

HEALING OLD WOUNDS: TRANSFORMATION AND REBIRTH IN A LEPROSY VILLAGE

BY ADINA MATISOFF

A project by an international NGO (INGO) inadvertently builds bridges between residents of a leprosy village and the wider society where they have suffered discrimination for decades. But will the lessons of this project be applied to preserving basic human rights in other scenarios, such as the handling of HIV/AIDS?

Fifty years of solitude

He enters Dingwo Village at lunchtime, with his friend hanging back at the entrance. Stopping just beyond the large red banner that reads “Habitat for Humanity House Build 2006,” the man seems caught between his excitement at spotting a group of foreigners and his uneasiness at being in the lepers’ village. He makes his way awkwardly from the open gate to a little cluster of tables in the back and stands over my table, staring down at the villagers and me as we shovel rice and chicken wings into our mouths. The villagers glance furtively back at him, shifting uncomfortably in their chairs. I’m beginning to think that inviting him here was a bad idea, and that I’m just the ticket seller to the local freak show.

My intentions seemed purer a couple of hours before, when I came across this elderly man on the little dirt road leading away from the village. I had walked past the ramshackle collection of houses in the tiny leprosy rehabilitation village and woven my way through the handful of homemade gravestones, all marked with the surname Huang, into endless fields of green and yellow sugarcane stalks. At the next bend, the silhouette of a man sitting quietly by the side of the road had come into view. Engrossed in chopping sugarcane, he had not noticed my presence until my greeting broke through the steady drone of grasshoppers in the brush. He blinked a few times in disbelief from under his Mao cap, and ignoring my formalities, he stuttered out questions in one long, run-on sentence: “Where did you come from? What nationality are you? What are you doing here?” His teeth gleamed white against skin tanned and wrinkled from decades of toiling in

the sun, and his agility as he sprang to his feet to inspect me from all angles removed decades from his age.

My dirty jeans, NYC RoadRunners t-shirt and bright yellow construction hat hardly matched the image of an affluent foreigner some rural Chinese expect, and when I told him I was American, he was incredulous. When I said I had come from Nanning he was equally mystified, saying, “Yeah, but this isn’t Nanning! How did you get out here?”

The excitement on his face turned to dismay as I explained the leprosy village reconstruction project that had brought me there. “You shouldn’t go near them, you don’t want to get sick, do you?” he asked while contorting his hands and pointing at his legs and face for emphasis. When I told him they were not contagious and he should not be scared, he added ghoulish noises to his description. In a moment of sincere concern he asked, “Do you eat with them?” At my affirmative reply, he took on the expression of a parent with a rebellious child, yearning to warn me and frustrated by my rejection of his grave advice.

Having reached an impasse in our conversation, I decided it was time to go back to Dingwo. As I turned, he yelled after me that I was the first American he had seen in his 70 years. I responded with a wave and a casual invitation to come visit the village later on if he wanted to.

As I walked back to the village, I wondered why it hadn’t occurred to me to explore this road the first time I was here, just two weeks earlier, on another volunteer build sponsored by the INGO Habitat for Humanity (Habitat). I had been wrapped up in meeting the ten leprosy-affected villagers and trying to gain even the vaguest understanding of what their life-long isolation had been like. It was an existence incomprehensible to most of the volunteers.

Charity and new houses did not address the stigma that confined the residents.

The Dingwo Leprosy Rehabilitation Village was set up by the Chinese government in 1956 as a special quarantine zone for people who contracted leprosy in Fusui County, Guangxi Province. The village held more than 200 people at the height of the leprosy outbreak in the 1950s and 60s. Fear of leprosy ran rampant through the county at that time, spurred on by a

lack of knowledge about the spread of the disease and physical symptoms of the sorts seen in horror movies. According to the doctor who tended to the village, it was not unheard of in the greater community for a person displaying the effects of leprosy to be stoned to death.

By 1982, a cure for leprosy was found, and the government finally allowed people to return to their home communities. Some enjoyed joyous reunions with family, while others set out to try their luck making a life for themselves beyond the confines of the village. Others, however, felt trapped by the curse of their physical scars. The government had released them from their mandatory residence in the lepers' village, but who would free them from the discrimination that was already deeply ingrained in society?

Fifty years after the village's founding, maintenance was a bare-bones operation. The government provided the residents with spartan monthly stipends for food and new shoes once a year, but gave nothing to fix the broken windows, cracked walls and leaky roofs that accumulated over the years. Habitat signed on to improve the village infrastructure, but charity and new houses did not address the stigma that confined the residents there.

