

Assessment and Observations Arising from a Visit to Beijing and Chengdu, China, to look at Human Rights, Civil Society and aspects of the Chinese Government's Response to HIV/AIDS

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Introduction: Background to the visit

This is a report of observations from a visit to China in October 2009 by Mark Heywood, the Executive Director of the AIDS Law Project (ALP) and Adila Hassim, the Head of ALP Litigation and Legal Services. The visit was officially hosted by the Chinese Ministry of Health. As our report explains, the Chinese government is in the process of establishing a forum on AIDS and human rights and the invitation was connected with Heywood's position as the chairperson of the UNAIDS Reference Group on HIV and Human Rights and Hassim's work on AIDS, human rights and law in South Africa.

In addition, the UNAIDS China office, together with the ALP's local partner, the Korekata AIDS Law Centre (KALC)¹, organized and facilitated many valuable meetings. These meetings allowed us to interact with both civil society and officials of the Chinese government and to look at and discuss the human rights dimensions of the response to AIDS, and particularly human rights issues on which China has been criticized nationally and internationally.

In brief the background to our work in China is as follows:

In 2006 the ALP was introduced to the KALC, a non-governmental organization which – like the ALP - seeks to protect and promote human rights of people with HIV by using the law. In 2007 Li Dan, then the coordinator of KALC, made a short visit to South Africa to meet with the ALP. In November 2008, Heywood, reciprocated with a visit organized by KALC to participate in a training

¹ Korekata AIDS Law Center (www.korekata.org), China's first legal aid center for people with HIV/AIDS, was established in January 2007. The center aims to defend the rights of people living with AIDS and to advance the development of Chinese rule of law. Through casework, publications, advocacy and workshops, the Korekata Center promotes access to and participation of people with AIDS in China's developing legal system. The issues it deals with include combating discrimination against people with HIV/AIDS, advocating for compensation for people infected with HIV through hospital blood transfusions, advocating for treatment access, and promoting respect for the rights of vulnerable communities. Korekata is establishing a broad network of relationships with domestic and international AIDS lawyers, experts, NGOs and people with AIDS. In addition to establishing a long-term AIDS legal aid center, it also aims to provide an online resource and organize events to promote exchange and cooperation between Chinese and international AIDS law experts.

programme on AIDS and the law with lawyers in Wuhan, in Hubei Province, and to have meetings with a number of civil society organizations in Beijing.

Parallel to this Heywood had also begun a discussion with senior officials from NCAIDS (the Chinese National AIDS programme), within the Centre for Disease Control (CDC). This arose from public criticism he had made at the 13th International AIDS Conference in July 2006 of China's disregard for human rights and victimization of civil society activists in its response to AIDS. This criticism led to an invitation by Professor Wu Zunyou, the Director of NCAIDS, to visit China and look more closely at its AIDS programme. This was accepted on condition that there would also be access to civil society organizations working on HIV.

During a visit in November 2008, organized by KALC and the Chinese HIV/AIDS Information Network (CHAIN) Heywood met with Prof Wu Zunyou and other senior NCAIDS officials in Beijing: a special meeting was organized by NCAIDS to present details about the government's response to AIDS in China, including on human rights issues. NCAIDS also facilitated several other meetings.

During this visit the ALP and KALC agreed that our partnership should be strengthened and formalized. In particular we agreed on a plan for training on legal advocacy which could be conducted by Adila Hassim, the head of the ALP's Litigation and Legal Services. The aim was to transfer some of the ALP's experience on AIDS law to KALC, as well as other civil society organizations. In 2009, this part of the visit was generously funded by the Open Society Institute (OSI).

We consider the visit a success. However, as we reviewed our findings and recommendations (at the end of this report) we were conscious that most have already been made in other reports and that, by and large, they echo the calls being made by civil society organizations for a more meaningful role in HIV prevention and treatment as well as for greater openness and respect for human rights in all areas of life in China. Therefore, our findings must primarily be seen as reason to re-emphasise the need to implement measures that have already been recommended by others.

HIV in China:

Currently it is estimated that about 700,000 people are infected with HIV, in all parts of China, although with infections concentrated in particular provinces and among particular vulnerable groups (described by UNAIDS as 'most at risk populations').



Although the incidence of HIV infection is now believed to be highest through heterosexual transmission, amongst those already infected the bulk of people come from marginalized/stigmatised and or criminalised groups, particularly injection drug users (IDUs), men who have sex with men (MSM) and sex workers. It is still not fully known how many people have HIV due to blood sales in the central provinces in the 1990s, or due to contaminated hospital blood supply.

Distrust of the official statistics was one of the common themes of people we talked to. In 2006 UNAIDS had claimed that the Chinese AIDS epidemic could take off rapidly and projected 10 million people could be infected by 2010. However, this projection was discarded. Nonetheless, UNAIDS believes that "the total number of people who have a high risk of exposure to HIV could be that 25-30 million people."

Although the numbers of people infected are high, proportionate to the size of the population and to the challenges of other health issues, HIV is a relatively 'small' health issue in China (that is, relative to other health and social challenges). We think that it is unlikely that AIDS would get the attention that it does were it not for the global focus on HIV (as a result of UNGASS in particular) and the lure of significant funding from the Global Fund on AIDS TB and Malaria (GFATM), which China has been very successful in attracting.

China's Action Plan (2006-2010) for Reducing and Preventing the Spread of HIV/AIDS, sets ambitious targets for increasing knowledge about HIV throughout the population. But despite this, knowledge of HIV does not exist widely outside the risk groups. Instead, based on what we were told, it would appear there is widespread ignorance and fear about AIDS and consequently stigma remains very high.

