuelled the ethnic clashes that we witnessed in 2009 and again in 2011. The slow and insufficient response to the HIV/AIDS epidemic from the Chinese state is not unique to Xinjiang but characterises state response across the board, as the following analysis demonstrates. However, this kind of response only intensifies the sense of victimisation among the Uyghurs—for them there is no escape from being positioned at the periphery geographically, socially and culturally by the Han Chinese social imaginary. It also inflames the historical discontent in the region; as Hayes warns in her article, "Should cultural, religious and linguistically appropriate HIV/AIDS prevention strategies not be scaled up and widely implemented throughout all of Xinjiang, there may be an increasing likelihood that further discontent among Xinjiang's minority nationalities will surface."

The major second route of HIV infection is through contaminated blood transfusion among commercial plasma donors. The practice of illegal blood collection was rampant throughout the 1990s in central rural China. Thousands of blood and plasma collection stations were set up around the country, with concentrations in Henan and Anhui, two of the poorest provinces in the central plateau, offering RMB50 for plasma and RMB200 for blood for each donation. Failure on the part of the collection stations to screen and separate donations resulted in the so-called "blood disaster" (*xue huo*), a vernacular term for the HIV/AIDS epidemic. Although the problem was well known from 1995, unsafe blood collection was not stopped but rather continued to grow. Local authorities had encouraged blood collection up to this point, but now obstruct any effort to disclose the HIV problem since the "blood disaster" was revealed to the public through the efforts of local doctors and whistle blowers such as Gao Yaojie, Gui Xi'en and Zhang Ke. High rates of HIV were found not only among FPDs and their spouses, but also children, suggesting mother-to-child transmission. FPDs account for most of the known AIDS patients and deaths—as well as the AIDS

orphans—in China today. Most civil rights defense cases involving HIV/AIDS have originated in the central plateau (north-central China). Stories of HIV contamination through blood—blood sales and transfusion—are most visible in the Chinese media and HIV/AIDS campaigns. In the moral hierarchy of HIV/AIDS, this group of PLWHA is ranked the highest as "innocent" victims (referring to recipients of contaminated blood products) or at worst greedy peasants (referring to blood sellers), whose PLWHA status is considered to have been acquired innocently. This contrasts sharply with the moralistic judgments imposed on PLWHA infected from other modes of HIV transmission. Sexual contact is one such mode.

Along with the new sexual openness following China's Economic Reforms and Opening Up (*gaige kaifang*) came an increase in sexually transmitted disease (STD) including HIV through unprotected sex. Chinese are among the most "risk-taking" (*maoxian*) people when it comes to unprotected sex. A 2003 Durex global survey on unprotected sex found that China ranked number three when it came to unprotected sex with new partners—70% refused to use condoms with new sexual partners (including one-night stands) and 40% refused to disclose their STD status to their partners (Anon 2004). The increasing number of cases of infection among the spouses and sexual partners of IDUs and FPDs is telling in their lack of awareness of and sense of responsibility regarding safe sex.

Commercial sex work is on the rise in China. Most estimates of the number of sex workers in China range from three to five million. The fastest growing HIV cases today are found among CSWs and MSM. Figure 3 illustrates the profiles of HIV cases from 1985 to 2009. It is clear that, apart from infections among IDUs, sexual transmission has become the main route of HIV transmission. Among the 740,000 PLWHA, 59% have been infected through sexual contact and 14.7% through transmission between same sex partners (MOH 2010: 12). Among pregnant women in high-risk areas, HIV prevalence has also grown from nil in 1997 to 1.4% in 2009. China is experiencing a typical Asia epidemic model described by Tim Brown (2004): the transmission route is moving from IDUs to CSWs, their clients and sexual partners of clients. This has caused lots of concern among policy makers, healthcare professionals and researchers. In this issue, Evelyne Micollier examines issues related to sexuality and gender in China's HIV narratives and research. She views HIV and AIDS as a gendered and sexualised issue in Chinese official, expert and lay/popular discourses on HIV/AIDS. Her article, "Sexualised Illness and Gendered Narratives: The Social and Human Science Problematic in China's HIV and AIDS Governance" discusses the issues of sexual transmission of HIV, the sociocultural imagining and mapping of sex and sex workers and problems in China's HIV and AIDS education, research and governance. The

persistence of gender stereotypes, the naturalised definition of gender differences and normative sexual behaviors, lack of representations from the "margins" such as sex workers in HIV and AIDS policy and research programmes, the inadequate quantitative methods in data collection on gender and sex, and the lack of social and human science approaches to HIV/AIDS governance—all these need to be addressed in order to effectively improve China's governance of the sexualised epidemic.

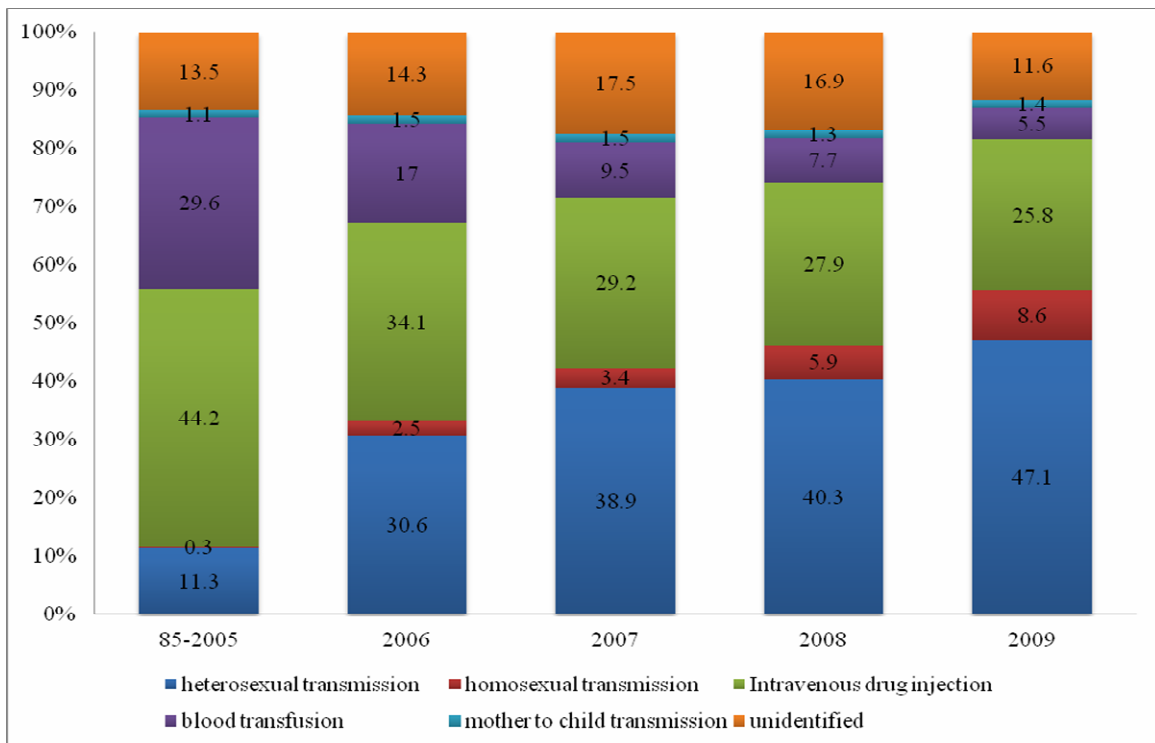


Figure 3: Profiles of HIV infections in percentage 1985–2009 (MOH 2010: 12).

