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On the Politics of Representation: HIV/AIDS and Development in China

Working with HIV/AIDS in China requires understanding the many diverse voices that have something to say about the disease and the people affected by it. Understanding how non-governmental organizations (NGOs), groups that often function as representatives of the many voices involved in the world of AIDS in China, operate in relation to each other and other political entities requires an examination of the negotiations that these groups make when they talk together about HIV/AIDS. Drawing in part on anthropologist Sandra Hyde's framework for thinking about conceptualizations and representations of HIV/AIDS, this report looks at AIDS NGOs in China, their relationships and negotiations with each other, and their negotiations with other groups, most notably the Chinese government.

The story of AIDS in China, according to the country's own government, might be said to have begun in 2001. That is the year the government officially recognized the disease as existing in China and began combating it. Publishing a document entitled "China's Action Plan for Reducing and Preventing the Spread of HIV/AIDS (2001-2005)," China's Center for Disease Control (CDC) launched its coordinated efforts against the disease.

Coming from a different perspective, the country's numerous non-governmental organizations might argue that the story of AIDS in China begins in 1994, the year that Wan Yanhai founded Aizhixing. Aizhixing, an organization started and run by Chinese people, was the first NGO of its kind to work with and talk about HIV/AIDS in China.

Known as “local NGOs,” these organizations have become increasingly common in the last decade, particularly since the government’s acknowledgement of HIV/AIDS.¹

Local NGOs operate in regions all over China, with the greatest concentration in Beijing, and different groups tend to cater to different populations of people living with HIV/AIDS (PLWA).² Populations include injection drug users (IDU), male and female sex workers, men who have sex with men (MSM), and recipients of illegal and unclean blood transfusions. In addition to local NGOs there are also “government organized non-governmental organizations GONGO’s. The government also runs programs of its own under the auspices of the CDC. To complicate the matter even further, this array of groups that operates out of China is joined by countless international organizations, groups ranging from private sector actors such as Bayer to foundations such as the Ford and Clinton Foundations. Also very important is the role that the UN, including UNAIDS and UNCHINA, plays in this mish mash of players in the Chinese AIDS NGO scene.

As this variety of organizations designed to assist PLWA demonstrates, the precise nature of AIDS in China is difficult to pin down. Anthropologist Sandra Hyde argues, “...HIV/AIDS becomes culturally inhabited at each site where it appears on the map” (Hyde 2007: 2). In other words, all of these organizations are at once culturally discreet entities, independent nodes with their own conception of the disease, and, at the same time, part of a unified group.

NGOs tend to be born out of specific, culturally discreet, affected populations that they, the organizations then work with and represent. For example, the organization I

¹ For a very well-organized directory of different organizations see <http://www.china-aids.org/index.php?type=directory>. Also <http://www.china-aids.org> is a varied and valuable resource, particularly for the English speaker.

² For a map of distributions of PLWA and NGOs see <http://www.china-aids.org/map.php>

worked with from June 4, 2007 to August 1 of the same year, Arc of Love (AOL), was run by and catered to men who have sex with men living with HIV/AIDS. The organization technically qualifies as a support group, but operates in a variety of capacities. Running their office out of a hospital, they are able to visit patients with HIV/AIDS. People throughout the city are able to come in and receive support. In addition to general emotional support, AOL also provides PLWA with information, including information regarding what networks of people and organizations to tap into, how to apply for medical assistance, seek legal representation &c.

Individuals at AOL spend much of their time working to secure funding, often from large international NGO's. Much of their activity also involves networking, going to conferences and lunches, meeting people and other organizations. Conferences in particular are of great importance in the AIDS NGO world. They are a common place and important forum for NGO's of different kinds to get together and discuss HIV/AIDS in China from a variety of perspectives.

Some conferences address topics of law, for example. They may be run by lawyers and focus on policy in China related to HIV/AIDS. Alternatively, a conference might discuss the role of advocacy groups in shaping AIDS-related legislation. An altogether different conference might address an aspect of the disease related to medicine. This kind of conference may address the side effects of Antiretroviral medicine (ARV) and the intended function of the drug. A conference like this would be particularly important for representatives of organizations from certain rural regions of China where it is not uncommon for PLWA to terminate their medical treatment because in the short term the side effects of the ARVs are more severe than the disease itself. These

representatives would then be in a position to return to their native province and hold conferences with other organizations there in order to disseminate this information about ARV treatment.