As human rights lawyers, we adopted the same approach to that which we use in South Africa in our day to day work: we sought to measure our observations about China's response to HIV/AIDS against its own legal and policy obligations, particularly:

- Relevant provisions of the Constitution of the People's Republic of China, 1982;
- The Regulations on AIDS Prevention and Treatment, 2006 (Decree of the State Council of the PRC, No 457);
- ▶ The UNGASS Declaration of Commitment, 2001;
- ▶ The National Human Rights Action Plan (2009-2010)

China is a signatory to the 2001 UNGASS Declaration of Commitment and, indeed, we saw evidence of a high level of commitment to AIDS from both government and civil society. But despite this the full extent of the response to AIDS that is recommended by UNAIDS in its recent publication *Joint Action for Results, Outcomes Framework 2009-2011* would not seem to be possible in China. This is because the drivers of the epidemic, and the broad social response that is required, are enmeshed in a political and legal framework that – at this stage -

limits the possibility for a genuine and full partnership between civil society and government.

What do we mean by this?

China is a country in the process of a rapid social and economic transition. There are significant although carefully controlled political reforms taking place, as evident in the National Human Rights Action Plan (2009-2010) which we refer to later. However in two areas that have been accepted internationally as being essential parts of the equation for a successful response to AIDS, there is limited scope at this stage. These areas are:

- a. the capacity of civil society organizations to act independently as leaders of implementation through effective monitoring, policy advocacy and campaigning;
- b. the possibility to use law and litigation as a means to remedy wrongs and acts of discrimination that are directed at people with HIV, and to create broader awareness in society and government of the wrongfulness of such acts.

Both of these issues are explored further below. However, what was striking is that there appears to be some will to address these issues.

One of the most exciting aspects of the trip was to observe and participate in an advisory meeting, hosted by UNAIDS, to set up an AIDS and Human Rights Forum. This meeting, on October 13th 2009, was co-chaired by Wang Longde (President of the Chinese Preventative Medicine Association and member of Standing Committee of the National People's Congress) and Bernhard Schwartlander, the UNAIDS Country officer. It was attended by Ren Ming-Hui, Director General Department of International Co-operation, Ministry of Health; Wan Yanhai, one of China's most respected and independent AIDS activists; Meng Lin, the chairperson of CAP+ as well as a number of academics.

At the meeting's conclusion, Mr Wang summarized the consensus as follows:

- an AIDS and Human Rights Forum is necessary to jointly address the challenges of HIV and AIDS;
- it should be a long term project;

- the purpose should be to:
 - strengthen the AIDS response from a human rights perspective;
 - collect opinions on where the challenges are in the AIDS response and find solutions;
 - build trust and be meaningful
 - foster better publicity and communication to encourage a favourable environment for engagement;
 - to assess the contents of legislation and recommend revisions where necessary, for example, the limitation of entry into China of PWAs
- a secretariat should be established that can begin to do the preparatory work for setting up the Forum and its core members;
- it should have a government representative as its Chair and a civil society representative as co- Chair; and
- members should come from government, researchers, grassroots organizations, women’s organizations and international organizations.

Similarly, in a meeting set up to receive feed-back on our observations, the Director of National Center for AIDS/STD Control and Prevention (NCAIDS) acknowledged the need to improve communication with civil society and expressed an openness to receiving and acting upon bona fide recommendations on policy and implementation.

In our view, whether there is progress in these two areas will be a litmus test of political change and China’s ability to effectively control HIV and AIDS.

List of Meetings and Visits:

Below is a list of meetings that we attended:

October 2009	Meeting
10	Supper with Mr Ren Ming-hui, Mr Hao Yang, Mr Wang Longde, Prof Wu Zunyou and Dr Bernard Schwartzlander

11	Meeting with Ms Shen Tingting
12	Briefing from UNAIDS on the AIDS situation in China Briefing on the Chinese legal system from Prof Qiu Renzong, Chinese Academy of Social Sciences Philosophy Meeting with Mr Li Dan, Mr Xu Haibo and Ms Shen Tingting
13	Advisory meeting on China AIDS and Human Rights Forum *
14	Korekata Law Centre, Lawyers' Salon *
15	NGO Networks Salon,* facilitated by UNAIDS
16	Discussion on collaboration between ALP, Dongjen, Korekata and CHAIN Meeting with NGO and PLHIV CCM Working committees*
18	Meeting with Chengdu Disease Transmission Hospital Meeting with Aibai Chengdu LGBT Centre
19	Meeting with Sichuan NCAIDS CDC Meeting with Sichuan Global Fund Site visit to sex worker outreach project, Pi County, Chengdu
20	Meeting with PLHIV and NGO activists in Chengdu* Site visit to San Ye Cao (Needle and Syringe Exchange Centre), Chengdu Site visit to Chengdu Gay Care Organisation
21	Lecture on the Right to Health to students at Peking University*
22	Meeting with Jia Ping; Meeting with Korekata and China HIV/AIDS Information Network (CHAIN); Meeting with Prof Wu Zunyou, Director, NCAIDS CDC.
24	Meeting with staff members and volunteers of Aizhixing Institute Meeting with Meng Lin, co-ordinator of the Chinese Network of People Living with HIV (CNPLWH)

The Role and Place of Civil society in the AIDS Response:

It is an internationally agreed principle that whilst governments must lead the response to HIV/AIDS civil society has a crucial role to play in making

government programmes effective (UNGASS, Declaration of Commitment para 33).

In theory this principle is endorsed by China. For example, the 2006 regulations repeatedly refer to the need for: “strong societal participation” (Art 2) “the establishment and improvement of co-operative working mechanism with respective duties” (Art 4). They also require that “people’s governments ... shall take measures to encourage and support relevant organisations and individuals ...” in a range of activities on HIV and AIDS (Art 7 & 18).

More recently, section 6 of the Human Rights Action Plan (HRAP) refers to “The Right to Participate”. It states that:

“The government encourages social organizations to participate in social management and public services, encourages the establishment of private non-enterprise entities in the fields of education, science and technology, culture, health care, sports and public welfare. It gives play to the social functions of social organizations such as industry associations, societies, and chambers of commerce, and develops and standardizes all kinds of foundations to promote programs for the public good. “

We were privileged to meet and hold discussion with many of the most important individuals and organizations who constitute that part of organized civil society that is working on HIV in China. This included Meng Lin, Wan Yan Hai, Li Dan, Jia Ping, elected members of the NGO and PLHIV Country Coordinating Mechanism (CCM) working committee, various networks, and organizations including Dongjen, CHAIN, Aizhixing, Aibai and the Chengdu Gay Care Organisation.