Limiting a general account of the Chinese HIV epidemic to a description of its three major transmission routes (illicit drugs, sex and blood) risks over simplification and generalisation, since this picture is true for any country or area where the HIV epidemic is an issue. However, the HIV/AIDS epidemic is situated in particular national contexts. National and cultural specifics give the epidemic features unique to each locale. In the Chinese case, a more detailed look at the epidemic splits it into several sub-epidemics. As the following table shows, the HIV epidemic in China consists of eight different but overlapping sub-categories and phases that correspond to the evolving stages of China's entry and integration into the global AIDS regime.

Table 1: HIV/AIDS sub-epidemics in China (Wang 2007: S3–S5).

Sub-epidemics	Characteristics
Sub-epidemic 1	1985–1989; Sporadic, non-indigenous, confined to foreigners, Chinese returnees, and Chinese infected by imported, contaminated blood products.
Sub-epidemic 2	1989–2002; Indigenous cases found in IDUs in Ruili County, Yunnan Province, then discovered along main drug-trafficking routes and reaching all provinces by 2002.
Sub-epidemic 3	1990s; HIV infection found among former commercial plasma donors and became a key transmission route.
Sub-epidemic 4	1990s; HIV infection increased through blood transfusion, from contaminated blood. Sub-epidemics 3 and 4 account for 10.7% of HIV infections.
Sub-epidemic 5	Sexual transmission from infected individuals (IDUs and FPDs) to their spouses and regular sexual partners.
Sub-epidemic 6	Heterosexual transmission, esp. through commercial sex. Sub-epidemics 5 and 6 constitute the major source of infection.
Sub-epidemic 7	MSM transmission; the fastest grown infection area, a major challenge for HIV governance.
Sub-epidemic 8	Mother-to-child transmission, small but potentially growing group, despite the nationwide screening practices.

In face of the "titanic peril" (HIV/AIDS: China's Titanic Peril: 2001 Update of the AIDS Situation and Needs Assessment Report) and under pressure from domestic and international advocacy, China's AIDS response has moved from denial to taking positive action, from policy advocacy to policy implementation. Even before the 2003 SARS outbreak, the Chinese government demonstrated its commitment to taking more initiatives to control HIV/AIDS and to do so with more transparency. It abolished the quarantine of AIDS patients, removed homosexuality from the list of pathological disorders, decriminalised homosexuality as a form of hooliganism, dramatically increased educational intervention measures and stepped up laboratory and epidemiological research. The Beijing government participated in U.N. summits and forums, signed declarations of commitment on HIV/AIDS control and prevention, and issued a series of policies and laws to provide for a more effective framework of support for PLWHA and communities affected by HIV/AIDS. The SARS outbreak was the final blow to China's approach to infectious diseases. The outbreak arguably posed the most serious socio-political crisis since 1989 and had serious economic, political and international implications. It opened opportunities for the Hu-Wen leadership to take a new approach to tackling health-related issues and problems (Huang 2006). What emerged from the SARS crisis was an intensified commitment by the top leadership and the health bureaucracy to fighting HIV/AIDS and other infectious diseases. Moreover, a post-SARS Chinese government provided for a bigger

international engagement and the relaxation of strictures on participation by a revitalised civil society in HIV/AIDS governance. Since then China has moved aggressively from a health-oriented response to a multi-government, pan-societal and humanitarian response to HIV/AIDS. Pragmatic guidelines have been established for behavioral intervention; at-risk groups have been identified and targeted; a nation-wide HIV education and prevention campaign has been launched. Demonstration projects such as the methadone clinics and comprehensive drug-rehabilitation services have been implemented and are being scaled up nationwide. China's experience and progress in HIV/AIDS control, prevention and care has been documented and analysed by various organisations and individual researchers (for example, Cui 2009; Kaufman 2010; Hague 2008; Gill 2006). These are central to the discussions in this issue.

China's efforts in tacking the AIDS epidemic have been widely recognised. It has also been recognised that the battle is far from over. A number of challenges loom large. Various findings and reports such as those from Center for Strategic and International Studies (CSIS) by Gill et al. and the volume on AIDS and social policy in China by Joan Kaufman, Arthur Kleinman and Tony Saich (2006) indicate that bureaucratic and political obstacles remain the biggest challenge to putting into action a nationwide and comprehensive surveillance, testing and care system. The Ministry of Health's lack of authority and budget (despite the increase in recent years) coupled with China's fraying public healthcare system means it has a limited capability to avert a delinkage between national policies and their local implementation. A few factors, such as skepticism of the seriousness of the epidemic, lack of incentive for local officials to implement some policies, local protectionism and officials' own political interests (fear of demotion), often mean that cover-ups persist and that national policy is not always carried out at local levels. Under the "Four Free and One Care (*simian yiguanhuai*)" policy and the China Comprehensive AIDS Response programs, PLWHA should have access to free antiretroviral treatment, voluntary counseling and testing, mother-to-child transmission prevention treatment, schooling for orphans of HIV/AIDS victims and medical care and economic assistance for PLWHA households (National Center for AIDS/STD Prevention and Control 2006). These are not, however, implemented evenly and effectively: in some places there are multiple fees charged for HIV/AIDS related health services; patients pay for tests and treatments of opportunistic infections such as tuberculosis and pneumonia; AIDS orphans do not receive adequate care and schooling; and HIV/AIDS patients have been refused treatment. Part of the difficulty is the lack of human resources to assist in translating policies into action particularly at local levels. This phenomenon has raised concern from non-governmental and sometimes governmental organisations.

Social prejudice against PLWHA and their families still exists despite the HIV/AIDS public awareness campaigns. These campaigns have targeted mainly high-risk populations by focusing on HIV awareness and behavioural change, but frequently have expanded their scope to encompass the broader public by addressing the full spectrum of HIV-related discriminatory practices. As will be discussed later, these efforts have their limitations. Public discussion of sexual topics such as condom use, needle exchange, homosexuality or unconventional sexual behaviours remains awkward and may be subjected to censure. The Internet remains the only venue where open sexual discussion is tolerated. The stigma of HIV/AIDS often stops people from voluntary HIV testing and disclosure of their sexual history to their sexual partners. There is currently a debate within China CDC on the feasibility of universal testing to replace the existing voluntary counseling and testing (VCT) program (personal communication with a China CDC official, August 2011).

In the present issue, Scott Wilson and Jinmei Meng discuss the legal responses to HIV governance in China. Meng's article, "HIV governance through law: Achievements and challenges of China's legal environment" reviews China's legal response to the HIV/AIDS epidemic—how it moved from prohibitive laws and regulations to behavioural intervention. More importantly, she identifies five challenges in China's HIV governance: demands for 1) behavioural intervention as opposed to laws against IDUs and CSWs; 2) observance of universal human rights versus punitive measures against vulnerable groups; 3) enforcement of anti-discrimination laws versus weak law enforcement; 4) full participation of civil society as opposed to a restrictive legal system; and 5) an end to the lack of transparency and accountability in governmental politics and laws. She calls for a legal system which better serves China in responding effectively to HIV/AIDS. Meng's analysis supplements and resonates with Scott Wilson's. As Wilson demonstrates in his article, "Settling for discrimination: HIV/AIDS carriers and resolution of legal claims," despite the improvement in political attitudes in relation to, and legal protections of, PLWHA (often through advocacy from NGOs, INGOs and U.N. agencies), an underdeveloped legal system and a political system not up to the task have perpetuated rather than reduced stigmatisation and discrimination against PLWHA in Chinese society. Indeed, courts often refuse to hear cases on HIV/AIDS and often rule against PLWHA when such cases are heard. This has caused out-of-court settlement, or alternative dispute resolution settlement, to become the only viable option for most PLWHA. The individual pursuit of justice and civil rights in a legal environment that is in favour of the defendants and would-be defendants has proven to be extremely difficult. This has serious implications for China's rights revolution. As Wilson aptly points out, "Rights revolutions are littered with

lost legal cases until plaintiffs begin to gain the courts' favor." Until then the litigation will likely have a positive feedback and demonstration effect on social movements in China.

