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AIDS and Social Policy in China

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AIDS and Social Policy in China

edited by

Joan Kaufman, Arthur Kleinman, and Tony Saich

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Abbreviations

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ARV Medications

3TC	lamivudine, Epivir®
API	active pharmaceutical ingredient
AZT	zidovudine
CMZ	cotrimoxazole
d4T	stavudine
ddI	didanosine
EFV	efavirenz
IDV	indinavir
NVP	nevirapine

General Terms

AAI	(UN) Accelerated Access Initiative
ABC	(stategy combining) Abstinence, Be faithful, Condom use
AIDS	Acquired Immune Deficiency Syndrome
amfAR	American Foundation for AIDS Research
AFP	Agence France-Presse
ART *or* ARV	antiretroviral treatment/therapy
AusAID	Australian Government Overseas Aid Program
BCC	behavior change communication
BHIVA	British HIV Association
BIIC	Beijing Institute of Information and Control
CCP	Chinese Communist Party
CD4	T4 count, T-helper cells
CECC	Congressional Executive Commission on China
CEEC	Central and Eastern European Countries
CFPA	China Family Planning Association
China CARES	China Comprehensive AIDS Response program

China CDC	Chinese Center for Disease Control and Prevention
CIPR	(UK) Commission on Intellectual Property Rights
CIPRA	(US NIH) Comprehensive International Program of Research on AIDS
CME	continuing medical examinations
CNY	Chinese *yuan*
CSW	commercial sex worker
DFID	Department for International Development
DOT *or* DOTS	directly observed therapy or directly observed treatment, short course
ELISA	enzyme-linked immunosorbent assay
EPS	epidemic prevention station
EU	European Union
FDA	(US) Food and Drug Administration
FDC	fixed-dose combination
FEMA	(US) Federal Emergency Management Administration
FHI	Family Health International
FSW	female sex worker
G8	Group of Eight (Canada, France, Germany, Italy, Japan, UK, US, and Russia)
GAP	(US CDC) Global AIDS Program
GDP	gross domestic product
GIPA	greater involvement of PLWA
GNP	gross national product
HAART	highly active antiretroviral treatment
HCV	hepatitus C virus
HIV	human immunodeficiency virus
IAS	International AIDS Society
ICPD	International Conference on Population and Development
IDU	injection drug user/intravenous drug user
IEC	information, education, and communication
ILO	International Labour Organisation
IPR	intellectual property rights
IRB	institutional review board
IUD	intra-uterine device
JICA	Japanese International Cooperation Agency
KAP	Knowledge, Attitude, and Practices survey
LPS	life-planning skills

M&E	monitoring and evaluation
MCA	Ministry of Civil Affairs
MCH	Maternal and Child Health
MCT	mother-to-child transmission
MOH	Ministry of (Public) Health
MOU	memorandum of understanding
MSD	Merck Sharp & Dohme
MSF	Médecins Sans Frontières
MSM	men who have sex with men
NCAIDS	(China's) National Center for STD/AIDS Prevention and Control
NGO	nongovernment organization
NPO	non-profit organization
OI	opportunistic infection
OVC	orphans and vulnerable children
PBD	paid blood donor
PEPFAR	(US) President's Emergency Plan for AIDS Relief
PLWA	people living with HIV/AIDS
PMCT	prevention of mother-to-child transmission
QQ	a form of instant messaging in China
R&D	research and development
RMB	Renminbi ("People's Currency," Chinese *yuan*)
RTI	reproductive tract infection
SARS	Severe Acute Respiratory Syndrome
SCWGA	State Council Working Group on AIDS or State Council AIDS Working Committee
SEZ	special economic zone
SOE	state-owned enterprise
SSB	State Statistical Bureau
STD/STI	sexually transmitted disease/infection
TB	tuberculosis
TRIPS	trade-related aspects of intellectual property rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United National Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNICEF	United Nations Childrens' Fund

USAID	United States Agency for International Development
US CDC	United States Centers for Disease Control and Prevention
US HHS	(US Department of) Health and Human Services
US NIH	(US) National Institutes of Health
USD	United States dollar
VAT	value-added tax
VCT	voluntary counseling and testing
WHO	World Health Organization
WTO	World Trade Organization

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PREFACE

A Biosocial Understanding of AIDS in China

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Paul Farmer

It is hard to avoid making grand statements when writing about AIDS and China, especially now that news magazines across the globe speak of the twenty-first century as "the Chinese century." Even without the hyperbole, how the world's most populous nation responds to AIDS obviously has great consequences for the future of public health. That future is, of course, difficult to predict: witness the brave hopes voiced three decades ago when the Chinese delegation took part in the signing of the famous Declaration of Alma Ata, which proclaimed the goal of "health for all by the year 2000." That vision of the future does not look much like our present, either in China or elsewhere.

Health for all remains an elusive goal. AIDS, now the world's leading infectious killer of young adults, was entirely unknown at the time of Alma Ata; no one could have guessed that a new pathogen, HIV, was soon to alter human history. China in 1975 was still largely a rural nation, and was undergoing great upheaval and transition as Mao's exit neared. China's current epidemic, it can be argued, has its roots in the political and economic transformations that began in the late 1970s .

It is wiser to speak of China's many epidemics, however, for China is not only vast and populous but is a nation with more social (economic, cultural, linguistic) diversity than most nations large or small. Anthropologists and

other social scientists are quick to pose questions about how social differences and cultural practices affect the small handful of practices and processes associated with HIV transmission (from sexual activity to childbirth to intravenous drug injection). Rapid economic transitions, unevenly experienced across China, have had an enormous impact on general levels of health and well-being. Generalizations, like comparisons, are always hazardous; even as China's AIDS epidemic remains mostly rural, those who know little about China but a good deal about AIDS will be quick to recognize that an urban epidemic is inevitable and that the rural and the urban epidemics will take different trajectories, grounded in the relationship between rapid, uneven economic growth and industrialization and migration, which is widely associated with HIV transmission. It is even possible to consider the impact of what has been termed "health care reform" on the Chinese AIDS epidemic, in the form of a paradoxical outcome similar to the experience of other formerly socialist countries: as the economy booms, the public health infrastructure frays. The control of endemic diseases (malaria, leishmania, tuberculosis, schistosomiasis) appears to be less effective than before but also, in the wealthier regions, less important: China's ranking health problems increasingly come to resemble those registered in affluent and industrialized economies.

In short, "biosocial complexity" abounds, and it is difficult to point to a *national* Chinese AIDS epidemic, even though nation-by-nation AIDS reporting is what we get. Such reporting is necessarily distorted, since China already incorporates myriad regional sub-epidemics of AIDS. Heterogeneity within cities and rapidly changing social policies add further layers of distortion. Of course, the same might be said of any large country—Russia, for example, or the United States or Brazil. But those involved in AIDS work, whether delivering clinical care or formulating health policy, are well aware of the complexities of sub-epidemics in the more mature epidemics (those in the United States and Brazil). Concurrent tuberculosis epidemics have pointed to the complexities and peculiarities, rooted in history, economy, and culture, of the Russian AIDS epidemic.

We are just now learning about China's epidemic. The English-language bibliography on AIDS in China is growing rapidly, but it remains small, and interdisciplinary work that would inform a properly biosocial analysis of AIDS in China is vanishingly rare. A deep understanding of China's AIDS epidemic is both daunting and urgent. It is daunting because capturing the sort of complexity mentioned above is still a nascent art in the epidemiology of infectious disease. Reliable data are often hard to come by. An honest and

comprehensive picture of the dynamics of the AIDS epidemic in China will necessarily draw on the work not only of epidemiologists and infectious disease experts, but also of anthropologists, historians, and those familiar with the economic and health policies adopted and implemented (again, unequally by region and economic stratum) in recent years. These biosocial complexities are best examined as continuous processes because they change constantly, and often quickly.

Why is it so urgent that we have a proper biosocial understanding of AIDS in China? Obviously, a sound understanding of AIDS in China is essential to planning effective medical and public health responses. Although China's is an immature epidemic, there are probably already as many people living with HIV in China as in the United States, where the epidemic began decades ago. A proper biosocial analysis of AIDS in China can guide China's policies on this and other epidemic diseases. A multidisciplinary study, as described above, including practitioners and policy makers (as well as addressing them) is what is needed.

This is just such a book. The editors have done us all a great service in bringing the English-speaking world a biosocial look at AIDS in China. Emerging from a conference held at Harvard University in 2004, this volume is sure to be important for at least four reasons. First, and perhaps most pragmatically, there is still a chance for success as we mark the first decade of the epidemic in China. I am writing this preface in transit between the United States and central Africa, two settings in which mature epidemics have taken many lives and left ruined communities behind. The early years of an AIDS epidemic are the time to ensure that sensible and informed policies are adopted and explosive epidemics averted. China still exerts some centralized control over the nation's health policy, another reason for hope. In Russia, as in most of Latin America, such control has largely been ceded in an effort to promote "decentralization." Decentralization may serve certain political ends—so say its cheerleaders, many of them American—but whatever its effects on political and economic organization, its impact on public health has been grievously deleterious over the past decade. Chinese health authorities would be wise to consider both "health care reform" and "decentralization" with a critical eye.

Second, there remains, in China, a chance of integrating AIDS prevention and care early in the epidemic, and of strengthening the broad-based primary health care efforts for which China was once justly praised. It is important to integrate prevention and care; only where excellent services are available to the afflicted will noncoercive means of promoting widespread

screening succeed. The quality of prevention efforts is enhanced when such integration occurs, in large part because people living with HIV have major contributions to make to this effort. Our experience in Haiti and Rwanda has shown us that the infusion of resources necessary to launch proper AIDS programs can reinvigorate primary health care by linking AIDS efforts to those designed to control tuberculosis and vaccine-preventable illness and to strengthen women's health initiatives. These three aspects of public health are connected at many levels, and have better chances of success when treated as interlocking parts of a single program, not parallel and independent "fronts" in a war on disease.

Third, China can formulate more humane policies, ones designed to protect the Chinese majority and at the same time promote the rights of all those living with HIV, including those who are, for example, injection drug users (IDUs) or who endure occupational risks for HIV. Unswerving respect for human rights—from political and civil rights, traditionally weak in China, to the social and economic rights of the poor or otherwise marginalized, traditionally weak in many self-described Western democracies—should be a cornerstone of new Chinese AIDS policies. As China's political culture changes, we might at last see there the integration of what have often been opposed views of human rights.

Fourth, this book is important because what happens in China is always important. As Napoleon said, "When China awakens, the world will tremble"; we might update his prophecy to suit the age of jet travel and say, "When China sneezes, the world catches a cold." China's regional and global influence is not set to stop growing soon. The SARS epidemic is a particularly sharp reminder of China's importance. Many eyes will be watching as the Chinese AIDS epidemic, and social responses to it, unfold.

For all who work on AIDS—clinicians, scholars, and policy makers—there is always ample cause for pessimism. But ten years ago, the tools we now regard as indispensable to the fight against AIDS, whether in China, Haiti, or the United States, were simply not available. This book is itself neither pessimistic nor optimistic. Rather, it affords any reader a basis from which to understand AIDS in China, and it is to be hoped that its pages will be read with care by policy and decision makers around the world.

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PART I

Background and Policy

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CHAPTER 1

Introduction

Social Policy and HIV/AIDS in China

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Joan Kaufman, Arthur Kleinman,

and Tony Saich

China's AIDS epidemic began in the early 1980s as a localized epidemic among needle-sharing intravenous drug users along the border with Myanmar in China's Yunnan Province. HIV infections are now found in all of China's 31 provinces, municipalities, and autonomous regions, with new infections growing at an estimated rate of 30% annually since 1999 and 44% in 2003 (Wu, Rou, and Cui 2004). The epidemic has been unfolding for at least a decade and accelerating for the last few years (Kaufman and Jing 2002), and a narrowing window of opportunity exists to avert a much larger epidemic.

Many of these infections still occur among injection drug users (IDUs) in provinces bordering Myanmar (Yunnan), Vietnam (Guangxi), and Central Asia (Xinjiang), but a separate epidemic among former paid blood donors (PBDs) in Henan and adjoining provinces (Anhui, Hubei, Hunan, Hebei, Shanxi, Shaanxi) in central China accounts for a large proportion of identified cases in recent years. Beyond these two groups of primary infections through tainted blood, a sexual epidemic has now begun. The sexual epidemic has the potential to become widespread for a number of reasons: (1) the size of China's young sexually active population; (2) changing sexual

behaviors and norms; (3) widespread prostitution; (4) massive internal migration; (5) low knowledge about transmission routes among the general population; (6) even lower perception of self-risk among the general population; and (7) an HIV/AIDS epidemic among men who have sex with men (MSM) that has only recently been recognized.

Since mid-2003 the national response has become significantly more aggressive and open, resulting in important policy and program initiatives. A State Council Working Group on AIDS (SCWGA) was established in early 2004, elevating the importance of the AIDS issue at the national level. In late 2003 a new national policy, the "Four Frees and One Care," announced the provision of free antiretroviral (ARV) drugs for all rural residents and poor people in cities, free counseling and testing services, free treatment for pregnant women and testing for their babies, free school fees for children affected by HIV and AIDS, and financial support for affected families (State Council AIDS Working Committee 2004). With this policy the government squarely recognized the need for treatment and care, not only as a means of improving the lives of people and functioning of communities affected by HIV and AIDS but also as a means of preventing further transmission of the disease. Following similar moves as a result of the SARS epidemic in 2003, the government has clearly stated its intention to hold all government officials accountable for their honesty in dealing with AIDS and for heightened attention and resources for infectious disease.

This overdue and more aggressive government AIDS response points to the mustering at last of the Communist Party's high-level political commitment so essential in the China context for mobilizing local-level action. These actions, and the greater transparency that has accompanied them, come from a new leadership that is defining itself as more willing to prioritize the poor and more concerned with both equity and social development. The last twenty years have witnessed remarkable economic growth and rising prosperity for many in China, but have also been characterized by widening economic and social disparity on a scale not seen since the founding of the People's Republic in 1949. Within this context the AIDS epidemic has unfolded, fueled by economic and social inequity (as elsewhere) and still largely confined to the rural poor.

The outbreak of SARS in the winter/spring of 2002–2003 alerted the Chinese government not only to the relative weakness of its rural medical system but also to the dangers of epidemic, life threatening infectious diseases that could undermine economic growth (Saich 2005). Subsequently, it is clear that more serious policy attention is being paid to the threat posed by

HIV/AIDS. This is best exemplified by Premier Wen Jiabao's visit to HIV/AIDS patients at Ditan Hospital, Beijing, on World AIDS Day 2003. Given the many pressing policy challenges that China's leaders face and the concentration of the epidemic in marginal areas with respect to economic growth, HIV/AIDS policy was placed on a back burner until recently.

In fact, many important national-level efforts by China's Ministry of Health (MOH) preceded these changes. An earlier (2001–2005) plan for AIDS Prevention and Control already included aggressive goals and innovative plans, but in the absence of strong national leadership, programs were difficult to implement at the provincial level and below. In 2002 China's Ministry of Health and the Expanded UN Theme Group on AIDS engaged in a joint planning effort for China's AIDS response and disseminated a "Joint Roadmap" with key recommendations for an accelerated AIDS response with the objective of harmonizing donor input to achieve them (China MOH and UN Theme Group 2003). This report is updated yearly.

The Chinese government estimates that in 2003 840,000 persons were infected with HIV/AIDS. Most are former blood plasma donors in the central provinces of Henan, Anhui, Hubei, Hunan, Hebei, Shanxi, and Shaanxi, or IDUs concentrated in border areas and cities (Yunnan, Xinjiang, Guangxi, Guangdong); 82% are under 40 years old, and 70% live in rural areas; moreover, infections among women are increasing, rising from 15.3% of infections between 1989–2003 to 39% in 2004 (State Council AIDS Working Committee 2004). Although total estimated infections still represent less than 1% of China's vast total population, if examined subregionally (e.g., Zhumadian Prefecture in Henan or Dehong Prefecture in Yunnan), they represent high numbers of infections in several heavily concentrated locations: central China, the long border with Myanmar and Vietnam, the northwestern border with Central Asia, the drug trafficking routes in China's west. These regions, where the epidemic unfolded during the 1990s, are seeing large numbers of AIDS patients requiring treatment and interventions to mitigate the social and economic devastation to families and communities. Even if China were able to keep new infection rates to 2–3%, similar to Thailand's success during the 1990s, it would still yield an infected population of 27.5 million by 2020. (Saich, Chapter 2).

The burden of providing services and AIDS treatment to these large numbers of infected in poorer regions is already straining local finance capacity and will only increase. Because HIV/AIDS is a "long wave disease," infections do not become evident for 8–10 years. More than 90% of China's HIV infected do not know they carry this deadly retrovirus (Yip, Chapter 9).

Given even the lowest estimates of infection today, many more will be requiring treatment in the decade to come. Current estimates predict that by 2020 China, India, Southeast and Central Asia will have the largest number of AIDS cases and the most rapidly increasing component of the epidemic. China has been singled out as one of five countries that will experience the most new infections by 2010, an estimated 10–15 million, because of the size of the population at risk and delays in early intervention (NIC 2002). The 89,000 Chinese who currently require treatment are approximately equal to the number now requiring treatment in Botswana, a country in sub-Saharan Africa with the world's highest infection rate, 37% of the adult population in 2003 (UNAIDS 2004). Of these, 19,456 Chinese had already begun treatment with ART by June 30, 2005, with a 8% drop-out rate and 10.2% death rate (Zhang et al., Chapter 5 in this volume), although most of these patients were in central China. While China should be lauded for its commitment to providing ART to its population, there is concern that the substandard regimens being used will lead to drug resistance with global impacts.

Sexual transmission of AIDS is accelerating in China. Urban injection drug users infect commercial sex workers who, with their clients, are becoming the bridge to the sexual spread of AIDS into the general population. Studies in Yunnan and Sichuan reveal that many sex workers also inject drugs (Yuan 2002). Sexually transmitted HIV infections are now increasing, especially in China's southern cities and provinces that border Hong Kong and the Taiwan Strait (Guangdong, Hainan, Fujian, Shenzhen), and are being amplified by high rates of sexually transmitted diseases, a facilitator of increased transmission (Galvin and Cohen 2004). Shen Jie (director of China's National Center for AIDS Prevention and Control) noted in February 2004 that over the next few years, heterosexual transmission will become the major route of AIDS spread in China (Agence France-Presse 2004). The rates of HIV infection among commercial sex workers and gay men in Shenzhen, bordering Hong Kong, are already reported to be 1–3% (*Science Daily* 2005), and official surveillance data revealed that the infection rate among commercial sex workers in Guangdong was already 3% in 2000 and 10% in Guangxi (UN Theme Group 2002). A typical "Asia epidemic model" described by Tim Brown (Brown and Peerapatanapokin 2004) with transmission moving from injection drug users to sex workers is underway in China and, if the model is correct, infections are also occurring among clients of sex workers and their sexual partners.

Set against this expanding HIV/AIDS epidemic are shortcomings in data collection and data use for planning a response. An effective epidemiological surveillance system exists in many of China's most heavily hit southwestern and western provinces, but population surveillance in other regions has been less comprehensive and provides little information on general population trends, although this is being improved. Of greater importance is the shortage of social, economic, and behavioral research in planning the China AIDS response. In other countries, such data have been crucial for understanding the potential for epidemic spread through individual risk behaviors and sexual networks, and to understand the social and economic determinants of these behaviors, such as poverty and social exclusion—all with an eye for designing effective intervention strategies. Other studies provide important information on access to care, health seeking, and health systems requirements for ensuring effective prevention and treatment programs. And studies outside the health sector on social and economic impacts and strategies for mitigating these impacts at the individual, household, and community levels have provided essential information for multi-sectoral relief programs for affected areas. Yet the limited research of this nature that has been done is not being taken up sufficiently and used for policy and program planning.

This volume contains a series of chapters aimed at elucidating some of the most serious data gaps in planning an AIDS response in China. The chapters were commissioned from leading Chinese and international AIDS researchers and experts personally involved in China's AIDS response. These chapters were presented at a Harvard University faculty seminar series during the 2003–2004 academic year, culminating in a May 2004 workshop on Social Policies and HIV/AIDS in China (the Fourth W. H. R. Rivers Symposium of the Department of Social Medicine, Harvard Medical School, and the Third Asia Public Policy Workshop of the Kennedy School of Government, Harvard University). The seminar series and workshop examined a number of issues in depth, including: (a) gaps in research and data currently used by the Chinese government to formulate national and provincial HIV/AIDS policies; (b) social impacts of China's HIV/AIDS epidemic in poor communities; (c) stigma and psycho-social impacts of AIDS and HIV risk behaviors; (d) issues related to newly announced Chinese government plans to make AIDS treatment available to those in need, including access to effective medicines produced by multinational pharmaceutical companies; (e) local governance and national and local

coordination of public policies with respect to HIV/AIDS in China; (f) health system capacity to respond to AIDS; (g) China's unfolding AIDS orphan situation and a critical review of current programs and policies; and (h) current foreign assistance to China to address HIV/AIDS and recommendations for the future, with special reference to new global efforts at donor harmonization at the country level.

New economic policies in China that prioritize the poor are trying to address some of the greater social and economic inequities that have accompanied twenty years of reform. Saich (Chapter 2) examines these inequities and new policy initiatives. China's health care spending, though average for other Asian countries, has a strong urban bias and reflects substantial personal spending on health care. Government contributions to rural health care provision were two-thirds of the national average, while that for urban China was almost twice the national average (Economics Research Department 2000, p. 25). Rural financing is focused on the county and township levels, whereas 60% of outpatient services are provided by village clinics or the private sector. Only 25% of rural health services are provided by the township hospitals, and only 14% at the county and the township level (World Bank 2002, p. 125). This distortion in government spending contrasts sharply with where most people infected with AIDS live and seek services: at the local level. This backdrop of insufficient public spending and subsidy for the rural health system will affect the ability of local government to carry out its AIDS response in poorer areas, and was bemoaned by China's Minister of Health in an unusually frank critique of the rural health system and its inequities (Project Team of the PRC 2005).

Along with attention to these inequities in health and new pro-poor policies and programs are a greatly intensified transparency and commitment by the Chinese government on AIDS. In 2003–2004 senior government officials have at last publicly spoken out about AIDS, announcing new national policies on free antiretroviral treatment to the poor and financial relief to AIDS-affected communities and individuals. A State Council Committee on AIDS has been strengthened and now includes provincial governors and strong central government leadership. Two sites have been chosen as demonstration districts for the AIDS response (Dehong Prefecture in Yunnan and Zhumadian Prefecture in Henan), with increased financing to serve as national and provincial models. A national program, China CARES (China Comprehensive AIDS Response), is working with 127 hard-hit counties nationally to make prevention, treatment, and care available to those in need.

In fact, as already noted, many important national-level efforts by China's Ministry of Health preceded these changes (see China MOH and UN Theme Group 2003, SCWGA and UN Theme Group 2004). As prevention and care programs are scaled up, the need for social science research and improved data will be essential. Kaufman and Meyers (Chapter 3) point out shortcomings in current data used to formulate AIDS policies and programs in China and propose a number of topics requiring better evidence, especially on risk behaviors and determinants. Though some research about risk behaviors and their determinants exists (Parish and Pan, Chapter 10; Yuan 2003; Zhang et al. 2001), this information is not routinely incorporated into AIDS policy and program planning. New models for the AIDS epidemic's spread in Asia highlight the important core role of injection drug users in the spread of the virus (Cohen 2004). An important policy development in China is the belated government endorsement and promotion of proven strategies to mitigate spread among illegal drug users, such as harm reduction and drug substitution (see Hammett et al., Chapter 11). In 2005 China moved rapidly forward with establishing 100 methadone maintenance sites for drug users. Hammett describes both the difficulties in promoting harm reduction (needle exchange programs) at the community level in a pilot project aimed at increasing knowledge about and practice of needle sharing by drug users, and the importance of understanding the attitudes and behaviors of all stakeholders when setting up such programs.

Sex workers are becoming the bridge that will introduce the HIV epidemic into the general population in China. The epidemic is also spreading among men who have sex with men—a population whose sexual networking and risk taking are not well investigated in China, and one that is unable to escape enormous stigma despite the fact that over 90% are married. Some epidemiologists note that Asia may be spared the Africa AIDS trajectories because sexual networking differs (Cohen 2004). In reality, little research on sexual networks has been undertaken in China, and what has been done suggests that there is greater partner exchange among some subgroups of the population than commonly believed (Zhang et al. 2001, Pan 2001), especially among the more educated and affluent. These studies highlight the fact that unaddressed risk factors for sexual transmission of HIV are already present and will drive the epidemic in the coming years. According to Pan, the wealthiest 5% of men are 33 times more likely to visit commercial sex workers than the poorest 40%. Managers, factory owners, and businessmen are 10 times more likely to have visited a commercial sex worker in the last week than urban manual workers, and 22 times more like

than male laborers in rural areas (Pan 2001). These men, recently dubbed "mobile men with money," are rarely exposed to workplace HIV education programs or other targeted prevention messages. A number of studies by social scientists has begun to map and outline the characteristics of paid sexual transactions in China, their volume, characteristics of clients, AIDS awareness, and condom use. It is crucial to understand sexual networking among commercial sex workers and their clients, men who have sex with men, youth, and other sexually active members of the population, in order to model the likely spread of the epidemic over time and to direct AIDS prevention messages to persons at risk. Parish and Pan (Chapter 10) provide perspectives on these issues from a large national survey, and their findings on sexual behavior both within and outside marriage have important implications for AIDS policy and programs. Ru (Chapter 12) points out that despite the large number of AIDS cases among youth (51.5% of infections among 20–29-year-olds), policy debates continue on the appropriateness of explicit school-based AIDS education about safe sexual practices and little education exists for out-of-school youth, including migrant youth, who are more at risk. An examination of data on youth sexual behavior clearly demonstrates that young people are engaging in unprotected sex and are at risk for HIV. Most researchers attribute Uganda's dramatic decline in HIV incidence in the last decade to explicit sex education for youth leading to delayed sexual debut and safer sexual practices (Nantulya and Green 2002).

China's AIDS orphans problem is unfolding on a massive scale in central China as a result of tainted plasma donation practices during the mid-1990s, with some estimates suggesting that there may be as many as 200,000 AIDS orphans in central China (*Time Magazine* 2003). Limited research has been undertaken on social and economic impacts, although the "Four Frees and One Care" policy begins to address issues such as orphans' school fees and care for the elderly whose children have died from AIDS. West and Wedgwood (Chapter 13) provide an overview of the orphan situation and its history in one community in Anhui Province in central China and describe local efforts, supported by an international NGO, to respond. They emphasize the importance of protecting the rights of children in policy and program planning for orphan care. These children, whether AIDS infected or not, are highly stigmatized, as are all identified HIV-positive persons in China. Thomas Cai (Chapter 8) articulates his own experience as an HIV-positive person in China and describes the needs of individual PLWAs in China and of the grass roots organizations that are emerging to represent them. Jun Jing

(Chapter 7) explores the isolation and suffering caused by AIDS stigma in personal interviews with AIDS sufferers in a hard hit county in Henan Province, where 20,000 persons are estimated to be infected from blood selling during the 1990s. This is a mode of infection particular to China that has devastated entire villages, creating a large number of AIDS victims who acquired HIV not through known high risk stigmatized behaviors such as drug use, prostitution, or homosexual activity, and who, for political reasons, have been given priority status for treatment by the government.

The government estimates that in 2003 840,000 people were living with HIV in China, of which 89,000 had progressed to AIDS and required immediate treatment (Zhang et al., Chapter 5). China has been awarded several large grants from the Global Fund to Fight AIDS, TB, and Malaria to carry out its China CARES program to provide voluntary counseling and testing (VCT), prevention, and treatment in seven provinces where people infected through paid blood donation during the 1990s are falling ill in large numbers. Recent grants are supporting prevention and treatment in border areas and among IDUs and commercial sex workers. At least 250,000 people may be infected among the estimated 1.5 million former plasma donors in central China alone. The Global Fund support is being used to scale up treatment from 3,000 to 40,000 AIDS patients in 127 counties by 2008; by mid-2005, 19, 456 persons had initiated therapy (Zhang et al., Chapter 5). The lessons learned from this ambitious scale-up in treatment will be applied elsewhere in China and the world. On the one hand, the rapid infrastructure building and rollout of treatment for so many is unparalleled in the world and provides many lessons about how to organize efficiently testing sites, drug logistic systems, and personnel training to manage the complicated drug regimens for so many patients. On the other hand, the rapid rollout of the program in 2003 without adequate patient counseling and follow-up led to higher than acceptable drop-out rates and criticism of the program. The large-scale rollout of the treatment program provides additional evidence (highlighted by China's SARS response) that, with political will and resources, much is possible in China, even despite the weakened health system (Kaufman 2005). Liu and Kaufman (Chapter 4) point out the deficiencies in China's rural health system after twenty years of privatization and decentralization. They also highlight the resulting reduced capacity of the health care system and its personnel to carry out the requirements of a comprehensive AIDS response that includes health education and outreach to vulnerable groups, as well as testing and treatment of those infected.

Because of this, China's AIDS prevention and treatment effort has been mainly carried out by its preventive health network, and by the Chinese Center for Disease Control and Prevention (China CDC) system at the national, provincial, and county level. As the CDC-based director of China's national treatment program, Zhang Fujie's chapter (Chapter 5) provides an overview of the government's plans and achievements for scaling up AIDS treatment to all who require it, noting the significant challenges that are being faced and approaches to resolving them. Ray Yip (Chapter 9) reviews the crucial challenge of setting up voluntary testing and counseling services in China and notes that focusing resources on testing and tracking the epidemic among the highest risk groups may be the most effective and cost-efficient mechanism of controlling spread. Jean-François Dechamp and Odilon Couzin (Chapter 6) discuss issues of global patents for AIDS drugs needed in Chinese, pointing out how global trade issues are adversely affecting access to appropriate drugs and the potential consequences this may have for drug compliance. These three chapters, taken together, provide a detailed look at the shortcomings of the current treatment effort. The global patent issues have played a critical role in determining which drugs China has made available for its national treatment program, which have been mainly off-patent drugs. These substandard, "one size fits all" regimens are more difficult to comply with because of toxicities and side effects, and even with the fairly high levels of compliance reported, are likely to lead to multi-drug-resistant HIV. There is already evidence of such drug resistance in cohorts in Wuhan, Hebei Province (Kaufman personal communication, 2005). Drug resistance will undermine not only China's longer-term efforts for lifetime treatment of HIV disease, but will have regional and global impact on the effectiveness of currently available drug therapies as well.

The chapters in this volume contain important recommendations for improving China's AIDS response. A key theme of many chapters is the crucial need to collect and incorporate more social science data into modeling the trajectory of China's epidemic and planning the response. Better surveillance and monitoring of epidemic trends—both in the general population and among vulnerable groups like youth, migrants, businessmen, and their spouses—is also needed to improve risk reduction efforts. A "policy research" group should be established to pull together studies and data from multiple sources to provide improved analysis and recommendations to policy makers. Because so few HIV-infected persons in China are aware of their infections, new approaches to population-based testing, beyond traditional VCT programs, are needed to identify more HIV-infected

persons and thus make a dent in disease transmission. Stigma and fear of discrimination continue to impede uptake of testing, counseling, and treatment, and despite national-level antidiscrimination legislation, local implementation is weak. These policies must be enforced and the public educated to encourage more persons to come forward for testing. And China's AIDS treatment program, laudable for its rapid rollout and for the number of patients now on ART, requires significant and urgent changes if global drug resistance is to be averted. Concern about patent protection and affordability of drug regimens has resulted in substandard drug regimens, insufficient compliance, and the probability that multi-drug-resistant HIV will emerge.

It is our hope that the topics discussed in this volume will provide useful information both to the government of China and to AIDS researchers worldwide who are working to support an effective and timely response to China's AIDS epidemic. As the epicenter of the epidemic shifts from Africa to Asia, China has the opportunity to benefit from the harsh lessons learned in Africa and keep its epidemic in check. The consequences of not doing so could be life or death for hundreds of thousands of Chinese citizens.

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CHAPTER 2

Social Policy Development in the Era of Economic Reform

✳

Tony Saich

The outbreak of severe acute respiratory syndrome (SARS) in winter/spring 2002–2003 provided a salutary warning to China's new leadership about how disease can have a severe economic impact. It also brought to public and government attention the weaknesses in China's public health system, particularly in the rural areas. This awareness was used by both domestic and international advocates to encourage China's leaders to pay more attention to the threat posed by the spread of HIV/AIDS. A major breakthrough occurred on World AIDS Day, December 1, 2003, when new Premier Wen Jiabao and Vice Premier Wu Yi, who had led the policy response to SARS, visited people living with HIV/AIDS at the Ditan Hospital in Beijing and announced the "Four Frees and One Care" policy (see Chapter 1 in this volume).[1] Since this time, several policy initiatives have been launched and China's most senior leaders have kept up the public visits.[2]

1. This refers to: (1) free antiretroviral (ARV) drugs for AIDS patients in rural areas and for those in financial difficulty in urban areas; (2) free voluntary counseling and testing; (3) free drugs for HIV-infected pregnant women to prevent mother-to-child transmission and testing of newborn babies; (4) free schooling for AIDS orphans; and (5) care and economic support to households of those living with HIV/AIDS.

2. Most notable was Premier Wen's visit during the Chinese New Year 2005 to HIV-positive people in Shengcai County and the "Sunshine Home" in Xincai County, Henan Province, places at the center of the government-led blood donor drives that led

It is clear that more serious policy attention is being paid to the threat posed by HIV/AIDS. Although infection rates are still low, cases have been reported in all provinces and trends are beginning to show that China stands on the edge of a spread from specific regions and communities to the population at large. The central government seems to have recognized this, for an institutional framework for dealing with HIV/AIDS is being set up and various policy initiatives, described in other chapters, are being promoted. However, China has found it very difficult in the past to adopt the kind of multi-sectoral responses that would be necessary to deal with HIV/AIDS and to allow a greater role for civic organization. In addition, social trends such as large numbers of migrants and the more relaxed social mores will make monitoring and evaluation more difficult. Last but not least, it remains to be seen whether there are sufficient incentives for local governments to act responsibly.

This chapter analyzes the social policy evolution under the period of economic reform, to provide a broader context for understanding the health care challenges and conditions under which HIV/AIDS is spreading. First I review the tremendous progress that has been made in social policy but highlight how progress has slowed over time. Second, I analyze the reasons for the differential trend of progress, including the structure of incentives for local governments. Third, I make a number of policy suggestions and also draw a number of lessons from China's experience of dealing with SARS.

Investment and Progress in Social Policy Under Reform

Although China's achievements for social development have been impressive, especially for a low-income country, progress slowed in the 1990s and new challenges arose as a result of reforms. As a result, China's new leadership has focused on achieving balanced growth that is more equitable in distribution and that will produce a comfortable (*xiaokang*) society by the year 2020. The new leaders have eschewed the almost exclusive focus on gross domestic product (GDP) growth rates that dominated much of the 1990s and are trying to develop a more comprehensive framework for development. They hope this approach will address the concerns of (1) those who have not benefited so much from reforms (many farmers and grain

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resulted in to significant levels of infection because of the unsanitary conditions for collection.

producers), (2) new groups that straddle the now artificial urban-rural divide (migrant families), and (3) the new urban poor who are the product of reforms (pensioners and laid-off state enterprise workers).

Standards of living have been raised for the vast majority, and for those able to afford it there is a wider range of education and health providers to choose from. However, many remain who cannot afford the higher costs for social services, and for the absolute poor there may be no service provider available. Access to services is more dependent on income now than in the past, and this has both created new and exacerbated old inequalities. In particular, the disparity of welfare provision between urban and rural China has increased, and within urban areas the old cradle-to-grave social compact for the privileged working class has been abandoned. In rural areas the impact has been particularly severe.

Institutional reforms, combined with broader budget constraints, have caused the dismantling of state collective agencies that carried much of the welfare burden in rural and urban China, and the government is in the process of building social safety net programs. However, this needs to be placed in context. In recent decades, China has ranked well in terms of the human development index (HDI) adopted by the United Nations Development Program (UNDP) as a composite measure of social development.[3] China's HDI rose from 0.248 in 1960 to 0.566 in 1990 and 0.721 in 2001. However, in comparison with other countries, China's HDI ranking declined in the 1990s, from 87 in 1999 to 104 in 2001. The difference between China's HDI and gross national product (GNP) also dwindled rapidly in the 1990s, with rapid economic growth and increased per capita income. In 1993, China's HDI rank was 41 places above its GNP per capita rank, but by 2001 China's rank was –2 (UNDP 1993 and 2003). In terms of attaining the United Nations' Millennium Development Goals, China has performed well. It is on track to achieve most of the targets by 2015, with the exceptions of HIV/AIDS control, promoting gender equality, and providing safe drinking water for the rural population (UNDP 2004).

Although China's overall HDI ranking is comparable to a high/middle level of human development, this covers significant regional variation. Five of the western provinces had an HDI ranging from 0.650 to 0.5921, putting

3. The HDI composite index is based on three indicators: (1) longevity, as measured by life expectancy at birth; (2) educational attainment, calculated from adult literacy (two-thirds weighting) and secondary and tertiary enrollment ratio (one-third weight); and (3) standard of living, calculated by GDP per capita.

them in the middle development category, and even Tibet, with the lowest ranking (0.5921), is above the cutoff for low development (0.5). By contrast, three of the major municipalities (Beijing, Shanghai, and Tianjin) have an HDI over 0.800, placing them in the high level of development (Hu Angang 2004, p. 8, and UNDP 2004, p. 3). It is interesting to note that regional disparity in the HDI index is lower than that for per capita income, also attesting to relatively good social development. However, two of the worst-affected provinces in terms of HIV/AIDS infections are ones that have lower HDI levels.

Reforms have affected the nature of poverty in China. During the Mao years the strict household registration system separated rural from urban China, and the bloated workforce in the state-owned sector with relatively high welfare provision kept absolute urban poverty to negligible levels. Reform has brought migration of anywhere between 80 and 120 million people that has broken down this divide. These migrant workers are fuelling the urban economic boom while remitting significant amounts of income to their rural homes. Chinese policy is to push ahead with urbanization and to have 800 million citizens living in cities and towns by 2020. In the cities, however, harder budget constraints have caused large numbers to be laid off in the state-owned sector. Official statistics show that employment in the sector and collectively owned enterprises fell by 31 million and 19 million, respectively, from 1996 to the end of 2002 (SSB 2003, p. 126), while Hu Angang calculates that 55 million workers were laid off from 1995 to mid-2002 (quoted in Solinger 2003, p. 67). Not surprisingly the real unemployment rate is probably three times the official rate of 4.3% (end 2003). This puts a greater strain on welfare budgets and creates newly disadvantaged people. There were some 19.63 million urban poor at the end of 2002 (Hong 2003), and the number of urban residents who received minimum subsistence support was 21.4 million in March 2003.

While the urban poor are increasing, China's spectacular success in reducing those in absolute poverty in rural China has slowed. The remaining 28 million (according to official statistics) will not be pulled out of poverty by relying on higher GDP growth alone. China's official figures (using $0.66 per day) underestimate the real level of rural poverty. Using the norm of $1 per day in purchasing power parity and the preferred consumption norm, the Asian Development Bank suggests that China would have about 230 million poor residents, some 18.5% of the population (Asian Development Bank 2001). If one applies a norm of $2 per day, this would cover 53.7% of

total population. This puts China roughly on a par with Indonesia for the $2 per day indicator (17.2% and 55.4%, respectively), and considerably better off than India (34.7% and 79.9%, respectively; World Bank 2003, p. 59). Such statistics reveal the fact that, despite tremendous progress, China confronts major policy challenges. First, a significant group of rural poor have not responded to policy measures, market openings, and the benefits of "trickle down" economics. Second, a very large group is vulnerable to economic downturn and liable to recidivism. Third, a smaller but rising number of urban poor is the product rather than the beneficiary of reform. This argues for better public policy based on a better understanding of who are poor, and why.

The slowing progress is clearly seen with respect to health care indicators. According to the *World Health Report: Report of the Director-General 2000*, out of 191 countries, China ranked 188 in terms of fairness in financial contributions, 144 for the overall performance of the health system, and 139 in terms of health care expenditure per capita in international dollars. Whereas China ranked above most African countries, it is ranked below other large developing countries such as India, Bangladesh, and Indonesia. In terms of health quality, China ranked better (61), but this may be because of the residual impact of the old collective medical system (WHO 2001, p. 152).

Government spending on welfare has been low in international terms, even for a middle-/low-income country. Although investment has grown strongly in absolute terms (annual budgetary increases of 14.2%), this has been below the growth in total government revenue (17.5%), indicating that social investment has not kept pace with overall increases in government revenue (UNDP 2004, p. 4). The structure of spending has changed, with individuals and non-state agencies contributing more.

Government spending on health is roughly comparable to other Asian middle-income countries. As a percentage of GDP it was 1.9% in 2000, down from 2.0% in 1990. This is better than most other Asian countries, with the exceptions of the fast-growing East Asian economies and Malaysia (2.1). Despite the relatively comparable spending on health, China's indicators for under-five infant mortality are worse. The rate for China is 39 deaths per thousand live births, while it is 8 for Malaysia it is 8, 28 for Thailand, and 29 for the Philippines (see Table 2.1).

Two other features of China's social policy spending should be mentioned. First, spending programs have a strong urban bias, and second, personal spending on health has been rising sharply. China's total health

Table 2.1
Health Indicators for Selected Countries

Country	Under-five infant mortality/ thousand, 2000	Government health spending as percentage of GDP, 2000
China	39	1.9%
Malaysia	8	2.1
Philippines	29	1.5
Singapore	4	1.3
South Korea	5	2.6
Thailand	28	2.1

Source: UNDP (2003), pp. 208, 255–56, and 267–68.

expenditure in 2001 had risen to 5.4% of GDP, but the growth was largely attributable to the strong increase in personal spending. Between 1991 and 2000, accumulated government spending on the health budget for rural areas was only 15.9% of total government spending (69 billion *yuan*), and though health spending increased by 50.7 billion *yuan* over this period, the increase for rural areas was only 6.3 billion, a 12.7% increase. Rural government spending fell to 6.59% from 12.54% of total spending (Han 2004, p. 18). In 1998, per capita health expenditure for rural China was 193.91 *yuan* (up from 38.81 in 1990), while that for urban China was 595.27 *yuan*. Rural spending for health care was two-thirds of the national average, while that for urban China was almost twice the national average (Economic Research Department 2000, p. 25).[4] Moreover, effectiveness is reduced as financing is focused on the county and township levels while 60% of outpatient services are provided by village clinics or the private sector. Only 25% of these services are provided by the township hospitals, and only 14% at the county and the township level (World Bank 2002, p. 125).

Government budgetary expenditure stood at 15.5% in 2001, down from 25% in 1990 (SSB 2003; Gu 2004, pp. 1–2). However, the formal budgetary allocation alone underestimates government spending as a percentage of total health care expenditure. Chinese statistics include the category "social spending," which contains a large component of state-owned enterprise (SOE) contributions to health insurance and related health spending. This

4. From 1991 to 2000, the rural share of total health care expenditures fell from 34.9% to 22.5% (Li and Zhu 2004, p.10)

amounts to a further 20–25% depending on how one calculates it. Thus, the World Bank calculates government expenditure on health at 36.6% (1997–2000) of total health expenditure. This is much higher than India (17.8%) but is generally lower in international terms. The Malaysian government allocates 58.8% and the Philippines 45.7%, while the average for lower-middle-income countries is 49.4% (World Bank 2003, pp. 92–94).

Through the 1990s, spending by companies dropped from 37.9% to 24%, while personal spending increased from 37.9% to 60.5% of the total health care expenditures (Gu 2004, p. 2). In the rural areas we see a particularly dramatic shift to farmers assuming greater responsibility. In 1991, farmers' input to health care spending was 80.73%, but this rose to 90.15% in 2000 (Han 2004, p. 18). Annual medical expenses per capita rose from between 2–3% of total income in 1990 to 8–11% of income in poor areas in 1998, and this is continuing to rise (Liu, Zhen, and Wen 2000).

Over the reform period, health costs have been rising. The unit cost of an outpatient visit at a county hospital in 1998 was roughly four times higher than the cost in 1993. At the township level the cost was more than twice as high (Ministry of Public Health data).[5] Yet we see government support for hospitals declining as a percentage of revenue as health institutions are required to cover more of their own basic expenses. In 2002, government funding covered only 10.2% of the costs of government-run hospitals, down from 15% in 2001, while 44.17% came from user fees and 43.04% came from drug sales.

The consequences of these trends are becoming increasingly visible. When combined with the increasing income and regional inequality, we see a very varied picture of access to and quality of health provision. In 1998 the Shanghai government spent 90 *yuan* per capita on health care, while in poorer Henan, the government only spent 8.5 *yuan*. The difference in hospital beds per thousand between the richest and the poorest regions rose from 3.1 in 1982 to 4.2 in 2001 (Li and Zhu 2004, p. 10). In fact, though the rural share of the country's hospital beds increased from 40% in 1965 to 60% in 1975, during the reforms (1982–2001) the total number of rural hospital beds dropped from 1.22 to 1.02 million. The number in urban China rose from 0.83 to 1.96 million. Between 1975 and 2001, the number of rural doctors fell from 1.5 million to around 1 million, while the number of nurses dropped from 3.28 million to 0.27 million (Li and Zhu 2004, p. 11). Thus, in

5. Wang Shaoguang (2003) calculates that between 1989 and 2001, the average outpatient charge increased 965%, while the average hospitalization charged rose 998%.

relatively wealthy Zhejiang Province, infant mortality per thousand live births was around 20, whereas in poor Guizhou it was 60. This mirrors the findings in a study of health conditions in 30 poor counties that found an infant mortality rate of 52.3 per thousand live births compared to a national overage for rural areas of 21.5. The rate of maternal death during childbirth was 216.8 per hundred thousand, as compared to a rural average of 114.9 (Meng and Hu 2000, p. 67). Both the infant mortality rate and maternal mortality are closely correlated with the use of prenatal care and attended safe delivery, two preventive services that have been adversely affected by the privatization of health care in rural China (Saich and Kaufman 2005).

With the disbandment of the rural collective institutions and with state-owned enterprises (SOEs) under increasing financial pressure, it is not surprising medical insurance coverage has declined. Coverage through the rural collective medical system dropped from almost 80% in 1979 to only 2% in 1987, before improving to 6.57% in 1997 (*Zhongguo nongcun* 2000, p. 21). A survey of 3,697 urban and rural households conducted in fall 2003 (Horizon 2003) found that nationwide 75.4% of individuals did not have any medical insurance: 88.3% in rural areas had none, and a lower 45.7% in major cities had none (see Table 2.2). Equally alarming is the fact that 72.8% had no insurance for catastrophic illness and were not intending to purchase any. As a result, we see more people not seeking medical help when they need it. According to the survey, those in major cities dedicated 10.3% of household income to health care costs (9.6% for those in rural China). This might not sound like much, but many families are going without the medical help they need. The survey revealed that for 25.1% of respondents cost prevented them from visiting a doctor, with 15.3% unable to stay in hospital when needed (these figures were 25.1% and 17.2%, respectively, for farmers). Other surveys have revealed an even more problematic situation. The Ministry of Public Health has calculated that 37% of farmers who should have seen a doctor did not do so, while 65% of patients who should have been hospitalized were not treated because of inability to pay (see UNDP and ILO 2002, pp. 21–22). Medical costs are closely associated with poverty. A Ministry of Public Health survey revealed that among the rural poor 22% attributed their poverty to unmet medical needs, while another study suggests that 30–40% of the urban poor are in poverty because of unmet medical problems (Li and Zhu 2004, p. 16; Qiu 2003).

Such statistics indicate the need for a more concerted policy effort in the next phase of development if China wants to maintain its former impressive

Table 2.2
Percentage of Residents of Rural and Urban Households in China with Some Medical Insurance (by type of location)

	City		Town		Village	
Coverage	No.	%	No.	%	No.	%
Some medical insurance	507	54.3%	176	33.2%	292	11.7%
No medical insurance	427	45.7	354	66.8	2210	88.3
TOTAL	934	100.0	530	100.0	2502	100.0

Source: Horizon Survey (2003), p. 91.

achievements in social policy. The trends have pushed the new leadership to focus on a more balanced and equitable growth strategy and to tackle major health challenges, such as those presented by HIV/AIDS. Premier Wen Jiabao has proposed a number of measures to improve the lot of migrant workers, to raise farmers' incomes, and to redress the most blatant inequalities in the system. Measures such as the "Four Frees and One Care" policy for dealing with HIV/AIDS sufferers also form part of this approach. Importantly, the government has established a set of 16 indicators by which it will measure its progress toward the target of building a comfortable society (*xiaokang shehui*) by 2020 (see Table 2.3). These indicators are broader than the usual economic indicators that China uses to measure its progress. Thus, for example, life expectancy is expected to rise from 71.8 years to 74, and the number of doctors per thousand people from 1.6 to 2.5. Whether these targets can be attained is open to debate, but such indicators are important in alerting officials to the fact that their future work performance may not be judged solely on the basis of GDP growth, the ability to maintain social order, and the ability to keep population growth under control.

Factors Promoting Change in Social Welfare Delivery

The reforms and the promotion of market usage in the delivery of social welfare services have changed significantly where people seek service and the kind of service that they can expect. This has brought in new actors and

Table 2.3
Xiaokang ("Comfortable Society") Indicators and Targets for 2002, 2010, 2020

Indicator	2002	2010	2020
GDP (trillion *yuan*)			
Low	1.024	1.764	3.311
High	—	1.838	3.616
Population (in billions)	1.285	1.38	1.48
GDP per capita			
In RMB	8000	12800–13320	22370–24430
In US dollars (1:8.28)	962	1546–1610	2790–2950
Percentage of urban population	39.1	48.0	60.0
Percentage of workforce in third sector	27.7	38.0	51.0
Education spending as percentage of GDP	2.3	4.0	4.5
University students as percentage of age group	7.8	12.0	20.0
Average life expectancy	71.8	73	74
Doctors per thousand people	1.6	2.0	2.5
Urban disposal income (RMB)	7703	12300	22000
Rural net income (RMB)	2476	3830	6860
Urban per capita living space (m^2)	20.8	24.5	30
People's average electricity consumption (KWh)	140	330	712
Engels coefficient (%)	43	33	30
Urban-rural income gap	3.1:1	3.2:1	3.2:1
Poverty-wealth gap (Gini coefficient)	0.458	0.45	0.40

Source: Saich

has spurred discussion about the changing relationships among the state, the market, and civil society. State capacity to deliver social welfare has declined, and among the many factors contributing to this, changes in the financial system have been the most important. Three major factors have affected the state's financial capacity to provide adequate welfare support. First, the diversification of the economy and the abandonment of collective structures in the countryside have diminished state capacity to raise adequate revenue. Second, de facto financial decentralization has redistributed incentives among the different levels of the government bureaucracy and reduced their respective capacities. Third, tightening financial constraints have caused SOEs to shift their former welfare roles to underfunded local governments.

Before the economic reforms began, it was relatively easy for the central state to extract revenue from the communes in the countryside and the SOEs in the cities to provide rudimentary welfare coverage. Most agricultural and industrial production was sold at state-fixed prices, while the banking sector simply acted as the cashier for the state's development priorities. Many collective organizations in the countryside and SOEs in the urban areas provided basic medical facilities that were considered impressive given China's level of economic development. Twenty years later, the situation has changed dramatically, with major consequences for the role of the state and its fiscal capacity. With state banks required to think more commercially, they have focused less on investment in public goods and more on projects that will generate profits. Insofar as most bank lending still goes to SOEs, there is an indirect impact on the provision of social welfare, since SOEs traditionally have been major urban providers of education, health, and housing. This has exacerbated inequalities not only between urban and rural China but also between workers in affluent well-connected enterprises and those in less well-endowed ones.

The lack of an effective tax system, even after the 1993–1994 reforms, has left the central state with too little revenue to cover essential public goods or to deal successfully with redistributive issues. The government, lacking sufficient tax revenue, has relied on extracting resources from its citizens through mobilization of their bank deposits, and when invested these deposits are not used to create public goods. The financial reforms have meant that the government has in effect taken public funds (household deposits) and converted them into private goods (assets in enterprises). This has become increasingly the case as many SOEs have begun to drop social welfare obligations either by privatizing them or by transferring responsibility for their provision to local governments. The problem is compounded by the state's difficulty in raising revenue from the rapidly growing non-state sector of the economy (now 75% of industrial output) and its continued reliance on large SOEs for its revenue base. This continued reliance on SOEs at all levels of government encourages investment in enterprise development and perpetuates the bias against investment in social development.

The decline in central state revenue has been a major cause of the drop in the provision of public goods and services in poor areas, but even more important has been the shifting balance between central and local budgetary streams and the incentive system for local officials. Central state revenues as a percentage of GDP dropped from 36% in 1978 to a low of 10.7% in 1995 before reviving to 18% in 2002. This has severely restricted the central state's

redistributive capacity and has meant that local governments have been largely left to their own devices to raise the necessary funds for development priorities. The relative decline in the central state's fiscal capacity to guide development has created pressures at all levels and in all Chinese government agencies to meet recurrent costs from locally generated revenues. This means that local resources and power structures increasingly determine political outcomes. Within the same province, and even in adjacent counties, one can see radically different socio-political outcomes deriving from the reforms.

The increase in locally controlled revenues from a variety of sources has more or less matched the decline in central revenue (see Saich 2002, pp. 78–81). To try to restore central capacity, a new tax system was introduced in 1994, both to raise the overall percentage of budgetary revenue and to increase the center's share to around 60% of collected revenues. This would allow 10% to be used to meet redistributive and related goals. Reforms have gone partway to meeting these objectives. Total budgetary revenue revived to 18% of GDP in 2002, with the center taking 55%, up from 22% in 1993 (SSB 2003). However, the tax reform has had unexpected consequences. For example, the value-added tax (VAT) is split 75–25 between the center and the localities. Prior to the reform, Guizhou Province had derived fully 45% of its revenue from liquor and tobacco. Much of this revenue now accrues to the center.

Yet it is local government that has the main responsibility for spending on social welfare. One inheritance of the Soviet fiscal system has been that the local government has always provided the bulk of the basic public goods, with very few exceptions. In addition, the Cultural Revolution reinforced the notion that each local authority should minimize "dependence" on support from higher levels (Wong 1997, p. 11). This has contributed to the large variation of service provision across different administrative jurisdictions in China. The local level of government retains the major responsibility for financing infrastructure and providing social welfare.

Apart from nationally designated poor counties that receive transfers from the center or the province, localities are by and large on their own to raise funds. This concern with revenue generation is exacerbated by the fact that, despite fiscal decentralization, the central government has retained control over the policy agenda. While the accounts of localities avoiding or deflecting central policy are many, the center still sets many tasks that must be carried out and imposes burdens to be met. Funding for health is overwhelmingly a responsibility of lower-level governments. An Asian

Development Bank survey of five counties in Guizhou and Shandong revealed that between 40 and 45% of the total outlays went to social services, by far the largest category (Wong 1997, pp. 170–173). Cities at the prefecture and county levels cover all expenditures on unemployment insurance, social security, and welfare, whereas in most other countries the central government will cover social security and welfare, with education and health shared between the localities and the center.

