The Transnational Origin of a Local Response to HIV/AIDS in Henan Province

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For several years now, at a time when Henan remains one of the areas of China most heavily affected by the HIV/AIDS virus, peasants in several of the worst affected villages have supplemented the official policies and strategic approaches to deal with its spread by progressively mobilising and organising their own local measures to deal with the social challenges that AIDS imposes on rural communities. This article is particularly concerned with the transnational origin behind this local mobilisation.

The social, political, and epidemiological context of the mobilisation

The commercial blood collections at the source of the epidemic

In the 1980s and 1990s, many villagers in Henan Province as well as other provinces (Anhui, Hubei, Hebei et al.), under the twin pressures of poverty and official exhortation, sold their blood at collection points organised by the local authorities. (1) These authorities, who paid them 50 yuan for each donation, viewed such measures as a way of enriching the peasants while also meeting the need for blood, the importation of which had been forbidden since 1985, largely out of fear of HIV. (2) Massive numbers of poor villagers turned out to give their blood several times a week in exchange for a pittance that enabled them to feed their families, pay their taxes, or provide for their children’s education. However, these blood collections were carried out under minimal sanitary conditions. The syringes were reused, there was no system for tracing the blood bags, and when all the blood had been mixed together and put through a centrifuge to extract the plasma, it was re-injected into the donors. This blood was then sold on to the provincial hospitals and clinics, or even beyond, without any testing for the presence of HIV.

Despite the fact that the presence of HIV in the blood collected in this way was discovered by the Henan authorities in 1995, and the villagers themselves were astonished at the increasing number of deaths and illnesses around them (some even questioning local officials about the prevalence of this “unknown” disease (3)), the provincial and local authorities decided to conceal the truth, and knowingly continued with the profitable trade in blood at the expense of the health of millions of Chinese.

In 1996, Gao Yaojie, a gynaecologist working in a hospital in Zhenzhou, the provincial capital of Henan, discovered HIV in a peasant woman who had given blood several years earlier at a rural collection point. Aware that this case represented the tip of an iceberg, Dr. Gao decided to launch a preventive campaign at her own expense, using explanatory
leaflets and a book that she compiled, in order to inform as many Henan residents as possible of the risks they were running through their paid blood donations. At the same time, she also gave financial support to several villagers and orphans affected by the disease. Yet the Henan authorities maintained their silence, denying the presence of AIDS in their province, and trying by all possible means to prevent Dr. Gao and her team of helpers from continuing with their preventive work in Henan, and specially from mentioning the situation in public. It was particularly after the year 2000 that a certain amount of information about the HIV/AIDS situation in Henan Province came to light. In October of that year, Dr. Gui Xian revealed that out of the 155 blood samples he had secretly collected in Shangcai County, where the sale of blood had become commonplace, 65 percent had tested positive for HIV. Also, China News Weekly revealed that in several villages in that county there were families who had lost members to AIDS. For its part, the international press revealed that a doctor from Beijing, who had inspected a number of rural hospitals in Henan without permission, had discovered an abnormally high number of HIV infections, and that the village of Wenlou in Shangcai County had experienced 800 deaths from AIDS in two years.

International governmental organisations and NGOs, as well as some prominent figures in Chinese medical circles and other concerned groups, paid close attention and alerted the central and provincial authorities to the urgent need to respond to the situation in Henan if they did not wish to face an HIV/AIDS epidemic spreading throughout the whole of China. At the beginning of August 2001, in order to clarify the situation in Henan, the central government sent in a team from its working group on the prevention and treatment of HIV/AIDS. They concluded that “illegal” blood collection centres were the main source of the widespread propagation of HIV among paid blood donors. A few weeks later the Ministry of Health officially acknowledged, for the first time, that villagers from some provinces in central China had been infected by HIV after selling their blood in the collection centres, and that drastic measures needed to be taken against the trade.

The extent of HIV infection in Henan and its social consequences

Whereas in 2001 the central authorities had very little information about the spread of HIV/AIDS in Henan, in 2002 they stated that since its discovery in the province in 1995, there had been 6,524 officially registered cases of HIV, out of which 1,940 had developed into AIDS. Yet in 2003, when it was clear that the whole of China had been affected by the trade in blood, some experts in epidemiology estimated that there were actually 35,000 people in Henan who had tested positive. In 2004, the central health authorities declared that they had diagnosed 16,000 HIV cases in Henan, but they also acknowledged that this represented a minimum number, since many blood donors had not been traced. In the same year the reality of this situation was confirmed by a study concluding that 25,036 people in Henan had contracted HIV, and that 11,815 of them had gone on to develop AIDS. It also established that, depending on the county concerned, between 8 percent and 20 percent of those who had sold their blood had been infected. In 2005, following a huge official tracing exercise among Henan’s 100 million inhabitants, the Chinese Ministry of Health registered 29,337 cases of HIV, which included 16,456 cases of AIDS. Out of those who tested positive, 90 percent were former blood donors and 98 percent were peasants. By the end of 2006, according to the Chinese government, the number of HIV cases in Henan stood at 35,232, out of whom 21,828 had AIDS and 75 percent had given blood at least once.