In other words, the HIV/AIDS conference functions as a vehicle for conceiving of HIV/AIDS in different ways. This brings us back to Hyde who writes about approaching the disease “in terms of the circulation and movement of conceptualizations of the disease across various boundaries...” (Hyde 2007: 3). Hyde's work combines fieldwork among female sex workers with extensive interviewing with government representatives, thereby viewing alongside each other two conceptualizations of the disease that are often characterized as being in opposition to each other. In applying the idea of different conceptions of the disease to NGOs, one can examine and flesh out the fissures between conceptions of the disease, different culturally inhabited nodes, that are too often lumped together and portrayed rather monolithically in opposition to a drastically different perspective, such as the government.

Also very important in Hyde's analysis of HIV/AIDS is the role of representation and way in which the disease is constituted through its myriad representations. She writes about her focus on “...how people simultaneously represent, understand, and respond to epidemics through writing about practices that emerge in everyday life” (Hyde 2007: 13). Returning to the world of NGOs, one might view the medical conference described above as a representation of HIV/AIDS as a fight against ignorance, for example.

Evidence supporting this representation of the disease can be found in discourse about raising awareness of HIV/AIDS. Much of the conversation among NGOs about combating AIDS focuses on fighting the stigma against it. In my interviews I encountered

stories about patients in hospitals refusing to share rooms with AIDS patients. Less commonly, nurses sometimes refuse to work with AIDS patients or even admit them into the hospital. One interviewee told me an anecdote of PLWA being hired as debt collectors, forcing borrowers to make payments under the threat of getting infected. Evidently, greater knowledge of the HIV/AIDS can have a tremendous impact on both the way in which unaffected communities conceive of and treat PLWA and also the way in which PLWA think about and deal with their disease.

One final example that emphasizes the significance of the representation of HIV/AIDS as a fight against ignorance can be seen in the organization CHAIN.³ This group is primarily an information service. Rather than working with PLWA in the direct way that a support group might, this organization channels most of its resources into the expansion of its thorough Chinese language website and conference packets of HIV/AIDS literature. Many NGOs, regardless of their specific orientation, hold in high regard and rely on CHAIN as a important information source. The organization therefore serves as a good example of how the NGOs, which are to some degree culturally discreet nodes, overlap and come together in sharing resources. The UN holds a similar position in being highly regarded source of authoritative information. The does its own research, whereas CHAIN does not. However, CHAIN was started and is operated by Chinese people.

Wan Yanhai is a Chinese man for whom a representation of AIDS as a fight against ignorance is unsuitable; rather I am going to argue that he represents the disease

³ <http://www.chain.net.cn> The English version is under heavy construction and at the time of this report contains almost no resources at all, but the Chinese version is very thorough.

as a path toward better political practices for China. Wan Yanhai is one of China's most famous activists. He started Aizhixing, China's first local non-government organization, in 1994, seven years prior to the government's official acknowledgement of the disease's presence in China. Journalist Albert Chen describes Aizhixing as "a case of a social organization that attempts to be as independent of the state as possible" (Chen: 2003). This independence, however, has gotten Wan into trouble over the years. One simply has to Google the activist's name to find not only his Wikipedia page but also countless articles from Western news sources about his frequent "disappearances." On a number of occasions, and most recently in November of 2006, Wan has been picked up by the government and held for periods of time ranging from days to weeks.

In 2003, Wan spoke in front of the United States Congress at an event called "China's Mounting AIDS Crisis and the Proper US Response: a Roundtable Discussion."⁴ His contribution to the discussion consisted of a brief prepared speech that outlined what he saw as two of the most pressing issues in the then-current fight against HIV/AIDS, information transparency and public participation. Wan addresses the need for the Chinese government to more public with its information and the need for Chinese people, both affected and unaffected communities, to become more actively involved in the struggle against the disease.

Wan concludes his speech with the following remarks:

"What I want to emphasize is the importance of informal groups, because of the difficulties of getting official registration for labor rights organizations, gay/lesbian rights organizations, women's activities, organizations for immigrant workers and some religious groups to get involved in the work... I want to thank the people in the United States and the U.S. Government for helping Dr. Ma

⁴ For a full transcript of the roundtable discussion see http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=108_house_hearings&docid=f:91218.wais

Shiwen to be released, and also to ask for human rights protection in China's AIDS crisis.”

In an interview I had with Wan this summer I asked him to readdress the central points that he originally brought up in his speech at the roundtable discussion. His response had three components, the third of which I will set-aside for now. His response began with the assertion that the government has grown more transparent with its information but that it still held back on some very important matters, such as how they spend money with regard to the HIV/AIDS. The second part of the response stated that a great improvement in public participation could be seen in the large number of HIV/AIDS NGOs that had sprung up in the last four years. Continuing with this train of thought he added that in fact the abundance of new NGOs has generated new problems. According to him, organizations are operating with each other in a very unprofessional way and need to develop more democratic practices. For example, a lack information transparency has now become a problem of the NGO's as much as of the government.

