China Takes Charge of a Changing Epidemic

Zunyou Wu and Elizabeth Pisani

We said to them: you are supporting China; that means you need to support our national needs... Donors can be very strong-minded, but we are even stronger minded.

(Zunyou Wu, Director, NCAIDS)

When the AIDS warriors in China’s academies and health institutions started experimenting with responses to the epidemic, their efforts were largely funded with foreign money. UN agencies; the international development wing of the governments of Australia, the United Kingdom, the United States and other nations; multilateral organisations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria; and private charities such as the Ford Foundation and the Bill and Melinda Gates Foundation – all of these provided support for HIV prevention and/or treatment activities in China. The Chinese government’s contribution to the response rose dramatically following the “tipping point” described in Chap. 4. But even then, most of the original funding for provision of treatment to people in areas with epidemics driven by plasma sales was provided by the Global Fund.

As noted in Chap. 3, China benefited a great deal from partnership with foreign donors and lenders. But there were downsides, too. Donors tended to have their own priorities, ones that didn’t necessarily match China’s needs. Especially in the early years, their support sometimes overlapped – popular causes or locations got more funding than they needed, while some important issues were left wanting. Most importantly, though, they all had different reporting requirements, and they rarely shared the information they collected. This made it hard for the government to keep

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track of service provision or to plan effectively, because they didn’t always know who was doing how much of what, where and for whom. For health officials at the local level, the different reporting requirements were a nightmare. Here’s an account related by Elizabeth Pisani, an epidemiologist who worked with China CDC to develop national estimates of the size of populations at risk for HIV in 2005:

Wang [not his real name] had been pulled out of Dali to be trained in how to estimate the number of prostitutes locally, and he was quite cross about it. He’d already counted prostitutes in Dali three times in the previous year, he said. Once for the China–UK prevention programme, once for a US-funded programme and once for the Chinese government. Now he was being asked to do it again with Global Fund money. ‘Count, count, count. And no money for prevention.’ Wang was getting louder as he got more worked up. I could see why he was upset. ‘Why don’t you just give all the donors the same count and have done with it?’ I asked. Wang looked shocked. ‘But they’ve all given me money to count!’ he bellowed. ‘If I didn’t count for each of them, that would be corruption!’ (Reprinted with the permission of Pisani [1])

Local health workers found themselves filling the same data into different forms over and over. Sometimes, the very same donor required data in more than one format, depending on the year the project was approved. The forms demanded by the Chinese government were different again. “It was driving everyone crazy”, remarked NCAIDS Director Zunyou Wu. It is entirely understandable that funders should want to know how the money they provide is being spent. Rigorous monitoring of what a programme spends and what it achieves is necessary to make sure that programmes are being run efficiently; reporting achievements also helps increase public support for continued funding. But people running HIV programmes shouldn’t have to spend more time and funds monitoring what they do than doing it.

The fragmentation was not a problem exclusive to foreign funders. Even within China CDC, information related to HIV programmes was held in eight different databases. Databases for sentinel surveillance, case reporting, treatment, prevention, methadone provision and other indicators were often run by different divisions; there was no easy way of looking at the big picture.

7.1 A Single, Integrated Data System

In 2006, NCAIDS decided that everyone would benefit from a single, integrated data platform designed primarily to meet national needs. The first order of business was to decide which data would be included. It was a mammoth task. Two senior staff worked full time collecting and reviewing all of the monitoring and evaluation forms and standardised indicators used for data collection and reporting by government agencies and by foreign-funded projects. They then held a series of consultations and workshops to agree on a single set of indicators and reporting forms. The process took two full years and entailed a lot of argument. “Some of the
foreign projects, they complained a lot. Each donor lobbied to have their own indicators, complaining that they would not be able to show accountability”, recalled Zunyou Wu. “We said to them: you are supporting China; that means you need to support our national needs. If you don’t want to support our integrated system, then you can just quit”. The NCAIDS director chuckled. “No one quit. Donors can be very strong-minded. But we are even stronger minded”. China was also in a relatively strong position because by the time the system was launched in 2008, the Chinese government already provided the majority of funding for HIV prevention and care in the country. “It’s harder for other countries to do, because they have to respect their donors’ requirements”.

The system, known as Comprehensive Response Information Management System (CRIMS), provides a single, web-based portal which allows programme managers to see what is going on in the national epidemic in real time. It provides simple web-based data entry forms which minimise data management requirements and provides standardised statistical reports which allow for at-a-glance analysis of trends. The platform was developed by a private contractor at the cost of some CNY400,000 (around US$55,000); maintenance costs about the same again each year. Highly secure, it allows data for everyone diagnosed as HIV positive in China to be entered at patient level, including their CD4 test results and treatment status. Patients on methadone can also be tracked at the individual level. Other data such as use of prevention services are reported in aggregate by site.

