



Back in Sight, Back in Mind

**HANDA: Healing Wounds for the
Traumatized and Stigmatized**

*Zhu Jiangang, Center for Philanthropy at Sun Yatsen University
and Gene Mustain, Centre for Asian Philanthropy and Society*

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In partnership with people taken from their families and confined to remote camps before a cure was found for a destructive disease, HANDA Rehabilitation & Welfare Association helps the leprosy-afflicted find comfort and dignity while contending with the emotional and physical consequences of lives lived in isolation.

Most people think of leprosy as a thing of the past. For about 21,000 people in China, it isn't. They live in tiny isolated villages and contend with the emotional and physical consequences of one of history's most dreaded diseases.

Leprosy became treatable and curable over the late 1970s and early 1980s, and a Chinese government policy to take leprosy-afflicted people from their homes and families and confine them to prisoner of disease camps ended in 1989. But the policy change meant little for many of the afflicted.

Many of their former communities and their relatives did not welcome them home with open arms, but instead a cold rebuff born of a continued fear of leprosy. Many had no choice but to stay and live with the only



What is now their backyard is where villagers used to live.



Huang Tanlin of HANDA offers encouragement to villager whose right foot was partially amputated in surgery 10 days before.

communities they had known most of their lives – others like them, disabled or disfigured in some way, including having lost all feeling in the nerves of their arms and legs, which in many cases had become stumps, robbed of hands and feet.

And so, in China, as in other developing countries, such as Brazil and India, leprosy villages live on. In recent years, the Chinese government moved to improve conditions in its villages, but for years after 1989 and in some places still today, the villages were forlorn and ramshackle places, an uncomfortable symbol of how the unfortunate can be shunted aside, out of sight and out of mind.

The government located the villages high on mountains and deep in forests, many kilometers from other rural communities. Most who live in the nearly 600 villages today arrived 40 to 50 years ago, traumatized by disease and separation from loved ones – and stigmatized by society as people best to avoid. There is no reason to avoid them; they cannot spread the disease to others because

they are no longer infected with the bacteria that cause it. Even so, a kind of a public scorn still shadows them, as if they had committed some disgraceful act.

“There has been deep-rooted prejudice against people affected by leprosy, a prejudice that still exists today,” said Dr. Michael Chen, secretary general of HANDA Rehabilitation & Welfare Association, a NGO headquartered in Guangdong province that provides services to leprosy villages in 12 of China’s 23 provinces, but mainly focuses on Guangdong, Guangxi and Yunnan provinces, the three with the most villages.

The NGO is commonly known as simply HAN-DA. The first three letters come from the surname of a Norwegian doctor, Gerhard Hansen, who in 1873 identified the bacteria that cause leprosy and which typically breed in areas with low-quality water and sanitation. The last two letters of HANDA are a tribute to the first name of Damien de Veuster, a Belgian priest who devoted his life to helping residents of a leprosy village in Hawaii.

The organization’s name was the idea of a Chinese professor and doctor, Yang Lihe, who spent his professional life researching the treatment and prevention of leprosy. In 1994, he traveled to Brazil for a conference of leprosy experts from China, Cuba, India, Korea and the United States. The conference led to the formation of the International Association for Integration, Dignity and Economic Advancement, which became known by the acronym, IDEA, for Integration, Dignity, and Economic Advancement. The choice of words signaled an approach beyond medicine and research to activism by national branches of IDEA on behalf of people isolated against their will and powerless to do anything about it.

Dr. Yang returned home and retired from his academic and medical careers. With the support of leaders of leprosy villages that he began visiting in Guangdong, and with the support of colleagues and the necessary cooperation of national and provincial health officials, he laid the regulatory, governance and administrative frameworks for an IDEA branch

in China. In 1996, HANDA became the nation's first NGO working on behalf of people affected by leprosy. Technically, as is the case with most NGOs in China, it is a GONGO – government-owned NGO, but Dr. Yang had built enough bridges that he could deal with government rules and politics.

At the beginning, Dr. Yang used the balcony of his home as the HANDA office and paid its expenses from his government pension. As is the case with other NGOs in Asia that begin with the compassion and determination of one person, Dr. Yang is revered today at HANDA, by former patients, colleagues and HANDA beneficiaries. He died at age 82 in 2011, but lives on in name as one of two honorary members of the HANDA Committee, HANDA's board of directors. HANDA also still operates by principles that Dr. Yang and his colleagues at IDEA adopted at the outset – including the right of residents of the leprosy villages to elect board members and to help design and run programs.

