

# HOPE

A report on the Work Camp at Hansen's disease "Recovery Villages" in China



## What is Hansen's disease?

Hansen's disease (also known as leprosy) is a chronic bacterial disease caused by *M. leprae* that mainly affects the skin and nerves. *M. leprae* is not very infectious and over 99% of people have a natural immunity or resistance to it. If treated early, it can be cured without impairment or permanent disability.

In 1981, Multi Drug Therapy (MDT), an effective cure for the disease, was developed and officially recommended for use by the WHO. It is now available free of charge to all who need it.

Nevertheless, people affected by the disease, as well as their family members, continue to be marginalized, facing stigma and discrimination worldwide to this day.

### Hansen's disease in China

China isolated people affected by Hansen's disease till as late as the mid-1980s, though it never enacted any official legal measures to this effect. People were isolated at special Hansen's disease hospitals that had two distinct sections: a medical ward, and a residential area that was located far from the hospital proper. Over the years, the success of MDT has led to the closing of the medical part of the hospitals. However, close to 20,000 people still live in the residential areas, in spite of the fact that they were clinically cured of the disease many years ago. These people remain here because

they have not been able to return home or find places to live in the general populace. The places where they live are still feared and isolated. While it must be stressed that the individuals living here are completely recovered, for lack of a better term these communities will be referred to as "recovery villages" in this booklet, to differentiate them from other villages.

605 of the recovery villages are known to exist today, mostly in the south of the country. Living conditions vary, but are generally impoverished, lacking such basics as safe housing, water, electricity, or basic sanitation. Residents must subsist on a meager subsidy from the local government—not nearly enough to pay for anything more than their most basic living expenses let alone their medical needs. Those who suffer the most are the aged with severe disabilities who can no longer earn.

Stigma and discrimination contribute to further hardships. People living in these villages seldom communicate with the outside world, including nearby villages, or even their families. They have been isolated and forgotten. Many have lost hope. Recently however, a number of recovery villages in the South have been undergoing exciting changes that are bringing down the 'walls' that have cut them off for decades. These changes are being wrought by work camps run by student volunteers.





## What is a work camp?

Work camps were originally started by the Quakers after the First World War. Work camps usually last from one to three weeks, during which some 25 or so volunteers work together for on construction and repair works.

One result of their work is of course the concrete outcomes, such as house repair, installation of water pipes or building toilets. Another, equally important product is the bonds that form among the volunteers and local people.

Recently, work camps at these Chinese recovery villages have also proven their potential as an engine for social change.



## Work camps in China

The first recovery village work camp in China was organized in 2001 by Japanese and Korean students. No Chinese students were involved then, and the residents of the recovery villages themselves had no expectations that they would be.

“It will probably take another 15 years before any Chinese students participate in a work camp,” said one resident.

“Young Chinese aren’t interested in this kind of activity,” said another.

Fortunately, that day came much earlier than anyone had expected. The change was brought by a Japanese college graduate, Harada Ryotaro, who in 2003 went to China to live in a recovery village called Linghou. With Linghou as his base, he began visiting universities in an attempt to persuade students to take part in the work camps.

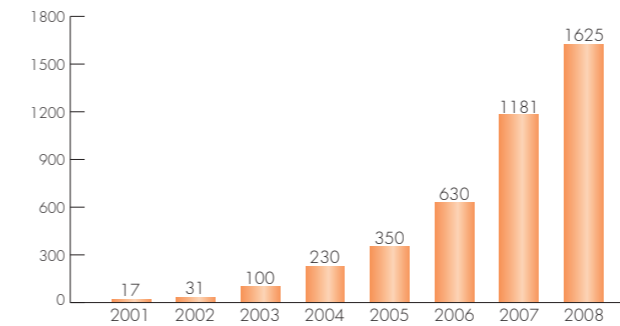
When he first approached students and asked them to join the work camp, their response invariably was, “Are you really

sure we won’t catch the disease?” Harada met with a lot of suspicion at first, but over time he was able to persuade increasing number of students to take part. As the number of Chinese students increased, they started to take up central roles of the work camps, such as conducting preparatory surveys and raising funds.