The civil society organizations we met are vibrant, committed, skilled in the areas in which they focus and playing a very important role in HIV service delivery. However our abiding impression was of the schizophrenic position in which civil society finds itself; acknowledged and encouraged (at least on paper), but (with a few notable exceptions) not involved in advocacy, or an equal partner with government.

This reality seems to reflect a comment made in an essay by Andrew Watson where he writes:

“The Party and government remain suspicious of organized groups outside of the formal system. While keen to welcome those working in social welfare and charitable areas, the Party-state is determined to avoid the emergence of organized groups antagonistic to it. This underlying premise has been an important element in shaping the types of organizations that have been established and the type of work they can do.”²

Every NGO that we met with complained that they felt unable to influence policy and be heard; that they had difficulties with legal registration (indeed most are either not registered or registered as companies, rather than NGOs); and that they had difficulties with organisational autonomy as a result of receiving funding only for programmes and not for core costs.

There are onerous and restrictive regulations governing NGOs. Again, Watson writes:

“Overall, the existing regulatory framework has established a set of rules under which civil society type associations may register and operate, but as yet this framework is far from complete or fully articulated. In many ways, the legal space is constrained. Nevertheless, as has been observed, the ‘institutional space’ (*zhidu kongjian*) laid down in regulations is much narrower than the ‘actual space’ (*shiji kongjian*) enjoyed by existing organizations.”

We raised this in our meeting with Prof Wu Zunyou who agreed that there is a reform of regulations but that it is not happening quickly enough to assist NGOs. However there are some, such as Wan Yanhai, who fear that the new regulations governing NGOs may be even more restrictive than at present. For example the NHRAP promises to support the work of social organizations – including a revision to the Regulations on the Registration and Management of Social Organisation, Interim regulations on the Registration and Management of Private Non-Enterprise Entities, and Regulations on the Management of Foundations. But ominously it states that these revisions will be to ‘ensure social organizations conduct activities in accordance with the law and their respective charters’.

In our view, this is an issue that UNAIDS and the international community should monitor and take seriously.

² Civil Society in a Transitional State: The Rise of Associations in China

It must also be said that there are many organisational challenges facing NGOs: there is evident and serious disunity and division, something that has manifested most recently in the process leading to the 2009 election of the CCM Working committees. There are various fractures in the NGO community; one of the most evident is the tension between the Director of Azhixing, Wan Yanhai, and the leader of CAP+, Meng Lin. Although this is sometimes presented as a conflict between a confrontational approach and a more collaborationist approach, in reality both leaders have much in common, both are committed to human rights and much more would be achieved by working together. There is justification both for being outspoken and for seeking to work in and expand the slowly growing space that the government is opening for engagement with NGOs. There is good cause to generate discussion about the human rights approach to HIV and to discuss what it means to apply it in the Chinese political context. If this were to happen it would offer greater protection to leaders such as Wan Yanhai who often court arrest (and a similar fate to that of people like Hu Jia, a human rights and AIDS activist now in prison until 2011) by demanding respect for human rights, but are partly isolated even within civil society because of fear and misunderstanding of their approach. On the other hand, a purely reformist approach will do little to change the current limitations on NGO activity.

With one or two exceptions (primarily Azhixing) there is an unspoken fear of crossing the line of what is considered as politically acceptable activity and of organizational innovations and collaboration that might be seen as a threat to the state. There is also an uncertainty about what constitutes acceptable (non threatening) activity in the eyes of the state.

For example, in a meeting with NGO networks facilitated by UNAIDS there seemed to be a palpable fear to jointly draw up a letter to NCAIDS setting out the problems that are occurring around HIV testing – as a result the letter was not drafted. There was also a reluctance to establish an informal ‘network of networks’ because this too might seem a challenge to the state. In fora such as this the inexperience of civil society is revealed. Leaders of networks appeared unwilling to represent their members officially without going back and conducting a consultation to get agreement from all members. This highlights the

limited understanding of the role of Networks in advocacy and how to democratically represent the voices of their constituencies.

In addition, there appears to be a competition amongst NGOs for recognition and resources. In the NGO salon, despite good progress in the discussion and agreement that a joint statement should be drafted, a suggestion (from us) that the first draft of a statement that had been prepared by the CBO network should be used as a starting point was met with fierce resistance.

In our view, greater unity amongst the various networks and the definition of a common strategic vision (which NGOs could agree upon but contribute to in different ways),³ would both increase their reach and legitimacy in society and their effectiveness in relation to government. We also argued that it would be valuable for NGOs to strengthen their ties with academia and with NGOs that are working on other major social issues that face China.

However, many of these problems are created by the situation in which the NGOs find themselves – without a domestic tradition and models for civil society activism, denied access to information, competing for very limited financial resources and unable to develop strategy because of political limitations on their activities.

Despite this a vibrant, ingenious and committed NGO sector exists. We believe that through ‘spaces’ such as the NGO PLHIV Working committees and AIDS and Human Rights Forum there is an opportunity to strengthen NGO monitoring, information sharing and activism.

Finally, NGOs in China face serious challenges around sustainable funding. We would argue that international donors and foundations should allocate additional funds to Chinese civil society. This is necessary both to improve the response to the AIDS epidemic and to deepen civil society and chances of democracy.

The Chinese Legal System

³ In discussions we held we gave the example of how in South Africa the development of the Charter of Rights on HIV/AIDS, laid the basis for a vision (expressed in a document) that provided a framework for much NGO activism for over a decade.