The system greatly simplifies the once torturous task of reporting on internationally mandated targets such as the Millennium Development Goals, designed to measure progress in human health and welfare. Far more importantly, however, it provides programme managers with an easy way of spotting possible problem areas in the HIV epidemic and the response, so that they can quickly take necessary action. “Once we implemented it, everyone stopped complaining”, observed Wu, who directed the project.

The value of the system became apparent almost immediately. Three early examples highlight the different ways in which it proved useful. In the first example, the system was used to spot an unrecognised area of very high prevalence. Data from a voluntary HIV testing site in Liangshan Prefecture in the south-western province of Sichuan reported that over a third of all clients were testing positive. In the old reporting system, staff in Beijing would probably have assumed a typo, or an error in transcription as the data got sent through paper records and by e-mail from testing site to county office, from county to prefecture and on up through the chain. In the new system, there is little room for such errors. CRIMS allowed staff in Beijing easily to check other data from the same site (data that would previously have been in a different database held by a different division). Sure enough, the data for HIV prevalence among women in the same county who were routinely tested during pregnancy were also very high, between 2.6 and 5.1% at different sites, compared with a national average of just 0.2%. China CDC staff in Beijing then contacted local staff to organise a population-based survey. They tested some 31,100 villagers in one county, an area with a large ethnic minority population, and found that 7.0% of general public aged 15–60 were living with HIV. Much of
the infection was linked to drug injection. The central and provincial governments quickly committed extra manpower and funds to help the remote prefecture step up prevention and cope with high levels of infection. Furthermore, Premier Wen Jiabao spent World AIDS Day 2010 in Liangshan.

Ironically, Liangshan was one of the sites in which a UK-funded HIV prevention programme had been operating for some years. The project’s activities included supporting local data collection, so the high levels of risk and infection should have been no surprise. “There may have been good data, but no one paid attention”, said Zunyou Wu. “It belonged to whoever collected it; everyone owned their own bit”. With the CRIMS, data from every source go into a single integrated system that is scanned daily by four full-time staff in China CDC in Beijing.

CDC staff at other levels also have access to all the data for their own areas, but they do not always have the skilled manpower to track the data and analyse their implications. This was perhaps the case in the second example of the early use of CRIMS, this time to spot problems with the treatment programme. The province of Guangxi, bordering Vietnam, has a busy sex trade and a fair number of heroin users; it was one of the earliest provinces to develop an indigenous HIV epidemic driven by risk behaviour, and by the time the CRIMS became active, many people in Guangxi needed treatment. Staff in Beijing had for some time been under the impression that Guangxi was rolling out their treatment programme quite effectively. “But then we looked at the data pulled together in CRIMS and we saw that they had unexpectedly high mortality. The CD4 data suggested the epidemic was really horrible, and so many people were dying without ever getting any treatment”, said Zunyou Wu. “They had the highest case fatality in the country”. Staff from Beijing went to discuss their observations with provincial officials. “When we showed them the data their faces just went ashen”. The exchange led to a huge leap in political commitment from provincial leaders and thus in resources. Guangxi is now the only province in China which has a deputy director in the health bureau dedicated entirely to responding to HIV.

CRIMS has also come into its own as a prevention monitoring tool. The third example of quick-fire use of the system comes from methadone clinics, which report consumption of the opiate substitute as well individual client visit data. In a quick analysis which calculated average consumption per client and compared averages across clinics, the data from a single site in the southern province of Guangdong leapt out at CDC staff. The clinic was consistently consuming much more methadone than was justified by its client load. A site visit and investigation quickly established that clinic staff had been illegally selling methadone on the black market. CRIMS is not just a health database, it seems; it’s also a tool for spotting misconduct.
7.2 The Evolving Epidemic

The CRIMS has helped Chinese officials and others to see “the big picture” of the epidemic. Many people, especially those who have worked for many years at the local and provincial levels, now perceive shifts in the epidemic that require shifts in the response. One major shift is in the epidemiology, in who is getting infected. But there is also a shift in time horizons and in perceptions about what strategies are needed in the face of new challenges.