The expenditure responsibilities for townships are similar, although they often have a weaker financial base and carry the heaviest load for social spending. The county and the township together account for 70% of budgetary expenditures for education, and 55–60% for health (World Bank 2002, pp. 34, 94, and 111). In Xiangyang County, Hebei, budgetary contributions to education finance amount to 40.6% of the total expenditure. Of the government contribution, the township provides 84.6% and the county 15.2%; the remainder comes from the province (Han 2003, p. 12). In fact, before 1984 the equivalent of the township did not raise revenue independently. Villages, which do not form a formal level of government, have significant expenditure responsibilities even though they have no independent fiscal powers. They have inherited many of the obligations of the old collective economy, such as salary, care for the aged, and even support for health and education (Wong 1997, p. 174). This drives village and township leadership to seek various off-budget revenues from user fees and other unsanctioned levies to support these activities.

This need to generate revenue lies behind the spread of HIV/AIDS through blood and blood products, especially in Henan. The practice was quite extensive, and in 1995, 23 provinces, municipalities, or autonomous regions reported HIV infections among blood sellers, accounting for 44.5% of reported cases that year (*SARS and AIDS*, n.d., p. 12). To raise revenues, local governments had been organizing plasma donors and had been mixing the blood samples and with insufficient oversight and control, so that the disease was spread to both the donors and the public at large. Official accounts mention 2,046 AIDS orphans in Henan (*China Daily*, February 14–15, 2004), while unofficial guesstimates talk of as many as 200,000 (*Time Magazine* 2003). HIV infection among the plasma sellers was as high as 10–20%, and in some regions it was as high as 80% (*SARS and AIDS*, n.d., p. 12). The central government was certainly aware of the problem, and as early as 1994 the Ministry of Public Health called for the need to educate people to prevent blood-transmitted diseases. However, it had little capacity

to rein in the activities of local governments that were driven by revenue-generating needs.

This need is common. For example, in three counties surveyed by the Development Research Center of the State Council (Han 2003), expenditures exceeded revenue, and this increased the need to raise even more off-budget revenue. Nationwide, extrabudgetary funds may total 20% of GDP, while in the three counties surveyed they ranged from 30% of total income (Xianyang, Hebei) to 69% (Taihe, Jiangxi).

The disincentive to invest in social development is exacerbated by the functioning of the political contract system and the performance contracts (*gangwei mubiao zerenshu*) that local governments and officials have to sign (Saich 2002, pp. 92–96). The hard targets set in these agreements, with the exception of family planning and maintaining social stability, are primarily economic and favor concentration on short-term revenue maximization rather than long-term comprehensive development.

Combined with the rising income inequality, the unequal distribution of resources across local authorities and the incentives for spending priorities account for the huge variation in the provision of public goods and services. Access to health and education services was still widely available in the 1980s but became more dependent on household incomes in the 1990s (World Bank 1997, p. 23). For example, in 1998, 22.2% of those in high-income areas were covered by cooperative medical facilities, but only 1–3% in poorer areas was covered (Zhu 2000, pp. 41–43). As the World Bank concluded in its 1996 report, "The downturn in China's health performance relative to its income level coincided with agricultural reform that reduced the ability of the village to tax the peasants" (World Bank 1996, p. 127).

Policy Solutions and Alternatives for Providing Social Welfare

It will be impossible and fiscally irresponsible for China to extend the kind of integrated social welfare that used to exist for the urban elite to the new urban population, let alone to those in the countryside. As Wong and Heady (1997, p. 324) have pointed out, the "concept of a self-reliant rural public sector is no longer workable." This is a dilemma that will require new policy approaches to resolve. Progressive urbanization will help by moving citizens off the land and into better-paying jobs through which certain basic welfare guarantees can be developed. For those who will remain outside of these developing sectors, either in rural China or as part of the new urban poor, China will have to effectively implement various programs of minimum

support to ensure that they do not fall below an acceptable minimum level of poverty. Insurance against catastrophic illness is an important case in point.

Policy change falls into three categories. First, certain fiscal and administrative reforms would be beneficial. Second, the state needs to understand better citizen demands for social welfare rather than relying exclusively on its the current supply-side approach. Third, this will mean fundamentally rethinking the relationship between government, the market, and civil society in providing social welfare. Some of these suggestions will improve the general framework for social policy provision, while others can have a more direct impact on dealing with HIV/AIDS. In addition to these there are certain lessons that can be drawn from the way the Chinese leadership dealt with SARS.

With respect to fiscal policy, several adjustments should be made. One of the central government's most significant policy challenges is how to reconfigure an industrial policy and associated fiscal policy that is premised on support and bailout of the state-owned sector. Concentrating precious credit on SOEs has led to relative neglect of the more productive private sector and insufficient investment in the social sector. Although there are strong political and ideological reasons for this bias, the SOE sector is a net destroyer of assets, while the rapidly growing and more productive non-state sector is penalized and starved of the necessary capital for development.

Policy to date has reflected the political bias of the most powerful, vociferous, and visible groups. This has meant that policy has focused on the needs of state officials, has been receptive to the policy prescription of its (urban) professional classes, and has sought to soften the blows of the market transition for the urban proletariat. By contrast, it has left the rural poor, the migrants, and the non-state sector employees to their own collective or individual devices, and they have remained politically marginalized. If the Chinese Communist Party (CCP) wishes to maintain social stability over the long term, this may not be the best road to follow, and the dangers in such a course have been recognized by the new leadership.

The dismantling of irrational urban subsidies has provided a good starting point, but too many subsidies are still misdirected. A key component of the Maoist development strategy was to provide an intricate complex of subsidies to urban workers to offset their low wages. Subsides covered clothing, food, education, housing, medical care, and so forth, but they have become too expensive to maintain. In 1988 urban residents received approximately 39% of their per capita disposable income from subsidies net

of taxes. By contrast, those in rural China paid 2% of their per capita income in net taxes (Khan et al. 1992). Urban subsidies have dropped drastically in recent years and stood at around 22% in 1995 (UNDP 1998, p. 54), but price subsidies that benefited urban residents still amounted to 104.2 billion *yuan* in 2000, up from 36.5 billion in 1995 (SSB 2001, p. 283). Further rationalization of these urban subsidies would mark a more realistic starting point than trying to extend them to new social categories.

One clear case for government engagement is rural health care, especially in poor regions. Although privatization of medical insurance might be feasible for the wealthier, and most may well find means to deal with curative procedures, rural health care provision, especially preventive care, appears to be a clear case in which the "public goods" argument applies. This will become all the more important should HIV/AIDS spread more broadly in the Chinese countryside. There has been a marked growth in private medical provision and a shift away from preventive medical care to fee-for-service care, with local governments in poor areas less able to provide adequate support. This increases the financial burden on the rural household that, in the absence of sufficient state financing, must provide the necessary social support. In this situation, many rural residents are having to choose between poor-quality private medical care and better-quality but more expensive public medical care.[6]

The basic problem of health care delivery derives from changes of the ownership structure of village networks and the nature of the incentive system that has arisen from these changes (UNDP 1998, pp. 36, 38). In 1981, health care facilities were informed that user charges would have to be used to cover recurrent costs, with the exception of staff costs. By the mid-1980s preventive medical care facilities were also charging users on a fee-for-service basis (Hu and Jiang 1998, p. 192). This caused the drop in participation in the cooperative medical schemes and the shifting of health cost burdens to the household. We can see this in the statistics for health spending in the rural areas. In 1991, actual expenditures were 258 million *yuan*, of which 229 million were fiscal expenditures. By the year 2000, actual expenditures were 1715 million *yuan*, but fiscal expenditure had actually dropped to 184 million (Gu 2004, p. 7). These trends resulted in an initial decline in immunization rates that required remedial intervention. Immu-

6. One household survey noted that for one-third of those asked, their last visit to a doctor was to a private clinic.

Table 2.4
Infection Rates for Selected Contagious Diseases
(per 100,000)

Disease	1997	2001
Viral hepatitis	32.73	44.06
Gonorrhea	12.87	65.15
Syphilis	1.68	4.56
HIV/AIDS	0.01	0.03

Source: Li and Zhu (2004), p. 14.

nization coverage dropped to 60% in urban areas and 33% in the countryside (Anson and Sun 2005, p. 69).[7] This drop is also seen in the slowing progress of dealing with contagious diseases, a worrying sign with HIV/AIDS beginning to spread to the population at large (see Table 2.4).

The central government needs to tighten the regulatory framework to ensure that guidelines on health are followed and that in poor areas better provision is provided at central government expense. The central government would be well served to be the provider and supporter of public health, ensuring more equitable access, rather than focusing its efforts on subsidizing the salaries of those in the health system (on these issues, see Saich and Kaufman 2005).[8] In fact, one recent Chinese study suggests that for wealthier rural areas with increasingly commoditized economies, social medical insurance will become the norm. For the poor areas, it will be necessary for the central government to increase its transfer payments to provide medical support for those unable to afford it. For the middle areas, it is suggested that the cooperative medical schemes be revived with seed funds from government and with the government providing a financial subsidy for basic public health services (Li Weiping 2002).

The central government has now earmarked certain funds for public health priorities, including HIV/AIDS. In 2004 central government investment in HIV/AIDS work was 810 million *yuan*, up from 390 million *yuan* (SCWGA and UN Theme Group 2004, p. ii). This will cover activities such

7. This trend was reversed by targeting funding and the use of simple medical insurance. As a result, measles immunization increased from 78% in 1985 to around 95% at the end of the 1990s (Anson and Sun 2005, p. 70).

8. Recently, subsidies to urban hospitals have amounted to only 7% of total income, but this actually accounts for 30% of total payroll expenditures (Li and Zhu 2004, p. 12).

as the free antiretroviral therapy (ART) for the rural and urban poor patients and the continual expansion of the China CARES program. However, there needs to be better oversight, to ensure both that local governments spend the funds responsibly, as intended, and that incentives are in place to ensure that local governments match funds where necessary.

A better focus for central government subsidies should be combined with restructuring local government finance (for thoughtful analysis, see Wong, Heady, and Woo 1995; Wong 1997). As in many other countries, we have seen the de facto transfer of new responsibilities to lower-level authorities without the complimentary transfer of the necessary financial resources to carry out these functions. In China this has been exacerbated by a declining capacity to tax the rural sector. As Wong and Heady suggest (1997, p. 325), rural finance should be unified at one level—preferably the county level, since in most of China the township is too small to be redistributive. This would make planning more effective and allow the central authorities to provide a sufficient revenue base to carry out those functions that they deem essential. In the mid-1990s, more than half of the 2,000 counties in China could not meet their expenditure requirements from the revenues they derived (West and Wong 1997, p. 285). The three counties surveyed by the Development Research Center of the State Council had debts in the year 2000 ranging from 47.64 million to 79.4 million *yuan* (Han 2003). The situation is even worse at the township level. One survey of 81 counties nationwide revealed that the average debt of each township was 10.9 million *yuan* within a lower budget figure, bringing them to the brink of bankruptcy (Liu Xitang 2000, p. 74).

A system that better integrated the capacity to raise and distribute finances would be beneficial. This would provide the central state with enhanced capacity to ensure that local authorities have sufficient funds to carry out those tasks that are mandated for them by higher levels. A particular problem arises at the village level, which has to carry out many residual and mandated obligations but cannot formally raise revenues. Villages need to be provided with adequate budgets to prevent further increases in charging illegal fees and levying fines on farmers. It would also help if extrabudgetary and off-budget revenues could be incorporated in a unified transparent budget, with a realignment of expenditure and revenue assignments for the various levels of government. One option would be to allow local governments to retain a higher percentage of specific taxes collected to cover education, health, and public infrastructure.

The overstaffing of local governments, resulting in higher administrative expenses, further undermines state capacity to provide adequate welfare. Many localities have difficulty not only in paying staff costs but also in meeting the wage bills for teachers and medical workers. Wages, entertainment allowances, and transportation for local officials comprise the overwhelming majority of expenditures for local authorities. Indeed, some reformers have suggested that local unrest could best be tackled by drastically cutting the number of local officials who rely on illegal fees and levies to cover their salaries and benefits. One national survey conducted in the late 1990s showed that, in a medium-sized county with a population of around 0.5 million and 5,000 administrative staff, 60% of this staff had their salaries covered by financial revenues,[9] 30% had to raise their salaries themselves, and 10% found their salaries by fining farmers directly. The situation is even worse at the township level (40,000 population with 100 staff). Here, 35% collected their salaries directly from farmers (Guo 1998, pp. 34–35). The central government has estimated that around 60% of county-level staff is effectively redundant (*South China Morning Post* 1999). If this figure is correct, redundancy at the township level must be even higher because township government has expanded rapidly under reforms. The problem has been exacerbated by the 1994 Budget Law, which prevents local governments from using debt financing and requires them to balance their budgets. The first concern is to cover personnel costs, driving fund-raising for investment and social welfare off the budget or to users' fees. In three townships surveyed by Hermann-Pillath and Feng (2004, p. 407), the amount of regular budget devoted to salaries ranged from 100% in Tongxiang (Zhejiang) to 80% in Gujiao (Shanxi) and 65% in Zhangjiagang (Jiangsu).

In the early 1980s, a township of 20,000–25,000 people was served on average by less than 10 party officials and no more than 20 state officials. Now the numbers have risen to 200–300, with some townships having more than 500 officials on staff (Wu 2000, p. 22; Liu Xitang 2000, p. 74). The number of departments and offices has risen from around 40 to 80 (*South China Morning Post* 2001). Those that are expanding most rapidly are those that can bring in extrabudgetary funds, such as health facilities that can charge fees and family planning agencies and public security organs that can levy fines and fees. These problems have led some reform-minded officials to raise the suggestion of abolishing the township as a level of government,

9. The commonly used phrase to describe this phenomenon is a "budget only for eating" (*chifan caizheng*).

while others have proposed raising the level of direct elections from the village to the township level (interviews with government officials and scholars, Beijing, May–June 2002).

Not surprisingly, such a situation makes it even more difficult to fund the salaries of those working in medical institutions and drives the shift to privatization and fee-for-service care. Especially with respect to Maternal and Child Health (MCH), government resources are too limited at the township and village levels, where need is immense, and too great at the county level, where there is less need. Subsidies are being used to finance county-level MCH salaries, which are disproportionately high. The subsidies for township- and village-level MCH workers are very low, creating incentives for providers to concentrate on curative care rather than on preventive care and education. MCH workers are one group who could play an important role in monitoring the local population for the spread of diseases such as HIV/AIDS.

It is clear that much could be saved if restructuring local authorities was combined with new thinking about (1) what kind of government structure would best serve the new economy, and (2) which tasks that structure should continue to oversee and which could be delegated to the private sector or other organizations. Budget savings will only be useful if they are directed toward productive investment and support of necessary social welfare. This would be helped by changing the incentive system to place a higher priority on social development when appraising local government performance. Local performance contracts make it clear that economic development is one of a complex set of tasks, yet these contracts neglect social development. Assessment of performance varies somewhat from place to place, though Zhao Shukai has outlined a fairly standard contract for village officials. Evaluation is based on a 1,000–point scale in which 400–500 points are allocated for success in collecting revenues, 200 points for maintaining social stability, and 100 points for meeting family planning targets. This means that very little attention (200 points) is paid to social policy targets or public infrastructure projects (Zhao 2004, p. 220). There are multiple principle-agent relationships that operate between the levels of local government, and they need to be understood better in order to improve analysis of the local state, its functioning, and the incentive structure for local officials. Incorporating progress in achieving the *xiaokang* goals into the scale would help with this.

Senior leaders have recognized this with respect to treating HIV/AIDS more seriously. State Council Document No. 7 (March 2004) announced that government leaders would be held accountable for their work con-

nected to HIV/AIDS and that this would be assessed as part of their job performance. Those guilty of misconduct would be held to account for it (SCWGA and UN Theme Group 2004, p. 10). This will help if implemented effectively.

The fiscal and administrative changes noted above would enable both central and local governments to play a more effective role in providing social welfare. Concentrating finances at the county level would permit more effective funding decisions on social welfare provision and would provide a more effective geographic unit for redistribution. Reduction in staffing levels, especially at the township level (even including its possible abolition as a formal level of government) would lift the financial burden on the local state and community. Better incentives are needed to encourage local officials to pay more attention to social development. These reforms should be supported by greater understanding of what kind of services citizens expect from the government and how they prioritize them. Government cannot provide complete welfare services and should be supplemented by an enhanced role for alternative providers.

Like most countries, China takes a supply-driven approach to the provision of social welfare. The central government sets certain social policy goals, such as providing nine years of compulsory education, reviving some kind of collective health system for the countryside, or providing some minimum funding guarantees to families in distress. These are laudable goals, but they are essentially unfunded mandates and the burden falls on local governments to implement them. As we have seen, local governments have neither the finances nor the incentive to implement such policy directives effectively. As the Chinese saying goes, "The Central hosts the banquet, the Local foots the bill" (Cheng 1995, p. 72).

It might be beneficial to consider the demand side of the equation. In other words, what do citizens think of the provision of specific public goods by local governments, and how do they prioritize different needs? To answer this question we conducted a survey of 3,697 rural and urban households, together with Horizon Group, to understand which areas of government service citizens approved of and which frustrated them. Citizens tended to be more satisfied with those services that the old planning system was good at providing, such as physical infrastructure and water and electricity supply, while dissatisfaction was highest with service that related to pressing social concerns faced by households. Citizens identified the following areas where government work was poor and improvement was urgently needed: (a) job creation, (b) unemployment insurance, (c) hardship family relief, (d) medical

insurance, and (e) public sanitation. This suggests that the areas of work citizens really wish government to concentrate on are job creation and providing basic guarantees to protect against the shocks of the transition to a market economy. Labor and medical insurance were high priorities for all residents. The general strengthening of social welfare infrastructure will help improve the capacity of the health system to deal with HIV/AIDS. To satisfy these needs, government will have to encourage the further development of alternate service providers and form new partnerships.

To complement the financial and administrative reforms, better use needs to be made of market institutions and those of civil society (see Saich 2003). To facilitate these decisions, discussion is needed about what kinds of public goods government should supply and which current services should be treated as a private good that need not be funded out of public revenues. With respect to HIV/AIDS prevention, marketization measures are likely to be less helpful than a greater role for alternate service providers and the expansion of community-based and self-help groups.

As noted above, there has been a reduction in state provision of health care and a rise in individual responsibility to purchase medical services in the marketplace. Collapsing government support has been accompanied by a growth in private medical provision. Of the 698,966 village health clinics in 2001, 36.5% were privately owned, with a further 13% owned by the doctors. Some 41% were owned by the village community, and 6% had been set up by the township (Zhang 2002, p. 307). There is much to be gained from an increased use of privatization of services, but the change to date has been by default rather than by design. The change has also produced unexpected outcomes, with a precipitous decline in access to rural health care provision and a clear shift from preventive to curative care. In part this shift to more expensive curative care is understandable, since with the exception of HIV/AIDS, communicable diseases have declined significantly and earlier immunization programs have been successful. However, as noted above, this progress is slowing and is even reversing in some areas. Combined with the dramatic drop in medical insurance, this is a worrying trend that itself needs to be reversed.

With declining financial capacity and further reductions in the government workforce, the nongovernmental sector will have to take on many functions that will be shed by the government or that are not covered at all (see Saich 2000). In other countries, such as Thailand, that have adopted effective strategies to confront the spread of HIV/AIDS, the government has forged strong partnerships with nongovernment organizations (NGOs)

and has mobilized the resources of civil society and community-based organizations. There is evidence of increased NGO activity with respect to HIV/AIDS work in China, but senior CCP leaders remain ambivalent about the development of the sector. While keen to mobilize the resources that NGOs can raise, there is concern to keep strong control over the sector. CCP leaders prefer that the sector be developed within a highly restrictive legislative and organizational framework that ensures party and state control. This is driven in part by the CCP's Leninist predisposition, which creates suspicion of organizations outside its direct control. It also stems from an awareness that the next phase of reforms will shrink the role of the state in people's lives even further. As a result, the NGO sector is still dominated by those organizations in which the government plays a strong role, often having set up the organization as a way to mobilize funds more effectively. Yet recognition that the state cannot meet many of the obligations it claims for itself has allowed for significant expansion of community-based organizations to provide a wide range of social services.

Growing official tolerance has allowed more organizations to develop, while ones with close party-state ties, such as the Youth Development Foundation set up by the Communist Youth League, have provided significant funding through Project Hope for basic education. In a major departure from past practice, the current ten-year plan for poverty alleviation explicitly states the need to bring NGOs on board to help implement government development projects in poor areas (State Council 2001). In March 2004, Premier Wen vowed to turn over responsibility for more activities the government should not be engaged in to enterprises, NGOs, and intermediary organizations (*China Daily* 2004).

Both domestic and international NGOs and government-backed NGOs are taking on important roles in dealing with HIV/AIDS. A directory of NGOs published in July 2005 listed 101 civil society organizations and projects working in the areas of HIV/AIDS prevention, treatment, and advocacy (see *China Development Brief*, July 2005, p. 1). These ranged from well-established groups such as the China Association of STD/AIDS Prevention and Control to small groups providing help and care for children or working with "same sex love groups." In Yunnan Province, traditional mass organizations such as the Women's Federation have been very active, while the provincial Red Cross has conducted peer education among young people and has organized 1,500 training courses for some 30,000 people (Yunnan Center for Disease Prevention and Control 2004, p. 26). In addition, international NGOs such as Save the Children UK have been very active working

with AIDS orphans in Yunnan and other provinces, such as Henan and Anhui, while People Living with HIV/AIDS has established a number of self-support groups in Xinjiang, Shaanxi, Shanxi, Guizhou, Shanghai, Beijing, Guangdong and Sichuan (SCWGA and UN Theme Group 2004, p. 13).

If alternate service providers are to play a sufficiently effective role, however, a number of substantial changes must made in government attitude and practice. The current ambivalence about the nongovernmental sector and need to seek approval through registration with a sponsoring agency favor the larger organizations, many of which have been set up by government itself. The confusing Public Welfare Donations Law that took effect in September 1999 also favors those organizations that are close to government.

This preference for the larger quasi-official organizations is reflected in the regulations on social organizations, which stipulate that "similar" organizations are not allowed to coexist at the various administrative levels. This requirement has been used to deny registration for some groups. It ensures that the "mass organizations," such as the All China Women's Federation and the All China Federation of Trade Unions, enjoy monopoly representation and cannot be challenged by independent groups seeking to represent the interests of women and workers (Saich 2000, p. 131). As a result, the emergence of smaller, local organizations that could play a valuable role in identifying and responding to social needs within the locality is restricted.

Yet as noted above, even without official encouragement community-based organizations are developing and alternatives are emerging to take over functions that were previously considered the preserve of government. Research by Tsai (2001 and 2002) concludes that in some areas social capital substitutes for governmental performance and officials allow social institutions to take over the provision of public goods. These alternatives for mobilizing community resources are especially important because, village elections notwithstanding, the incentives to encourage village officials to provide public goods are weak. Certainly there is no direct incentive for township officials to invest in village infrastructure.

Moreover, China's experience with SARS has provided some lessons—beyond exposing the weakness of the health system—that could be helpful in dealing with HIV/AIDS (on SARS, see Saich 2005). First, and perhaps most important, is the lesson that *the central leadership must send a clear signal if local leaders are to take a particular issue seriously*. Local leaders are sensitive to any

signals provided by the center, yet they have many ways to evade (and few incentives to pursue) central directives unless and until they are sure that the center will be consistent about the issue in question. This was clear, for example, in former General Secretary Jiang Zemin's commitment to crush the influence of the spiritual movement Falungong, but it is less clear in the case of dealing with HIV/AIDS. Certainly, the central leadership has promulgated a number of regulations and set up a new institutional framework for HIV/AIDS policy, and top leaders have kept up their high-profile visits to HIV/AIDS patients. However, local leaders have neither duplicated these visits nor publicly embraced HIV/AIDS patients as have their leaders Hu Jintao and Wen Jiabao, in marked contrast to when Jiang Zemin publicly administered polio vaccine to children and many provincial leaders quickly followed suit (see *China Development Brief*, May 2005, p. 16).

Second, *China needs to build better systems that can deal in an integrated way with crisis management and the spread of contagious diseases*. The way China dealt with HIV/AIDS initially mirrored the way SARS was dealt with. The initial response was denial and cover-up, combined with effects of the fact that the vertical and segmented structure of China's bureaucracy hampers effective action once it is called for. It is notoriously difficult in the Chinese system to gather information across the different sectors and to coordinate actions. China needs to develop a system that encourages cross-sectoral collaboration to provide comprehensive, integrated solutions. As noted, local governments often work in their own interests to undermine national policy. Although the Ministry of Public Health remains a weak player institutionally, the central leadership has been trying to set up better systems.

In mid-May 2003, China announced that it would set up an Emergency Response Bureau under the State Council to act as a powerful new agency to deal with future health crises and natural disasters (*South China Morning Post* 2003). The bureau is modeled on the US Federal Emergency Management Administration (FEMA) that was absorbed into the Department of Homeland Security in March 2003. In February 2004, a new State Council AIDS Working Committee was set up to improve coordination. It is headed by Vice Premier Wu Yi and includes the vice ministers of 23 key ministries and mass organizations, together with the vice governors of China's worst-affected provinces. These working committees have been set up in all of China's provinces. In Yunnan, the first province to be significantly affected, a leading group for AIDS prevention and control was already established in 1990 with 18 different sectors represented, and this was expanded

to 24 in 1997 and 27 in 2003 (Yunnan Center for Disease Prevention and Control 2004, p. 15). Such administrative structures will help if they are backed by strong political support.

Third, *better and more open reporting systems need to be developed*. One issue much debated after SARS was the need to create a better system of information management. There is a fundamental tension between a political system structured to control and manage information flows and a society that is information savvy and "wired." This tension becomes dysfunctional when the official media report that all is under control while information available online tells a different story. China's leaders claim that they have provided sufficient information about HIV/AIDS, but major incentives persist for local leaders to deny the problem or to underreport it. To be fair, the underreporting is exacerbated by the general weakness of the rural medical system and the poor levels of training, which can mean that cases are not diagnosed properly. In fact, Chinese estimates of infections are consistently lower than international ones, while studies of particular at-risk groups suggest higher rates than official statistics. For example, in Yunnan, based on data of HIV prevalence and population size of subgroups, there were an estimated 80,000 people with HIV/AIDS at the end of 2003, as opposed to the official figure of 14,905. The death toll is around 10,000, rather than the official figure of 558 (Yunnan Center for Disease Control and Prevention 2004, pp. 3, 12). The confusion in 2005 about the situation with respect to Asian Bird Flu (H5NI) does not bode well for transparency and clarity in reporting.[10]

Many local officials have been concerned that revealing the presence of HIV/AIDS might not only reflect badly on their career prospects but also that it might affect investment within their jurisdiction. Yet, evidence from Yunnan suggests that openness is more effective in dealing with HIV/AIDS than trying to bury the problem and hope that it will go away. The *Xinhua* journalist, Lin Gu, reviewed HIV/AIDS control strategies in two counties of Guangxi Province. Prevalence slowed in the county that acknowledged the epidemic and confronted it with public education campaigns, whereas it rose in the county that kept the situation secret for fear that its reputation would be damaged (*China Development Brief*, May 2005, p. 2).

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10. See also the initial delay and secrecy surrounding the outbreak of pig-borne bacterium streptococcus in Sichuan, which is reported to have killed more than 35 people (http://news.bbc.co.uk/2/hi/asia-pacific/4742319.stm).

Concluding Comments

Economic reform over the last 25 years has led to fundamental challenges for the provision of social welfare. Neither the central nor the local state has the financial capacity to provide the same levels of welfare as in the past. This suggests that better provision can be achieved by rethinking the role of the state and its relationship to the market and institutions of civil society. Crucially, social development needs to be integrated better with economic development plans, rather than being considered something that can be dealt with once society has become wealthy.

The analysis presented above suggests that there will be significant challenges for implementing an effective policy response to the spread of HIV/AIDS. In the past, China has been very successful in dealing with communicable and epidemic diseases, which accounted for only 5% of fatalities in 1998, compared with 23% in India (Wolf et al. 2003, p. 45). Although tuberculosis still claims around 0.25 million lives per year, China has dealt well with such health problems given its level of economic development. However, as shown above, the health sector has not fared well under reforms because incentives have changed and the rural health system has begun to focus more on expensive, curative care rather than inexpensive, preventive medical care. This makes interventions to deal with HIV/AIDS more difficult to achieve.

This difficulty of controlling HIV/AIDS will be increased further by three factors. First, at all levels of government China has found it difficult to adopt multi-sectoral policy solutions to problems. The vertical, hierarchical nature of the system makes it hard to develop networks horizontally within the government structure, let alone between the government and organizations of civil society. As we have seen, the government remains ambivalent about NGOs, which have formed an important part of the policy response to dealing with HIV/AIDS in other countries.

Second, China has a number of features that are conducive to the spread of HIV/AIDS. China has a hugely mobile population that is more difficult to control than in the past. In addition, there is a burgeoning surplus of males over females, and this will result in a rise in the already rapidly growing numbers of commercial sex workers (CSWs). However, the incentives in the health system to provide good sexual health education are weak, and the possibilities for frank discussions at school and in the media are circumscribed. As a result, China has low levels of awareness about the disease and how it is spread, in conjunction with an increasingly large CSW community

and attendant rise in sexually transmitted diseases (STDs) and low rate of condom use (see Yuan 2003).[11] China's official figures for HIV/AIDS are generally seen as underestimating the scope of the disease in China, in part because of poor surveillance mechanisms and also because of low levels of knowledge about the disease within the health community.

Third, although the central government has clearly recognized the importance of dealing with the disease early, it remains to be seen whether sufficient incentives will be developed for local governments to treat the challenge with similar urgency. A major problem is that it is a long-wave disease, with deaths only occurring some ten years after the initial infection. This means that impacts such as AIDS orphans, loss of breadwinners in the household, and the enormous strain on the health system will not be felt on a significant scale for another decade or so. Since local government officials already face so many immediate challenges with insufficient human and financial resources, why would they prioritize dealing with HIV/AIDS? Further, as we have seen, the incentives for local governments to tackle social development and welfare issues are relatively weak, and the preference is to concentrate on those activities that will generate income for local government coffers. Indeed, many local government officials may well feel that acknowledgement of HIV/AIDS as a problem will reduce their economic attractiveness, which may be an incentive to cover up the spread of the disease. Therefore, unless the central government is able to come up with significant funding for the program to combat HIV/AIDS, and with strong incentives for local leaders to take the policy initiatives seriously, progress is likely to be limited.

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11. In July 2004, six ministries and departments launched a national condom promotion strategy to encourage 100% condom use among high-risk behavior populations (State Council AIDS Working Committee 2004, p. ii).

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CHAPTER 3

AIDS Surveillance in China

Data Gaps and Research for AIDS Policy

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I. *Introduction*

This chapter reviews the quality and comprehensiveness of data being used by Chinese policy makers—the data required for an effective policy and program response. It also highlights current shortcomings in AIDS policy research and makes recommendations for improved mechanisms for data collection and use for AIDS policy research. Based on surveillance system data, the Chinese government estimates that 840,000 Chinese citizens are infected with HIV (Shen 2003). China's AIDS epidemic began in the early 1980s as a localized epidemic among needle-sharing intravenous drug users along the border with Myanmar. HIV infections are now found in all of China's 37 provinces, municipalities, and autonomous regions, with new infections growing at an estimated rate of 30% annually since 1999, and 44% in 2003 (Wu, Rou, and Cui 2004).

China's AIDS epidemic continues to expand. Many of these infections still occur among injection drug users (IDUs), but a separate epidemic among former paid blood donors (PBDs) in central China accounts for a large proportion of identified cases in recent years. Beyond these two

groups of primary infections through tainted blood, a sexual epidemic has now begun. The sexual epidemic has the potential to become widespread for a number of reasons: the size of China's young sexually active population; changing sexual behaviors and norms; massive internal migration; low knowledge about transmission routes among the general population; even lower perception of self-risk among the general population; and an HIV/AIDS epidemic among men who have sex with men (MSM) that has only recently been recognized. China has been singled out as one of five countries that will experience the most new infections by 2010—an estimated 10–15 million—because of the size of the population at risk and delays in early intervention (NIC 2002).

Set against a potentially explosive HIV/AIDS epidemic are shortcomings in data collection and data use for planning a response. The primary source of most estimates of the size and characteristics of the epidemic and its trends is the HIV sentinel surveillance system set up in 1996. Confirmed HIV/AIDS case reporting is also part of the mandatory communicable diseases case reporting system, and as of September 2004, there were 89,067 confirmed cases of HIV/AIDS in China (SCWGA and UN Theme Group 2004). The surveillance system and the case reporting system are far from comprehensive (UN Theme Group 2002), though they are being improved with international technical assistance.

Since mid-2003 the national response has become significantly more aggressive and open, resulting in important policy and program initiatives. A State Council Working Group on AIDS (SCWGA) was established in early 2004, elevating the importance of the AIDS issue at the national level. In late 2003, the "Four Frees and One Care" provision was announced (SCWGA and UN Theme Group 2004). With this policy the government squarely recognized the need for treatment and care, not only as a means of improving the lives of people and the functioning of communities affected by HIV and AIDS but also as a means of preventing further transmission of the disease. Following similar moves as a result of the SARS epidemic in 2003, the government has clearly stated its intention to hold all government officials accountable for their honesty in dealing with AIDS and for heightened attention and resources for infectious disease surveillance, including improved surveillance of HIV/AIDS by the health sector. However, an effective and targeted response to the epidemic will require higher-quality data and a more sophisticated policy research function. Shortcomings in surveillance and the paucity of a social science evidence-base on both the

determinants and the impacts of HIV/AIDS are limiting policy makers' understanding of the unfolding epidemic and how best to prevent and respond to it.

II. *Overview of China's AIDS Epidemic*

To understand the data requirements for planning a comprehensive AIDS response, it is important to review the history of the epidemic and the key infected and affected groups to date.

A. TRANSMISSION THROUGH BLOOD

1. *Injection Drug Users* (*IDUs*). The epidemic began among needle-sharing injecting heroin users in the late 1980s. The epidemic spread along drug-trafficking routes from Central Asia and Myanmar through south and southwest China during the 1990s (Beyrer et al. 2000), and the greatest concentrations of HIV infections among drug users are found along that route, in Xinjiang, Sichuan, Yunnan, and Guangxi provinces (UN Theme Group 2002). The Public Security Bureau reports one million registered drug users, with the actual number estimated to be two or three times that many (China's Country Coordinating Mechanism 2004). According to 2003 sentinel surveillance figures, drug users make up 44% of cumulatively reported infections (SCWGA and UN Theme Group 2004). Data from government sentinel sites suggest 5–8% HIV prevalence among IDUs nationally; over 20% prevalence among IDUs in Yunnan, Guangxi, Sichuan, and Xinjiang provinces; and over 80% in certain counties. Ethnic minority groups, though they make up only 8% of the population, are disproportionately affected by drug use and consequently by HIV/AIDS (ibid., China's Country Coordinating Mechanism 2004). In Yunnan, ethnic minorities made up over 50% of reported cases until the mid-1990s, and still accounted for over 20% in 2004 (Lu 2005). HIV education, delivered mainly by the police while drug users are in criminal detention and forced detoxification centers, has limited both a thorough understanding of total numbers and the effectiveness of educational efforts. Due to the historical absence of drug substitution programs (e.g., methadone), relapse rates to injecting heroin use and the chance of infection from sharing needles have been very high. However, harm reduction approaches, including the provision of methadone and clean needles, have been piloted in Yunnan over the past few years, and in March 2004 the SCWGA extended such permissive regulations nationwide (Xinhua 2004).

Since then the eight pilot methadone maintenance clinics have been scaled up rapidly, with plans for over a hundred by the end of 2005 (Zhang and Kaufman 2005).

2. *Paid Blood Donors* (*PBDs*). IDUs traveling through Henan Province in central China, a major transportation crossroads, have been identified as the source of tainted blood that resulted in the central China epidemic spread by unclean plasma donation practices (Xinhua 2004). During the mid-1990s, many poor farmers in Henan and bordering provinces sold blood plasma for money at semi-official plasma collection stations that used contaminated collection practices. As a result, 24% of all infections to date are attributed to blood sale and transfusion (SCWGA and UN Theme Group 2004). Official figures suggest that 200,000–300, 000 persons may have been infected during those years in seven provinces (ibid.)—namely, Henan and its six bordering provinces, Hunan, Hebei, Hubei, Anhui, Shaanxi, and Shanxi. Unofficial studies have reported that in some villages as many as 60% of the adult population is HIV-infected. A large government survey of seroprevalence (of blood) found 21,703 HIV-positive cases among 280,000 tested in Henan—a provincial prevalence rate of 7.75% (Guo 2004, Agence France-Presse 2004), although the number is probably closer to 10% if those who have already died are included. Many are becoming symptomatic at the same time, creating a large cohort of sick and dying adults who are unable to care for their children and elderly parents. High medical costs impoverish already struggling households, and single and double orphans are increasingly common (Li 2002). The extent of infection through tainted blood in other parts of China is not known, although Gansu and Qinghai have both reported similar problems of infections attributed to unhygienic paid blood donation practices (Chang 2002, *Shanghai Star* 2002).

B. SEXUAL TRANSMISSION

A sexual epidemic is now beginning among commercial sex workers (CSWs) and men who have sex with men (MSM). Sexual transmission accounted for 31% of all reported infections in 2004, with 20% attributed to heterosexual and 11% to homosexual transmission (SCWGA and UN Theme Group 2004).

1. *Commercial Sex Workers and Their Partners.* Prostitution, both direct (main profession) and indirect (sometimes engaging in transactional sex), is

widespread in China, accompanying the past twenty years of economic reforms. Sex workers are found from the most remote rural towns, along trucking routes, and in big cities along China's booming eastern seaboard, with government estimates of one million nationwide (Pan 2001), although one million is likely a gross underestimate since statistics are based on arrest data from public security. Sex workers in three provinces in southern China have shown alarming increases in HIV prevalence in recent years. The highest documented rates of HIV prevalence among CSWs are in the southern provinces of Guangxi (10%), Guangdong (3%), and Yunnan (5%). In Chongqing Municipality the proportion of HIV infections attributed to sexual transmission rose to 23% in 2002, up from 10% just a few years earlier (Agence France-Presse 2002); in Yunnan the proportion was 21% as of 2004 (Lu 2005).[1] Many are infected through their own injecting drug use or by having IDUs as sexual partners (either clients or regular sexual partners). The World Health Organization's 2003 report on HIV/AIDS in the Asia Pacific region reports that close to 30% of CSWs in provinces with large IDU epidemics are also IDUs (WHO 2003a). Another recent survey from two provinces in China showed that 58% of CSWs and 33% of partners of CSWs had used drugs (though not necessarily through injection) in the week before the survey (Yuan 2002).

Of particular concern is the possibility that sex workers and their clients are the bridge for the epidemic to take off in urban centers, especially the booming cities of China's southern provinces, special economic zones, and other areas bordering Hong Kong. Research by Pan (2001) documents that the main clients of CSWS in China are middle-class men and entrepreneurs. Pan reported that men in the highest 5% of income were 33 times more likely than men in the lowest 40% of income to have bought sex, and that one in six urban men aged 25–29 had bought sex in the year preceding the survey (Pan 2001). Recent data from Shenzhen note that new infections are increasing by 25% a year, and that migrants and temporary residents constituted 95% of HIV infections in 2004, 76% among men and 33% from unprotected sex (*Science Daily* 2005). Experts working in the AIDS field are becoming increasingly concerned about a group dubbed "mobile men with money"; although no data have been collected on the risk profile of this

1. Data for 2004 show that 27% of reported cases have unknown routes of transmission, of which many may be sexual, further reinforcing that heterosexual and homosexual transmission is on the rise.

group, anecdotal evidence suggests that men traveling for business are very likely to pay for sex while away from home (*China Daily* 2005).

2. *Men Who Have Sex with Men* (*MSM*). Most MSM in China are married, making them especially hard to reach with sexual health messages (Zhang and Kaufman 2005). The government reports a national HIV prevalence rate of 1.35% among the MSM population, though smaller studies in various cities have found prevalence rates of around 3% (Settle 2005, Zhang Beichuan et al. 2002). Surveys undertaken between 1998 and 2001 found that most MSM engaged in unsafe sexual practices and that less than one-third used condoms (Zhang Beichuan et al. 2002). A full 30% of AIDS cases in hospitals in Beijing in 2001 were among MSM (*China Health News* 2000). A study conducted by the Chinese Center for Disease Control and Prevention (China CDC) estimated that by 2010, MSM would account for more than 1.5 million of 10–15 million infections in China (Settle 2005).

3. *Youth*. Sexual behavior among unmarried young people in China is changing. Although sexual initiation continues to occur later and numbers of sexual partners remain fewer than for their counterparts elsewhere in the world, nonmarital sexual relations among China's youth have nevertheless been increasing, especially in urban areas. This puts China's 200 million young people aged 15–24 at serious risk. Girls under 20 years old make up 15% of all women who have had abortions (*China Daily* 2004). These changes have been driven by the family planning policy promoting later marriage, increased information and interaction with the world via the internet and television programming, retreat by the government from interference in people's personal lives, and the increasing education, urbanization, and economic opportunities available to women. A senior official in the Family Planning Association has reported that, cumulatively, 9.5% of China's HIV carriers are under the age of 19 (Zhao 2003), and the Xinhua newswire story covering his statement concluded with the statement that "Sex without proper sexual knowledge has become a big threat to adolescents' health in China" (ibid.). However, the appropriateness of sexual health education in school curricula is still being debated.

4. *Rural Women*. Rural women remain unidentified as a group particularly vulnerable to HIV infection. Anatomically, women are more susceptible to HIV infection than men; they are two to four times more likely than men to

become infected during unprotected sex (WHO 2003b).In addition, high rates of reproductive tract infections (RTIs) among these women make them vulnerable to infection from potentially infected migrant husbands who return home once or twice a year from their urban jobs. Certain sexually transmitted infections (STIs), such as trichomonas, can increase HIV transmission for women fourfold (Wasserheit 1991). A population-based study in rural China revealed that 19% of women were infected with trichomonas and most were undiagnosed and untreated (Kaufman et al. 1999). Given the movements of China's largely male migrant population between urban and rural areas, rural women with untreated trichomonas may be at significantly increased risk for HIV transmission from their husbands if the sexual epidemic becomes firmly established in China's booming eastern seaboard, where it has already begun among sex workers and where most rural migrants move for temporary work.

III. *Data Requirements for Effective Policy Making*

In the following section we lay out the data requirements for effective policy making and planning, and review the information currently collected in China. We then identify gaps in the present system.

A. SURVEILLANCE

HIV/AIDS sero-surveillance is the most important mechanism with which to monitor HIV/AIDS epidemic distribution and trends (Walker et al. 2001). Since the WHO introduced standards and procedures for doing so in 1998, most national governments have instituted such systems (ibid.). The long incubation period between infection and development of AIDS means that a surveillance system that relies only on AIDS case reporting is not effective, so mechanisms to test important subgroups of the population for infection are used instead. First-generation surveillance involves only serological testing. Second-generation surveillance includes collection of behavioral data and provides information on a set of HIV/AIDS proxy indicators that will increase the ability to track the course of the epidemic and assess the impact of interventions. According to Neff Walker and his colleagues, the quality of any AIDS surveillance system depends on the frequency and timeliness of data collection; the appropriateness of populations under

surveillance; the consistency of the sites, locations, and groups measured over time; and the coverage and representativeness of the groups for the adult populations (ibid.).

With today's knowledge about risk factors for and transmission routes of HIV/AIDS, and the difficulties in reaching those with risky behavior, proxy indicators have been used to supplement the data from the surveillance system to provide a fuller picture of a country's epidemic and the future trajectory of the disease. Such proxies include infection with sexually transmitted diseases, tuberculosis (TB), injection safety-related diseases such as hepatitis C, increased risk of HIV for women with certain RTIs, and the practice of circumcision. Such data can provide useful information about risk behavior and vulnerability to infection. For instance, HIV and TB are closely linked throughout the world, as HIV increases susceptibility for TB to become active once infected because of the weakening of the immune system. Unfortunately, data from proxy indicators are often collected by disparate departments within the government and are therefore poorly integrated into national planning processes for a national AIDS response.

1. *China's Surveillance System.* The main source of information used by Chinese health officials to monitor trends in the HIV/AIDS epidemic has been the sentinel surveillance system. Mandatory reporting of laboratory-confirmed HIV/AIDS cases is also required. China's HIV/AIDS surveillance system was established in 1986, and mandatory reporting of HIV was required under China's Infectious Disease Reporting regulations established in 1989 (Law on Preventing and Treating Infectious Diseases, enacted September 1989, Article 23, as cited in Huang 2003). With assistance from WHO, China's National Center for STD/AIDS Prevention and Control (NCAIDS) set up 42 national sites in 23 provinces in 1995. By the end of 2004 these had increased to 247 sites in China's 31 provinces, autonomous regions, and municipalities (SCWGA and UN Theme Group 2004). Many provinces supplement the national system with provincial surveillance sites (over 400 nationwide; SCWGA and UN Theme Group 2004), but it is unclear how fully these data are incorporated into the national system. In accordance with international good practice, the national surveillance approach involves serological testing among five groups twice a year: IDUs in detention centers, CSWs in detention centers, public STD clinic patients, truck drivers, and antenatal clinic attendees. Of the sentinel sites in 2002, 40% targeted STD patients; 22% targeted female CSWs; 24%, IDUs; 6%,

long-distance truck drivers; 8%, pregnant women; and 0.6% (1 site), MSM (China CDC and US CDC 2002).

Data on the prevalence of STDs, tuberculosis, and hepatitis B and C are collected in China but are not shared freely among separate departments in the government. STD prevalence is monitored through a parallel STD surveillance system that is coordinated out of the National STD Center in Nanjing. Because HIV and STDs are part of the same division under the Infectious Disease Unit in the Center for Disease Control, there is relatively close coordination between the two systems in terms of identifying and following up on individual cases. However, the majority of patients at STD clinics are men. Women's sexual health, including STIs and reproductive tract infections, is the purview of the Maternal and Child Health (MCH) and primary health care departments or of the family planning institutions. These systems are in a parallel but separate government "stovepipe" (i.e., vertical network), making collaboration and information sharing more difficult (Meyers and Stiefvater 2002).

Private clinics raise additional complications in surveillance because the data from these clinics are generally harder for the government to access. However, many people testing for STDs or HIV prefer private clinics where their anonymity is guaranteed. As nongovernment institutions, these clinics are difficult to regulate and data from such clinics are not systematically included in national estimates (Meyers and Stiefvater 2002).

The WHO estimates that 400 million persons have been infected with TB in China, with 1.3 million new cases and close to a quarter of a million people dying from it every year (WHO 2005). China has made great progress since 1990, when TB was the cause of half of all infectious disease deaths there. That significant decrease in mortality has been attributed to improvements in surveillance and pilot projects in directly observed therapy (DOTS), which have had a treatment success rate of 94% (WHO 2000). Tuberculosis is managed within the Infectious Disease Unit of the CDC, although no institutional mechanisms exist for information sharing between the TB and HIV/AIDS departments.

High rates of hepatitis B and C have been linked to unsterile injecting practices in medical facilities in China, and the potential parallels for HIV transmission are obvious (60%, versus 1% in the US). Some 30–40% of cases of hepatitis B and C in China have been linked to medical exposures, suggesting that HIV may be spreading through medical exposure as well.

Though based on relatively small sample sizes, Zhang Linqi and his colleagues report convincing data which show that rates of hepatitis C virus

(HCV) and HIV co-infection are extremely high among IDUs and blood donors. In Yunnan, out of 22 HIV-positive IDUs, 21 were co-infected; in Xinjiang all 33 patients were co-infected; and in Henan the rate was 73% of 89 patients (Zhang Linqi et al. 2004).

2. *Shortcomings of Data Collection.* To date, China's AIDS response and surveillance system have focused more on the primary risk groups (drug users, commercial sex workers, former plasma donors) and less on other vulnerable populations. Vulnerability to HIV/AIDS is not a widely understood concept in planning the AIDS response, in part because the response has been focused on a "risk group" (rather than a "risk behavior") approach, with insufficient analysis of the individual and societal determinants driving the epidemic. Now that the government has rolled out an extensive treatment program, it is also essential that patients be monitored closely, both for their own well-being and for early identification of virus mutations and drug resistance. (See Chapters 5 and 6 in this volume for discussions of drug resistance monitoring.)

The major shortcomings of China's current surveillance system are its minimal surveillance of the general population, weak second-generation behavioral surveillance, and poor surveillance among gay men. For example, trends in HIV incidence in the general population are usually assessed by anonymous testing of pregnant women in prenatal clinics. Legislation mandating the testing of all pregnant women was promulgated in 2004, but implementation varies greatly and in rural areas most women neither give birth in hospitals nor seek prenatal care there. The surveillance system does yield important and useful information about HIV prevalence and trends among the five populations tested in the 247 sites in 31 provinces that it covers, but it does not gather information on the spread of the epidemic beyond these high-risk groups. Even for the populations tested, there is likely to be significant bias in the figures. For example, all sentinel surveillance of CSWs and IDUs takes place in detention centers, and prevalence rates among detainees may not be representative of those among CSWs and IDUs who have not been detained.

The government has recognized the need for behavioral surveillance of high-risk and vulnerable groups and also of the general public, and since 1999 international donor support and technical assistance have bolstered government efforts to add behavioral surveillance to the system. Yet such surveillance remains weak. There are now 42 behavioral surveillance sites across China (SCWGA and UN Theme Group 2004). NCAIDS has de-

veloped surveillance standards and guidelines, and disease surveillance in general has gotten a boost in post-SARS China. Increased financing and attention to the importance of infectious disease surveillance is speeding up the move to a networked computerized and responsive surveillance function at the China CDC. The US CDC Global AIDS Program (GAP) is also providing technical assistance to improve overall surveillance and case reporting.

Again, the "stovepipe" nature of the Chinese bureaucracy makes it difficult to forge the necessary linkages between services and data collection of proxy indicators undertaken by different divisions and departments.

If an STD patient tests positive for HIV, his/her file will be passed on for follow-up to the HIV/AIDS Department, but as of 2002, there were no efforts to relate the STD epidemic curve to the HIV epidemic. It is crucial to understand the links between RTI infection and HIV risk for rural women. Only through such an understanding can the data collected by other parts of the health system be incorporated into targeted prevention efforts. At present rural women are still considered at low risk for HIV infection, although the fact is that high rates of trichomonas and ulcerative STIs like condyloma make them extremely vulnerable to sexual transmission of HIV from their potentially infected migrant or businessmen husbands.

Because co-infection with TB causes HIV to progress much faster than it otherwise does, linking TB prevalence data, especially active cases, with HIV data is very important for identifying likely co-infected populations and their families and communities. These groups can then become a special focus of prevention and treatment, including making better use of the TB DOTS program both for case identification and for surveillance and treatment support.

The implementation of universal precautions in medical facilities is designed to help prevent hepatitis B and C and other nosocomial infections. However, a better understanding of the issues surrounding injection safety and hepatitis B and C infections is essential for designing interventions to prevent both hepatitis B and C and HIV infections through unsterile injections.

B. THE NEED FOR SOCIAL SCIENCE DATA

There is a crucial need to integrate social science research into the Chinese government's planning for its response to the country's AIDS epidemic. Data on determinants of vulnerability to HIV, research on risky behaviors

and their determinants, research on the efficacy and cost-effectiveness of packages of interventions, and realistic understanding of the current health system are essential to designing and targeting interventions to maximize their efficacy.

1. *Social Science Data in China.* Although the last ten years have witnessed a resurgence of good-quality social science research (after many years of neglect associated with the Cultural Revolution and the political discrediting of such efforts), government planning of the AIDS response has suffered from the lack of systematic input of evidence from this research. Excellent qualitative studies and surveys have been carried out about sexual behavior and networking among sex workers (Pan 1999) and the general population (see Parish and Pan, Chapter 10; Parish et al. 2003), including migrants and youth (Cui et al. 2000; Gao, Tu, and Luo 2000; Pan 2001; Yuan 2002). But there is no systematic process in place to complement the surveillance data with social science in order to draw a more comprehensive picture of the trends of the epidemic. Moreover, the focus on high-risk groups in the government's response has led to the false impression that the general population is not at risk. The limited social science data that are being collected by independent researchers, academics, and NGOs suggest the contrary.

2. *Understanding Social and Economic Vulnerability.* As Paul Farmer has noted, "A behavioral model of HIV prevention . . . needs to be embedded in a much broader social analysis" (Green and Farmer 2003). Social science evidence is needed to strengthen an understanding of these "structural" factors that determine individual vulnerability to HIV/AIDS. As is the case elsewhere, China's epidemic is closely associated with social and economic disadvantage, especially ethnicity, gender, and poverty. The surveillance data collected by the government provide evidence, in broad strokes, that the epidemic has been concentrated among the rural poor in central China and among poor and socially disadvantaged ethnic groups in border areas. However, additional social science data are necessary to understand the structural determinants that make some groups of people more vulnerable to infection than others due to their socio-economic circumstance.

For instance, lack of economic opportunity has been associated with commercial sex work and drug trafficking in other settings, and the efficacy of interventions developed to address them has been repeatedly documented. In northern Thailand, the Thailand Population and Community

Development Association has established a small loan program for schoolgirls to keep them in school and help them find gainful employment in their communities after graduating. Without good social science research on vulnerability and AIDS, the government cannot design economic and social policies to address the root causes of risk behavior.

Risk behaviors are themselves embedded in a set of health beliefs and practices that may also contribute to risk and vulnerability. In China, for example, traditional beliefs about losing blood and other bodily fluids have led to shortages of voluntary blood donations and contributed to widespread purchase by hospitals of blood from vendors who pay for blood donations. Such beliefs have also contributed to the popularity of blood tonics, transfusions, and use of blood products (especially red blood cells and plasma products) for medicinal purposes. There is a long history of blood selling in China, and the Henan plasma selling situation that led to the current HIV epidemic in central China is not a historical anomaly. Selling blood as a means of livelihood is an accepted practice, often done frequently rather than just once or twice. Other religious and cultural traditions—such as polygamy or matriarchy among certain ethnic groups in the southwest, or the practice of male circumcision by the Hui minority in Xinjiang, Ningxia, and other western provinces—may either contribute to increased risk or be protective against HIV.[2] A better understanding of the relationship between these practices and beliefs and HIV risk behaviors may help to shift the current attitude that blames the victim.

Sexual transmission of HIV is embedded in the gender power dynamic inherent in heterosexual relationships. Gender analysis is critical to understand that in most cultures women are expected to play a more passive role in sexual relations, making it difficult for them to refuse sex or demand condom use. Both violence or the threat of violence and economic dependency affect girls' and women's ability to refuse sex or demand condom use not only in commercial relationships but also with spouses or regular partners (Jewkes et al. 2004).