Apart from learning about HIV policies in China, the visit included an engagement with legal professionals and civil society organizations that use the law to protect the rights of people living with HIV. This was of special interest to us given the scope of the work of the ALP, but also because of the role of the law to break down apartheid (which was a legal system itself). The ALP has grown in the tradition of anti-apartheid lawyering.

Prior to arriving in China, we read several texts on the laws that are relevant to HIV and AIDS in China. This provided a very basic insight into the legal system. It was important therefore to have a private briefing in relation to the legal system that would allow for a deeper understanding. UNAIDS arranged a briefing with Prof Qiu Renzhong and Mr Wang Ruaou Tao. While this provided us with a valuable opportunity to ask questions and Prof Qiu and Mr Wang were generous in making themselves available to us, they are not legal experts and therefore were unable to respond to certain questions.

Below we set out our observations, which are based on preparatory reading, discussions with individuals and organizations.

The Constitution and legal system

The Constitution provides that it is the supreme law. All law and conduct (by all levels of government as well as individuals) must be consistent with the Constitution. Article 11 specifically provides that 'all acts in violation of the Constitution should be investigated'.

However, in contrast with South Africa (where the Constitution is also the supreme law) there is no independent legal system to enforce this provision. The courts are not empowered to review law and policy against the Constitution. We are not aware whether there is another semi-judicial body to which one could report violations of the Constitution in terms of Article 11, which would allow for investigation into such violations. For these reasons, we were told, "Sometimes human rights lawyers and activists like to uphold the constitution by citing it in cases and pasting it on their chests in protest marches".

Rights in the Constitution:

Fundamental rights and duties of citizens are provided for in Chapter Two of the Constitution. The Constitution (adopted in 1982) has gone through four amendments (in 1988, 1993, 1999 and 2004). These mainly reflect a growing shift in the attitude to private property, resulting in the explicit protection of private property in the 2004 amendment. The 1999 amendment also proclaimed that China abides by the rule of law.

Some of the key human rights that are protected include: the right to equality (Article 33), freedom of speech, of the press, of assembly, of association, of procession, and of demonstration (Article 35), personal freedom (Article 37) and personal dignity (Article 38).

Of particular interest is Article 41, which provides that citizens 'have the right to criticize and make suggestions to any state organ or functionary' and to lay complaints or charges against any state organ or functionary for violation of the law. It goes on to provide that the state organ concerned must deal with the complaints responsibly, and that no one may suppress complaints or charges or retaliate against citizens who make them. Finally, it provides that citizens who have suffered loss through the violation of their rights are entitled to compensation.

The National Human Rights Action Plan (NHRAP):

The National Human Rights Action Plan was published in April 2009. It acknowledges that 'China still confronts many challenges and has a long road ahead in its efforts to improve its human rights situation'.^{4[1]} The stated objectives of the NHRAP are, inter alia, to improve laws and regulations that address human rights, and to strengthen 'the protection of civil rights in the

^{4[1]} Page 3.

execution of administrative laws and in judicial practices, and raising the level of ensuring people's civil and political rights'.^{5[2]}

The NHRAP requires that all public and private institutions shall give it 'vigorous publicity' and 'expedited implementation'. Yet, many within and outside of China are not aware of the plan. Some key individuals that we spoke to within academia had not seen the NHRAP. A common view is that the Action plan was drafted to satisfy the UN and international community and there was a skepticism as to the level of implementation that would take place.

Despite the skepticism and the vague language in many places, it is significant that this document was adopted by China's Cabinet and its real worth lies in the ability to test its implementation and the depth of government commitment to the stated principles. But given the fragility of civil society and the enormous challenges NGOs face, testing the true value of the NHRAP is unlikely to take place.

The following aspects of the Plan are particularly relevant to the current challenges of civil society and the legal system:

- The state undertakes to improve supervisory mechanisms for enforcement of law, including a system for accountability where cases are mishandled or where there are unlawful infringements of human rights by state functionaries. Given the reality that good laws and policies are not implemented, this is an important commitment but remains on paper.
- Democratic decision-making through expanded public participation in the formation of laws and policy is promoted.
- The Action Plan provides that 'institutional guarantees for the legitimate rights of news agencies and journalists will be strengthened', consonant with the right to be heard. As repeated elsewhere in the document the right to criticize, comment and publish is subject to 'the law'.
- The rules and laws governing the Internet 'will be improved to promote the orderly development and application of the Internet and guarantee citizens' rights to use the Internet in accordance with the law'.⁶

^{5[2]} Page 13.

- The Action Plan calls for an increase to the content of law and human rights education that takes place in schools and tertiary institutions. The Plan states that ‘scholars from universities and colleges are encouraged to carry out human rights studies’.⁷

As with the issue of supremacy of the Constitution, the rights have not been meaningfully protected. The Action Plan demonstrates the gulf between stated commitments and platitudes by government and the reality that NGOs face. Despite the constitutional assertion of civil and political rights, there is a consistent and forceful opinion amongst the lawyers and NGO representatives that we met that they cannot be seen to be challenging government or else there will be a ‘crackdown’.

Activities of public interest lawyers

On 14th October we participated in a ‘lawyer’s salon’ organized by Korekata AIDS Law Centre which included a range of organizations and individual lawyers who have been using law around HIV/AIDS. It soon became apparent that the legal environment makes litigation extremely time-consuming, costly, frustrating, and in some cases ineffective.

Participants lamented the lack of an independent judiciary. Despite recent reforms proclaiming the rule of law, there is no system of accountability of organs of state. Both the process and ultimate decision of a court may be influenced by the executive.

Some of the difficulties reported by Ms Liu Wei, a lawyer at Aizhixing Institute, include:

- Difficulties in launching a case because of a) cost and b) courts often refuse the admission of cases without any clear pre-determined criteria.

⁶ This is an extremely weak articulation of government’s intent, which suggests that not much will change in relation to opening access to information.

⁷ Again, what the HRAP says is contrary to the experience of those who are attempting to do just that. Recently Dongjen’s attempt to run a course for students from six universities on human rights education, led to three of the student groups being approached by officials from the Public Security Bureau, leading to their withdrawal from the programme.