Shaohua Wang, deputy director of Xinjiang Health Department, summarises these shifts. “In the early stages of the epidemic in China, HIV prevention and control took on the appearance of acute infectious disease management”, he said. At the time, it was a necessary response. “If we hadn’t done that, we wouldn’t have got to where we are today. But it was hard on resources and unsuitable for the long term”. His description of the initial fire-fighting approach was echoed by Guohui Wu, the director of CDC’s AIDS division in Chongqing City. “I remember when I began to work on AIDS it resembled more of a disaster response, a state of emergency. We would address issues as they came up, and made plans as we went along”. That has changed. “Now we have a stronger infrastructure and better regulatory controls”. He and others are happy to take a more structured, longer-term view. “This is not a short-term battle, we have to think of it as a long-term war”, observed Lin Lu, director of Yunnan CDC.

But it is not just the time horizon that needs to shift. People who have been on-the-ground observers of the evolving epidemic observe that in fighting a long-term war, great generals avoid fighting the same battle over and over again. China has been winning battles one by one: first, infections through poor blood donation practices were virtually eradicated. Then, effective prevention among drug injectors brought the rate of new HIV infections in that group right down. Condom promotion and treatment of other sexually transmitted infections among female sex workers prevented the virus from ever taking off in commercial sex in China. Most recently, treatment services have been extended to most of the people that need them. Inevitably, the spotlight now turns to the challenges that remain.

Most observers of China’s response to HIV, and indeed many of the actors in that response, are full of praise for what has been achieved, but they note that most of the effective prevention strategies so far have centred on biomedical service provision. Some find it frustrating that these biomedical successes have not, by themselves, been enough to shut down the epidemic. Guohui Wu, the microbiologist who now heads the AIDS division in Chongqing CDC, expressed this disappointment: “With other outbreaks, I can isolate the bacteria, use the right antibiotics, and a week later the epidemic is controlled and there is a great sense of accomplishment in my heart. But with HIV/AIDS, we work very hard, but still we keep discovering new infections. This perplexes me: why is there still so much infection? . . . Do people not know they are at risk? They do know, so how with that knowledge do they still get infected?” This frustration sometimes takes a personal toll: “When I look at old photographs, when I was a manager in the microbiology department and had less stress, I had a lot more hair!”, the doctor said ruefully.
7.2.1 A Socially Embedded Disease Requires Social Responses

The realisation that new infections continue despite the best efforts of health authorities has led many to argue that it is now time for an approach that does more to shape the social and cultural contexts which contribute to risky behaviour and which stand in the way of specialised prevention and care services.

“AIDS is not only a medical disease, but also a social problem”, said Xi Chen, deputy director of Hunan Province’s CDC. “If we take a social and psychological approach as well as a biological one, HIV prevention will go better”. Xiping Huan, head of the AIDS Division in Jiangsu CDC, absolutely agrees. “We prevention people are a little bit like scavengers on the waterfront. We run about, salvaging what we can when the tide comes in, with the foam. But why are the waves producing foam like that? As a society, we need to think about that. Family upbringing, social relations, why someone engages in risky sex – this disease is driven by more than just a pathogen”.

As pointed out in Chap. 1, HIV pathways into China and its early spread were facilitated by the sweeping social changes that came with the Open Door Policy. Now China is undergoing another wave of social change. In common with the rest of the world, China is seeing traditional ways of communicating, of building relationships and of doing business disrupted by technology. The country has also experienced nearly three decades of rapid economic growth – millions have been catapulted out of poverty and into a consumerist society in which traditional collectivist values are less esteemed than disposable income.

Jiangsu CDC’s Xiping Huan puts it succinctly. “The country is awash in drugs, new and old. Social media and all these new dating apps – these new platforms emerge just at a time when the economy is booming and people are beginning to assert their individuality. We need to think forward about these things, because they will allow AIDS to develop in different ways”.

Community organisations working in HIV agree wholeheartedly. But they point out that however much they would like to, the health authorities now tasked with controlling HIV have no clear way of taking a more socially embedded approach. “There has been a huge amount of progress over the last decade or more; we absolutely have to recognise that”, said Lin Meng, who heads the China Alliance of People Living with HIV/AIDS (CAP+). “It’s not wrong that the government takes care of the biomedical side of the epidemic. But we currently need to deal with social and cultural aspects as well. The government knows this perfectly well. They know that HIV is a rights issue, that they also need to respond culturally, politically structurally. But if they admit this, who will do what’s necessary? Whose responsibility is it? A change in approach would require the health sector to give a lot of resources and authority to other people...” With a shrug, the activist let the sentence trail off.
7.2.2 Gay Men on the Frontlines

Jiangsu CDC’s Xiping Huan was quite right when she pointed out that social media, drugs, ready cash and a desire for self-expression “will allow AIDS to develop in different ways”. In fact, it is already happening. In the decade and a half since infection through plasma sales was halted, the HIV epidemic in China has shifted from being an epidemic driven by drug injection to one dominated by infections transmitted in sex between men. Just 10 years ago, in 2006, 1.4% of gay men included in sentinel surveillance tested positive for HIV. That’s about 1 out of every 70 gay men tested. Figure 10.2 in the Chap. 10 shows that by 2015, that fraction had risen to 8% – around 1 in 12.