“Dr. Yang was one of the most important people in my life, my mentor,” said Dr. Chen, who began as a volunteer for HANDA and saw how nervous people were in the presence of the leprosy-afflicted, or even those who had been in their presence. “In the early years, I was afraid of telling people I volunteered for HANDA,” he said, “because I knew how people would react when they heard the term, ‘leprosy.’”

By the time he retired and founded HANDA, Dr. Yang, born poor in Jiangxi province, was one of the world's leading researchers on leprosy. He began achieving some success in treating patients during the 1960s, using dapsone, an antibiotic, in tandem with traditional Chinese medicine. But success was limited because he was one man against a plague-like problem in a nation with a startup national healthcare system. In the 1970s, he focused on counseling patients and teaching rural doctors how to recognize the disease. In 1985, he joined the government's main leprosy research center and was soon its deputy director.

Meanwhile, World Health Organization researchers and others developed a mix of antibiotics

known as MDT, for multi-drug therapy, that was found to be the best treatment for those starting to show the first telltale sign of leprosy – pale and scaly skin. WHO and NGOs, including the Sasakawa Welfare Foundation of Japan, began supplying China with MDT. The combination worked so well that by 1998 China announced that leprosy had been eliminated in China, using the WHO standard of only one new case for every 100,000 people.

As deputy director of China's leprosy research center, which had been cooperating with WHO and NGOs, Dr. Yang saw the cure coming, and with the founding of HANDA in 1996 and the principles of IDEA, he shifted his focus to helping people still living in the leprosy villages, traumatized and stigmatized.

THE PEOPLE OF SHANGPING

The road gets narrower the farther the van penetrates the forest two hours north of Guangzhou. Stands of grapefruit and orange trees lean closer on both sides, squeezing the van into a sandy brown dirt lane leading to Shangping Leprosy Village in Boluo County, one of Guangdong province's 67 leprosy villages. It's easy to see why a Chinese government paranoid about leprosy began hiding victims in a forest like this after the revolution came to an end in 1949. It was a long hike to the nearest town, about 20 kilometers in the case of Shangping.

The coordinator of a community development program for HANDA, Huang Tanlin, an earnest and engaging 26-year-old who goes by the name Circle, is in the front seat, briefing visitors about Shangping and its citizens. The village was built in 1950. Eighty-six people live there. Their average age is 71. Most never had children, not because they didn't want to, but because they were not allowed. Most arrived between aged 20 to 30 years, destined in many cases to grow worse rather than better, objects of fear rather than compassion.

“Some may have brothers and sisters, but none to take care of them,” Circle says.

The villagers were cured of leprosy in the 1980s and 1990s, after the multi-drug therapy became

widely available, but many had been damaged in ways that cannot be repaired, but can be improved or made easier to bear – HANDA’s mission, which it pursues with social, psychological, physical and economic-empowerment programs run by its staff and by village leaders, aided by many volunteers.

Recently, the government also has stepped up. It increased the villagers’ monthly subsidy from US\$77 to US\$128 the last two years, and three times a month it sends a van to transport some to the community 20 kilometers away to buy food. While there, they get the chance to sell, at least to those who don’t feel jittery around them, the dried sesame seeds and honey they produce back in Shangping.

“Why honey?” a visitor asks.

“Because they have the skills,” Circle says. “They had one villager who started feeding the bees, Mr. Hu, and now they have six who can feed the bees.”

Circle explains that Mr. Hu and the other bee feeders breed many thousands of bees that then yield the honey that with HANDA’s help the villagers have learned to harvest, package and sell. It’s economic empowerment in which scale doesn’t matter so much as self-worth and sense of achievement.

The van suddenly comes upon a bright green field where off to the right a dilapidated shack, probably an abandoned chicken coop, is engulfed in weeds. The van continues past the field, slightly up a hill and into Shangping village, which is just an off-white, one-story concrete rectangle of one-room, motel-like compartments that open onto a central courtyard.