Finally, and perhaps most importantly, research is needed to document the important impacts of social stigma as both a determinant and outcome

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2. A study at the third International AIDS Society Conference on HIV Pathogenesis and Treatment in 2005 found, in a randomized trial of over 3,000 sexually active men in South Africa, that circumcision appears to be 65% protective against HIV infection. Interpretations of the findings are mixed, with activists warning that this should not undermine ongoing AIDS prevention efforts. The study was carried out by researchers at the University Versailles Saint-Quentin.

of HIV. Underlying stigma related to minority status or group identification (IDUs, CSWs, poor farmers, and rural migrants) contributes to HIV vulnerability through the psycho-social impacts of marginalization and restrictions on access to employment or services. For example, rural migrants living in urban areas cannot send their children to school or use health services, and until recently could be forcibly returned to their home communities. These factors contribute to vulnerability and risk of infection for migrants and their families. The government's "Four Frees and One Care" policy does not provide support to infected drug users—the population in which the epidemic is presumably increasing the fastest—in effect creating a national policy that reinforces stigma. Documenting the impact of stigma and absent legal protection on risk of infection is critically important for planning the AIDS response, especially for public education, for implementing national laws and standards, and for establishing norms and accountability for health workers, and is also vital in ensuring confidentiality for patients and their families.

3. *Risk Behaviors Research.* In the last five years there has been a growth in research on HIV risk behavior, particularly related to sexual transmission (Pan 2001, Yuan 2002). This research has been conducted by academics, NGOs, and international organizations and has seen little incorporation into the government's policy planning process (Pan Suiming, personal communication, December 2002). A groundbreaking study by Pan Suiming provided badly needed information on the organization of the commercial sex industry in China (Pan 1999), the taxonomy of sexual services offered, and intermediaries involved. Other studies have provided important information on the clients of sex workers, their knowledge and practice of safe and unsafe sexual practices, and number of sexual partners (Pan 1999). Studies are underway investigating sexual networking and social perspectives in epidemic areas (Uretsky 2002). Yet few intervention programs have been designed using the important findings from these studies as a basis, and there is no systematic mechanism for incorporating the findings from such studies into the policy and planning process.

Similarly, there is an increasing body of knowledge on the sexual networking and behaviors of MSM, their knowledge of AIDS and AIDS prevention, and their use of safe sexual practices (Zhang Beichuan et al. 2002). Yet these studies, again carried out by NGOs or independent researchers, are largely left aside in planning. A greater understanding of the social dimensions of gay life—sexual networking, including sexual partner

communication about risk; the social and economic profiles of married gay men and their sexual relationships; and communication and condom use with spouses—is essential both to understand how the HIV epidemic may spread and to design interventions to check that spread.

In contrast, little has been studied about the social dynamics and bonding among needle-sharing IDUs in China, although this issue has been examined elsewhere. Understanding IDU movements along drug-trafficking and major transportation routes, as well as IDU sexual relationships and networking is crucial. In addition, policy makers need to have a clear picture of the relationship between drug use and the common income-generating activities to support drug use—selling blood and commercial sex—in order to make assumptions about the potential spread of the disease and where to intervene.

4. *Treatment Research.* The government's free treatment program, China CARES, elaborated in by Zhang Fujie and colleagues in Chapter 5, remains largely focused on central China. Nearly 25,000 people have been treated through this program, and it is saving lives (SCWGA and UN Theme Group 2004). However, many problems have emerged in its implementation. First, the dearth of properly trained doctors, nurses, and health care workers has led to large numbers of patients skipping doses or stopping medication altogether. Experienced AIDS doctors in China and abroad fear that this inadequate adherence has led or will lead to drug resistance. With a very limited range of drugs currently available in China, resistance would leave China's patients without alternative drug regimens. Research into patient adherence and patterns of resistance would yield important information that could guide priorities. For instance, resources could appropriately be allocated to domestic drug development efforts, the importation of existing antiretroviral drugs from abroad, or improving compliance through community-based interventions.

To a large extent, China CARES has not yet reached marginalized populations, like IDUs and CSWs, though this is changing with support from the Global Fund Round 4 Grant. As in many other countries in the world, there is much debate about the viability of treating drug users. From a public health stance, it is paramount that HIV-infected drug users be provided with treatment to decrease their viral load, thereby decreasing transmission rates while benefiting their well-being. Conversely, many policy makers and doctors fear that drug users will not adhere to their regimens, and conclude that providing them with treatment would lead to further re-

sistance. Without social science research into patterns of IDU mobility, behavioral surveys on injection practices, information on adherence rates, as well as clinical research into virus mutation and ensuing resistance, this is a difficult debate to conclude. The government has recently allocated funding for a pilot project in Yunnan to treat drug users who are enrolled in methadone maintenance clinics that incorporate research of such treatment (Zhang Linqi, personal communication, June 2005).This study may provide useful information on these issues for policy makers.

5. *Social and Economic Impacts Research.* Several studies since 1994 have attempted to project the likely macroeconomic impact of China's AIDS epidemic (Socioeconomic Impact of HIV/AIDS 2002). These efforts have faced significant challenges, including insufficient input data for modeling the epidemic; the problems of applying other modeling programs to China's unique epidemic; and the inaccessibility of economic data needed for modeling economic impact. For instance, although economists calculated a national production function in the early 1990s, no subnational production functions have been calculated since, making it impossible to use this simple model to calculate the impact at the provincial level, where an effect is most likely to be seen (Ha and Wu 2003). The studies to date that have focused on the national economic picture have not predicted significant macroeconomic impacts, although a study by The Futures Group International (TFGI) suggested a loss to GDP of 14–21 billion *yuan* by 2010—a mere 0.3% decrease in GDP growth at worst (Socioeconomic Impact of HIV/AIDS 2002). The Futures Group study analyzed data from three typical counties representing different transmission dynamics to model trends and impacts, focusing on GDP. A Rand Corporation study attempted to model economic impact using existing epidemiological data (from the sentinel surveillance system) and six speculative scenarios (Wolf et al. 2003).

A major problem with applying existing projection models to China is the uniqueness of China's epidemic and the sheer size of the country (e.g., Henan Province alone has a population of 100 million). Treating the country as one uniform epidemic will not be the best approach—rather, a subregional analysis is likely to yield more useful information. China has a distinct sub-epidemic among IDUs in the south and northwest that is beginning to cross over into a sexual epidemic. The IDU epidemic in the southwest may be similar to epidemics elsewhere and might benefit from projection models applied in Southeast Asia. These models require understanding of levels of

commercial sex work, STDs among CSWs and clients, numbers of sexual partners, and other data that are not currently collected and used for surveillance. The scope and dynamics of the blood-borne epidemic among paid blood donors requires a different modeling approach. Migration patterns for Henan farmers and movement along transportation routes in central China (including long-distance truck drivers) will be crucial for understanding the potential for further spread. Contamination of the blood supply through paid plasma and blood donation in other provinces is also not known. Economic migration in China is also likely to contribute to the spread of the epidemic.

Projecting the likely economic and other impacts of the HIV epidemic in China requires a clearer model for estimating the number of cases by geographic region and subtype, as well as a better understanding of the behaviors and other factors that contribute to its spread. This requires making assumptions about those behaviors and other factors based on research already undertaken. It also requires a fuller understanding of the economic and social impacts of the epidemic where it is currently unfolding.

In the communities where the epidemic is concentrated, the micro-impacts are already tangible and will only escalate over time. Studying this micro-level impact will be critical to designing the types of community-level interventions that are needed now to avert widespread poverty and social disruption later. Research should focus on understanding the impacts of the large numbers of adult deaths, and hence of young orphans, on communities now and in the future, especially in terms of loss or deterioration of human capital and loss of immediate and future livelihood knowledge. Such microanalysis might include the impact of loss of education, the psycho-social impacts of loss of parents on future socialization of the children, and impacts of social stigma on a community's ability to market its goods.

In addition to basic understandings of the determinants and impacts of the HIV epidemic, it will be important to undertake social science studies on the efficacy of behavioral and other interventions in preventing HIV risk behaviors and transmission. These should include studies on the impacts of community and people living with AIDS (PLWA) involvement in both program development and service delivery, peer group approaches to accessing hard-to-reach at-risk or vulnerable populations, and the impact of protection against stigma and discrimination on the success of HIV initiatives.

C. HEALTH SYSTEMS RESEARCH

1. *The Need for Health System Information.* To date, there has been little evaluation of the capacity of China's weakened health system to take on the requirements of an effective medical response to the AIDS epidemic, both for prevention and for treatment (see Chapter 4 by Liu and Kaufman). China's health system has been weakened by twenty years of privatization and decentralization, resulting in a substantial deterioration in health education (Kaufman and Fang 2002) and gross inequities between urban and rural areas and between richer and poorer ones. Health systems research is important to understanding not only the manpower capacity and requirements for the planned scale-up of the antiretroviral (ARV) treatment program (staff training, staff mix, etc.), but also for evaluating financing mechanisms. For example, despite government commitment to free ARV treatment for rural villagers in September 2003 (Gao 2003), access and use was severely limited by the facts that HIV diagnostic tests were not free and were too expensive for most rural villagers. While this problem has now been addressed with the "Four Frees and One Care" policy (Shen 2004), other issues, such as poor health-worker attitudes, lack of coordination between the CDC and the hospital system, and numerous other barriers to quality care, are continuing to have an impact on the rollout of the free national program. Moreover, there is an urgent need for cost-effectiveness studies of different prevention and treatment modalities in the Chinese context. China's health care system distortions—and provider incentives to oversell costly and unnecessary drugs to supplement income—are likely to have serious implications for desperate AIDS sufferers. As *China Economic Net* (2005) put it, "The imbalance of resource distribution makes it ever harder for rural residents to access needed medical care. Nearly 48.9% of Chinese people cannot afford to see doctors when they fall ill and 29.6% are not hospitalized whenever they should be." The Brazil experience in universal access to ARV treatment (Coriat et al. 2003) has demonstrated that providing treatment does support prevention efforts by providing an incentive for HIV-infected persons to come forward for testing and counseling.

2. *The Health System Situation in China.* Extensive health systems research over the last two decades in China has documented many of the problems and inequities resulting from health privatization and decentralized funding

of China's primary health care system. Tony Saich (Chapter 2) reviews the twenty-year trend in underinvestment in health in rural China and outlines its impact on numbers and quality of health personnel and facilities. Numerous studies have documented that poor rural residence has an adverse effect on health access; that low health-worker subsidies cause health providers to overcharge for drugs and services in order to earn adequate livelihoods (Bloom, Tang, and Gu 1995); that health education and other preventive primary health care functions have deteriorated for lack of adequate staff and guaranteed funding (Kaufman and Fang 2002); and that medical insurance no longer covers most rural citizens (Hsiao 1984). There are numerous distortions in incentives and financing for China's rural primary health care services. New rural health insurance schemes just being started will only cover costs for hospitalization. These health system issues are discussed further in Chapter 4 (Liu and Kaufman), which outlines how these weaknesses will affect the capacity for AIDS prevention outreach and education, the potential for scaling up treatment for AIDS, and the ability to monitor and evaluate these efforts. It is important to note, however, that the health system challenges facing China are the "overlay" for any HIV prevention education and treatment efforts that must be undertaken in rural areas. It is essential that these underlying system issues be understood and analyzed fully with respect to plans for the AIDS response. For example, from a surveillance point of view, new policies aimed at testing pregnant women for HIV infection during routine prenatal care will miss pregnant women not using prenatal services and delivering at home (i.e., the majority of women in poor areas), a result of the increasing cost barriers to reproductive health screening due to privatization in the rural health sector.

IV. *Consequences of Using Poor Data: Resource Allocation and Policy/Program Distortions*

A major consequence of these data gaps has been that policy makers' understanding of the AIDS epidemic and its dynamics remains inaccurate and incomplete, yet retains far-reaching influence on how resources are allocated for the response.

Shortcomings in the surveillance system result in poor understanding of national (as opposed to regional) trends, plus probable distortions in understanding of the magnitude of the epidemic and distribution by route of infection, infection in the general population, risk behaviors, and geographic

completeness. For example, the overabundance of sentinel sites in China among IDUs and the paucity of surveillance sites for MSM has resulted in a probable overrepresentation of IDUs in the breakdown of affected subgroups relative to, say, MSM. The recent attention and policy shift on promoting harm reduction for IDUs is a positive development, but the lack of resource allocation and programs for MSM remains worrisome.

Due to the difficulty of measuring true incidence (as opposed to higher number of reported cases due to increases in testing), there is a critical gap in understanding incidence, which is particularly important data for IDUs and CSWs. But new assays have been developed over the last few years that can measure the point of infection from a single sample. It took the United States Centers for Disease Control and Prevention ten years into the epidemic to realize the centrality of understanding incidence to track the epidemic among populations over time (US CDC 2002), and several more years passed before effective assays were developed to enable such tracking with single samples. China has the opportunity to learn from the US in adopting such technology sooner. Without knowledge of how quickly prevalence is rising, the government is limited in its ability to monitor the epidemic, evaluate interventions, or plan for the financial burdens that will arise with new infections and required resource allocation.

These data gaps also result in a poor underpinning for the rationale for working in other sectors besides health. For example, the lack of rigorous studies of the economic and social impacts of HIV on rural communities in central China is probably directly related to the paucity of impact mitigation programs by local government focused on intervention targets, orphan support, and community poverty reduction. Furthermore, the undersurveying of geographic areas has most likely resulted in the misconception that pilot programs in southwest and central China are sufficiently addressing the epidemic, whereas in reality a scaled-up national effort is required. Similarly, the lack of studies on determinants and the role of stigma and discrimination in undermining HIV prevention efforts indicates that interventions addressing these issues are limited. Finally, the lack of studies linking youth sexual behaviors and the shortage of explicit sexual knowledge to HIV risk, along with poor understanding of vulnerability concepts, has impeded efforts to move beyond the more prevalent and culturally acceptable "abstinence-only" messages.

V. *Recommendations and Conclusion*

A. THE NEED FOR A POLICY RESEARCH FUNCTION

The elevation of the SCWGA to the Vice Premier's office should be accompanied by a similar elevation in the AIDS policy research function. A high-level policy research office at the State Council level or above would have access to necessary economic and other social science information currently collected and used for national planning for other sectors and issues, such as economic policy. However, use of social science research on AIDS remains weak even at the highest levels, and a better understanding of epidemic determinants will help shape appreciation for needed commissioned research and its use for policy planning. For example, few economists or social scientists from the Chinese Academy of Social Sciences have worked on AIDS, with most research conducted by independent academic sociologists with limited links and access to national or provincial policy and program planning. Most such planning is currently done at the National Center for AIDS Prevention and Control in Beijing, as well as at provincial-level branches of the Center for Disease Control and Prevention under the provincial health bureaus, and continues to be based mainly on surveillance system data. A national-level research office with branches at the provincial level could advise the recently strengthened multi-sectoral coordination bodies (SCWGA) at the central and provincial levels and could thus access and synthesize information about social policy, poverty, health systems, welfare and relief to make evidence-based policy recommendations on needed budget allocations for different sectoral responses.

B. CONCLUSION

As China's AIDS epidemic expands and as government efforts to control it intensify, shortcomings in data about the epidemic and its trends will hamper efficient targeting of resources. This chapter has outlined a number of serious gaps in knowledge about the AIDS epidemic and has noted why such information is necessary for planning the response. Once the epidemic breaks out of its initial primary risk groups and into the general population, as has already begun to happen, responses limited to the health system alone will be even more inadequate than they already are. The determinants of

HIV vulnerability and risk cannot be addressed by health sector responses alone. Furthermore, the development impacts of AIDS undermine the work of every sector of government. A fuller understanding of these factors and of the responses that work to influence them will require a level of data gathering, research, and analysis that has not yet been undertaken in China's AIDS policy circles. Whereas in China this "policy circle" refers exclusively to groups within the government, in many countries there are a number of nongovernment actors involved as well. For instance, in the United States, universities often work closely with government to analyze data. Since large research universities tend to be the leaders in sophisticated data analysis, the reluctance of the Chinese government to collaborate with researchers outside the government is a wasted opportunity. Failure to address these shortcomings will have serious consequences for effectively shaping and targeting China's response to an expanding HIV epidemic and other emerging infectious disease threats in the coming years.

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PART II

Treatment

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CHAPTER 4

Controlling HIV/AIDS in China

Health System Challenges

✶

Yuanli Liu and Joan Kaufman

Even though estimates of the number of AIDS cases in China are still uncertain, there is a growing consensus that HIV/AIDS there is entering a period of rapid disease spread. The epidemic is beginning to break out of localized populations of former plasma donors and intravenous drug users and into the general population. Without effective interventions, between 10 and 20 million Chinese could be infected by 2010 (Kaufman and Jing 2002). If that occurs, China would have the world's largest or second-largest number of HIV-infected people by the end of the decade.

Set against the potentially large AIDS epidemic is a health care system that has been seriously weakened by twenty years of relaxed government support and inadequate regulation in the health sector, along with overall fiscal decentralization. China's primary health care system was held up as the model for the call for "health for all by the year 2000" at the World Health Organization's (WHO's) Alma Ata conference in 1978. But in 2000, China ranked 188 out of 191 countries in terms of fairness in financial contribution to health, and in 2001 21.6% of poor rural households fell below the poverty line from medical expenses (see Chapter 2 in this volume). The average cost of a hospitalization at township or county level in China is about equal to the per capita income of a rural farmer (Saich and Kaufman

2005). Health care is mainly provided on a fee-for-service basis at rural health clinics, and most care provided is curative. Preventive health services and health education outreach have been seriously weakened by twenty years of reform (Kaufman and Fang 2002).

Although serious efforts are underway to revitalize rural health care financing and equity, the urgent and heavy requirements of AIDS prevention and treatment cannot wait until these efforts are completed. China's AIDS epidemic is unfolding in China's poorer areas with only a limited amount of local financing for health, creating shortages of trained staff and quality service as a result of chronic underfunding. In addition to institutional constraints on horizontal collaboration between different programs (e.g., maternal and child health [MCH] and infectious diseases), especially when carried out by different government sectors (e.g., health and family planning), there are a number of challenges facing China's health system's capacity to respond to AIDS.

China still has a limited window of opportunity in which to control the epidemic, and the Chinese government has begun to take aggressive actions to contain further spread. The SARS crisis exposed both serious deficiencies in China's public health system (Liu 2004) and the importance of political will and resources for mobilizing public health action (Kaufman 2005); consequently, strengthening China's public health system has since topped China's public policy agenda.

In conjunction with a new action plan announced in 2001, central government spending on HIV/AIDS prevention and treatment was increased to 100 million RMB a year (approximately $12 million USD). The safety of national blood banks has been upgraded, funded by a recent 1.5 billion RMB government bond issue. In September 2003, Executive Vice Minister of Health Gao Qiang, citing directives from President Hu Jintao, announced a new policy in combating HIV/AIDS that would provide free treatment to the urban poor and rural patients. In early 2004, the new policy of "Four Frees and One Care" was instituted (see Chapters 1 and 5 in this volume). During his visit in November 2003, former US president Bill Clinton publicly embraced an HIV-infected person. Shortly afterward, on World AIDS Day in December 2003, Premier Wen Jiabao shook hands with HIV-infected patients on national television, followed by a highly publicized visit to severely afflicted regions in Henan Province by Vice Premier and Health Minister Wu Yi. These developments reflect important "signal changes" by some of China's top leaders to mobilize the nation against HIV/AIDS.

China, therefore, seems to be steadily moving forward in its response to HIV/AIDS. But will progress be substantial and quick enough to forestall a generalized epidemic? The AIDS response will require multi-sectoral support for public health efforts, which must be carried out by a well-functioning health system. China needs a comprehensive and integrated AIDS response that includes prevention, treatment, and social and economic impact mitigation. AIDS interventions are most effective when these components are offered together. For example, comprehensive HIV prevention includes multiple strategies that work together to reduce HIV risk, such as (1) sexually transmitted disease (STD) diagnosis and treatment, (2) behavioral interventions aimed at increasing knowledge, teaching skills, and changing behaviors, (3) harm reduction programs for injection drug users (IDUs), (4) voluntary counseling and testing (VCT), and (5) programs to prevent mother-to-child transmission. These interventions are synergistic (Gayle 2003) but must be carried out by different actors in China's health system. For example, effective VCT programs are critical for motivating infected persons to come for HIV testing, because HIV testing is the gateway to antiretroviral (ARV) treatment.

But accessing services to learn HIV status also provides the opportunity for HIV counseling—both for those who test positive and those who test negative—on how to prevent either onward transmission or initial infection. Is China's health system prepared for the work involved in the AIDS response? What are the major challenges? What areas of the health system must be strengthened so that it is up to the urgent task of HIV prevention and treatment? This chapter provides a critical review of the major health system challenges facing China's HIV/AIDS prevention and treatment requirements and offers some policy recommendations for needed reforms.

I. Health System Challenges

In this section, we provide a working definition of an effective health system and its major components (or subsystems). We then discuss China's major health system challenges in the AIDS responses by applying a matrix approach: examining major challenges facing the different components of China's health system in terms of adequacy and capacity for HIV prevention and treatment.

A. DEFINING THE HEALTH SYSTEM

Health systems today provide the critical link between the development of interventions capable of achieving significant population health improvements and the realization of these improvements. WHO recently defined health systems as including four major functions: creating resources, financing, service provision, and stewardship (WHO 2000). M. J. Roberts and colleagues (Roberts et al. 2004) further developed the notion that health systems' performance can be affected by five "control knobs," or areas of policy action: financing, payment, organization, regulation, and behavior. These frameworks provide a useful conceptual basis for health systems research and can be linked to important questions, theories, and methods used in such research.

For the purpose of this chapter, we adopt the following working definition: a health system can be defined to include the people, organizations, and institutions that

Deliver health care, including treatment, prevention, and promotion;

Finance and pay for health care;

Produce or provide the specialized inputs to health care; and

Organize, control, and regulate those that do the above.

Therefore, a health system can be described by a web of interrelationships among the five major stake-holders (Fig. 4.1):

Consumers: patients as well as general public;

Resource producers: producing material as well as human resources, such as pharmaceutical manufacturers and medical schools;

Service providers: hospitals for providing inpatient care and schools for providing health education;

Payers: government, employers, insurance companies, and, of course, households; and

Organizers and regulators: government agencies and professional associations.

We believe that this provides a useful framework for analyzing the major challenges in responding to the AIDS epidemic because it captures the interdependence of the different components of a health system, and that it is

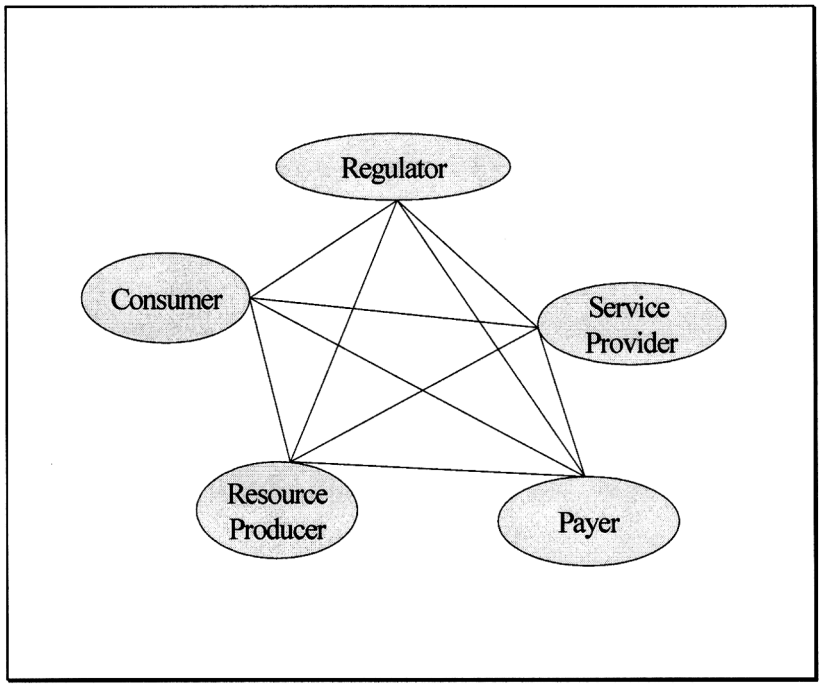

Fig. 4.1 Major Share-holders of Health System

the interactions among these components that determine the outcome. Using this framework, we first examine the gaps in service provision with regard to needs in treatment and prevention. We then analyze the underlying correlation between the gaps in service provision and deficiencies in resource production, financing, and regulation.

B. HEALTH SYSTEM CHALLENGES IN TREATMENT

Recently China has committed itself to provide free HIV/AIDS treatment to its population. Providing highly active antiretroviral treatment (HAART) puts a heavy demand on health systems for laboratory testing, drug prescribing and follow-up, side effect and adherence management, drug logistics systems, and the management information systems required to keep these aspects coordinated.

AIDS treatment is important in its own right, but also for prevention and control. Treatment provides a powerful incentive for people to come for-

ward for testing, which is a critical first step toward controlling the epidemic. Given the early stage of the epidemic, China still can afford to treat AIDS patients, whose numbers are substantial (the official estimate is 80,000, see Chapter 5 in this volume) but not overwhelming. Access to treatment services is determined by three factors: availability, affordability, and appropriate use of drugs (Liu 2003). HIV testing must also be available so that cases can be identified for treatment.

1. Resources and Financing. A minimum set of material resources is needed for treatment: antiretroviral (ARV) drugs; blood testing kits and diagnostic equipment, both for diagnosing HIV and for monitoring CD4 counts and treatment efficacy (individual and population); medicines for opportunistic infections; materials for universal precaution procedures; and storage and logistic capabilities to keep supplies in stock (there must be a consistent and dependable supply to prevent the development of drug resistance). Drugs for opportunistic infections are also being provided at no charge or at reduced charges to AIDS patients in economic hardship within areas of high HIV prevalence (see Chapter 5 for a detailed description of the national free ARV treatment program in China).

More importantly, adequate human resources are needed—namely, doctors trained in universal precautions, in doing viral load and T-helper cell (CD4) testing (taking samples, running the equipment, and interpreting the results), in what medicines to prescribe at proper dosage and in knowing/testing for contraindications (like hepatitis, TB, or pregnancy), as well as in recognizing and knowing how to treat opportunistic infections of AIDS.

Price constraints have so far limited the quality of AIDS drugs used in the government-sponsored treatment program. Four off-patent drugs with side effects and some toxicities (e.g., liver toxicity for patients with hepatitis, a common ailment in China) have been provided to date, and pediatric formulations have only recently become available for a very few children who are being treated (despite the growing numbers of AIDS orphans, many of whom are also infected with HIV). But given the significant price reduction of ARV drugs resulting from recent successful private (Clinton Foundation) negotiations as well as China's domestic pharmaceutical manufacturing capacity, the supply of more appropriate drugs (e.g., 3TC) and more formulations and affordability of the treatment will most likely be resolved soon.

The supply of drugs will not be China's main problem. Manpower issues—in terms of both quantity and quality—will be the greater challenge.

Treating HIV/AIDS is not just about access to medication. Antiretroviral regimens are complex, have serious life-threatening side effects, and are difficult for patients to adhere to. Current treatment regimens in China involve four generic ARV drugs made in China, which are older and off-patent. Because these are not state-of-the-art drugs they can cause many side effects, which makes compliance much more difficult to manage. To safely treat HIV sufferers with powerful and antiretroviral drugs, it is crucial to have trained physicians with access to laboratories that can carry out advanced blood testing. The most important tests measure the HIV "viral load" and CD4, which measures the degree of immunodeficiency. These tests must be carried out on each patient to determine whether the prescribed drug cocktail is effective or whether potentially drug-resistant strains are surviving provider attitudes toward treating AIDS patients, such as fear and stigmatizing behaviors. Provider respect for confidentiality is also a critical human resource factor in successful AIDS care.

The current plans within the national treatment scale-up program (the China CARES program, and the Global Fund Round 3 and 4 projects) are to set up laboratory capacity at the prefectural and local levels. Under such a system, local-level skills are required in taking blood, handling the samples, and transferring the blood samples up the line. Strict adherence to "universal precautions" will also be required to prevent health worker or other nosocomial transmission. Capital costs such as those associated with setting up labs will be financed by the central and provincial levels of government, but maintenance and other recurrent costs must also be assured. Most recurrent health system costs are usually borne locally, which will be a strain in poorer areas.

Beside lab capacities, the most urgent challenge in resources is lack of trained doctors. To date, about 700 provincial- and county-level doctors, who have been trained to diagnose and treat HIV/AIDS in Beijing, are working in Henan, Hubei, Hunan, Anhui, Sichuan, and Yunnan provinces. The shortage of trained personnel, along with the shortage of adequate drug regimens, has been the major constraint so far to offering treatment. About 25,000 AIDS patients had been offered ARV by mid-2005, mostly in central China.

To provide adequate geographic access to treatment, China will need to train many more doctors in many more localities. In the longer run, HIV/AIDS clinical management can be integrated into the medical graduate training curriculum. But in the short run, the most effective strategy to develop the needed human resources is through continuing medical educa-

tion programs to supplement the ad hoc training efforts now being planned for the 127 counties in 28 provinces covered under the China CARES program (Phase I, 51 counties in 11 provinces; Phase II, 76 counties in 23 provinces).

In recent years, China codified its continuing medical education program, in which physician licenses are to be renewed regularly on the basis of the doctors fulfilling their obligations of taking certain credits courses in the continuing medical examinations (CME). If HIV/AIDS can be included in the CME curriculum, it would help train many more doctors in a relatively shorter time than the special training programs to be supported by the Global Fund grants. This suggested initiative implies updating China's regulations on CME.

2. Service Provision and Organization. A major health system challenge in treatment consists of case identification, treatment protocol management, and coordination of providers at different levels. Serious stigmatization and social discrimination against AIDS patients exist in China and are a barrier both to VCT and to treatment. Fear of discrimination is a greater barrier to testing than is the cost of testing, especially given the government's new "Four Frees and One Care" policy. Unless health care providers know how to ensure patient confidentiality and win people's trust, case identification and treatment follow-up will remain difficult in China.

3. Service Coordination. Another challenge is coordination of different organizations involved:

1. *Coordination between prevention and treatment.* Most VCT services are provided throughout China's public health sector (China CDC and its counterparts at different levels of the provincial and local governments). This system is separate from the medical care sector (e.g., hospitals), and traditionally the linkage between the two sectors is rather weak (Liu 2004).

2. *Coordination of service providers at different levels of the administrative line.* Health care providers at the national, provincial, city, county, and township levels are subject to regulations by different levels of the government and operate as independent organizations. Therefore, there is no formal referral system for coordinating treatment depending on the patient's needs, nor is continuity of care guaranteed.

4. Commercial Orientation of Health Providers. The commercial orientation of many health care providers in China nowadays is another potential threat to the quality and effectiveness of AIDS treatment programs. In the mid-1980s, the Chinese governments decided to "harden" budgets for public hospitals and other health care organizations (Liu, Liu, and Chen 2000). This meant that, except for basic salaries of a designated number of personnel, which continued to be subsidized by the governments, public-sector health care providers were expected to cover the balance between the total costs and government budget allocation by generating revenues.

Although prices of medical services, relative to costs, have been kept low by government policy, health care providers were allowed a 15–20% mark-up over the wholesale price of drugs. In essence, under the new financing and medical pricing structure, public health care providers have strong financial incentive to prescribe and sell more drugs, even though patient may not need them. The problems associated with commercialization of the health sector are most pronounced in China's rural areas. A UNICEF study found that the practice of unsafe and unnecessary prescription is widespread among China's village medical practitioners. In 1998, 20–36% of the prescriptions given by village health posts contained corticosteriods. The percentage of children receiving intramuscular (IM) injections for the common cold was as high as 46–64%. Most of the village health posts (62–85%) did not keep patient records (Yip 2000).

Therefore, both the technical and the ethical standards of China's health professionals need to be raised. For example, though AIDS drugs were provided free in the China CARES program during 2003, many patients were unable to afford the HIV tests required to become eligible. There have also been numerous reports of local doctors prescribing unnecessary and expensive additional drugs and tests to desperate AIDS patients.

International experience, as well as China's own, has shown that for treatment and care programs to be successful, health care providers must work together with nongovernmental organizations (NGOs), community organizations, and the families (Jin 2003). ARV treatment must be taken as prescribed, with nearly no doses missed, in order to be effective. It must also be taken for a lifetime. The regimens can be complicated, requiring taking numerous pills and formulations multiple times per day. (By comparison, some of the newer drugs come in combination pills and only need to be taken twice a day.)

The most successful programs in poorer countries (like Haiti) involve community members supervising patients to take their medicines (like DOTS programs for TB) or even using the DOTS infrastructure for HIV treatment. Paul Farmer and colleagues have demonstrated that community support by non-health workers in Haiti has been successful in achieving high rates of drug-taking compliance in a very poor setting (Farmer et al. 2001). Without such compliance, drug resistance will develop, with serious consequences.

C. HEALTH SYSTEM CHALLENGES IN PREVENTION

Until recently, China's AIDS epidemic has been concentrated between two primary risk groups: PBDs who acquired the infection from unclean blood collection practices and needle-sharing IDUs. In the last five years, the sexual epidemic of HIV has begun to gather steam, with worrisome rapid increases of prevalence among CSWs regularly monitored by the national sentinel surveillance system and among MSM who are neither monitored nor targeted with AIDS prevention messages.

Once the virus becomes firmly established between these two groups, it will spread rapidly in China, fueled by several factors:

Low public knowledge of AIDS;

Low condom use;

China's huge population of young persons in the sexually active 20–to 34–year-old age range;

The nearly universal rate of marriage by MSM;

China's large migrant population;

Limited capacity of the weakened health system to undertake the necessary prevention and care programs;

High rates of untreated reproductive tract infections (RTIs) among rural women; and

Political reluctance of many local governments in taking on HIV/AIDS.

1. Resources and Financing. The components of HIV prevention that are required of a well-functioning health care system include:

Health education outreach capacity, both to the general population and to vulnerable and susceptible groups;

STD testing and treatment;

Table 4.1
Health Care Spending in China, 1991–2000

	1991	1995	2000
Percent of GDP spent on health	4.11%	3.86%	4.82%
Percent of total health expenditure by government	22%	17%	14%
Percent of total health expenditure by individuals (out of pocket)	38%	50%	60%
Percent of government health spending on public health	75%	72%	70%

Source: MOH 2004.

Establishment of VCT clinics with trained HIV counselors;

Programs for the prevention of mother-to-child transmission (PMCT);

Prevention counseling through other relevant health services, such as TB, STD, MCH, and family planning;

Condom promotion and distribution; and

Establishment of universal precautions in medical facilities treating AIDS patients.

These programs require specific and often new kinds of human resources (e.g., how to do VCT) and financial resources. Although the SARS crisis has brought about a significant increase in public investment in the public health system, the situation of underfunding will not change overnight and will be a major constraint to staffing qualified personnel.

As indicated in Table 4.1, although China's total health spending as a percentage of GDP increased from 4.11% in 1991 to 4.82% in 2000, all government spending on health as share of total health spending decreased from 22% in 1991 to only 14% in 2000. By contrast, individual out-of-pocket spending as a share of the total health spending increased from 38% to 60% during the same period of time. Basically, access to health care in China today is dictated by ability to pay. Furthermore, the share of government spending on public health has decreased over the years (from 75% in 1991 to 70% in 2000).

This relative reduction of government spending on health took place at a time when China's public health problems were becoming more complicated than ever before, due to such factors as industrial pollution and increasing mobility of the society due to the easing of restrictions on internal travel

(Hu 1995). Government disinvestments in health have undermined the provision of public goods such as health surveillance and prevention services (Liu, Rao, and Hu 2003; see also Chapter 2 in this volume).

China's annual budget for HIV/AIDS prevention and treatment has hovered around 100 million RMB per year ($12 million USD) since 2001 (UN Theme Group 2002). From 1996 to 2000, the national budget was about $1.8 million USD. UNAIDS noted that the funds that China allocated to HIV/AIDS prevention and control were one-seventh of funds that Thailand invested (Sun et al. 2002). Though investments, funded through bonds, have been used to improve the blood collection system, these central government funds are inadequate supplements to provincial budgets.

The problem is not only underfunding but the financial incentive structure within the public health system, which is unfavorable to effective and efficient prevention programs. As already noted, in the mid-1980s, the Chinese governments decided to "harden" budgets for public hospitals and other health care organizations (Liu, Liu, and Chen 2000). Health care providers are allowed a 15–20% mark-up over the wholesale price of drugs, producing a strong financial incentive to prescribe and sell more drugs—and virtually no incentive to provide preventive services such as health education (Kaufman and Fang 2002).

Even the epidemic prevention stations (EPSs), which are supposed to provide public health services, have paid more and more attention to revenue-generating activities than to preventive services. Figure 4.2 indicates the changing sources of income for EPSs in China. In 1985, government budget and grants accounted for close to 80% of the stations' total income. In 1997, this had decreased to less than 40% (MOH 1998). EPSs generated the majority of their income from fee-charging activities, including annual physical examinations for urban enterprise workers and middle-school students.

We can conclude from the above analysis that, under the current system, unless the health education programs targeted at controlling HIV/AIDS are well-funded, prevention will continue to face serious challenges. Despite the latest policy of publicly financing the costs for testing and treatment, it would be unrealistic to expect the central government or international donors to pick up the entire tab. For example, it remains to be seen who will be paying for "100% Condom Use" and "Needle Exchange" programs, or for those provided through other sectors, such as youth HIV education in the

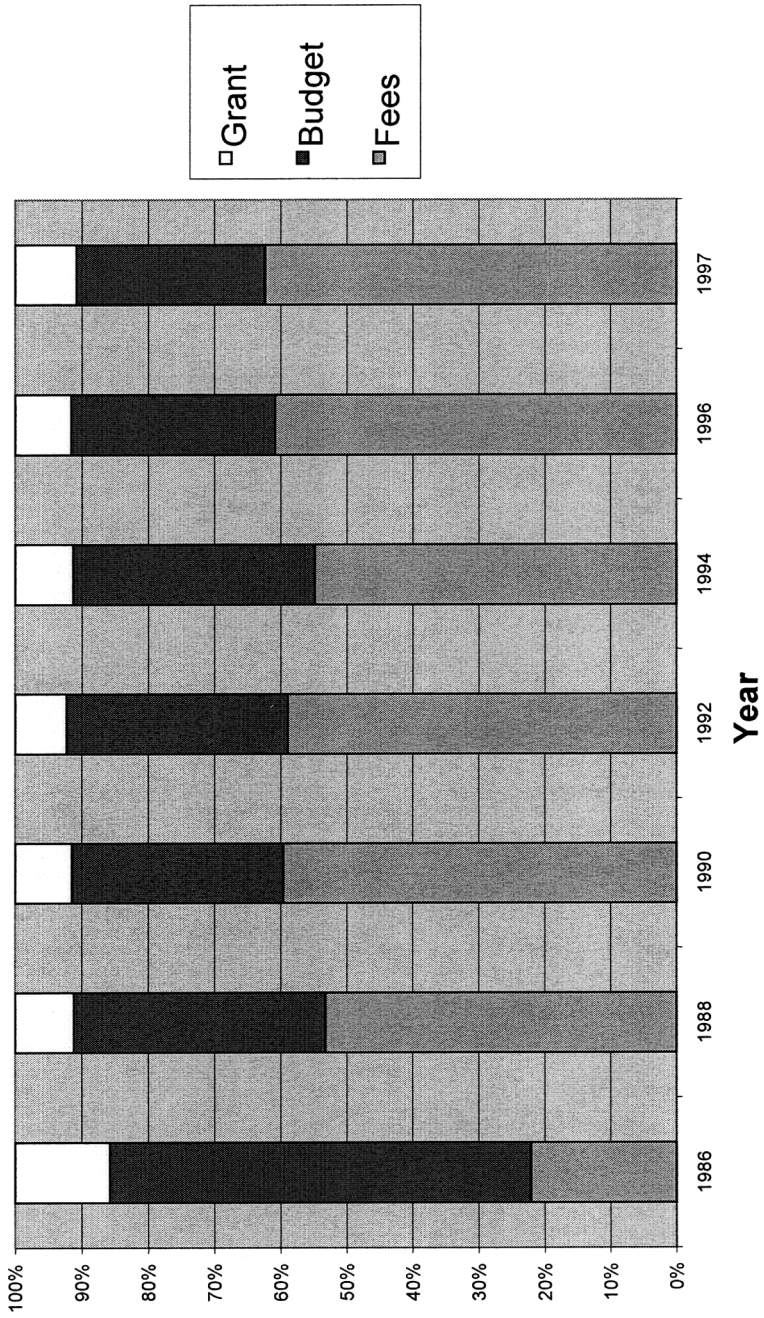

Fig. 4.2 Income sources of China's epidemic prevention stations (Sources: MOH 1994, 1999)

schools. Different sectors (public and private), as well as different levels of government, must all contribute to supporting prevention programs for the general public as well as for their target groups.

2. Service Provision and Organization. HIV prevention outreach is needed within the formal health system for vulnerable or susceptible groups in the population who may access other services, such as MCH, family planning, STD, and TB services, as well as for groups who have less routine contact with the health services, such as youth and married men. These groups can often be reached best through community- and workplace-based AIDS education programs, with the support of the public media. China faces two major challenges in organizing its AIDS prevention and control programs:

1. How to coordinate the public health system's "internal" activities, and
2. How to expand the program to include other players, such as schools and NGOs.

As indicated in Fig. 4.3, China's public health system is comprised of EPSs at different administrative levels—province, city, and county. In addition to conducting health surveillance at the same level, including collecting information on infectious diseases from hospitals under the same level of government, each lower-level EPS is supposed to report to and receive technical guidance from an upper-level EPS. In reality, however, influence and control from the upper-level EPSs are very weak (Hu 1995). Each EPS reports primarily to the government health bureau at the same administrative level, rather than to an upper-level EPS (and thus to the Ministry of Health). The MOH's annual statistical report indicates that there are provinces and cities from which no data were reported. With limited financial resources and very few national administrative mandates, the role of the MOH in initiating and sustaining public health programs has diminished. The building of the Chinese Center for Disease Control and Prevention (China CDC) was approved by the State Council as late as in 2002 (shortly before the SARS epidemic), and much of the infrastructure of a nationally integrated public health surveillance and response system has yet to be established.

To combat SARS, China established a national command and control center under the leadership of Vice Premier Madame Wu Yi. This centralized mechanism turned out to be very effective in coordinating communications and emergency responses to the SARS crisis. But a critical question

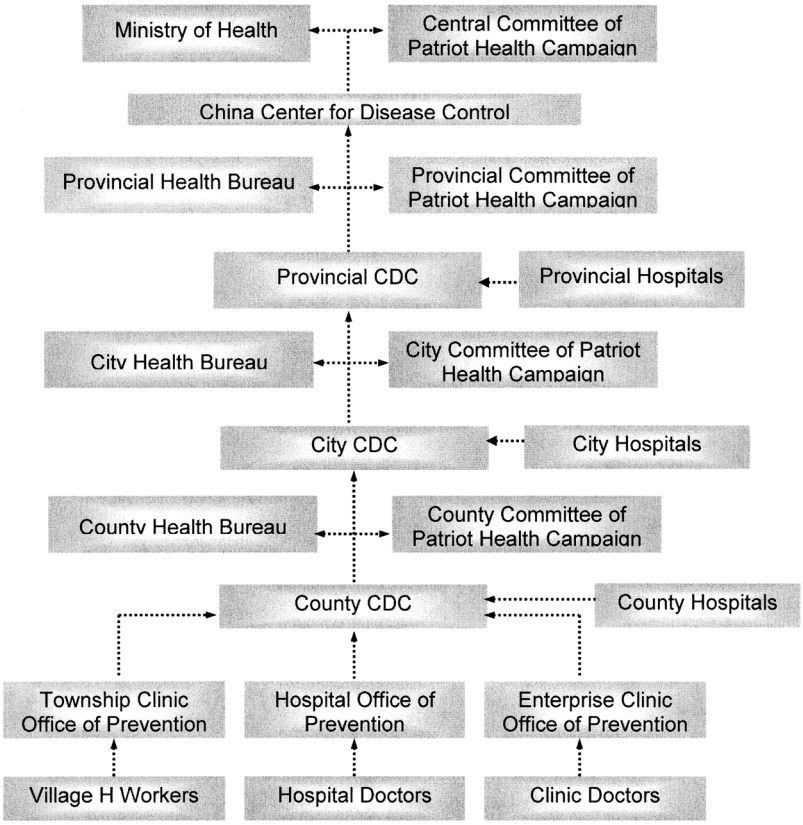

Fig. 4.3 Administrative structure of China's public health system

may arise: Can this kind of crisis management mechanism be sustained in the absence of crisis? To strengthen vertical communications and control, one strategy would be to nationalize part (if not all) of the public health system (e.g., the subsystem of public health surveillance). This means making regional and local EPSs (or parts of these stations) branch offices of the China CDC, by giving the China CDC the necessary financial and organizational levers.

Similar successful reform measures have been adopted in reforming China's taxation system (Forster 2001).This would also mean further strengthening the technical capability of the China CDC to supervise and guide public health work at regional and local levels. Regional and local functionaries will then have a strong incentive to report to the upper levels,

and effective solutions to the local problems can be worked out with competent guidance given by the China CDC.

Prevention within health services also involves the thorough adoption of "universal precautions." These procedures are designed to protect health workers from accidental infection from needle pricks and other sharp points. They include use of proper protective gear, such as rubber gloves; proper disposal of all single-use needles; and proper disinfecting and sterilizing of equipment to prevent transmission to other patients. Use of properly tested blood and blood products is also critical to safety in medical settings.

The adoption of such procedures in other settings, along with accurate information on routes of transmission and risk behaviors, has reassured health workers and other patients about their safety and made it possible for PLWA to access routine health services anonymously (i.e., without t health workers being afraid that they might become infected). Because the great majority of HIV-infected persons do not know that they are infected, this an especially important (see Chapter 9 in this volume).

Prevention outreach is also needed through other health services, especially those that access sexually active adults, or adults with health problems closely associated with HIV risk or infection. These include TB services because TB is the opportunistic infection most closely associated with HIV. Worldwide, the incidence of active TB has increased in direct relationship to HIV infection. One-fifth of all Chinese are infected with TB, or 5 million active cases—perhaps a marker for the increasing rates of HIV infection (WHO 2000). In several countries with high TB/HIV co-infection burdens, the DOTS program structure has been mobilized for HIV prevention, VCT, and treatment support (Farmer et al. 2001).

Family planning services, although provided through a separate vertical structure in China, also offer an important opportunity to communicate HIV prevention messages to sexually active rural women, especially those with migrant husbands who spend months away from home in urban centers (and who may have other, higher-risk sexual partners there). Because most women must visit family planning centers on a regular basis for mandatory contraceptive check-ups, they are an easy-to-reach population for HIV prevention messages.

Routine counseling for the mostly male clients of STD clinics is also important because these men are engaged in risk behaviors that predispose them and their partners to HIV infection (Parish et al. 2003). Unfortunately, most STD patients seek care at private, often unregulated STD clinics

(Stewart 1997) outside the formal health system, and therefore may be harder to reach.

HIV prevention through MCH services is essential both for prevention education and for the prevention of mother-to-child transmission (PMCT), one of the three routes of HIV infection. Single-dose nevirapine (NVP), administered at birth to the mother and shortly after birth to the baby, has been shown to reduce MCT to under 20%. Zidovudine (AZT) is a slightly less effective drug for preventing MCT but is available in generic formulation in China. As part of the Chinese government's commitment to free ARV treatment through the "Four Frees and One Care" policy, PMCT is a guaranteed and free service. But identifying HIV-infected pregnant women requires an effective HIV testing mechanism in rural clinics, and with it, a capability for VCT. These two components of the HIV response through the medical system are discussed below.

Perhaps the most important and difficult challenge in AIDS prevention is inter-sector collaboration. The reduction of risky behavior, such as needle-sharing or unprotected sex with multiple partners, will require aggressive and effective programs of behavioral intervention and general education campaigns to prevent the spread of HIV/AIDS in China. Since these risky behaviors often involve criminal activities, such as illegal drug use and the sex trade, law enforcement agencies will have to be involved in HIV/AIDS prevention. In many other countries, NGOs provide counseling and outreach to marginalized groups while simultaneously generating valuable data for the scientific and policy community about population size and behavior. The Chinese government's general distrust of and resistance to the development of NGOs deprives China of important opportunities to develop effective interventions.

To understand the important role that the private sector now plays in health service delivery in China, one can look at responses to the increasing problem of STDs. STDs not only indicate the potential future extent of HIV infection but actually facilitate the spread of HIV. China's society is rapidly changing, with extramarital sexual contact becoming increasingly commonplace. Though the Chinese government maintains clinics devoted to treatment and surveillance of sexually transmitted infections, many patients visit private clinics. This presents both a challenge and opportunity. On the one hand, these unregulated clinics are partly responsible for the spread of some infections, due to improper reuse of medical equipment such as syringes and catheters (*People's Daily* 2003). On the other hand, since many people prefer to use the private sector for confidential testing, coun-

seling, and treatment, a strong case can be made for developing a necessary and effective public-private partnership in AIDS prevention and control.

II. Discussion: Health System Responses

What major challenges exist in China to prevent and treat HIV/AIDS? As analyzed above, the challenges are not only the lack of financial and human resources, but also how to effectively and efficiently utilize existing resources. From a system analysis view, we have identified three major system constraints that necessitate a three-pronged set of policy recommendations for responding to the HIV/AIDS epidemic in China. These recommendations are called a "PIC" strategy: "P" stands for politics—namely, putting the health system challenges into the context of China's political system; "I" stands for integration of major interventions; and "C" stands for collaboration.

A. CREATING A POLITICALLY ENABLING ENVIRONMENT FOR AIDS RESPONSES

One of the major factors underlying the lack of resources allocated to combating HIV/AIDS is lack of political commitment. A health system cannot function in a vacuum. It is closely intertwined with the national and local socio-economic and political context. Political commitment from the central government is crucial, but because of China's decentralized fiscal system, local governments' political commitment is also needed. The strongest political commitment needs, of course, to come from the Chinese Communist Party (CCP)—and to understand China's policy making process, it is critical to understand the CCP's role. Even though other democratic parties exist, China is still ruled by the one-party system.

Except for the village heads, who are now elected by the villages, all government officials (ranging from mayors and governors to the prime minister) are appointed by the CCP. The executive branch (including the line ministries) and the Party apparatus (e.g., party secretaries at different levels of the administrative chain) jointly decide on major economic and social policies, with the Party holding the veto power. If public health performance, including controlling HIV/AIDS, were included in the performance evaluation criteria for Party leaders at all levels of the government, this would create a powerful incentive for the policy makers in China to take action.

B. INTEGRATING SERVICES TO MAXIMIZE IMPACT AND EFFICIENCY

Given the inherent linkage between prevention and treatment in controlling HIV/AIDS, it would make sense to integrate the two components so that scarce resources can be best utilized. Such integration can take place in two areas: training and system organization. Both prevention and treatment should be incorporated into primary and continuing medical education curricula. This may be easier than system reorganization; in China, prevention work is under the CDC line, and treatment falls under the hospital line. The two rarely collaborate. It remains to be seen how the two components can be integrated into a more effective system of controlling HIV/AIDS.

C. COLLABORATION, COLLABORATION, AND COLLABORATION!

The complexity of the AIDS epidemic requires a comprehensive and intersector response. Therefore, collaboration between different stake-holders is critically important for China's success in controlling HIV/AIDS. This includes horizontal collaboration among different agencies within the health sector, as well as between health sector and other non-health sector players. This also includes vertical collaboration among different levels of institutions. In particular, China needs to learn how to mobilize, guide, and work with NGOs and the private sector.

D. CONCLUSION

Twenty years of underinvestment in China's rural health care system has created inequity and uneven quality, especially in poorer areas. The AIDS epidemic will rely heavily on the health system for effective prevention and treatment programs, since it will create significant additional burdens for health service provision, health education, monitoring, logistics supply, and manpower specialization. A number of recent actions have indicated the Chinese government's willingness to deal aggressively with AIDS. But further effort will be needed to subsidize programs and staff training at the local level—beyond the direct costs of medicines and testing—to ensure adequate supervision and monitoring of the program. A narrow window of opportunity is quickly closing to avert an even costlier epidemic, in terms

both of human suffering and of medical care system costs of dealing with large numbers of sick and dying patients. The time to act is now, and investments made today will be well worth it.

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CHAPTER 5

Initiation of the National Free Antiretroviral Therapy Program in Rural China

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Yi Wen, and Jennifer Pan

I. Background

According to the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), only 8% of approximately 6 million people in developing countries receive needed antiretroviral therapy (ART; see WHO and UNAIDS 2003). Although antiretroviral (ARV) treatment is not a cure for HIV/AIDS and comes with multiple challenges, it has greatly reduced mortality and morbidity rates and improved the quality of life for people living with HIV/AIDS (PLWA). ARV treatment has revitalized communities and has provided a clear rationale for interventions, such as wide-scale HIV testing, that strengthen prevention programs. Although the fear of creating a drug-resistant epidemic lingers, the debate challenging the feasibility and cost-effectiveness of providing ARV treatment in the developing world has largely ceased. There has been a worldwide call to action, and China is answering this call.

China is experiencing one of the world's most rapidly expanding HIV/AIDS epidemics. The most recent national report, released at the end

of 2003, estimates that 840,000 people are infected with HIV, of whom 80,000 are in need of ART (China MOH and UN Theme Group 2003, p. 1). China's first major outbreak of HIV/AIDS occurred in 1989 among intravenous drug users (IDUs) in Yunnan Province. Since 1999, the annual rate of increase in reported HIV infections has been around 30% (ibid., p. 8). Although the bulk of the impact can be found in approximately 200 of China's counties, characterized by their rural setting and high levels of poverty, HIV/AIDS to a certain extent affects all areas of the country (China Global Fund 3 Proposal 2003). At present, the main modes of transmission are intravenous drug use (43.2%), prior commercial blood and plasma selling (26.8%), and sex (8.3%; Wang 2005). IDU transmission is primarily concentrated in the southern, southwestern, and western regions of China; transmission through prior commercial blood and plasma selling is concentrated in central China, and sexual transmission is found primarily in major cities, especially in the south (China Global Fund 3 Proposal 2003).

ARV drugs first became available in China in 1999. Several clinical trials were conducted in large urban hospitals, creating a group of physicians with experience and knowledge of ART. Aside from those enrolled in clinical studies, patients received treatment at these hospitals on a fee-for-service basis. In 2002, the central government decided to pilot a free ART program in Shangcai County, a rural region of Henan Province heavily affected by HIV due to blood and plasma selling activities in the first half of the 1990s. Local physicians received emergency field training and 100 patients were successfully placed on an ARV regimen of domestically produced zidovudine (AZT) and imported didanosine (ddI) and efavirenz (EFV).

Following this initial pilot, the decision to scale up free treatment and care through the Chinese Center for Disease Control and Prevention (China CDC) system was made in February 2003. One month later, the Chinese government initiated the China Comprehensive AIDS Response (China CARES) program in 51 counties across central China, with treatment and care as the main priority. China CARES was later expanded to 127 counties, forming a programmatic foundation for the National Free ART Program that would be implemented under the "Four Frees and One Care" policy announced in December 2003.