Yet these figures are in reality vast under-estimates, largely because of the extreme difficulty in carrying out tracing procedures among the peasants in Henan. Given the wide

12. “More HIV cases expected in Henan,” China Daily, 29 June 2004. This under-estimation could be explained by the example of the town of Zhumadian (Henan), where only 30,000 of the 74,800 former blood donors were traced.
extent of the blood trade and the length of time in which the risk of HIV infection was concealed from donors and recipients, a far more probable estimate of the number of infected people in the province would seem to be between 370,000\(^{(16)}\) and 1 million, a figure proposed by some Chinese epidemiologists in 2002 and supported by the WHO at the time of their visit in 2003.\(^{(17)}\) Although it is still difficult to assess the exact extent of HIV infection in Henan, there are many who recognise that the official Chinese statistics are very far from reflecting the true level of infection in the province. Here I would just take from the official statistics the decline (from 90 percent to 75 percent) in the proportion of blood donors among all those who tested positive in Henan between 2005 and 2006. This trend clearly shows that since 2006 HIV has no longer been restricted to blood donors but has started to spread among the general population, while remaining concentrated in the rural areas (90 percent) and mainly among native inhabitants aged between 30 and 50 (70 percent).\(^{(18)}\)

But beyond the statistical data, HIV/AIDS remains above all a personal disaster for tens of thousands of peasants and their families, whose life even before the AIDS epidemic was already extremely hard in many respects (such as poverty, very restricted access to primary health care, scarcely any civil rights, etc.). Three main consequences related to the epidemic have quickly come to light: far-reaching family break-up, increasing levels of impoverishment, and a far higher level of social discrimination.

By infecting or killing one or even several members of a family, the HIV/AIDS outbreak has profoundly disrupted the family unit, which normally consists of grandparents, parents, and a single child. This disruption of the family structure is particularly serious when both parents are at an advanced stage of AIDS, or when it has killed them, or when the surviving parent decides to migrate in search of work. In these circumstances, it is the child and the grandparents, if they are still alive, who bear the brunt of the disease. Grandparents are left taking care of their sick child or his offspring, if the former has died, which means they can no longer rely on financial and material support from their own child, and that they must return to work to support both him/her and the grandchildren. In this way, HIV/AIDS threatens to undermine the whole organisation of peasant family life, structured as it is around the filial piety that plays such a major role in the life and well-being of the older generation. As for the orphans left by one or both of their parents, they are entrusted to their grandparents or, when circumstances dictate, to other close relatives, or are simply left to fend for themselves. In any event, they are deprived of the overall sense of family support with which they were raised.

For the Henan peasants who have tested positive, or whose relatives are carriers, HIV/AIDS becomes synonymous with increased levels of poverty, because the sickness of a family member has a direct impact on a peasant family’s income and food stock. Anyone badly affected by the infection no longer has the strength to work the land as efficiently as before, while taking up time and effort that his or her partner then needs to spend on double the amount of work. Consequently, the productivity of the family plot goes into steep decline, causing both loss of revenue and diminishing food stock. This forces the family to sell some of its animals, not only to meet the immediate need for food but also to buy medicine for the sick family member. This drop in family income also has a direct impact on the grandparents’ living standards, particularly in the case of the very old who depend on a child’s support to survive. That is why the links between AIDS and poverty has turned out to be particularly marked in Henan. While it was poverty that led men and women alike to sell their blood in the first place, the HIV/AIDS outbreak has caused a further impoverishment of those peasant families struck down by it.

Finally, the spread of HIV/AIDS throughout Henan has also become synonymous with discrimination against its peasantry, and especially against those from the counties and villages worst affected by the virus. This discrimination operates at every level and in many different areas of daily life (such as hospitals, schools, public services, markets, etc.).

The response of the central government and local authorities in Henan

When AIDS first appeared in China, the authorities considered it to be a “foreigners’ disease,” and then a “social curse” linked to capitalism or immoral conduct. As a consequence of these perceptions, early official responses were punitive and discriminatory. From 1998 onwards, recognising that their measures had been ineffective, the central authorities launched two national action plans (20) and a pilot scheme (20) to deal with the ongoing increase in HIV/AIDS infections. However, these measures were largely hampered by low budgetary commitments, insufficient attention by the central government, and a lack of co-ordination between the various ministries. (21)

This situation did not change until 2002-2003. Then, partly as a consequence of the international community’s increasing awareness of both the HIV/AIDS situation in China (especially after the revelation in 2001 of the blood contamination in Henan) and of the weaknesses of the Chinese health system revealed by the SARS crisis, but also as a result of the accession of a new generation of Chinese policymakers to positions of power, the official approach to the HIV/AIDS problem finally underwent a genuine transformation. (22) Among the measures taken by the Chinese government in response to HIV/AIDS, two sorts specifically target the situation in Henan: those aimed at controlling the spread of the virus among peasants, and those providing a medical and social response to the consequences of the disease for individuals and families.