Circle escorts the visitors past banana trees to a patch of dirt just beyond the rectangle and introduces Mr. Hu, the village’s first bee feeder. Mr. Hu has skin baked brown by life in the sun, grey stubble, wisps of white hair and a bit of a paunch beneath a frayed white T-shirt. He’s standing beside a grey wooden ventilated box about as high as his knees. It contains hundreds of bees clinging to mesh screens, and he pulls one of the screens out of the box like it was toasted bread.

“This is not the right time to feed the bees, not the season for it,” he says.



Hands of village residents point to bees feeding on sugar-covered screen.

So instead of feeding the bees flour, as he does in the season for harvesting their honey, he soaks the screens in sugar so they’re sated and don’t fly off.

He extends the screen toward his visitors to offer a very close look at the bees. The bees, gnawing at the sugary screen, couldn’t care less.

Mr. Hu puts the bees back in the box and starts walking up a small rise and then along a dusty path parallel to the back wall of the rectangle, past broken-down sheds, rusty buckets, garbage, and a communal outhouse. The sheds housed the Shangping people until a few years ago, when their concrete motel-like rooms were built. A little farther down the path is a vegetable garden the villagers use for augmenting food purchased with their government subsidies from the town. The villagers have the medications they need now to protect them, but the conditions along the path are terribly ironic; they comprise a virtual recipe for incubating the leprosy bacteria that defeated their immune systems years ago.

Mr. Hu says he taught himself how to breed bees after a commercial bee farm donated a box of them to the village. He stops by a partially intact shed, where he stores some of his older bee boxes. He stands in the doorway and talks about his past. The government sent him to Shangping 50 years ago. He was 15. His parents were still alive.

“I was very sad,” he says. “I didn’t want to go.”

He leans against the shed's doorframe and looks silently downward, as if to consider some private moment. Following his downward glance, a visitor sees for the first time that his right hand has only two gnarled fingers.

THE TENT CIRCLE

Give orders to the children of Israel to put outside the tent-circle every leper, and anyone who has any sort of flow from his body, and anyone who is unclean from the touch.

—Numbers 5:2 BBE

Those Old Testament words underline the trauma and stigma leprosy victims have faced at least since the authors of the Hebrew Bible began telling their story of life many centuries ago. A lot of other evidence shows leprosy has stalked humans at least since ancient times, but some scientists say it is actually millions of years, and that it is possibly the oldest infectious disease to specifically target human beings. Whether the oldest or merely ancient, leprosy has been a marauder on virtually every continent. The bacteria that cause it are believed to have originated in Africa and then spread across the world as people migrated and colonized.

Leprosy ignited panic wherever it went. It was incurable, emotionally and physically destructive, and led to forced isolation in many societies over different eras because it was assumed to be highly contagious. In the 13th century, Europe had 19,000 leprosy villages. Today, it is curable before the worst symptoms manifest, unless an infected person has gone undiagnosed and untreated, as still happens, in Brazil and India, and in many small and poor countries in Africa and Asia. Contrary to common belief that merely being in the presence of someone with leprosy was highly dangerous, it was never very contagious. Researchers today say that up to 95% of people may have a natural immunity to it, and that even for those who don't, it can be contracted only through repeated and close contact with droplets of moisture from the nose or mouth of an infected, untreated person.

Leprosy is insidious for more than the emotional and physical damage it brings. Its symptoms can take years to appear after a person is infected – as long as 20 sometimes. The bacteria that cause it move slowly through the body, unlike the bacteria that cause diseases such as strep throat or tuberculosis. Although slow-growing, they will, in the absence of treatment, multiply into many trillions and create patches of scaly skin on the face, arms and feet that will over time attack the body in many worse ways. Until treatment became available and doctors learned to diagnose the onset of symptoms, many victims were struck in the prime of their lives, seemingly out of the blue. Over the course of about a year of treatment, the multi-drug therapy now available stops the bacteria from spreading. But it came too late for many, many people – an exact toll impossible to calculate.

In 2014, HANDA published a book, “Beauty of the Spirit”, that contains many dramatic stories of the leprosy-afflicted who live in the villages it serves. One story, that of Yu Hong, a soldier, dancer and musician when leprosy came, illustrates its insidiousness, and the public scorn and humiliation accompanying it. Yu had learned to play the accordion in the Chinese army and was vice-chairman of a military dance ensemble. In 1953, he was named his military region's representative to a national group that performed in many events over the next 19 years. His proudest moment was marching in Tiananmen Square and getting a salute from Mao Tse-tung.