China's HIV/AIDS governance is the *sine qua non* among its efforts to build a harmonious society within and a harmonious global order without. It is structured at the international-domestic, state-society and public-private nexuses. China has vowed to adopt a multilateral, cooperative approach for coordinated actions in HIV governance. A number of actors are involved in carrying out "AIDS work." In the following analysis, I discuss the major participants in conducting China's AIDS work and the challenges they face.

AIDS WORK

AIDS work is done by major actors at three different levels: the state at the macro-level; U.N. agencies, INGOs and foreign governments at the meso-level; and civil society at the micro-level. It is commonly accepted that the commitment of the top leadership to the fight against HIV/AIDS played a major role in the changes in China's HIV/AIDS governance. Since the official recognition of the HIV/AIDS epidemic in China in June 2001, the central government has strengthened its commitment to fighting it. This includes increased visibility of state leaders (including Premier Wen Jiabao and President Hu Jintao) in the media on their high-profile visits to AIDS patients, hospitals and medical professionals on World AIDS Day (1 December); the promulgation of a series of policies, regulations and laws to strengthen the prevention and control of the spread of HIV; ensuring care, treatment and a harm reduction program for victims of the disease; educational programs to raise the level of awareness of HIV and to eliminate discrimination by the general population against PLWHAs. Some of the major policies—such as China's 5-year action plans (2001–2005, 2006–2010), the "Four Free and One Care" policy (2003) and the Regulations on AIDS Prevention and Treatment (2006)—have had an impact on the AIDS work in China. The state at the macro-level makes policies and laws that direct and govern the national health management systems, but their implementation depends on various governmental and nongovernmental agents. As mentioned earlier, the widespread problems with access to, and implementation of, policies and laws must be addressed. There is a need for better data collection and surveillance systems more attuned to the changing demographic and epidemiology of the epidemic. These logistical improvements, in conjunction with improved research and data analysis, would work to better create informed social policy vis-à-vis HIV/AIDS thereby targeting more effectively a growing epidemic. All of this poses huge challenges to China's policy makers, researchers, health

practitioners and non-governmental agents (see Kaufman et al. 2006 for further discussion).

AIDS work at the macro-level is inseparable from that at the meso-level, that is, AIDS work by international communities, U.N. agencies, INGOs and foreign governments (especially Australia and the United Kingdom). China has cooperated with over 50 INGOs, charitable foundations and countries in AIDS-related areas since 1994. Many of China's multilateral partnership projects are initiated, supported and carried out in a cooperative approach by the Chinese government at various levels with their international partners. The various U.N. agencies (e.g., UNAIDS, WHO, UNICEF, UNESCO, UNFPA and the World Bank) play a prominent role in assisting the Chinese government in developing guidelines and programs in research and data collection, national surveillance and intervention. The "Four Free and One Care" policy mentioned above is implemented nationwide with the assistance of UNICEF. As early as 1996, UNICEF China formed a U.N. Theme Group on HIV/AIDS in China which, along with other U.N. agencies, INGOs and domestic NGOs, urged Chinese authorities to make HIV/AIDS a top national priority and to integrate China into the global health regime in HIV/AIDS governance. UNAIDS Beijing office acts as a secretariat to the Theme Group. The "Titanic Peril" report (2002) is a milestone work produced by the Theme Group. Working with the Chinese authorities at the national and provincial levels, the Theme Group has made headway into China's battle against the peril of the century.

Similarly, INGOs responded to the HIV epidemic in China as early as the beginning of the 1990s. For example, Red Cross Australia started its work with the Yunnan government in the area of AIDS prevention in 1994, two years before UNAIDS opened its office and the formation of the U.N. Theme Group on HIV/AIDS China in Beijing. The Ford Foundation started its AIDS programs in the late 1990s. China's proactive engagement with INGOs, however, did not start until 2003, the year in which the Chinese leadership took a new approach to HIV/AIDS governance and which saw a considerable increase in the number of INGOs working in China. Apart from the Bill & Belinda Gates Foundation and the Clinton Foundation, the most prominent partnership that China has formed is with the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). Since its first successful application to the Global Fund for funding in 2003, the Chinese CDC has been granted more than USD180 million to fund various projects including four major ones: a project targeting high risk populations; a second project directed at particularly vulnerable, transient groups of people residing within one or more locations; a third project aimed at setting up a comprehensive program in HIV/AIDS treatment, care and prevention; and a fourth one directed at fostering a fuller participation of civil society in HIV/AIDS control. Some of these INGOs work in China on independent

missions. They use their own established networks along with local Chinese staff members to put localised projects and practices into effect directly with Chinese citizens. They often have programs which have been diversified to extend beyond HIV/AIDS. INGOs have played a unique role in HIV/AIDS prevention and control in China. They provide technical and financial support and training to Chinese health institutions and organisations; as educators, they bring the latest information on HIV/AIDS policies and treatment to remote regions and populations; they support Chinese grassroots community organisations in building a capacity in HIV/AIDS care and relief work (Wu 2005). Table 2 gives an example of the roles of INGOs operating in China. Often these INGOs work in more than one area and function in more than one category.

Table 2: Examples of INGOs working on HIV/AIDS
(data partly drawn from Liu and Kaufman 2011).

Main functions	Representative INGOs
Access to medicine and care.	International Treatment Preparedness Coalition, Treatment Action Campaign, Médecins Sans Frontières (MSF), Clinton Foundation.
Constituent and societal education and participation.	Global Network of People living with HIV/AIDS (GNP+), Global Alliance of Sex Workers, Marie Stopes Chin, Save the Children (UK), Oxfam Hong Kong.
Domestic NGOs capacity building.	Global Fund and its "Country Coordinating Mechanism"; Australian Red Cross.
Business social responsibility.	Global Business Council on HIV/AIDS, Product Red.
Sustainable financing.	UNITAID, Advance Market Commitments, Ford Foundation.
Comprehensive.	Bill & Melinda Gates Foundation.

Foreign governments also play a key role in China's AIDS work. The Australian Government's Overseas Aid Agency (AusAID) and U.K.'s Department for International Development (DFID) are the two major donor agencies providing financial support for China's HIV/AIDS prevention and control efforts. AusAID has established cooperation networks with the Chinese government and research institutions. It has sponsored trips to Australian universities for thousands of Chinese government officials, lawyers, researchers and NGOs, providing opportunities for study and the exchange of experiences with their Australian counterparts. At the National Centre for HIV Social Research at the University of New South Wales (UNSW-NCHSR), three training and experience-sharing workshops (as of August 2011) sponsored by AusAID have been organised for Chinese Communist Party leaders, China CDC officials, lawyers and NGO personnel.