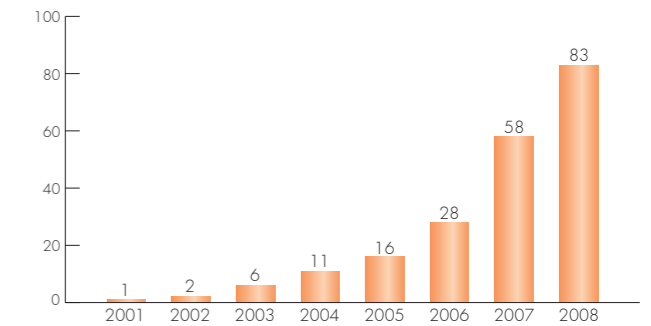
The biggest boost to the growth of these camps, however, was the founding of an NGO, called Joy in Action (JIA). JIA was established by Harada in 2004 to organize support work camps at recovery villages. Since its creation, they have increasingly taken root in China.

JIA has developed at a remarkable speed since its inception. In 2008, no fewer than 83 work camps were held in 5 provinces, drawing the participation of 1,625 young people. While no Chinese student participated in 2001, by 2008, fully ninety percent of the participants were Chinese.

The Number of Volunteer Participants in the Work Camps



The Number of Work Camp Projects



Harada Ryotaro, Social Change in South China

## Changes that work camps brought about

The work camps at recovery villages have had an unexpected effect as described below. They have facilitated not only the improvement of living conditions, but also personal and social changes for the residents and society.

### From nameless people to personal relationships

In the beginning, a work camp consisted of a group of villagers and student volunteers who do not know each other. However, through the shared experiences and projects at the work camp, they begin to recognize each others' individual personalities. Gradually, their relationships develop to the point where they no longer see each other as nameless members of "that group" but form ties as individuals. Those who once had Hansen's disease realize that student volunteers are naturally easy to get along with. The students also realize that some of the villagers they are helping have stood up against the hardships with strong spirit and have overcome the fact that they once had the disease. This awareness generates strong bonds among them, thereby motivating and energizing the both sides to work to change society in many ways.

### Changing the attitudes of neighboring communities

Intrigued by the situation of people living in recovery villages, student volunteers have repeatedly returned to the villages to stay and help the villagers in their daily life. Gradually,

it has become natural for the student volunteers to be seen moving to and from the recovery villages. Then the people in the surrounding communities began to take an interest in the students' activities themselves, and start visiting the villages. Watching the student volunteers talk, eat, drink, and play normally with the "fearsome" people of the recovery villages has gradually erased the fear that the neighbors had felt.

### Media interest

As students' volunteer activities have increased and become known to outsiders, they have attracted the interest of the media. Newspapers and television stations produced reports that have attracted the attention of even more people. Charity organizations, hospitals, corporations, governmental organizations and volunteers have begun to help the villages with financial, material, medical, and spiritual support.

### Familial relationships

Students' volunteer projects have not stopped with the development of village infrastructure. They have gone on to create projects in such fields as public education, day-to-day living assistance, entertainment and art. Through these projects, the bond between the residents and the student volunteers became stronger, and eventually lead some residents to revive their hitherto suppressed desire of restoring their family ties.



Some expressed their wish to be taken home—a place where they had never visited for decades. Thus, the work camps have started a new initiative that is to rebuild ties between villagers and their families.

### Recovery villages are not a social problem

As mentioned, recovery villages are not a social problem. The people who live in these recovery villages are not a weak group of people for whom we must feel sorry. Rather, they are a group that has motivated the student volunteers and the

general community to begin to regard social problems as their own problems. The recovery villages are not a social problem but it empowers people and the community to jointly find a cooperative solutions. Work camps are the tool through which this can be achieved.



We went to a market, hand in hand with our Korean and Japanese friends, and the people at the market got startled. They gazed at us, forgetting their business. The stigma, I think, has been erased from their mind.

The most important things are not toilets and canteens being built and repaired. It is the comfort, care and support they give us.

Our friends from Korea and Japan have a deep affection to us. But we always wondered why Chinese students would not come.