In 1973, signs of “leper”, the Greek word for “scaly”, appeared on his face. He tried traditional Chinese medicines and other treatments. None worked. In 1976, he was diagnosed and confined to a village in Shaanxi Province. A few years later, after some of the early treatment for leprosy became available, he was deemed cured. He applied to return to his former region's dance ensemble, but was rejected. The job now required different skills, Yu was told.

He remained in the village and kept playing his accordion in the event he was invited back. He never was. He stayed in the village for the next 40 years.

Stigmatization, particularly in the countryside, remained a dispiriting fact of life after the government ended its isolation policy in 1989 and announced, in 1998, that leprosy had been eliminated in China, per the World Health Organization's one case-for-every-100,000-people standard. Nonetheless, uninfected children from families in the villages were denied the chance to attend school. Drivers refused to enter villages. Hotels declined rooms to visitors from the villages who had been cured.

Sometimes, stigmatization arose in unexpected places. In 2008, people with leprosy in their past, were on a list of foreigners to be banned from entering China by the Chinese Olympics Committee. Representatives of WHO and an international group, Human Rights of People Affected by Leprosy, protested in a letter to Premier Hu Jintao and the exclusion order was withdrawn.

The people of Shangping still feel the occasional sting of scorn. Even though they now go to the village 20 kilometers away to sell their sesame seeds and honey to those who do not feel jittery around them, workers from a government hospital there still balk at entering Shangping.

"These people have no significant contact with the outside world," says Theresa Chi, a volunteer from a Catholic religious order, as she helps clean the room of a Shangping villager. She and another volunteer come to the village twice a year for two weeks to help with home care, cooking and other necessities before moving on to another leprosy village for two more weeks of the same.

"We ask their needs," Chi said, "and then do what they need."

MEETING NEEDS

Every time Yahua Yuan drives into a leprosy village to help someone get an artificial leg, or provide maintenance for an existing one, he drives into his past. He was a child with leprosy when Dr. Yang discovered him living in a village populated mostly by adults and then treatment that led to his recovery and a new life that eventually included

marriage and a child of his own. But the HANDA founder also arranged for him to be trained how to design and maintain prosthesis for villagers who had lost feet and parts of legs to infection that went undiagnosed and untreated for too long.

Soon, Yahua began working for HANDA as a prosthesis technician. A couple years later, he was promoted to project manager for one of its key services, its Mobile Prosthesis Workshop – his transformation another example of why people revere the late Dr. Yang.

"Everything I have today is attributed to Dr. Yang," Yahua told Tina Xue Teng, a researcher for the School of Philanthropy at Sun Yat-sen University.

In 2013, Yahua led his HANDA team and their specially equipped van into 43 villages in Guangdong, Guangxi and Yunnan provinces, and helped more than 150 people stand again, including 11 who had lost both legs. They repaired and provided maintenance for nearly 400 more. In 2014, it increased capacity, serving up to six villagers a day.

Once infected with the leprosy bacteria, people in the countryside who were farmers or manual laborers were particularly vulnerable. The bacteria destroy nerves in the arms and feet, meaning its victims do not feel pain and don't know how much damage is occurring until it's too late, and their limbs must be amputated in order for them to survive.

The Mobile Prosthesis Workshop is part of a larger physical rehabilitation project at HANDA that also includes another mobile service, taking medical teams from a cooperating hospital in Guangzhou into the villages to perform cataract surgeries and provide other eye care for people whose vision might be lost to leprosy if untreated.

Programs dealing with the physical consequences of leprosy are one of four major areas of HANDA service that emerged over the years to aid villagers. Service in the other categories – economic, social, and psychological – is provided through many different programs whose benefits often overlap.

In all categories, HANDA abides by a founding idea, and that is to make sure those it serves help design and implement programs. "The very core

principle of HANDA's operation is to involve people affected by leprosy in planning activities, conducting projects and seeking solutions," Dr. Chen said. "HANDA relies on them to take on the roles of counselors, teachers, spokespeople and lobbyists."