With regard to the application in Henan Province of the government’s measures for controlling the spread of HIV in the countryside, the principal initiatives have been those aimed at improving the blood collection and distribution processes, which since 1998 have normally been covered by the Blood Donations Law. (23) The enforcement of higher standards in these systems of blood collection and management was initiated in 2002 with the closure of hundreds of collection centres that failed to comply with the 1998 law, the arrest of their organisers, the destruction of contaminated blood stocks publicised in the media, and by a policy of central and provincial government investment totalling

20. A pilot scheme to provide care and treatment to people living with HIV/AIDS, which was mounted in 100 counties beginning in October 2002.
21. On a certain number of sensitive issues, the lack of consensus between the different administrative branches was plainly visible. For example there was a deep disagreement between ministries over the issue of generic production of antiretroviral drugs. This set its supporter, the Ministry of Health, against the ministries of Foreign Affairs and Overseas Trade, which considered it a threat to the country’s reputation among foreign investors, and a derogation from China’s commitments as a member of the WTO.
25. PRC Ministry of Health Order No. 44, 1 March 2006.
2007, and the reported percentage of blood from unpaid volunteers used by hospitals and clinics rose from 22 percent in 1998 to 85 percent in 2004, \(^{(26)}\) 91.3 percent in 2005, \(^{(29)}\) and 98 percent in 2007. \(^{(30)}\)

In parallel with these measures for controlling the infection, which were particularly relevant to Henan Province, the authorities also put forward several strategies to confront the social challenges posed by HIV/AIDS in the countryside, including the province of Henan. Among the most important of these we would highlight the so-called “Four Frees and One Care” strategy (si mian yi guan huai), which the government launched in 2003. This national programme called for the free provision of 1) antiretroviral treatment for those who have tested positive, whether they are rural or urban residents, and who face financial difficulties, 2) tracing and counselling services, 3) antiretroviral treatment for pregnant women who have tested positive, and the tracking of their newly born children, and 4) access to education for AIDS orphans. It also covered the provision of care required by people living with HIV/AIDS, along with financial support for their families. In February 2006, the State Council incorporated this strategy into its overall action plan for combating HIV/AIDS in China, known as China’s Action Plan for Reducing and Preventing the Spread of HIV/AIDS (2006-2010). \(^{(31)}\) This gives clear policy directives to provide support for peasant families affected by HIV/AIDS. The “Four Frees and One Care” programme has been supplemented by several other official campaigns initiated by certain ministers to reinforce the existing response to the challenge posed by HIV/AIDS in the Chinese countryside, particularly in Henan. For example, in March 2006, the Ministry of Civil Affairs published a series of “Suggestions for improving the aid to orphans,” emphasising the need to build orphanages and improve the living conditions of such children.

While the drawing-up of national policies backed by a genuine willingness on the part of the government represents only a first step on the road to an effective response to HIV/AIDS, it cannot be denied, in view of the national action plans set out by the Chinese government to meet the challenges of this disease in the countryside, that since 2003 China has passed this first hurdle, and that the central authorities have become fully aware of the gravity of the situation, and of the need to act swiftly and decisively. As Peter Piot, the UNAIDS chief, stated clearly in 2007, “The central government leadership and the national policies are practically as good as they could possibly be.” \(^{(32)}\) However, the effectiveness of the struggle against HIV/AIDS, and of the aid given to those affected in particular, is going to depend directly, in China as elsewhere, on the implementation of national strategies at the provincial and local levels.

In Henan, the provincial authorities have taken an ambiguous approach towards the policy directives from the centre. Admittedly, the Henan authorities did implement the central directives on the struggle against HIV/AIDS in some counties, but at the same time, taking advantage of the autonomy they gained from the decentralisation of 1979, they imposed restrictions on information about the disease, and adopted a policy of repressing all the social forces demanding improvements to those initiatives. According to some officials, such people represented a threat. With regard to the implementation of the national strategies within the province, we should take particularly note of those concerned with improving the procedures for collecting and managing blood supplies. Since 2003 the Henan authorities have come down heavily on collection centres that do not follow the rules, and they have opened new centres that do comply and have properly qualified staff. They have also taken steps to promote the use of non-commercial blood donations in hospitals and clinics. As a result, in 2004 the Medical Policy Office of the Ministry of Health reported that 100 percent of the blood used in its establishments in Henan consisted of unpaid donations. \(^{(33)}\)

The Henan authorities have also attempted to implement the national “Four Frees and One Care” strategy. In February 2004, \(^{(34)}\) the provincial government sent 76 officials, increased to 114 in March 2005, \(^{(35)}\) to 38 villages to detect HIV infections free of charge, to supply antiretroviral treatment to peasants who tested positive (amounting to 6,700 in 2005), and to provide support and care to AIDS orphans. Henan has also provided investment to build clinics in a certain number of villages so as to provide care near the homes of peasants infected with HIV, as well as orphanages to shelter children who have lost their parents to AIDS. \(^{(36)}\) The first official orphanage in Henan was built on two hectares.
of land in the village of Wenlou (Shangcai), which was especially badly hit by HIV. (37)

In April 2004, the Poverty Reduction Office, the Department of Civil Affairs, and the Henan Finance Office issued a joint document that set out standardised procedures and strengthened the support for AIDS orphans and for the elderly living alone as a result of AIDS in their family. (38) This document, which was inspired by the “Four Frees and One Care” strategy, restated that the orphans must have free access to education and that the elderly had a right to financial support. The ceiling for the monthly payments was set at 180 yuan for orphans under 18 years of age, and at 160 yuan for the elderly over 60, with 240 yuan per year added to cover medical costs. Adopted children were to receive 130 yuan per month. Eighty per cent of this assistance was to come from provincial government funds.