Our expectation was that, maybe, Chinese students would come in about 15 years. But look! We now have you. I have changed my mind. I have started to have hopes.

Ou Jingzhao





## Stories of Linghou Village

The following pages describe the changes that took place in Linghou, little changes that eventually led to the organization of 83 work camps attracting over 1,600 participants each year.

The story is told through the eyes of Harada Ryotaro, the young Japanese volunteer who called on Chinese students to participate in a work camp, and Cai Jiesshan, a university student who took the time one day to listen to what Harada had to say. In their writing, the word "village" refers to recovery villages, and similarly "villagers" is a reference to the people who live there.

It is our hope that the little changes that took place in the recovery village of Linghou will spread like ripples reaching beyond China's borders to touch the hearts of people far and wide and bring about a big change to end stigma and discrimination against Hansen's disease worldwide.



## Linghou Village

Linghou Village, Chaozhou City, Guangdong Province, was established in 1960 by the Chinese government as a place to isolate those with Hansen's disease.

In 1960, more than 300 patients arrived from Chaozhou City to receive medical treatment at Linghou Hospital and were forced to stay in the village. Due to the shortage of beds in the ward, 4 patients had to share one small room that was, in most cases, about 30 square meters.

With the development of a cure for the disease, many people were discharged, and the hospital gradually stopped treating both Hansen's disease and other illnesses. However, of those who had been cured, there were many who had serious physical disabilities and others who did not have a home to return to. These people had no choice but to remain in Linghou.

In 2002, more than forty years after Linghou hospital was built, there were only 14 people remaining, with average age of 65. The houses were falling apart. Not only was the buildings dangerous, but there was no water, electricity, sanitation, kitchen, gas, nor source of income or medical care. Many of the residents had no communication with their families or friends.

Residents had to draw water from a well with a broken hand pump. Their only sources of light at night were candles and lanterns. Firewood was used for cooking, which was dangerous, especially to those who have lost sensation at some parts of their body. Toilets were no more than buckets that they kept in the dilapidated rooms, which were darkened with soot and ashes. They had to care for themselves medically, especially for injuries on the numb parts of their bodies. The bandages with which they wrapped their numbed limbs had to be repeatedly washed, as they would turn dark with blood and pus.

The living conditions, aftereffects of the disease, and appearance of the people scared outsiders. Moreover, the lack of the correct knowledge about Hansen's disease added the stigma. As a result, most people outside avoided to come near to the village. This included family members.

Linghou is no longer a hospital, but just a poor village managed by the government. It is still called Linghou Hospital but because of its stigma it is called "Hansen's disease village". It is neglected, abandoned and forgotten by most of the society including the families of the residents.





## My First Impression of Linghou

Cai Jiешan

I clearly remember September 13, 2002; it was the first time I became aware of work camps and began to take part in volunteer activities.

After a presentation on work camps by volunteers from Japan, some of my classmates were curious about their activities, but were at the same time slightly worried about the effects of the disease. We looked up the term in the dictionary and found that it was called "Hansen's disease" in English. After some debate, my friend and I decided to visit Linghou.

We took a bus and got off at the crossroad in the town of Guxiang, where there were a lot of tricycles - the only possible means of transport to Linghou village.

To our immense surprise, when the tricycle drivers heard that we wanted to go to Linghou, they first confirmed whether we want to go to the "Hansen's disease hut," and when we said yes, they refused to take us. When we inquired why, they laughed and asked us why we wanted to go there and made comments on what could possibly motivate people to go there.

Finally, one of the drivers agreed to take us, at a higher rate, to Linghou Hospital, which was about 300 meters away from where the villagers lived. When we arrived at the hospital, the driver drove away immediately.