In sheer numbers of newly identified cases, gay men have traded places with drug injectors. In 2011, about the same number of cases was newly identified in both populations – 10,570 among drug users and 10,917 among gay men. Newly identified infections in drug users have fallen every year since then, while among gay men they have risen every year, as illustrated in Fig. 10.3 of the Chap. 10. By 2015, newly identified infections among drug injectors had fallen by more than half, to just over 5000. Among men infected via sex with other men, on the other hand, the number of newly identified infections more than tripled, to over 32,600. These infections are not concentrated in China’s west and south-west, the site of the epidemics driven by drug injection and commercial sex. However, the gay epidemic is different: high rates of infection are springing up in big cities all over China. Finally, three decades into the course of HIV in China, the country has the epidemic it originally anticipated, way back in the mid-1980s when the first cases of AIDS were identified.

Homosexuality is far from unknown in Chinese culture – it is frequently depicted in classical art and described in many novels of the imperial era – and it is not illegal. However, the modern Chinese state has little tolerance for same-sex relations, and families frown on the behaviour in part because it stands in the way of procreation and the continuation of the family line, which remains all important in Chinese culture. Le Geng, the founder and CEO (Chief Executive Officer) of BlueD (pronounced “blue dee”), China’s biggest gay dating app, explained the attitudes of different groups. “The government disapproves of homosexuality because they associate it with corrupted Western values”, he said, “And ordinary people disapprove because of the carrying on the family line thing”. He himself has experienced both sorts of disapproval. He had to leave his job as a policeman after his sexual preference was made public in an internet video. “As for my family, they’re very supportive of what I’m doing in a business sense, but they’re not so happy on the personal level”.

One of the effects of this social disapproval is probably that estimates become skewed. As the Chap. 10 describes in greater detail, the proportion of men reporting being infected heterosexually is suspiciously high compared with the proportion of women who are infected. Anecdotal evidence suggests that many men infected through sex with another man don’t want to admit it. Ray Yip, formerly the head of a US CDC-supported HIV programme in Beijing, tells of a day when he was invited
out by a community group that works in HIV prevention. “We were up near the
Great Wall, it was a nice hot day, and I was hiking with a group of ten guys, all of
them HIV-positive. I asked each and every one of them about what they reported
when they got diagnosed, and not one of them, when they did their first epidemi-
ological intake form, ‘fessed up’ to being gay. They all said they had sex with a
[female] sex worker, only once”. Yet every one of these men was in fact infected
via anal sex with another man. China CDC has done its own assessment of the
accuracy of initial risk reporting and estimates that about 15% of gay men misreport
their route of infection.

The fear of social disapproval affects more than just the statistics. For many
years it acted as a strong brake on sexual relations between men in China just as it
did in Western countries. That fear was eroded fairly slowly in the West, beginning
in the 1970s in large cities. There, the braver gay men would gather in bars, clubs,
saunas and even specific parks to meet one another. For the first time, it was
relatively easy to identify potential sex partners; it was no coincidence that the
HIV epidemic followed rather quickly on this small social opening and in this
limited circle.

The very same social opening that allowed people to exchange sex partners and
spread HIV also provided the platform for an effective response. In the face of
government indifference, gay men in the United States gathered together to face the
crisis their own community was suffering. Activists went to the very venues where
people were looking for sex partners. They began educating, entreating, persuading
and even shaming their peers into using condoms when having sex. The owners of
gay bars and saunas participated actively in these efforts. Since this same commu-
nity was watching its members die, month after month, year after year, it was not
hard to develop a sense of shared responsibility and accountability. In San
Francisco, the epicentre of the epidemic, condom use during anal sex between
men rose from 0 to 70% between 1982 and 1985, and new infections began to fall.