While undertaking these official initiatives, the provincial and local authorities in Henan are still very careful to maintain control over information concerning the true extent of the HIV/AIDS problem in their region, and the methods used in their struggle against it. Indeed, after having denied the presence of HIV in Henan until 2002, the authorities there are still practising a policy of withholding information and of repression against all the social forces (such as infected peasants, associations, activists, journalists, etc.) who might question the reality or the appropriateness of the authorities’ activity in the struggle against HIV/AIDS. Up to the present, the practical application of this twin policy has been to control access to the most infected villages (particularly in the counties of Shangcai and Shenqu), and its main objective has been to prevent journalists, researchers, and Chinese and foreign activists from getting hold of any information not supplied by the provincial authorities concerning the progress of the disease among the peasant population and the real living conditions of those infected and their families. In other words, no information on the HIV/AIDS situation in Henan can come from the villages, the counties, or the province except through official channels.

This control over information is particularly apparent in the response of the Henan authorities to those whom they consider a threat. For example, in August 2003, the Assistant Director of the Henan CDC, Ma Shiwen, was arrested and accused of betraying “State Secrets” because he shared information on the spread of the contagion in his province with an unofficial association. (39) He faced a ten-year prison sentence (40) but was released three months later, a few days after a visit to China by the American Secretary of State for Health, Tommy Thompson. (41) Ma has since confirmed that

visits by Chinese and foreign officials, particularly to Shangcai County, are all tightly controlled by the local authorities to prevent the release of any information that might differ from official statements. (42)

The most recent example of the Henan authorities’ obstinate desire to limit the information about the HIV outbreak is the physical violence and robbery inflicted on two Belgian journalists in November 2008 (43) as they were making a documentary about AIDS in Henan. In other cases too, the Henan authorities have tried to muzzle, mostly by repressive means, any move that they interpret as questioning their actions (or uncovering their inaction) in the fight against HIV/AIDS. A particularly striking example among many of this official repression is the large-scale raid in June 2003 by a force of 500 policemen on the village of Xiongqiao in Shangcai (where 24 percent of the inhabitant were infected with HIV), and the arrest of 16 infected farmers who were accused of attacking local government, police, and Party offices when they called for a clinic to be built in their village. (44) There was a similar occurrence in July 2004, with the arrest of four HIV-positive people from Henan who had decided to go to Beijing to petition the central authorities about the lack of the promised antiretroviral treatment and the banning of their children from attending school. (45) The list of these repressive acts in Henan is long and continues to grow.

Finally, if the Henan authorities until now have been extremely vigilant against the activities of certain Chinese associations and activists struggling against the social consequences of HIV/AIDS in the province, they have openly forbidden entry to international NGOs trying to contribute medical and social assistance in that area, such as Médecins Sans Frontières in 2006. (46)
Consequently, although the Henan authorities have been trying since 2003 to show the central and overseas governments, as well as the international organisations, that their province has finally become fully committed to the fight against HIV/AIDS by following the directives laid down in the national plans, the fact is that because of their absolute control of information, their tight restrictions on access to those villages heavily infected by HIV/AIDS, and their repression of all those who question the official programmes, there is still very little clarity about what concrete measures have been taken and their actual results, particularly in the remote areas of the province. But this situation of systematic and more or less total obstruction by officialdom of the fight against HIV/AIDS in Henan has not prevented a transnational player like the Taiwanese NGO Harmony Home from intervening to foster a peasant-based response to the contagion. This is indispensable if the province is to genuinely confront social consequences to which the authorities have not yet responded adequately.

The organisation and motivation of a transnational actor in the fight against AIDS in Henan Province: The case of Harmony Home

Although only registered with the Taiwanese Ministry of Public Affairs since 2003, Mrs. Yang and certain other members of the NGO known as Harmony Home (guan’ai zhijia xiehui) have been engaged in the struggle against the social consequences of HIV/AIDS in Taiwan since 1997. Their activity is essentially focused on three main fronts: the prevention of HIV/AIDS, the fight against the discrimination faced by those infected, and support for HIV carriers in their families. (47) The prevention strategy adopted by Harmony Home depends mainly on organising information sessions in schools and other communities. The second front, the fight against discrimination, depends generally on demonstrations during which the organisation’s members plead with the public to understand the social limbo imposed on adults and children who have tested positive. With the support of other local NGOs, they also call for the legal protection of carriers in Taiwan to be strengthened. (48) Finally, Harmony Home provides practical support to those infected by providing lodging for men and women who are homeless or who need temporary shelter, (49) and also provides care or assistance in finding work. (50) In general this help is provided with maximum discretion, largely because of the persistent discrimination against HIV carriers in Taiwan. (51) Inscribed at the heart of Harmony Home’s commitment is the principle of greater involvement of the people affected by HIV themselves, (52) expressed by the acronym GIPA. (53) This formula articulates the main principle behind the operational mode of the NGO, enabling it to maintain its independence, as well as the main thrust of its activities in Taiwan and, as we shall see, in mainland China.