In 2003, free treatment and care was a government-led initiative, managed and implemented as an emergency response by the CDC system without utilization of the hospital system. Due to the fact that most infections stemming from blood and plasma selling occurred in the first half of

1990s, many who were infected had progressed to the AIDS stage of the disease by the early 2000s. Given this concentration of people needing treatment, the government deemed it imperative to distribute ARV drugs quickly to save lives. At the national level, responsibility for management and technical assistance was given to the Division of Treatment and Care within the National Center for STD/AIDS Prevention and Control (NCAIDS), China CDC. CDCs at the provincial, prefectural, and county levels were responsible for local management and implementation. ARVs flowed from NCAIDS to local CDCs. Treatment initiation, follow-up, and drug delivery occurred at the county CDC, or at township hospitals and village health clinics that were overseen by the county CDC, depending on the local situation. Due to resource limitations and system constraints, the ability of the local level to provide basic laboratory tests, manage opportunistic infections (OIs), and conduct patient education varied greatly. Short-term training and guidelines were provided by national-level physicians and NCAIDS. A basic three-month reporting system was set up to monitor patient enrollment and attrition. In this early emergency response phase, many obstacles and challenges were encountered. For instance, adherence levels were frequently poor, probably as a result of insufficient patient and community education as well as suboptimal ART options. Many lessons were learned from these experiences and applied to the subsequent efforts to standardize treatment and care.

By the end of 2003, 7,000 patients had been treated with ART. By the end of the next year, a cumulative total of 15,558 patients, mostly from rural central China, had been treated with ART.[1] The most recent information, dating from June 30, 2005, shows a cumulative total of 19,456 patients on ART, with an 8% dropout rate and a 10.2% death rate. These patients live not only within the 127 China CARES counties but in a total of 441 counties in all of China's provinces, autonomous regions, and special municipalities, with the exceptions of Shanghai, Tibet, and Ningxia, which are in the process of preparing to initiate the free treatment and care program. NCAIDS expects that by the end of 2005, more than 20,000 patients will be covered by the National Free ART Program.

A unique characteristic of China's HIV/AIDS epidemic is its concentration in rural rather than urban areas. The rollout of free treatment

1. Prevention of mother-to-child transmission (MCT) has also been initiated on a limited scale through the Maternal and Child Health (MCH) system but is not addressed in depth here.

in China therefore bypasses urban centers for rural locales where infrastructure, human resources, management, logistics, and issues specific to rural patients pose major challenges. Innovative interventions to address these challenges are being implemented and include directly observed therapy (DOT) following the Partners in Health model in rural Haiti; medical worker education based on rural training centers and rotating preceptors; linkages to drug dependence treatment services such as methadone maintenance therapy; a treatment model based at the community level but linked to provincial and national resources to provide the closest access to services with sufficient levels of monitoring and expertise; a network of HIV/AIDS treatment teams at national, provincial, prefectural, and county levels; and patient education initiatives.

China is poised at a critical juncture where targeted and expeditious interventions can limit the spread of HIV from high-risk groups to the general population. The Chinese government has designated ARV treatment as an urgent need, and China's National Free ART Program is evolving from an emergency response to a standardized treatment program. This political backing is crucial to China's ability to overcome challenges and achieve the end goal of providing nationwide access to high-quality treatment and care. This chapter details China's treatment and care policies, funding support, current programs, and future plans to give a general picture of China's response, as well as lessons and experiences for use in other countries.

II. National Free Treatment Policies

In 2001, the "China HIV/AIDS Prevention and Control Five-Year Action Plan (2001–2005)" (hereafter "Action Plan") set the goal of having 70% of medical institutions above the county level—including general hospitals, infectious disease hospitals, and traditional Chinese medicine hospitals—able to provide standard diagnosis, treatment, counseling, and preventive health services for people infected with HIV. The "Action Plan" also set the goal of 50% of HIV/AIDS patients having access to community-based and home-based medical and social care by 2005. The plan is now undergoing revisions for 2006–2010, and an evaluation of its targets is being conducted by the Ministry of Health (MOH). Preliminary data suggest that while China is far from reaching the first goal, it has exceeded the second. Interestingly, the causes of this divergent outcome are similar, stemming from an initial lack of clarity about how and where treatment would be provided, a set of

targets that was difficult to assess, and ongoing tension between treatment coverage and quality.

At the end of 2002, the Chinese government issued a series of policies to increase access to ARV drugs. For instance, tariffs and value-added taxes (VATs) for imported ARVs were waived. ARV drugs were fast-tracked for approval by the state food and drug administration. Direct price negotiations were carried out with GlaxoSmithKline (GSK), Bristol-Myers Squibb (BMS), and Merck Sharp & Dohme (MSD). Four domestic pharmaceutical companies were licensed for generic ARV production, allowing access to domestically produced generics of AZT, ddI, stavudine (d4T), and nevirapine (NVP). These drug access policies formed the necessary basis for initiating the National Free ART Program.

At the UN General Assembly in November 2003, Gao Qiang, then the Executive Vice Minister of Health (he is now the Minister of Health), stated that the Chinese government was committed to providing free treatment and medicines to HIV/AIDS patients facing financial difficulties, including low-income patients in urban areas and all patients in rural areas. In addition, he announced that central and local governments would devote resources to train health care professional in HIV/AIDS prevention and treatment. Clarification and expansion of Minister Gao's announcement came on World AIDS Day of the same year, when Premier Wen Jiabao announced the "Four Frees and One Care" policy during his visit to Beijing Ditan Hospital. This policy states that free ARV drugs will be given to all rural AIDS patients and urban AIDS patients facing financial difficulties; free voluntary counseling and testing (VCT) will be provided in high prevalence areas; free VCT and prevention of mother-to-child transmission (PMCT) services will be provided for pregnant women; free education will be available for children orphaned by HIV/AIDS; and care will be given to all AIDS patients facing financial difficulties.

The creation of the State Council AIDS Working Committee, headed by Vice Premier Wu Yi and consisting of the heads of relevant ministries and affected provinces, occurred in early 2004. Provincial, prefectural, and county governments followed suit to form similar high-level committees dedicated to rapid, multi-sectoral responses to the epidemic.

To assist the implementation of the treatment component of the "Four Frees and One Care" policy, two policy documents were promulgated at the beginning of 2004. The first policy, the "Measures for Management of Drug Treatment of HIV/AIDS and Common OIs at No/Reduced Charge" (hereafter "Measures"; see MOH and Ministry of Finance 2004), clearly

delineates the roles of different institutional actors and broadens the scope of responsibility for treatment and care from the CDC system to the hospital system, which is headed by the MOH Department of Hospital Administration. It assigns financial responsibility for the various facets of treatment and care, with the central government responsible for the cost of ARV drugs, PMTCT drugs, and reagents for infant testing; and with local governments responsible for all other costs, including the cost of drugs for treatment of common OIs, training, outreach, and eliminating barriers to access. "Measures" also provides procedures for drug procurement, distribution, and forecasting; a framework for monitoring and evaluation (M&E); a directory of free ARV drugs, and a list of common HIV-related OIs.

The second policy, "Opinions Concerning the Management of HIV Antiviral Treatment" hereafter "Opinions"; see MOH and State Administration of Traditional Chinese Medicine 2004), outlines operational responsibilities of treatment and care for the county, prefecture, province, and national levels, thus setting up a tiered referral system and a national network of HIV/AIDS physicians.

According to this document, at the national level, the MOH is responsible for the overall management and supervision of HIV/AIDS treatment and care. It is also responsible for the creation of an expert panel, the HIV/AIDS Clinical Taskforce, to develop guidelines for diagnosis and treatment, technical documents, training for provincial-level health professionals, and technical guidance for treatment-related issues.

Provincial bureaus of health are responsible for managing and supervising treatment within the province. Health authorities at this level must create expert panels to provide lower-level training and technical guidance and designate either infectious diseases hospitals or general hospitals to treat patients with critical illnesses, serious OIs, concurrent illnesses, and complications.

The bulk of responsibilities are centered at the prefectural and county levels and distributed among health authorities, disease control departments, and clinicians.

Expert panels should be formed by health authorities at both levels to develop treatment protocols and to provide training, guidance for diagnosis, assessment of treatment efficacy, and management of serious OIs, adverse reactions, and complications, as well as guidance in the development of patient follow-up at the township, village, and community levels.

At the prefectural level, hospitals should be designated to also provide health-related counseling, antenatal and delivery services for HIV-positive pregnant women, and regular follow-up and monitoring of patients.

Disease control departments at both the county and prefectural level are responsible for coordinating home-based treatment, which is the cornerstone of treatment in China; for creating patient treatment records; and for drug management and distribution. County and prefectural clinicians should provide follow-up diagnosis, routine examinations for patients receiving ART, and fine-tuning of treatment regimens.

III. Funding

Over the past few years, funding has increased for HIV/AIDS activities, with a substantial portion allocated for treatment and care. In 2000, the overall central government budget for HIV/AIDS was 10 million CNY ($1.2 million USD). By the next year, the amount had increased tenfold to 100 million ($12 million USD), by 2002 to 300 million ($37 million USD), by 2003 to 470 million ($58 million USD), and by 2004 to 810 million ($100 million USD).

Since the initiation of the pilot sites, the China CARES counties each received 300,000–600,000 CNY ($37,000–$64,000 USD) each year from the central government, which was matched by local funds and allocated to comprehensive treatment and care activities. In the 2003 budget, 270 million CNY ($33 million USD) was allocated specifically for ARV treatment in 15 highly affected provinces. Additionally, to combat the problem of illegal blood selling, the government has raised over 2 billion CNY ($247 million USD) to improve the safety of the blood collection and supply system.

From 2004 to 2009, Round 3 of the Global Fund to Fight AIDS, Tuberculosis, and Malaria is bringing nearly $99 million USD to China with a target of having 40,000 patients on ART. These funds support approximately half of the China CARES counties in the central provinces of Hebei, Henan, Hubei, Shanxi, Shandong, Shaanxi, and Anhui. Round 4 of the Global Fund was approved for nearly $64 million USD, with additional Chinese government matching funds, and will support the provinces of Yunnan, Xinjiang, Guangxi, Sichuan, Guizhou, Hunan, and Jiangxi, which have IDU- and commercial sex worker (CSW)-driven epidemics. Approximately 45,000–50,000 patients are targeted for ART over five years (China Global Fund 4 Proposal 2004).

Other funding sources for treatment and care include international initiatives from the Clinton Foundation, Merck Sharp & Dohme, the US CDC Global AIDS Program (GAP), the WHO, the Department for International Development (DFID)-funded China–UK Project, Bristol-Myers Squibb, and the US National Institutes of Health's (NIH) Comprehensive International Program of Research on AIDS (CIPRA), as well as site-specific support from the Australian Government Overseas Aid Program (AusAID), Médecins Sans Frontières (MSF) France and Belgium, Project Hope, and the US Agency for International Development (USAID) via Family Health International (FHI).

IV. Current Status

A. THE DIVISION OF TREATMENT AND CARE

In January 2002, the Division of Treatment and Care was created within NCAIDS in the China CDC. Dr. Fujie Zhang has been director of the division since its inception and is supported by a staff of 14, including a number of HIV/AIDS clinicians from major hospitals.

B. TREATMENT COVERAGE AND CRITERIA

As mentioned, a cumulative total of 19,456 patients, primarily former plasma donors living in rural areas, had been initiated on ART as of the end of June 2005. From official evaluation reports submitted to NCAIDS, 1,551 have discontinued ART and 1,982 have died, leaving 15,923 patients on therapy.[2] Data for 2004 from select provinces show that 94.2% of deaths were caused by HIV-related diseases and that 65.3% of these patients died within three months of initiating treatment. These data also show that 60.1% of the patients who discontinued therapy did so within the first three months of treatment. Information from June 2005 shows that the top five reasons for discontinuing therapy were "other," side effects, patient request, difficulty with adherence, and progression of disease. Investigations are ongoing to determine the nature of the "other" causes given, but initial

2. Data include patients treated by MSF France in Guangxi Province and by MSF Belgium in Hubei Province.

hypotheses revolve around resource constraints and limited local capacity. Data from 9,262 patients reporting side effects show that 43.9% reported nausea and vomiting, 19.4% rash, 12% peripheral neuropathy, and 11.6% "other" symptoms.

Due to limited availability of ART in China, the majority of patients received AZT/d4T + ddI + NVP at the beginning of the free treatment program. Lamivudine (3TC) was introduced in early 2005, and the first-line treatment recommendation has since been changed to AZT/d4T + 3TC + NVP. The majority of patients who have discontinued therapy therefore reflect the earlier regimen. However, due to the recent introduction of 3TC, 80% of patients are still on the AZT/d4T + ddI +NVP, among whom 77% use AZT. An estimated 18% of patients are using the recommended regimen with 3TC, among whom 63% use d4T. Also available to patients receiving free treatment are indinavir (IDV) and EFV, the latter being added to the directory of free ARV drugs in June 2005. Eligibility for ART is predicated on confirmation of HIV-positive status and is based on clinical criteria of WHO Stage III or IV, symptomatic disease, or extrapulmonary TB, or laboratory criteria of a CD4 count below 200 cells/mm^3 or, in the absence of CD4 testing, total lymphocyte count below 1,200 cells/mm^3 (China CDC 2005).

C. PROGRAM MANAGEMENT

Over the course of the past two years, the government has pushed China's treatment and care efforts from the emergency response detailed above to a standardized treatment system. As mentioned, in the initial emergency stages of treatment delivery, the CDC system was solely responsible for program management. In 2004, responsibility for HIV/AIDS treatment and care shifted to include the hospital administration system, in order to achieve the goal of community- and home-based care described in the "Action Plan" and "Opinions." The Division of Treatment and Care still sits within NCAIDS, in the China CDC, which falls under the Disease Control Department of the MOH; however, under the current scheme, it receives funding and mandates from the MOH Hospital Administration Department. At the provincial level, the bureau of health determines which organization takes the leadership role in management and local implementation in order to develop the treatment model most appropriate to the locale. For example, the Henan and Yunnan bureaus of health have decided to give management of treatment and care activities to the hospital administration

system. In other provinces, such as Anhui and Shandong, the management responsibility lies with the disease control system. In still other provinces, the decision of who will lead has devolved to the prefectural or, in some cases, to the county level. Regardless of these variations in management and leadership, in accordance with "Opinions," the CDC system, from the national to the local level, remains responsible for (1) drug supply management and distribution; (2) data collection, reporting, and analysis; and (3) patient support services at the county level and below, such as patient education and DOT. Hospitals and physicians, under the direction of the hospital administration system, are responsible for treatment initiation and follow-up, change of ART regimen, and the management of medical complications such as diagnosis and treatment of opportunistic infections. Also, as stated in "Opinions," each level delivering ART, from the province to the county, has set up expert panels of physicians, nurses, laboratory technicians, and CDC personnel to guide their programs.

D. NATIONAL EXPERT GROUP

The MOH HIV/AIDS Clinical Taskforce, headed by Dr. Fujie Zhang and composed of 25 infectious disease physicians with HIV/AIDS clinical experience, was formed in early 2002. This taskforce is responsible for drafting technical guidelines and conducting training for health professionals. As mentioned above, similar expert panels have already been formed or are in the process of formation at the provincial, prefectural, and county levels.

E. GUIDELINES

In December 2004, the HIV/AIDS Clinical Taskforce, with support from the WHO, Clinton Foundation, Institute of Human Virology at the University of Maryland, Project Hope, MSF France, US CDC GAP, UNAIDS, and China AIDS Info, developed the "China Free ART Manual." This manual is a technical resource for local authorities as they implement the National Free ART Program. It describes standard requirements for implementing the Free ART Program, treatment strategies, entry criteria and preparations for ART, ARV treatment, follow-up plans, management of side effects, treatment failure, and adherence, as well as other information to support treatment. The HIV/AIDS Clinical Taskforce has also produced the "HIV/AIDS Clinical Treatment and Nursing Training Curriculum 2003." Together with the Chinese Medical Association, the taskforce de-

veloped the "Guideline for AIDS Diagnosis and Treatment." To supplement the work of the taskforce, the Division of Treatment and Care has produced the "HIV/AIDS Basic Knowledge Reader" and the "HIV/AIDS Basic-Level Physician's Manual." In conjunction with the National Maternal and Child Health Center and UNICEF, the division has produced the "HIV/AIDS Pediatric Treatment and Care Manual." The division has also collaborated with the WHO to produce the "Comprehensive Care Operational Framework" and "TB/HIV Management Manual," and with the China–UK Project to produce the "Clinical Management of OIs" and "Home-Based Care" manuals.

F. NATIONAL PHYSICIAN TRAINING PROGRAM

The MOH Department of Hospital Administration gave the Division of Treatment and Care responsibility to design and implement national-level health worker training. Beginning in the middle of 2002, three-day pedagogical training of trainers courses were organized at the national level for provincial- and county-level physicians as a supplement to emergency field training. Since that time, more than 700 physicians, mostly from the provincial level, have participated in short-term training courses, which were extended to five days in 2003. That same year, the MOH designated nine hospitals as national training centers where physicians could participate in mini-residency training courses for two to three months at a time. As of July 2005, approximately 520 provincial- and county-level physicians from regions that have started providing or that will soon provide ART have gone through this type of training. In the fall of 2004, US CDC GAP and the Clinton Foundation, in partnership with NCAIDS, set up a rural training center in Lixin County, Anhui Province, where county-level physicians are trained by a US physician for three months at a time. The training involves clinical consultations at township hospitals and village clinics, as well as home visits and pedagogical sessions. Web-based HIV/AIDS education is available to physicians, and a VCD training curriculum has been developed. National-level physicians have also received HIV/AIDS clinical training at top universities in the US with support from the Clinton Foundation.

The national training curriculum emphasizes the adaptation of materials to the level of the provider. For example, the content of the curriculum for county-level physicians differs greatly from that for provincial-level physicians, in that it focuses more on practical actions and less on pathogenesis.

The national curriculum contains clinical content such as epidemiology, HIV pathogenesis, OI diagnosis and treatment, post-exposure prophylaxis, adherence, psycho-social support, and nutrition. Training courses also include information on government policies, program management, and patient data reporting. In addition to the national training curriculum, the Division of Treatment and Care collects Chinese-language training materials from various international organizations as supplemental resources on a regular basis.

National-level trainings organized by the Division of Treatment and Care focus primarily on providing clinical knowledge to physicians. The MOH, with assistance from Yale-China, has been training nurses in HIV/AIDS. Other organizations, such as Project Hope, MSF, UNICEF, and the Clinton Foundation, support training for counselors and outreach workers in addition to medical workers. Provinces that have begun providing free ART have conducted additional trainings for health workers within their respective regions.

G. DATA COLLECTION

In place of the initial three-month data collection system, information on patients receiving free ART is now collected via a DataFax patient monitoring system at treatment initiation, each follow-up visit, each regimen change, and treatment termination. Data forms, which also function as simple clinical records, are faxed to the National Center for Public Health Surveillance and Information Services, China CDC, and automatically converted into an electronic database with data verification and data cleaning capabilities. Information collected includes demographics; laboratory test results, such as CD4 and biochemistries; clinical signs and symptoms; and self reported adherence. This real-time data collection system is being used by all provinces providing free treatment, with the exception of Henan, which has set up its own electronic medical record system.

H. LABORATORY SUPPORT

Local CDCs are responsible for most laboratory tests, and over the course of the past year have been equipped with machines for CD4 counts (such as Becton Dickinson FACSCount and FACSCaliber), as well as machines for routine blood tests and biochemistries. The purchase of this machinery and the utilization of already existing flow cytometry capacity have greatly en-

hanced laboratory testing capacity to support ART. In addition, the National Reference Laboratory, situated at NCAIDS, has instituted quality control and quality assurance measures, including CD4 guidelines and training courses, to promote standardization and improve laboratory quality.

I. SPECIAL POPULATIONS

As of the middle of the 2005, the majority of patients who had received ART were former plasma sellers living in central China. However, the bulk of HIV/AIDS patients are IDUs living in China's west and southwest regions. For political and technical reasons, service delivery to IDUs is more challenging than to former plasma sellers. For instance, IDUs are generally more mobile and marginalized by society, making the steady delivery of drugs and the regularity of access to medical care difficult. In the beginning of 2005, however, the first IDU treatment and care site was launched in the Liangshan Yi Autonomous Prefecture of Sichuan Province. A two-pronged strategy of linking ARV treatment with drug dependence treatment services and of providing DOT was adopted for this site. As China expands its methadone maintenance treatment program, linkages will increase between drug dependence and ART services.

Co-infections of HIV with tuberculosis (TB) and hepatitis pose serious challenges to the Chinese patient population. The National TB Center at the China CDC and international organizations such as the WHO have begun working on HIV-TB co-infection issues. Widespread testing for TB among HIV patients was conducted in the first quarter of 2005, and linkages between TB treatment and ART are being built. Additionally, operational research has been designed to examine HIV and hepatitis co-infections.

In 2003, 2.5 million children worldwide were living with HIV/AIDS, and an estimated 700,000 children under the age of 15 were newly infected with HIV (Forum for Collaborative HIV Research 2005). Although children only account for 6% of the global epidemic, one in six HIV/AIDS deaths is a child. Most infected children live in the developing world, but few receive treatment because of limited access to pediatric ARV formulations and limited pediatric HIV/AIDS expertise. Due to the presence of both limitations in China, children living with HIV/AIDS there had not been able to receive ART. However, in February 2005, the Clinton Foundation signed a memorandum of understanding with the MOH to provide an emergency donation of pediatric ART and cotrimoxazole (CMZ) formulations, other-

wise unavailable in the Chinese market, for the 200 children who had been identified as needing treatment at the time. The Clinton Foundation is also supporting the Chinese government's efforts to establish a long-term solution for pediatric ART, and the foundation has since expanded its commitment to provide pediatric formulations for as many as 2000 children.

Treatment sites in Henan, Anhui, Shanxi, Hubei, Yunnan, and Guangxi provinces were selected on the basis of prevalence and the strength of established adult treatment to form the initial rollout phase of the pediatric treatment program. A national-level training for physicians, nurses, and laboratory personnel involved in providing pediatric treatment was conducted in January 2005. Additional local-level trainings have been conducted in Henan and Hubei provinces. Family and patient education has also been provided with support from UNICEF and the Clinton Foundation.

J. OPERATIONAL RESEARCH

Operational research is being conducted to help improve delivery of HIV/AIDS treatment and care. Ongoing projects include:

A study evaluating ART delivery models and evaluation methodologies in resource-limited settings;

An ART adherence study in the IDU population;

A general study of adherence programs;

A cotrimoxazole adherence and side effects study;

A pediatric cohort study;

A study comparing the effectiveness of DOT in primary care and tertiary care settings;

Other behavioral intervention studies; and

Drug resistance studies.

Recently, the Division of Treatment and Care, in conjunction with other divisions of NCAIDS and sites around the county, applied to the US National Institutes of Health (NIH) to become a clinical trial unit for optimization of treatment, vaccine research and development, and behavioral and biomedical prevention. The Division of Treatment and Care is also leading the effort to apply to the NIH International Epidemiology Database for the Evaluation of AIDS, which, if successful, would support China's efforts to link various HIV databases and to improve the quality of these databases.

K. INTERNATIONAL COLLABORATION

Much of the progress that has been made over the past two years has been with the support of international partners, who have provided not only funding but, more importantly, technical expertise and treatment experience. Partners who have been active in working with the Division of Treatment and Care include the WHO, US CDC GAP, the Clinton Foundation, and UNICEF. Other partners who have provided technical assistance include MSF, Project Hope, and the Institute of Human Virology at the University of Maryland. In addition to UN organizations, foundations, and NGOs, pharmaceutical companies including Merck Sharp & Dohme, Bristol-Myers Squibb, and Pfizer have programs to support the Division of Treatment and Care. Research funding is also available from the US NIH to support partnerships with American universities and researchers.

V. Lessons Learned

China's experiences in delivering treatment services have shown that a variety of interacting factors, ranging from the technical to the social, affect the success of implementation efforts. Many of these topics deserve much more thorough discussion than can be accomplished here, but they can be highlighted through the case studies detailed below. Many of the technical and programmatic challenges to treatment delivery are universal, and it is hoped that China's experience will be helpful in other resource-limited settings initiating ART programs. Technical challenges include how to:

Conduct strategic planning;

Be effective in price negotiations;

Manage drug procurement and distribution systems;

Start ARV therapy in a setting without strong OI management capacity or a comprehensive care framework;

Make ARV regimen decisions based on a limited number of drugs;

Develop treatment protocols most suitable to the patient populations and health care system capacity;

Design an effective laboratory network, including quality assurance mechanisms; and

Train rural health workers.

However, the underlying question is, What policies will be most effective in bringing about the delivery of high-quality treatment and care? This question must be answered within the context of resource limitations, both human and financial, at various levels of government and within the context of complex political landscapes and variations in health care systems capacity in different regions of the country. In addition to the dilemma of determining the right policies, the best means for implementing these policies is often not clear. From involving and motivating the right group of institutional actors to ensuring that resources achieve their intended use, it is apparent that solutions to the technical issues faced by China in delivering treatment are embedded within the country's economic, political, and social context.

ART is a lifelong commitment that demands excellent adherence and tolerance of side effects. The social environment of the patient and the patient community play a crucial role in patient prognosis and the overall success of the free treatment program. In China, patient identification and follow-up have been difficult due low levels of education and awareness and varying levels of stigma and discrimination. In cases where these barriers were overcome, other factors have influenced the success of free treatment, including poverty, migration pressures on ART patients, the special attention placed on HIV/AIDS as opposed to other diseases with higher rates of mortality and morbidity, and relationships among patients, the government, journalists, activists, and alternative healers.

Moving from a patient perspective to a health care provider perspective, additional challenges arise. Due to inadequate understanding and implementation of universal precautions and infection control measures, significant fear of contracting HIV exists among health workers. In China's fee-based medical system, health workers face pressures to maintain a livelihood and advance their careers, both of which are difficult to do in this poor and largely rural population, but especially when providing free treatment and care.

However, despite these many challenges, the main lesson learned from China's experience is the overriding importance of educating patients and health workers on the benefits and challenges of ART for patients, their families, health workers, and the community. Many subjects outlined above deserve much more extensive analysis. The case examples below illustrate more vividly some of these issues. The majority of lessons were gained from

implementing free ART among former plasma sellers and recipients of blood transfusions, who are mainly farmers living in rural China. It is expected that additional challenges will develop as treatment expands to IDUs, CSWs, ethnic minorities, and men who have sex with men (MSM); however, at present, there is not enough experience to clearly describe those challenges.

A. SUIZHOU COUNTY, HUBEI PROVINCE

Located in central China, where patients were infected through commercial blood selling activities, Suizhou County began its Free ART Program with a high degree of initial success. From the outset, the local government and health care workers were highly motivated to implement the free treatment program, which received technical assistance from NCAIDS and the WHO. The site also received support from Wuhan Zhongnan University Hospital; Dr. Gui Xien, who is a well-recognized HIV/AIDS expert in China; and Project Hope. Stigma was a serious problem in Suizhou, however, and many patients preferred to travel to the county-level clinic rather than go to township clinics closer to their villages and homes.

Working from the "China HIV/AIDS Comprehensive Care Framework" developed in conjunction with the WHO, the Division of Treatment and Care and local health workers set up activity centers called "warmhouses" at both the county and township levels to provide health education, counseling, psycho-social support, and health worker training. Responsibilities were clearly delineated among all partners, including the local CDC and township hospitals, and levels of cooperation were very high. Patient support activities were organized but initially were poorly attended because patients were reluctant to gather. However, despite the stigma, most patients were eager to begin therapy and trusted the local health workers, who in turn took an active and personal interest in the patients. Local health workers were dedicated to conducting regular home visits and took the time to counsel and talk with patients.

As therapy progressed over time and patient clinical conditions improved, the problem of stigma lessened. Peer support and group activities became possible. Patients became willing to been seen at township and village clinics and willing to disclose their HIV-positive status. With support from the WHO, local health workers traveled to Thailand to learn about the country's community-based response to HIV/AIDS. After their return, local health workers decided to try to improve adherence by training patient family

members as adherence buddies. A community center was set up at the village level for patient-led and health-worker-led trainings and discussions. Income generation activities, such as making and selling woven-straw pillows, were carried out. Disclosure of HIV-positive status became increasingly common. Subsequent reported adherence levels have been very high, with over 98% of patients reporting no missed doses at eighteen months. Patient monitoring has been carried out through the DataFax system.

The main lessons gained from this site are the importance of local government support, health worker motivation, effective cooperation between various partners, beneficial initial treatment outcomes, patient trust of health workers and the government, and devoting sufficient resources to patient education. These factors synergized to provide a solid foundation for the free treatment and care program and for determining the most appropriate model of service delivery. Innovative adherence strategies and supportive care frameworks further strengthened the success of Suizhou's treatment program.

B. HEZE COUNTY, SHANDONG PROVINCE

Heze County in western Shandong Province is also affected by the commercial blood and plasma selling of the early 1990s. Two symptomatic patients expressed their intent to leave Heze County for Jinan, the provincial capital of Shandong, and it was well known in the Heze community that these patients expected to die in Jinan. Health officials from the provincial and county CDCs were very committed to helping these patients and started them on ART. Both made quick recoveries, gaining weight and returning to work. This galvanized the entire patient community and garnered their respect for local health care providers and their trust of ARV drugs.

Subsequently, education on adherence and side effects was easy to manage. Patients have had very high reported adherence levels and positive attitudes toward their recovery and future. Laboratory tests have all been performed regularly and appropriately, and the provincial CDC and infectious diseases department of the county hospital have worked together to provide guidance on a regular basis. Similar to Suizhou, key factors to successful treatment initiation were the commitment of local health workers, trust between patients and the local health care system, and initial success in patient outcomes, which bolstered confidence in ART and made education and adherence easier to achieve.

C. LIXIN COUNTY, ANHUI PROVINCE

Lixin County's patient population, also consisting of former plasma sellers, experienced an unfortunate incident early in the implementation of treatment. Two very sick patients were started on ART but died shortly after treatment initiation. After this occurred, large numbers of patients in the county discontinued therapy due to rumors and suspicions that the ARV drugs were harmful rather than beneficial. It took significant efforts on the part of local health workers to seek out patients and educate them about the nature of the ARV drugs they had been given. Gradually, patients came back and restarted therapy. This situation indicates the importance of thorough patient education about the risks and benefits of ART. It is difficult for patients and communities to understand and accept the fact that some patients will die despite or even because of treatment, but that the vast majority will respond extremely well.

Today, a year and a half after this initial experience, large numbers of patients in Lixin are on therapy, and the county is home to China's first rural training center. It is also a focal point for Global Fund Round 3 activities to strengthen program management and make available the basic components of care.

D. SHANGCAI COUNTY, HENAN PROVINCE

Shangcai County has one of the highest HIV prevalence rates in China among former plasma sellers. Interestingly, due to this high prevalence, stigma was not a problem in this county. However, it could be argued that prevalence was the main obstacle to delivering ART because the local health care system had to function above its capacity to manage this large patient burden. The number of health care workers was increased to alleviate some of this burden, but the problem of high prevalence in Shangcai was compounded by the complex relations among patients, the local community, and the local government, as well as by attention on this county from activists and journalists (see Chapter 1 for the delayed response and cover-up in Henan).

Given the high patient burden and emergency nature of initiating free ART in Shangcai, the local government, health system, health workers, and patients were not fully prepared, and the management system was not well established. As a result, relationships among patients, HIV-negative members of the community, and local authorities were not ideal. For instance,

when patients were given cotrimoxazole, a drug familiar to them, to prevent certain OIs, rather than ARV drugs, they felt that the government was not taking their illness seriously. Some patients felt that the government owed them more, and expressed ongoing dissatisfaction that negatively affected patient-government relations and program implementation. Voucher systems were developed to cover the costs of OI diagnosis and treatment, but these vouchers were misused by HIV-negative community members to obtain free health services. Some HIV-negative individuals also tried to obtain fake HIV-positive status in order to receive benefits given to HIV-positive people.

Notably, the success of implementing ART varied considerably among the villages in Shangcai County. Since patient populations were largely the same, the differences can be attributed to varying styles of local management and patient-government relations. Different village leaders took more or less active roles in operations and had varying approaches to management. As a result, implementation and patient outcomes were different.

Since the initiation of treatment in Shangcai County, a great deal has changed. The Henan provincial government, the prefectural government, and the county government have devoted substantial resources to improve basic infrastructure and medical resources. In high-prevalence areas of Henan, new roads, water towers, schools, and clinics have been built. Thousands of physicians, nurses, and health workers have participated in provincial training courses on HIV/AIDS. An extensive list of free medications for HIV-related conditions has been made widely available to supplement ARV drugs. HIV/AIDS has clearly been a top priority for the Henan government and Henan health authorities. They have been able to overcome huge obstacles by learning from earlier lessons and have successfully placed a large number of patients on ART.

E. XINCAI COUNTY, HENAN PROVINCE

Xincai County is situated near Shangcai County and shares many similar characteristics, including income, education levels, ethnicity, and culture. One major difference, however, is a lower prevalence of HIV infection. Xincai County experienced dramatically different results in program implementation compared to Shangcai County. One probable reason is that county officials were very eager and active in implementing the treatment program and in initiating patients on therapy. Another reason may be that Xincai did not have the same complex relations among patients, non-

patients, government, activists, and journalists as Shangcai did. Clinics were set up in some villages so patients could have closer access to treatment. A DOT program based on the Partners in Health Haiti model and China's Global Fund Round 3 proposal was developed with assistance from Dr. Yi Wen of the Division of Treatment and Care. With UNICEF funding support, Dr. Wen helped to designate patients and village leaders as DOT workers, providing them with a basic work stipend. DOT workers stored ARV drugs in their homes and visited patients every day to watch them take their drugs and to provide basic peer support and counseling. The DOT workers reported to local health workers, who monitored their progress and the patients' progress. DOT workers reported a high degree of satisfaction with their work and high levels of adherence among the patients they monitored. With slight variations in DOT worker selection and reporting methodology, this intervention has been adopted across Henan Province with considerable success.

VI. Future Plans and Challenges

Although many lessons have been learned through China's experience implementing free ARV treatment and care, much remains to be done and a large number of challenges remain.

A. MANAGEMENT AND IMPLEMENTATION

Even with the best policies, technical resources, and intentions, China's treatment and care program cannot be successful if it is not managed effectively. Given China's size and complexity, effective management is a Herculean task. The concept of management can be broken down into two categories: clinical management and systems management. As with other issues that have been examined, the more technical issue, clinical management, is easier resolve, but one that is often embedded within the challenge of systems management.

Clinical management refers to the ability to carry out technical protocols and deliver medical services. The development of the "China Free ART Manual" has provided a general framework for clinical management and implementation. In addition, a network of expert groups at the national, provincial, prefectural, and county levels has formed to provide technical and managerial guidance appropriate to each level and area. Due to lack of expertise and experience, however, implementation of technical guidelines

has been uneven. As training is reinforced and experience deepens, clinical management is expected to improve.

Some problems that seem to arise from poor clinical management actually stem from the functioning of China's HIV/AIDS treatment system, and from its health system in general. These problems include the refusal of some hospitals to accept HIV/AIDS patients, the lack of personnel to conduct needed laboratory tests, the irregular follow-up of patients, and the uneven reporting of patient data. As described earlier, the CDC system has responsibility for overall leadership in dealing with China's HIV/AIDS epidemic; however, in treatment delivery, the hospital administration system has been involved because hospitals, physicians, and nurses are a necessary component of high-quality treatment. Unfortunately, due to the verticality of China's governance system and differing priorities at each level of government, the integration of the two systems is uneven and responsibilities are not always clarified. In this environment, conflicts over authority, neglect of responsibilities, and lack of accountability occur simultaneously. The MOH and NCAIDS have been working extensively with various levels of government to resolve these problems.

Another crucial underlying challenge to management is the current state of the Chinese rural health care system and its fee-for-service payment structure (see Chapter 4 above). Most HIV/AIDS patients are farmers with no medical insurance and must pay for their health care out-of-pocket. Hospitals, especially those at the county level and below, must make money from patients in order to stay open (see Chapter 2 for the burden of rural health costs on the poor). Available health care services at those levels are of low quality, even when supported by monetary incentives from the government. Combine these factors with the lifelong nature of ART, and it becomes clear that success in managing the Free ART Program is inexorably linked to the nature and quality of rural health care. Rural health care reform is a top priority for the national government, and there is an ongoing search for ways to link ART to general medical reforms. There are various plans to create appropriate incentives, both monetary and otherwise, for physicians to treat HIV/AIDS in rural locales. For instance, the government is experimenting with schemes to provide vouchers for patients to obtain services and to provide direct subsidies to service sites. The government is also developing programs to provide well-trained physicians from higher levels with financial stipends and research opportunities if they commit to working in rural areas on HIV/AIDS. The characteristics of China's rural health care system continue to create daunting challenges but also hold

opportunities for innovation and for synergies between work in HIV/AIDS and general health systems reform.

B. COLLABORATION AND COORDINATION

Given the size and diversity of China, collaboration and coordination among multitudes of organizations pose considerable difficulties. The policies and regulations described above help clarify the mechanisms for coordination among the different components and levels of the health system involved in providing ART; however, integration with other sectors, such as maternal and child health (MCH), preventative health services, TB services, sexually transmitted infection (STI) programs, and social welfare services remains incomplete. The political commitment expressed by the central government in the formation of the State Council Working Committee on AIDS has sent a strong message to all levels of government about the need to improve coordination and strengthen multi-sectoral collaboration.

In addition to the numerous government actors, a plethora of international organizations and programs have simultaneously overlapping and divergent aims and goals. Although collaboration and coordination are essential in this arena to make efficient use of resources, these goals are often difficult to achieve as existing organizations seek to expand their influence and new organizations seek to enter China. However, in early 2005, the MOH International Cooperation Department began to streamline and consolidate responsibility for managing international partners.

C. DRUGS, EQUIPMENT, AND PROTOCOLS

Improvements made to ARV access, drug management, treatment of OIs, equipment availability, and detection of co-infections show that China can overcome some of the technical challenges of ART delivery. However, there is still a ways to go. The Chinese government continues to stress the importance of taking a scientific approach to treatment, and plans are in motion to overcome remaining obstacles.

At the time of this writing, only first-line ART is available in China. The addition of 3TC to the directory of free ARV drugs greatly improved the tolerability of the first-line regimen; however, resistance to first-line drugs, which is exacerbated by poor adherence and which increases over time, will make many of the currently used drugs ineffective. Cases of treatment failure have already been identified at various sites around the country, but

second-line ARVs have either not been registered or they have been registered but not marketed in China. The majority of first-line ARVs are generic drugs manufactured by domestic pharmaceutical companies, but due to patent restrictions, these companies are not able to produce generic second-line ARVs. The Clinton Foundation is working with various domestic pharmaceutical companies to improve and expand production. In July 2004, the foundation announced an agreement with the Mchem Pharma Group to export pharmaceutical intermediates and active pharmaceutical ingredients to Clinton Foundation partner suppliers, as well as to produce finished formulations of ARVs. Over the next year, Mchem will submit dossiers for WHO prequalification and tentative approval by the US Food and Drug Administration (FDA)—steps crucial to bolstering China's generic ARV production capability. The MOH has also begun discussions with companies, such as Gilead and Abbott, to explore the introduction of new ARVs into the Chinese market.

Even if a wider array of ARVs were available, the management of the drug system is in need of improvement. Drug procurement occurs through a bidding process that is currently determined solely by price. The drug forecasting and distribution network is not always able to ensure rational distribution, nor is it always able to avoid drug stock-outs. The MOH and NCAIDS have been working to improve this system, and UNICEF, in conjunction with the WHO, Clinton Foundation, and MSF, recently conducted an assessment of the drug procurement and management system to identify problem areas. Independently, the Clinton Foundation has also been providing forecasting tools to the MOH and NCAIDS, and China may in the future join the foundation's global procurement network.

In addition to problems with ARV drugs, the need for drugs to treat OIs poses a barrier to overall treatment and care efforts. OIs must generally be treated before ART can be safely initiated; however, costs of diagnosis and management of OIs are high and the funds are often unavailable. According to "Measures," the responsibility for managing OIs falls to provincial governments. Some provinces, such as Henan, have delineated a number of free drugs for HIV/AIDS patients that are readily accessible, but in other provinces patients must pay out-of-pocket to obtain OI treatment.

Laboratory capacity and quality also pose considerable challenges for China. Over the past two years, China's capacity to conduct CD4 testing has been greatly strengthened through purchases of CD4 testing machines. All provinces and all high-prevalence areas are able to conduct this test, although actual availability in some locations is lagging behind this expanded

capacity. The National Reference Laboratory has conducted extensive trainings to improve quality control and quality assurance. However, the cost of reagents for testing remains high for the volume of tests conducted, and the sustainability of testing is in question. China is also in the process of considering how to provide viral load and resistance testing, which are needed to effectively roll out second-line treatment. Unfortunately, costs of these tests are even higher, and until China can find ways to decrease the cost of these tests, it cannot use these technologies in an effective or sustainable manner. The MOH and NCAIDS are currently working with the Clinton Foundation, as well as American universities such as the University of Maryland, to explore various options. To improve the quality of testing and decrease costs, increased centralization of testing is being considered.

The high incidence of co-infection with hepatitis B, hepatitis C, and TB is a distinctive aspect of China's HIV/AIDS epidemic. Given the complexity of treatment of these diseases and drug interactions among various treatments, there is a need to create protocols to manage co-infections in the Chinese population. The Ministry of Science and Technology provides grant support for clinical research into this area, and it is hoped that a successful application of China as a NIH clinical trial unit will bolster knowledge in this realm.

D. HUMAN CAPACITY AND TRAINING

Even though large numbers of physicians, nurses, and other health workers have received training in HIV/AIDS and ART, large gaps exist between gaining knowledge, applying knowledge, and building experience over time. Therefore, to date, there are still relatively few HIV/AIDS treatment experts in China who are able not only to treat patients but also to act as effective trainers.

National-level trainings will continue, and the Division of Treatment and Care plans to strengthen provincial trainer capacity, to provide assistance in provincial-level training planning, and to create an electronic database of human resource and facility assessments that will be updated once a year. There are also plans to create a decision support "warmline" system to strengthen the national treatment network, and plans to make guidelines and training material available online for local access. Guidelines are being developed to address the need for more stringent universal precautions and infection control measures, so that health workers will be safer while treating HIV/AIDS patients. Global Fund Round 3 is also working to increase

general HIV knowledge among health workers and to improve their skills in counseling, interpersonal communications, and education. As mentioned above, incentives to motivate well-trained physicians to work in HIV-stricken areas are also under development.

In addition to the need to bolster health worker capacity, there remains a pressing need to improve program management capacity. In many areas, there is a shortage of personnel to oversee and manage HIV/AIDS programs, which have become numerous over the past few years. Combine this phenomenon with weak managerial skills, and many policies and programs become difficult to implement, with treatment quality suffering as a result. NCAIDS is in the process of developing management training programs, as well as incentives for better management.

E. PATIENT AND COMMUNITY INVOLVEMENT

Many patients across China have done well with ART, and in the examples of successful free ART sites, there is always a visible group of patients who have done well on therapy. These patients could play a valuable role in promoting effective treatment for other patients; however, this valuable resource is currently underutilized. Efforts by various organizations, such as Global Fund Round 3, UNICEF, and the Clinton Foundation, are underway to encourage patient and community mobilization, in particular peer education and outreach. Though in some areas patient organization has met with great success, stigma and discrimination remain basic challenges. The State Council, China CARES, and Global Fund Round 3 have been conducting widespread awareness and anti-stigma campaigns. Policies are being developed to improve the rights of PLWA and their families.

In addition to the need to increase patient education and decrease stigma and discrimination, a broad array of patient-related challenges exist, ranging from financial barriers to patient migration pressures. Other costs of treatment and care—such as the cost of drugs other than ARVs, routine laboratory tests, hospitalization, transportation to and from treatment sites, and basic living expenses—form signification barriers to treatment. For most patients, the national policy of waiving agricultural taxes and school fees has already been instituted. In some areas, basic income generation and poverty alleviation schemes have been initiated. However, the need to scale up these types of activities remains, and the sustainability of current programs is questionable. Given the poverty of regions afflicted by HIV/AIDS, many patients who are becoming healthy on ART face the pressure to mi-

grate for work. These pressures not only affect adherence through behavioral changes, but also disrupt ARV supply, since to prevent drug diversion current policy mandates that a patient can only obtain ARV drugs in his or her place of residence. In some areas, the amount of drugs given to patients who travel for work is increased to a month's supply from a few days' or a week's supply. Plans are also underway to pilot alternative methods of ARV distribution to migrant populations in cities such as Beijing and Shenzhen.

F. MONITORING AND EVALUATION (M&E)

An effective and comprehensive M&E system is essential to the success of China's HIV/AIDS programs. An M&E framework for treatment has been under development for the past year with assistance from the WHO, US CDC GAP, and Clinton Foundation. It is hoped that this treatment framework will catalyze the development of a broader M&E system. A key challenge that has delayed implementation of the M&E system is the need to balance feasibility and usefulness. Many county and lower-level agencies perceive the associated data collection as a burden and as something that is only beneficial to the central government. There is a need to promote lower-level ownership of information that is gathered, which is tied to the previous discussion of improving management of programs. At the central level, the effort to create a simple-to-use yet useful M&E system continues.

VII. Discussion

Among developing nations, China has been one that has answered the call to provide free treatment and care for HIV/AIDS patients. With strong political commitment and support, all HIV-positive Chinese citizens who face financial difficulty are entitled to free ART. Although many challenges were encountered in the initial phases of treatment, many lives were saved and many lessons were learned. With this basis, the Free ART Program is moving from an emergency response to a more standardized treatment system striving to provide wide access to high-quality services. Many hurdles remain, but the program is clearly contributing to China's overall efforts to control its epidemic.

As the National Free ART Program develops, challenges will continue to emerge. However, interesting lessons can be taken from China's experience thus far. In particular, China is unique for its implementation of ART programs in rural areas within a large, geographically and administratively

complex country. Also, it is dealing with the consequences of initially bypassing several administration levels in implementing an emergency response and the subsequent actions needed to standardize and scale up this foundation. Furthermore, China's initiation of a large-scale ART program, while simultaneously building OI management and comprehensive care capacity, may provide a contrast to other nations who built up OI and care capacity before introducing ARVs. Some of the innovations implemented in China—such as DOT, linkage of drug dependence services with ART, and rural-based training—can provide insights for other programs and potential avenues for collaboration with other resource-poor countries trying rollout of universal access to ARVs. Other countries may also learn from China's mistakes, taking care, for example, to emphasize patient and health worker education in the earliest stages of the rollout.

The work that China has done and the progress it has made mean that it will play a role regionally and globally in terms of drug access, experience sharing, and leadership. Given the emphasis on ARV treatment and care in China, there are opportunities to effect broader improvements to the country's overall health care system. China must take advantage of these opportunities but also learn from other countries, both developed and developing, as its treatment program develops and expands.

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CHAPTER 6

Access to HIV/AIDS Treatment in China

Intellectual Property Rights, Generics, and Barriers to Effective Treatment

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JEAN-FRANÇOIS DECHAMP AND

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I. A Brief Introduction to Access to Treatment in China

To address properly the regulatory and legal aspects of "access to treatment," a few basic realities about access in China should first be clarified. Everyone would probably agree that most people living with HIV/AIDS (PLWA) in China do not have access to treatment. However, access includes much more than just cheap antiretroviral (ARV) drugs and depends on many factors:

Access to information. An estimated 93% of HIV-positive people in China do not even know that they are infected, and a large percentage of Chinese surveyed in 2003 showed a serious lack of understanding of HIV/AIDS.

Access to medical care. Most PLWA in China are in rural areas, and have little or no access to qualified medical staff who can recognize and treat opportunistic infections (OIs), know how to use ARVs, or even know when to check for HIV infection. Even those in urban areas usually do

not have access to medical caregivers who are able (and willing) to provide them with basic care for OIs and other medical services for essential health problems.

Access to affordable medicinal products. Price is a major issue in China. Chinese generic ARVs are priced higher than equivalent Indian or Thai versions, and the few preferential pricing schemes (namely, Merck Sharp & Dohme [MSD] and Roche) are minimal. Indeed, for most Chinese, even if the lowest Indian generic prices ($140 USD/person/year; World Bank 2004b) were available in China, which they are not, the cost would be a significant part of their total income or savings.

Availability of appropriate medicinal products. A few examples:

1. Despite a clear need, GlaxoSmithKline (GSK) failed to market 3TC (lamivudine, Epivir®), even though the product is already registered in China, thus gaining time before the expiry of the patent. In late 2004, GSK finally provided the Chinese government with discounted 3TC, which is probably the most important drug for scaling up first-line antiretroviral treatment (ART).

2. For patent reasons, only powdered didanosine (ddI) is legally produced in China. The side effects of powdered ddI are very hard to tolerate, and this appears to have caused seriously reduced adherence.

3. Lack of adequate fixed-dose combinations (FDCs) of ARVs prevents the introduction of a simplified regimen that, although criticized by some, is widely acknowledged as an important tool in scaling up treatments, ensuring compliance, and reducing misuse of ARVs, as well as bringing the cost down to a sustainable level for many Chinese.

4. Kaletra® (an Abbott FDC containing lopinavir and ritonavir), which Chinese health authorities have said they would like to use in their second-line treatment, is registered in China but is not currently marketed for what appear to be strategic reasons on the part of Abbott headquarters (it would likely be prohibitively expensive). Despite continued negotiations with Abbott, Kaletra remains unavailable.

5. None of the few pediatric formulations of ARVs that exist is marketed in China at present, despite a rapidly growing number of children and infants who are HIV-positive or have AIDS. However, a new pediatric ARV initiative has recently been launched in two locations that may push this forward (see Chapter 5).

This chapter is a brief study of what has happened to access to treatment in China as of June 2004. It should be noted that the Chinese government is a not a homogeneous body, and that local governments and different departments often work at odds with or in isolation from one another. Though many choose to blame "the government" for blocking access, it would be more accurate to blame "the system," including the medical system. Also, many of the barriers are not in China at all, but have their roots in international bodies or other governments' trade policies.

Globalization cannot be ignored: the lack of access in China is not just a Chinese issue. AIDS is global, the World Trade Organization (WTO) is global, the pharmaceutical industry is becoming more and more global, and any discussion of the AIDS epidemic in China must include a number of global issues. As China embraces a market economy, it is adopting the rules of the market; joining the WTO is a concrete manifestation of this trend, and pressure to fall in line with intellectual property rights (IPR) protection practices has been intense, especially from the United States. Indeed, the US government consistently stands out as a barrier to developing countries' attempts to pursue their rights to issue compulsory licenses (Cls) in accordance with WTO rules.

There are many ways global trade issues directly affect access to treatment for people with AIDS in China. Trade-related aspects of intellectual property rights (TRIPS) are viewed by many inside the Chinese government as a restriction on China's ability to produce generics, rather than the other way around. Because maintaining China's high rate of economic growth is seen as critical to social stability and macroeconomic planning, China's Ministry of Health (MOH) is not in a position to risk offending multinational companies by threatening to break patents and produce domestic generics. The production by generic companies of FDCs of single ARVs originally registered and produced ("owned") by different pharmaceutical companies is a clear improvement for patients, but widespread use of generic FDCs is viewed as a direct threat to the interests of multinational (research-based) pharmaceutical companies. By insisting on US regulatory approval of generic ARVs, the US President's Emergency Plan for AIDS Relief (PEPFAR) has delayed rapid scale-up of treatment in Africa, and the strong stance of the US trade representative plays a role in effectively limiting access for people across the developing world, including in China. If Chinese companies were allowed to produce and export generic copies of ARVs, and if the quality of Chinese generics were improved to meet World Health

Organization (WHO) prequalification standards, the potential size of the market could significantly reduce the price of Chinese ARVs. However, if current prices are taken as a guide, Chinese companies could not compete with imports from India, for example.

It is impossible to discuss "access to ART in China" without recognizing these dynamics. Although there are many domestic problems that must be addressed, some of the major problems faced by people with HIV/AIDS in China have their roots at least partly in these global trade issues.

II. What Does "Access to ART" Mean, and Why Is It an Issue in China?

ARV treatment is by definition lifelong therapy, and continued access to both the drugs and good medical care, along with strict adherence, are all essential for the treatment to be effective. Under free market reforms, China's medical system has evolved into an insufficiently regulated, highly commercialized system in which most drugs, including some ARVs, are available "over the counter" without a prescription. International experience has shown that information, medical care, and support structures are essential for ARV treatment to be effective. Self-prescription of ARVs is never advisable.

However, access to the ARV drugs is still a critical element in any treatment plan—and one that has until recently been missing in China and that is still only partly resolved there. In late 2002, China started producing four ARVs—AZT (zidovudine), ddI (didanosine), d4T(stavudine), and NVP (nevirapine)—enough to make two different combinations. This was trumpeted as a major achievement, one that would give Chinese patients access to affordable ARV therapy. It was possible to achieve without breaking any patents because all the drugs, or certain formulations of them, were either "off-patent" in China or had been waived by the original patent holders.

But the devil is in the details, and the plan did not go quite as smoothly as anticipated. Many patients could not tolerate the heavy side effects of the treatment, or were not properly informed about such side effects, and thus adherence was too low to be called a success. The most common first-line combination used was ddI + D4T + NVP, a combination well known to produce strong side effects, and one that is potentially dangerous for people co-infected with hepatitis B. It is estimated that more than 10% of people in China have chronic hepatitis B. Also, in November 2003 the US National

Institutes of Health (NIH) added the ddI + d4T combination to the category of "antiretroviral regimens that should not be offered at any time" except when "no other antiretroviral options are available and potential benefits outweigh the risks." Though this information was available in China, it was impossible to legally avoid using ddI + D4T in the available domestically produced first-line regimens. Indeed, even in mid-2005, many patients are being put on this combination, despite the availability of better regimens.

In April 2004 the Chinese MOH announced that there were five ARVs being produced in China, making four different combinations possible. Technically, this was true. The five drugs—AZT, ddI, D4T, IDV (indinavir), and NVP—could be combined to form four different combinations. But the media quoted health officials as saying that China had effectively localized the production of "all basic ARV drugs" and that this was enough to "satisfy the treatment needs of people with HIV in China." This is a fundamental misrepresentation (or misunderstanding) of the true availability of treatment in China: most people do not have access to medical facilities or staff who willing and able to diagnose and treat them, or who know how to properly use ARVs in that treatment; moreover, the five drugs being domestically produced in China did not include the most important drug, lamivudine (3TC), which is the backbone of all internationally recommended first-line treatments. In fact, despite the availability of these five drugs, there is still insufficient access to generic combination therapies in China.

III. Access to and Choice of Antiretrovirals (ARVs) in China

A. The World Health Organization (WHO)'s Essential Drugs

Essential medicines are those that satisfy the priority health care needs of the population. According to the WHO, "Essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford." Which medicines are regarded as essential remains a national responsibility—but the WHO defined the most common ARVs as "essential medicines."

Access to essential drugs depends on rational selection and use of medicines; sustainable, adequate financing; affordable prices; and a reliable health and supply system. Access to medicines is particularly sensitive to costs.

Among the four elements needed to ensure access, the affordability of essential drugs—specifically those still under patent—is most likely to be affected by trade agreements. The WHO list that sets the minimum medicine needs for a basic health care system is a recommendation, and should not be heeded as an obligation. Unfortunately China does not have such a national list, and many of the medicines on the WHO list are unavailable in China.

B. ANTIRETROVIRALS (ARVS)

AVAILABLE IN CHINA

In China, as of June 2004, only seven ARVs (including one combination, ZDV + 3TC) were available, and none of them with the pediatric formulation (when there is one; see Chapter 5 in this volume).When asked during summer 2003 why their ARVs were not being marketed in China, the local representative of one pharmaceutical company replied they were "not interested in the ARV market at the moment" and were "waiting for some positive signs from the Chinese authorities in terms of commitment to tackling HIV/AIDS."