China’s social opening, however, has happened at a very different time. Two
factors in particular mean that the shape of the HIV epidemic among gay men in this
country will look different to that in the West. The first is technology. As Xiping
Huan suggested, social networking apps have changed the face of sexual risk, not
just in China but the world over. Apps such as Grindr and Hornet allow men in
many countries to find potential sex partners without having to go to a bar where
they might be seen by a family member or work colleague, without having to suffer
the sometimes excruciating embarrassment of the face-to-face meeting. In 2015,
Grindr had some six million monthly users worldwide, including in China. BlueD,
founded by former policeman Le Geng, has 27 million registered users, mostly in
China, at least two million of whom are actively looking for dates on any given day.
Technology has allowed more men, including those who may be wary of going to
gay venues, to meet one another and thus to find sex partners. But it has simulta-
nearously made it harder to reach those men with the sort of face-to-face interaction
that created a sense of shared responsibility in the early years of the community
response to HIV in Western countries.
The second, perhaps bigger, change is the advent of effective treatment for HIV. When AIDS invaded the gay bars of San Francisco, Sydney, London and Amsterdam, it was a visible and terrible syndrome that led to a rapid and often painful death. By the time Beijing, Shanghai, Qingdao and Chengdu had active gay scenes, AIDS was practically a thing of the past. HIV, of course, is very much alive and spreading rapidly. But most gay men in China have probably never seen a person with symptomatic AIDS. The fear factor that comes from seeing your friends and loved ones die is simply no longer there. This is of course a very good thing. But it does mean that it is harder to convince people of the need to take measures to protect themselves from the virus. This new reality has not been well understood by Chinese health authorities; they continue to speak of the importance of “awareness”, as though gay men would change their behaviour if only they were more aware of HIV and knew how to prevent it. But new cases of HIV infection are on the rise in gay communities worldwide, even in countries where prevention knowledge is 100%. Although the Chinese language makes no distinction between HIV and AIDS in daily speech, the fact is that the two are not synonymous. Treatment has broken the inevitable progression from invisible HIV infection to visible illness (symptomatic AIDS) to death. Treatable HIV infection simply doesn’t elicit the same kind of community response as AIDS once did, and no amount of “awareness raising” will change that.

“Health concerns, including HIV, should be very important to the gay community”, said Lingping Cai, who runs the China HIV/AIDS Information Network (CHAIN), a non-governmental organisation supporting HIV prevention and care efforts. “But it’s hard to convince people of that. There are natural leaders in the gay community but they think about being able to come out, about equal rights in employment, about gay marriage. These are the important issues for them now – things like making internet platforms for gay friendly jobs. They are not really working on health”.

Following the strategies that worked with other risk populations, HIV officials in the government have tried to address the HIV epidemic in gay men by starting small pilot studies offering biomedical solutions, including circumcision and pre-exposure prophylaxis or PrEP, in which HIV-negative people take antiretroviral drugs every day to help them stay uninfected. The PrEP study was a typically bold experiment on China’s part; though very effective as a prevention method, it has proven politically controversial in many countries. For example, in early 2016, the politically conservative government in the United Kingdom was still not providing PrEP to gay men at risk for HIV, despite a good evidence base and very strong demand from the gay community. In China, the opposite problem arose: though the government offered PrEP, gay men were not willing to take it – perhaps a throwback to the days when the quality of antiretroviral drugs in China was poor and side effects common. In a feasibility study in three eastern provinces, only 197 out of 1033 uninfected gay men surveyed said they would be willing to take the medicine to protect themselves from HIV, and only 26 men – just 2.5% of the study population – actually took it. A rather higher proportion of men said they would be
willing to be circumcised to prevent catching HIV, but only 3% actually showed up for their appointments and underwent the procedure.

Other than awareness raising, the main approach to preventing HIV among gay men in China is currently to test as many of them as possible for HIV and to put those who test positive on antiretroviral drugs, both for their own benefit and to reduce the likelihood that they might pass HIV on to others. According to CHAIN’s Lingping Cai, the approach doesn’t match the needs and desires of gay men. “Because of community movements, gay people are expressing themselves more and there’s more [social] acceptance. What gay men demand is respect. But the response strategy is still medical. The strategy is to test, the intervention is to draw blood, and the output is a testing target achieved. There’s no respect for human beings”. Faced with this new challenge, she said it was more necessary than ever to design prevention programmes around the needs and desires of communities. “We need a strategy for humans, not for a disease”.

Again, the government is aware that strategies that worked with sex workers, drug users and people so poor they sold blood for money – socially marginalised communities sometimes living on the wrong side of the law – will not necessarily work for young, educated men scattered throughout all the major cities of the nation. Health authorities are casting around for solutions. “I’ve even heard a senior government official wonder aloud if legalising gay marriage might reduce risk among gay men”, said Le Geng. “He was speaking personally. But still, the government is growing more and more pragmatic in the face of all these new infections. They have no other choice”.

Certainly, the government agrees that community groups should be involved in the response, and it has taken steps to support such groups. To understand the current position, we need to look at how the funding streams for HIV in China have changed in the decade since the government pledged to tackle the epidemic head-on.