Harmony Home has been able to benefit from a certain kind of publicity in Taiwan, since it has occasionally been an object of attention in the island’s press, especially when some HIV-positive individuals it was sheltering were threatened with expulsion, or when its members deliberately let themselves be arrested after attempting to steal bedding from a department store in order to call attention to the lack of financial support for young children affected by the virus. This NGO has likewise enjoyed a high international profile comparable to its exposure in Taiwan, largely on account of its regular participation in numerous international demonstrations addressing the HIV/AIDS problem, and its maintenance of a close and wide-ranging network of overseas contacts.

The morphology of a transnational actor from Taiwan

Harmony Home’s involvement dates back to 2003, and since then it has been active in the provinces of Guangdong, Guangxi, Yunnan, Shanxi, and Henan, where, depending on the local social and political situation and the support it


48. In this respect the important role played by Harmony Home should be emphasised, and in particular the petition it circulated in persuading the Taiwan government in July 2007 to promulgate the “Law on the protection of the rights of patients infected by HIV.” See http://www.cdc.gov.tw/public/Data/7121918211771.doc (consulted on 4 January 2009).

49. By 2008, Harmony Home had opened four centres in Taipei (2), Kaohsiung, and Pingtung, receiving a total of 77 HIV positive people.

50. A certain number of HIV positive people work in the flower shop opened by the NGO in Taipei, and in enterprises in partnership with the organisation.

51. On several occasions this NGO has faced protests from residents or local officials in areas where the locations of their reception areas for positive carriers had been divulged.

has found, it has backed different projects for providing shelter, meals, medical assistance, care, counselling, support, prevention, and training, often modelled on its work in Taiwan. The initial impetus for the extension of its activities into China, and into Henan in particular, goes back to contacts made by its members, especially the woman who heads it, when attending international conferences such as the AIDS summit in 2001. This international gathering, attended for the first time by several Chinese activists in the fight against HIV, enabled Harmony Home to make initial contact and to gain first-hand information about the situation in China. Following this opening move, Harmony Home’s leader was invited by a group of HIV-positive activists to visit the mainland and take part in some of their meetings, in the course of which they advised the Taiwanese organisation to focus its activities on Henan. They took Mrs. Yang to the province in secret, so she could judge for herself the extent of the social repercussions of HIV infections there.

Before going to China, Harmony Home had been working on a project to open a dispensary for terminally ill AIDS patients, but following the visit by its leader to Henan, a new priority arose: the protection of children who had lost their parents to HIV/AIDS. On returning to Taiwan, in order to obtain funds from their international providers for this new venture in China, the members of the Harmony Home association had its status as a Taiwanese NGO officially registered, and they started to consider the best ways of intervening in China.

When the leader and members of Harmony Home are asked about their motives for becoming involved in the fight against HIV/AIDS in China, the humanitarian motives that remain primary for their voluntary activities on the mainland are accompanied by two more strategic perspectives. The first concerns the organisation’s desire to expand internationally, both in terms of projects (in this regard, after China, Africa seems to be its next field of activity) and in terms of financial backing. This is because by operating exclusively in Taiwan until recently, the group was largely restricted to funding from Taiwan; by opening up its field of activity into China, however, it can hope to diversify its financial sources, and especially to turn for support to the main international providers of funds for the fight against HIV/AIDS. There is also a national security aspect to the arguments advanced by this NGO’s members in justifying their involvement in China. Their speeches frequently reiterate the idea that epidemics such as SARS, Avian flu, and AIDS represent a real health threat to the population of Taiwan, particularly in view of the rapid expansion of exchanges and individual movement across the Taiwan Strait. If the number of HIV-positive carriers in China rises to a critical threshold, that situation will have repercussions on the population of Taiwan.

By emphasising this point, Harmony Home highlights the issue often raised at international conferences on infectious diseases, namely the interdependence of security concerns shared by all societies in the face of the spread of such diseases, and it signals at the same time its willingness to take part in the global struggle against epidemics.

The ways and means of transnational intervention, and the building of a local response to AIDS

A strategy for strengthening the response to AIDS at the village level

Starting in 2003, and well aware of the extreme sensitivity of the HIV/AIDS issue in Henan and of the additional problems facing a foreign NGO intervening in the most affected villages in the province, Harmony Home focused its intervention on supporting mutual aid among individual peasants and their families facing the consequences of the disease. In the case of the worst affected villages, this support took the indispensable form of vigorous initiatives to develop community activities in which the main players would be the villagers themselves, and peasant HIV carriers in particular. This approach, based essentially on the participation of the whole village community, has led to three main projects aimed at reinforcing the villagers’ response to the AIDS epidemic. These have developed over the last five years, thanks to assistance from Harmony Home and the involvement of the peasants from the province. Their main aim has been to compensate for the deficiencies in the provincial anti-HIV/AIDS programmes.

53. As ONUSIDA points out, this “Great Involvement of People living with or affected by HIV/AIDS,” formally adopted at the Paris summit on AIDS in 1994, is neither a programme nor a project but “a principle aimed at guaranteeing people living with HIV the enjoyment of their rights and responsibilities, including the right of self-determination and participation in the decision-making process affecting their lives.” See http://www.unaids.org/fr/PolicyAndPractice/GIPA/default.asp.