Many international companies went through the process of registering their ARVs in China without putting them on the market, effectively keeping the patented products out of the reach of Chinese patients and often, because of patents, putting off any generic copies from being registered. This strategy is means that, once there is a market opportunity, the product can be launched in a minimum of time and with minimal bureaucratic delay. Though they are commercial products, drugs, especially when they are essential, are not simply another commodity. TRIPS safeguards are a crucial tool for governments to use to protect the rights of their citizens to access to essential drugs, but due to international trade pressures very few countries dare to use—or even to threaten to use—TRIPS.

C. FIXED-DOSED COMBINATIONS (FDCS)

FDCs can be defined as a single medicinal product resulting from the combination of two or more active pharmaceutical ingredients (APIs) and in which each active component contributes to the benefit of the product. From a public health perspective, the development of FDCs of individual ARVs, administered together in a single tablet form, is an important approach to addressing the management of HIV/AIDS in resource-limited settings. FDCs promote adherence, decrease the potential for resistance, and

facilitate stock and procurement management. The WHO has strongly recommended FDCs in its guidelines for initiating scaling-up treatment in developing countries.

Notwithstanding these benefits, there are challenges related to the use of FDCs, such as proper dosages, intolerance to one or more of the components (hence the need for availability of each component separately), different absorption and metabolic rates, and so forth. Currently, there are no uniform, independently defined principles, guidelines, or international standards addressing the development of FDCs and their potential benefits or possible disadvantages in treating these diseases.

In the case of ARVs, FDCs can also be significantly less expensive than originator companies' products, which are not available combined together. The most adequate FDCs cannot be produced when one company owns the patent to a necessary API and another company owns the patent to a secondary component.

D. IMPORTATION OF FOREIGN MEDICINAL PRODUCTS INTO CHINA

Asked about the lack of access to some ARVs, certain companies reply that if their products are not marketed in China, those that are registered can be imported. Technically, this is true. (An unregistered medicinal product cannot be imported to China, unless under exceptional circumstances.) There are, however, many constraints for the purchaser (additional costs, uncertainty about the final price, unpredictable delivery dates, length of the procedure), the importer (burdensome administration), and the manufacturer (the product must comply with the dossier of the Chinese Marketing Authorization as well as specificities other than a Chinese labeling).

It is important to remember that with ART, a consistent supply of drugs is essential, and bureaucratic or other delays for any reason compromise the effectiveness of the treatment and can cause resistance to develop.

IV. Access and Affordable Pricing in China

A. DESCRIPTION

Despite pockets of wealth in China, it is still a developing country, and cost is a critical factor in medical care. For years, imported ARVs have been available, but only a handful of Chinese could afford thousands of US

dollars per year for treatment. Now that the price is dropping and generics are becoming available, the Chinese government has made a firm commitment to provide these drugs to those of its citizens who cannot afford it themselves. However, the government's budget is also limited, and from a public health point of view it is evident that lowering the price of ARVs will greatly increase both the government's and patients' ability to access essential treatment.

B. PREFERENTIAL PRICING PROGRAMS

Originator companies and some generic companies may, under certain conditions, offer "discount" ("preferential," "tiered") prices for their ARVs to potential buyers in selected low- and middle-income countries. The conditions of those charitable initiatives are made public, unlike "one-on-one" initiatives such as the United Nations' Accelerated Access Initiative (AAI). The lack of a uniform preferential pricing system however, has resulted in each company defining a unique series of terms and criteria for its offers worldwide. As a result, only MSD and Roche have elected China for their preferential pricing programs. Roche headquarters in Switzerland claimed that Viracept® (nelfinavir) and Invirase® (saquinavir) have been available at the "access price" in China since February 2003. However, Viracept® could not be imported since it is not registered in China, and Invirase®, which could in theory be imported, was not marketed. In summer 2003, when asked about their "access program," Roche local representatives hardly knew about it, and the "theoretical" importation procedure was excessively cumbersome. Despite public relations efforts by Roche headquarters, it is hard to imagine that this "access price" can really make any difference in China, since the two ARVs are, in practice, not available. MSD headquarters in the US claimed that Stocrin® (efavirenz) and Crixivan® (indinavir) could benefit from a preferential price in China. Only recently has Stocrin® 600 mg been issued a Chinese Marketing Authorization, however, and despite a 2002 announcement that the once-a-day 600 mg product would be sold at a preferential price in China (MSD 2002), that price was still not available.

The ARV preferential pricing programs of the other pharmaceutical companies (Abbott, Boehringer-Ingelheim, Bristol-Myers Squibb [BMS], GlaxoSmithKline [GSK], and Gilead) are not offered in China. As the

examples of MSD and, in particular, Roche sadly illustrate, even when such programs exist in theory, they may be blocked by cumbersome implementation, a failure of company headquarters to empower local branches to act on such commitments, or some other bureaucratic details.

C. PRICES OUTSIDE THE SCOPE OF PREFERENTIAL PRICING PROGRAMS

It is interesting to note that in 2002, the retail price of Combivir® (GSK) in China was 3,643 RMB (approx. $440 USD) per box, which made it equivalent to the retail price in some European countries. In 2003, GSK decreased the price to 1,800 RMB per box (approx. $218 USD). Despite the 50% cut in retail price, $218 USD per box (per month), for only part of the necessary ART, is out of reach for the vast majority of Chinese patients. This "discounted" price is particularly high considering that one of the two components (AZT) is already off-patent.

The AAI grew out of the partnership initiated in May 2000 between the UN (UNFPA, UNICEF, WHO, the World Bank, and UNAIDS Secretariat) and the main ARV-producing pharmaceutical companies. AAI plays a role in facilitating (detractors say "providing an umbrella" for) price negotiations between developing country governments and originator drug companies. The terms of agreements between companies and governments are usually kept secret.

D. TAX-FREE IMPORTATION

In October 2002, the Chinese Ministry of Finance National Tax Bureau issued a document in which Heads of Customs Offices were informed that, from January 1, 2001 until December 31, 2006, ARVs would be exempt from import duty and value-added tax (VAT; see Ministry of Finance 2002). There were many inconsistencies in that list: some drugs were missing (ddI from BMS and AZT from Ranbaxy), and one was technically and legally not an ARV (Heptodin® from GSK). When contacted in summer 2003, pharmaceutical companies' representatives claimed they had not been consulted at the time the list was drafted. Although this is a positive initiative, confusion reigns with a text in which the context is full of inconsistencies, the legal status ambiguous, and the implementation unclear.

E. GOVERNMENT ATTEMPTS TO MAKE BASIC MEDICAL TREATMENT "AFFORDABLE"

Access to affordable medicinal products is a major barrier in China, because for most Chinese the cost of even non-AIDS-related medical care is a big problem. A medicinal product may exist, but if it is too expensive for mass treatment—in the case of ARVs, if it is a branded product—then there is no interest for companies to seriously market the product. For most Chinese, even if the lowest Indian generic prices were available in China, which they are not, the cost would be a significant part of their total income or savings.

Unlike in many African countries, preferential pricing is not available in China, largely due to its World Bank classification as a "lower-middle income" country. Both NGOs and government departments have discussed price reductions with major pharmaceutical companies. As of June 2004, there were a few results (GSK and MSD), but no truly affordable prices.

Although the details of ongoing negotiations between the Chinese government and pharmaceutical companies over ARV pricing remain secret, there are clear indications of the tactics that are likely being taken by the companies. In 2003, in an attempt to slow the rapid rise of public health expenditures, the Shanghai city government tried to institute a number of purchasing control mechanisms that threatened to limit the amount of "imported" (i.e., foreign branded) drugs in public hospitals. A foreign pharmaceutical lobby group in Beijing put a lot of pressure on the city government and health authorities not to implement the plan, even threatening that the plan might prevent them from going ahead with planned investment in Shanghai. While the same level of lobbying has not been documented with regard to the ARV market, pressure from both industry and foreign government representatives has been cited privately by members of the Chinese government as a factor in why China is not pursuing compulsory licensing (CL) or pressuring for voluntary licensing (VL) for ARVs. As noted by the WHO (2003a), "Voluntary negotiations can lead to substantial price reductions for on-patent medicines in developing countries. China will be strongest in negotiating for voluntary discounts if it has reviewed its options for CL and domestic production, and can credibly present these approaches as an alternative to deep discounts."

V. Access and Generics/Branded Medicinal Products in China

A. DESCRIPTION

A generic medicinal product is a usually intended to be interchangeable with the innovator product. However, the concept of a "generic" drug can have different meanings in developing and developed countries. In Western Europe, the US, and other developed countries, the term generally refers to "off-patent" drugs like aspirin or amoxicillin. In the developing world, the term means "not patented here," and often includes drugs that would be protected by patents in developed countries. Thus, when we talk about generics in the context of China and access to ARV treatment, it is important to remember that China sits somewhere between the two regulatory realities. There is an ongoing dispute and debate over IPR and protection of patented products in China, though since entering the WTO, Chinese regulatory authorities have been moving toward the more restrictive "developed" country model of intellectual property rights (IPR) protection.

B. CHINESE AND INDIAN GENERICS AVAILABLE IN CHINA

A growing number of Chinese generic companies is producing and marketing ARVs. Shanghai Desano and North-East Pharmaceuticals were the first, but now other producers are also registering ARVs in China. There is also a nondomestic generic company that has registered two ARVs in China: India's giant generic manufacturer Ranbaxy has registered two ARVs for sale in China. More and more Chinese people are also seeking to smuggle Thai or Indian ARVs into the country for personal use, which is creating an irregular supply of medicine for patients who are often self-medicating and not properly monitored by medical professionals.

C. GENERIC COMPETITION: A WORLDWIDE CHALLENGE

Generic competition has proved to be a critical factor in reducing prices, with the cost for ARV treatment dropping from many thousands of US dollars per year to about $500 USD per year. However, competition has been

limited, and especially considering the new restrictions on generic production in the Indian Patent Law, there is no guarantee that prices will continue to fall. In China, there are two major barriers to large-scale generic ARV production: First, Chinese regulatory authorities are reluctant to override patents by issuing compulsory licenses (CLs) or government use licenses; and second the size of the market for ARVs in China is severely limited by the small number of people who have actually been tested (this is a result of many factors, including lack of confidentiality, insufficient understanding of treatment options, and a lack of trained and skilled medical practitioners to provide ARV therapy in China). It also worth mentioning that the private market for ARVs is virtually nonexistent; the "lucky" Chinese patients who have access to treatment are enrolled in the government's free treatment program (China CARES), participating in clinical trials, or enrolled in NGO treatment programs (Médecins Sans Frontières, MSF).

There are global forces at work. The US has been the major international force opposing the looser interpretation of "generic" and widespread production of generics in the developing world. The logic behind the argument is twofold: either that cheap generics will sneak back into developed markets—a black market—or, more insidiously, that cheap generics do not meet strict safety standards, so that their use in the developing world will endanger poor populations. It is interesting to note two examples outside China. First, ARVs are not protected by patents in Guatemala. In spite of this, the government spends most of its scarce budget on branded ARVs and makes use of no generics at all. Critics say this is out of fear of upsetting the US administration, though such claims are usually difficult to document and negotiations usually take place in secret. Second, Canada, a member of the G8, is pursuing CL legislation that will allow it to produce generic ARVs for export to African countries heavily affected by the AIDS epidemic.

VI. Access and Off-Label Use in China

A. DESCRIPTION

Every medicinal product is approved for use for specific indications, dosages, and patient populations by the national drug authorities, as are its packaging, labeling, and insert materials. The use of a medicinal product for a disease (indication) or a dose not listed on the label is considered to be a "non-approved" or "un-label" or "off-label" use of the product. However, based on their knowledge and on available current information, physicians may

employ a medicinal product for a use not indicated in the "approved" labeling if it seems reasonable or appropriate.

B. THE EXAMPLE OF HEPTODIN® (GSK)

It is indispensable, from a medical approach, to have 3TC as a multiple of 150 mg (Epivir® or a generic equivalent) available as a single ingredient. From both an ethical and a public health point of view, it would not be advisable to base a program on the off-label use of a product without exploring all possibilities.

C. ACCESS AND CLINICAL TRIALS IN CHINA

Chinese regulations on clinical trials of medicinal products are quite strict and adopt a number of international norms and standards. For example, the regulations on clinical trials require that each trial have an ethical review board, that participants be fully informed of the risks, and that the benefits of the trial outweigh the risks to participants. Medical establishments that conduct clinical trials must have ethical review boards, and those boards are responsible for approving or rejecting trials. It is only natural for global pharmaceutical companies to want to hold trials in China because the cost of clinical research is high and costs tend to be lower in China, as they are, for instance, in Central and Eastern European Countries (CEEC).

In reality, various factors mean that medical and ethical standards are often not kept, certainly not in a way that would be acceptable in the home countries of most multinational pharmaceutical companies. First, there is a well-known lack of real ethics committees in hospitals and other health facilities that are authorized to conduct clinical trials. Second, though central authorities have passed many laws on clinical trials, local regulatory authorities appear to have the power to approve clinical trials, effectively bypassing the authority of central government regulators. But more than anything else, the critical factor that compromises the ethics of drug trials in China is a combination of poverty and a lack of good treatment options, which means that many patients turn to clinical trials as a primary source of treatment. This dynamic effectively eliminates the element of choice for participants, seriously compromising the foundation of the informed consent agreements. If a drug trial is a patient's only choice over illness and death, "consent" takes on an altogether different meaning. This is not to suggest the absence of an ethical review process in China. There are insti-

tutional review boards (IRBs) where complaints about unethical treatment of patients are reviewed. However, it is fair to say that most participants—especially those from rural areas, who often lack advanced education and feel powerless—usually do not dare complain unless they feel their rights have been trampled upon. The threshold for recourse is usually much higher than in developed countries.

A trial of Trizivir® (ABC + AZT + 3TC) currently underway in Yunnan Province raises a number of ethical issues. The trial began in mid-2002, and has continued despite the fact that similar trials in developed countries were halted in 2003 due to inferior viral suppression, according to the US NIH and the Second IAS Conference on HIV/AIDS (NIH 2003a, IAS 2003). According to initial reports, the trials included 300 HIV-positive people, though provincial health authorities now say only about 80 people are participating. The trial results were said to be good, but some patients are known to have had bad reactions to Trizivir® and to have gone off the trial. This raises questions about the efficacy of the trial and, combined with the poor results from Trizivir® trials in developed countries, has prompted some calls for the trial to be reviewed. As of June 2004, no review of the treatment protocol had been announced by investigators, and all indications were that no such review would take place. There are also ethical issues concerning costs of the trial. Some participants reported that they could not participate in the initial trial because they were told they needed to pay 10,000 RMB (approx. $1,200 USD) per year for their own CD4 and viral load tests. Indeed, a news report published at that time clearly states that participants would be required to pay for their own testing, a highly questionable arrangement from an ethical point of view. Testing includes both CD4 and viral load tests every few months. This sort of testing can only be required by the needs of the drug study, not the medical needs of the patients. Furthermore, the combined price for those tests at the local government health facility is approximately 2,000 RMB (approx. $240 USD), a price that includes a hefty profit margin above the cost for such tests in China.

It is unclear whether all patients on the trial have been required to pay for their own lab testing, but certainly some were. The result is that these participants were paying considerably more than they expected and could afford. The market price for a year of triple therapy from Thailand or India is around $300 USD, less than the cost of two viral load tests in Yunnan.

Initial announcements on October 17, 2002 by the investigators (Aaron Diamond Research Center, in conjunction with China Academy of Medical Science and the Yunnan Provincial Centre for Diseases Prevention and

Control) indicated that the trial was designed to "answer critical questions about the feasibility of treating large numbers of HIV positive individuals in China" (www.china-aids.org/english/News/News013.htm). However, it seems highly unlikely that Trizivir® will be a probable choice for Chinese patients; moreover, it is not even recommended by the WHO as a first-choice treatment in developing countries. The Trizivir® was supplied free of charge by GSK.

What we see here is that, by their very nature, drug trials in China tend to be seen by patients, and presented by doctors, as the patient's best opportunity to get good treatment. Doctors routinely tell their patients that this is a "chance" to get superior, imported treatment, a chance they cannot afford to forego. Seen in this light, the "informed consent" agreements signed by Chinese patients mean very little, and ethical guidelines and international guidelines have no weight.

VII. Access, Compulsory Licenses (CLs), and Other Trade-Related Aspects of Intellectual Property Rights (TRIPS) Tools in China

TRIPS established intellectual property standards for WTO members, historically based on the standards of developed countries. TRIPS requires patent protection for all products and processes, with a minimum duration of twenty years from the original date of filling. Without any special consideration for medicinal products, TRIPS specifies the rights conferred on a patent owner, but allow for limited exceptions and CLs, subject to specified conditions. The "Doha Declaration" (on TRIPS and Public Health), agreed upon at the Doha WTO Ministerial Meeting in 2001, states that the TRIPS Agreement should be interpreted and implemented in a way that supports public health—thus clarifying some flexibilities allowed by the Agreement for that purpose. The subject of intellectual property is very complex, particularly for medicinal products. The flexibilities affirmed by the WTO when IPR can be connected to public health issues have been the subject of many debates. Those multiples issues have been very well explained and summarized in recent documents from the World Bank and MSF.

A. PATENTS

Patents are used to give inventors a fixed monopoly time in a marketplace to recoup funds expended on research and development (R&D). However, more and more concerns are raised that such costs are usually recouped well

in advance of the twenty-year patents that the US trade representative is pushing on poor countries through bilateral and regional trade agreements. TRIPS specified that patents must be available for all discoveries that "are new, involve an inventive step and are capable of industrial application" (Article 27). Yet because "new" and "inventive" are not defined, countries must establish their own criteria for these terms. It is also well known that many ARVs were produced through public financing (even through the clinical trials stages), and that 85% of the basic and applied research for the five top-selling drugs on the market was produced through taxpayer funding. According to the pharmaceutical industry's own tax records, in 2003 MSD spent 13% of its revenue on marketing and only 5% on R&D, Pfizer spent 35% on marketing and only 15% on R&D, and the industry overall spent 27% on marketing and 11% on R&D.

B. COMPULSORY LICENSING (CL)

CL is a legitimate implementation of one of the safeguards allowed by the TRIPS Agreement to protect public health. If patents have been granted, an appropriate government authority can indicate that, in the interests of public health, a decision can be made that patents will not be enforced. A government use license (a form of CL) authorizes the procurement authority to make (or purchase or import) and distribute a medicinal product without the consent or approval of the patent holder. The granting of CL creates competition by one or more compulsory licensees, which may in turn force prices down. The grant of a compulsory license is legal; it is not a "hold-up" scenario. Compulsory licensing enables a competent government authority to license the use of an invention to a third party of a government agency without the consent of the patent holder. The patent holder, however, retains intellectual property rights and "shall be paid adequate remuneration" according to the circumstances of the case (Article 31), generally in the form of a royalty. It is also important to note that CLs must be granted on a nonexclusive basis since the TRIPS Agreement provides for nondiscrimination between locally produced and imported products (Article 27:1), and that a CL may be granted for importation to satisfy local needs (Article 31). In short, a CL should not also be used to promote domestic manufacturing.

CL is widely used in some industrialized countries, and is an integral part of the intellectual property system. It is the developed countries that have been the most active users of CL (not only in the pharmaceutical field) for a number of purposes, including important anti-trust cases in the US. Canada

used CL extensively in the pharmaceutical field from 1969 until the late 1980s. This resulted in the prices of licensed medicinal products being 47% lower than in the US in 1982. More recently, in 2001, the US Secretary of Health and Human Services (HHS) publicly envisaged the possibility of procuring generic equivalents prior to his negotiations with Bayer (the patentee) on the purchase of the product Cipro® to deal with the consequences of anthrax attacks, although in the end an agreement was reached with Bayer. The threat of CL has been successfully used by Brazil in the pursuit of its national STD/AIDS Program.

C. GOVERNMENT LICENSING

As discussed above, government use licensing is a type of CL that allows a country to produce patented products for public use (i.e., government production rather than private production). It also involves payment of a "reasonable royalty" to the original patent holder. According to a World Bank 2004 Procurement Guide for ARVs (World Bank 2004a), even if a country's patent law does not specifically allow for government use licensing, "this does not mean the government cannot authorize its own use of patents. It should simply follow the rules laid out by the WTO, which recognizes the special nature of 'government use' licensing."

D. COMPULSORY LICENSING IN CHINA

The Chinese Patent Law provides that CLs may be issued in the case of patent holder refusal to grant voluntary licenses (VLs) on reasonable commercial terms (Article 48), or to address a national emergency, an extraordinary state of affairs, or public interest needs (Article 49). It would be hard to imagine a more ideal condition for the use of compulsory licenses permitted under TRIPS by the national government than the case of 3TC (Epivir®, GSK) in China. The basic situation is already clear: China needs 3TC, has the manufacturing capacity, and Chinese patients cannot afford to purchase it at the market price. GSK registered the drug but has not marketed it. In July 2004, after more than two years of negotiations, GSK granted the Chinese government a discounted price on 3TC, though the details of this deal have been kept secret and it remains unclear whether the current supply is for 150 mg or 300 mg dosages of 3TC. During the years of delay, GSK continued to enjoy a lucrative hepatitis B treatment market (because Heptodin® is used to treat hepatitis B), and Chinese PLWA con-

tinued to lack adequate ARV treatment. There are strong indications that the Chinese government was ready to pursue CL at the end of 2002, when rapid scale-up of ARV treatment was being planned. In September 2002, a high-level Ministry of Health official, Qi Xiaoqiu, announced that if drug companies didn't significantly lower prices China would pursue compulsory licenses. Two days later, he abruptly changed course, saying that there was no such policy.

CLs (and other means, such as government licenses) need to be viewed as a means to an end. Compulsory licensing is neither a form of pirating, nor a legal loophole, nor a way to steal intellectual property. It is, in the words of the WHO expert team that visited China in late 2002, a perfectly legal and appropriate response to a medical problem:

> If China chooses to proceed with the issuance of compulsory licenses for some essential medicines, it will be showing its commitment to the patent system. That is, rather than ignoring patents or engaging in underground counterfeiting, the government would be addressing access concerns from within the patent system. The government would be indicating its respect for the patent system, even where crucial public health matters are at stake. (WHO 2003a)

VIII. Access to Lamivudine (3TC): A Chinese Puzzle

There is one drug (lamivudine), there is one company (GSK), and there are two products (Heptodin® and Epivir®). Lamivudine (3TC) is also licensed for the treatment of chronic hepatitis B. However, the effective dose for hepatitis B treatment is 100 mg daily, a dose at which it also causes anti-HIV activity, although the effective and appropriate dose in ART is 150 mg twice daily, or one dose of 300 mg in slow-release form. Lamivudine (3TC) 100 mg is marketed and distributed in China by GSK under the brand name Heptodin® (Zeffix® in certain countries, e.g., the UK). Sales figures in China are difficult to find, but GSK has proclaimed that "Heptodin® reached No. 2 in the market in terms of sales revenue" in 2002 (GSK 2002). According to a GSK press release issued in 2002, Heptodin® "was the leading therapeutic product for the treatment of hepatitis B in China last year (2001), with total sales of around USD 72 million and a 17% market share" (ibid.). GSK also noted in the press release that "the total national hepatitis B drug market is growing by around 18% annually and was valued at around USD 427 million in 2001, of which hospitals accounted for 61%"

(ibid.). According to China Medipharm (quoted by GSK in ibid.), there are around 30 million chronic hepatitis B patients in China. Regarding Heptodin®, unverified figures from the China Pharmaceutical Economics Institute refer to $1 million USD sales in 1999, $21.3 million in 2000, and a constant progression up to an estimation of $85.97 million in 2004. One internet source mentioned a market of 450 million RMB in 2002 (approx. $54 million USD). Those figures cannot be confirmed as exact, but it is nevertheless clear that in China the total sales of Heptodin® is quite sizable in terms of revenue and as a strategic, leading product for GSK in China.

The availability of 3TC as a single ingredient in the appropriate dosage is indispensable in terms of a medical approach. On the one hand, under the current Chinese scenario, if patients begin not to tolerate AZT and the need arises to change to another ARV, even well-tolerated 3TC must be abandoned, putting patients at further risk. On the other hand, the use of Heptodin® also raises the issue of inducing resistance to HIV when treating patients for their chronic hepatitis B who do not know that they are HIV positive, hence compromising their future antiretroviral treatment. As indicated in the Electronic Medicines Compendium (2005), "For HIV co-infected patients not requiring antiretroviral therapy, there is a risk of HIV mutation when using lamivudine alone for treating chronic hepatitis B." According to the British HIV Association, in cases of co-infection, lamivudine 100 mg "should not be used [for the treatment of chronic hepatitis B] except in combination with effective combination antiretroviral therapy" (BHIVA 2003). It also says that "treatments with antiretroviral activity (e.g., lamivudine and tenofovir) must only be given as part of, or in addition to, an effective antiretroviral regime" (ibid.). We will not develop this point further in this chapter, but the issue should not be ignored in China.

Lamivudine (3TC) is protected by many patents in China, hence no generic production is legally possible either as a single ingredient or in a combination. There is a patent on Combivir® known to expire in May 2007. Although the patent that protects AZT has been waived, a patent known to protect ABC expires in December 2005, and one of the patents known to protect 3TC expires in April 2006. An additional patent protecting the triple combination Trizivir® (AZT + ABC + 3TC) expiring in March 2016 makes a generic copy of this product impossible in China. Although Epivir® is registered but not marketed, GSK put Heptodin® on the market. Apart

from price considerations, the use of Heptodin® in HIV/AIDS therapy would be both "off-indication"—that is to say, not for approved use in China (hence on the verge of legality if applied on a large scale)—and inappropriate for both patient and physician.

In short, it seems that GSK has registered and is marketing Combivir® (AZT 300 mg + 3TC 150 mg), but is keeping 3TC 150 mg out of reach of patients while simultaneously benefiting from the large and profitable hepatitis market with 3TC 100 mg (Heptodin®). What appears odd, though, is that Heptodin® is on the National Tax Bureau's duty free and VAT exemption list for ARVs. This is confusing and inappropriate when many Chinese PLWA still await a single-ingredient 3TC to be marketed in the correct dosage. The possibility cannot be excluded that, although the main patent on 3TC will expire in 2006, there could be an additional patent on the *once-a-day formulation* of 3TC 300 mg that would further postpone any possible generic versions of this advanced drug therapy. Thus it could be the case that, until 2006, Chinese patients will have access only to Combivir® and, finally, Epivir® 300 mg. After 2006, generic versions of 3TC 150 mg could be produced, but a generic FDC AZT/3TC (equivalent to Combivir®) is not likely before at least 2007. Access to generic 3TC 300 mg depends on the additional protection of the patent on that product and the time of its expiry. In a curious twist, in a document released by MSF in June 2005, it now appears that GSK's many patents on 3TC are only *process* patents—meaning that if the Chinese government were determined to import generic FDCs containing 3TC from India or Thailand for noncommercial distribution under the government's Free ART Program, it could legally do so.

IX. Next Steps: Partners Working Together to Improve Access

Access to treatment for PLWA in China depends on many factors, key among them being price of ARVs, medical system reform, and medical training. Central government policies are changing quickly, becoming much more aggressive and progressive. Originator companies are not easily keeping up with these policy changes and are not in a hurry to relinquish patent rights or compromise sufficiently on pricing. International pressure, primarily from the US and in the guise of "patent protection" and WTO trading rules or "quality issues," continues to be a strong force impeding access to ARV treatment.

A. THE ROLE OF CHINESE AUTHORITIES

The Chinese regulatory, trade, and health authorities have the power to address key issues such as CL, parallel imports, quality control of generic medicines, and universal access to affordable information, care, testing, and treatment. China CARES is a unique chance for China to create a coherent and comprehensive HIV/AIDS control plan that incorporates prevention, treatment, and public education, and that has the full political and financial backing of both the government and the international community. Though not the focus of this discussion, all "classical" public health tools—such as political commitment, coherent training programs for medical personnel, development of proper monitoring and evaluation systems, and so forth—should be put in place. High-risk behaviors must be decriminalized (as is currently happening), and the fundamental rights of stigmatized groups like sex workers, injecting drug users (IDUs), men having sex with men (MSM), and prisoners must be protected if HIV/AIDS is to be controlled within these populations. Trust must be built between PLWA and health services, as its lack also constitutes a major barrier to effective treatment. Measures that have proved to be efficient in developed countries must be encouraged, such as programs of exchanges of needles, methadone substitution, and the like. Most importantly, PLWA need to be respected, empowered, and involved in the development and implementation of China's AIDS control and prevention plans. Officials in the MOH have expressed a willingness to do this, but there needs to be increased policy support for such an approach, which is still regarded as unconventional in China.

B. THE ROLE OF INTERNATIONAL ORIGINATOR COMPANIES

There is no cure without drugs, and pharmaceutical companies should be encouraged to respect their own commitments (e.g., preferential prices, community involvement, clinical studies and ethical guidelines for research, marketing, etc.). Obstructing access to drugs in the absence of alternatives is particularly sensitive and should not be regarded as a viable commercial strategy. In short, international rules of trade should be applied equally to all producers and countries, including WTO rules such as TRIPS. If there is an alternative, such as a quality generic drug, it is ethically unacceptable to block production simply for profit.

C. THE ROLE OF CHINESE AND INTERNATIONAL GENERIC COMPANIES

Quality in drugs cannot be compromised. China's recent law requiring generic ARVs to pass bioequivalence by July 2004 is an excellent start, but industry insiders report there are still quality flaws in Chinese generics. WHO prequalification for Chinese generics should be introduced and achieved as soon as possible. As to pediatric formulations, they are urgently needed: Chinese authorities officially acknowledge the existence of AIDS orphans but not of HIV-positive or AIDS-affected children, though NGOs and others working on the ground in China are now seeing an increasing number of children with AIDS (see Chapter 12 for data on children and Chapter 5 for treatment incentives).

D. THE ROLE OF CHINESE PEOPLE LIVING WITH AIDS (PLWA)

Like it or not, PLWA are obtaining their own medicine from Thailand and India, and often self-medicating depending on what is available. This is already producing resistance and other dangers such as dangerous toxicity levels, and will continue to occur until there is a reliable, affordable supply of ARV therapy in China. Chinese PLWA must voice demand for equitable treatment from both the government and pharmaceutical companies.

X. Conclusion: Real Progress Despite Regulatory Restrictions

The new Chinese administration that took office in 2003 has made a clear policy shift, and repeatedly promised access to treatment and care for PLWA. After the Severe Acute Respiratory Syndrome (SARS) outbreak in spring 2003, there has been intense scrutiny of the public health system. An open and at times critical dialogue has included HIV/AIDS, the rights of people with HIV/AIDS, and the government's responsibility to protect those rights. Although critics will say that these promises are empty and will never materialize, there are many indications that the central government is taking these issues seriously and is determined to see them implemented on the local level. The full details of many of these changes—such as a policy for universal free testing or the ARVs used in first- and second-line treatment—had not yet been released at the time of writing, having only been drafted at

an April 6, 2004 meeting of the new State Council Working Committee on HIV/AIDS. However, what we can see of the new government's work plan indicates that real progress is being made.

In April 2004, China submitted an application to Round 4 of the Global Fund for AIDS, TB, and Malaria. (The application was successful; see Chapter 5). The application initially aimed to treat 45,000–50,000 people (including IDUs, sex workers, and their partners) in seven high-burden epidemic provinces in southern, southwestern, and northwestern China. Also in April 2004, a new policy addressing these high-risk groups was rolled out: a number of provinces announced instituting needle exchange and methadone programs for IDUs, as well as aggressive condom promotion in saunas, bars, and other places where sex workers are based. Though there will always be moral conservatives in any society who either deny the existence of these groups or argue that they do not "deserve" help, and China is no different from other countries in this respect, the new policies show a practical and determined effort on the part of central authorities to minimize the risk of HIV/AIDS infection in these high-risk groups. Perhaps more importantly, there is an open and nonmoralistic debate on the need to protect IDUs even if they continue to use drugs—an argument that has never been made publicly by Chinese officials.

The State Council AIDS Working Committee (and corresponding new provincial working groups) has taken an aggressive attitude and demanded that local governments put the "Four Frees and One Care" policy into place (SCWGA and UN Theme Group 2004). Vice Premier Wu Yi has also made repeated promises to punish any officials found concealing the extent of the epidemic or failing to properly implement the national treatment and care plans (see also Chapter 3). While it remains to see how this policy will be enforced, it marks a significant shift from the last administration. Access to ARVs and adequate treatment is a necessary component in winning the battle against HIV/AIDS. It is not the only component though, for the political will of the Chinese government is the cornerstone of all efforts in combating that disease.

To date, "free treatment" plans in China have been plagued by incomplete and ineffective implementation. For example:

> The free first-line ARV treatment still includes a combination that is no longer recommended internationally, with strong side effects and other formulation problems (imported medicinal products were, and continue to be, too expensive).

Expensive Western Blot confirmation tests, required by law for notification of patients' HIV status, and therefore for treatment, usually have to be paid for by patients. This has created a bottleneck and prevented many from ever accessing treatment or even knowing their status.

Physicians often require that patients buy other drugs and treatment (e.g., OI treatment) in order to maintain their own incomes, which often rely on drug sales.

OIs are often ignored, not recognized, or not included in the treatment provided by government health bodies.

These attitudes are slowly changing. The central government now appears ready to ensure that whatever is necessary to implement treatment—including testing, confirmatory testing, OI treatment, and so forth—will be provided, free or at an affordable price, with central or local government funding. Hopefully this will be accompanied by a standardization of services and strict regulation of prices for *all* HIV/AIDS–related testing and treatment across China, to prevent local authorities and physicians from using testing and treatment as income-generating medical services. There is a clear indication from the central government that this sort of standardization and regulation is part of their overall plan (SCWGA and UN Theme Group 2004).

Price negotiations with multinational pharmaceutical companies continue, and will be a critical factor in allowing the rapid scale-up of treatment to PLWA in China. If multinational companies are allowed to dictate terms (such as GSK keeping the price of 3TC secret and not allowing domestic production of essential ARVs), the government will have a much more difficult time fulfilling its commitments. Revised national treatment guidelines have been issued by the Chinese Center for Disease Control and Prevention (China CDC), and those guidelines now include 3TC-based first-line treatment. It remains to be seen what the second-line treatment will be and whether the Chinese government will be forced to spend millions of dollars on expensive imports. Though much training and infrastructure building will need to be done, the foundations of an effective treatment program are being laid. The speed at which it is built up and at which the access to affordable, effective treatment is improved will be pivotal factors in preventing the continued rapid growth of China's AIDS epidemic.

There are two fundamental principles that should be recognized, and that if followed would help resolve some of the regulatory and profiteering barriers to access to affordable HIV/AIDS treatment in China. First, no

government—including the Chinese government—should wait until a disease has reached epidemic proportions before being able to act to control it. The TRIPS Agreement is very clear in stating that even in non-emergencies, even if there is only a "public health need," a member state has the right to issue compulsory licenses. Second, no government—including the US government—should hamper other governments from taking all possible legal actions against HIV/AIDS, even if this may not suit its political/economic agenda. Simply put, the protection of markets and intellectual property rights must not take precedence over the lives of people infected with HIV/AIDS.

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CHAPTER 7

The Social Origin of AIDS Panics in China

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Jun Jing

This chapter examines AIDS rumors occurring in China from 2001 to 2005. The analytical framework for my interpretations of such rumors is informed by scholars who have dealt with issues of moral panic and social trust. I point out in particular that the Chinese news media have criminalized people living with HIV/AIDS. This criminalization has been articulated in various news reports, creating an environment of public opinion that has become an impediment to China's efforts in AIDS prevention, care, and treatment. Furthermore, I argue that the public panics caused by AIDS rumors are moral panics that can be traced to a crisis of social trust in contemporary Chinese society.

AIDS Needle Rumors

On December 1, 2001, China Central Television aired a show called "Flying Red Ribbons" to mark International AIDS Day. More than twenty celebrities from China's news media, film industry, and art circles, including the well-known television journalist Cui Yongyuan and the top-notch stage actor Pu Cunxin, appeared on the show and spoke vehemently about the need not to discriminate against people living with HIV/AIDS. Li Ziliang, a farmer from Hebei Province, also appeared on the show. As China's first AIDS patient to talk in front of a camera, he spoke of his fear about stigma and his wish for public support. In a news report afterward, a journalist said

excitedly: "The image of Chinese AIDS patients is no longer one of evasiveness" ("Confront AIDS" 2001).

This prediction was soon proven wrong. Right after the International AIDS Day, even AIDS patients who badly needed to go to the city of Tianjin avoided it altogether. An extremely sensational rumor had spread throughout this port city of nine million people. Transmitted via the internet and text messages on cell phones, the rumor had it that a group of AIDS patients from Henan Province had come to Tianjin to do harm by using syringes to inject their HIV-positive blood into people taking the city's buses, shopping on the streets, or dancing in nightclubs. It was rumored that younger women were an especially targeted group. Because of the ensuing public panic, the city's Department of Public Security investigated the rumor and then declared the police had not found a single AIDS patient from Henan or anywhere else who had been poking local residents with contaminated needles ("Why did the voice of authority come so late?" 2002).

Four years later, International AIDS Day was marked in all major cities in China again. A show called "China's Warmth" was run on Central China Television. This 2005 show was supported by many more ministries of the Chinese central government than in previous years and was staged for the first time in the Great Hall of the People in Beijing, an indication that the Chinese Communist Party and the State Council have been giving the country's campaign against the AIDS epidemic greater attention and encouragement. The artistic performances during the show were choreographed in three segments and were printed on the show's program as "Control AIDS, Keep the Promise, and Love under the Sunshine." Celebrities, health officials, and pop singers held hands and made various short speeches. Again, a main message of their speeches was the importance of ending discrimination against people living with HIV/AIDS.

And again, just after International AIDS Day in 2005, AIDS patients were rumored to be using dirty needles to harm innocent people. This time many rumors circulated in such large cities as Shanghai, Wenzhou, Fuzhou, Nanjing, Xi'an, Shenzhen, Yinchuan, Jinan, Lanzhou, Nanning, and Guangzhou. The Jinan rumor had it that "AIDS needles" had been deliberately hidden in chairs and benches in public places in the city proper. A text message transmitted via cell phones in Nanjing said that a gang of AIDS patients had drawn blood from their own bodies and put it into syringes for poking and piercing people at random. In Shenzhen, it was rumored that criminals were using "AIDS needles" to attack schools and had caused two students to become infected with HIV. The rumor in Shanghai had it that

AIDS patients from Xinjiang were using "poisoned needles" to pierce people at train stations. The public image of AIDS patients very quickly became one of crazed criminals. In every case a public panic occurred. And in every case police investigations turned up nothing but the fact that the rumors were indeed rumors. Police authorities in different cities made various statements in the news media to dispel the AIDS needle rumors in 2005. (One example is "AIDS needles in attacks on schools?" 2005).

Collective Moral Panics

For sake of brevity, I use "AIDS needle rumors" in the discussion that follows. Such rumors also occurred in 2002, 2003, and 2004 in different Chinese cities, although the rumor in 2001 led to the most serious public panic to date, while the rumors of 2005 were the most widespread in terms of the numbers of cities and people they reached. When the rumor of 2001 seized the city of Tianjin, local police quickly launched an investigation and apprehended four robbers who had put mercurochrome into syringes and then threatened their victims by claiming that they had "AIDS needles." None of these robbers was from Henan. In 2005, public security authorities in cities such as Shanghai and Guangzhou drew on the Tianjin experience and immediately suspected that the hearsay about AIDS patients deliberately trying to infect other people must be a rumor. Follow-up investigations proved their hunch to be right. In retrospect, the rumors were easily exposed and public fear disappeared as soon as government officials called the rumors total lies in the news media. What gave rise to these rumors, however, has remained unexamined by scholars. And the question of why the rumors caused panics also needs scrutiny because these panics were rooted in public perceptions of AIDS patients in China.

Many scholars have already informed us of why deep-grained stigma is attached to AIDS in China. The specific reasons include the association of HIV infection with certain high-risk behaviors (e.g., injection drug use and casual sex), the linkage of HIV infection with poverty and low awareness of risks (e.g., the excessive selling of blood by impoverished and little educated farmers in central China), and the tensions between dominant social values and what is still perceived as deviant individualism (e.g., the rift between heterosexuals and homosexuals with regard to love, sex, and marriage). Yet focusing on these explanations merely reinforces the public's assumption that, in the final analysis, the fault lies with the victims of AIDS. For example,

a woman representing a government agency in charge of the protection of women's rights in China said, at a policy forum held at Tsinghua University's law school in 2001, that Chinese female sex workers were attracted to the sex trade for two reasons. First, they loved the easy money because they were lazy and greedy. Second, they loved the sex because they developed such a craving for sex over time that they did not want to have other jobs. Different but equally biased views apply to public perceptions of gay men's failure to be just like other, "normal" men, and of drug users for not having the personal will or intelligence to resist the temptation of substance abuse in the first place.

Even in the case of those impoverished farmers who became infected with HIV after selling their plasma at blood collecting centers where the procedures to collect the blood and plasma were unsafe, part of the fault is still delegated to the victims, who are perceived by local officials and co-villagers as having chosen a quick and easy way to get extra cash instead of finding hard work in order to earn needed money. It is true that these farmers are perceived by the Chinese public at large to be "innocent" victims, but they are also regarded as so ignorant that they continued to sell blood after the government shut down the plasma collection centers and drove the plasma trade underground in the mid-1990s.

The AIDS needle rumors fed on these perceptions of morality, causing what I refer to as "collective moral panics." By this I mean the collective fears of and reactions to a perceived threat to a society's basic values and interests. According to Stanley Cohen, who coined the term "moral panic," the perceived threat takes on a new dimension of meaning when it is moralized with references to a particular group of individuals who have been stereotyped in the news media, so that the threat in question is easily sensationalized and the public imagination inflamed (Cohen 1972). And according to Frank Ferudi, large-scale moral panics occur in societies that are experiencing rapid and difficult social transformations, which often generate a great deal of uncertainty and even a sense of loss among members of the public. Moral panics play the role of focusing the public's attention on a common threat, more often imagined than real, thus leading to a restored sense of control, albeit a short-lived one (Furedi 1997; see also Goode and Nachman 1994).

Moral panics, as history shows us, have three "exits," or ways of subsiding. First, they may suddenly become a farce and disappear when the perceived threat turns out to be false beyond any doubt. Second, they may become part

of the collective memory of a society, remaining dormant in the public consciousness and coming back when the right occasion again arises. Third, they may become social policies and even a driving force of political or religious persecutions. Past examples of moral panics that turned into the third exit are many. In 1692, the Salem Witchcraft case in New England led to 19 executions, the imprisonment of 185 people, and the filing of accusations at courts against more than 200 individuals (Boyer 1974). In 1768, the Soul Stealing case in China sent a shock throughout the Manchu empire, resulting in the killings of hundreds of people, including officials (Kuhn 1990). In 2002, the Greek government feared that online chess games would lead to widespread gambling and therefore banned the installation of software for electronic games on computers in private homes and internet cafes ("Greek electronic game ban" 2005). An AIDS-related moral panic took place in upstate New York in 1997, when a black young man by the name of Nushawn Williams was suspected by health authorities of intentionally transmitting HIV to about 100 women. Although it was hard to prove his intentionality because he may have infected only 14 women who had histories of drug abuse and multiple sex partners, the Nushawn Williams case caused a public panic that led to passage of a bill by New York State legislature requiring people to provide their real names and addresses when they test HIV positive (Shevory 2004).

In China, there has been a strong belief that AIDS patients are bound deliberately to hurt other people and that one of the means they would adopt to do so is the use of "AIDS needles" (*aizi zhen* in Chinese). This belief was first articulated by police authorities and lawmakers in 2001. Thus appeals to build special prisons for offenders living with HIV/AIDS were proposed at provincial legislative bodies and in the news media. Appeals for a special law were also made with regard to intentional acts to cause HIV infection. Although the AIDS needle rumors were all proved to be totally groundless, the ensuing moral panics have served to strengthen law-enforcement appeals for tougher actions against "AIDS criminals." Given this background, we can examine the rumors and the panics as a two-act social drama. In the pages that follow, I focus on the roles played by ordinary people who believed and helped spread the rumors. I also examine how government officials and AIDS experts tried to calm the public. Special attention is given to the role of some journalists who have described AIDS patients as a threat to society and how their news stories about such a threat contributed to the AIDS needle rumors.

The Rise of Rumors and the Public Response

On a cold afternoon in December 2001, a student of mine heard that I was planning to have dinner outside my university and she immediately warned me that I should be careful when going out because AIDS patients were using dirty needles to harm people in Tianjin and Beijing. She said that she had been told this by a friend and that many students at the university had heard about it, too. I asked her to perform a sociological exercise by tracing the source of her information, person by person. Soon she called me to say that by the time she reached the third person by phone she discovered that the rumor had originated on the internet and that students at the university were discussing the matter in online chat rooms. I turned on my computer and searched cyberspace, looking for messages posted at Tianjin University because I suspected that students there would be more nervous. A message soon caught my eye that specifically identified Henan AIDS patients as the troublemakers. I noticed that the message has been copied many times before appearing on the website of Tianjin University, making its original source hard to trace.

The Chinese AIDS needle rumors have found the most modern means of communication via which to thrive. Along with cell phones, the internet is a nest of all kinds of rumors. The most sensational AIDS rumor was one that originated on the internet, claiming that 5,000 people in the southern city of Guangzhou had been injured by "AIDS needles." The posted message responsible for the rumor had this to say:

> A week ago, someone found a sharp object in a seat in a Guangzhou cinema. He stood up and found a needle cutting through the seat cover and a note saying "You are infected with AIDS now." By the confirmation of Guangdong Provincial Center for Disease Control, 5,000 people in the city of Guangzhou have been infected and the needles were tested HIV-positive. Everybody should be on high alert and examine public benches and chairs before sitting on them. ("AIDS needles hidden in cinema seats?" 2005)

Since the creators of the AIDS rumors have been hard to find, it is hard to determine their motivations. But from two cases in which the creators were found, we see that malice and irresponsibility are both at work. The first case was that of a young man in a small town of Guangdong who had developed a bad relationship with a young woman. He sent malicious text messages via a cell phone, telling the woman's friends that she was an AIDS

patient and that she had secretly put her blood into a syringe to infect other people. This message was circulated so widely that eventually police in Macao became concerned and asked Guangdong police to track down its original sender ("Police refute AIDS needle rumors" 2005). The second case involved four people. Two were students at a vocational school in Shanghai who started the rumor purely on the basis of imagination. They did not use cell phones or the internet to spread the rumor but simply talked about it, and their conversations became known among other students at their school. A Mr. Wu in Shanghai heard the rumor, wrote it down, and posted it on the internet. A Mr. Gui in Shanghai also heard the rumor and text-messaged it via his cell phone to his friends. Shanghai police arrested both men. The two students were only given a stern lecture by the police, partly because they did not use cell phones or the internet to spread the rumor and partly because the police considered them too young to be subject to legal punishment ("Police expose AIDS needle hearsay" 2005).

When we trace the history of the AIDS needle rumors in China, we realize that the 2001 Tianjin rumor was the earliest and had extremely colorful details, though its creator was never found. In an article published in reaction to a new AIDS needle rumor in 2003, a journalist wrote about the earlier Tianjin rumor, saying that it had changed every day and that everyone heard a slightly different version, often claiming that Henan AIDS patients picked women and even children as their targets. Regarding the rumor's impact, he had this to say:

> The criminal investigation department of the Tianjin Public Security Bureau and doctors of criminal justice set physical checkup services and every day they received people requesting checkups to see whether they had been needle-pierced. Eventually, there were not enough doctors to perform the services. A university student came back home for the holidays. When she was shopping on a street she felt she was being pierced. Her parents took her to the criminal investigation department and the doctors there used a magnifying glass to look for a needle's hole on her buttocks and yet could not find it. ("Memories of the Tianjin Needle-Piercing Incident" 2003)

The public panic in Tianjin was such that even its busiest commercial streets, such as the Street of Peace and the Riverside Road, lost their usual crowds of shoppers. And this was the time between two important holidays—the New Year on the Western calendar and the New Year on the Chinese calendar. To calm the city, 300 police officers were ordered to sit on the city's buses, dance halls were shut down, and old ladies who were members of neighborhood committees kept a watchful eye on strangers.

And by the end of January 2002, the Tianjin city government announced that the police had apprehended four criminals using false AIDS needles to rob people, but that absolutely no AIDS patients had committed any crime in Tianjin. Immediately, the public panic disappeared.

While police officers and government officials used very simple language to tell the public that what had caused the city's nervousness was the act of a gang of criminals using mercurochrome and syringes to threaten and rob people, Chinese AIDS experts tried to use complicated scientific terms to calm the city. In interviews aired on television and printed in newspapers, they talked about how short-lived HIV is when it is taken out of the human body and how many units of the virus are needed to cause infection. These explanations fell on deaf ears because the public had not yet received enough AIDS education fully to understand these medical concepts. The public fear hinged on the questions whether or not AIDS patients were using HIV to engage in urban terrorism and whether or not ordinary citizens would be victimized. Thus the biggest failure of Chinese AIDS experts was their reluctance to say that AIDS patients themselves were in fact being victimized by the rumor, and that it was extremely unlikely that Henan's rural AIDS patients would come to Tianjin in groups to harm total strangers. These experts could have described the AIDS epidemic in Henan and emphasized the fact that if Henan AIDS patients had any extra money they would spend it on medicine or to send their children to school, or save it for their own funerals. After all, this was a time when the death toll of AIDS patients in rural Henan was on the rise and local officials had already sent urgent reports to the Ministry of Health about the unusually large number of AIDS-related deaths in rural counties such as Xincai and Shangcai, where the plasma trade had once thrived. Behind the reluctance of Chinese AIDS experts to clear the name of Henan AIDS patients was a suspicion compatible with the public belief that somehow Henan AIDS patients would try to harm society.

The News Media's Contribution to AIDS Needle Rumors

The core of the 2001 Tianjin AIDS needle rumor was that AIDS patients in Henan were taking revenge on society, presumably because local government officials there were trying to cover up the devastating impact of the plasma trade in Henan and were thereby preventing the Ministry of Health from launching prevention and treatment programs to save lives in the province. Thus the Tianjin rumor clearly identified the Henan AIDS patients as "innocent" victims of government actions. The assumption was

that these farmers were retaliating against the government by hurting people they could hurt—namely, civilians without much power or protection. The identification of AIDS patients as "innocent" victims in the Tianjin case was forever lost in later rumors, replaced by the label of "immoral" troublemakers. This change of character identification had a lot to do with government policies, too. The effort by the Chinese central government to save lives in Henan was undertaken in 2002, right after the AIDS panic in Tianjin. By September 2003, the Chinese government embarked a larger scale of prevention and treatment in rural Henan by declaring a policy known as the "Four Frees and One Care" (*si mian yi guanhuai*). It included the offer of free ARV drugs, free counseling and testing, free drugs to HIV-positive women who were pregnant (so as to stop mother-to-child infection), free schooling for children orphaned by AIDS, and economic assistance to families suffering from AIDS. The rumors in the years that followed never again involved AIDS patients in Henan, focusing instead on "immoral" individuals.

The shift from innocence to immorality in the rumors can be traced to sensational writings in Chinese print news media on the threat that AIDS patients pose to society. In the past five years, a string of articles has been published in newspapers and on newspaper-run websites about how criminals use "AIDS needles" to harm society and escape legal punishment. A careful reading of these articles shows that these criminals were not real AIDS sufferers and were merely claiming to be AIDS patients so as to scare civilians and resist police arrest. Moreover, the syringes they had did not contain any HIV-positive blood or any blood at all. But these stories are written in such as way that they have outdone American tabloids. An example is an excerpt from an article published on November 3, 2005, in the *Chongqing Times*:

> Around 1 p.m. yesterday, a college student by the name of Xiao Li got onto the No. 404 Bus at the Sha Ping Ba station and later ran into a horrifying passenger who swindled her out of 200 yuan. Afterward, Xiao Li came to the Yubei Police Station to report the crime. According to Xiaoli, she and two of her classmates got on the No.404 Bus at 1 p.m. on their way to Yang Jia Ping. "You, come over here. I must talk with you," a young man said to Xiao Li. He was a total stranger to her but sounded friendly. Xiao Li stood up from her seat and followed the young man to a corner on the bus. "I am holding a needle in my hands and it is infected with HIV. Give me your money or I am going to pierce you with this needle," the man threatened and looked thoroughly ferocious. At the same time, he slowly took out a white-colored plastic syringe and had a very strange look on his face. ("Man on Chongqing bus holds AIDS needle" 2005)

Note that the man who "looked ferocious" was holding a white syringe, not one containing any blood. The reader has no way of knowing if the criminal was an AIDS patient, yet the headline of this story was "Encounter with AIDS Needle on City Bus."

Other news stories have identified "AIDS gangs" (*aizi tuanhuo*) supposedly consisting of AIDS patients who rob civilians and resist police arrest by using contaminated syringes as weapons. For example, an evening newspaper in Yunnan reported on December 11, 2004, that a policeman in the city of Zhaotong had been injured by a young woman who was an AIDS patient ("Full coverage of AIDS needle attack" 2005). According to this report, the young woman committed a robbery and was on the run when she was apprehended by the policeman. She pulled out a syringe and stabbed his right hand. The city's center for disease control administered treatment immediately and sent the policeman to the city of Kunming for HIV testing three months later. He tested negative. The news story never mentioned whether the syringe was tested for HIV, so the paper's readers had no way of way of knowing whether or not the blood in it was HIV positive. When writing this chapter, I asked a friend to contact the director of the Yunnan Provincial Office for HIV/AIDS Prevention and Control to verify the news story, and learned that the young woman involved in this case was indeed HIV positive and an injection drug user. But she did not deliberately put her blood into the syringe to use it as a weapon. She was merely carrying the syringe with her for drug injections and used it to resist arrest.

Although the journalist responsible for the above news story neglected to differentiate between a premeditated crime and an act of resisting arrest that ended in a policeman's injury, other journalists in China simply adopted an all-round attitude of irresponsibility in reporting the so-called AIDS needle incidents. On April 2, 2003, for example, an article appeared on the *Today's Morning News* in Zhejiang with a sensational headline: "AIDS in Crime, We Cannot Avoid"(2003). The opening paragraph of the story was equally sensational:

> HIV carriers hold syringes in their hands to threaten and blackmail shop owners and pedestrians and even coerce doctors to give them pethidine injections. This is not a scene out of horror movies. In recent years, social chaos has been created in some areas of this country because some AIDS patients declared themselves to be AIDS carriers and unafraid of anyone, so that they could rob, steal and commit other crimes. Early this year, Today's Morning News reported a criminal case of using AIDS needles to commit the crimes of extortion and rape in the city of Hangzhou. Although the AIDS needles are fake ones, there is an ongoing trial in the Jianggang

District of Hangzhou and another criminal case in the city of Wenzhou that both have linked people living with HIV/AIDS to crimes. While the advocacy in society is to love and care for AIDS patients, the crimes they commit are a problem not encountered before.