### 7.2.3 Taking over the Purse Strings

As we have seen, almost all of the early response to HIV in China was foreign funded. From the start of the epidemic to 2009, China received over US$526 million from some 40 foreign agencies and foundations. The money was spent on 276 separate projects; though all were implemented in partnership with Chinese authorities, many were driven by the priorities and interests of the international partners. Even after China began firmly to set its own national priorities with the “Four Frees and One Care” commitment of 2004, funding for implementation was often provided by foreign sources. The first large-scale treatment services for people infected while selling plasma were mainly paid for by the Global Fund, for example. But as those services rolled out in provinces most affected by poor plasma collection practices, the government realised that it could not neglect other populations. It began to fund large-scale testing and provision of treatment to other populations out of the national budget. Details of China’s spending on HIV are
shown in Fig. 10.8 of the Chap. 10. From an initial contribution of CNY100 million in 2001, spending increased astronomically to reach CNY3.7 billion by 2015. As the proportion of HIV-related funding coming out of national pockets grew, so did the government’s desire to reduce the fragmentation that comes of having so many different foreign partners funding so many different projects.

The international community had themselves recognised this problem as early as 2003 and had tried to address it by agreeing on three rules to try to bring all elements in a country’s response into a single coherent framework. Known as the “Three Ones”, the rules were one agreed National HIV/AIDS Action Framework within which all partners work, one National AIDS Coordinating Authority and one agreed country-level monitoring and evaluation system.

Though badly needed by countries that were being pulled in different directions by different donors, these rules were roundly ignored by the very organisations that dreamed them up. “China was the first country to step up and say: we don’t want to run our national programme as just the sum of a lot of different projects”, said Bernhard Schwartländer, who represented UNAIDS in Beijing at the time China began to take full control of its response to HIV. The Chinese government had previously developed five-year plans to guide the national response. However, they had never before taken charge of the contribution of foreign-funded projects to that response. CRIMS was a very important first step in unifying the response – it was certainly the first example of the sort of unified, government-led national monitoring and evaluation system envisaged by the Three Ones. Another radical step was taken in 2010, when the government rolled four separate Global Fund-backed programmes, each managed by a different entity, into a rolling continuation channel which put all of the programmes firmly under national leadership.

The government did more than just assume ownership of money from foreign sources; it significantly increased the amount it spent on HIV from domestic coffers. The proportion continued to rise until, by 2014, over 99% of funds for HIV programmes in China came from domestic sources. “The leap in commitment as China took charge of its epidemic was astonishing”, said Schwartländer. “It was an amazing time”. Other important policy changes were also made at this time, including the end of the ban on HIV-infected foreigners visiting China.

An additional spur to national ownership of the response came from a commentary published in the influential US-based journal *Foreign Policy* by the former US government and WHO health policy adviser Jack Chow. In the July 2010 issue of *Foreign Policy*, Chow launched a blistering attack on China for taking a billion dollars from the Global Fund, a multilateral mechanism that was intended to help the world’s poorest countries cope with HIV, TB and malaria.

It is audacious for China to assert that it needs international health assistance on par with the world’s poorest countries. In fact, at the same time it is drawing from the Global Fund, China is building its entire global image as one of economic growth, accumulating wealth and international stature. To boost its public profile and prestige, China spent billions to host the Beijing Olympics and the Shanghai World Expo. Surely it could spend another $1 billion of its cash on health as well. (Reprinted with the permission of Chow [2]).
Though China is also a contributor to the Global Fund, it was taking out far more than it put in. Chow argued that poor countries were unable to get funding because China’s successful bids were using up so many of the available resources. But, he said, neither the poor countries that were losing out nor the rich countries that were underwriting the fund dared to complain, for fear of damaging relations with China, an increasingly important investment partner for rich and poor nations alike.

The article prompted a rapid rethink at the Global Fund’s headquarters in Geneva. From November 2011, China and a number of other middle-income countries were “graduated” from the Fund – they would no longer be eligible to apply for grants. On the Chinese side, “It was a slap in the face”, according to one government official. “After SARS the government had really taken on board that it was responsible for the health of its citizens. That article made everyone so ashamed”. The government did not even apply for the transition funds that would have helped smooth the passage to a post-Global Fund financing model. Funding from the Bill and Melinda Gates Foundation, which had supported access to prevention and treatment services among gay men and other groups, ended at roughly the same time.

The rapid withdrawal of foreign funds provoked headaches, especially in provinces with relatively high HIV prevalence. “We faced a very difficult situation when vast international cooperative projects pulled out of Yunnan”, said Lu Lin, director of Yunnan CDC. The provincial government faced an unexpected shortfall of CNY10 million (around US$1.6 million at the time). But Chow had been right that China’s booming economy had reduced the need for the country to rely on international grants. No longer able to rely on the Global Fund or other outsiders for help, Yunnan dug into its own coffers and made up the shortfall in HIV spending itself.