54. From interviews with Mrs. Yang, leader of Harmony Home, and several other members, conducted in Taipei on 20 November 2005, and 3 and 26 May 2006.
The first of these projects addressed the need to organise a local response to the problem of orphans left by HIV/AIDS in a number of villages, particularly in Shenqiu County, which has seen a large increase in the numbers left to fend for themselves or to depend on their grandparents. It would seem, moreover, that this county did not benefit from the attention that the provincial authorities reserved for Shangcai and, as we have seen, for the village of Wenlou in particular. According to many peasants from the neighbouring county, the latter village was turned into a showcase for the central government and foreign agencies in order to demonstrate that local authorities had really taken charge of the HIV/AIDS problem and its orphans. So in late 2003, in one of these remote villages in Shenqiu County, where a large number of tombs rising like small mountains amidst the fields shows how severely the AIDS virus has struck its inhabitants, the Taiwanese organisation contributed to opening a reception centre for AIDS orphans. After a careful search for trustworthy local partners to manage this project, Harmony Home made an arrangement with a peasant couple who agreed to shelter and feed about 20 orphans in their home. Subsequently, Harmony Home’s principal role became that of providing funds for this reception centre. In fact, within the framework of its “Food for Hope” programme, which currently covers 1,000 orphans, the organisation provides 130 yuan for each child enrolled, to which, as we have seen, since April 2004, the provincial government has added an equal amount intended mainly for the orphans’ basic needs and education. While Harmony Home retains the role of both supervisor and producer of the annual report to donors, the daily running of the centre rests entirely with the village couple, assisted by several peasants, some of whom are HIV-positive and others not. In this way, they are the ones who ensure the safety of the children, their health, their school attendance, and their daily lives, and provide consolation for bereavement when needed. All of this takes place in a family atmosphere where freedom, respect, and the right of each child to be heard are vigorously defended.

According to the peasants participating in this project, such an atmosphere is not to be found in the official orphanages, and this has inspired Harmony Home to seek to open more reception centres in the county. It should be emphasised that these villagers have also undertaken the task of informing the orphans’ grandparents, or others who have taken them in, of the importance of enrolling them on the official register of AIDS orphans in order to receive the government subsidies mentioned earlier. Because of the lack of information in the most remote villages, many of these orphans have not in fact been officially registered by an adult, and therefore do not receive their due allowance.

The second of these projects is aimed at giving peasants effective means of dealing with the recurrent problem of the abandonment of AIDS treatments, and the consequent risk of increased resistance to the antiretroviral drugs. In fact, while it is undeniable that since 2004 the provincial authorities have built a certain number of clinics in Henan’s villages (the village in Shenqiu County mentioned earlier has actually had one since 2005), and that they have given large amounts of antiretroviral drugs to thousands of AIDS sufferers, there are still a number of challenges to be overcome that seem to require the involvement of the peasants themselves. Among these challenges two in particular stand out.

The first of these is the increasingly frequent abandonment by HIV-positive peasants of their combination therapies after several years of treatment. There are two reasons for this. The first is the side effects of the treatment. While the Chinese government, in pursuit of its “Four Frees and One Care” programme, bought six first-generation antiretroviral drugs (which are now produced as generic drugs in China itself), and this enabled courses of treatment to be set up at one twentieth of the cost of courses using second-generation antiretroviral drugs, the drawback has been reputedly painful side effects that lead many HIV-positive patients to abandon their treatment.

In addition, there is a severe lack of medical personnel for this programme in the Chinese countryside. The opening years of this official initiative were marked by laxity in the way the antiretroviral drugs were prescribed for the peasants, due to the inadequate training of the young doctors working in the newly built clinics. Lacking instructions on how to take the antiretroviral drugs, for several years the peasants were free to take them as they felt inclined, with a resulting risk that they would not follow the treatment correctly and would eventually abandon it. Although the doctors in these villages themselves are often unable to ensure the safety of the children, their health, their school attendance, and their daily lives, and provide consolation for bereavement when needed, all of this takes place in a family atmosphere where freedom, respect, and the right of each child to be heard are vigorously defended.

55. Interviews with several villagers from Shenqiu County, in May 2006 and June 2007.
56. In accordance with a request from Harmony Home, the name of this village has been omitted.
57. Zidovudine, Didanosine, Nevirapine, Stavudine, Efavirenz, and Lamivudine.
58. A year’s treatment using second generation antiretroviral drugs would cost the government 20,000 yuan per patient.
clinics are better trained nowadays, particularly in Shenqiu County, their numbers and those of nurses trained in AIDS treatment are lower than required to meet the needs of all the HIV-positive patients and to provide adequate follow-up care. Their ability to make proper AIDS diagnoses, to establish a suitable antiretroviral regimen for each patient, or to follow the developments of the virus in HIV-positive carriers, is still extremely limited. As a result, in many of the villages in Shenqiu County, HIV-positive peasants undergoing treatment are still not receiving close and effective monitoring of their illness. In many extreme cases, patients severely weakened by the disease have even chosen to remain at home, where at least there is some support, rather than staying in a clinic where they receive treatment but not the necessary care or follow-up. It is not unusual to come across villages without any of the patients for whom they were originally built, and to find these same AIDS sufferers at home by themselves or helped by a partner. This increases the risk of treatment being abandoned. Although there are no official statistics on the abandonment of the prescribed combination therapies among the peasants of Henan, some doctors from Zhengzhou and Shenqiu County believe the figure to be around 40 percent and even higher in some villages. (62)

The inappropriate way of taking medicine, and the abandonment of combination therapies, feed into the second problem facing official AIDS treatment programmes, namely resistance to treatment. For several years in the Chinese countryside there has been a growth in cases of resistance to the first generation of antiretroviral drugs, which are virtually the only weapons currently available to doctors for the treatment of Henan’s peasants. Whereas official reports put the cases of patients developing resistance to the antiretroviral drugs at 17 percent, (60) doctors working in the Henan countryside put the figure at 50 percent.