China's efforts in improving provisions for public health match its commitment to engage with the global health regime. It is both recipient of international aid and provider of international assistance to developing countries in combating HIV/AIDS. The partnership with U.N. agencies, INGOs and foreign governments in tackling HIV/AIDS prevention and control in China is just one side of the coin. The other side is its role in providing medical assistance to sub-Saharan Africa and cooperating with neighbouring countries (Vietnam, Laos and Myanmar) to prevent, contain and treat HIV/AIDS and other infectious diseases. As Lai-Ha Chan (2011) points out, China's no-strings-attached, hands-off-politics policy behind its health contributions to African countries has been welcomed as an alternative to the international model in foreign aid predominant in Western countries. This has earned the Chinese regime political legitimacy at home and prestige and support internationally. China has also started to play an active role in global health governance, as exemplified by its proactive approach to the World Health Organisation (Chan 2011: 118–121). Whether China is going to challenge the international order or remain an uncritical participant remains uncertain. Chan argues that while China is eager to demonstrate its role as a "responsible developing great power" and a true friend of developing countries, it will "offer vocal support to its brethren in the developing world but work in concert with the more advanced powers in the West, which dominate the operation of global governance on the ground" (160). This conservative posture will see China's continuing compliance with demands from both international and domestic players for delivery of better health governance to its people and an ongoing, active, and tactically non-confrontational role in global health governance.

The war on HIV/AIDS has brought significant changes to Chinese society. China's changing policy on HIV/AIDS governance has taken shape from a combination of pressure from the outside and the demands of an emerging civil society from within. The Chinese authorities became aware of a lack of capacity to accomplish its goals in health service provision especially after the 2003 SARS crisis, a political disaster which exposed the serious deficiencies in China's public health and emergency response systems. Several factors have contributed to the gradual opening of the political space in which NGOs carry out HIV/AIDS work. The need to target hard-to-reach populations (IDUs, sex workers, MSM and economic migrants) in HIV/AIDS education and prevention, coupled with an outburst of panic arising from rumours, largely unfounded, of AIDS patients seeking revenge on innocent people in Tianjin and Ürümqi prompted the authorities to take action. The emergence of "innocent victims" of FPDs in the public discourse on HIV/AIDS also lends a certain respectability to AIDS work performed by civil society organisations, helping to remove the social restraints on working in HIV/AIDS relief and services. As such, we have

seen a huge growth in NGOs working on HIV/AIDS. It is estimated that in 2010 there were more than 600 community and university-based groups and grassroots organisations working on HIV/AIDS in China (China CDC and CHAIN 2010).

State and civil organisations have been involved in ongoing negotiations on a plan to share provision of social services—a scheme whose dynamic is still largely controlled by the state, although increasingly the state has been supported by international funding. For example, Round 6 of the Global Fund was aimed exclusively at mobilising and supporting NGOs in scaling up HIV interventions among IDUs, sex workers, MSM and PLWHA in 15 provinces; the Bill & Melinda Gates Foundation also funded a program that encourages greater involvement of NGOs in targeting at-risk groups. Many observers believe that Chinese NGOs operate in a very restricted political space, a space beset by a climate of mistrust and intolerance of political and legal advocacy. The Chinese regulatory environment is designed to prevent independent groups from developing a nationwide network that could challenge state authority—the example of Falun Gong still looms large for the communist regime. Furthermore, the fear of losing control has seen many government-owned NGOs (GONGOs) being set up to work in the AIDS relief areas. They receive funding from the government which in turn controls GONGO policy. Even some AIDS NGOs are spinoffs of, or have evolved from GONGOS. Their leaders normally have affiliations with government and/or academic institutions. They use their social standing or personal connections with China CDC and local health officials as well as international networks to attract funding and volunteers. The successful operators among AIDS NGOs form practical partnerships with local CDCs, local governments and village heads. Quite contrary to Western speculations, they consider their relations with government authorities relatively positive—cooperative more often than not—and are optimistic about the future. Recently, we have witnessed a growing number of collaborations between local governments and service-focused grassroots NGOs in HIV/AIDS work.

This relaxed attitude on the part of the government toward AIDS NGOs is most evident during crises when the government-NGO hierarchy may reverse itself so as to better respond to the immediate demand for essential social services. The result is the potential for a rapid change in relations between the state and social organisations (Schwartz and Shieh, 2009). NGOs have played a key role in HIV/AIDS prevention. As seen in other countries, AIDS NGOs and volunteers in China provide outreach services to hard-to-reach and under-represented groups. Experience has shown that, by engaging local communities and social networks, peer education and community-based intervention programs have been more successful in promoting condom use and safe sex practices among MSMs,

and among CSWs and their clients (Gao et al. 2007; Yang et al. 2010) as well as in carrying out HIV prevention and stigma reduction programs (Li et al. 2010). NGOs provide HIV/AIDS educational support and access to treatment in rural communities where the resources for such are scarce. In China, most AIDS NGOs are based in cities. Very few operate in under-resourced rural areas with mounting problems and where NGOs services are pivotal in advocating rights on behalf of PLWHA. The relaxed attitude toward AIDS NGOs still needs to be extended to advocacy on topics that go beyond financial compensation for those affected by HIV/AIDS. In a political system wary of NGOs, any outspoken demand for human rights and criticism from below of the existing legal and political system is still considered a threat to social stability by the establishment.

Chinese NGOs are still in the process of finding their feet and shaping their identity. This process is also fraught with internal conflict. In-fighting among groups (especially within the MSM community), disputes among AIDS NGOs over funding and media visibility, lack of professionalism, shortage of trained staff and management capacity, poor understanding of fundraising and a frequent turnover of volunteers—these hinder interorganisational solidarity and play into the hands of the government (Kaufman 2009). As Julia Greenwood Bentley (2004) points out, "the real constraints on civil society organisations are time and money rather than politics." Despite the challenges, NGOs serve as a forum at the grassroots level for allowing the voices of ordinary citizens to be heard, and as intermediaries, serve to channel international funding and democratic practices to the local level. "With the right encouragement from the Chinese government—or rather, in the absence of specific regulatory or political discouragement—these organisations, already ingenious at meeting current challenges, face promising prospects" (Bentley 2004).¹

The three levels of participants in China AIDS work—the state at the macro-level, U.N. agencies, INGOs and foreign governments at the meso-level, and civil society at the micro level—are not the only faces of Chinese AIDS work, or AIDS talk, as the following section illustrates. AIDS work has brought change to Chinese society, as evidenced in the more tolerant attitude toward civil society on part of the government, the emergence of sympathy and charitable actions among the public, an open attitude toward previously taboo topics and cooperation between government and NGOs in providing services and (to a lesser degree) advocacy. These major players—comprising policy makers, health professionals, foreign experts, public intellectuals and volunteers—are joined by celebrities, activists and ordinary citizens in doing AIDS work and AIDS talk.

¹ This optimism seems to have been shared among Chinese participants in the UNSW-NCHSR leaders' workshops.

AIDS TALK

In this section, I examine Chinese HIV/AIDS media and AIDS activism as constituting what I call "AIDS talk." In my earlier research the term "AIDS talk" refers specifically to talks on AIDS given by PLWHA (Yu 2007: 37). I expand its meaning here by incorporating all forms of discourse on HIV/AIDS in traditional as well as non-traditional forms and media. It includes "telling AIDS" in Chinese HIV/AIDS media, "recording AIDS" by independent documentarians, "fighting AIDS" by PLWHA and "righting AIDS" by HIV/AIDS activists who are not HIV carriers. From public health campaigns and media education programs in the official media, to individual initiatives asserting rights and community efforts toward self-help—all players utilise both old and new media and communication technologies to voice their concerns and get their voice heard. This in turn impacts on China's AIDS work.