- ‘Policies’ are adopted in relation to whether some categories of cases should be heard at all – for example, the blood transfusion cases often get refused access to the courts. In some cases such matters are launched ‘in disguise’, where the issue of blood transfusion is only raised during the course of the case.

For example, in the case of cases for compensation for hospital-acquired HIV infections, there is no consistency between courts and provinces as to which cases will be accepted for hearing, whether cases based on very similar facts will receive the same treatment, what amount of compensation will be awarded in the event of a finding in favour of the patient, or indeed whether the hospital will pay the compensation despite the court order.

Obtaining a court order is a slow process. It was reported that not only does the respondent frustrate the process, but that the courts themselves are not keen on moving controversial cases forward. One reported view was that magistrates themselves discriminate against people with HIV and ‘think that the applicant is dying anyway’.

But despite the challenges of the political and legal environment, there are organizations working on HIV and other issues, that continue to battle for the protection of rights in the court.⁸ According to Asia Catalyst: “Lawsuits on blood transmission have only been refused in Henan and Hebei. In other areas, people have successfully sued and won high settlements.” A comparative analysis of social justice litigation in China within the AIDS movement (and on other social issues) is sorely needed.

Sometimes, in spite of the courts, there are victories linked to legal advocacy and litigation. For example, in July 2009 the Insurance Association of China issued a new document requiring insurance companies to include PLHIV and passive drug users into their liabilities in insurance contracts. According to the new document "Specimen Life Insurance Products" from October 1st, 2009, no insurance company may exclude PLHIV or passive drug users from their due

⁸ These include the Korekata AIDS Law Centre www.korekata.org, the Aizhixing Institute www.aizhi.org, the Beijing Yirenping Centre www.yirenping.org, and the Yunnan Daytop Drug Abuse and Treatment rehabilitation Centre www.daytop.com.cn

obligations. Ironically, this victory was as partly the result of publicity around a case brought by the Legal Advocacy Project of Yunnan Daytop Centre which failed in Court!⁹

In addition, where there are successes the result is a vindication of the rights of some individuals without a corresponding shift in policy or broader public impact (such as we would expect in South Africa).

In our view it is important for NGOs to continue engaging the legal system. However we feel that there has to be a bigger (even if long term) strategy for legal reform if such efforts are to be truly effective. In this regard we had meetings with Dongjen and CHAIN to discuss what steps need to be taken, both within a litigation strategy and outside of it, to ease forward a non-aggressive discussion on legal reform. While some NGO members are skeptical about what change is really positive, others with whom we consulted are optimistic (for example Prof Qiu).

The first step is to develop a common understanding of the concept of the rule of law. In order to advance understanding of the rule of law we have suggested to Judge Edwin Cameron that he speaks about the issue when he visits in January.

The Place of Human Rights in the AIDS Response

Because of its political history and the argument that human rights are a 'Western' notion that aims to destabilise China, there is fear and

⁹ 'Insurance Fix a Win for HIV patients', China Daily, 15 July 2009.

According to one report we received a process to look into the discriminatory insurance policies had already been started at SCAWCO following a submission made by UNAIDS. This was before the initial failing of the Yunnan court case and advocacy efforts. "It should be recognized that in China changes do not occur overnight, especially when it comes to changes in policies or regulations, and that often these are facilitated through official processes. In addition, despite a few notable victories in court, these rarely lead to corresponding shifts in policies or broader public impact and so far no NGOs working on AIDS and law are working on advocacy at this level."

misunderstanding about human rights generally and human rights in relation to HIV particularly. Although there is the appearance of freedom of activity civil society activists are aware of activists, such as Hu Jia¹⁰, who have been imprisoned or detained because of their rights work.

The restrictions on human rights activism are in contradiction with the HRAP which states:

“The realization of human rights in the broadest sense has been a long cherished ideal of mankind and also a long-pursued goal of the Chinese government and people. ..

“It is worth mentioning that, since the introduction of the reform and opening-up policy at the end of 1978, China has enshrined respect for and protection of human rights in its Constitution as a major principle of government, and has taken effective measures to promote the cause of human rights, ...”

“Infectious diseases will be brought under control. Endeavors will be made to strengthen the prevention and treatment of AIDS, and the prevention and control of major infectious diseases.”

Neither the HRAP or the Regulations explicitly refer to human rights. However, the 2006 Regulations reflect and respect core human rights principles of:

- ▶ Autonomy –see Art 23 on counselling and testing;
- ▶ Privacy – see Art 38 on disclosure;
- ▶ Equality and Non-discrimination – see Articles 3 & 41;
- ▶ The Right to health – See Art 44 dealing with the ‘Four Frees’;

But despite these provisions we discovered is that these rights appear to be being breached widely. The fact that NGOs do not have an avenue to make their complaints heard properly means that these violations are not acknowledged or addressed.

In the meeting with Prof Wu Zunyou we argued that this situation undermines both the HIV strategy *and* human rights. For example, laws

¹⁰ According to Wikipedia: **Hu Jia was detained on December 27, 2007** as part of a crackdown on dissents during the Christmas holiday season. On April 3 2008, he was sentenced to 3.5 years in jail. Hu pleaded not guilty on charges of "inciting subversion of state power" at his trial in March 2008.

criminalizing commercial sex workers and drug users, put sex workers and drug users in a position in which they often cannot gain access to HIV education, testing, treatment, care and support. According to one person we spoke to a law recently passed by the Chinese legislature prohibiting drug use “gives the police much power to harass drug users, and this Law still requires compulsory detoxification, still denies drug addiction is a chronic illness, that drug users are patients and the only effective way to treat them is medicines, not coercion, nor education.”