7.2.4 Finding New Platforms

As it turned out, the biggest effect of the loss of Global Fund money was not financial. It was the erosion of the voice of community groups in the response to HIV.

Since the earliest World Bank-funded projects of the early 2000s, foreign funders had encouraged the Chinese government to engage with civil society on the issue of HIV. But it was the Global Fund that formalised their participation in planning and delivering HIV prevention and care services. In every country, Global Fund proposals and grants are governed by a Country Coordinating Mechanism or CCM, which must include representatives from government, international partners and civil society organisations. No civil society representation, no cash; it’s that simple. What’s more, in China the Global Fund stipulated as a condition of providing a grant that a certain proportion of the funding should go to Non-governmental organisations or NGOs: a fifth for the first and second round of grants, half for the third and all of the money for the fourth.
As was seen in Chap. 3, there was no body of established NGOs in China, so this presented something of a challenge. Many groups sprang up to absorb the money – around 1000 by 2012. The process was not always an easy one. There were no clear mechanisms in Chinese law through which these community organisations could even establish themselves as legal entities. Sprouting up from nothing, they naturally lacked organisational capacity, and some of them were also somewhat opportunistic. “Some of the NGOs see the community as a client, as a source of money, nothing more. But communities are not stupid: they know when an NGO is doing nothing for their rights”, said CHAIN’s Lingping Cai.

In addition, many Chinese officials resented the imposition of these groups. In the past, they had used government channels to reach those most likely to be in need of HIV services – former plasma sellers, drug users and sex workers. “But the gay community is different [from plasma sellers, drug users or sex workers]; it’s more diffuse”, explained Ray Yip, who directed both the US CDC and the Bill and Melinda Gates Foundation AIDS programmes in China. The need to adopt new approaches to reach gay men combined with the need to meet the stringent rules of the Global Fund led to a change in attitudes among officials in the central government. “In China, international supporters pushed gay-men-based NGOs to become part of the response. That has forced CDCs and NGOs to work together, which is not an easy alliance”, Yip said. “But over the years it has created higher level political permission for this arrangement. There’s still quite a bit of animosity and discomfort on both sides, but at the top political level, they see NGOs as necessary but not sufficient, and CDCs and the medical establishment as necessary but not sufficient. So now, both sides respect this compromise as a necessary part of the solution”.

Community-based organisations say that they learned a great deal from their interaction with the Global Fund and through that with government authorities. “There were a few community organisations before the Global Fund, but they were mostly just doing peer outreach. With the support of the Fund, we moved into operations research, advocacy, anti-stigma work, all kinds of things”, said Lin Meng, of CAP+, who represented civil society organisations on the Country Coordinating Mechanism, the Global Fund’s governing body in China. “Participating in the CCM also helped us to understand how democracy operates, what the rules and procedures should be. This was important knowledge for civil society; we learned about rights, respect, all sorts of things. During the process I had to deal with governments, donors, international organisations, academics in institutes. I learned how to work with them and how to fight for something, how to negotiate. The impact of the Fund was huge”.

After the Global Fund announced that it would no longer be supporting programmes in China, there was a great deal of concern about the fate of these non-governmental organisations. In some areas of the country, for example, in Yunnan, local authorities recognised the vital contribution they could make in working with marginalised populations. “We need to cling vigorously to grass-roots institutions and move the key battleground to the communities and rural areas”, said Lin Lu, director of Yunnan Province’s CDC. “It makes AIDS
prevention and control more tangible and specific”. However, as we saw earlier, the closure of major foreign-funded programmes left the province with a large hole in its budget. The Yunnan government itself created a fund which mirrored the procedures of the Global Fund. “The bidding procedure is organised by NGOs and assessed by experts from several fields”, said Lin Lu. His colleague Xiping Huan, head of the AIDS Division in Jiangsu CDC, spoke very specifically of the special role that community organisations have to play in the response, especially as the epidemic shifts to gay men as a result of social change. “From the viewpoint of the government, or society, or personally, it’s very easy to just see the disease”, she said. “But you have to look at what is behind the disease. I’ve said to community based organisations, ‘You must start addressing the cultural drivers of the disease’”.

Not all local governments were as quick to recognise the potential contribution of domestic non-government partners. In May 2011, 6 months before China was “graduated” from the fund, the Global Fund management had frozen payments to Beijing because many provinces and prefectures were not doing enough to involve civil society [3]. NGOs and others worried that without the leverage of the Global Fund, they would have even less room to do their work. “The truth is, we failed to professionalise the NGO community, and they still find it difficult to make their voice heard”, said Bernhard Schwartländer, who has served as both UNAIDS and WHO representative in China. “The CCM gave them an internal lever which has now gone”.