Because the opening sentence claims that HIV carriers use syringes to threaten and blackmail various people, one would assume that this report is about the use of syringes by AIDS patients to commit crimes. But the only two people mentioned in the story had nothing to do with such crimes. The first person is called Ah Si, a petty thief from Xinjiang, and the second is a Chinese student who returned from Jordan. Both are HIV positive but have never used dirty needles to rob or steal. And this is how the journalist wrote about Ah Si:

Ah Si had nothing to do and decided to get on a long-distance bus from Jiaxing to Hangzhou. He got off the bus before the bus reached its destination. He was wandering when he saw a woman in her twenties coming toward him on a bicycle. He was delighted to see a cell phone lanyard hanging out of the young woman's breast pocket. He quickly decided to steal it. He ran to the young woman and snatched the cell phone from her. Now Ah Si has been convicted of theft, placed under police custody for four months, and fined 1,000 RMB. Apart from the price he has to pay for his crime, he is sick. ("AIDS in crime" 2003)

Note that this Ah Si stole a cell phone but did not use a dirty needle to harm the young woman. He did not even know that he was HIV positive. After he was arrested, he tested positive in a prison hospital. In other words, he could not have used his HIV-positive status to commit crimes even if he had wanted to. As for the student who has returned from Jordan, he does not have any criminal record but is just someone about whom the journalist heard from local doctors. In fact, all the references in the story to so-called AIDS criminals came from secondhand sources and I suspect that they were made up because no full names of any key informants were given.

The Crisis of Social Trust and the AIDS Needle Rumors

The root of all the AIDS needle rumors—and of the news media's depiction of the threat that AIDS patients pose to society at large—is the notion that AIDS sufferers are vengeful and would not hesitate to hurt other people. The readiness of many Chinese citizens to believe this must be analyzed in the context of the idea of social trust. Georg Simmel points out that trust is an integrating force in society, in that the absence of basic social trust would

mean the collapse of society (Simmel 2004). Niklas Luhmann views trust as a form of social capital that serves as a moral constraint and therefore reduces the costs of punishment and supervision (Luhmann 1979). Francis Fukuyama argues that trust is a form of social virtue that creates different patterns of economic development and business culture. He believes that great social trust is vital to the scale of business and national competitiveness in economic globalization (Fukuyama 1995). The Chinese sociologist Zheng Yefu has examined various theories of social trust and concluded that Chinese society is strong in "particular trust" but weak in "universal trust." In other words, Chinese culture places great emphasis on interpersonal trust built on three conditions—the degree of familiarity, the degree of intimacy, and the degree of reciprocity. Zheng is convinced that the Cultural Revolution (1966–1976) damaged an already weak culture of public trust and also eroded interpersonal trust. And after China entered a phase of transformation from the Maoist centrally planned economy to a market economy linked to a global production system and culture of consumption, interpersonal relationships and society-state relationships in mainland China took on a greater uncertainty, affecting not only the relationship of trust between individuals and state agencies but also contexts of trust between colleagues, friends, and even family members. If the Cultural Revolution created a crisis of trust for political reasons, argues Zheng Yefu, economic reforms in post-Mao China have created a culture of low expectations as interpersonal familiarity, intimacy, and reciprocity are defined by transformations of economic relations, work patterns, and family structure (Zheng 2001).

We might find it useful to extend Zheng Yefu's argument by suggesting that low expectation of others has characterized the moral panics set off by the AIDS needle rumors in China from 2001 to 2005. Although the panics were based on hearsay, imagination, and groundless rumors, they reflected a collective distrust of AIDS patients in particular. Although this kind of distrust may constitute a social fact or even a crisis of trust in mainland China, we cannot lose sight of another social fact—namely, that so far no AIDS patient in China has tried intentionally to harm anyone else by using a dirty needle or syringe as a weapon against society. Many of these patients have encountered varying degrees of social discrimination and rejection, yet very few are entertaining thoughts as bad as the public imagination suggests.

The fear of AIDS patients in China is a projection of the society's psyche at a time of rapid social change—change that has infused many uncertainties into people's relations with one another and lowered their expectations of other people. In the last two years, I have led a team of young researchers to

collect oral histories from AIDS patients in China, focusing on their illness narratives. We have collected 70 narratives thus far. As Arthur Kleinman has suggested, the importance of these narratives lies in their power to make us look at and critique the society in which we live from the perspectives of the patients and on the basis of the meanings they attach to their suffering (Kleinman 1988). In all our interviews to collect such illness narratives, only two patients ever said that they once wanted to take some form of extreme action to harm people. In both cases they said this out of anger and never actually tried to hurt anyone.

The first of the two tested HIV positive in 2002 and received treatment at a Beijing hospital. He returned to his hometown in Shaanxi with medicine, and after eight months his health deteriorated rapidly instead of getting better. His father, his wife, and an elderly brother escorted him in a borrowed car to Beijing's Ditan Hospital, hoping to get medical assistance for his high fever. At the hospital's front gate, police stopped them, saying that the hospital had been converted into a SARS hospital and that they were not allowed to enter. The family went to find a doctor who had treated him before. After they sneaked into the heavily guarded hospital complex, security guards captured them and the hospital ordered them to be quarantined:

> As a result, we were declared suspected SARS cases. The car driver, my father, my wife, my second brother, and I were all detained. What I never could have expected was that we were reported to the Beijing Municipal Government and we were declared to have caused the May 25 Incident. The Shaanxi Provincial Government was alerted, along with the CDC. The Phoenix Television Station in Hong Kong exposed our identifies, and the Minster of Health Gao Qiang designated me as the "first imported SARS case" in Beijing. Everything about me was exposed. In fact, I was not suffering from SARS and therefore I could not have been the first imported SARS case in Beijing.
>
> But as soon as I got into the hospital, I was treated as if I were a SARS patient. The hospital found the acting mayor of Beijing and told him that he had a "laoxiang" (fellow townsman) suffering from SARS and asked what the hospital should do about me. The mayor said if he is sick he should be treated. I was indeed having SARS-like symptoms and they treated me likewise. My father became so desperate and begged the doctors to stop treating me like a SARS case and warned them that if they continued to do so my life would be finished. Eventually, Shaanxi sent a team of officials to Beijing and both sides discovered that a mistake had been made. But I suffered the consequences as I had been declared to be the first imported case of SARS to Beijing and everybody in my hometown got word about my case.
>
> I was later released, but every member of my family was quarantined. My oldest brother was quarantined for a month. They came to my home with iron chains and a

welder. I could do nothing about it and they sealed my home's anti-theft gate. I am currently extremely upset. My child cannot go to school anymore, no matter how many transfers we have made for him. Where else can I send him to study? Everybody here now knows that I am not a SARS patient but that I am an AIDS patient.

I had a traffic accident and had a blood transfusion. That was back in July 1996. I used to read newspapers but always felt AIDS was a remote disease and I would never get it. Then the doctors started to run blood tests on me constantly. So I teased them by asking them if they would find AIDS in me. Two days later, the result came back and it was HIV positive. I was dumbfounded. The local anti-epidemic station notified my wife and asked her if I had sex with other women. My wife said that we have been a good couple and they really should have thought of me in that manner.

What reflections do I have about my experience in living through all this? I want to blow up the hospital. I went there for a treatment and paid every cent for it. The doctor in charge of my case was totally irresponsible. He should have told me that I needed a blood transfusion but he did not.

In the narrative cited above, the patient says he wants to "blow up the hospital" merely as an expression of anger built up inside himself in reaction to his infection, which was caused by the hospital's failure to screen the blood supply and the doctor's failure to inform him of his need for a blood transfusion. He was further angered by the fact that he and his family were forcibly quarantined during the SARS epidemic. Notice that his father begged doctors in Beijing not to treat his son like a SARS patients but the doctors were under direct orders from the city government of Beijing to treat him as a SARS patient anyway. And once he and his family caused the so-called May 25 Incident and became known as the first imported SARS cases in Beijing, his HIV-positive status was "exposed" as he described it. A consequence of this exposure was the family's repeated failure to find a school to accept his son for a normal education. While this rejection is actually against the Chinese government's policies on the education of children living with parents who are AIDS patients, local schools that declined to enroll his son did not suffer any punishment. The local school authorities had ample excuses for not enrolling his son; they did not have to say outright that their refusal had to do with his father's HIV-positive status.

The second case was that of a young man, originally an orphan from Inner Mongolia, who had wandered around the country and ended up in an orphanage in Guangzhou. He became acquainted with what he described as "bad boys" and began to use drugs. He was sent to a hospital by a group of missionaries and tested HIV positive. Then he went to live and work on a construction site. A foreman there got to know him and gave him food and

light work to do. This young man used to live on picking pockets at Guangzhou Railway station. A lot of kids working at the station used drugs. An English missionary group took these kids to a church to stop them from taking drugs. He stayed there for two weeks and came out of the church free of drug addiction but he felt the pain of other problems. He had fever, sores, and TB. This is what he said about his experience living with HIV/AIDS:

I was forced to see doctors at the No. Eight Hospital and they found me HIV positive. I did not care. For me, to live one extra day is a pretty lucky thing. At a police station, I heard people saying that those who have acquired AIDS are rich. They did not know a damn thing.

I later came to Hubei. I got into a fight and was arrested. The cops wanted to beat me up and I told them I had AIDS. They did not believe me. They said they would take me to see a doctor and they would beat me to death if I did not have AIDS. When the test was positive, they treated me very nicely and gave me food to eat. They even gave me 50 yuan. I did not have proper clothes and the cops took down a curtain. They had the curtain made into clothes for me. Later on, they often arrested me but let me go every time.

Once someone told my friends that I had AIDS and my days were numbered. I was very angry, and that night I slashed him a few times with a knife. It is fine that he knows I have AIDS but he should not have told other people. After I knifed him, nobody around me dared to talk about my disease. The cops are very curious about my illness. They often put me in the center of a crowd and ask me all sorts of questions. They ask what use is it for me to live in this world. Policewomen don't dare to come near me and they look at me through a window.

When I stayed in a Hankou hospital, no doctors came to see me at all. Only nurses came and they were better than the doctors. I know I have this disease and I will try not to infect other people. Occasionally, I run into drug users and am offered drugs to inject. I always refuse such offers. But [once,] when they asked me if I had AIDS, I became mad and smashed their syringes.

Not long ago, I was robbed of 400 yuan and it was the only time I thought of getting other people infected with AIDS. I told the police I had been robbed and they told me to find that guy by myself. I thought about buying a syringe, putting my own blood into it, and injecting that guy with my blood. You know, barefooted people are not afraid of people wearing shoes. I really asked around to see if my method of revenge would be effective. I was told it would not be because the poison would not be powerful enough if I had to wait for hours for that guy to appear. Dr. Gui told me to drop the idea of revenge. If I did not, I would betray his trust. So I did not go after that guy.

This young man experienced several incidents of institutionally permitted discrimination. While in policy custody, he was looked upon as if he were a rare animal and, indeed, showed off as if he were one. Notice that policewomen were extremely curious about this patient but, since they were afraid of getting infected by him, they kept looking at him through a window.

Also notice that at a Hankou hospital, doctors ignored him and only nurses took care of his needs. Despite all this, the young man said: "I know have this disease and I will try not to infect other people." The idea of taking revenge only crossed his mind when he was robbed of a large sum of money that he badly needed and the police refused to help him retrieve it. Even this tough young man, however, was persuaded to be tolerant. In this case the lesson on tolerance was delivered by a kind-hearted doctor by the name of Gui Xi-en who had taken the young men in for free treatment. I should mention that Dr. Gui's decision to provide free treatment for this patient caused a controversy in Wuhan medical circles, with some medical professionals declaring his decision an unpractical act of humanity. Some doctors even suggested in private that it was a waste of medicine on a lowly person.

Conclusion

People living with AIDS have been stigmatized worldwide since the epidemic began. However, that does not mean that the problems of stigma associated with AIDS are always identical in different cultures and societies. To combat AIDS-related stigma in China, we must understand how it has been culturally constructed. With the exception of the 2003 SARS epidemic, no infectious disease in China during the last twenty years has had a greater impact than HIV/AIDS in exciting the public imagination. Here I refer to how AIDS is talked about and interpreted by suspicious citizens and irresponsible journalists. The AIDS needle rumors are a perfect example of how an epidemic's threat to society can be imagined and exaggerated.

These rumors reflect the growth of a conspiracy theory in Chinese society. The public's fascination with the conspiracy theory is perhaps a clear indicator of the uniqueness of the Chinese public's perceptions of the AIDS epidemic. For instance, the assumption of revenge was so taken for granted that even Chinese doctors trying to prove the AIDS needle rumors wrong through the news media concentrated their comments only on the technical difficulties of deliberately getting somebody infected with HIV, failing to challenge the underlying premise of these rumors. Thus these Chinese doctors did not bother to explain what matters most to AIDS patients, what is really at stake when a person discovers his or her infection, and what kind of reactions an HIV-positive person usually has. What these doctors could have cited to quiet the AIDS panics is a well-known study by Liu Kangmai and his research team, who discovered that one-third of Chinese AIDS patients think of committing suicide and that nearly 10

percent of these patients actually attempt suicide. In other words, it is not the thought of hurting the others but the thought of hurting oneself that preoccupies Chinese AIDS patients.

Although the Chinese news media did not participate directly in creating the AIDS needle rumors, some journalists wrote very sensational articles about the assumed threat of AIDS patients to society at large. Such news reports laid the foundation needed for the AIDS needle rumors to be effective and to spread. The very words "AIDS criminals" in the Chinese news media are based on an extremely thin layer of evidence, mostly on the fact that some AIDS patients are injection drug users who from time to time have troubles with the law. Yet these problems are amplified, sensationalized, and distorted to serve the purpose of criminalizing already marginalized sufferers of AIDS. While the Chinese government claims to have done a great deal to combat AIDS-related stigma, no government officials have tried to examine and critique the news media's role in creating an environment of public opinion hostile to AIDS patients. This failure indicates that government officials are not fully aware that China's crisis of social trust is the driving force of the panics associated with the AIDS rumors. From one AIDS rumor affecting only one city in 2001, China encountered a multiplication of such rumors in many cities by the end of 2005. The progression of these rumors and associated panics indicates that China has a long way to go in combatting social discrimination against AIDS patients.

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CHAPTER 8

Perspectives on Stigma and the Needs of People Living with AIDS in China

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Thomas Cai

It is my honor to speak on behalf of the people living with HIV/AIDS in China. We all agree that HIV/AIDS has become the one of the most critical challenges to all human societies in the world. China has more than 1.3 billion people, or about 20% of the world's population. China is facing a great challenge from HIV/AIDS. Years of experience from many countries' wars against the HIV/AIDS epidemic show us that HIV/AIDS is much more than a medical issue—it is also a social and political issue. The response to HIV/AIDS from society, not only doctors and scientists, greatly influences the outcome of this war. And society's response is greatly dependent on the level of civil society development, as well as awareness of HIV/AIDS by the political leadership. I would like to share my understanding of Chinese civil society development and the political commitment of the Chinese government on HIV/AIDS.

Civil Society

Compared to the rapid rate of economic development in China during the past decade, civil society development has been very slow. Due to thousands of years of feudalism, Chinese society lacks a sense of democracy and a tradition of civil society. In addition, the Cultural Revolution (1966–1976) created a crisis of belief or of social trust (see Jing Jun's discussion of this in

Chapter 7). These factors have become the main obstacle to Chinese social development. Reforms of the economic and social systems since the 1980s have created the miracle of Chinese economic development, but social problems have also grown, such as:

Commercialized health care and education systems;

The huge and growing gap between the rich and the poor;

Overwhelming materialism;

Increasing unemployment; and

Drug use and commercial sex.

These growing issues, driven by the recent economic policies, need to be addressed by the government but also by society at large to really achieve a more successful response. This is crucial to the overall health and well-being of the Chinese people, and will be crucial to containing HIV, which is fueled by poverty and other social problems.

In addition, there is a lack of understanding of the role that civil society can play—both by government officials and by society at large—making legislative and attitudinal change a major challenge. For example, NGO registration is extremely difficult in China—a problem exacerbated by the legal vacuum that characterizes legislation and policy making in China today. Civil society development in China is facing a rough, long march.

Due to the sensitivity surrounding HIV/AIDS in China, which has resulted both from the government's earlier denial of its existence and from the stigma and discrimination that follows the disease around the world, civil society's response to HIV/AIDS has been weak. What response there has been is hampered by many problems:

Lack of support and cooperation from local NGOs in other sectors;

Difficulty in mobilizing resources from the community, such as volunteer and support services;

Lack of compassion for HIV/AIDS sufferers;

Poor awareness of HIV/AIDS among the general public, which is itself a massive, vulnerable population; and

Discrimination and stigma against PLWA, as a result of ignorance and denial.

As mentioned above, the negative response from society in China is fueling the HIV/AIDS epidemic instead of contributing to controlling it.

Government Commitment

In the 1990s, the Chinese government was not fully aware of the HIV/AIDS epidemic, and this resulted in poor political commitment. Responses to the epidemic were limited to simple prevention and advocacy interventions conducted by the health sector. This limited response was not able to contain the epidemic, so that the disease gained a stronghold among vulnerable groups (such as IDUs, CSWs, and MSM) and began to spread into the general population.

During the past few years there have been many positive changes in the central government's response to HIV/AIDS, primarily in terms of making a strong political commitment to controlling the epidemic. Many actions are being implemented, with more programs being planned.

But all these efforts still face resistance from the mid- and low-level officials. Thus, even though good policy may be coming from Beijing, the execution of such is limited by poor commitment at the lower levels. This is due to continued misunderstanding, ignorance, and discrimination. Persistent and increased efforts are needed to reduce these barriers to effective policy implementation. The best example of this barrier is that, even though an anti-discrimination law on HIV/AIDS has existed for years, little to no enforcement exists. Such prejudice within the policy system, coupled with the weak development of civil society, has led to the whole society tolerating and sometimes encouraging discrimination against HIV/AIDS.

The Role of PLWA in China

Internationally, we have learned that a more effective response to HIV/AIDS must include the greater involvement of those infected with and affected by HIV/AIDS. This concept has been termed GIPA (greater involvement of PLWA) and has been promoted internationally to help in the fight against HIV/AIDS.

As mentioned earlier, the PLWA in China are in a deeply stigmatized and discriminatory society. Besides the physical suffering brought on by the virus, they suffer severely from the discrimination within their communities. Poor civil society development restricts their access to receiving any assistance from the community—and they dare not make a claim to their rights, either. With increased, stronger commitment to containing HIV/AIDS by the central government, as well as influence from international NGOs and agencies working in China on HIV/AIDS, the plight of PLWA in China has

been brought to light. Some PLWA activists have been supported to work on the HIV/AIDS issue, but the movement is still at the very early stages, with only a few HIV-positive groups having formed. Given China's poor civil society environment, the development of these groups is like cultivating seeds in rocky soil. Thus the involvement of PLWA in policy and program development is still at a very low, almost nonexistent level.

Even though experience from many countries shows that involvement of PLWA in the response to the epidemic is very important, and even though the Chinese government also realizes this and is ready to promote the GIPA movement, we still face many obstacles, such as:

- The fact that PLWA are deeply victimized by the general public and also by themselves, making a strong collective group voice or network impossible to form;
- Poor recognition of GIPA and low awareness of HIV/AIDS among mid- and low-level officials, who tend to use PLWA as tokens, or simply ignore the role of PLWA;
- China's poor civil society environment, which means a lack of support and resources;
- The low capacity of PLWA activists, caused by discrimination, stigma, lack of NGO culture, and overall poor support, which results in weak, ineffectual PLWA groups and networks or in PLWA being used as tokens.

The fight against the HIV/AIDS epidemic in China needs the greater involvement of Chinese people living with HIV/AIDS. In light of the challenges just mentioned, PLWA need the following support from social policy makers:

- A supportive policy environment in which to establish and develop PLWA support groups and networks at all levels;
- Full involvement of PLWA in decision making, formulation, and implementation of social policy;
- Training opportunities for PLWA activists, who should then be hired as experts in the national HIV/AIDS program; and
- Promotion of humane practices by providing comprehensive high-quality care to PLWA.

These supportive social policies will also greatly benefit overall civil society development in China. For example, groups working on poverty, women, children, and so forth can all incorporate HIV/AIDS into their projects. It is

time to strike a better balance between economic and social development in China. The HIV/AIDS issue could be the entry point, because it makes clear to us that if we do not have matching civil society development, progress in economic development could be lost. In China HIV/AIDS could be a disaster—or it could be a great opportunity to bring about much-needed social change.

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PART III

Prevention

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CHAPTER 9

Opportunity for Effective Prevention of AIDS in China

The Strategy of Preventing Secondary Transmission of HIV

Ray Yip

I. Introduction

In early 2004, the official estimated number of people living with HIV and AIDS (PLWA) in China reached 840,000 (MOH 2004). The overall prevalence of HIV based on this estimate is slightly less than one per thousand, making China a relatively low-prevalence country. Since late 2003, China's senior leaders have clearly indicated that the government is committed to responding to the challenge of AIDS. This high-level response while China is still in a relatively low state of prevalence presents an opportunity to keep HIV prevalence low, provided an effective strategy can be quickly put into place. Moreover, the HIV epidemic in China is still mainly limited to two groups of higher-risk individuals (drug users and former plasma donors) in a limited number of geographic locations (MOH 2004). This well-defined distribution in limited areas presents a cost-effective opportunity to use targeted intervention to prevent the wide spread of HIV in China. The key

question is, what are the essential measures that must be put into practice to capitalize on this window of opportunity for effective prevention of AIDS?

The proposed strategy of preventing secondary transmission of HIV is an essential component of the national response to AIDS. This strategy is premised on the fact that the majority of current PLWA can be identified through voluntary counseling and testing (VCT) in the limited number of communities in which they live—communities that are already known. Thus the principal challenge lies both in finding China's PLWA and in providing them with adequate protection and care. If proper protection and care can be assured through the government's increasing commitment, then the opportunity to prevent secondary transmission of HIV can be fully exercised. The current analysis indicates that China is in a very good position to benefit from such a targeted intervention strategy. The purpose of this chapter is to examine the key components and relevant issues that must be addressed to implement this proposed strategy rapidly.

II. Current HIV/AIDS Epidemic Situation

By the end of 2003, the official estimated figure of those infected with HIV/AIDS in China had reached 1 million (840,000 currently living, and 150,000 who had died; MOH 2004). The AIDS epidemic has been growing at an annual rate of 30%. Even though the overall prevalence of HIV is relatively low (approx. 0.8 per 1,000), there are several locations across China where AIDS has reached hyper-epidemic proportions, up to 20% in some small communities.

The AIDS epidemic in China has been mainly fueled by intravenous drug users (IDUs) since the first major outbreak in Yunnan near the border of Myanmar. Currently, IDUs make up 50–60% of the people living with HIV in China, and HIV has spread to many communities beyond the China-Myanmar border (MOH 2004). To a large extent the HIV epidemic is driven by the IDUs, and this group has reached an average HIV prevalence of 20–25% (MOH 2004). In areas where HIV related to IDUs has a longer history, such as in Yunnan and Xinjiang provinces, HIV is now spreading to the commercial sex workers (CSWs), and in selected communities HIV prevalence among CSWs has reached 5%. Nationally, the average seroprevalence of CSWs is approximately 1.5%. Limited information of HIV prevalence among men having sex with men (MSM) found HIV seroprevalence to be also near the 1–2% range.

In the mid-1990s a major outbreak occurred in the central provinces due to unsafe plasma collection, mainly among rural farmers (UN Theme Group 2002). This epidemic was also due to the interaction of drug users within the plasma donor pools. The unsafe blood collection practice had stopped by 1996. By early 2000 members of this cohort of HIV-infected plasma donors started to manifest clinical AIDS and to die at an alarming rate. The 2003 National HIV Survey estimated that former plasma donors made up approximately 20% of all PLWA in China. One unusual feature of this unsafe-plasma-induced epidemic is that the majority of the infection took place from 1993 to 1995. This cohort of infected rural farmers, with greatest concentration in the southern part of Henan Province, started to manifest clinical AIDS and die in 2000 to 2001, resulting in many villages suffering an intense impact.

A. THE CHINESE GOVERNMENT'S CHANGING RESPONSE TO AIDS: FROM SILENCE TO ACTION

It is fair to say that until 2002, the Chinese government's overall response to AIDS was limited (UN Theme Group 2002). This is evident from the fact that the majority of the funding for AIDS prevention and care came from international assistance. However, the government's commitment and response became very strong by the end of 2003, and by April 2004 AIDS had become a priority of the State Council and a high-level response body chaired by Vice Premier Wu Yi was put into operation.

Two major factors prompted the rapid shift in the government's response (Cohen 2004). The first consisted of the concentrated epidemic, manifestation of clinical AIDS, and resultant deaths in Henan Province starting in 2001. This tragic situation in the so-called AIDS villages caught domestic and international media attention, despite local government efforts to suppress the information. Exposure of the plight of AIDS-affected families eventually gained the attention of the country's senior leaders. Toward the end of 2002, the State Council authorized a program known as China CARES (see Chapter 1), aimed at providing care and treatment to those communities most affected by AIDS. This program, which began in March 2003, signaled a major shift in the government's position, from silence to action.

The second fact was the SARS epidemic during the Spring of 2003, which elicited an unprecedented response from the central government and

mobilized the entire country. The SARS crisis exposed the weakness of the Chinese public health system, and led to the pursuit of a more transparent policy in the handling of epidemics in general. The more hands-on involvement of the senior leaders in the SARS control efforts probably contributed to the strong position taken by the State Council in responding to AIDS by the end of 2003. On December 1, 2003, Premier Wen Jiabao made a public appearance in a Beijing hospital that specializes in AIDS treatment and greeted AIDS patients there. This clearly indicated that the government of China was taking the AIDS epidemic seriously.

In February 2004, the State Council announced the formation of a multi-sector State Council AIDS Working Committee, which convened at a national AIDS conference in April 2004, requesting the attendance of senior officials from all provinces. A specific policy (the "Four Frees and One Care"), including free ARV treatment, VCT, PMTCT, and school fees for orphans, was announced as part of this new commitment (see Chapter 1 in this volume).

In essence, in the span of a little over one year, the Chinese government became fully committed to responding to the challenge of AIDS. The next step is to formulate a sound strategy for the effective prevention and control of AIDS, building on the political commitments and resulting financial resources now available for the AIDS response.

B. THE HIV/AIDS SITUATION IN CHINA, AS OF 2004

A sound strategy must be based on the current situation of AIDS in China and must match the response capacity. What is the current situation?

Focalized epidemic: The AIDS epidemic affects only a small subset of communities across China.

Epidemic still concentrated among the source population—namely, IDUs: The bridge population (CSWs) and general population are still relatively unaffected.

Two highest groups with most HIV—IDUs and former plasma donors— make up 80% of all Chinese currently living with HIV.

Most communities with a concentration of drug users or plasma donors are in rural areas and have been identified, which makes targeted intervention feasible.

The general public has a limited understanding of AIDS and a great deal of fear of it, which has resulted in an environment of strong stigma for those living with HIV.

The current response mechanism can be summarized as follows:

Widespread testing capacity, with a large volume of HIV testing in health care settings, but usually done on an uninformed basis and with inadequate counseling and follow-up.

Very limited experience and capacity for AIDS care and support at health care facilities and in communities.

Very limited access to ARV drugs for AIDS treatment, with the exception of some of the China CARES project sites.

Most government and international funding mainly invested in areas related to primary prevention in the form of health education, with limited input in areas that require direct interaction with people with HIV/AIDS.

Limited capacity by the health care system to provide basic care related to HIV/AIDS, and health workers often fearful in dealing with patients with AIDS.

The above conditions lead us to consider a targeted intervention, through testing, to determine HIV status among those who are at higher risk for HIV infection. The major constraint is proper protection and adequate follow-up support for those who are found to be HIV positive. Limited observation and experience thus far in China indicate that it is feasible to exercise the strategy of targeted intervention. In fact, the window of opportunity still exists to achieve a meaningful containment of the spread of AIDS in China because of the unique set of circumstances of high-level government response, when the HIV epidemic is still at a relatively early stage and localized in a limited number of communities (China MOH and UN Theme Group 2003).

C. THE STRATEGY OF PREVENTING SECONDARY TRANSMISSION OF HIV

The cornerstone of prevention of second-generation HIV transmission is to be able to identify those who are currently infected and provide them with the knowledge, skills, and social support to prevent their transmitting HIV to others. In 2002, the United States adopted this strategy of focusing on

those who are HIV positive as an intervention (secondary prevention), in addition to the longstanding focus on those who are HIV negative through education and information to prevent HIV infection (primary prevention; US CDC 2003). The principal reason was the recognition that primary prevention is necessary but not sufficient in preventing the spread of AIDS, and increasing evidence that greater effectiveness of prevention can be achieved by adding the component of secondary prevention (Allen et al. 1992, 2003; Janssen et al. 2001; Kamenga et al. 1991; Weinhardt et al. 1999; and Wolitski et al. 1999).

The latency and subclinical period after HIV infection—averaging five to seven years—presents a long period for possible transmission. The only means to identify those who are HIV positive before they manifest signs and symptoms of AIDS is through HIV serological testing. Globally, there is increasing evidence that asymptomatic HIV carriers who know about their HIV-positive status are much less likely to transmit HIV than those who are unaware that they are HIV positive. Estimates from various studies put the average reduction of HIV transmission in the range of 60–70% (Allen et al. 1992, 2003; Janssen et al. 2001; Kamenga et al. 1991; Weinhardt et al. 1999; and Wolitski et al. 1999), based on knowing HIV-positive status. It is this line of evidence that resulted in the significant shift in HIV prevention strategy in the US in 2002 (US CDC 2003). The earlier strategy focused on risk reduction for the majority who are HIV negative, by providing knowledge and skills related to HIV transmission. The later strategy added the focus of finding those who are HIV positive through increased access to HIV testing, in order to reduce their transmission potential.

By the end of 2003, the official epidemiologic estimates of people living with HIV in China and United States reported comparable case loads—approximately 840,000 for China and 900,000 for United States. However, reflecting the difference in case-finding and HIV-surveillance mechanisms in the two countries, 75% of the infected individuals in the US were known to be or knew that they were HIV positive, whereas less than 10% of those in China were in this position. In essence, 90% of PLWA in China have a very high transmission potential because they do not know they can infect others. The current US prevention strategy is to accelerate the effort to identify the remaining 25% who are HIV positive but unaware of their HIV status (US CDC 2003). It is logical to propose such a strategy for China as well. Given the relatively low prevalence of HIV in China—less than one per thousand—such a strategy to prevent secondary transmission presents an

opportunity to keep the HIV prevalence low. The question is, how feasible is it to implement such a strategy in China?

D. THE CRITICAL ROLE OF VOLUNTARY COUNSELING AND TESTING (VCT)

The key measures for implementing the strategy for preventing secondary transmission of HIV from infected individuals can be summarized as follows:

Case finding of HIV-positive individuals through a functional VCT mechanism; and

Case management of HIV-positive individuals by providing long-term follow-up of both care and treatment, and support to reduce the risk of HIV transmission to others.

Table 9.1 summarizes the essential or desirable features of the key measures for implementing the strategy for preventing second-generation HIV transmission. Also included in Table 9.1 is an assessment (rated by the author) of the current capacity and near-term potential for improvement in China.

E. CASE-FINDING MECHANISMS: IDENTIFYING PEOPLE WHO ARE HIV POSITIVE

1. *HIV Testing Capacity*. HIV testing is the only way to identify people who are HIV positive before they manifest as clinical AIDS patients. In the case of China, scaling up HIV testing or laboratory capacity is not a physical infrastructure but a human resource problem. Rather, the number of fully trained personnel available to carry out these tests is limited and quality control is inadequate. With the exception of a few extremely isolated areas, all county-level hospitals and anti-epidemic stations have the laboratory capacity to perform ELISA-based HIV testing. There are more than 3,000 laboratories across China performing HIV screening, and about half of these are supposed to undergo quality assurance monitoring. A relevant issue that has not been adequately addressed is how quality is assured for all these laboratories (see Chapter 4 for a more detailed discussion of health system capacity for the AIDS response).

Table 9.1
Case-Finding and Case-Management Mechanisms for the Effective Prevention of Secondary HIV Transmission in China

I. Case-finding mechanism	Current capacity/ status	Near-term potential/ feasibility
1. Surveillance system to define high-risk communities	4	5
2. Detection of high-risk groups in a community	4	5
3. Availability of HIV testing capacity in a community	4	5
4. Adequate quality assurance of HIV testing	3	5
5. Proper operation of testing system meeting VCT standard	1	4
a. Informed and voluntary testing	2	4
b. Outreach mechanism to high-risk group for testing	1	5
c. Confidentiality observed	3	4
d. Inform the HIV status with adequate initial counseling	2	4
e. Provide follow-up or confirmatory testing	2	5
II. Case-management mechanism	2	4
1. System and facility for the follow-up/support of HIV+	1	4
2. Medical care and treatment capacity	2	4
a. Health care workers for basic AIDS case	1	4
b. Provision of basic and OI treatment	2	4
c. Laboratory monitoring for immune status (CD4)	1	4
d. Provision of ARV treatment	2	4
e. Higher level or referral facility for AIDS care	2	4
3. Community-based care and support capacity	1	3
a. Social and relief service	1	3
4. Risk reduction measures to prevent HIV transmission	1	4
a. Long-term counseling and support mechanism	1	3
b. Access/provision of condoms—sexual transmission	2	4
c. Access/provision of harm reduction for IDUs	1	3

Note: The current capacity or status of each category is rated on a scale of 1 to 5, where 1 = little or nonexistent capacity or status, and 5 = advanced or well-developed capacity or status. The near-term potential for developing such capacity across China is also rated on a scale of 1 to 5, where 1 = low potential or feasibility, and 5 = high potential or feasibility.

2. *Lack of Testing That Meets the VCT Standard.* Most of the HIV testing that is currently performed across China is done by hospitals at the time of admission or before surgery. For the most part, patients are not aware that the testing is being done, even though they pay for it. The overall yield of

HIV-positive cases under routine hospital-admission and blood-bank screening is low—far below one person per thousand tested. This routine testing can certainly contribute to finding more HIV-positive cases because of the large volume of testing done. The key is to improve the procedures of pre-testing consent and post-testing follow-up. At present, the most effective way to find HIV-positive individuals would be to target high-risk groups, especially those with a history of intravenous drug use. The IDU group has an average HIV-positive rate of 25%, based on the 2003 National HIV Survey. The majority of the testing done for high-risk groups thus far, including IDUs, is part of the national or provincial sentinel surveillance system. Under this system, those tested are not informed of the test results, so testing is being done without subsequent counseling for risk reduction, even though both the public security and the public health authorities are often aware of who has been found to be HIV positive. In essence, there is a serious risk involved in the proper protection of confidentiality, in that tested individuals do not learn the very results that could help them prevent HIV transmission to others. Thus efforts to meet the VCT standard (i.e., confidential testing and provision of results to the person tested, together with counseling on risk reduction behaviors for both positive and negative results) for wider routine or surveillance-based testing would increase the opportunity to find more cases of HIV-positive individuals (Osmond et al. 1999, US CDC 2003).

3. *Outreach VCT for High-Risk Groups.* Given the fact that two of the highest-risk groups for HIV—IDUs and former plasma donors—are located in well-defined communities, and in the case of IDUs often under the management of public security facilities, there is an excellent opportunity to develop an outreach or "within drug detoxification facility" mechanism to offer VCT services and thus enhance the case-finding effort. The limited VCT services that now exist in China are based in health facilities that are not used by high-risk groups. The limited testing done each year for high-risk groups has been for surveillance purposes and has engaged only a small proportion of known high-risk communities, hence constituting a missed opportunity. The combination of improved testing and VCT with outreach service will greatly improve China's case-finding efforts to prevent secondary transmission of HIV. The existing sentinel surveillance system is well established and provides a functional platform from which to expand the case-finding mechanism for higher-risk groups or communities. The concept of using an ongoing surveillance system to expand the identifica-

tion of PLWA goes beyond the original intent of the monitoring of this epidemic trend. It might even be considered "surveillance plus"—using the same mechanism for case finding and for reducing the further transmission of HIV.

4. *Adequate Follow-up and Management for PLWA.* In most parts of China, the greatest obstacle to expanding the case finding of HIV-positive individuals is the lack of adequate provisions for follow-up service and case management. The national project known as China CARES is striving to develop this capacity in communities that are strongly affected by AIDS (China CDC 2003).

F. CASE-MANAGEMENT MECHANISMS: PLWA CARE AND SECONDARY TRANSMISSION RISK REDUCTION

1. *The Rural Health System's Need for Greater AIDS Treatment Capacity.* More than 80% of the estimated 840,000 PLWA in China are rural residents. Chronic underfunding of rural health services, resulting in lax management, means such services have only a limited capacity to treat AIDS. Moreover, most rural health workers rely on profits from the medications they dispense as their main source of income, since there are restrictions on collecting service fees and their entitled base salaries are not provided in full by local governments. As a result, the quality and efficiency of service is low. In such a service environment, the provision of AIDS-treatment-related drugs and training is necessary but not sufficient to ensure the development of a basic AIDS treatment capacity. The China CARES project is exploring options that, at least in an AIDS-related service, yield a greater input to health workers' income, and that add management as part of the overall system development for AIDS treatment. Without input to ensure the basic function and quality of the rural health service in areas with a significant burden of HIV and AIDS, it will not be feasible to develop a basic AIDS treatment capacity.

2. *The Need to Increase Basic Clinical Care Capacity for HIV and AIDS.* Across China, there are only a few dozen infectious disease specialists who have the basic training and ongoing clinical care experience to treat patients with HIV and AIDS. Virtually all the AIDS clinics are based at major medical centers in major metropolitan areas. The cost of service at most of the referral centers is beyond the means of most PLWA who are rural residents or

farmers. Yet in rural areas where there is a concentrated HIV epidemic, the relatively underfunded health services have not been able to develop the basic clinical capacity needed for AIDS-related diagnostics and treatment (see Chapter 4 on health service capacity to respond to AIDS). This mismatch of clinical resources and economic access for AIDS-related care must be addressed in order to provide meaningful basic AIDS care to the majority of PLWA. This is an urgent problem in part because there are acute needs for treatment services in a number of HIV endemic areas. Even more importantly, however, in the absence of a meaningful treatment program, it will not be possible to implement the strategy of preventing secondary transmission, which requires expanding the scale of an HIV case-finding effort. The most important criterion in case finding through VCT is to be able to offer those found to be HIV positive long-term follow-up for care and treatment. Fortunately, the government's increasing attention and input to China's AIDS response ought to ensure such basic care, including the provision of ARV treatment as a priority.

3. *Risk Reduction Support: The Key to Prevention of Secondary Transmission of HIV*. With the adequate provision of care and treatment, the ability to expand case finding of those who are HIV positive through VCT can rapidly scale up. Evidence thus far indicates that when people are informed of their HIV-positive status, this in itself is an effective intervention, leading to behavior change that reduces the risk of secondary HIV transmission (McNeil and Anderson 1998). However, additional efforts to support risk reduction are also needed. For example, lack of access to condoms can impede prevention of sexual transmission for PLWA who are sexually active. Perhaps the group with the greatest challenges are the IDUs. Experience has shown that drug detoxification in detention centers or labor camps in China has had minimal impact on drug use. This is mainly attributed to the lack of support and follow-up mechanisms after a drug user is released from the mandatory detoxification center. In view of the fact that HIV prevalence has reached an average of 25% among IDUs, it is imperative that an effective mechanism be developed to prevent the further transmission of HIV by this group. This need is particularly urgent given the epidemiological evidence, which shows that the IDU group was the primary source of the HIV epidemic in those communities first affected in China. Well-established harm reduction measures such as drug substitutes and needle exchange programs are being tried at several sites across China (see Chapter 11). At the same time, the public security system needs to consider appropriate policy and procedures

that will enable the meaningful implementation of risk reduction efforts. One example of a contradictory policy is that, in one city where needle exchange is being piloted, police still use needles and syringes as evidence when arresting drug users. As a result, few drug users are willing to carry injection devices, hence creating a greater likelihood of sharing needles with others. Special attention to risk reduction policy for the IDU group is therefore a crucial issue for China.

III. Summary

China is in the unique position of having the opportunity to develop an effective program to keep HIV from becoming widespread among its populace. Several conditions have made this proposition feasible:

Relatively low prevalence;

Limited areas with a significant burden of HIV and AIDS;

HIV largely limited to high-risk groups, mainly IDUs;

High-level government attention and commitment to containing the spread of AIDS;

Adequate capacity for HIV testing and surveillance; and

Efforts to develop care and treatment for AIDS already underway.

However, effective measures must be put into place quickly to capitalize on the unique opportunity to contain AIDS effectively. Efforts are needed to:

Define prevention of secondary transmission as a priority action for prevention;

Improve the testing mechanism to reached the criteria of VCT and support the outreach effort to high-risk groups such as IDUs;

Ensure the access and quality of the treatment, so that scaling up VCT for the purpose of finding HIV-positive individuals becomes feasible; and

Develop risk reduction programs for those found to be HIV positive, especially IDUs.

Given the overall commitment of government and the available global experience that China can draw on, I am optimistic that an effective program to prevent secondary transmission can be rapidly developed within the next two years.

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CHAPTER 10

Sexual Partners in China

Risk Patterns for Infection by HIV and Possible Interventions

✳

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This chapter is in two parts. The first part provides a statistical analysis of risky sexual behavior in a national survey of sexual behavior completed in 2000. The second notes indicators of rapid changes in sexual behavior since 2000 and the types of radical interventions that might be necessary to cope with these recent changes.

I. Risk Patterns in 2000

Data from our national survey suggest that the greatest infection risk for women in 2000, besides being below age 45, was to be married or to be in any long-term sexual relationship with a man (Parish et al., 2003). As indexed by chlamydia infection in urine samples, men were most likely to be infected when they reported unprotected intercourse with a sex worker during the previous year. In the population-based sample, neither men nor women reported many noncommercial sex partners during the year, and when they did, the respondent was still not at higher risk for chlamydia infection. Thus in 2000, when this survey was completed, intercourse with commercial sex workers (CSWs) rather than casual sex with peers posed the most important

risk for chlamydia infection. With studies from some provinces showing a steady rise in HIV infection among CSWs, these CSWs could soon become the major bridge population for HIV infection.

As the second section of this chapter suggests, that situation could be changing rapidly. Thus the first part examines patterns of unprotected sex with both casual and commercial sex partners in 2000. Given the more frequent risky behavior among males discovered in earlier studies, the emphasis in this study is on male behavior.

A. DATA

Data come from a population-based and a clinic-based sample, both completed in 1999–2000.[1]

With the exclusions of Tibet and Hong Kong, the population-based sample (hereafter "population sample") was nationally representative of the adult population of China between the ages 20 and 64. Following standard procedures for complex samples, the probabilistic sample was drawn from 14 strata and 48 primary sampling units, with probabilities of selection proportional to population size at each of the four sampling steps down to the individual (for details, see http://www.src.uchicago.edu/prc/chfls.php; Levy and Lemeshow 1999). The sampling frame was from both the standard household register and from the register of migrants in each neighborhood. So as to produce more observations of risky sexual behavior and sexually transmitted infections, the sample oversampled urban areas, and particularly southern coastal cities. From known sampling weights and post-interview comparisons to national census results, we typically weight reported results to approximate national totals. Standard errors are adjusted for the sampling design, using survey techniques in Stata 8.0.

Participants responded to an hour-long computer-based interview. Most interviewers were trained mid-aged social workers and researchers who remained with the project throughout the interview period of one year. For the sake of privacy, interviews took place outside the homes of the respondents, normally in a private room in a hotel in big cities or in a meeting facility in smaller locales. Respondent and the interviewer were of the same sex. Of 5,000 individuals initially sampled, 3,806 participants completed the inter-

1. Primary support was provided by the National Institute of Child Health and Human Development (NICHD) grant #RO1 HD34157 to Dr. Parish. Additional support was provided by the University of Chicago/NICHD Population Research Center (P30 HD18288) and University of North Carolina/NIH Fogarty Center (P30 AI50410).

view and provided valid data for analyses, giving a final response rate of 76.1%. Participant and data losses were of three types: refusal to participate of some of the sampled persons (n = 857, 17.1%); sampled person always absent, of poor health, too old or young (n = 308, 6.2%); and computer/data handling loss (n = 29, 0.6%). This study uses reports from 1,899 men who completed questions about sexual partners during the previous year.

The clinic-based sample drew from patients who attended 16 large and small STD clinics in five cities (Beijing, Shenyang, Yichang, Fuzhou, and Guangzhou) during 1999–2000. In each clinic, approximately 50 patients answered a shortened version of the computer-based questionnaire used in the population sample. This provided 627 males with complete data for this analysis. Research protocols were approved by the Social Science Division Institutional Review Board at the University of Chicago and by Single Project Assurance Boards at Renmin University and the Peking Union Medical College.

B. MEASUREMENT

"Income" was the report by the respondent of his monthly income, reported in Chinese currency (RMB). "Entertaining" indicated whether the man often (weekly or more often) socialized with colleagues or others, absent his wife or other steady sexual partner. Popular opinion says that these events often end with a visit to a sex worker. "Travel" indicated whether the man ever traveled out of town over night without his wife last year. "Migrant" indicated a man who had been in the city for up to five years and still had no official residence permit. Coming from the neighborhood migrant registration system, these men were among the more fixed migrants on construction sites, in hotels, and in other more stable urban jobs. "Urban residence" indicated a man living in a locale in which 15% or more of the labor force was in non-farm work. "Southern Coast" indicated residence in Fujian Province or Guangdong Province, abutting Hong Kong. "Southeast Coast" indicated residence in Shanghai, Hangzhou, or other places along the coast in southern Jiangsu or Zhejiang Province.

Knowledge about sexually transmitted diseases was tapped by the question, "For those who have contracted STDs (excluding AIDS), what do you think are the chances for them to fully recover?" Besides, "Don't know," responses could include "None," "A few," and "Most" or "All." A separate set of questions was asked about AIDS knowledge, but because levels of

AIDS knowledge were unrelated to unprotected sex with short-term partners, those results are not reported here.

Short-term partners included both CSWs and other, noncommercial sex partners with whom the men reported having sexual relations during the previous year.

C. RESULTS

1. *Partnering Practices.* In the population sample, among urban and rural men of all ages, 5.0% (95% CI [confidence interval] = 3.7, 6.7) reported two or more noncommercial sex partners last year, while 6.2% (CI = 3.6, 10.7) reported one or more commercial sex partners last year (Table 10.1, last row). Additional short-term noncommercial sex partners were more common in cities than in rural areas (11.8% versus 2.2% when unadjusted for other conditions). Short-term partners were more common along the coast, with commercial sex partners more common along the Southern Coast. Additional short-term partners, both commercial and noncommercial, were more common among the young—where "young" extended to men well into their thirties (more detailed year-by-year data showed high percentages among men in their late thirties). Short-term partners were also more common among high-income men, men who entertained often, and men who traveled out of town. Net of other background conditions, these income, entertaining, and travel effects were most important (i.e., statistically significant) for commercial sex (Table 10.1, final two adjusted columns). In this sample, migrant men were not at higher risk for either type of short-term relationship. More precisely, because they were young, in cities, and often living in coastal locales, the migrant men shared with other young, urban, coastal men a tendency to have more noncommercial partners (10.4% vs. 4.9%). However, once the effects of age and residence were netted out in the final columns of Table 10.1, migrants were statistically no different from non-migrants in their partnering practices.

2. *Commercial Sex Outlets.* By the time field investigators arrived in 1999–2000, commercial sex outlets were common in our urban field sites. We collected data on 52 of the 60 communities where we did interviews, including 12 rural and 40 urban sites. Unsurprisingly, three-fourths of the population in rural sites did not have nearby commercial sex facilities. However, all but 16% of the population in urban sites—and these mostly in

Table 10.1
Male Sexual Partnering Practices During the Previous Year and Risk Factors

		Number and types of partners last year (%)				
		Noncommercial			Adjusted risk ratios	
Factirs	Percent commercial distribution	0 or 1	≥2	≥1 commercial	≥2 noncommercial	≥1 commercial
Income per month						
High (≥ RMB 400)	54	80.7	8.2*	11.1**	2.89	16.75*
Low	46	98.3	1.3	0.4	–	–
Entertaining						
Often (≥ weekly)	35	80.6	7.2*	12.2**	1.18	2.35**
Seldom or none	65	93.1	3.8	3.1	–	–
Travel last year						
Any	21	74.6	8.9**	16.5**	1.92	3.18**
None	79	92.5	4.0	3.5	–	–
Migrant (urban)						
Yes	2	80.1	10.4**	9.6	0.60	0.64
No	98	88.9	4.9	6.2	–	–
Age						
20–29	25	83.8	5.3	10.9**	2.63*	4.49**
30–39	25	81.2	8.9*	10.0**	5.01**	4.06**
40–49	24	93.6	3.9	2.5*	2.16	1.40
50–64	26	96.8	1.8	1.4	–	–
Residence:						
Urban	30	78.8	11.8*	9.4	3.45**	1.33
Rural	70	92.9	2.2	4.9	–	–
Region						
Southern Coast	5	66.5	16.4**	17.1**	2.87**	2.65**
Southeast Coast	7	74.4	18.0**	7.6	2.35**	0.79
Other regions	88	91.0	3.4	5.5	–	–
TOTAL	100	88.7	5.0	6.2		

Notes: Sample consisted of 1,898 men aged 20–64 from China's 1999–2000 national population sample. Weighted results adjusted for sample design throughout. Multinomial logit results in final two columns, with risk ratios providing comparisons to having only one or no noncommercial sex partners. * $p < .05$ ** $p < .10$

Table 10.2.
Predominant Type of Commercial Sex Outlets in Respondent's Locale
(percent)

	Rural	Urban	Total
Big hotel	0.00%	16.61%	4.49%
Dance hall	17.31	16.41	17.06
Sauna	8.11	16.90	10.49
Barbershop	1.13	18.17	5.74
Inn	0.00	6.73	1.82
Barber, karaoke	0.00	9.08	2.46
None	73.45	16.10	57.94
TOTAL	100.00%	100.00%	100.00%
OBSERVATIONS	767	2,546	3,313

Notes: 1999–2000 population sample. Weighted distribution of all respondents, both male and female. Number of observations in the last row are unweighted, and limited to locales for which commercial sex facility data were collected, which was 52 of 60 locales.

small towns—had commercial sex outlets readily available within easy travel distance (Table 10.2). Some of these were primarily in large hotels, which would be too expensive for most men—this for 16.6% of the urban population. However, for most people there was an ample supply of dance halls, saunas, and barbershops where female sex workers (FSWs) reputedly plied their trade. Some could turn to small inns, bars, or karaoke parlors to find female sex workers.

3. *Sex Worker Contact and Condom Use.* The availability of outlets corresponded to what men reported for their most recent contact with a sex worker (Table 10.3). The data for these statistics came both from the population sample and the clinic sample. Rural men were more limited in their choices. Urban men were less limited, though they tended to concentrate in slightly more upscale locations in 1999–2000—in high-class hotels, large saunas, and nightclubs, rather than in small salons or inns or on the street or in a park.

Among sex workers contacted in high-class hotels, consistent condom use reached an unweighted total of 56.7%. This fell to 29.9% in sex with women contacted in bathhouses, massage parlors, and barbershops. Below that, consistent condom use was mostly in the 15–20% range (see Table 10.3 for contact points and condom use among female sex workers).

Table 10.3
Female Sex Worker (FSW) Contact Point and Consistent Condom Use
(percent)

	Contact point (% distribution)				Percent using condom consistently		
	Population		Urban		Urban locales by type of sample		
	Rural	Urban	Clinics	"Total"	Population	Clinics	"Total"
High-class hotel	0.0%	18.4%	13.7%	13.9%	66.3%	52.1%	56.7%
Bathhouse, massage parlor, barbershop, etc.	0.0	16.0	26.3	24.7	63.1	22.8	29.9
Karaoke, dance hall, restaurant, etc.	57.1	19.1	19.7	19.9	34.2	14.5	18.8
Ordinary hotel/inn	0.5	6.1	13.4	11.8	11.5	14.9	15.7
Small barbershop/inn	0.0	8.5	10.9	10.6	14.1	15.8	19.6
Street, park, bus stop	4.3	9.2	2.3	3.5	5.4	12.5	13.3
Partner's home	0.0	6.5	4.7	5.0	21.5	12.5	13.6
Respondent's home	0.5	1.6	2.0	2.8	43.8	10.0	16.7
Other	37.8	14.8	6.3	7.8	13.6	13.6	17.6
TOTAL	100.0%	100.0%	100.0%	100.0%	34.0%	21.7%	25.9%
OBSERVATIONS	16	82	350	432	82	350	432

Notes: Men's reports in 1999–2000 samples. Population figures are weighted to estimate total urban and rural populations. Clinic samples are from 15 clinics distributed among Beijing, Shenyang, Yichang, Fuhou, and Guangzhou. Clinic and "total" columns are unweighted, with the total column being the simple combination of urban population and urban clinic data. Numbers of observations are based on unweighted raw data.

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Table 10.4
Consistent Condom Use by Short-Term Partner Type

	Percent distribution		Condom prevalence		Condom odds ratios	
	Commercial?		Commercial?		Commercial?	
	No	Yes	No	Yes	No	Yes
Education						
High school or more	66.5%	62.9%	20.4%	30.6%**	1.26	1.78*
Junior high or less	33.5	27.1	14.9	17.5		
Marital status						
Never married	24.4	26.2	29.6*	33.3*	2.79*	1.55
Ever married	75.6	73.8	15.0	23.0		
Times had sex						
Only once	33.5	66.0**	29.7**	33.9**	4.82**	8.86**
2–5	29.4	20.6	18.5*	12.0	2.25	1.94
6+	37.1	13.4	8.5	6.7	–	–
Can cure STDs:						
Can cure none	6.3	5.1	21.4	52.2**	1.76	5.54**
Can cure a few	11.8	3.4	23.1	40.0*	1.77	3.36+
Can cure most or all	67.0	63.5	15.5	25.3	–	–
Don't know	14.9	28.0	27.3	20.0	1.92	0.93
Contact point:						
High-class hotel		13.9		56.7**		5.29**
Bathhouse, massage parlor		24.7		29.9*		1.59
Other place		61.4		17.0		–
TOTAL	100.0%	100.0%	18.6%	25.7%		

Notes: Unweighted data from 1999–2000 clinic and urban population samples for men reporting a sexual partnership of less than a month's duration. Including only the most recent partnership with complete data, 221 were noncommercial and 447 were commercial. For simplicity of analysis, all figures and statistical tests posit a simple random sample. * $p < .05$ ** $p < .01$

4. *Consistent Condom Use.* In addition to point of contact, several other conditions promoted consistent condom use with both noncommercial and commercial partners (Table 10.4). First, the characteristics of men having any short-term sex were similar in many respects for both commercial and noncommercial sex (see first two columns of Table 10.4). Both involved men who were more educated and married (yes, married, or "ever married," but usually currently married). And the beliefs about curing sexually transmitted diseases were shared. The only major difference was that commercial

sex was more likely to be a one-time affair (66%), whereas only 33.5% of noncommercial sex involved a one-time event. Second, consistent condom use was more common among more educated men. In commercial sex, the percentage rose to 30.6% among men with at least a high school education, in contrast to only 17.5% among men with less education. This difference was statistically significant in both the bivariate prevalence and adjusted odds ratio results. Never-married men were more likely to use a condom, a difference that was statistically significant for noncommercial sex in both bivariate prevalence and in adjusted odds ratio results. Men were more cautious in a single encounter, but then adjust downward as they have repeated contact with either type of partner. For commercial sex, belief that few or no STDs could be cured increased consistent condom use. And again, in both prevalence and odds ratio results, commercial sex with sex workers in high-class hotels was more likely to involve a condom.