Before the lunchtime guest arrived, all eight men and two women who remained in the village sat on little wooden stools and chairs in the courtyard enclosed by their newly built

houses, telling the volunteers about the effect of leprosy on their lives, their abandoned hopes and their efforts to come to terms with their identity. Despite their ages, all between 67 and 88, they spoke with immediacy and clarity of the pain they had experienced in decades past.

The 71-year-old village leader, Lu Xianwen, had been in the leprosy village from the beginning. He was just 16 when he was diagnosed with leprosy at a hospital in Nanning, and 17 when the government told him he would not be allowed to return home with his mother, but would have to go to the leprosy village instead. He spoke with confidence and authority until he recalled his first nights in his new home. Beginning to cry, he said, "I felt so hopeless, and all I could think about was when I would see my mother again."

Huang Jianxue, with an infectious smile, mused about the "what ifs"—what if he had not contracted the disease from his cousin when he was 14? What if he had not had to spend 10 years during his teens and twenties in a hospital? What if he had been allowed to hold a job and make something of his life? Despite the anger and tension evident in his face, he seemed positive about his own resolve to educate himself through studying and listening to the radio every day. Grinning proudly he said, "I can even speak a little Mandarin."

Others who were sent to the village a little later in their lives had gotten a taste for what normal adult life was like. Li



The author (R) and village residents. Photos courtesy of the author

Weibin was married with a baby and had just begun serving in the People's Liberation Army when he was diagnosed and sent to live in the village. His wife soon divorced him, taking their 10-month-old son with her. He shook his head; thinking about the adult son he had never seen was still too upsetting to talk about.

Ma Nengxian, from a minority mountain village, said she knew what he meant. She too, had been married with children when she was sent to the leprosy village. She could count on one hand the number of times her daughters had come to visit her in the three decades since she had arrived. "I really wish my daughters would visit," she said, anxiously knocking on her artificial leg. Well aware of how social perceptions of her disease must have affected her relationship with her daughters, Ma was grateful that she had not been completely abandoned; her parents had invited her home every Spring Festival until they died two years ago.

In each individual's history was the shared experience of discrimination, isolation and social ostracism. Dr. Mou, an official from the state Skin Disease Department who had been caring for the Dingwo villagers, and who served as the middleman between the NGO and the villagers during the reconstruction project, regretted the Dingwo residents' continued hardships. In an earnest speech to volunteers before that day's lunch, he emphasized that every person in Dingwo was



A decrepit old home (top) and new houses provided by Habitat.



Huang Jianxue (L) and other village residents: healed but still waiting to rejoin society.



cured. “There’s no need to be afraid of anybody here. Although they retain permanent skin and nerve damage from the illness, nobody here is contagious. You will not contract leprosy from contact with the villagers.”

He went on to say that following the lifting of the quarantine for leprosy-affected people in 1982, it was only years of separation and continued social stigma that prevented the villagers’ reintegration into society. “It’s been difficult to break the stereotypes against these people in Fusui’s wider community. Part of the Skin Disease Department’s mandate is to educate people around here about what leprosy is, how it is contracted and most of all, that there is now a cure.”

Apparently this message has not reached the curious neighbor standing over us as we eat lunch. With visions of him harassing the villagers before an international audience, I move quickly to divert his attention toward the group of young volunteers. He grills me on their countries of origin, but has never heard of Canada and Poland, and is clearly skeptical that the dark-skinned girl of Bangladeshi descent is genuinely American. The increasing annoyance on everyone’s faces indicates that the cultural lesson is at an end, and I send our visitor back to the fields with the best gossip heard around these parts in years.

I cannot help but feel disappointed that my attempt to facilitate understanding has devolved into a two-ring circus, and I tell Dr. Mou what happened. He gives me a sheepish look as someone else mockingly asks about the local government’s clearly ineffective leprosy awareness campaign. Breaking old taboos

among local residents has been a more formidable challenge for Dr. Mou than providing lessons to open-minded volunteers.

New beginnings?

Driving once more up the newly graveled road to Dingwo several months after the project has been completed, I see a handful of residents fanning themselves in the shade of a large tree just outside the village. Despite the stultifying heat and humidity, they summon expressions of surprise and pleasure, and soon my colleagues and I have joined them in the shade. As I commence a tally of the familiar faces in preparation for our project evaluation, I notice an unknown younger man among the group. He soon gives his companions a nod goodbye and heads off into the fields surrounding the village.