The next weekend, we went to Linghou again. When we

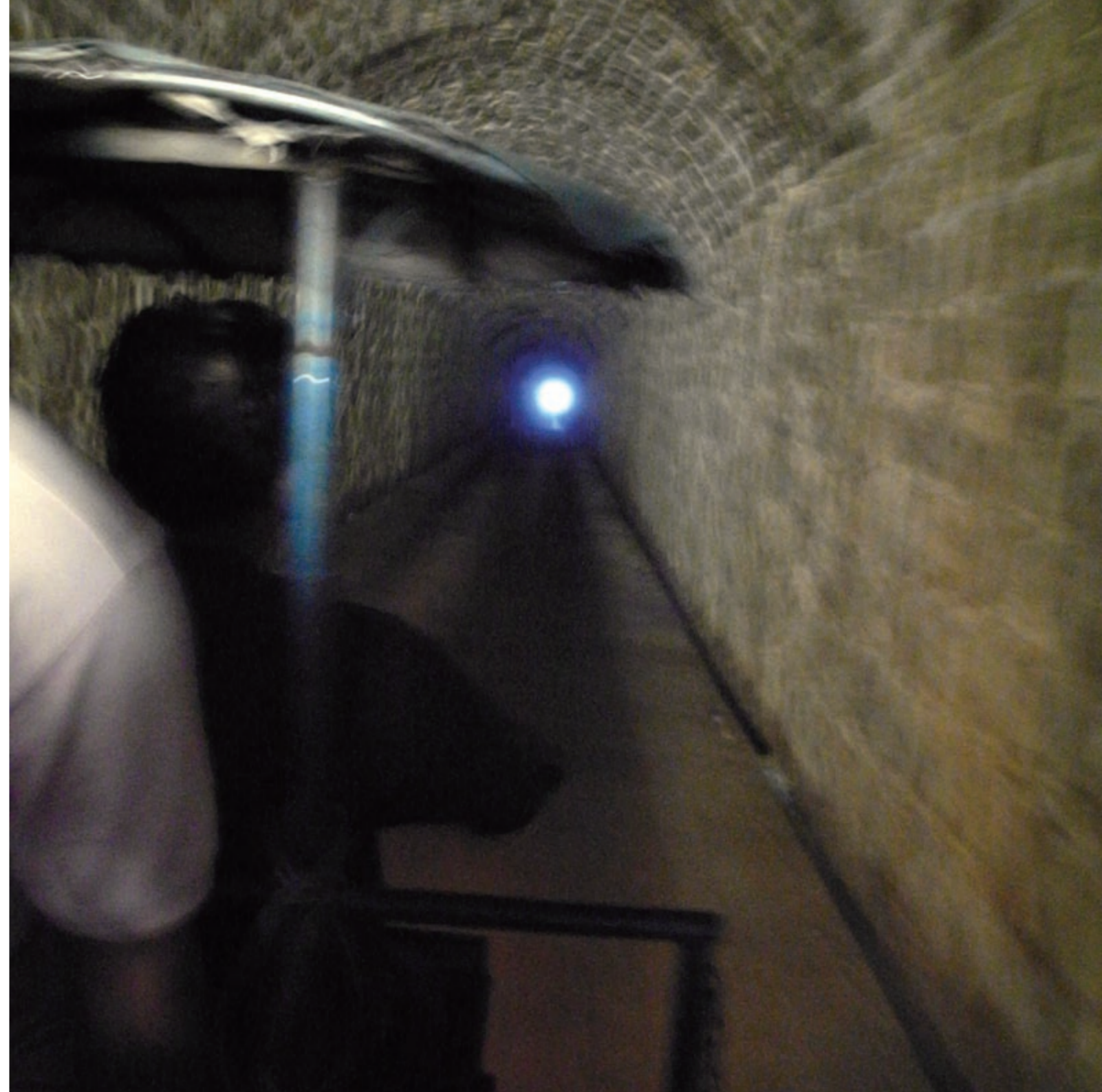
arrived at the crossroad, the same driver saw us and asked us whether we were going to Linghou again.

We nodded and he offered to take us on his tricycle. When we asked him whether he could take us to the village directly, he hesitatingly said that the mountain was very hard to drive on. We replied that it was a very short road, and he reluctantly agreed and waved us onto his trike. On arriving at Linghou, while we visited the villagers' houses; the driver shuffled around watching us.

Other volunteers also asked for the driver's telephone number, so that he could take them to Guxiang market every morning. Soon, most of the drivers at the crossroads of Guxiang knew us and knew about Linghou.