Here we see Wan representing HIV/AIDS as a path toward better political practices. This rather imprecise name for his representation of the disease might also be referred to as a path toward democratization or a path toward the development of civil society. He expressed disappointment for what he characterized as a lack of democratic principles among NGOs, a state of affairs that he perceived as especially disheartening because of his view of AIDS in China an opportunity that if used correctly could lead to real improvement in China's political climate.

To illustrate the problem that Wan saw NGOs as having, he described an important conference that took place in Wuhan in December 2006. The conference was held to elect a representative of local Chinese NGOs for the Global Fund Country

Coordinating Mechanism (CCM). The Global Fund is a financing mechanism composed of governments, organizations, actors from the private sector, and individuals from affected communities that distributes enormous sums of money around the world to combat tuberculosis, malaria, and AIDS.⁵

The conference at Wuhan, which was also an election, lasted for three days and was by most accounts quite successful. The only snag however fell at the end of the final day when one individual who ran an NGO got on stage with a microphone and erupted into a polemical attack against the leader of another NGO with whom the speaker had ideological differences. Relaying this story, Wan emphasized the degree to which it demonstrated a lack of democratic principles and made bad use of the opportunity that AIDS afforded Chinese people seeking political change.

Wan Yanhai was not the only individual with whom I spoke who represented HIV/AIDS as a path toward better political practices. Another man I interviewed who ran an NGO described AIDS as primarily important insofar as it strongly contributes to the development of civil society. This representation can also be seen in a publication by the organization Human Rights Watch entitled “Restrictions on AIDS Activists in China,” that asserts that the relations between the government and AIDS NGOs are “significant not just because of its potential impact on the country’s AIDS epidemic, but also because it sheds light on the government’s tolerance for the growth of civil society in general” (HRW 2005: VII).

Still others do not subscribe to this representation of the disease at all. One interviewee understood this reasoning and even identified some organizations, including

⁵ For a list of the CCM members and a robust labyrinth of information, see <http://www.theglobalfund.org/programs/CCMMembers.aspx?CountryId=CHN&lang=en>

Aizhixing, as having a particularly “philosophical” bent, but did not believe that HIV/AIDS was concerned with the political development of China. She instead believed that the AIDS movement was primarily concerned with helping provide for the sick and educating the healthy so as to keep them from getting sick.

Turning away from different representations of HIV/AIDS, we now examine the process of representation, namely speech about AIDS. Because for a long while AIDS could not be spoken of in China, and because the list of sensitive topics that require Chinese people to speak warily is quite long indeed, a good portion of ink has been spilled on the topic of speaking about AIDS.

Nick Young is a British journalist who began living in China in the nineties. Operating a periodical called *China Development Brief*, Young constructed a team of Chinese people to report on matters to do with development in China. In a scholarly article for a book on philanthropy in China and India, Young states, “So long as they do not articulate political opposition to Communist Party rule, independent organizations are able to address quite sensitive issues, and the range of issues they do address is becoming steadily wider and more adventurous” (Young 2004: 57).

In the context of HIV/AIDS NGOs this may mean not only that organizations can speak with greater liberty, but that more organizations, each bringing with it into the public sphere its own representation of AIDS, the representation itself functioning as a unit of speech. As an example, maybe organizations that cater to MSM are able to be more open about the relationship between homosexuality and AIDS, or organizations that cater to male prostitutes, known in China by the English term “money boys,” are able to develop. Furthermore, Young’s claim emphasizes an important point about AIDS speech,

and therefore the representation of AIDS, in China, namely the way in which all public AIDS speech is engaged in a fragile conversation with the government. This conversation, as can be seen by Young's statement, consists of certain rules and must be conducted with caution.

Technology also plays a large role in the production of AIDS speech in China. Scholar Haiqing Yu writes about technology and AIDS speech, describing new media such as TV, the internet, and instant messaging, as a "privatized public space to exercise citizenship in urban China" (Yu 2007: 53). Yu considers spaces like the Internet public, insofar as they are easily and widely accessible, and at the same time private, insofar as they possess some degree of anonymity. These spaces allow people to get together and express things they would not be able to express in another setting. A sense of community is developed as people express themselves, all the while remaining fundamentally anonymous individuals. Also, this anonymity impacts, and potentially disrupts, the way in which speech about AIDS exists in conversation with the government.