D. DISCUSSION

This analysis has several limitations. In this study the correlation between reported condom use and chlamydia infection in lab tests of urine provides some evidence of valid reporting by men. Nevertheless, the validity of self-reports of sexual behavior is always suspect. We sampled not all migrants but only the more stable migrants. The clinic data are not from a probability selection of clinics, and when combining clinic and population data we have no means of properly weighting the data or of properly adjusting statistical tests for sample design effects. Much of the data on sex worker contacts come from clinic patients. Judging from reports in the population sample about where the respondent got treatment at the last sexually transmitted infection, 60% went to clinics. This 60% tended to be better educated, with more income, and in larger cities. These tendencies are also associated with greater condom use with sex workers, which implies that our data on condom use could well be overstated. Also, the figures on where men contacted a sex worker could overstate proportions in high-class hotels and in other better establishments. The only reason to think that overstatement is not severe is that the percentages contacting sex workers at different types of establishments and the percentage using condoms were broadly similar in both the population and clinic data (Table 10.3). An additional limitation is that the clinic data were not from a probability selection of clinics.

Regardless of these limitations, several themes emerged from the study results. First, in contrast to many societies, where short-term partnering is concentrated among the very young and the unmarried (Caraël 1995), Chinese short-term partnering in 2000 started later—often in a man's early twenties, and then continued until his late thirties. A further implication of this pattern was that the greatest risk for women in 2000 was to be married, which means that in time HIV transmission from pregnant women to unborn children would also be common. This husband-to-wife transmission path is common in many societies, and this was repeated in China in 2000 (Fonck et al. 2000; Gangakhedkar et al. 1997; Klouman et al. 2002).

Second, in common with many developing societies (Caraël 1995), the greatest sexual experimentation occurred not among the poor and uneducated but among the educated and rich. This tendency may have been exacerbated in China because commercial sex was so much a part of business and government entertaining. This could imply that as HIV infection China leaves its original concentrations among IDU and blood transfusion networks and enters commercial sex networks, the first to be hit will be the best-and-brightest groups in China (and their wives)—a pattern shared with the early stages of the HIV epidemic in sub-Saharan Africa (Ali, Cleland, and Caraël 2001; Armstrong 1995). The one bright note is that in 2000 the more educated were already more cautious in their condom use. However, even among those with at least a high school education, only 30.6% consistently used a condom in commercial sex. This was higher than the 17.5% with less education (Table 10.4) but still low given that HIV infection among sex workers was rising (UNAIDS 2002). Moreover, even increasing knowledge about HIV and STDs may have had only limited effects. In unreported results, correct answers about HIV transmission were unrelated to consistent condom use, a repetition of a common finding in many countries that the link between AIDS knowledge and risky behavior is complex (Amadora-Nolasco et al. 2001, Wulfert and Wan 1995). In the results reported here, beliefs about cures for STDs were related only in the most extreme—and erroneous—belief that no STD could be cured. Providing information that corrected that particular belief would lead not to more but to less condom use. Thus, more education and propaganda may well help, as it has in other societies. Nevertheless, optimism about education alone should perhaps be tempered.

Third, consistent with the finding that it is high-income men who are most at risk, low-status male migrants were at no higher risk than other

urban men of the same age and coastal residence. This is a controversial finding that goes against considerable popular and academic opinion in China. It could be distorted by our sampling from registered migrants who were in more stable work situations. At least one other probability sample of migrants in southwest China found that migrant men were at greater risk net of other background conditions (Yang 2004). Nevertheless, most of the migrants in our sample worked at menial construction and service jobs at modest wages—exactly the types of men commonly thought to be prone to risky sex practices. If the findings in our study hold up in other studies, intervention efforts should move from the train station to the airport in order to have the greatest impact on men engaged in risky behavior.

Fourth, in 2000 it was only a narrow stratum of CSWs working out of high-class hotels who were able to secure consistent condom use from their male clients. Though far from perfect, at slightly over 50%, the consistent condom use among these high-class hotel workers in 1999–2000 was above that for women in other work situations, where condom use of only 15–20% was common. Other studies in China through 2000 report similar condom use figures and a similar patterning by the sex worker's place of work (van den Hoek et al. 2001, Qu et al. 2002, Rogers et al. 2002). Low as they are, even these percentages for consistent condom use may be optimistic. In 1999–2000 most men reported they were contacting sex workers in more up-market outlets. The following section on recent changes suggests that in the last four years, sex work and clients have moved sharply down-market. If so, then the price for commercial sex may have been driven down and the demand for higher client turnover with less safe sex may have increased, which poses even greater challenges for effective intervention.

II. Recent Trends and New Intervention Challenges

The second part of this chapter draws on other sources of data to get glimpses of changes in sexual behavior since 2000. This part is more frankly prescriptive, suggesting politically and socially unpopular solutions. The second author of this chapter, Pan Suiming, continues to be highly involved in the study of sexual behavior in China (Pan et al. 2004). He and his students are interviewing sex workers and sex work managers about their business and life (Pan 1999, 2000, 2004). He and his students monitor the very active chat rooms on sexual behavior on free-wheeling Chinese internet services. And he often sits on evaluation committees for domestic- and foreign-directed HIV intervention efforts. It is his alarm over the rapidity of

change, and frustration with what he views as ill-informed domestic and international intervention efforts, that have prompted many of the more radical proposals below. This discussion is in four sections: sex workers, casual sex, stable (married) sex, and effective interventions.

A. SEX WORKERS

The major thesis of this section is that much more risk comes from the nature of the sex industry (in its "production relations," if you will) than from the individual traits of "bad people."

1. *Nature of the Sex Industry.* The work situation for female sex workers (FSWs) varies radically, from more educated sex workers in major hotels, who in some ways act as self-employed workers serving higher-income, more educated clients, down to the lowest street workers, who can in many ways be justifiably characterized as enslaved to their situation. In the hierarchy of work situations described in Table 10.3, one has to descend only slightly below the top before women lose most of their ability to bargain over condom use and before male clients lose any concern about the health of the sex worker (see details in Pan 1999, 2000).

2. *Sources of the Sex Industry.* There are several tendencies that may well have increased the number of sex workers at the bottom of the hierarchy of commercial sex sites in Table 10.3 and made those FSWs at the bottom even less able to insist on condom use. One of those tendencies is an increasing lust for economic growth ("GDPism," one might term it) on the part of many local governments. One example comes from a 2002 study of three towns in southwestern Sichuan Province (details in Pan 2004). In a remote town, the local government sponsored an economic development zone that took over farmers' land. The farmers invested the small reimbursement for their land back into improvements for the new zone. Unfortunately, however, the new zone attracted no additional investment, with the result that running sex businesses was the only way for farmers to recoup some of their investment. The farmers attracted some voluntary sex workers who were already in the trade and inveigled some new recruits who were not volunteers. The girls fled due to a lack of clients. The farmer-managers pursued and recaptured the girls. Local government leaders turned a blind eye, responding, "We are indebted to the farmers" and "The girls provide one of our three meals every day," through the taxes the sex businesses pay to local government.

A second type of example is common in town-level brothels in hinterland areas. In this instance, after being arrested, female sex workers were fined as much as RMB 5,000 (half a year's salary for a male blue-collar worker in Beijing). They could not afford this fine and had no friend to help them pay because they were not from the town in question. Only the manager of the sex business could pay the fines because he was the sex workers' only local acquaintance (most work away from their home locale). They thereby became debt-slaves of the manager. Afterward, they had to solicit many more clients, even if this meant accepting clients who demanded sex without a condom. They also had much less money to visit a doctor, or even to buy condoms. To escape from the police, they fled to a new location, carrying STD/HIV with them. Some sex workers sold themselves to the manager of a sex business because the manager had strong official/gangdom supporters, which was the best way for a sex worker to avoid being caught and fined. Managers knew this. Unsurprisingly, they liked the slave system.

A third type of example often appears in the Chinese media. Local police remain unpaid or without a bonus. One solution is for the local police office to get additional funds from a proportion of the sums taken from fines of female sex workers. Arresting female sex workers is easy, safe, and important-sounding work that has become a significant way of "creating income" (*chuang shou*) for some local police and their deputies.

The spread of these types of stories exacerbates the problem of social stigma against sex workers. Judging from opinions expressed in chat rooms and written in articles on the internet, a rapidly increasing income gap has made common people angry about sex workers. Sex workers are perceived as being able to "work easy and earn much." The involvement of police officers intensifies these reactions. In popular opinion, sex workers are seen as promoting corruption due to some officers' visiting a prostitute or having a mistress (second wife) on the side. Female sex workers are at higher risk of being scapegoated for corruption than they are of contracting HIV infections. "Bad women corrupt good men" continues to be heard often. Good women are now fighting against these "bad women."

3. *What Should HIV Intervention Attempt to Accomplish?* The highest goal would be to legalize sex work relatively soon, so as to eliminate the semi-slave system and its root, rather than eliminating and punishing the actual women trapped in the sex trade. A middle goal is to empower FSWs to bargain with recruiters/captors, managers, and clients for support in pro-

moting consistent and unconditional condom use. The goal that will take the longest to achieve strives for 100% condom use in the sex industry in China.

4. *New Trends in the Sex Industry.* Changes are occurring rapidly, including the following seven kinds of sex services, which have become commonplace, at least in popular discourse:

> Internet-based girls (*wang ji*) solicit through the web, BBS (bulletin board services), QQ (a form of instant messaging), forums, and short letters over mobile telephones.
>
> Chat-escort girls (*pei liao*) ostensibly accompany men for conversation, though sex is the outcome for some couples.
>
> "Full service nanny" (*quanhuo baomu*) is the popular title for someone not only working as a nanny but also in the role of "night worker" (*ye-huo*).
>
> "False marriage introducer" (*hun-tuo*) indicates soliciting through a marriage introduction institute as an unmarried or single woman.
>
> "Selling sex in her home or apartment" (*jia-ji*) services and "husband-wife shops" (*fuqi dian*) are increasing.
>
> Oral sex or masturbation in cinemas and similar places (*pei kan*) appeared several years ago and has now spread to other forms of sex, including more and more strippers selling sex.
>
> "Sexual bribe" (*xing-hui-lu*) indicates paying for a police officer's visit to a prostitute or sending him a prostitute.

5. *HIV Intervention.* What is the significance of all this for HIV intervention? Faced with the rapid diffusion of these new types of services in the sex industry, intervention workers must understand that there is no longer a single type of sex worker but many different types, making intervention ever more difficult. For the traditional types of sex workers (which are themselves internally differentiated), there are several lessons. As already mentioned, the ideal goal would be to legalize sex work immediately, thereby reducing official entanglements—including eliminating the fines that help enslave young sex workers. This is not an absurd proposal but one consistent with arguments for crime control in US cities many years ago (e.g., Morris 1970) and with Nevada practice today (e.g., Albert 2001). Short of this ideal goal, we need new methods for helping empower FSWs in bargaining with agents, managers, and clients, so as to allow the women to insist on condom use with their clients. Thailand, with its 100% condom use campaign, pro-

vides one model of how this might be put into practice (Hanenberg and Rojanapithayakorn 1998).

We need radical new ideas if we are to stop or slow current trends. One radical, untried method would be to get male clients more involved in efforts to promote condom use for everyone. The traditional methods of intervention—booklet distribution, condom distribution, and peer counseling—would be supplemented by a new method of contacting and training volunteers from among male clients. This would involve changes in many attitudes, including the old view that clients are "bad men." Many clients are higher-income men (Parish et al. 2003). These client volunteers would be able to do work that is impossible for anyone else: They could find and interview every kind of sex worker everywhere and at any time. They could very easily teach sex workers how to require men to use a condom and pay the sex worker more money. Indeed, most sex workers already learn condom use from clients, instead of from managers, friends, or others. They might also establish cooperative relations with local police more easily than either sex workers or HIV intervention workers can. Moreover, they would be powerful enough to advise, or even force, the managers of sex businesses to accept a 100% condom use project in their sex establishments.

An example of where the customer makes a difference is found in the prevalence of condom use among Hong Kong men crossing the border to China to visit sex shops. This requires only a short train ride, and is available to men of all backgrounds. Among these men, consistent condom use during commercial sex approaches two-thirds (Lau and Thomas 2001). Though no data are available on the class of sex worker visited by Hong Kong men, the sheer volume of contacts among Hong Kong visitors to China suggests that Hong Kong men are contacting a wide variety of types of Chinese sex workers. If so, then, the relevant comparison is to Chinese men, among whom only about one-fourth report consistent condom use with sex workers (Table 10.3). The much higher prevalence of condom use among Hong Kong men visiting similar types of sex workers is consistent with condom use being controlled more by the customer than by the sex worker.

B. CASUAL SEX (NONCOMMERCIAL PARTNERS)

In 2000, when we completed our national survey, casual sex with noncommercial sex partners was not a major risk factor in STD transmission. However, this appears to have changed rapidly since that time. The available

evidence, informal as it may be, suggests that casual, noncommercial sex is increasingly a source of risk, particularly among the young.

Changes in discourse alone are no proof of behavior change. Nevertheless, the proliferation of new terms and the revival of old terms in internet chat rooms and on the street suggests the emergence of a new sexual culture, free of top-down social control. The rapid spread of this culture among urban youth poses challenges for intervention in new patterns of risky sexual behavior. The following types of terms are now commonplace in popular culture:

> Extramarital love (*hunwai lian*); most Chinese think it includes sex.
>
> One-night love (*yi ye qing*); actually, most are one-night stands.
>
> Internet-based love (*wanglian*), developed from internet-based friendships leading to love or sex.
>
> The fourth kind of feeling (*di sizhong qinggan*); the other three kinds are friendship, love, and sex. This term means something in between any two kinds of feeling.
>
> Importuning a girl (*pao niuer*), as in boiling tea—that is, spending a longer time to seduce someone, usually a girl-stranger, without being shy and never shrinking from the task.

Other, more derogatory expressions describing new sexual behavior have also blossomed. Four examples come to mind: hired (paid) second wife (*bao ernai*), which is different from a simple extramarital lover; keeping "a sexual girl secretary" (*yang xiaomi*), or "a young sweetheart," or, literally, a "small honey"; unmarried girl fed by a rich man (*bang dakuan*), which is focused on female students now; and the third person (extramarital lover, *di sanzhe*), implying that he/she wants to break up the original marriage.

The current popular discourse on sex in China pays no attention to HIV. In popular discourse there is much attention to the following types of dichotomies: spiritual love (*qingai*) vs. sexual love (*xingai*); sexual felicity (good luck in having sex, *xingfu*) vs. unhappy sex (*xing fannao*); sexual interest (*xingqu*) vs. oppressed sex or non-sex marriage (*xing yayi* or *wuxing hunyin*); "sexual quotient" (mimicking the intelligence quotient, *xing shang*) vs. sexual blindness (*xing mang*); love-making (*zuo ai*) vs. sexual intercourse (*xingjiao*); and sexual health (*xing jiankang*) vs. sexual disability (*xing wuneng*). In all these terms and dichotomies, there is nothing about HIV. Despite the many other new terms concerned with sex, the term "HIV" still has no brief, popular, vivid "name" in either oral or written Chinese.

One worrisome aspect of this new popular discourse is that it pays little or no attention to the issue of sexually transmitted diseases or HIV. "Safe sex" remains an unknown term. These facts pose several problems for HIV prevention efforts. Analysis of degree of HIV risk typically emphasizes the number of sexual partners. In contrast, for ordinary Chinese people, the issue is whether or not you have an extra partner. HIV prevention typically asks whether sex is safe or unsafe, whereas Chinese popular opinion is more concerned with whether or not sex involves love (or marriage). As in the US, much popular discourse is divided into two camps: on the one side are those stressing the freedom of love, and on the other are those stressing the stability of marriage. Neither camp is concerned about HIV risk—and, typically, neither side puts sex in the forefront per se.

Among developed countries, there is a divide between a European approach that is more accepting of sex among young people and a US approach that is much more moralizing and unaccepting of sex among youth (e.g., Boonstra 2002; Danielsson, Rogala, and Sundstrom 2001; Darroch et al. 2001). Many analysts find the most extreme version of the moralistic, abstinent American approach problematic, arguing that it simply does not work or has unintended consequences that are as dire as the sexual behavior it delays (e.g., Bearman and Bruckner 2001; Hock-Long et al. 2003; Jemmott, Jemmott, and Fong 1998). Indeed, net of many other potentially confounding conditions, European adolescents, exposed to more matter-of-fact sex education and cultural norms, have lower levels both of teenage pregnancy and of other negative outcomes of sexual behavior.

Forces could easily move China in the potentially problematic American direction. From the 1950s through the 1970s, China was the land of "Just say 'No'" when it came to sex (Liu 1992, Pan 1993, Ruan 1991). Those heavy-handed bureaucratic instincts are still common in China. More recently, some foreign groups have begun emphasizing "ABC"—abstinence, be faithful, condom use—for China. This type of ABC is problematic for several reasons. In popular thinking, most people have never believed that a man can be "A." Given the rapid spread of a new culture of sex among the urban young, proposing "B" to Chinese urban youth is, arguably, unrealistic—much like "playing piano for cattle." Even for "C," one needs to translate condom as "love sheath" (*aiqing tao*) and not its usual "pregnancy protection sheath" (*biyun tao*). Moreover, the more effective approach among Chinese urban youth is likely to be one that gives them the "carrot" of a hope of love rather than the "stick" that showcases scary propaganda. This means adding love skills into HIV education; opposing any intervention into

the sex rights of youth, especially by government authorities; and lowering the legal marriage age from its current 22 for men and 20 for women to an earlier set of ages. More generally, we need to emphasize love first and safety second. Or, returning to comparisons between European and American approaches to sex education, the challenge is to move China more toward the European than the American model of intervention.

To understand the place of sex in Chinese society, one needs a little history: A "sexual revolution" emerged in China after 1985, particularly among young, educated urban males. The "father" of this sexual revolution was the Cultural Revolution (1966–1976), which developed a "non-sexuality culture." This does not mean there was no sexual behavior during that decade, but that any kind of outward appearance of sex, even thinking of sex, was condemned and prohibited. Another aspect of the sexual revolution was the "birth revolution"—namely, the "one child policy" implemented after 1980. One of the unforeseen side effects of this "state policy" (*guoce*) was to separate sex and birth—in other words, to free sex from old social constraints.

Moreover, because traditional culture was destroyed in the Cultural Revolution and its successor, Maoism, died after 1980, by the 1990s there was no Chinese ideal or cultural basis with which to oppose the sexual revolution. It is this absence of a cultural or religious basis in secularized China that makes any morality-based call for "abstinence" difficult to implement. This absence of religious and other traditional social norms sometimes leads to other approaches. HIV risk appeared just as China was becoming more open to the West. This coincidence caused some people to identify HIV with both the sexual revolution and the West, providing them with an ideal political weapon. Opponents of the sexual revolution proclaimed that "AIDS is a punishment for sexual freedom issued from Heaven." They made HIV prevention into a moral movement and part of the "spiritual civilization building" (*jingshen wenming jianshe*) that, along with economic development, is one of the two main aims of the CCP (Chinese Communist Party).

This politicized conflict caused both sides to misunderstand HIV risk. On the one side were Chinese ideological leaders always eager to put considerable energy into stopping "sexual disorder," while hesitating, even fearing, to popularize condom use. They considered condoms a major catalyst for sexual freedom—a pattern that will be familiar to American readers. On the opposite side, few people really felt that the issue was a simple one of health and life, especially among "sexually liberated persons."

Thus the focus of HIV prevention propaganda, particularly among high-risk populations, was diminished.

C. SEX IN STABLE RELATIONSHIPS

In the Chinese Health and Family Life Survey completed in 2000, the biggest risk factor for a woman was to be married—particularly to a high-income man who engaged in frequent business entertaining (Parish et al. 2003). Women did not adequately appreciate this risk, both because many of the current infections were asymptomatic and because they probably underestimated the degree to which their husbands had extramarital partners. Among currently married urbanites with a husband age 20–49, only 5.5% of women reported that their husband definitely had an additional sexual partner during the lifetime of their relationship. Another 19.3% allowed that their husband might have had an additional sex partner, though they were not sure. The percent saying that their husband definitely had had an additional partner was not nearly high enough. Among married men in the same age range, a full 24.0% reported that they had had an additional sexual partner while with their wife—in many cases a commercial sex worker. In short, the women's percentages for "definitely" and "maybe" need to be added together to produce a figure closer to the men's actual behavior. Unsurprisingly, fewer women in the same age range reported that they had had an extra partner (6.4%), even though their husbands were more likely to suspect (11.9%) or to be convinced (2.0%) that their wife had had an extra partner.

Despite the added element of risk, only 6.7% of urban couples age 20–49 reported consistent use of a condom during sex in the previous year. Even more problematic, condom use was unrelated to a man's report of having had unprotected sex with a sex worker during the last year. For both the commercial-sex-using man and the non-using man, condom use was 6.8% in 2000. Also, women's suspicions did not increase condom use. Instead, the more suspicious women reported even less condom use (2.8%) than the non-suspicious women (8.0%; $p<.01$).

Condom use among married people is low in most societies, for obvious reasons. For one partner to suddenly insist on condom use would raise questions both about the behavior of the person calling for the condom use and about the level of trust in the couple's relationship. Arguably, the tendency toward modest condom use is exacerbated in China because the birth control campaign has placed so much emphasis on intra-uterine device

(IUD) insertions, on birth control pills, and on sterilization. In this climate, one cannot hope for a rapid increase in condom use, short of several drastic and improbable changes in government policies. These changes would include greatly raising the price of IUDs and the Pill while keeping condoms free. The Family Planning Committee would need to award condom users widely publicized prizes. Moreover, rules would need to be changed so that if one was infected with HIV by his/her married partner, it would be the strongest justification for divorce. At the same time, the partner would need to be forced to offer significant compensatory damages to his/her victim(s), including unmarried and extramarital lovers as well as spouses.

D. EFFECTIVE HIV INTERVENTIONS

Those seeking to accomplish effective intervention in China need both to learn from the West and to be aware that any intervention efforts must be contextualized within Chinese cultural and social traditions. The learning from the West must include the message that no single approach provides the key to effective intervention (e.g., Becker, Rankin, and Rickel 1998; Kirby 2002) and the message that some of the most effective interventions, particularly among youth, involve shaping norms and mobilizing peer pressure (e.g., Bearman and Bruckner 1999, Kirby 2001).

Traditional Chinese thinking presents several challengers to effective HIV intervention. Two such challenges stand out. First, any intervention campaign that focuses on individuals will encounter problems with traditional concepts of the individual. In traditional Chinese culture, there was no "individual" in either ideology or practice. Even today, this cultural background (arguably frozen in place by three decades of socialist rule) causes people to confuse individualism with selfishness. The latter word is a serious term of opprobrium, even now. Second, similar problems exist in the concepts that attempt to describe sexual behavior. Traditionally, sexual behavior was serious conduct connected with having offspring (*chuang zong jiedai*), with filial piety toward parents (*xiao*), with the linking of two families (*lian yin*), and so forth, rather than happy play between two individuals. Sexual relations within marriage were less valued than the relations between brothers, not to mention those between parents and children.

Given this kind of cultural background, it is unfortunate that some westernized specialists have presented HIV infection as an illness that is harmful to one's own life first, and then, through transmission, to one's sexual partner. This gives the mistaken impression that HIV is less dan-

gerous to one's children, parents, and extended family than it is to oneself. Workers from the countryside flooding into cities (*nongmin gong*), who are a high-risk population, are particularly likely to gather that risky behavior will harm only themselves and not their larger family (which would be a greater source of social disapproval).

Current intervention efforts are problematic on several other dimensions as well:

> *Life first?* This call rings hollow for the most oppressed groups in society. For example, it rings hollow for "peasant-workers" who are doing hard and dangerous jobs, and for FSWs who suffer violence and even death from women-hating offenders, managers of sex businesses, clients, and policemen.
>
> *Health first?* This has little meaning for persons suffering absence of sex, unhappy sex, sex-without-love, foolish sex, insertion-only sex, and dysfunctional sex. According to ordinary peoples' understanding of "sexual health," these "illnesses" are more harmful than HIV risk.
>
> *Safety first?* At least for men attuned to the new sexual discourse, "sexual felicity" (*xingfu*) seems like orgasm worship. Which one will they choose—happy but unsafe sex or the opposite?
>
> *Sex or life?* For the sexual risk population, a traditional poem (which has become a saying) reads, "Rather die under flowers, still being an honored ghost" (*ningyuan hua xia si, zuo guiye fengliu*; i.e., it's better to "die a happy man").

In any event, current propaganda in China educates those with little chance of contracting an HIV infection, while to the "boldest persons" who take the greatest risks, the message is weak and poorly targeted. Current intervention efforts are also inhibited by the absence of an adequate set of categories in Chinese for describing sexuality. All Chinese words and their connotations concerned with sex remain male-female-based, penis-vagina-focused, birth-aimed, body-medicalized, and dysfunction-fearing. Given the difficulty of finding a proper Chinese word for "sexuality," it is difficult to popularize the idea. Few scholars are studying sexuality, and even fewer want to do related intensive research, especially among HIV prevention workers.

Such a situation makes it difficult for people to discuss sexual issues openly and frankly, even setting aside gender issues, especially homosexuality, and considering HIV as just a medical problem. It also causes medical workers to pay less attention to both practical and socio-cultural issues,

leading them to design unsuitable and less effective HIV intervention projects. For example, a picture booklet for promoting condom use was printed and given to FSWs in dance halls. However, the booklet was much bigger than the girls' handbags, even after it was rolled up. Predictably, all the booklets were abandoned in the trash.

Particularly in China, an emphasis on approaching people not as individuals but as members of family networks might well be the most effective. Use of social networks is urged in the literature for developed countries (e.g., Bearman and Bruckner 1999, Kirby 2001). In China more emphasis would need to be put on family networks, particularly when rural migrants are involved. An example of how this might proceed occurred in Hunan Province, where intervention workers helped farmers send letters and make phone calls to family members and relatives working in cities. There is a Chinese saying that family letters are worth a thousand pounds of gold (*jiashu di wanjin*).

An additional emphasis, more akin to what occurs in European sex education (as opposed to some efforts in the US), would emphasize not fears from risky sex but the benefits of "good sex," thus switching from the "stick" of fear of harmful consequences and administrative sanctions to the "carrot" of healthy sex with beneficial consequences. Parts of this effort could include more attempts at positively communicated sex and marriage counseling, including more instruction on sexual techniques. Another example might be to teach youth not only how to refuse unwanted sex but also how to seek mutually agreed on, mutually enjoyed sex. This approach would see "sexuality" as a basic human right in which all Chinese would deserve to participate in beneficial ways.

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CHAPTER II

A Delicate Balance

Law Enforcement Agencies and Harm Reduction Interventions for Injection Drug Users in China and Vietnam

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I. Background: Injection Drug Use, HIV/AIDS, and the Harm Reduction Approach

As of 1999, 136 countries on all continents of the world had reported having injection drug users (IDUs), and 114 of these had reported cases of HIV infection associated with injection drug use (UNAIDS 2002). These two epidemics are inextricably linked: where injection drug use occurs, almost inevitably there will be sharing of injection equipment among users, and where sharing occurs, there will be HIV infection. Sharing of needles

and syringes, involving as it often does the injection of another person's blood directly into a vein of the recipient, is one of the most efficient methods of transmitting HIV, as well as hepatitis C virus (HCV).

In China and neighboring Vietnam, HIV prevalence rates among IDUs have reached 60–70% in some areas, and HCV prevalence is probably even higher. Injection drug use is particularly prevalent in border areas and among poor, unemployed, and ethnic minority people who are already marginalized. Drug users and people living with HIV are highly stigmatized and suffer from serious discrimination (Hong, Anh, and Ogden 2004, Khoshnood and Weber 2003).

In most areas of China and Vietnam, the HIV epidemic remains largely concentrated among IDUs. However, contrary to popular mythology, many IDUs are sexually active and thus there is the real possibility of HIV bridging to women who have sex with IDUs (sex workers as well as wives, girlfriends, and casual partners). In this way, a transition from concentrated to generalized HIV epidemic could occur, with large numbers of people in the "general population " being affected. There have been troubling recent increases in HIV prevalence among sex workers and antenatal women in both China and Vietnam, indicating that this transition may be beginning (McCoy, Kane, and Rushing 2004; China MOH and UN Theme Group 2003; Strathdee and Sherman 2003).

There are three major approaches to drug prevention and control: supply reduction, demand reduction, and harm reduction. Neither supply reduction nor demand reduction has yet been shown to be successful in substantially reducing, let alone eliminating, illicit drug use (Centre for Harm Reduction 2003). In this context, only harm reduction approaches have a reasonable chance of reducing HIV and HCV transmission among IDUs and between male IDUs and women who might then spread these infections in the larger community. Philosophically, the harm reduction approach does not condone drug use. Indeed, comprehensive harm reduction programs incorporate substance abuse treatment and other strategies to help addicts stop using drugs.

Although harm reduction does not condone or in any way encourage drug use, it does acknowledge that many addicts will be unable or unwilling to stop using, so that drug use will continue to occur. Therefore, harm reduction focuses on reducing the harms associated with drug use, including HIV infection. Harm reduction strategies emphasize achieving short-term, practical goals and generally offer a hierarchy of risk reduction methods acceptable to people in different situations and contexts. Successful harm

reduction programs depend on the active involvement of drug users and on a sound basis in research and evidence (Centre for Harm Reduction 2003).

A comprehensive harm reduction program for IDUs will include a range of interventions, including information and education, substance abuse treatment and drug substitution (e.g., methadone or buprenorphine), community outreach and peer-based programs, needle/syringe exchange and safe disposal of used equipment, pharmacy sales of new needles/syringes, voluntary counseling and testing (VCT) for HIV, and sexual risk reduction, including condom promotion and distribution. Although this chapter focuses on peer-based programs, needle/syringe exchange, and pharmacy sales of needles/syringes, it is important to understand that all of the above components are needed for harm reduction to have full effect. To be successful, harm reduction programs must also have the support of the communities in which they seek to operate. However, widespread and deeply entrenched misinformation about and misunderstanding of harm reduction approaches—such as the common misperception that needle and syringe exchange programs encourage or facilitate increased drug use—have led to adverse decisions and actions at all levels of government and society. A prime example is the ban imposed by the US Congress on the use of federal funds to support the provision of sterile needles and syringes to drug users. This ban, and prohibitions against needle exchange programs elsewhere, fly in the face of overwhelming evidence that such programs do not increase drug use; rather they reduce the sharing of injection equipment, HIV incidence, and, ultimately, HIV prevalence among IDUs wherever they are established (Coffin 2000; Des Jarlais et al. 1995; Doherty et al. 2000; Gibson, Flynn, and Perales 2001; Gibson et al. 2002; Hagan et al. 2000; Hurley, Jolley, and Kaldor 1997; Metzger and Navaline 2003; Monterroso et al. 2000; and Vlahov et al. 2001).

Multi-sectoral collaboration and the active support and cooperation of multiple stake-holders, including political leaders and police, are critical to the success of many harm reduction strategies, particularly those involving needle/syringe exchange, pharmacy sales, and peer-based programs. In this arena, there is clearly a tension or delicate balance between the perspectives of law enforcement and those of HIV prevention and public health. Even United Nations agencies have issued seemingly contradictory statements, with the UN Office of Drugs and Crime criticizing harm reduction and UNAIDS strongly supporting it. Such confusion within the UN understandably fosters confusion and uncertainty within national governments (Wolfe and Malinowska-Sempruch 2004).

Law enforcement agencies may cooperate with harm reduction programs for IDUs passively (e.g., simply "looking the other way" and allowing programs to operate without interference) or more actively, through outright endorsement and open participation and referral of clients. Such active participation is quite rare but very desirable (Burris 2004). Passive cooperation often involves police exercising discretion in their day-to-day activities on the street. Some argue that police are sworn to enforce the letter of the law in every circumstance and that failure to do so undermines respect for the law in the community. In reality, however, police frequently can and must exercise judgment in choosing what criminal activity is most (and least) important to target. This is often a matter of opportunity cost and resource allocation.

There may be a moral calculus as well as an economic one. According to a senior officer from the Liverpool (UK) police, it is true that police are sworn to enforce the law, but they have an even higher duty to preserve life. In his view, supporting harm reduction programs and encouraging IDUs to access them represent choosing the preservation of life over the rigidly consistent enforcement of every law (Sayers 2004).

Law enforcement officials face conflicting pressures and demands even if they opt for a broader definition of public safety than one demanding the literal enforcement of every law. Citizens have a right to demand that their law enforcement agencies protect their communities, and police are bound to respect those demands (Hansen 2004). Some citizens believe that the presence of drug users (for example, attending needle exchange programs) threatens community safety and increases neighborhood crime rates. This may or may not be true, but the assertions must be taken seriously. At the same time, proponents of harm reduction programs can legitimately make the case that prevention of HIV infection as well as the removal of potentially dangerous used needles/syringes from the community in fact advance public safety. Law enforcement agencies must ultimately decide how best to respond to and balance such competing arguments. Advocates of harm reduction programs will be most likely to win the support of police when they (a) provide clear and honest information about their proposed activities, (b) demonstrate an understanding of and sensitivity to the roles and concerns of law enforcement and how harm reduction programs can actually help law enforcement agencies achieve their goals and do their jobs better, (c) cast harm reduction programs as part of an overall strategy that makes room for supply and demand reduction, and (d) afford law enforcement officials the opportunity to observe the street-level operation of harm re-

duction programs. Direct observation can help overcome the perceived threat to public order and to the achievement of drug control goals that can arise from abstract descriptions of these interventions (Lemouchoux and Effendy 2004).

In the context of specific programs and communities, law enforcement action, the threat of such action, or even the perception among drug users that it will occur can have very harmful effects on participation in interventions (Bluthenthal et al. 1997). A study of the counterproductive effects of actual and perceived law enforcement actions on drug users and harm reduction programs in California identified three major ways such negative influences operate: (1) fear of arrest for possession of needles/syringes reduces drug users' participation in needle/syringe exchange programs, thus increasing sharing and other unsafe behaviors; (2) arrest of needle/syringe program volunteers reduces coverage of the target populations of IDUs and the number of needles/syringes distributed; and (3) fear of arrest discourages the summoning of emergency medical services in cases of drug overdose (Kral and Bluthethal 2004). In Indonesia, IDUs' fear of arrest occasions their reluctance to carry needles/syringes (Lemouchoux and Effendy 2004). Thus it is not simply the formal legal environment but the management policies of and training provided by law enforcement agencies—as well as actual street-level practices of law enforcement officers (any of which may or may not be strictly consonant with the laws "on the books"), and IDUs' perceptions of them—that materially affect drug users' attitudes and behaviors. This multilayered impact structure suggests the need for much more thorough and ongoing collaboration between public health and law enforcement agencies in the related realms of drug abuse and HIV prevention (Burris et al. 2004).

II. The Legal and Policy Environment for Harm Reduction in China and Vietnam

As in the US and many other countries of the developing and developed worlds, in both China and Vietnam the laws and government policy toward drug users are quite repressive. Possession and use of drugs are illegal, and drug users may be committed to potentially long terms in detoxification or rehabilitation centers. Repeat offenders may be sent to prison. In Vietnam particularly, drug use as well as sex work are explicitly termed "social evils" whose perpetrators need to be removed from society and receive intensive

moral re-education. Vietnam has established and continues to construct many new "05" and "06" centers for the housing and rehabilitation of female sex workers (FSWs) and drug users, respectively. These centers are under the control of provincial departments of labor, invalids, and social affairs. To incapacitate drug users and reduce crime and other problems associated with drug use, the Vietnamese government has dramatically increased average terms of commitment to the 06 centers—from three–six months to as long as three years. In China, drug users may be sent for up to six months to detoxification centers run by the public security departments or to re-education through labor camps for up to two years.

In these settings in China and Vietnam, very little if any of what would normally be termed "substance abuse treatment" is available. "Treatment" is generally limited to detoxification with little or no medication, and "rehabilitation" to moral education and vocational training. Relapse rates to drug use are extremely high. In this situation, harm reduction becomes even more important.

Though the overall approach to drug use and drug users in China and Vietnam is quite repressive, there are certain aspects of the policy and legal environment that are almost schizophrenically progressive. In particular, new needles/syringes are legally sold at pharmacies at very low cost. Despite the legality of pharmacy sales, however, some pharmacists refuse to sell to persons they believe to be IDUs, either on moral grounds or because they fear alienating their other clientele and their neighbors or getting into trouble with the police.

This is one way in which the delicate balance between harm reduction and law enforcement comes into play. It is legal to buy and possess needles/syringes but it is illegal to use them to inject illicit drugs. Police and law enforcement are charged with enforcing the laws against drug use, but they may also be asked to take a more tolerant, public health orientation toward needle exchange and pharmacy sales of needles/syringes to IDUs (Burris et al. 2004). It may be difficult for them to reconcile these roles, but this is necessary for effective HIV prevention. In Vietnam and China, tensions exist between overall policies treating drug use as a "social evil" to be dealt with in a largely punitive manner and central government endorsement of harm reduction interventions among IDUs, as in the recently adopted National HIV/AIDS strategy for Vietnam (Government of Vietnam 2004). In China, a recently issued State Council document urged health, public security, and other government agencies to work together more closely on HIV/AIDS prevention (Zhang 2004).

We now turn to the experience of a specific harm reduction project in China and Vietnam to illustrate some of the issues raised heretofore in a more general way.

III. The Cross-Border HIV Prevention Project: China and Vietnam

With joint funding from the National Institute on Drug Abuse, US National Institutes of Health (NIH), and the Ford Foundation offices in Hanoi and Beijing, a cross-border HIV prevention for IDUs was launched in 2001 in Ning Ming County, Guangxi Province, China, and Lang Son Province, Vietnam. This is the first-ever HIV prevention project for IDUs in which the same interventions are being carried out both sides of an international border. This China-Vietnam border area lies along a major heroin transshipment route from the "Golden Triangle" of Burma, Laos, and Thailand to Hong Kong and the rest of the world (Beyrer et al. 2000). As heroin began to be available in the traditional opium-smoking regions on this and other shipment routes, residents began to use it, at first by inhalation and smoking and quite quickly by injection; users then began to share injection equipment, and HIV infection began to occur.

Four sites in Ning Ming and five sites in Lang Son are employing an outreach model peer-based intervention. Provincial and local health department staff are implementing and overseeing the intervention. Salaried cadres of peer educators, most of whom continue to use drugs, contact IDUs in the community, provide HIV risk reduction information, and distribute new needles/syringes, condoms, and vouchers redeemable at participating pharmacies for new needles/syringes, ampoules of distilled water, and condoms. The peer educators also collect used needles/syringes from IDUs and shooting places, parks, and other locations in the community. At each Chinese site, a project center has been established where peer educators meet and IDUs can obtain needles/syringes, condoms, and pharmacy vouchers and return their used needles/syringes (Cohen 2003; Hammett et al. 2003). At additional sites in Guigang Township, Guangxi Province, and in Ha Giang Town, Vietnam, peer-driven interventions (PDIs) for IDUs are in operation as part of the cross-border project. A PDI differs from the outreach model in that it has no salaried peer educators but rather involves much larger numbers of drug users through a chain referral process. Drug users educate their peers on specific bodies of HIV risk reduction information and recruit them to come to a staffed project storefront where they

can receive more risk reduction information, new needles/syringes, condoms, and pharmacy vouchers, and have the opportunity to become recruiters themselves. Drug users receive modest rewards for visiting the storefront, recruiting new participants, and turning in used needles/syringes. Recruiters also receive a graduated reward based on how well their recruits perform on a test of the specific risk reduction knowledge on which they are supposed to have been educated (Broadhead et al. 1998).

Because of the sensitive issues involved in this project and the potential for disruption of the interventions by the police and public security, the support of all key stake-holders is absolutely essential to its smooth functioning and ultimate success. The cross-border project received from the beginning, and still maintains, the full support of political leaders, police officials, mass organizations, pharmacies, and other stake-holders in all of the project sites. The support of government and police agencies was memorialized in written instruments in both countries. In Ning Ming, the health department and public security department entered into a written agreement whereby the police agreed to support and refrain from interfering with the interventions. In Vietnam, the Lang Son Provincial People's Committee issued a written opinion supporting the project and calling on all agencies under its jurisdiction, including police, to provide full support and cooperation. People's Committees issued similar rulings at the local level in each project site. Written agreements, such as memoranda of understanding (MOUs) have been used successfully in other countries to document law enforcement and other governmental support for harm reduction interventions (Lemouchoux and Effendy 2004).

The ongoing support for the cross-border project has been achieved through regular community education carried out by project staff and peer educators, and by regular meetings between project staff and the various government and community stake-holders. A similar effort initiated by leaders of the health department in Pingxiang Township, adjacent to Ning Ming, was able to enlist the coordinated support of political leaders, police, and other key agencies in the initial acknowledgment that the community had a problem with HIV/AIDS and in the adoption of broad community education and harm reduction approaches to combat HIV among IDUs and sex workers. The health department and public security department negotiated an agreement allowing IDUs to access the interventions on certain days without fear of arrest (Szlezak and Howitt 2004).

Largely as a result of the cross-border project's ongoing efforts of coordination and education, there has been no police disruption of or inter-

ference with intervention activities. In Lang Son, project staff report that, pursuant to the endorsement of the project by the provincial and local People's Committees, the police posture toward the project is to have "one eye open and the other eye closed." This does not mean, however, that law enforcement activities, and the perceptions of them by IDUs, have had no effect on the interventions. Quite the contrary, it is apparent in multiple ways that law enforcement is having a strong influence, whether intended or not, on the extent and patterns of IDUs participation in the cross-border interventions. This influence can be seen in the changing levels of IDU participation, patterns of IDU preference for ways to receive new needles/syringes from the project, the extent to which IDUs are willing to retain used needles/syringes for exchange with peer educators or at project centers, and the geographic patterns of receiving and redeeming pharmacy vouchers. Each of these is discussed below.

A. IDUS' LEVELS OF PARTICIPATION

IDUs' levels of participation in the interventions of the cross-border project are influenced by actual law enforcement practices as well as by perceptions of such action and its association with the interventions. Police have continued to arrest drug users and carry out periodic crackdowns on drug users—and this ebb and flow of law enforcement activity, although it bears no relation to the project's activities, has affected IDUs' willingness to participate in the interventions. Not surprisingly, IDUs consider the regular proximity of police to intervention activities to be problematic. When staff were searching for a building to house the project center in Ning Ming City, one of the men being considered as a peer educator advised against a building that backed up on a police station. Encouraging IDUs to come to this location, he said, would be like leading them into "the mouth of the tiger" (Hammett et al. 2003).

Figures 11.1 and 11.2 show how the total number of needles/syringes provided by the Ning Ming and Lang Son sites—a surrogate measure of IDUs' levels of participation in the intervention—changed during the period November 2002–February 2004. The total numbers of new needles/syringes provided by the project by direct distribution and through pharmacy vouchers increased from 6,000–7,000 per month in each country in the early months of intervention to 13,000–15,000, retreated to about 11,000 per month in the last few months of 2003 and very early in 2004, and then began to rebound in February 2004. The early increases are attributable

to the typical problems of start-up, and to staff and IDUs becoming familiar and comfortable with the project. The declines in late 2003 and early 2004 appear to be related to drug crackdowns in both countries during this period that resulted in the arrest of many IDUs. Predictably, this hampered IDU commitment to rehabilitation/detoxification centers, drove other IDUs underground, and generally lessened levels of participation in the interventions. Though this is not related to the interventions themselves, it is nevertheless troubling because declines in receipt of sterile injection equipment may well result in increased sharing and other unsafe injection practices. The rebound in needle/syringe distribution in early 2004 signaled the end of the crackdowns and related increases in IDUs' willingness to access the project and receive its services.

The changes over time in the numbers of needles/syringes provided to IDUs reflect a larger policy issue that is beyond the scope of the project to address: namely, are arrest and forcible commitment of drug users the most humane or the most effective way to combat drug use and HIV? All the project can do is make certain that there is no connection between IDUs' participation in the interventions and their being targeted for law enforcement action—and, of course, try to assure IDUs of the truth of this proposition.

Despite the project's efforts at such assurance, IDUs may continue to believe that their contacting the project was related to their being arrested, and shun further contact with the project on this basis. The early experience of the project's PDI site in Ha Giang Town, Vietnam, illustrates this problem. In the spring of 2003, consultants to the project conducted formative research to assess the drug scene in Ha Giang and the feasibility of implementing a PDI for IDUs there. This research involved a series of qualitative interviews and focus groups with IDUs. Soon after this research was conducted, the police began a crackdown on IDUs around the observance of an international drug control day. This crackdown was entirely unrelated to the formative research and to the plan to implement a PDI. Indeed, the local authorities, including the police, had all given their support to the project. Purely by coincidence, however, a number of the IDUs who had participated in the qualitative interviews and focus groups was arrested soon thereafter as part of the crackdown. Inevitably, the IDU community perceived a connection between the two, where none in fact existed. It has taken many months of effort to counteract this perception and to assure IDUs that it is safe to come to the PDI storefront and participate in the intervention.

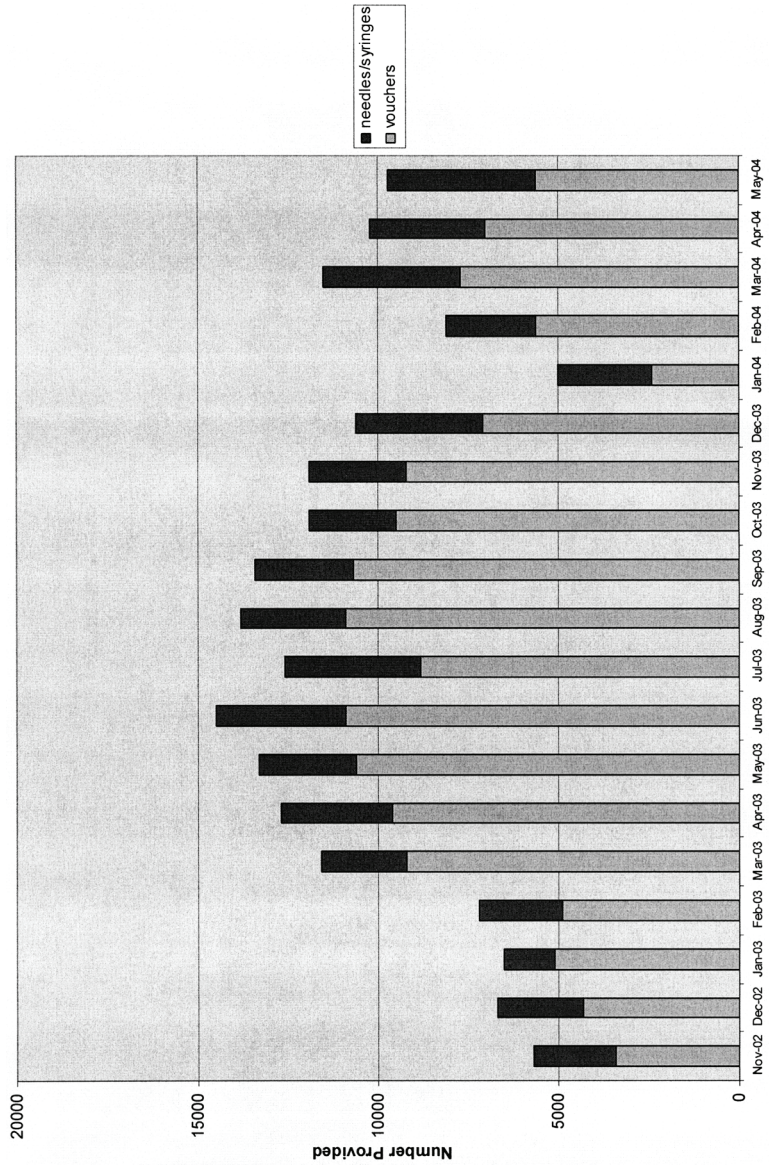

Fig. 11.1 Vouchers and new needles/syringes provided, Vietnam, November 2002–May 2004.

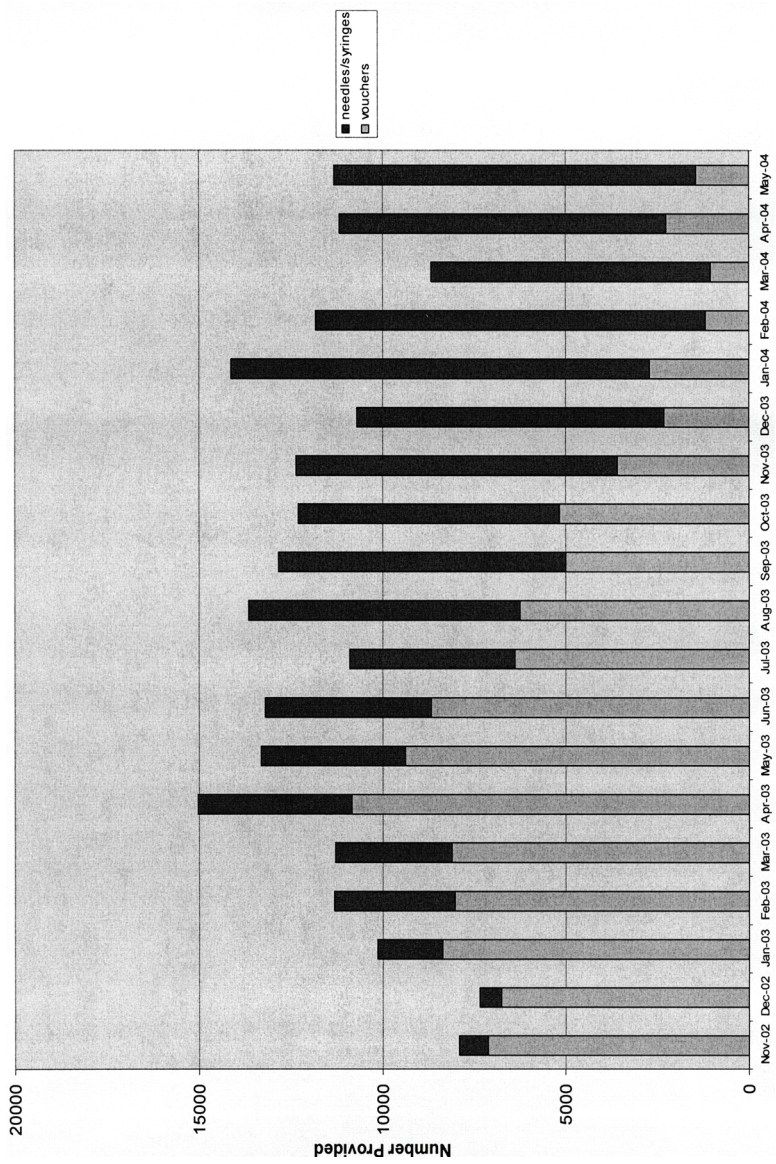

Fig. 11.2 Vouchers and new needles/syringes provided, China, November 2002–May 2004.

B. IDUs' PREFERENCES FOR WAYS TO RECEIVE NEW NEEDLES/SYRINGES

As already described, the cross-border project provides new needles/syringes to IDUs both directly and through the distribution of vouchers that the IDUs must take to participating pharmacies for redemption. These preferences fall into very different patterns in Lang Son and Ning Ming, as shown in Figures 11.1 and 11.2. In Lang Son, the IDUs have from the beginning of the project strongly preferred vouchers to direct receipt of needles/syringes. According to interviews with peer educators and project staff, this preference reflects several factors: the greater convenience and unobtrusiveness of vouchers, the fact that for each voucher the IDU can receive an ampoule of sterile injection water or a condom in addition to a new needle/syringe, and IDUs' fear of carrying new needles/syringes for any length of time. Instead, they prefer to redeem the vouchers at a pharmacy near their planned shooting place just before they intend to inject. A potential problem with this is that pharmacies are not typically open during the late-night hours in which IDUs are often most active.

In Ning Ming, although IDUs initially preferred vouchers, a period of police crackdowns seems to have prompted a pronounced preference for direct receipt of needles/syringes. In contrast to the Lang Son IDUs, those in Ning Ming seem to feel that appearing at pharmacies to redeem vouchers poses more of a threat of apprehension than receiving needles/syringes directly from peer educators or project centers. Perhaps different patterns of law enforcement activity in Ning Ming and Lang Son occasion these different responses on the part of IDUs.

C. IDUs WILLINGNESS TO RETAIN USED NEEDLES/SYRINGES FOR EXCHANGE

Just as law enforcement activity may affect IDUs' levels of participation in the interventions, so an actual or perceived law enforcement threat may influence IDUs' willingness to retain drug injection equipment for exchange. Fear of arrest for possession of injection equipment is widespread in the US, where many states outlaw possession of drug paraphernalia (Bluthenthal et al. 1999, Clatts et al. 1998, Koester, 1994). At the cross-border project sites, as noted above, police have not interfered with the interventions, and possession of needles/syringes is lawful. Nevertheless, many IDUs persistently

fear arrest for carrying used needles/syringes. This is based at least in part on their past experiences with police. Such fears may die hard, and only with the accretion of evidence that its basis is false. The fear of police seems more prevalent among the IDUs of Lang Son than among those of Ning Ming.

At the Ning Ming sites, many IDUs are willing to carry their used needles/syringes at least long enough to give them to the peer educators or take them to the project center for exchange. This pattern has persisted even as IDUs have shifted to a preference for direct receipt of needles/syringes over pharmacy vouchers. In other words, at the Ning Ming sites the intervention works largely as a needle/syringe exchange, except that IDUs are not required to return used needles/syringes to receive new ones. In Vietnam, by contrast, few if any IDUs are willing to retain used needles/syringes at all for fear of arrest. Instead, they tend to discard them immediately after injecting, so the peer educators make regular rounds of shooting places to collect the discarded equipment. IDUs are concerned that even the tiny amount of illegal drug that remains in the syringe after injection may constitute possession and be grounds for their arrest.

D. GEOGRAPHIC PATTERNS OF RECEIVING AND REDEEMING PHARMACY VOUCHERS

In Lang Son Province, the project is able to track each pharmacy voucher according to the commune in which it was given out and the commune in which it was redeemed. Analysis of these patterns reveals that many vouchers are redeemed in communes other than those where they were given out. Between July 2002 and May 2003, only 11% of the vouchers distributed in Hoang Dong commune, Lang Son City, and only 15% those distributed in Vin Trai commune, Lang Son City, were redeemed in pharmacies in those communes. Less than half the vouchers distributed in Tam Thanh commune, Lang Son City, were redeemed there, while about three-quarters of those given out in Dong Kinh commune, Lang Son City, and in Cao Loc Town and Loc Binh Town were redeemed there. Within Lang Son City, IDUs can simply go to another commune to redeem their vouchers, but those in Cao Loc and Loc Binh would have to travel farther, probably to Lang Son City, to redeem their vouchers.

These patterns may simply reflect IDUs' normal preferences for obtaining needles/syringes close to the places they prefer to inject. In addition to convenience, however, these preferences may evidence IDUs' fear of being seen obtaining or using needles/syringes in their own neighborhoods.

This fear is probably more a function of identification and stigmatization by neighbors than of a fear of law enforcement. However, the two are related. An IDU may be more likely to be identified redeeming a voucher in his own neighborhood, and being identified by a neighbor increases the likelihood of being betrayed to and arrested by the police. These are tightly knit, family-centered communities where secrets are hard to keep.