The tremendous importance of media to health education and communication has long been recognised by national and international communities and organisations. UNAIDS, for example, has utilised and supported media initiatives for mobilisation and communication through both online and traditional media. The HIV/AIDS communication network (<https://www.comminit.com/hiv-aids/category/sites/global/hiv-aids>) is one example of UNAIDS partnership projects with other U.N. organisations, nation-state agencies and INGOs. Its initiatives and partnership programs include those in China, joined by state, semi-state and non-state organisations, such as CHAMP (China HIV/AIDS Media Partnership). The "AIDS talk" these U.N. and international players engage in are often embedded in the four categories that I introduce in this article. Although it is an important factor that contributes to and impacts on the typology of China's AIDS talk, it will not be analysed in details here. Rather, the focus is on the domestic factor and domestic participants in AIDS talk.

TELLING AIDS

In the field of AIDS talk (which of course goes hand in hand with AIDS work), the state-dominated mass media play a major role in agenda setting and news framing in the discourse on AIDS. It is through the mass media that most people get to know about HIV/AIDS (CHAMP et al. 2008). Since 2000, media have been enlisted into China's comprehensive HIV/AIDS prevention schemes. A sharp increase in AIDS stories occurred in 2001, coinciding with the issue of the Action Plan (2001–2005) on 25 May in the same year. This document specifically stated that central and local newspapers must publish news stories or public service announcements

(PSAs) related to AIDS prevention at least once a week. Mass media campaigns usually involve a variety of media including television, print, and Internet and mobile platforms. Such campaigns are generally staged as part of the publicity around the World AIDS Day (1 December) but also of the multicomponent programs in various collaborative projects of (GO)NGOs, INGOs and government agencies, in areas such as safe sex/condom use, needle exchange, counseling and peer education, and the stigma reduction. Table 3, which draws some findings from Hood (2011: 5) and Li et al. (2005), illustrates the progress of HIV/AIDS media in China.

Table 3: HIV/AIDS media in China.

Stages	Major features
Stage 1: prior to 1989	"Romantic period"; HIV/AIDS as a nonlocal disease among nonlocal sufferers.
Stage 2: 1998–2000	"Demonising period"; Chinese sufferers identified, although nonlocal content still dominated.
Stage 3: 2000–2005	"Indigenising period"; Chinese sufferers started to appear in media reportage and HIV/AIDS framed as China's "century plague."
Stage 4: 2006–present	"Diffusing period"; HIV/AIDS coverage in various media, still concentrating around World AIDS Day; problems in HIV coverage discussed and being addressed.

Media coverage of HIV/AIDS in China has gone from denial to acceptance, from "hidden corner to front page" (Liu and Zhang 2005) and from being framed as international news and a foreign problem to being a Chinese domestic problem. Telling AIDS is also moving from demonisation to the humanisation of HIV/AIDS-related issues and persons. Mass media coverage of HIV/AIDS related topics increased between 1995 and 2001 (Bu and Liu 2004) and has continued to increase substantially especially after 2002 (Li et al. 2005). Governmental and nongovernmental initiatives to promote HIV/AIDS media coverage has seen the rise in the amount of AIDS media research and media training workshops for journalists working in public health-related areas. Despite the progress made in HIV/AIDS reportage, several problems have been identified. Various studies have noted the advances as well as the existing problems in the portrayal of HIV/AIDS in the Chinese media, among which are the problems caused by (1) a state-centred approach, (2) a distancing perspective and (3) the lack of a tolerant, humanistic spirit.

Telling AIDS in Chinese media is first of all confined to a state-centred approach. The Chinese government is always blamed for the spread of HIV in China through its denials, cover-ups and slow response in the earlier stages of the epidemic, through its unequal modernisation policies

that have dismantled the socialist medical care and social welfare systems, and through its neoliberal developmentalism that excludes and marginalises the rural and the peripheral. The Chinese media have colluded in the process through a contradictory role as the Party-state's "tongue and throat," as educator of the masses, and as fearmonger responsible for the persistence of AIDS phobia and homophobia. Since "discovering" the topic after over a decade of ignoring and obscuring the AIDS epidemic in China, the media has struggled to frame HIV/AIDS within the existing structure and political economy of the Chinese media system.

On the one hand, the news media have ignored the real issues behind the HIV/AIDS epidemic, issues which have significant political implications. On the other hand, they have linked AIDS stories to official policies. In this linkage, the story of AIDS in China has been concerned less with what actually happens in society and more with what the authorities have or have not done, less with the socio-economic conditions and more with the (decontextualised) individual cases, less with the voices and faces of PLWHA and more with leaders and experts. Researchers such as Li et al. (2009), Li and Zhang (2005), Li et al. (2005) and Dong et al. (2008) have shown that HIV/AIDS reportage in the official media (represented by the *People's Daily*) focus predominantly on health policy, official knowledge and expert interpretation on prevention and treatment; that Chinese AIDS media centre on national policies and programs while the HIV/AIDS situation on the ground is seriously under reported. The sources of such reports come from government departments, foreign and domestic health experts and intellectuals, as well as visiting officials from U.N. agencies. The lack of diversity of new sources, voices and perspectives means that HIV/AIDS is largely confined to a policy and medical framework rather than situated more broadly on its social and political horizon. This lack is compounded by narrowness in coverage: China's HIV/AIDS media is still Han-Chinese dominated; the struggles with the epidemic among minority nationalities have been effectively a non-issue. This state-centred approach to HIV/AIDS reportage has created a media environment where health news is abundant but of little practical use either to PLWHA in pursuing their medical and legal rights or to the general public in raising the level of HIV awareness.

Since 2000, China's HIV/AIDS media has been characterised by two interrelated trends: indigenisation and diffusion. HIV/AIDS is no longer treated as exclusively international or medical news. Domestic or local content has gained exposure in various media. News journalism has also edged away from political dogma toward objectivity and fact when it comes to HIV/AIDS reportage. I have written elsewhere on Chinese investigative journalism and its double-time narration strategy in reporting SARS (Yu 2009). Like Chinese journalism in general, HIV/AIDS and health

journalism also comprises two streams: Party journalism and the professional journalism. While Party journalism continues its state-centred approach in HIV/AIDS reportage, the new journalism, represented by *Southern Weekly*, *Southern Metropolitan News* and *China Youth Daily* (Pan and Chen 2004), ventures into new territories and tests political boundaries in order to expand the public sphere for exercising citizenship in China. In HIV/AIDS reportage, this new breed of journalists tends to frame HIV as a social issue rather than a medical problem. The new journalism relates public health issues to social justice and equality and gives a human face to the HIV epidemic by giving voice to the marginalised and disadvantaged in society (Zhang 2009). Progressive journalism of this type serves to remind people of the downside of China's modernisation project and the urgency to address it.

The second major problem in China's HIV/AIDS media is a distancing perspective toward HIV/AIDS. Johanna Hood in *HIV/AIDS, Health and the Media in China* (2011) examines this theme in detail. Hood's research as well as those of others (e.g., Dong et al. 2008) document how HIV/AIDS was portrayed as a non-Chinese problem in earlier HIV media and how it is portrayed as non-Han and non-local when HIV/AIDS is no longer a "state secret" and is now on the front page. From 1985 to 1996, for example, an overwhelming majority (97%) of AIDS stories in *People's Daily* concerned the United States and were associated with drug abuse and "sexual deviance" (a category which includes homosexuality) (Dong et al. 2008). Apart from serving to remind readers of the social ills of Western societies (represented by the U.S.), such reportage also represents the disease as irrelevant or inconsequential to Chinese society at large.