One of HANDA's counselors lives in Shangping, a few rooms from where Mr. Hu lives. In fact, as mayor of Shangping, Xu Shi Shun also is a teacher, spokesperson and lobbyist. The villagers elected him mayor in 2005. He had left the village years before, after he was cured of leprosy, but a government official asked him to return to help his former neighbors however he could. Before scaly skin and other problems arose, he was known as the efficient coordinator of the local harvest-production unit, Mayor Xu told visitors the day they met Mr. Hu.

Mayor Xu, 79, came back with his wife, Long Xi. He helps administer medicine to the most infirm villagers, organizes group chores and tends to what other issues develop. "I am the man to call if



Xu Shi Shun is the Shangping mayor, but also, he says, its teacher, spokesman and lobbyist.

anything needs to be done," said the mayor, who also is member of the HANDA Committee, its board of directors.

The sesame-and-honey business in Shangping is one example of HANDA's economic-empowerment programs, which are part of its Community Development Project. Villagers also are learning to sew quilts and weave brooms for sale, and how to grow, harvest and market mushrooms, mangoes, chicken and fish. In Yunnan, volunteers working with HANDA are teaching villagers how to plant, grow and sell rice according to the principles of eco farming – using land to produce food while conserving its biodiversity. Other community development programs are aimed at improving the infrastructure of the more run-down villages. With other charities, the villagers and volunteers, HANDA has rebuilt houses and schools, refurbished community centers and installed clean-water and sanitation equipment.

Community development programs yield dividends on multiple levels. They help residents of the most dilapidated villages contend with unsafe and depressing conditions. For others, they bring in extra money, but also increase their self-esteem and confidence by taking them into a world beyond the villages, a world many have not seen for more than half a century.

The medical help and the community development efforts have improved life and lives in the villages, but when the mobile prosthesis and eye care vans leave for another village, when the volunteers and HANDA staff have to turn their attention to another economic-empowerment program elsewhere and when the infrastructure projects are finished and workers move on, the most difficult problem remains.

"The big issue in leprosy is loneliness," said Zhang Yan, vice secretary-general of HANDA.

Over the years, HANDA and the villagers have organized many programs to address that issue, socially and psychologically, but with 21,000 people spread over 12 provinces – most without children, most without other relatives willing or able to visit – coping with loneliness to a significant degree is

very difficult. “Usually, the residents have no company,” Zhang said.

HANDA tries to give what company as it can because social and psychological services are part of its mission. Every March 11 for the last few years, it observes International Day for Dignity and Respect, a commemoration that grew out of the meeting of Dr. Yang and other experts in Brazil that resulted in the leprosy-activist group, IDEA. The date was first observed in Carville, a town in the U.S. state of Louisiana, where America began confining its prisoners of disease in the 18th Century. Leprosy did not become a serious problem in the U.S., and Carville’s population never exceeded 400 people, who were given the option to leave after the multi-drug therapy was developed. Many chose not to exercise it, until they had to when the camp was closed in 1999.

HANDA celebrates the day with events that bring the leprosy-afflicted together with the mentally handicapped. In Guangzhou, about 200 danced and sang for a shopping-mall audience, whose members joined them to draw group paintings. In Xiaguan in Yunnan province, a smaller group together with university volunteers staged a drama about the difficulty of finding medical treatment.

Over the years, HANDA and the villagers designed many other activities and events – exchanges between villagers, carnivals of singing and dancing, and a “King of Chess” battle that went on for three days, and was won by Li Jian Jiao, who resides in a village in Taihe County in Jiangxi province, where Dr. Yang was born. In 2013, HANDA and the villagers organized 48 events, including another in a series of City Tours in which villagers are taken to cities to see other sides of life. For some, they are opportunities to return to cities where they once lived, before leprosy came.

“Visiting my old home has always been a dream,” said a villager from Jiedong District in Guangzhou after he walked around his old neighborhood, according to a psychologically poignant account in a HANDA report. “Now my dream finally comes true.”

LEARNING BY DOING

In 1996, in line with his and IDEA’s principles, Dr. Yang saw himself as the manager and developer of HANDA’s operations, with the villagers helping to run programs and provide oversight. And so only the leprosy-afflicted could serve on the HANDA Committee, or board of directors. The board members were elected through a nomination and voting process installed in the villages.