Given this situation, in order to give HIV-positive peasants the knowledge and tools necessary to deal with problems that could potentially undermine the whole fight against HIV/AIDS in Henan, Harmony Home launched a training programme in primary care, the proper taking of antiretroviral drugs, counselling, and patient follow-up. These two-day sessions in the town of Dengfeng were designed by Harmony Home in collaboration with AIDS Care China and AIDS Alliance, and they were then organised on the spot by the head of their mission in Henan, who is HIV-positive and comes from Taiwan, (61) and by a Zhengzhou resident who is a trained pharmacist and whose involvement in the struggle against HIV/AIDS was motivated by the death of several of his HIV-positive relatives. (62) These annual training sessions are attended by around 15 peasants from various counties in Henan, who then return to their villages with the means to act effectively in their communities and beyond.

The role of these trained peasants is twofold. Firstly, they make weekly visits to peasants undergoing antiretroviral treatments in the clinics or at home, in order to give explanations or reminders of the importance of taking their medicines, and of the proper way to take them. They also give moral support and listen to patients who are having particular difficulty with side effects. Second, but equally important, is the support these visits provide to family members, allowing them not to feel completely isolated in the face of their relatives’ suffering, and providing them with the tools to keep their relatives from abandoning treatment in anticipation of a less burdensome antiretroviral regimen. (63) On their return from training, it is up to these peasants themselves to set up a local mutual aid network (often under the name of an association), and to pass on their training to the inhabitants of their village and neighbouring villages. They also make visits, to the extent possible, to support the sick.

Interviews in Shenqiu County with many patients undergoing antiretroviral treatment and their relatives confirm the need, and in many cases, the real effectiveness, of this kind of mutual help at the village level. This group of village activists then went on to assist in the official registration of HIV-positive peasants, enabling them to benefit from government allowances and free treatment. They also offered free AIDS detection to peasants who had sold their blood in the past, with the help of kits supplied by the Taiwanese NGO, and they continued to publicise the need for free blood donation at a time when health authorities acknowledged that payment for blood donations was still ongoing in China. (64)

Support for the villagers’ response to AIDS in Shenqiu County takes the form of a third project aimed at making

59. From a meeting with two doctors from villages in Shenqiu County and one based in Zhengzhou.
61. He is about 30 years old, and has been involved for five years in Harmony Home’s activities in his native Taiwan in the field of training and providing shelter for HIV-positive people.
62. This 40-year-old pharmacist’s involvement goes back to the earliest days of Harmony Home’s presence in Henan.
63. This point is generally made by relatives of HIV-infected people.
this response fully independent by giving it control over its own income. Drawing inspiration from the experience of Harmony Home in Taiwan, and particularly from its establishment of a flower shop there, the project’s co-ordinator in Henan and his local colleague have drawn up a plan for economic independence through productive activity (shengchan zijiu). In this instance, they are involved in rabbit breeding, the stewardship of which will be handed over to HIV-positive volunteers from 2009 onwards. This initiative, financed by Harmony Home, will enable some peasants to return to the kind of social activity that is often lost as a result of AIDS affecting their physical and mental health. The sale of the animals raised will also in due course provide a financial basis for further activities in the struggle against the repercussions of the HIV/AIDS outbreak in the village and beyond. The field of productive activity chosen for this project was largely the result of a promise of support from a rabbit breeder who manages a farm raising a thousand such animals just a few miles from the village. This manager, who has lost several of his relatives and employees to the AIDS virus, has agreed to help NGO activists and villagers to set up their project for economic independence in the fight against HIV/AIDS, and to play a leading role in ensuring the smooth running and durability of this initiative. The manager has undertaken to sell several breeding pairs very cheaply to Harmony Home, and thereby to the future breeders, along with the equipment needed to raise the animals. He has also promised to provide several training sessions, including a visit to his farm, to buy the progeny from the villagers, and to sell them for their fur and meat to his customers throughout Henan Province and beyond. This project is supported by three main players: Harmony Home provides the investment, the village volunteers are the producers, and the professional breeder acts as buyer and middle man. According to those in charge, it should be a profitable enterprise, able in the longer term to provide ample support, or even a principal resource, for the various struggles against AIDS to be mounted in this village in Shenqiu. Such activities can then be replicated to produce still more independence.