Seven years have passed; Linghou has become one of the places where I feel like going whenever I have the time or when I just feel tired.

In July 2009, when I revisited Linghou, I was amazed that something happened. Before I left the village, I called the tricycle driver and asked him to come get me. I was still packing my things when he arrived. While waiting for me, he went into one of the houses and had Gongfu-tea with the villager. This turn of events sparked some hope in the volunteers' minds.







Su Zhenquan (right) and Harada Ryotaro



## The First Work Camp in Linghou Village

### You are not a patient anymore

Harada Ryotaro

At sunset in the middle of the work camp, I walked around Linghou after working on the toilet construction. Mr. Su Zhenquan lives far away from the rooms that the volunteers rented. On arriving at his room, I found him having supper. Mr. Su is of a small stature, and was sitting in front of a door, facing a small wooden table.

“Ni Hao, Ni Hao!” We greeted each other, and then, a small plastic tumbler, like a bottle of liquor, came into view. Mr. Su was drinking during his supper. He calmly asked me whether I drink.

The life of the villagers is economically hard. I sipped the drink very slowly, so as not to waste his liquor. There were a variety of simple foods on the table, including a leg of ham boiled with soy sauce, a white vinegar-based sauce with Chinese herbs and crushed garlic, fried peanuts, dry sausages, and soup with Chinese cabbage. He asked me, through gestures, whether I would like to eat. Mr. Su cannot stand up anymore. So, he used two cushions made of plastic bags to walk and brought me a set of chopsticks from his room.

“Hou Jia!” (Yummy!)

The front porch of Mr. Su’s house is surrounded by trees, and I enjoyed the relaxing feeling of watching the calm sunset with a drink, after a day of hard labor.

“Xie Xie!” (Thank you very much!) I said.

Mr. Su leaned back to laugh and waved his hand with deformed fingers to indicate that I was welcome, after which he began to write on a soft case of cigarettes in Chinese characters, “You are not afraid of Hansen’s disease patients; I am moved.”

“You are not a patient anymore,” I wrote.

After reading what I had written, he laughed and said something through hand gestures showing his bent fingers.

“That is only an aftereffect.”

On seeing what I wrote, Mr. Su happily raised his glass to me.

From that day on, I always visit Mr. Su whenever I have the time.

Mr. Su does not carry an atmosphere of sadness. Even in difficult conditions, he finds things to enjoy and lives life to the fullest. In the past, he was a good cattle breeder, but after he contracted the disease, he was isolated, and had to work to live. Then, because of the hard labor, his disabilities and deformities worsened, rendering him unable to walk. Still, he survives. He has overcome the fact that he contracted Hansen’s disease and has come to accept and live with it.







Zen Fanyu (left) with Cai Jieshan and her baby



## 8 years after the first work camp No more suffering

Cai Jiешan

I went to Linghou again in the Spring Festival (Chinese new year) with two friends.

The village looked the same and lacked the atmosphere of New Year; it was rather quiet. Only Uncle Guo came out to see who had arrived.

When we reached the porch in front of the villagers' house, we found some cooked pork and chicken in front of every door, along with bags of rice and bottles of oil.

We went to the leader of the village, Uncle Su. He was in his sitting room, talking to another villager, Uncle Xu. They told us that they had a busy New Year's Eve this year. In the past, the journalist, Ms. Xie, had been the only person to visit them every year during the new year. This year, to their surprise, not only Ms. Xie but also people from two charity organizations, one from the City TV station, and another businessmen from Chaozhou City had come, having heard that there were some student volunteers here. They donated food, snacks, cotton quilts, and money to the villagers.

While we were still having tea in Uncle Su's room, Uncle Guo came in and told us that another Uncle Su (Zhenquan) had invited us to have supper with him that night.

It was four o'clock in the afternoon; the second Uncle Su had already begun to prepare for supper.

In the corridor, he sat on a cushion, in front of the stove made by volunteers, cutting firewood. We could hear the sound of food boiling in the pot on the fire.

We greeted him and he raised his head, smiled at us, and took the cigarette out of his mouth; "Let's have supper together tonight," he said.