Apart from the villagers’ summer clothes and obvious tan lines, not much has changed since my last visit to the village. The villagers sit and watch the dogs play, rolling one cigarette after another from their pocket supplies. As they tell me about the structural problems they have encountered with the new houses—leaky roofs, intolerable heat and improper drainage—I wonder what has improved in their lives since the completion of this nine-month project.

With barely a pause, the village leader says with approving nods from the others, “People are not as scared of us anymore. The farmers come into the village to ask for tobacco when they run out, and they’ll sit and talk with us for a while. That never happened before the volunteers came.”

Ma Nengxian adds, “The farmers are nice and we enjoy the

chit-chat. Sometimes we ask them to get us supplies when they go to the county center, and they do.”

Dr. Mou has positive feedback as well. “Some of the farmers have asked about renting space in the old houses to use as barns. This must mean they’re not afraid of proximity to the leprosy-affected villagers.”

Although the project neither challenged the government policy of isolation nor directly confronted local discrimination, the example of interaction without fear put positive change into motion.

This sentiment is echoed by representatives from the county-level Disabled People’s Federation, who look after all disabled people in Fusui County but have less direct interaction with the Dingwo villagers. “The impact within the county has been great. Everybody knows that a foreign organization is coming to help disabled people here; they feel like they should also help the disabled people among them.” These stakeholders share a belief that after 50 years of isolation and ostracism from the greater population, attitudes towards the leprosy-affected villagers are finally beginning to change.

For the NGO, reduced stigma is an unexpected and welcome outcome of a project that sought merely to meet residents’ material needs. Although the project neither challenged the government policy of isolation nor directly confronted local discrimination, the example of interaction without fear put positive change into motion. Bringing half a dozen groups of foreign volunteers to work among the leprosy-affected villagers over the course of several months improved relations between the villagers and Fusui County residents to an extent that had eluded years of effort by local officials.

The change is better late than never for Dingwo’s present residents, but there are indications that the discrimination they long suffered might be passed on to a new set of tenants. When officials in Fusui County were asked about long-term use of the village once its elderly residents pass away, they mentioned housing AIDS patients as one possibility.

Liang Jiexiong, a program officer with the Futures Group that advocates to the Guangxi provincial government on HIV/AIDS, thinks this idea is most likely just the opinion of a few people and highly improbable because of “many problems about regulations, law and ethics.” Also, Dingwo does not have the capacity to handle the large number of people living with HIV/AIDS. According to Skin Disease Department officials, there have only been 615 cases of leprosy in Fusui County

since 1956, but there are currently more than 200 cases of HIV/AIDS. China’s Action Plan (2006-2010) for Reducing and Preventing the Spread of HIV/AIDS further notes, “. . . in some areas the trend of high epidemic appears . . . to be spreading from ‘high risk populations’ to ‘general populations,’” and there is speculation that the actual number of local cases is much higher than the official count.

Although it is highly unlikely that officials would be able to isolate people living with HIV/AIDS (PLHA) in the same way as people with leprosy, discriminatory attitudes that led to a policy of isolation persist. Liang Jiexiong observes, “Stigma and discrimination are the hardest parts of the [HIV/AIDS] work.” He says some officials hold the opinion that PLHA get preferential treatment over “normal people,” while there is a popular perception that PLHA are “bad people”—prostitutes and intravenous drug users—who contracted the disease through their own risky behavior. Other people in the wider community resent public funding for free education for the children of PLHA and psychological counseling for PLHA and their families when they themselves enjoy very little government assistance. This hostility allows some government officials to rationalize archaic policies such as isolating PLHA in “leprosy-style” villages rather than implementing progressive education, treatment and care policies. Without this kind of public education, can PLHA expect to be treated any better than the leprosy-affected villagers have been?

In the case of Dingwo, the policy of isolation proved destructive to the lives of the villagers, and created a new set of problems as leprosy-affected people were rendered completely dependent on the government and unable to reintegrate back into society more than 20 years after being cured.

Habitat’s home-building project in some ways reinforced this policy by acquiescing to fix problems created by discriminatory policy. At the same time, the INGO’s attention to the village inadvertently sparked better communication and mutual support between the villagers and their neighbors.

In these new beginnings lies a great opportunity for local authorities to start fresh as well, not only by continuing to reverse the fear and hostility towards leprosy-affected people that lingers from 50 years ago, but also by learning from their mistakes to address discrimination against people affected by HIV/AIDS. There is also an opportunity for INGOs working with local officials like those in Fusui to grow in their capacity. Through consciously choosing to participate in non-discriminatory projects, INGOs can effect positive societal changes instead of fixing problems created by bad policies. A paradigm shift in this direction could bring more effective implementation of AIDS policy.