Many individuals involved in AIDS NGOs have blogs, including Wan Yanhai.⁶ Blogs are an example of a new media that is often not anonymous. One anecdote relayed to me in an interview exemplified the idea of technological speech about AIDS constituting a conversation with the government. An NGO leader put a message on his blog that a government monitor found unacceptable in the next day had been removed. The man made slight revision to the material and reposted it on his blog. Afterward, it

⁶ I spoke with one anthropology student working toward her dissertation in Beijing who devoted considerable time and energy to keeping up with the blogs of AIDS NGO leaders. For Wan Yanhai's blog and an adorable photograph, see <http://blog.sina.com.cn/aizhixing>

stayed. In this example we see what constitutes a conversation in a very straightforward way. A man makes a statement, undoing the statement is itself a response and a statement of its own, and the original statement's revision constitutes the end of the conversation. One can see here the organized, seemingly rule-abiding nature of the conversation between the two parties.

Another anecdote from an interviewee emphasized even more strongly the importance of playing by rules in the conversation with the government that one engages in when producing AIDS speech. A man was going to have a conference. He advertised the conference as being related to one topic, but, in spite of his knowing that government officials would attend the conference, he intended to actually conduct the conference about an altogether different and considerably more politically sensitive topic. When I asked him how it was that he knew he would be able to do this, he replied that "there are things that you can say but not do and things that you can do but not say."

In the previous examples, individuals have successfully maneuvered through a conversation with the government while engaging in HIV/AIDS speech. Other times, however, an individual can push his end of the conversation too far and suffer the consequences. Ark of Love, for example, has had its on-line forum shut down a number of times.⁷ More severely, in the summer of 2007 Nick Young's *China Development Brief* was closed down. Officials came to his office and began questioning people. Ultimately Young was accused conducting "unauthorized surveys." Upon trying to reenter China in October, he was turned away under an article of the Immigration Law that addresses

⁷ For a piece (in Chinese) on Radio Free Asia about Ark of Love's web forum getting closed down: <http://www.rfa.org/mandarin/shenrubao/2007/10/09/aizhifangzhou/>

“Foreigners considered to be persons who might endanger the security of the State or the social order of China...”⁸

To explore from a different angle the complexity of the conversation with the government that AIDS speech constitutes, I return now to the third of three components of Wan Yanhai’s reappraisal of the topics he addressed in his speech at a roundtable discussion with the US Congress.⁹ He described the problem of human rights as still very difficult to talk about in China. This response is of particular interest because as the excerpt of his speech provided in this report indicates (see pg. 6 above), his only mention of human rights comes through as an after thought, occupying the latter half of his very last sentence. This may be the result of his having forgotten the exact contents of his speech, but it more than likely provides a clue into Wan’s cautious approach to his speech about HIV/AIDS, particularly in a highly public and politically charged setting such as a roundtable discussion the Congress of the United States.

Finally, one can also find cues from the government’s side of the conversation indicating their perspective with regard to speech acts, and therefore representations of HIV/AIDS, from parties such as NGOs. The Center for Disease Control’s “Action Plan” outlines “Implementation Principles for the Action Plan” the first of which states, “The government has primary responsibility, but participation from society at large must be strengthened.” Here we see the double standard that is responsible for the fragility of the conversation the AIDS speech constitutes, the government's primary assertion that they

⁸ For information about this and all of their previous work, a tremendous resource, see <http://chinadevelopmentbrief.com/>

⁹ To review, see page six of this report.

are going to be in charge is set up against their secondary commitment to being in dialogue.

What impact then does such a wide diversity of representations of HIV/AIDS, and the cautious manner in which they must be constructed and spoken, have on the AIDS movement? Looking back to the conference at Wuhan, was that group too disorganized and unable to focus or operate “democratically” because of its many disparate voices, or alternatively was the group able to summon a more resounding roar than it would have been able to do if it had been only a smaller, more ideologically unified presence. Wan Yanhai's evaluation might be a discouraged one, arguing that the multitude of voices is more complicated than the people involved are currently able to deal with. On the other hand I spoke with other individuals who were much more optimistic and believed Wuhan to be the single most important event to happen in the AIDS world in China since the government's recognition of the disease.

The multitude of voices, of representations of AIDS, can be seen as either a weakness or strength, and as Wuhan demonstrates, the same event or example can be interpreted to reveal both. Different representations of the disease are constantly developing, revealing myriad semi-discreet cultural nodes that overlap and merge as new nodes are born. The conversations that people engage in as they continue producing AIDS speech will continue to shift. Whether one is to privilege a notion of AIDS as a path toward democratization or as an opportunity to help the sick, representations continue to be born from the same common source, namely the disease itself.

Relevant Terms:

AIDS- acquired immune deficiency syndrome

ARV's- antiretroviral drug (HIV/AIDS treatment)

CCM- country coordinating mechanism

IDU- injection drug user

GONGO- government organized non-government organization

HIV- human immunodeficiency virus

MSM- men who have sex with men

NGO- non-governmental organization

PLWHA- people living with HIV/AIDS (alternatively PLA PLHA PLWA &c.)

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