Punitive laws that target vulnerable groups combined with the legal difficulties that face NGOs undermine crucial aspects of China’s response to AIDS. China will not achieve the targets it has set itself, or universal access, if people are afraid of HIV testing and if unfair discrimination and denial of health services is not addressed. We would argue that violations of individual human rights also undermine the treasured principle of people’s rights. Control of HIV in the wider population (that is, amongst ‘the people’) depends upon respect for the rights of the individual. In this regard it is important for the Chinese government to accept that ‘the people’s rights’ and human rights are not in conflict; respect and protection of human rights is necessary to achieve people’s rights, particularly when it comes to health.

The Country Response to HIV/AIDS:

The visit we made to China was intense and short. On this basis, we would not presume to assess or comment on the overall Chinese response to AIDS. China’s response is analysed carefully in documents such as ‘A Joint assessment of HIV/AIDS Prevention, Care and treatment in China, 2007’ prepared by the State Council working Committee Office and UN Theme Group on AIDS in China; and the China UNGASS Report, 2008. It is also discussed in a range of academic articles.

Therefore the analysis and recommendations below are based on what we observed and in particular on discussions we held with NGOs, service providers and AIDS activists -- views that do not often make it into official country reports (especially in China). We reproduce observations that were presented at a specially organized meeting on 22 October 2009 with Prof Wu

Zunyou, the Director of NCAIDS, and Sun Jiangping, the Deputy Director. We also reproduce, with permission, the response of Wu Zunyou to each of our observations.

HIV Testing and Counselling:

The 2006 Regulations state:

“Voluntary system on AIDS counselling and testing shall be implemented national-wide” (Article 23).

In particular, Article 38 states:

“People with HIV positive and AIDS patient shall perform the following obligations:

- (1) Accept epidemiological investigation and direction of agencies of diseases control and prevention or inspection/quarantine;
- (2) **Inform** the fact of being infected or suffering the disease to their sexual partner **in time**;
- (3) **Inform** the fact of being infected or suffering the disease to their medical doctor when they come to see the doctor;
- (4) Take necessary precaution measures to prevent others being infected.

People with HIV positive and AIDS patient shall not, on purpose, spread the infection to others by any means.” (Our emphasis)

Despite these provisions, no or insufficient pre & post test counselling was reported by many of the NGOs that we interacted with. Problems of disclosure without consent were also reported. Unfortunately, it is not possible to quantify the size of this problem.

We were also concerned about consistent reports we received from NGOs concerning the implementation of an HIV testing programme as part of a grant by the Gates Foundation.

According to one report:

“the key issue is related to the overall approach of the programme which is based on the assumption that risky behavior is reduced when HIV positive people become aware of their status. Therefore there is a

heavy focus on testing and case detection. The Gates programme emphasizes a comprehensive approach to their prevention programmes in formal literature, but it seems in the field activities are heavily focused on case detection and testing through paying NGOs to find people living HIV and then CDC take over on the follow-up care and support.

For example, NGOs are paid RMB20 for every person they bring in for testing and will receive over RMB 1,000 for a positive person. Also, it has been reported that people testing positive are not well taken care of, the level of personal consent is not good, testing is sometimes carried out by force by help of notifying the police, and that there are many examples of people opting to make money out of getting more people or the same people tested. Many NGOs have been complaining about the Gates programme, but unfortunately nothing has really been documented and no real assessment has been carried out yet.”

These issues were reported to the Director of NCAIDS. His response is summarized in the box below:

We have to balance the rights of people infected with the rights of the uninfected.

Any policy or law needs to protect the majority and there has to be a balance between protecting a few or a majority. Good or bad law is based on how many people you protect – good law protects the majority, no law can protect everybody.

Prof Wu Zunyou gave the example of a survey that showed a large number of discordant couples in Henan. He asked “whose rights are the most important? Some individuals care about their sexual partners, some need disclosure to take place for them.”

In response to the use of the language “in time” in the regulations relating to disclosure to sexual partners he reported that this is implemented differently depending on each personal situation and judgment. For example, in Yunnan a person with HIV must disclose to a sexual partner within one month ‘if not the obligation is upon the health authority to disclose’.

There are different approaches to disclosure. With MSM the policy is to only inform the person who tested ‘because disclosure of MSM’s sexual orientation to family members causes far more harm than disclosure of their HIV status’.

But with heterosexual people there is a tradition in China where family members care for the sick. In the case of plasma donation or blood transfusion victims it is often better to inform the family first ‘and let them break the news’ and give time for the infected individual to cope with.

Prof Wu Zunyou referred to the initiative and commitment of local health agencies.

He raised the problem of the growing number of heterosexual infections. He referred to the 'Testing Campaign' in Henan among plasma donors and former blood recipients, and that some people admitted that they had avoided testing. The challenge for NCAIDS is that since 2004 they have seen on average 2000 newly reported HIV infections every year among former plasma donors etc. This is because during the 2004 testing campaign many people did not want to get tested and even lied that they had been former plasma donors etc. This indicates the high level of stigma around HIV. These newly detected cases were people infected from the early 90s and not necessarily spousal transmission. He also mentioned that the Implementation Protocols to the Regulations provide more detail about implementation of the articles in the Regulations.

These regulations are ambiguous. They appear to create a legal duty to *both* practice safer sex and to inform a sexual partner and doctor.

In an article by Li Li et al¹¹ the authors, who include Prof Wu Zunyou, claim that "laws relating to disclosure are inconsistent", ambiguous and contradictory. They point to a widespread practice in Yunnan Province of informing a person's family first: of "1101 service providers in the study, 49% agreed that family members should first." They conclude that:

"There is an immediate need to re-examine the policies regarding HIV status notification in order to ensure consistent guidelines and procedures for providers throughout China. These guidelines should be culturally sensitive, with the goal of achieving balance between protecting individual privacy and maximizing family and social support for patients living with HIV/ AIDS. The policies and guidelines should be enforced by law and be fully implemented as a standard for medical practice in China."

However, our interpretation of this regulation is that it does not sanction routine involuntary disclosure by health professionals, and indeed – according to the Regulations - 'legal liabilities' should arise from misconduct.