He had cooked us a traditional Chinese stew. I was so excited to see the ancient-style stew with the fragrance of charcoal, and I like Uncle Su's style of cooking very much as well. He always cooked delicious food with very simple things like cucumber, parsley, and dried bean curd sticks.

As the food began to boil, we could smell its fragrance. Uncle Su poured us some alcohol. We raised our cups and toasted him for the New Year. He took a sip of the alcohol, stopped and looked somewhere far away. Then he smiled and said, "I read the book *"No More Suffering"* by Mr. Lin Zhiming (a person who has recovered from Hansen's disease). Today, I really feel no more suffering." He then raised his cup again and said "Kiac (Cheers)."





"Yesterday Tynoon (Harada Ryotaro's nickname)

nursed my foot again;

I always tell him not to do it.

My feet are too smelly.

But he would not listen to me.

He is so very kind."



## A Deeper Bond

Cai Jiешan

When I first walked the mountain road of Linghou, I thought that it was a utopia; When I first saw the people of Linghou, I thought that it was hell on earth. And when I met Aunt Cai Wanqing of Linghou, I could not stop from visiting her again and again.

It was dark in her room. The only light was from the window on the opposite side of the door. Just the window was bright, while everything else was dark. It was hard to see, but she was there, sitting on her bed in the corner. I entered and greeted her, and found that she was blind. Dust, mold, and the smell of pus were all that I could sense in her room.

There was a bamboo chair beside her bed. She did not ask me to sit down as Chinese people usually do, but I sat down anyway. She reached out and searched out a cigarette. She did not light it but kept it in her hand, which had only two fingers. “Where are you from?” she asked me. “I am a student from Hanshan Teacher’s College,” I said. She nodded.

That was our first conversation.

After that, I often went to Linghou Village and somehow always found myself in Aunt Cai’s room before going to the other villagers. Gradually, we became something like friends. I would always sit on her bed. Sometimes she asked me to light a cigarette; sometimes I kneaded her shoulders and arms.

Most of the time, we talked.

Once on a hot summer day, while talking with her as usual, I suddenly asked her, whether I could bathe her. I was a bit surprised when she agreed at once. I then made arrangements for the water and bucket. When she took off her clothes, I found that she was extremely thin. She seemed a bit shy, and I tried my best to help her relax. But when I saw her foot, I was shocked. I could not call it a foot. It had no toes and had lost its shape completely.

Tears welled up at once.....

Although she could not see a thing, she seemed to sense something and said, “Yesterday Tynoon (Harada Ryotaro's nickname) nursed my foot again; I always tell him not to do it. My feet are too smelly. But he would not listen to me. He is so very kind.”

In this way, I gradually came to know Aunt Cai and found her to be an elegant and pure lady. She asked me to call her “sister,” as she was not married and in her heart, she was still a girl.

Day by day, the story of this little girl was revealed to me.

She contracted Hansen’s disease when she was still little. Although her parents took her to doctors and tried many kinds of Chinese medicine, her disease was not cured and in fact

became worse.

One day, while looking at herself in the mirror, she was shocked to see her own face with the obvious symptoms of Hansen’s disease—white spots. From that time onward, she hid in the house and never went out.

During those endless days, she attempted suicide three times but was saved by her parents.

One day, a doctor from the local Center for Disease Control and Prevention (CDC) visited and asked her mother to let her go to a hospital for medical treatment.

Usually, when people visit a hospital, they receive medicine and then go home. But for those who contract Hansen’s disease, as the doctor from the local CDC told her mother, it was necessary to remain in the hospital and be segregated.

On hearing this, her mother held her breath and began to cry. The doctor then said, “You just think of her as your daughter who will leave you sooner or later anyway, since she will get married sometime in the future.”

Her mother had to agree with the doctor, since that was the policy toward people with Hansen's disease at the time.

Aunt Cai was listening to the conversation from behind the door. On realizing that even her mother had no power to protect her from being taken away from the family, she

collapsed and cried silently.

When the day came, she packed her clothes, quilts, and food from home, and began her life in an isolated hospital. That was the destiny of almost all people with Hansen’s disease at that time.