A relay to enable access to health services

Along with strengthening the mobilisation of several of the villages in Shenqiu County, Harmony Home also seeks to make health provisions more easily available to HIV-positive peasants. Because numerous medical resources, both human and material, are concentrated in the provincial towns, in 2004 the organisation decided to open an office in an apartment in Dengfeng. This place serves as the organisation’s base camp in Henan, being its administrative centre and residence for its co-ordinator, and it also operates as a reception centre for HIV-positive peasants passing through the town. As we have noted earlier, the lack of medical resources in the countryside, particularly in terms of care and patient follow-up, has encouraged the organisation to seek out establishments and doctors in the towns willing to provide consultations, counselling, and follow-up treatment to any peasant carriers who seek their help. This means that the peasants get the benefit of tests (CD4), diagnoses, and the type of care that is extremely limited in the countryside. The costs of these medical interventions are met by Harmony Home. In order to reduce as much as possible the expense of these town visits for infected villagers, Harmony House puts beds and clean facilities at their disposal, provides meals during their stay, and subsidises their transport costs. It also provides a place for receiving and sharing information on the developing health situation of the AIDS patients. By fulfilling the role of intermediary between the peasants and the urban medical institutions, and especially by enabling a close follow-up of the patients, this centre represents an additional tool in the fight against the abandonment of AIDS treatment, which remains one of the main problems in the countryside.

Intervention with discretion

The support provided by this Taiwanese NGO for the mobilisation of the peasantry against the ravages of HIV/AIDS in Henan should not make us forget that the issue remains very sensitive in the province. As emphasised above, the local and provincial authorities maintain a policy of tight control over information about HIV, and over the organisation of the response to AIDS. But in the face of the breadth and gravity of the situation, there is still a lot to be done, and the authorities cannot provide an effective overall response on their own. Intervention by various associations and the increased involvement of HIV-positive individuals themselves have become unavoidable. This raises the whole question of the relationship between officialdom and the people active in the civil mobilisation against AIDS.
In the case of Harmony Home’s intervention in China, this issue is particularly difficult, and it is given careful consideration by its members in Taiwan and Henan alike. While for obvious reasons this intervention was kept secret for a while, it is now rather more a matter for discretion, being presented as merely complementary to local official activities. Indeed, Harmony Home has chosen not to criticise the local authorities for their failure to respond to the social repercussions of the disease, and not to add their voice to the protests from the villagers (such as demands for compensation, or improving access to care facilities), but rather to help the peasants to help themselves through the provision of funding or training, and thereby reducing the impact of these failures on the population.

As for the Henan authorities, after forbidding every local initiative at first, they now seem prepared to accept those that do not directly or openly call official measures into question. Nonetheless, foreign interventions are still fraught with difficulties. That is why, in the light of the failures experienced by other transnational players in Henan, Harmony Home, at least at the local level, has reduced to a minimum the visible links between itself on the one hand, and its reception centre project and the village mutual help groups on the other, seeking to further promote the independence of their local initiatives. Thus, in the village in Shenqiu County, the reception centre is extolled by local political and health authorities, who present this expression of the village community’s sympathy for AIDS orphans as though it were a response to the national policy promoting the adoption of such children by volunteer families. This does not prevent the police and militia from keeping a strict watch over the reception centre and the doings of its HIV-positive peasant activists, who have become used to being interrogated about their activities. It is also worth pointing out the harassment dealt out to a sociology professor from a university in the province when he came to the centre to meet and interview HIV-positive villagers in order to study their situation since the inception of the “Four Frees and One Care” policy.

Such examples show the care taken by the local authorities to ensure that all initiatives undertaken by the population should be contained and prevented from leading to any challenge to their power. They also show how right Harmony Home is to be discrete in its work, since the training of HIV-positive villagers and the very existence of a reception centre in Dengfeng could be affected. Fearing that the officials in charge of the town of Dengfeng might refuse to accept this kind of service, or that the centre’s neighbours, frightened of HIV contamination and a fall in the value of their property, might turn against the location of such a centre on their doorstep, the organisation has exercised the greatest possible discretion as it opens its doors, receives HIV-positive peasants, and works with its network of supportive doctors.

Although the official approach to the fight against HIV/AIDS is not favourable to foreign aid, Harmony Home has been intervening since 2003, especially in the villages most afflicted by the virus. It has developed a way of conducting itself specifically adapted to Henan around four principles. The first is that people living with HIV/AIDS should become more involved in their community’s response to the repercussions of the disease. This response is then supported and strengthened by the NGO through a small but necessary financial contribution and by training sessions that enable the mobilised peasants to provide a viable and lasting response to the needs of AIDS sufferers and their families. The second principle follows as a consequence of this peasant-centred approach, namely that the progressive achievement of independence for this response is absolutely indispensable if it is to last. The third principle is the absolute respect for the rights of HIV patients enrolled in the different plans in China for the fight against AIDS. For this NGO, the defence of this principle comes down to facilitating the access of HIV-positive peasants and their families to the care provisions and subsidies to which they are entitled.

Lastly, the fourth principle governing Harmony Home’s activities in Henan is discretion. This is characterised by the refusal to criticise local officials openly, and by a complete self-effacement behind the peasants to prevent the authorities considering the various projects as instances of foreign interference in local affairs. Thanks to these specific forms of action, which could well serve as a model to other transnational agencies wishing to bring their help to the province, this Taiwanese NGO has managed to stimulate, support, and reinforce the peasant response to HIV/AIDS. Taken together, all this activity constitutes a valuable and dynamic approach to the numerous social challenges that this disease has inflicted upon the worst affected villages in Henan.

* Translated by Jonathan Hall