Access to treatment:

According to Article 44 of the 2006 Regulations:

¹¹ To Tell or Not to Tell: HIV Disclosure to Family Members in China, *Dev World Bioeth.* 2008 December ; 8(3): 235–241.

“The people’s governments at the county level or above shall take the following measures on AIDS prevention and treatment, care and succor:

- (1) Freely to provide drugs of anti-retro-virus to rural AIDS patients and urban AIDS patient with economic difficulties;
- (2) Properly to provide free or low-cost medicine to rural and urban HIV/AIDS patients who are in economic difficulties during the treatment of their opportunity (?) infections;
- (3) Freely to provide counselling and primary test to the people who are voluntarily received these services;
- (4) Freely to provide counselling and treatment to HIV infected pregnant women for the purpose of preventing the mother-child AIDS transmission.

This policy is known as the ‘Four Frees and One Care’. Again, however, according to reports that we received the policy and reality are different things.

In meetings with people living with HIV and their networks they reported:

- Some people being refused treatment;
- Problems with adherence to treatment;
- The unaffordability of medicines for opportunistic infections and the fact that such medicines are not provided free;
- A growing need for, but lack of access to, second line treatment. It was reported to us that the Ministry of Health has begun distributing second line regimens in select regions, reportedly Henan and Yunnan. However there are reportedly problems with implementation. Effective access to second line treatment is – for obvious reasons -- considered a priority issue by activists.

There were also reports of people being initiated late onto ARV treatment.

These issues were reported to the Director of NCAIDS. His response is reported in the box below verbatim:

People are starting treatment late, because they do not want to be diagnosed with HIV.
There is a big problem with stigma.
The Four Frees and One Care does not include free treatment for opportunistic infections (OIs). The government’s dilemma is not to create imbalances with other diseases where treatment is not free. Treatment for OIs can be covered by health insurance.

The obligation to treat OIs is placed with local government; in Henan treatment for OIs is covered by the Provincial Government because of acceptance of responsibility due to plasma collection and blood transfusion.

Prof Wu Zunyou also pointed out that even ART is not free if people are able to afford it in urban areas.

In a recent article¹² it is recorded that the baseline median CD4 cell count was 118 and that 81% of patients had at least 1 baseline symptom category.”

The article pointed out that:

“the unacceptably high initial mortality rate after treatment initiation emphasizes the need to begin treatment sooner, because of the significant association of low baseline CD4 cell count and baseline symptoms with mortality. The national treatment program needs to encourage earlier HIV treatment through increased screening and work to reduce stigma and discrimination, which deter persons from being screened and accessing care.”

‘HIV Infection among Vulnerable Groups’: Injecting Drug Use:

Injecting drug use is one of the major drivers of the HIV epidemic. It accounts for nearly 40% of existing HIV infections. In recognition of this China has broken ground internationally by adopting a policy to provide methadone maintenance to drug users as well as needle and syringe exchange programmes(NSEP).

Article 27 of the Regulations requires health authorities “to take active and well prepared measures in the implementation of drug maintenance treatment for drug abusers, and other planned interventions.”

In a November 2008 presentation to Mark Heywood, for example, Prof Wu Zunyou reported that there were 901 NEPs serving more than 38,000 IDUs. He also reported 503 methadone clinics, serving 97 554 people. During this visit, we visited San Ye Cao, a NSEP in Chengdu, and previously I had visited a Methadone clinic in a district of Beijing. At both visits I was struck by the commitment and professionalism of the staff.

On paper this is a bold and ambitious programme. In practice, however, a number of serious problems were reported to us. These can be summarised as:

¹² Five Year Outcomes of the China National Free Anti-Retroviral Treatment Programme, F Zhang et al, AUG 18 2009, *Annals of Internal Medicine*; 8/18/2009, Vol. 151 Issue 4, p241-251.

- ▶ A feeling that RMB 10 user fees for MMT extracts a high price from IDUs and is detrimental to the programme's objectives;
- ▶ Insufficient capacity to accept meet the demand (in Chengdu it was reported to us that the MMT clinic to which the NSEP referred people was 'full up' and unable to accept new clients).
- ▶ A need for independent evaluation & methadone quality control;

These issues were reported to the Director of NCAIDS. His response is reported in the box below:

There is flexibility in the way the policy is implemented. No one model fits all.

Prof Wu Zunyou agreed that RMB 10 is not affordable to a considerable number of drug users. 'We have now told clinics to reduce the price or provide MMT free for people with HIV. If your family is below the poverty line you can get it free or at a discount.'

However Prof Wu Zunyou stated that 'Free MMT treatment does not work' and cited the example of Zhijin county in Guizhou Province which had provided MMT free but after a year the results showed that it had been a failure.

He also reported that there is a problem with the general public asking 'why use tax money to support drug users free'; Central government have the capacity to provide methadone free, but if we do many other issues will be raised.

Pro Wu Zunyou said he would check on reports that the MMT clinics in Chengdu do not have capacity for new clients. He said that the district CDC should apply to open another clinic. 'There is no barrier to this'.

Given the centrality of injection drug use to the AIDS epidemic in China, it is important that government and civil society collaborate together to ensure effective HIV risk reduction among drug users. According to Michel Sidibe, the Executive Director of UNAIDS, this is a priority. In a recent public letter to civil society leaders (9 November 2009) he stated:

"The UNAIDS Outcome Framework clearly specifies that protecting drug users from HIV through effective harm reduction approaches and removing punitive laws, policies, practices, stigma and discrimination, which impede effective HIV responses are two of UNAIDS' nine key priorities for coming years. The Outcome Framework also places special emphasis more broadly on the protection of human rights."

Unfair Discrimination in Employment:

According to the 2006 regulations (Article 3) “Law Protects the legal rights of people living with HIV and AIDS patients and their relatives. It includes rights of marriage, employment, assessment of medical treatment.