The association of HIV/AIDS with the West is one side of the "imagined immunity" fallacy; the other side is the association of the disease with concepts like *hei* (black), *yuanshi* (primitive) and *bu kexue* (unscientific) (Hood 2011a). These concepts are key to Hood's book, a work which widens the focus of debate on health communication and media in China to include less discussed topics: race, racism and class. In "telling AIDS," Chinese HIV/AIDS media uses a distancing perspective by representing the virus as not only originating in places other than China but also as affecting people other than the Chinese. The black African has served as the ultimate, token Other. To urban Chinese, sub-Saharan Africa symbolises excess in poverty, disease, imbalance and disorder. A rampant HIV/AIDS epidemic on the "dark continent" signifies a lack of good governance, morality, social discipline and science. Gruesome photos of the emaciated bodies of black Africans, accompanied by sensationalised language reaffirm the Chinese urbanites' sense of racial superiority and overweening belief in China's superiority in material, scientific and cultural progress. Telling AIDS from afar appears "to help safeguard the health of

the local population, whilst actually doing the contrary by nourishing imagined immunity" (Hood 2011a: 133). This distancing perspective reinforces the Chinese sense of cultural superiority as a people and the illusion of a nation that can mobilise combined Eastern and Western scientific thinking in the fight against HIV/AIDS.

Such research findings are relatively recent and reflect the continuing evolution of China's HIV/AIDS media, albeit with some aspects that have remained unchanged. Representations of the disease as *Other, distanced* and presented as international or medical science news estrange "ordinary" Chinese people from the reality of HIV/AIDS and a host of problems associated with it. These representations have also had a lasting impact on how HIV/AIDS is perceived in China. More specifically, it reinforces rather than reduces the stigma of HIV/AIDS. It reflects the lack of a humanistic spirit in telling AIDS in Chinese media. In other words, the lack of a humanistic outlook reveals itself in the persistence of the HIV/AIDS stigma in China's media.

Research has shown that PLWHA in China experience isolation, discrimination and fear. Despite years of effort in HIV education and awareness campaigns, the average level of knowledge regarding AIDS and HIV transmission is low, a shortcoming which continues to fuel a high level of discrimination toward PLWHA (CHAMP et al. 2008). Not only ordinary people such as villagers (Sullivan 2010) and market vendors (Li et al. 2009), but also healthcare professionals (Leiber et al. 2006) have displayed their fear of and discrimination against PLWHA. The stigma attached to HIV/AIDS has deterred people from being tested, disclosing their HIV status or seeking medical assistance (Zhou 2007). PLWHA often lose their jobs if their HIV positive status is known; children of PLWHA are discriminated against in schools or barred from attendance, even if they themselves are HIV negative (Li 2008). Wilson's article in this issue illustrates the stigma attached to PLWHA and their plight when it comes to protecting their rights.

Chinese journalists' selection of metaphors, photos, and terminology serves to further demonise the disease rather than to disseminate current medical knowledge about the transmission and treatment of the disease. Although Chinese media have improved HIV/AIDS reportage by playing an advocacy role in anti-stigmatisation efforts, they continue to frame HIV/AIDS in stigmatising terms, even when discussing anti-stigmatisation efforts (Ren et al. 2010). In recent years, the use of overtly discriminatory terms such as "AIDS girl" or "AIDS couple" has declined in Chinese AIDS media. Covert stigmatising terms, however, still persist and the HIV positive continue to be represented as an underclass in Chinese media. As Johanna Hood (2011b: 2) argues, "the way the Chinese media has portrayed HIV in general, and the HIV positive in particular, has effectively created a

new social group belonging to what are known in China as othered (*tazhe* 他者) or underclass (*ruoshi qunti* 弱势群体, *diceng* 底层) people, who are thought to lack urban values and 'quality' (素质 *suzhi*) and are thus perceived as second-rate citizens." She calls these people the *Aimin* (艾民). The *Aimin* Hood examines are PLWHA who have been infected through the sale of blood. In Chinese AIDS media these people have been dehumanised due to their involvement in the plasma economy, the places where they come from (mostly Henan and Anhui), their physical suffering and social exclusion and their threat to China's social, political, economic and biological future. Rather than asking questions about the historical and political factors behind the *Aimin* phenomenon—the impact of urban-centred economic reforms on rural areas, the marketisation of the healthcare system and the lack of social welfare and a viable legal justice system—China's AIDS media help create a hierarchy of victimhood: "innocent" victims (FPDs, AIDS orphans, etc.) at the top, and at the bottom, "non-innocent" reprobates (IDUs, CSWs and MSMs). A new dichotomy separates the innocent needing love and care from the putative immoral who deserve punishment by the disease and must be isolated.

Indeed, the "discovery" of innocent victims allows the AIDS media to domesticate HIV as a local virus and to promote a more caring and tolerant society in China. On the one hand, *Aimin* are depicted as pitiful and exploited yet wilful victims of greed through involvement in illicit commercial activity—selling blood. On the other hand, they invoke a sense of compassion among the general public, especially toward AIDS orphans. This empathy has prompted urban citizens to become involved in a productive form of philanthropy through donation, adoption, or other forms of social activism.



Figure 4: AIDS posters, Beijing subway (Photos taken by Jeanne Boden, 2005).

In the fight against HIV/AIDS, there is an emergent culture of philanthropy in urban China. In the past decade, the Chinese government increasingly has enlisted the mass media in HIV prevention campaigns, as exemplified by Premier Wen Jiabao comforting PLHWA patients or President Hu Jintao shaking hands with PLHWA. It also has recruited celebrities as goodwill ambassadors in HIV/AIDS awareness campaigns. A range of celebrities have appeared as AIDS campaign spokespersons on television, in public service announcements (PSAs) and at public events to speak out against HIV discrimination, including Pu Cunxin (actor), Peng Liyuan (singer) (see Figure 4), Yao Ming (basketball player), James Chau (journalist), Leon Lai (actor and Cantopop singer), Cai Guoqing (singer), Xu Fan (actress) and even NBA star Magic Johnson. Humanitarian activism and HIV/AIDS advocacy by celebrities is sanctioned by the state and falls within a philanthropic culture guided by the state (Hood 2010). This attempt at a humanistic approach to telling AIDS still falls within the existing power structure that defines "epidemic citizenship" in China. As Johanna Hood argues in her contribution to the present issue, "HIV/AIDS and shifting urban China's socio-moral landscape: engendering bio-activism and resistance through stories of suffering," the HIV/AIDS media has not only helped create a new disease economy and image politics. It also provides new spaces for bio-activism, where "resistance may be leveraged, benefits gained, and through which a new modernity, and new conceptions of suffering and humanism, rights and entitlements, may be given local meanings."

The above analysis shows that the media function as an accomplice to the existing power structure and help legitimate the governance over the HIV positive while keeping them firmly at an (imagined) distance. It also illuminates agency in bringing changes to China's HIV/AIDS media. One key agent is the new breed of professional journalists who venture to test political boundaries through AIDS reportage. They have not only infused the HIV/AIDS news story with a more humane touch but have also reshaped Chinese journalism in general, as exemplified in the reportage of homosexuals and homosexual rights in relation to HIV/AIDS (Wu and Jia 2010). Another key group of agents is documentary filmmakers who record the ways PLHWA have suffered and survived; how they understand and respond to the disease that subjects them to economic, social and emotional deprivation, isolation and suffering; how they rebuild their lives; and how they fight for their own rights and dignity as well as help each other.