IV. Conclusions

A very delicate balance exists between law enforcement policies and actions on the one hand and harm reduction interventions for the prevention of HIV among IDUs on the other. Drug use is illegal as well as being heavily stigmatized in China and Vietnam. HIV infection is also stigmatized. Although a broader view of police discretion may be justified, harm reduction advocates should not simply expect law enforcement officers to "look the other way" when illegal or questionable activity occurs. Indeed, political and social imperatives may require the strict enforcement of drug laws and periodic crackdowns on drug users.

It is to be hoped that changes in the overall policy approach to drug use and drug users will occur in China and Vietnam—as well as in many other countries, for that matter—and that repression and moralism will give way to a more humane understanding of drug abuse and an approach more oriented to treatment and disease prevention than to punishment. In the meantime, harm reduction programs will play critical but also very challenging roles in attempting to control the spread of HIV and other infectious diseases both among IDUs and between IDUs and the larger communities in which they live. To succeed in this difficult endeavor, planners and implementers of harm reduction programs must pay close attention to the concerns and requirements of political and law enforcement officials, obtain their initial approval of such interventions in writing, and work to maintain that support and collaboration throughout the life of the project. In particular, it is important to address and combat—if possible with evidence and not just assertion—any misperceptions that the intervention will encourage or facilitate illegal activity. It is also very helpful to demonstrate how harm reduction programs can actually help police in their efforts to ensure safer communities.

Just as crucially, harm reduction projects must convince IDUs that it is not only beneficial but also safe for them to participate in the interventions. This means being diligent in protecting the confidentiality of participants

and information about them, and guarding against any actual or even perceived connection between participation in the intervention and adverse action by law enforcement officials. In short, the support of all stake-holders, including IDUs themselves, is critical to the success of harm reduction programs.

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CHAPTER 12

Youth and HIV/AIDS in China

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Xiaomei Ru

Young people aged 10–24 constitute 26% of China's 1.3 billion population (China Population Report, 2004). Although they are traditionally perceived as the healthiest segment of society, they are not immune to health problems—in fact, they are more vulnerable to HIV/AIDS than any other age group. The age distribution of HIV/AIDS is alarming, although no precise statistics for youth HIV/AIDS carriers are available: the 20–29 age group, 15–20 age group, and under-15 age group are reported to constitute 51.1%, 5.9%, and 1.0% of the total number of people with HIV/AIDS, respectively. In some locales the percentage is even higher: in Guangzhou, 90% of reported HIV/AIDS cases are youth cases.

Considering the challenges and related risks that young people are facing today in China, this is only the tip of the iceberg. Most youth are living in less developed rural areas with poor access to education, employment opportunities, and medical services. They lack knowledge and skills to empower and protect themselves from HIV/AIDS. A large proportion of these rural youths enter the migrant population to struggle for better employment and greater income. Over the past several decades, China has witnessed earlier ages of sexual maturity and an older age at first marriage—facts creating a "bio-social gap," a period during which young people become sexually active but are not fully addressed by the existing health care system, especially the reproductive health programs.

The 1998 National Fertility Survey found that the age at menarche decreased by 0.41 years per decade in the advanced major cities, and by 0.16

years in less-developed northwestern provinces of the country. It was reported that youth tend to undergo earlier sexual maturation (13 years old in 1992, compared to14.5 years in 1970) while marrying at a later age (24.5 years old in 1992, compared to 20.2 years 1970).

In another study, 57.28 % of the respondents reported that they had been interested in sexual matters since they were in middle school. Various studies and surveys show a more liberal concept of sexuality and more sexual activity among youth: 5–10% of males and 3–8% of females actually experienced premarital sexual activities, while 51% of university students responded that they found premarital sex acceptable. The result of premarital health check-ups in some cities revealed that 50–85% of youth were sexually active. The imbalance between young people's needs and the inadequate service system drives them to engage in unsafe sexual practices.

Many concurrent studies indicate a very low level of condom use for premarital sexual activities (less than one third persistently used condoms in premarital sex) as well as for the sexual activities of migrants, thus heightening the risks both of HIV/AIDS and STIs, and of unwanted pregnancies (UNDP 2003). As a result of changes in the present transitional period, young people are undergoing a change in values. They may feel less confident, as well as lost and confused. Just as they are susceptible to drugs, youth are vulnerable to high-risk behavior related to HIV/AIDS.

Young people generally have a poor awareness of HIV/AIDS. A recent survey revealed that less than 50% of respondents correctly answered questions related to the transmission of HIV/AIDS, and only 3% of those surveyed were aware that condoms could prevent HIV/AIDS and other STIs. Most high school students harbored negative perceptions of people with HIV/AIDS and had a limited understanding of the importance of eliminating discrimination (He, Xu, and Zhu 2002). The topic of youth and HIV/AIDS will mainly be dealt with as a matter of prevention in light of the vulnerability of youth, because the care and treatment will be carried out as a whole strategy for all the groups.

Policies and Debates

There are currently several policies and regulations related to sexual and reproductive health education, with a particular emphasis on HIV/AIDS prevention.

In 1988, the Education Commission and the State Family Planning Commission jointly issued the Notice on Conducting Adolescent Education

in Secondary School, a document representing the beginning of officially sanctioned reproductive health education in secondary schools. This paved the way to the subsequent inclusion of HIV/AIDS education in certain schools. The intention of the notice was to educate secondary school students in sexual health along three axes: physiological, mental, and moral.

In 1990, Chapter 13 of the Regulations on School Health stated that primary and secondary students should be given health education, which would include a component addressing issues of sexual health.

In 1991, the Minor Protection Law of the People's Republic of China stated that the education guidelines of Chapter 13 (see above) should include adolescent education.

In 1992, the Ministry of Health and the State Education Commission distributed the Basic Requirements of Health Education for Secondary School and Elementary School Students (trial). Though the requirement incorporated adolescent education into the subject of health education, primary school students would not be receiving adolescent education.

In 1992 and 1993, the State Education Commission issued the Guidelines of Health Education for Universities and High Schools. The chapters on Common Diseases Prevention and Sexology, Psychology, and Health included guidelines on STD/HIV/AIDS.

In 1997, the Ministry of Health, National Planning Commission, National Science and Technology Commission, and Ministry of Finance formulated the Medium- and Long-Term Plan for the Prevention and Control of AIDS, 1996–2000. All high schools and universities in cities, 80% of these institutions in the counties, and 70% of these institutions in townships and villages were instructed to deliver sex education.

In 1998, several ministries (the Ministry of Health, Central Committee of Chinese Communist Party, Ministry of Public Security, Ministry of Justice, Ministry of Culture, Ministry of Broadcast Film and Television, Family Planning Commission, and Chinese Press Bureau) issued the Principles of Health Education on STD/HIV/AIDS Prevention. This document directed all schools (including primary schools) to incorporate STD/HIV/AIDS prevention education within the health education curricula and activities. The Chinese government has made a clear political commitment to HIV/AIDS by setting medium- to long-term goals for the percentage of students they plan to reach. These policies emerged from the top of the political structure.

From 2001–2003, the Ministry of Education released the documents Guidance on Enforcing the Actions on Preventing HIV/AIDS in China

(2001–2005), Notification of Reinforcing HIV/AIDS Control in Schools, and Outline of HIV/AIDS Prevention in Schools. These documents outline clearer guidelines for school HIV/AIDS curricula and training materials, and present methods to monitor and supervise progress.

In 2000 and 2001, the Population and Family Planning Law of the People's Republic of China and the Population and Development of China in the Twenty-First Century white paper addressed the issue of sexual and reproductive health education. Through the collaborative efforts of the National Population and Family Planning Commission and the China Family Planning Association (CFPA), progress has been made in HIV/AIDS IEC (information, education, and communication), with a particular focus on youth as the target population. In April 2004 the Guangzhou Municipal People's Congress asked the Education Department and the local government to mandate sex education courses, taught by licensed teachers, in all primary and secondary schoosl and, in some cases, in kindergarten as well (*China Daily* 2004).

In 2004, the issue of Opinions of the Central Committee of the Communist Party of China and the State Council of the People's Republic of China on Further Strengthening and Improving the Construction of Ideology and Morality among Youth was believed to create a more enabling environment for youth reproductive health education.

All of the above policy documents provide grounds and guidelines for implementing sexual and reproductive health education, including HIV/AIDS preventive education in secondary schools. Debates remain on how to carry out sexual and reproductive health education for youth. In addition, because talking about sex has been traditionally considered taboo, many people worry that sex education will result in the collapse of the country's value system. Controversy and sensitivity about the distribution of condoms to unmarried people still exist. Conservative traditionalists have even insisted on abstinence-dominated education or the confinement of education to anatomic and physiological knowledge. Population and family planning professionals have been realistic to advocate safe sex as they have been actively implementing the International Conference on Population and Development's Program of Action (ICPD PoA). Along with the more and more intensive intervention to combat HIV/AIDS, it is expected that safe sex will become more accepted by the public.

The other concern is that some of the governmental policies are not very operative, thus reducing their efficiency. There are also some studies indicating contradictions between the policies and regulations

Current Programs by Government and NGOs

For decades the education sector has been making considerable effort to implement the policies mentioned above and to incorporate sexual and reproductive health, including HIV/AIDS issues, into the existing teaching systems. In 1990, the School Health Education Training Network for HIV/AIDS Prevention was established. In 1994, the Ministry of Education set up the Base of School Health Education for HIV/AIDS Prevention Trainer.

The provincial and municipal governments have taken leading roles, in collaboration with various international organizations, to promote HIV/AIDS prevention education in their areas. Examples of such projects include Save the Children in Yunnan, AusAID in Beijing and Shanghai, and UNICEF in Sichuan. All these projects have been successful in terms of KAP (knowledge, attitude, and practices) improvements, such as increased awareness, reduced discrimination, and decreased unsafe sex.

NGOs have been increasingly active in this field. The China Youth Development Foundation initiated and founded the China Youth HIV/AIDS Prevention Foundation and launched a "Red Ribbon Action" campaign. The China Red Cross has also made efforts to promote youth peer education for HIV/AIDS prevention.

The population and family planning sector has been positively and vigorously promoting youth sexual and reproductive health education. Beijing, Shanghai, Jilin, Fujian, and many other provinces are implementing education projects. On July 11, 2004, a World Population Day event with the theme of "the sexual and reproductive health and rights of youth" was held nationwide.

The CFPA, the leading and largest NGO in the family planning and reproductive health area in China, has identified adolescent sexual and reproductive health as one of its priority objectives. Since 2000, the CFPA has partnered with the Program for Appropriate Technology in Health (PATH) to implement a large-scale five-year project with funding from the Gates Foundation. This project, which initially covered twelve major cities and three rural counties as pilot areas, is now being scaled up nationwide to improve adolescent sexual and reproductive health (focusing on HIV/AIDS prevention). The project provides adolescents with accurate information, life-planning skills (LPS), counseling, and various other services; and creates a safe and supportive environment for adolescent reproductive health programs in China. The CFPA has also developed various models to reach floating youth at their homes and workplaces, both before and after they join

the floating labor forces. The workplace-based LPS training among migrant youth in Shenzhen is a successful example of intervention with this group and collaboration with the business community (see the last section below for quotations from LPS participants).

Despite limited funds, the State Population and Family Planning Commission has been very active in HIV/AIDS prevention. The committee's HIV/AIDS prevention objective is to promote a multi-sectoral, cost-effective approach with the emphasis on integrating HIV/AIDS prevention and reproductive health promotion. The focus of this intervention project will be youth and migrants. Under the UN Population Fund's (UNFPA) Reproductive Health/Family Planning (RH/FP) project, a collaboration with the Government of China, intervention projects are underway in eight provinces (Yunnan, Xinjiang, Guangxi, Guangdong, Sichuan, Henan, Jiangsu, Gansu), and there are adolescent sex and reproductive health education in six provinces (Liaoning, Zhejiang, Shanxi, Hunan, Sichuan, Qinghai). With the aid of the Japanese International Cooperation Agency (JICA), the committee has also recently finished a baseline survey of the reproductive health of migrants. The results of this survey will be helpful for further intervention.

It has been difficult thus far to collect systematically quantitative data to measure the success of the current programs. Yet facts like the related policy and legislation, the larger consensus on prevention (intervention) methods, the broader scope of program implementation, and the more vigorous efforts of all concerned support the idea that a positive outcome is being reached.

Future Needs and Constraints to Action

Despite the progress outlined above, there is still a visible lack of officially established mechanisms specifically to reach young people with effective HIV/AIDS prevention strategies. As mentioned earlier, current policies and structures for HIV/AIDS prevention education are mainly oriented toward young people in school, and they often lack operationalized strategies, measures, and resources for effective implementation. Initiatives to reach young people who are out of school remain limited in number and in scale. The following list of needs and challenges is far from exhaustive:

- *Lack of an effective, efficient leadership* and multi-sectoral coordinative mechanism;

Imperfect mechanism for effective, efficient HIV/AIDS prevention and reproductive health education and services for youth;

Lack of a youth-friendly HIV/AIDS prevention and reproductive health services promotion network;

Lack of efforts focusing on a migrant and rural youth HIV/AIDS prevention and sexual and reproductive health monitoring and evaluation (M&E) system;

Insufficient pooling of statistical data on youth (particularly unmarried youth) vis-à-vis HIV/AIDS and sexual and reproductive health, which hinders policy formulation, advocacy and IEC/BCC, project design and M&E;

Lack of a national youth HIV/AIDS prevention and sexual and reproductive health M&E system;

Insufficient strength devoted to scaling up the already successful prevention and intervention practices;

Inappropriate input in capacity building—although the introduction of peer education has been helpful to ensure that youth play a positive role in fighting HIV/AIDS, youth need to be more involved and take the lead; and

Inadequate attention to youth within the population at high risk: for example, a study from Shenzhen showed that among women working in hair salons (regarded as indirect sex workers), the average age is 24, 84.95% of whom are from the countryside, and 77.5% unmarried.

Recommendations

Establish and perfect a more powerful, efficient, multi-sectoral and cooperative mechanism. Integrate the scattered resources to enhance the overall input in youth HIV/AIDS prevention.

Pay more attention to HIV/AIDS prevention for rural youth, especially impoverished young migrants.

Address the rights of youth to sexual and reproductive health. Promote further communication to construct a favorable environment for youth HIV/AIDS prevention.

Since health education alone has proven to be insufficient, combine youth HIV/AIDS prevention with the learning of life skills, income generation, and the betterment of social security and income maintenance.

Introduce gender perspective into youth HIV/AIDS prevention, since women are in an extremely fragile position.

Scale up and replicate successful practices in youth HIV/AIDS prevention.

Set up a sustainable development mechanism for school youth HIV/AIDS prevention education.

Develop more population-specific youth HIV/AIDS prevention practices.

Pay more attention to young people living with HIV/AIDS (PLWA), providing them with comprehensive care and support, including psychological support. Practice GIPA in youth HIV/AIDS prevention.

Increase the role of civil society in youth HIV/AIDS prevention, thus facilitating the development of NGOs and NPOs.

Encourage more youth to become dedicated to HIV/AIDS prevention and control. Promote the youth volunteer movement in HIV/AIDS prevention and control.

Further perfect a youth-friendly HIV/AIDS prevention reproductive health service network.

Improve the capacity in collecting, researching, and utilizing statistical data on HIV/AIDS among youth and their sexual and reproductive health.

Make full use of the potential of the population and family planning sector, since integration of HIV/AIDS prevention and reproductive health service is an internationally recognized cost-effective approach. A comprehensive, systematic reproductive health service network has been completed in past decades, with around 40,000 clinics, 400,000 health professionals, and 1 million grass-roots staff at the village level working in a door-to-door service delivery way.

Develop support and technical assistance for curriculum development at all levels.

Quotes from Life-Planning Skills (LPS) Participants

Participating in the training sessions has helped clear up many of my misunderstandings about sexuality. I have adopted a more open attitude about discussing sexual issues. I know how to negotiate sex and how to be responsible for my sexual actions. I used to know so little about AIDS. But now I know about the virus that transmits it and the ways in which it is transmitted. Above all, I know how to protect myself from AIDS.

—Male LPS training participant, in his twenties

Negotiating condom use is the most useful thing I have learned. Women need to know how to protect themselves. By having a say in condom use, they earn the respect of their partners and learn to respect themselves, too.

—Female LPS training participant, in her twenties

I thought I could get AIDS by simply looking at an HIV-infected person, but I know all about HIV transmission now.

—Female LPS training participant, 18 years old

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PART IV

Impact Mitigation

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CHAPTER 13

Children Affected by AIDS

Orphans and Impact Mitigation in China

Andy West and Kate Wedgwood

Introduction

The rates of HIV/AIDS transmission in many places in the world indicate crisis. The epidemic in central China is comparable to an emergency: a rapid, massive, and devastating impact, with many adults suddenly becoming sick and dying and a lot of people quickly affected. Adults are dying when they are the main providers for family and carers for children. The number of orphans has led to rapid developments of large private orphanages and other inappropriate responses that do not address broader issues about communities' and children's welfare. The problems children face are compounded by discrimination and ignorance. HIV/AIDS-infected and affected adults and children are stigmatized and frequently isolated. Knowledge of HIV/AIDS transmission and prevention is inadequate, demonstrated by the startling ignorance of young trainee teachers in a badly affected prefecture in central China. In this same place, city schoolchildren did not know of the epidemic in villages just a few miles from where they live.

The HIV/AIDS epidemic in China is multi-stranded and perceived as localized. The first wave stemmed from intravenous drug use in Yunnan and later in Xinjiang, followed by a second wave through blood selling in central provinces. The epidemic spread, and sexual transmission is poised to become a major threat. Popular discourse has associated HIV/AIDS with ac-

tivities viewed as immoral and illegal, which has consequences for attitudes toward infected and affected adults and their children. But service provision for the impact of HIV/AIDS on children's lives must avoid a "knee-jerk" reaction based primarily on anxiety that something must be done urgently, which does not take account of the variety of ages, capacities, and potential inherent in childhood.

The two main channels of HIV/AIDS transmission in China have been publicized as "prostitution" and "intravenous drug use," and response measures—such as free distribution of condoms at entertainment venues, provision of clean syringes, and a methadone program—have been announced (Zhang 2004). Both channels include children and young people, those exploited (for sex and sex work), those establishing new relationships, and those susceptible to drug use. In terms of localized impact on children, it is in central China that the epidemic is now having devastating effect. Yet public attention has been largely drawn to the border provinces, and these areas were until recently the public focus of government. Southwest China is still believed to be the worst-affected area by some international organizations and individuals.[1] In deciding the Round 3 proposal for Global Fund monies should focus on seven blood-selling provinces, the government recently recognized the extent of the epidemic in central China (see Chapter 3).

The nature of the epidemic in central provinces has produced sets of extremely difficult circumstances for children that highlight broader issues for determining how best to respond and take action to the increase in HIV/AIDS in China. The methods of impact mitigation of HIV/AIDS in central China—particularly its effect on children as well as the provision of care and support for orphans and affected children—will provide lessons for the future. The spread of HIV/AIDS in other areas in China has been less dramatic, but children are increasingly affected in Yunnan, Xinjiang, and elsewhere as more parents become sick and die. Yet adults who become sick often demand and receive much attention, whereas children, who are generally expected to be passive, obedient, and not raise their voices or problems, are ignored. Children's opinions are not sought, which puts them at risk for being abandoned or placed somewhere unprotected. Even when the situation of children is suddenly realized by adults, children are still not included and involved in planning responses.

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1. This was stated in a 2004 draft survey on HIV/AIDS in the region, indicating how the central China epidemic has been little publicized.

This chapter explores circumstances and some of the problems experienced by orphans and children affected by HIV/AIDS, as well as issues and frameworks for developing effective responses. The term "children" is used in accordance with international definition: humans under the age of eighteen years. The diversity encompassed within this term is considerable, with a variety of ages crosscut by gender, ethnicity, disability, and other significant social categories. Developing policy and practice responses for children's issues must take account of this diversity and the evolving competencies of children. The local social constructions of childhood need also to be considered in planning. These strategies fit with child-rights programming—an approach to implementing policy and practice that is increasingly being taken up around the world—and provide a framework that can fit with policy and practice in China. Children's participation is the key to the approach, and is particularly important where academics and policy makers (both Western and Chinese) still conduct research on children's issues without even talking to children themselves. In this chapter, work initiated in Fuyang Prefecture in Anhui Province is drawn upon as an example. This project has already demonstrated how child-focused participation work can provide psycho-social support and promote resilience. Research with and by children contributed to understanding their perspectives and problems, and provided a foundation for future work.

The Epidemic in Fuyang Prefecture, Central China

Fuyang is a prefecture with seven counties in northwest Anhui Province, bordering Henan, a province notorious for its HIV epidemic, which is also derived from blood selling.[2] The Fuyang government's response to HIV/AIDS seems to have been a step behind that of Henan, which had led to demonstrations in Fuyang. But over the past year Fuyang gained a reputation of its own, for the spring 2004 deaths of babies due to the use of locally

2. The descriptions of Fuyang and the issues there are drawn from surveys undertaken prior to starting work in the area in 2003, when the Red Heart Club for people living with HIV/AIDS (PLWA) was established with the support of Save the Children, and includes individual and group discussions with government staff, training workshops with government staff, research with and by children, and field visits to villages. The research by children has been published as West and Zhang (2005) and Save the Children (2005).

made "milk" powder—an international scandal.[3] In spring 2005, a methamphetamine factory was found and destroyed; methamphetamine is a drug with implications for the lives of children and young people living in poverty, as well as for students looking for escape from school pressures (see West and Chen 2005).

The Fuyang epidemic derives from methods of buying blood in the mid-1990s, when unsterilized equipment and mixed blood being returned to sellers created a disaster. In addition to the legal and illegal blood banks operating in Fuyang, residents were able to make the relatively short journey to neighboring Henan for extra sales. The financial incentive, coupled with the relative ease and speed of earning cash, encouraged rural people living in poverty to sell blood. It was well advertised at the time, initially by the government and also through hard sells by agents. Blood buyers would call out to passersby, including students, "Is your blood so precious you cannot part with it?" The government withdrew when problems became known, but "underground" buying and selling apparently continued for some years; currently, illegal "bloodheads" are reported to have reappeared in the region (Xia 2004, p. 68).

The county of Funan and the district of Yingzhou are the worst-affected areas. The map of Funan County shows a far less densely populated area in its southern half, bordering the Huai River, which is subject to flooding.[4] It is in this southern half that the epidemic is most widespread in Funan County. Yingzhou, the central district, where Fuyang City is located, has the highest incidence of HIV/AIDS. Yingzhou recently developed a special economic zone (SEZ) through the compulsory purchase of land from local small holders. The SEZ has its own separate administration, and not all branches of government are yet fully established. The SEZ incorporates four of the most badly affected villages in Fuyang Prefecture, which seems to take them out of Yingzhou for statistical purposes.

But there is a double bind in the SEZ. The SEZ is concerned with attracting business and investment from outside. It does not want to publicize

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3. This raises broader issues about breast-feeding and practices used in the promotion of substitutes for breast milk for babies and very young children (issues raised before in China by Save the Children)—and also about the need for education and awareness-raising about breast-feeding and HIV/AIDS.

4. Severe floods in 2003 resulted in European Union ECHO funding rebuilding of schools and clinics, and rehabilitation of Fuyang Children's Welfare Home, implemented by Save the Children.

the existence of HIV/AIDS because it is feared that investors will be deterred. An additional problem is that payments for the compulsory land transfer have not been completed, most being made on an installment basis. This has left ex-farmers without land and without capital to start new businesses, and even the money allocated them for housing has not always been sufficient to acquire new homes. The creation of the SEZ thus seems to have compounded residents' existing problems and, with the onset of HIV/AIDS, exacerbated their poverty.

Blood Selling and Gender

In the mid-1990s both men and women sold blood, but probably more women were involved. Blood is regarded as important and not to be disposed of lightly. A single blood sale produced an income equivalent to a good month's wage for many people. But the practice of extracting plasma, and returning a mixture of blood and saline to the body, meant that it appeared that blood was not lost in quantity, only "loaned." Apparently many people often sold blood more than once a day.

The reason for the greater involvement of women is threefold. First, it is said that men need to hold onto their blood because they are active and do physical work (working as laborers, etc.). Second, it is thought that women make more blood and can replace it faster. Third, there is practice of out-migration from these villages to seek work. It is men who are mostly involved in this and so would be less likely to be around to sell blood. This gender divide has other effects and implications.

The practice of adult male out-migration in recent years, probably for nearly two decades, has left the women in the villages with child care, working the fields, and maintaining community/social life, which corresponds to the increasing feminization of agricultural work noted ten years ago (see Entwisle et al. 1995). Men migrate out from around the ages of 15 to 18 years, and also young women (including some girls from the age of 12, according to local informants). Officially the local migration age stated is 20–22 years, although migrants of 16 years and above are represented in other statistics (see Davin 1999). This context of involvement in migration work is important for children's lives and expectations.

Blood selling by women meant that they were at risk of contracting HIV/AIDS and then passing it on their returning husbands through unprotected sex, whereas with intravenous drug use it is more often men who are directly at risk and then pass infection on to women through unprotected

sex (see Chapter 11) Women are said to be less able to negotiate condom use, the decision resting on men, who are also expected to acquire the condoms (see Chapter 10). Many women have already died, and others are seriously ill, at a late stage of AIDS. Child care often falls to relatives, particularly grandmothers, depending on the age of the children. Husbands will still go outside the village to seek work while they can. Where husbands remain behind to care for children, this may be because they are already HIV positive, are not well enough, have no relatives to care for children, or do have some local business.

Most of the women (and men) involved in blood selling were young to middle-aged and in their reproductive years, so children have been born infected to these parents or become infected through breast-feeding. People of this middle age are likely to have a number of siblings. A grandmother today may have had several sons, and her work of replacement child care might be of children who have been orphaned or are in single-parent families from more than one son or daughter. Though grandmothers have been found to be "very involved in care" in any case (Short et al. 2001, p. 922) and fathers have also been found to care, "mothers maintain primary responsibility for child care and housework in most instances" (Short et al. 2002, p. 40). Thus, while child care my have been the responsibility of multiple carers, the HIV/AIDS epidemic is removing the central figure and reducing care options. The gender divide in care and housework also has implications. In some cases in Fuyang, even young daughters have been expected to take over their mother's domestic responsibilities when she is sick or has died.

Stigma and Discrimination

Some distinction is drawn locally between HIV/AIDS and the "blood disease." Children know that their villages have a blood disease that is causing deaths but, like adults, do not name it as AIDS, which is seen as far more serious, dangerous, and stigmatizing. Developing awareness of AIDS and its progress and transmission requires some openness, and the process of naming the "blood disease" needs to be handled very carefully so as not to exacerbate the stigma, discrimination, and exclusion that are already rife. At least one child at school whose mother died was named by teachers as "AIDS affected," rather than the assumed "blood disease affected."

In addition, there are moral overtones in the explanations of some local people that those who sold blood did so because they were looking for easy cash; that they did not work properly for the money and were too lazy to

work hard to earn money. AIDS might be seen as some sort of moral retribution. These views are linked to perceptions that blood sellers are undeserving of government funds. Similar views are also prevalent among some officials, whose perception is that once the government has provided some relief, people only want more. This provides a difficult environment for children affected by AIDS as well as for adults, and influences the incidence and attitudes of discrimination and stigma.

The Impact of HIV/AIDS

Although the further spread of HIV/AIDS could be prevented or reduced, many adults of young to middle age (reproductive age) are already infected. The comparatively sudden and widespread onset of HIV/AIDS exposed the lack of health, social service, and social security infrastructures in impoverished rural areas (although the Social Relief Department of the Ministry of Civil Affairs is now developing a rural *dibao* system).[5] As many village residents turn to providing care for the sick, dying, and for children, their income is reduced and existing assets depleted. Thus, a medical approach to provision of care and treatment is not enough. The epidemic has wide-ranging social effects, and the emotional impact of change, illnesses, and death on children, on surviving spouses, on grandparents, and on villages—all unexpected and unplanned for—especially requires provision.

Adult deaths in families reduce numbers to out-migrate for work, which also has an effect on the overall wealth/income of the village. Remaining adults may need to stay to care for children or elderly parents, thus also reducing income. The cost of seeking medicine and treatment, especially when HIV/AIDS has not been—or was not initially—diagnosed, further depletes family assets. The type of palliative care required, alongside child care, often needs additional support from outside the immediate family. There is an increased dependence on children as carers, heads of households, and to take on additional domestic work or outside employment, which reduces their schooling and thus diminishes the future economic worth and potential of the family and community. The only resources easily available are land and any subsidies from government. In the SEZ, the use of land is no longer an option, and without some local work (or out-migration), adults

5. *Dibao* is in common use and is short for *zuidi shenghuo baozheng zhidu*, the minimum living standard allowance and system.

have nothing to do all day long. This has resulted, for some, in large electricity bills because the whole day is spent watching television.

Government responses in Fuyang, announced in 2004, included free testing and ARV treatment, plus a payment of 50 RMB per month for HIV-positive people, 100 RMB per month for AIDS patients, 80 RMB per month for each child orphaned by HIV/AIDS, and 50 RMB per month for each child who has lost one parent. Other measures include free school tuition for children from families with parents with AIDS and free condoms for couples where one is HIV positive, as well as relief from agricultural taxes and compulsory labor (see Ma and Fang 2004). But many families do not want to take up benefits, such as free tuition, because of the long-term stigma and discrimination from identifying themselves and their children as AIDS affected.

Problem Responses to Children

Children are affected by the epidemic through their changed family circumstances and through the responses of government and private agencies. But the main public focus has been on orphans, and a major issue in some parts of central China has been the removal of children from their communities to orphanages. In Henan, for example, civil society responses have included local NGOs bringing together AIDS orphans in institutional care. According to staff, these children need "counseling." Such services are thought to be more important for children than for adults who are bereaved, perhaps due to a lack of knowledge and understanding of children's lives. This emphasis by adults on the need for AIDS orphans to receive individual psychological support must be considered in context, which here includes the problems of bringing together a large number of children, all with recent experiences of the death of parent(s), and separating them from their familiar community and from other children.[6] These problems are connected to targeting responses only at AIDS orphans and without apparent attention to community-based support.

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6. This is not to suggest that counseling is never useful, but it should not be a first resort, and how it is defined in practice must be clear. The term "counseling" is open to varied interpretation, and different agencies can have different approaches. Here it is used to indicate the person-centered, reflective practice models associated with the work of Carl Rogers, rather than complex therapeutic interventions that might rely on Western cultural constructions and worldviews for their theoretical underpinnings.

Already, experience in China is showing how institutional care for children orphaned through HIV/AIDS is causing distress to children: they experience stigma and discrimination from others in the community because they are placed and identified as AIDS affected; and if their carers do not like a certain child, he or she has no one to talk to. Some children are apparently running away. Meanwhile, grandparents of children orphaned through HIV/AIDS have said that they never see their grandchildren after their placement in residential care outside the village and community.

A global emphasis on providing psycho-social support for children affected by HIV/AIDS, especially orphans, has often highlighted counseling instead of looking first at the social environment (see West 2005). Recent work in Fuyang (see below) has indicated the benefits of participatory work for psycho-social support for children, through developing respectful relationships based on working with (not for) children and being prepared to listen and take children seriously, which promotes resilience and provides simple opportunities for children to come forward and talk to adults whom they trust (see West and Zhang 2005). The problems for children in orphanages lie in the way responses have developed—and in institutions excusing the epidemic as an emergency and therefore not taking account of evidence, learning, and best practice in response to children's circumstances.

Although institutional care in these central provinces might be of good material quality if sufficient overseas funding is found, research and practice findings suggest that these forms of care are generally detrimental to children's development:

> Hardly anyone today denies that institutions are unable to attend to physical and cognitive needs and the needs for social and emotional stimulation in any way comparable to what can be achieved in a setting which is open to life within society. The concept of deprivation is used constantly in specialised studies describing the consequences of life in institutions to indicate the lack of affective and personal care suffered by institutionalised children. (Crotti 2003, p. vii)

Apart from a range of problems in institutional care, there are also problems when leaving and moving to independent life (see Tolfree 1995). Targeting "AIDS orphans" is contentious, not only in stigmatizing them and other children affected by AIDS, but also because it begs the question of provision for other orphaned children: the same good quality of care and protection should be available to all (see Grainger, Webb, and Elliot 2001). While the nature of the epidemic is highlighting gaps in provision, welfare, trained personnel, and approaches for children's lives, none of this is new. Disabled

children have been in similar circumstances in China for many years, especially in terms of placement in institutional care, but have not received similar attention. The onset of the HIV/AIDS epidemic has been seen as cataclysmic, disastrous, and so requiring emergency attention.

But lessons learned from responses to emergencies indicate that it is not necessary to make hasty decisions to separate children from their communities, on grounds of their "best interests." Longer-term planning and solutions can and should be undertaken even in the face of disaster. One of the main features of good emergency work with children is particular attention to those separated from their family or usual carer—with the goals to establish "their identity, so that early action can be taken to reunite them, to give them basic care and protection in the meantime, to safeguard their basic human rights, . . . to reduce the number of separations, and to facilitate early reunifications with family or carers" (Uppard and Petty 1998, p. 13). The reasons for this lie with the recognition, as emphasized in the international Convention on the Rights of the Child (CRC), that a family setting is the best place for development, care, and protection of children. Clearly there are some families where this is not the case, but this holds as a general principle. Hence work in emergencies seeks to keep children with their families. Principles for work with children affected and orphaned by AIDS should follow similar premises based on children's rights. An obvious link is the need to keep infected the parent(s) alive as long as possible and keep children with their families. Attention must be paid to research on the circumstances of children, and in particular to seeking their ideas and opinions, taking children seriously in their own right and not viewing them simply as family appendages.

Frameworks for Action: Children's Rights and Policies

Concern for children's well-being has been a focus of an increasing number of children's charities, and local and international NGOs, across the world for many decades. Some organizations have been generalist in approach, while others have focused on particular groups of children that are often ill-defined, such as street children.[7] Some approaches have been welfarist, others guided or stimulated by religious beliefs and tenets.

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7. A classic example of an ill-defined group is "street children." Commentators have spent much time attempting definitions, to no real conclusion. See West (2003a), West and Yang (2000).

The inception of the United Nations CRC in 1989 provided a new approach, through internationally agreed criteria, for the lives of humans under 18 years. The CRC is almost universally ratified,[8] thus including children in recent rights-based approaches to development. This has brought an emphasis on holistic approaches to work with children, particularly children's involvement in decision-making and -setting criteria for projects across the world.[9] An holistic approach to children's circumstances involves looking not only at education or physical health but protection, emotional security, personal identity, and so on. It means taking children's views into account and so balancing a range of factors. In providing an almost globally accepted paradigm, while analyzing and beginning from local contexts, child-rights programming provides a framework for fulfilling hopes and expectations for children in an environment of rapid global change. This framework includes paying attention to local constructions of childhood and diversity. China ratified the CRC in 1991 and has been promoting children's rights through government and partnerships with international NGOs.

Rights-based programming rests on the notion of duty bearers. If children are rights holders, who is responsible for ensuring that rights are fulfilled, and supporting children to achieve those rights? Who has a duty in this respect? The question of the best interests of children must be taken into account in individual cases and through analysis of local situations when planning policy and practice. For example, the development of services for street children that enable them to attend school has led in some countries to

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8. Only two countries in the world—Somalia and US—have not ratified the CRC. Ratification obliges states to bring legislation into line with the Convention and report regularly to the UN Committee on Child Rights. The US non-ratification is despite accusations of a western/northern-centred bias in the composition of the CRC. Increasing use of rights discourse by governments and NGOs around the world has led to reviewing of older philosophies and how their roots fit with notions of rights (see An-Na'im 1992, Donnelly 2003, Jacobsen and Bruun 2000), including China (Angle 2002).

9. The heart of rights-based programming for children includes developments in the sociology of childhood that were coterminous with the CRC inception and provided fresh paradigms. The "new" sociology of 1990 (see Corsaro 1997; James, Jenks, and Prout 1998; James and Prout 1990; Jenks 1996; Lee 2001), comprised three main points: that childhood is not a homogenous state, and differs around the world (therefore there are no standard patterns of child development, or standard indicators); that within the period of human life defined as "childhood" there are significant differences (such as age, gender, ethnicity); and that children are "social actors"—they engage and have effect on the social world around them, and are not empty vessels waiting to be filled.

poorer families "abandoning" their children to shelters in order to access education. A better response might be to find ways of funding education that does not require families to pay fees; there is a duty on government and others to fulfill children's rights to education.

In practice, holistic approaches and integrated rights programming require multi-sectoral or multi-agency and cooperation across departments. This is not easy in many countries, given traditional government department boundaries and practices:

> Anyone with any experience with development in China will lament the country's chronic verticalism. There is a deplorable lack of horizontal communication between ministries and institutions, and even between different departments of the same institution. It is perfectly possible, indeed probable, that a person working in one ministerial department will have no idea of what is happening in the next corridor, let alone in other ministries. Each individual receives orders from above, and passes them down the line of command, with minimal sideways movement of information. (Wedgwood 1996).

Moreover, "coordination across and within different levels of government is very poor" (Hales et al. 2003), thus calling for a shift in structural operations to foster collaboration on important social policy issues.

Other Relevant Policies

Strategies for care of children orphaned and affected by HIV/AIDS must take account of the context of child welfare in China if services are to be inclusive and sustainable. In general, the Chinese government runs all child welfare provision with limited other internally or externally funded and run services. The Ministry of Civil Affairs (MCA) at the national level is responsible for making policies for children's welfare institutions and services, while local governments are responsible for financing provision for children who need special care.

Children made vulnerable and orphaned by HIV/AIDS[10] are not the first group of orphans or vulnerable children China has seen (see West 2002). For example, provision has been made for many disabled children who have been abandoned or orphaned. Existing systems for orphans and abandoned children have been slowly changing in policy and practice in recent years.

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10. The current shorthand term "OVC" for this group is stigmatizing, by referring to these children as a set of initials. It also makes no sense.

The underlying shift is away from an emphasis on developing institutions and toward a focus on alternative care and children's rights. Foster care is becoming a main approach to care for orphaned and abandoned children. In 2000 the MCA developed a policy to promote foster care and launched national standards and guidelines at a national conference in October 2003. The policy is seen as an important element in the "socialization of social welfare"—the development of civil society and community approaches in welfare provision.[11]

Kinship care has long been a first option in China, and recent research[12] suggests some 400,000 orphans are in kinship care, compared with under 60,000 in welfare institutions. But kinship care is not always available for children orphaned by HIV/AIDS. Other alternatives to large-scale institutions have included the development of small group homes. This approach marked a step toward "normal" family life for orphans by placing them and their house parents within the community.[13] The MCA now has a key role in promoting community-based foster care and support service provision for children orphaned by HIV/AIDS so that the potential major increase in orphans does not result in the re-filling of welfare homes and exacerbate problems of stigmatization and discrimination.

Articles 65–67 of the Declaration of Commitment on HIV/AIDS, "Global Crisis—Global Action" signed by China at the United Nations General Assembly Special Session on HIV/AIDS in June 2001 provide another practice framework. These articles cover the state's obligation to develop policy and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS.

Thus, removing children from their communities to provide separate accommodation, school and health care is in opposition to current Chinese policy and rights-based approaches of keeping children located in their communities and extended families. Rights-based strategies for alternatives

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11. Foster care standards and guidelines and the national conference were undertaken by the Ministry of Civil Affairs (MCA) in partnership with Save the Children, and included some research by children.

12. See ongoing research by Save the Children and the University of New South Wales, in collaboration with MCA.

13. Beginning in 1994, Save the Children worked with Civil Affairs Departments to develop small group homes, with a couple caring for up to four children as a family, initially within the old institutions but now housing children in existing residential apartments. This model is now promoted by the MCA as one alternative to institutions.

to institutional care begin with finding out and taking up children's perspectives.

Issues Raised by Children

A project with children in Fuyang was initiated in early 2004. The project will follow principles for child-rights programming, address current policies for children, and be participative and community based. The project began with a basic survey with adults, and then a participatory process to understand what is happening to children, including children conducting their own research. Subsequently, a forum where children presented their findings and issues to local government leaders was held in August 2004, and the project continues, following strategies outlined below.

The research involved 28 children meeting, raising issues, and then devising questions and interview schedules over two workshops in March 2004. During the following month they conducted 171 interviews with children in villages, with progress supported by visits from an adult facilitator. They met again to share their findings and an initial analysis. Their material was analyzed and written up by a Chinese academic researcher who helped facilitate the workshops (West and Zhang 2005).

Children's initial series of issues included school (especially tests, teachers), friendships, family (disputes), violence (from parents and teachers), health, the future, and the school and village environment.[14] These were refined into four areas for interview:

> *Study*—including how to deal with not being good at study (how classmates and teachers will treat you), what to do if parents do not let you go to school, what to do if there is not enough money to buy things for study;
>
> *Health*—including food, who cares for you if you are sick, whose health is best and worst in the family, and what happens if a family member gets a hard-to-treat disease;
>
> *Future life*—including what sort of job, living environment, and family lies in the future, and whether children feel confident they can live independently;

14. Material on research project findings is drawn from West and Zhang (2005).

Family—including how children feel about their family, whether their parents argue, the difficulties of family and the impact of those difficulties, and the attitude of family to study.

The main findings of the children's research project were twofold. The first is a set of experiences and issues relating to children's experiences and potential for exclusion, loneliness, isolation, and uncertainty, and their corresponding fears and worries both for the present and for the future. Children are most concerned about tensions and health within their family, friendships, stigma and discrimination, survival and the future of their families and themselves, and study—going to school and performing well. These provide a basis for developing interventions with children, in particular children's wish to stay in their communities with familiar surroundings, relationships, and family.

The second is a set of findings derived from the process of the workshops and project that also indicate what interventions will be useful. The feedback from the children involved shows how the methods and activities used, including the approaches of treating children with respect and having fun—participatory ways of working with children—were found to demonstrate and provide psycho-social support and personal development (from West and Zhang 2005).

Strategies for Constructing a Response

A primary principle is to keep children with their families and in their communities. The implications include the need to:

Keep parents alive as long as possible through treatment and patient education;

Enable orphans to live with extended families or in familiar surroundings;

Ensure that a variety of support services is provided to local communities;

Deal with processes of children's and others' bereavement;

Provide social security (income maintenance); and

Consider the needs of children of all ages, recognizing their rights to information, especially about prevention of HIV/AIDS transmission and protection from exploitation.

Other fundamental principles include focusing on children, on their participation, on promoting resilience, and on integrated collaborative ap-

proaches. These are closely linked because collaboration between civil society, NGOs, INGOs, and government, through multi-sectoral and multi-agency work, should involve children's perspectives. Strategies particularly need to take up principles of inclusion and to deal with discrimination and stigma attached to children affected by AIDS. A good example of these complexities is in the area of education, which is emphasized so strongly by children. Education policy and provision needs to go beyond simply removing school fees only for AIDS orphans, which exacerbates stigma. A broader issue of access to education and the role of duty bearers arises, suggesting a need for removal of school fees or equitable treatment for *all* children. But access to education is not merely about fees. It also involves getting to school, being able to study, and being treated well in the institution. Education also involves learning about local life and how communities operate, which in turn requires living in them.

Children's Participation and Resilience

Children's participation is integral to all practice and means that children should be consulted and involved in decision making and action. This is a major principle of the CRC and has practical benefits, such as the promotion of children's resilience and a means of providing psycho-social support, as demonstrated in the Fuyang workshops. Participatory methods work when children are taken seriously and treated with respect, and when adults and children work together according to certain principles and values. One of the problems with the social construction of childhood in most societies is that it emphasizes children's innocence, vulnerability, and need for protection, rather than their resourcefulness, skills, resilience, and strength. In these workshops, children who had been shy, withdrawn, or quiet became active, talkative, lively, playful, and highly participative. Even children living in difficult circumstances, vulnerable by their own definition, became thoroughly engaged and active.

These workshops provided evidence of resilience as well as indications for what needs to be done. Children do not need to be smothered in care, consideration, and pity, but treated with respect and as having ideas and skills of their own. In the workshops, the children analyzed their own reality of needing to prepare themselves for their future. This is not to suggest that they do not grieve or are not in need of emotional and social support—the children's forum in August 2004 provided a tremendous emotional outpouring, as children presented short dramas about their experiences of

discrimination, at school, in the local community, and when having to make a living. Children found this to be a beneficial experience because of the processes involved; relatively simple social activities, engaging children in fun but with some purpose, involving them in decisions and action, have considerable developmental and therapeutic effects that must be taken into account when designing strategies and activities for future work. An integrated strategy requires a focus and coordination of activities, and some existing practice can be drawn upon. Children's centers have been developed elsewhere in Anhui,[15] and multi-purpose centres can be initiated in Fuyang, which provide training, counseling, advice, treatment and other services (see West 2004).

Centers

Existing social networks of children, as well as their own skills, strengths, and resilience, can be made use of in developing strategies and activities. Children have already identified the fact that other children are confidantes along with their parents or primary caregivers, and that the people they would approach to share difficulties (apart from parents and some teachers) would be their friends. Mutual support can be developed through the use of children's centers that provide social activities and training (for example, peer counseling and support, life skills, nutrition), and through finding mechanisms to provide and share support services. Also, not all children will stay on at school or proceed to high school. The centers are places where vocational training can be provided, and where preparation for leaving school and the village—and thus for safer out-migration—can be facilitated for children and young people.

Apart from children's activities and support, a center can act as a base for medical care and treatment, as well as for information, legal advice, and counseling. Medical resources would include voluntary testing and counseling (VCT). Also treatment monitoring would include directly observed therapy (DOT), a mechanism for patient education and adherence to medicine regimes to support patient adherence, to keep people on ARV

15. Children's activity centers were developed in rural and urban areas around Hefei for different groups of children (including disabled children and the children of migrants); in Kunming, Yunnan Province (for children in conflict with the law); and in Tibet (outside Lhasa). The model has been promoted by the MCA and taken up in other provinces, and is being followed by other agencies. A major issue is ensuring quality of work (see West 2004).

even if they experience side effects or feel better and want to self-terminate treatment. The integration of medical and social approaches is important, and the use of a single, central base with primarily recreational associations is a means of fulfilling aims for an holistic approach to children and their families. Social support would include the development of networks of volunteers and staff who could provide simple services to enable families to stay together, to help children attend school, and to support children's physical and emotional needs. The center can be a focal point and meeting place for a local coordination committee for multi-sectoral, multi-agency work.[16] Continual mapping and assessment of local communities, including monitoring the changing levels and type of support required by families, can be done through such local coordination. Such a "center" is not envisaged as a complex construction but as a basic building providing a focused area of support resources and community involvement. (West 2004).

For centers to work, training will be necessary for adults, children, staff, volunteers, and local residents. Training on HIV/AIDS prevention for children is best done through peer education. Activities such as peer education, peer support and counseling, and domestic duties and other work that many children must do will take up some of their time, and this in turn means that greater flexibility is needed in education provision. Some teacher training, support for child-friendly schools, and "quality education" methodologies, as practiced elsewhere in China, would be useful.[17] There is also a

16. Multi-sectoral, multi-agency strategies are possible and practical. Initiatives are underway nationally and locally. DOT work is to be supported through the Global Fund. The US GAP program, set up to help the China CARES and Global Fund be better implemented and provide technical support, management support, and some funds for establishing a surveillance system, is to develop DOT in Lin Quan County in Fuyang. The China CARES program identified 127 counties, treatment has begun in 51, and weaknesses in treatment have been recognized by government. The China CARES/Global Fund system holds county-level government responsible for management, supervision, and opportunistic infection treatment. At the township level, if there are less than 50 AIDS cases, the township government is responsible for treatment or drug delivery; with over 50 cases, a village-level center will be set up for health education, ARV supervision, and VCT. These centers could link in with community centers that are necessary to develop and support other services especially for children.

17. Save the Children replicated HIV/AIDS peer education work in Fuyang from elsewhere in China. Development of "quality education" is a government objective, and links to child-friendly schools and child-centered learning methodologies are being promoted in Yunnan and Tibet (through Save the Children projects) and Gansu (through DFID projects).

need for HIV/AIDS awareness and prevention training for teachers (and other adults) in schools.

Accommodation for Children

Alternatives to institutional care exist, from fostering and adoption to peer and child-headed households and small group homes. Local fostering is often seen as a first option. Preparation for fostering, including children's decision making about placement (see West 2003c) and support and training for foster-carers, can be provided through the center; community processes of "mapping" could identify potential foster-carers. Some groups of older children might live together and be supported from a center. Small group homes have been developed in parts of Anhui and elsewhere.[18]

The term "child-headed household" means that a person under the age of 18 is the head, which obviously covers a wide range of ages and potential levels of competence of children, as well as a variety of situations. A child may be living with and caring for a sibling. Or a child may be the main decision maker in a household with an adult who is too ill to care for him/herself or the children. These situations are emerging now in Fuyang but are not new and are not unknown elsewhere. In many parts of the world, children are already the effective household head, acting as carers for adults who cannot look after themselves. These households acknowledge the reality where many children aged 15 and older are migrating out and living a semi-independent life. Some street children have proposed a similar arrangement for a "big house"—or peer-headed households—where they can live together, be protected, and attend school. Support for such households could be provided through a local center.

Conclusion

In its devastating impact, which might be considered more akin to an emergency or disaster than a medical epidemic, HIV/AIDS in central China is raising a number of significant issues for the care and protection of affected children, especially orphans. Rapid piecemeal responses based on

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18. There was an example of older children living together in Save the Children's original small group homes in Guangde, Anhui Province. Street children in China expressed their ideas for a "big house" where they would live together and have a base for work and study.

externally perceived needs and assumptions—in particular the development of institutional care approaches, which separate children from communities and even from their extended families—risk stigmatizing children, infringing on their rights, and causing more distress. Policy changes, such as the removal of school fees only for children orphaned by AIDS and the payment of *dibao* only to children orphaned by AIDS, also risk increasing discrimination and pose other problems.

Rights-based programming for children and holistic approaches have been found to provide an effective set of principles upon which responses can be based, in communities and nationally, at policy and practice levels. The role of duty bearers is particularly important. It may appear to external agencies to be easier to take some immediate action, but an understanding of children's lives and their participation is essential. An holistic approach, following the best interests of the child, based on analysis of his or her circumstances, requires multi-sectoral collaboration. Policy work is necessary in developing principles for programming that involve the coordination of local agencies and services, and their cooperation.

Following the principle of residential care as a "last resort" (see Dunn, Jareg, and Webb 2003), children affected by HIV/AIDS need support to stay in their homes and communities, rather than removal to a welfare home. Different community support and care packages can be devised and tested, just as with adoption and fostering services, and small group homes can play a part in keeping children in familiar surroundings. Children's participation is the crucial element to building resilience and psycho-social support, as demonstrated in the initiating work in Fuyang..

The aims of keeping children with families require community-based approaches to keeping parents alive, treatment services, and provision of physical and emotional support. Different services and contributions to a coordinated holistic approach can be provided by a number of agencies (government departments and NGOs) with different specialisms, working together in partnership. Such collaboration can be developed and delivered through local coordinating groups, the development of multi-purpose centers, and the provision of training, which must all come together in a response that looks holistically at needs and rights. For children, these need to be part of the development of integrated child protection services, involving and emphasizing children's participation. In the HIV/AIDS pandemic, a focus on children helps provide a focus for services for everyone in the communities, including all adults, parents, and grandparents, as well as those under eighteen.

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Afterword

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As the chapters in this volume have demonstrated, over the last few years the shift in Chinese government policy toward HIV/AIDS has been extraordinary. It is clear that more serious policy attention is being paid to the threat posed and the shift in central policy has been remarkable. In three short years Chinese policy has shifted from benign neglect to the promotion of most international best practices. While overall infection rates are still low, cases have been reported in all provinces and trends are beginning to show that China stands on the edge of a potential spread from specific regions and communities to the population at large if prevention efforts are not rapidly scaled up. The Central government has recognized this and an institutional framework for dealing with HIV/AIDS is being established and a number of policy initiatives promoted. However, promotion of the kind of multi-sectoral responses that are necessary to deal with HIV/AIDS is still difficult. In particular, expanding the role for civic organizations to reach the populations most at risk is essential. In addition, with such as de facto decentralized system, it remains to be seen whether local governments will have sufficient incentives, human, and financial resources to implement the policies and best practices. This is of particular concern for supporting China's free AIDS treatment program. Poor quality management of the treatment program might result in drug resistant virus strains with global implications.

In one surprising development the 2005 assessment of HIV/AIDS in China (Ministry of Health, 2005) lowered the previous estimates by 22 percent from 840,000 to 650,000 basing the claim on a more effective data gathering system.[1] There were said to be 75,000 living with AIDS, with

1. The data for the new estimates were drawn from special surveys and from 329 national sentinel surveillance sites rather than from the previous 194 and the estimates are taken from prefecture rather than provincial data (2003 data).

fewer than 100,000 deaths cumulatively (150,000 in 2003 survey). These revised figures have been met with skepticism by some in the HIV/AIDS community. Thus, the new figures give a low prevalence of 0.05 percent (0.07 in 2003 survey). However, given the recent enhanced policy attention, the report and its sponsors went to pains to point out that the lower prevalence was no cause for complacency as there had been around 70,000 new infections in 2005 (around 200 per day) and 25,000 deaths (Ministry of Health, 2005, p.1).

Currently, the largest group of infections remains intravenous drug users comprising 44.3 percent, down from 60 percent in 2003. The second largest category is the former blood and plasma donors who comprise 10.7 percent, up from 9.4 percent of the total in 2003. Yet, much of the reduction in the total number of infections is credited to a recalculation of this total figure for former plasma and blood donors from 199,000 in the 2003 survey to just 50,000 currently. In part this drop might be accounted for by an increased death count in this category. Of the 25,000 deaths in 2005, 210,000 were reported to be former plasma and blood donors. The shift of the disease into the sexually active population is revealed by the fact that 19.6 percent of the total is from commercial sex workers and their clients, 16.7 percent are partners of HIV positive individuals or members of the general public, and 7.3 percent are transmissions from men who have sex with men. In the 2003 survey, transmissions from heterosexual or homosexual activity only accounted for 8.4 percent of the total. In fact, of the new infections the latest survey reports that 49.8 percent were said to be from sexual activity, higher than IDU transmissions at 48.6 percent.

Whatever, the veracity of these figures, there is no reason for complacency. The prevalence rate is increasing rapidly among all at-risk groups. For example, the prevalence among IDUs has risen from 1.95 percent in 1996 to 6.48 percent in 2005. The link between IDU use and commercial sex work is strong and the originally separate epidemics have begun to merge. Female IDUs are more likely to engaged in commercial sex to support their habit. In a survey of Sichuan province in Southwest China, nearly 60 percent of female IDUs reported selling sex for money or drugs and lass than 30 percent reported consistently using a condom with customers (Choi et al., 2006).

Thus, while the new estimates show that there may be less people infected than originally thought, despite contestation by some working in the field, there is no reason for complacency. Outside of the unique epidemic in central China, the spread of HIV/AIDS in China now resembles more

closely that in other countries in the region and with prevalence rates among some at-risk groups rising quickly, it does make the general public, especially married women, more vulnerable. Despite the many different policy challenges that the Chinese leadership face and the competing demands for the allocation of funds, it would be prudent to not relax policy focus on the potential for the rapid spread of HIV/AIDS.

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