But discrimination against people living with HIV is prevalent, according to participants in the lawyer’s salon. We were informed that PWAs cannot be employed in government office, that the Regulations on Prevention and Treatment are used to discriminate against PWAs – for example, by requiring people who work in a ‘public location’, such as a waitress, to have a health certificate in order to do so and that private companies discriminate against employees and there is no recourse to a court for relief.

We also heard a number of anecdotal reports of unfair discrimination in access to employment, particularly from PLHIV groups that we met with. This is clearly contrary to both the Constitution and the 2006 Regulations.

Prof Wu Zunyou said that the regulation is clear that there should not be discrimination. The problem is with the implementation of the regulation.

Summary of Our Recommendations:

On World AIDS Day 2009 the Secretary General of the United Nations issued a statement saying the following:

On World AIDS Day this year, our challenge is clear: we must continue doing what works, but we must also do more, on an urgent basis, to uphold our commitment to reach universal access to HIV prevention, treatment, care and support by 2010.

This goal can be achieved only if we shine the full light of human rights on HIV. That means countering any form of HIV-related stigma and discrimination. It means eliminating violence against women and girls. It means ensuring access to HIV information and services.

I urge all countries to remove punitive laws, policies and practices that hamper the AIDS response, including travel restrictions against people living with HIV. Successful AIDS responses do not punish people; they protect them.

In many countries, legal frameworks institutionalize discrimination against groups most at risk. Yet discrimination against sex workers, drug users and men who have sex with men only fuels the epidemic and prevents cost-effective interventions. We must ensure that AIDS responses are based on evidence, not ideology, and reach those most in need and most affected.

Below is a summary of the recommendations that arise from our observations and occur in this report.

To UNAIDS:

UNAIDS occupies a very important strategic position in China. It is able to talk to government. It is also in touch with, and at the centre of processes involving, civil society. It is able to facilitate and open spaces between government and civil society and should continue to do this. In particular:

- 1) The AIDS and human rights forum, which will be launched in January 2010, provides an opportunity to create a formal space to raise and address human rights issues. Ensuring meaningful civil society representation in this forum is essential.

- 2) UNAIDS should be supported and commended for its efforts to support the development of civil society networks. It is a valuable space to host further meetings for discussion about the concept of human rights for China, democracy and role of civil society.
- 3) However we caution that some organizations expressed discomfort in working with UNAIDS – either because they feel that UNAIDS is too close to government, or that UNAIDS tends to take the lead in initiatives rather than merely facilitating. Whether this is true or not, the perception is real and should be dispelled.

To Civil Society Organisations:

Although it is still relatively small and new to the politics of post 1949 (and 1978) China, civil society working on AIDS, gender and sexuality in China has developed great skill and potential. Institutions such as the CCM Working committees and the AIDS and Human Rights Forum could be developed to create greater unity and more effective advocacy. We would recommend that:

1. There is a need for facilitated discussion between the major civil society networks (CAP+, the CBO Network) and organisations (Aizhixing etc) on the how to understand and argue for human rights in the political context of China.
2. Reports and documents produced by NGOs need to be of a high standard and better supported by evidence in order to gain the respect of donors and government.
3. The divisions and distrust between different organizations and leaders that (we believe) have essentially the same vision hold back civil society as a whole and weaken its influence on NCAIDS and the CDC. It should be possible for civil society organizations to articulate a common vision, build consensus and agree on priorities and actions. The idea of a Civil Society Charter on HIV and AIDS in China could be explored further.
4. Civil society organizations working on AIDS would benefit from establishing stronger links with other issues. For example, the NGOs that

engage with the law could benefit from strong links with the labour organizations that have had some successes in their litigation. Real partnerships can be developed around particular issues rather than loose networks. Civil society as a whole needs to be conscious of the need to consolidate and deepen its position in Chinese society and to prevent its suppression. This can be assisted by having a stronger international footprint.

5. Research and discussion should begin on law reform. Stronger links can be made with progressive academics and academic centres that are working on this issue. Because the rule of law is not established yet in China (although there is law and rule through certain law) litigation and legal advocacy do not have the same outcomes as, for example, in South Africa. Nonetheless, as we have seen through the work of Aizixhing, the Legal Advocacy Project and Korekata, litigation combined with advocacy can have benefits. In this respect we believe that more regular 'Lawyers Salon' between organizations and individual lawyers working on law would have definite benefits and outcomes.

To the Chinese Government and NCAIDS:

Many of our recommendations to government are contained in the section above and relate to specific improvements that can be made by NCAIDS to the AIDS programme, based on recommendations that are being made by civil society in particular. But in addition we would recommend that:

1. NCAIDS and the Ministry of Health work meaningfully with UNAIDS and civil society on the AIDS and Human Rights Forum and provide leadership to show that issues will be openly and fairly discussed and acted upon.
2. The State Council Working Group on AIDS (SCAWO) be asked to endorse independent monitoring of the AIDS programme, particularly interventions such as the roll out of second line ARV treatment and the provision of MMT and NSEP, where there have been questions raised about implementation, quality, access to and affordability of essential services.

3. That new regulations governing civil society are expedited and make registration easy and affordable, and recognize the role of civil society in relation to AIDS and other major social challenges that face China.
4. That the National Human Rights Action Plan be more actively publicized and that harassment of activists who are promoting human rights as called for by the HRAP stop.
5. That harassment of patriotic and committed AIDS activists who are seeking to focus attention on the human rights dimensions of the epidemic be stopped. It would be to China's advantage if those currently in prison, including Mr Hu Jia, were immediately released and pardoned.

To International Donors:

Chinese civil society organizations are desperately short of funding. Their existence and ability to function is important specifically with regards to AIDS as well as more generally in relation to the development of rule and law, democracy and respect for human rights in China. We recommend that:

1. There be a significant increase in core funding to civil society organizations; and
2. Donors should not be prescriptive to NGOs, but target funding to support implementation of the agreed priorities of the Chinese AIDS plan, and particularly support organizations that are working to protect and promote the human rights of marginalized, criminalised and vulnerable groups.

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