Two years after it started, however, HANDA was suffering growing pains. Dr. Yang did not have any management or accounting experience – he jotted down in a simple notebook how HANDA spent the money it received from donors, including its first big international donor, the Novartis Sustainable Development Foundation. To complicate matters, while HANDA Committee members and many electors in the villages were talented, as time would show, in many ways, including storytelling, poetry, and calligraphy, NGO oversight and administration were new to them.

A HANDA volunteer with business credentials reported to Novartis that HANDA’s books were a mess. It could have led to a crisis, but didn’t because the donor trusted Dr. Yang. It was, however, a wakeup call, and it came shortly before Dr. Chen stopped volunteering for HANDA and became a full-time staff member.

Dr. Chen had been volunteering for HANDA from the beginning, while working full-time in a hospital. He traveled to leprosy villages with Dr. Yang and helped lay the foundation for what became HANDA’s four-point framework for service – social, psychological, physical and economic. “I was deeply moved by Dr. Yang’s devotion and by the life stories of the people affected by leprosy,” Dr. Chen recalled. “I became passionate about what I was doing.”

After Dr. Yang received additional overseas funding that enabled expansion of HANDA’s services, he asked his new staff member, Dr. Chen, to help him manage the administrative side. The problem was, Dr. Chen did not have any management or accounting experience either. But he was

eager to learn, and the same volunteer who had tipped HANDA's first big international funder to HANDA's management shortcomings began teaching Dr. Chen how to take HANDA beyond the jotting-down-numbers stage. Dr. Chen also learned on his own – by reading management and accounting books and attending NGO-training courses. He was a good learner; he had taught himself how to speak and write English, using only a dictionary.

As it grew, Dr. Chen knew that HANDA needed to develop a homegrown donor base rather than rely too heavily on international donations, which were subject to the whims of corporate profit margins and financial crises, such as the one in 2008. It began producing a series of events designed to court local donors and increase public visibility in the provinces.

In 2009, Dr. Chen also introduced major internal management and administration reforms designed to formalize relationships with contractors in the mobile prosthesis and eye care projects; maximize and measure impact of other projects, and assess staff performance. Some staff members found the new modes of operation too sharp a departure from the less formal customs in place, and some eventually resigned. As his business acumen developed, Dr. Chen wanted a system with rules and procedures that assured efficiency and transparency. A year after the reforms, HANDA won a Model Philanthropy and Transparency Award issued by the One Foundation. It won again in 2014. It is the only NGO in China to win it twice.

As it improved its management, HANDA changed its oversight model as well, allocating five seats on the 15-member HANDA Committee to people with no history of leprosy – professionals from business, media, and public charity and welfare. The change was made because Dr. Yang and Dr. Chen came to see the value of expertise from the workaday world – the world many villagers didn't know even before they fell sick because most were poor and had little education. The new members had longer perspectives on shaping HANDA's future and more experience in program development.

“This was not an easy change for us,” Dr. Chen said. “It took us some time to accept the idea of allowing people from the outside to participate in our decision-making.”

Over the years, HANDA also steadily increased its use of volunteers, from other charities as well as individuals, to help conduct programs in the villages. It held workshops for the volunteers on the history and impact of leprosy as well as training sessions for how to deliver services to the villagers – 20 sessions in 2013, for 755 volunteers. The volunteers included Tao Yongshu, who had earlier been the recipient of another HANDA initiative, the HANDA Scholarship Project. After getting his university degree, he returned to his leprosy village in Yunnan to teach children. The Li Xinghang Foundation in Beijing heard about Tao and began subsidizing his efforts on behalf of young people growing up the way he had.

Despite the management and oversight changes at HANDA, Democratic principles are still much in play. In 2013, in what was the fifth HANDA Members Assembly, 54 representatives of the villages – elected by other villagers in secret balloting over four months – met and elected new members of the HANDA Committee as well as the three members of the HANDA Supervising Committee, which oversees the HANDA Committee and Dr. Chen, the Secretary General. The new members of each committee were elected to five-year terms.

Villagers also continue to participate in the management and design of some programs. In the case of a US\$17,800 program to stimulate economic activities in three villages in Yunnan province, a group of villagers elected by their neighbors had direct control over how the money was spent. Most went to environmental or construction improvement; some went to help elderly villagers living alone.