RECORDING AIDS

Recording AIDS on the screen started with television journalists such as Chai Ling and Dong Qian from China Central Television (CCTV). They have documented the lives of PLWHA in rural Henan and their struggles for survival and recognition; they have provided a national platform for AIDS experts and activists (including Gao Yaojie) to openly discuss the "Titanic peril" or "century plague" that China faces. CCTV broke the taboo to feature in 2002 the first HIV positive person who contracted the virus through commercial sex; it broadcast China's first public service announcement on condom use in HIV prevention in November 2003; it has staged annual anti-AIDS public-interest gala on or before the World AIDS Day since 2003; it showed the first AIDS awareness TV drama *Colours of Life* and invited China's first AIDS performance groups to its annual anti-AIDS gala in November 2004. Apart from the programs and efforts by the state national television and its journalists in communicating HIV/AIDS related messages, there is also a growing body of less publicised but equally important documentaries made by independent filmmakers and activists. Their efforts in recording AIDS add a grassroots and sometimes transnational perspective to AIDS talk in China.

A most famous independent documentary on HIV/AIDS in China is arguably the award-winning *The Blood of Yangzhou District* (*Yangzhou de haizi*) (39 min, 2006), directed and produced by US-based Ruby Yang and Thomas Lennon. It is a documentary film about the plight of AIDS orphans in remote villages of Anhui province—their tenacious and ferocious will to live despite ostracisation and isolation brought upon them by HIV (see the official website at www.bloodofyangzhou.com). Riding on their success in international film festivals for this AIDS themed documentary, Yang and Lennon have set up "China AIDS Media Project" to propagate HIV/AIDS awareness in China. They have worked with international and Chinese government agencies to produce a series of HIV/AIDS PSAs and documentaries. Yang and Lennon's overseas background, extensive experience in filmmaking and production, business savvy as well as social commitment helped in the establishment of the most prominent NGO on HIV/AIDS education and prevention through media in China. "China AIDS Media Project" has a new life as CHAMP (China HIV/AIDS Media Partnership), since 2008, to mobilise the communicative power of the media and marketing networks in the effort to raise awareness about HIV/AIDS and reduce stigma and discrimination toward PLWHA.

CHAMP is organised and operated under the media partnership model composed of state media, private media companies and businesses, NGOs, the government and U.N. agencies. Its work is officially sanctioned and its PSAs are broadcast on Chinese national television. Apart from *The*

Blood of Yingzhou District, Yang and Lennon also saw their first HIV/AIDS documentary about a university student (Zhuliya) who contracted AIDS through pre-marital sex aired in late 2005 on Chinese television. This is the first independent AIDS documentary ever shown on Chinese television. Their AIDS awareness PSA—"Life is too good: protect yourself, treasure others (*Shengming ruci meihao: baohu ziji, guan'ai taren*)"—was broadcast nationwide and viewed by more than 400 million people. It received over 10 million hits on the Internet (Chang Ai 2008). Yang and Lennon have expanded their business scope to cover topics such as gay awareness, tobacco control and environmental protection. With financial and policy support from the Chinese government, they produce big-budget documentaries and reach a wide audience. Government approval and well-financed productions are what separate mainstream documentary filmmakers from semi-independent ones like Chen Weijun and independent documentary activists like Ai Xiaoming.

Chen Weijun is a semi-independent filmmaker who works for Wuhan Television but makes documentaries like *To Live Is Better Than to Die* (*Hao si buru lai huozhe*, 2003) independently. Funded by a private entrepreneur friend of Chen's, *To Live is Better than to Die* enjoyed no government support; during the shooting the filmmaker was arrested several times by local police. The documentary portrays the Ma family whose members are in various stages of illness: the wife has full-blown AIDS; the husband is HIV positive; two children are also infected with HIV; only the eldest daughter who was born before her mother contracted HIV is virus-free. The documentary records a (lunar) year in the life of the Ma family in the village of Wenlou in Henan province, chronicling their bleak day-to-day existence and struggles under appalling circumstances. After the international success of the film and subsequent banning in China, Chen teamed up with overseas producers for his other films including *Please Vote for Me* (2007). Chen's local knowledge and expertise in digital video filmmaking plus financial and technical resources from overseas producers help his documentaries reach a large audience at film festivals and on public broadcast services. Although these films are not shown in China, they are available via private networks, pirated DVDs and on video-sharing websites such as YouTube, Tudou and Xunlei.

A group of intellectuals turned independent documentary filmmakers also have joined the work to document HIV/AIDS, often from anthropological and historical perspectives. Beijing based anthropologist Zhuang Kongshao's *Tiger Day* (*Huri*, 2002) is an example of early independent documentaries on HIV/AIDS related themes. It is an anthropological documentary on the use of an ancient lineage rite "Tiger Day" to fight the abuse of drugs. It seeks to understand the socio-cultural origins of drug abuse and trafficking among the Yi people in Southwest

China. It also demonstrates the resilience of the Yi community through the rehabilitation programs modeled on the "Tiger Day" rituals. Another prominent figure in documenting HIV/AIDS is Guangzhou-based gender studies professor Ai Xiaoming. Ai and her collaborator Hu Jie (independent documentary filmmaker and activist) are Chinese public intellectuals who have openly endorsed human rights declarations such as "Human Rights and HIV/AIDS: Now More Than Ever," "10 Reasons Why Human Rights Should Occupy the Center of the Global AIDS Struggle" and "Charter 08." Ai and Hu founded an audiovisual studio/NGO called the "Gender Studies Educational Forum" at the Sun Yat-sen University in 2004 and "Gender and Development in China" in Beijing in 2005. Both aim at promoting digital video (DV) technologies among the grassroots to empower the disadvantaged and marginalised through video story telling. In 2005 they organised a video training project "Beijing Plus 10: Recording China's Activities" and trained eleven volunteers from rural China on DV-making. These volunteers then made a series of documentaries on issues related to public health, environmental protection, HIV/AIDS prevention, women's rights and the rights defense movement in rural China.

Two documentaries on HIV/AIDS are representative of Ai and Hu's efforts in recording AIDS: *The Central Plains* (2006) and *Care and Love* (2007). *The Central Plains* documents the survivors of the so-called "blood disaster (*xue huo*)" in central China. It is about the struggles of rural people and other marginalised groups living with HIV/AIDS against conditions of extreme poverty and discrimination. It records the efforts of these brave men and women to reveal the truth of the blood scandal and to defend their health rights. *Care and Love* documents the story of Liu Xianhong, a woman villager who contracted HIV through a blood transfusion during childbirth, and how she used legal means and the media to seek compensation from the local hospital. It also records the sufferings of several families affected by HIV/AIDS and how they work together through their own organisation "Care and Love Group" to assert their medical and human rights. Growing social concern, media intervention and legal aid have forced the local government to modify its policies and to improve the situation for AIDS patients. The two documentaries reveal an increasing awareness of civil rights in rural areas and the importance of the role of NGOs in empowering local communities.