Community groups felt the loss keenly. “If I had to describe in a word how I felt when the Global Fund pulled out, I would say ‘grief’. It seems like when they left, NGOs and CBOs [community-based organisations] slipped back into silence”, said CAP+’s Lin Meng. The pull-out was sudden, and there was little time to prepare alternative mechanisms for civil society participation. “It felt like we were abandoned”.

The central government, however, was increasingly aware of the importance of community groups in reaching those most at risk. In December 2012, the then Vice Premier Li Keqiang met with the heads of eight NGOs involved in the HIV response. Ray Yip recalled the meeting: “He congratulated them on what they were doing, and they were very quick to point out that they were all supported by international funding, which was near the very end. What to do? And Li Keqiang said, ‘Well of course we’ll take over [the funding]’”, the former manager of the Bill and Melinda Gates Foundation programmes in China laughed. “That was one of sweetest moments. In other countries you don’t know if it will really happen, but in China, if someone at that level says that, you know it’s as good as the law”.

Li Keqiang was as good as his word. Because of his long-standing commitment to helping prevent HIV and care for those affected, the premier worked tirelessly to change both the thinking and the entrenched practice of colleagues in the bureaucracy and to set up structures that would for the first time channel government money to NGOs. By 2015 China’s Ministry of Finance was providing some CNY30 million (US$5 million) for community-based organisations responding to HIV. Not content with that level of commitment, Li Keqiang topped up the funding for NGOs with another CNY20 million (US$3.2 million) from the Premier’s Fund, a
discretionary spending pool used mostly for natural disasters. On top of that, some provinces make extra money available to support the work of community groups.

This provision of funds to non-government groups represents a remarkable departure from regular government practice in China. Not surprisingly, there are still issues to be resolved before it functions as smoothly as everyone would like. Thomas Cai runs one of the longest-standing non-governmental organisations supporting people living with HIV in China. Initially, he funded all of his work himself, sometimes collecting donations from friends as well. Even then, however, it was difficult to operate. “Our group was not considered a legal entity. Overseas you call it a charity but here in China there was no legal precedent”. This made it impossible to open bank accounts or track expenses and thus difficult to prove to outside donors that the money is well spent. More recently, it has become possible to register non-government groups in a single administrative area, but, as CHAIN’s Lingping Cai explains, it’s not easy. “We need to renew our registration every year. It’s expensive in terms of time and energy; it takes our finance and admin people two months every year”. Many community-based groups don’t make it through the registration process; they essentially become subcontractors delivering services for CDC offices.

Since national and local CDCs and other government agencies hold the purse strings, they are able to determine what activities are undertaken by the community groups they support. In early 2016, the vast majority of that activity centred on providing testing to at-risk communities. In 2015, none of the central government money was made available to community groups wanting to do advocacy, or hoping to work to protect the rights of people with HIV, including by attacking stigma and discrimination. “We want to see NGOs being more proactive in advocacy, working to promote the rights of the groups they represent”, said Lingping Cai. “But they can’t because they are taking money from CDC for service delivery. It stops up their mouths”.

The WHO’s Bernhard Schwartländer believes these observations are legitimate. “The way NGOs are set up, well, there’s no real framework for community accountability”, he said. “It requires a level of trust that doesn’t exist right now”. However, he’s optimistic that that can change. “There’s an incredible seriousness of purpose among China’s leaders right now; they have shown themselves to be remarkably willing to adapt”, he said. “The epidemic is changing. If the government can begin to see the gay community as a source of opportunity rather than just a source of risk, then it could continue in its great progress against HIV”.

Some mechanisms developed in the heady years when China’s government took full charge of the national response have survived and function well. The Red Ribbon Forum, for example, is a platform that brings officials from health, public security, education and other sectors together with people from the private sector and communities to discuss sensitive issues around HIV. “Those difficult discussions used to be convened by international organisations like UNAIDS”, said Catherine Sozi, who currently represents the United Nations HIV programme in China. “But Red Ribbon is a Chinese forum, with a channel to the State Council and other policy bodies. That makes it very powerful”. The forum has recently
brought together people to discuss the sex trade, continuing discrimination in healthcare, the challenges of hepatitis co-infection and other thorny issues. If policymakers can learn to take these discussions seriously, regarding all participants as equal partners and integrating the contributions into plans for joint action, the country will be well placed to meet the challenges posed by the evolving HIV epidemic.

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