Her story cannot be regarded simply as a girl who leaves her parents and gets married. In fact, it could be seen as the same as the destiny of a person with an unstable mental condition who lacks the love of family and friends. In her case, she was forced to live under terrible conditions with poor housing and only rudimentary medical treatment, and had to slave away on a farm just to survive. Due to these harsh conditions, people with Hansen’s disease continued to suffer from very serious aftereffects on their body.

As Aunt Cai told me, her boyfriend came to the hospital after she had been admitted. His first visit was his last.

Fifty years have passed. Aunt Cai has lost her eyesight, her toes, and has become an old woman. People can never regard her as a girl, especially at first sight in the darkness, the dust, the mold, and the smell of pus surrounding her. People can never imagine the story of that little girl is in fact the story of this old woman.

## The people themselves change

Harada Ryotaro

During a work camp, a volunteer was walking hand in hand with one of the villagers at a market near the recovery village. People in the market were shocked to see the “fearsome Hansen’s disease villager” shopping with a pretty girl! A huge crowd watched the two. Since that day, however, the stigma against that village has drastically decreased. One action is stronger than an infinite number of talks and pamphlets.

The volunteer was not trying to prove something by walking hand in hand with the villager, but it was a natural action for her because two weeks in the work camp had helped her form a good personal relationship with the villagers.

Inspired by this, other villagers also have felt encouraged to remain strong.

Mr. Fang Shaoping, a villager in Linghou, agreed to an interview at the local TV station during a work camp. The TV program aired in Chaozhou City with his name and face, and his family and neighbors saw it.

“My family feels uncomfortable about me because of the interview,” he said afterward.

They were surprised to hear that Mr. Fang, their own family member, was in Linghou Village, having recovered from Hansen’s disease. In fact, Mr. Fang had not told anyone that he had contracted the disease, but just said that he was going

to a place far away from Chaozhou, and that he would come back to town a few times a year.

Why, then, did he agree to the interview, I asked.

“Well, to complete a good media report on our work camp, it was necessary to have an interview with one of us. If it had not been for you, I would have refused to give the interview,” is what he said in response to my question.

After the TV program, he visited his home but was not welcomed or cared for by his family as he had been earlier. He cried in front of me because of their attitude.

Several months later, a newspaper printed his photo and name without obtaining his permission.

“No, I’m not happy about it. However, if it is necessary to show my face to the media, I will. I will never be defeated by my family’s opposition.”

He is determined to devote himself to reducing discrimination against people with Hansen’s disease.

“After you came to Linghou Village three times for work camps, I began to take a broader view of the matter.”

Since he said that, the villagers in Linghou Village are more than willing for me to use their photos and names as and when I like.



## An Afterword – Hope

Harada Ryotaro

On November 29, 2008, Jieshan and I were blessed with a daughter, and named her “Linghou.” The Linghou Village that once was a symbol of segregation and stigma is now a place where we can meet new people, build and strengthen relationships, and revisit time and again. Linghou has come to us to symbolize the bond between people, which is why we named our daughter after it.

When Jieshan and I took our daughter to Linghou Village in the summer of 2009, Uncle Zeng gave her many Nec Oi (dragon eye fruit ) to eat. Ever since, she calls him “Uncle Nec Oi.” In January 2010, while staying at my home in Guangzhou, I revisited the village. When I telephoned my daughter so that Uncle Zeng could talk with her, she said,

“Papa went there to Uncle Nec Oi.”

Uncle Zeng was overjoyed. After the phone call, he asked,

“You will come back here for the Spring Festival, right? And you will bring Linghou and Jieshan?”

Uncle Xu said,

“Let’s cook something delicious when the three of you return.”

He smiled and gazed off into the distance.

Uncle Guo drew me a picture of a child.

“Who is this,” I asked.

“This is Linghou,” he said, and laughed.

Will they live long enough for Linghou to remember them?

I hope that the souls of the people who lived and died in Linghou bring hope to the people still living there, and I hope further that this hope will be transmitted to the people of Asia and eventually the world.



# HOPE

A report on the Work Camp at Hansen's disease "Recovery Villages" in China

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