Recording AIDS by social activists and independent documentary filmmakers provides an alternative to state-dominated AIDS talk. It is also part of the civil rights movement that is awakening in China. The collaborative efforts among professional DV documentary filmmakers, NGOs, establishment journalists and independent DV makers have helped circulate awareness of HIV/AIDS and civil rights among disadvantaged groups such as PLWHA. Recording HIV/AIDS therefore should be viewed

as a social movement possessing the capacity to bring fundamental changes to China through the use of audiovisual technologies. But such efforts are confined and constrained by China's political and media system which controls what the public is allowed to hear and see. Apart from Ruby Yang and her team's work, independent documentaries on HIV/AIDS have not been shown officially on mainstream channels. Chen Weijun's *To Live Is Better Than to Die* was screened among friends, colleagues, fellow documentary filmmakers and at international film festivals. Ai Xiaoming's documentaries were shown to university students and villagers in central China. But even private screening was not unhindered. There have been several occasions when authorities banned all screenings (personal communication, November 2010, Guangzhou). These films, available on YouTube (blocked in China), cannot be seen on the Chinese Internet. Recording AIDS is largely an unofficial grassroots initiative. It is still the mainstream media that dominate AIDS talk in China today.

FIGHTING AIDS

Joining in AIDS talk are also PLWHA who have come forward and taken HIV/AIDS awareness and education campaigns on their own shoulders, in BBS, websites, autoethnographic or semi-ethnographic writings and art. Well-known examples are Li Jiaming (Li 2002), Zhuliya (2006) and Zhou Shengping (2007). Their writings document their lives living with HIV/AIDS, their struggle for survival against stigmatisation and their plea for better care and understanding of PLWHA. These writings are available both in hard copy and electronically online. While the stigma of HIV/AIDS still persists in Chinese society, the Internet has become one of the main venues through which individuals can discuss openly issues that they normally would not feel comfortable talking about in other settings. It also opens new spaces and opportunities to organise, lobby and distribute information. It has been widely used by the gay community to network and share information. It allows activists and volunteers to advance their concerns and publicise their projects (Yu 2009).

Some HIV positive activists, working with NGOs and INGOs, have devoted their lives to propagating HIV/AIDS awareness. The above-mentioned Liu Xianhong in Ai Xiaoming's documentary *Care and Love* is an example. China's "most mysterious person living with HIV/AIDS" Li Jiaming is another who has devoted himself to HIV/AIDS campaigns. Li is in charge of the Shanghai based "1+1 Sunlight of Love" project (<http://2008jiaming.com/main.asp>), which is funded by the Ford Foundation and Marie Stopes International China. It is a major network among PLWHA in East China promoting cooperative efforts in HIV/AIDS prevention, care and treatment. Its work has expanded from online information sharing and

counseling to offline consultation and information sessions with experts, peers, volunteers and public health officials and professionals. Another NGO supported initiative that is run by the HIV positive is the Positive Art Workshop. Founded in 2002, the workshop is sponsored by the Ford Foundation and Beijing You'an Hospital's Family of Love group, and run by Song Pengfei whose meeting with Bill Clinton in 2002 made him an AIDS celebrity, and two foreign artists (Jose Abad Lorene and Diana Valarezo). The Positive Art Workshop aims at empowering PLWHA to express their feelings through art and offering them a means to make a living through the sale of their art.

Fighting HIV/AIDS compels the PLWHA to express themselves through literature, video, art and performance. The now defunct "AIDS Performance Group" from Gongmin, Zizhong county of Sichuan, used the stage to dramatise its members' own experiences with HIV/AIDS (Anon 2006). Supported by the CHARTS (China AIDS Roadmap Tactical Support), the group made it all the way to the national platform through an invited performance at the anti-AIDS gala on the World AIDS Day in 2004. Unfortunately, the lack of financial support with the end of the CHARTS project and the deaths of several key figures in the group have deprived it of the resources with which to continue the endeavour. These and many others who are involved in peer and partner education programs have played a vital role in contributing to AIDS talk, despite their relative invisibility in the public sphere and vulnerability to financial, social and political strictures. Hundreds of named and anonymous PLWHA fight AIDS at the local level with no publicity from the domestic media; they often face detention, punishment and brutal treatment from the police and local governments. Their voices are rarely heard in the public domain and remain less known to the international community than the AIDS activists who are not PLWHA themselves. But often these groups of people work together in the fight against HIV/AIDS and HIV related injustice, corruption and oppression (see Human Rights Watch 2005).

RIGHTING AIDS

As discussed earlier in this essay, the Chinese government has shown a growing awareness and willingness to mobilise civil society in order to combat HIV/AIDS. As a result, NGOs and grassroots groups have sprung up in China. Grassroots activists and their NGOs have played an active role in reaching the most marginal and hardest hit areas and communities with urgently needed information and services. In the process, they have contributed to AIDS work as well as AIDS talk. In AIDS talk, AIDS activists are playing a leading role in championing medical rights and the

right to education, as well as work rights and the human rights of children. But the Chinese state remains wary of these groups.

Reports on arrest, jailing and harassment of AIDS activists in China are frequent in foreign media. The plight of prominent AIDS activists—Gao Yaojie (gynecologist and Henan blood scandal whistleblower; now in exile in the U.S.), Wan Yanhai (founder of Aizhixing Institute; also in exile in the U.S.), Li Dan (the founder of Orchid Orphanage in Henan), Hu Jia (rights defender; just released from jail after serving a three and a half year sentence) and Zeng Jinyan (Hu's wife and blogger)—offer vivid examples of the limited tolerance of advocacy and activism in China (Chan 2011, 86–89). These individuals have been monitored, threatened, beaten and detained. Their organisations have been shut down and they have been prevented from traveling overseas to receive awards. Human rights organisations and international pressure groups have helped publicise their respective plights in the international news media and have pressured the Chinese government to relax its restrictions on dissent. These people, however, have garnered only limited domestic space for publicity, except within the AIDS NGO community. Their plight sometimes deters rather than encourages any open challenge of China's state-dominated and engineered HIV/AIDS governance and discourse. The work they do under difficult conditions and the tribulations they suffer, rather than their words, contribute to AIDS talk in the international domain. In fact, more people who do not wish to be called activists are doing important work on the ground, sometimes compromised but still on the forefront, to advance the voices and rights of PLWHA. They—journalists, public intellectuals, public health officials and professionals, NGO workers and volunteers—are the backbone of China's civil society.

CONCLUSION

There is no single agent for change; nor is there a single tool or technology for empowerment. Michael Chanan's comments on the politics of documentary is illustrative of the key point that I wish to make in this introductory chapter: "this is not a single and unitary space of free and equal debate, but a network of parallel and overlapping zones, often of limited extension, and with unequal access to the mainstream forms of publication and broadcasting. There are central media and peripheral ones, but they're not disconnected, they overlap and rub off on each other" (Chanan 2007: 6). This introduction has aimed to provide an overview of the key issues and debates in governing and representing HIV/AIDS in China. It is a daunting task that is undoubtedly not without omissions and eclipses. Using a broad-brush approach, this essay has identified SOME key players and issues in Chinese HIV/AIDS governance and communication. The scope of this

essay, however, does not allow a more thorough examination of some key points raised in this essay. Rather, I encourage readers to read the articles included in the present issue. It features five original research articles on detailed analyses of China's legal responses to HIV/AIDS and its challenges (Meng), ineffective and inadequate legal system to settle HIV/AIDS disputes (Wilson), ethnic and security challenges posed by HIV/AIDS in China's borderlands (Hayes), gendered narratives and their problematic in education, research and governance of the increasingly sexualised epidemic (Micollier), and HIV engendered bio-activism and resistance through telling AIDS (Hood). Examining practices in governing and representing HIV/AIDS allows us to explore the myriad issues that intersect around the growing attention to the geopolitics and biopolitics of China's health regime. It is hoped that this thematic issue contributes to our understanding of health governance and communication in China and opens up further debates in the field.

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