Assistance for the elderly, by HANDA and by the villagers, has been a top priority since 2003, when HANDA launched a Medical Emergency Aid fund for the elderly. It is supported by donations from private and public sources – and from the villagers. In 2013, about US\$15,600, includ-

ing about US\$2,500 donated by the villagers, was awarded to 126 residents in 26 provinces.

A dramatic example of the priority villagers place on helping the elderly came in 2005 when someone important in their lives developed an aneurysm in his chest. If left untreated, the aneurysm could burst and cause fatal consequences. The cost of preventive surgery was placed at US\$32,100.

Across villages in 12 provinces, many thousands of the leprosy-afflicted dug deep into their pockets and raised the money. The surgery was a success. Dr. Yang Lihe, then 76, would live and keep contributing to them and HANDA until his death six years later.

LESSONS AND CHALLENGES

The life of Dr. Yang is not so much a lesson as an illustration of the value of a founder who is not only compassionate, but who also possesses the expertise and experience in his organization's field of service to know what is needed and how to develop it. Dr. Yang had credibility – in the villages, with the government, and with potential donors and partners. He had been a village doctor, a university researcher and government official. He was the ideal person to take service for the leprosy-afflicted to the next level – beyond treatment and cure and on to activism.

The way he went about it does contain lessons. One is the importance of making service recipients feel they are part of the process, not just receiving but contributing and helping to lead. The model wouldn't be practical or possible for many NGOs, but it worked for HANDA because communal notions about equality and responsibility already existed in the villages and in China.

At the same time, Dr. Yang and Dr. Chen recognized that it is important to adjust the model to match the reality of the situation as an organization begins to grow. HANDA's board needed members from outside the leprosy community to lend expertise and leadership to take it to higher levels of service. As organizations grow, they also have to keep reviewing and improving their internal management in order to maximize and measure

their impact, as Dr. Chen did when he instituted a series of business-style reforms in 2009. The price HANDA paid, some unhappiness in the ranks, is just a price that organizations sometimes have to pay. The reforms have made HANDA efficient and transparent, increasing donor confidence.

HANDA's experience also demonstrates the value of a different kind of donation – time. As fear of leprosy decreased among some groups, HANDA increasingly relied on volunteers to help it carry out some programs. But volunteers have to be briefed and trained; they can't be sent into the field without preparation, or else time is wasted.

The biggest challenge for HANDA is an obvious one. The 21,000 people in the leprosy villages are growing older. No one catches the disease anymore, at least not in China. The day when HANDA is not needed for its services to the leprosy-afflicted cannot be predicted, but it will come. HANDA will have to transition to some other kind of service. It may tilt toward providing eye, foot and other medical care to the disabled, particularly the elderly, since it already has so much experience serving the elderly of the villages.

It may also expand on a project it began in 2012, a Social Work Service Center, which offers training, consulting and evaluation services for social workers, NGOs and government agencies. HANDA could take branches of the center to many provinces and even to other developing countries, depending of course on whether it can hold onto its funders and nurture a qualified staff.

Finding and holding onto qualified staff is already a challenge for HANDA, as it is for most NGOs competing with private sector, for-profit organizations. Relying on volunteers works only up to a point. The HANDA branch in Yunnan, which has 200 leprosy villages, as opposed to Guangdong's 67, has only seven staff members.

Even though the need for services for the leprosy-afflicted will cease at some point, HANDA still has to serve the 21,000 in China now. That is what complicates its transition – it has to plan for and adapt to some new future, but also remain

devoted to its current clients. It also has to remain nimble enough to respond to crisis, such as the one that developed in 2012 when a television reporter discovered seven leprosy-afflicted people living in very dire circumstances. No electricity. No sanitation. No medical care. A completely forgotten village in Yunnan.

HANDA sent five staff to the rescue after the story hit. They stayed in Luduo Leprosy Village for four days and got the seven back on their feet, then worked with local officials to get them relocated to better conditions – near a village where many people strongly expressed their disapproval. Their cattle might get infected. It is believed that many tiny leprosy villages remain undiscovered in China.

Back in Guangdong, Huang Tanlin, otherwise known as Circle, escorts visitors into the room of Gao Yo, one of the very first residents of Shangping Leprosy Village. She's lying on an orange quilt covering a steel-framed bed. Circle, coordinator of HANDA's community development project, approaches her and yells a very loud but

friendly greeting into her right ear because, as he had explained earlier, she can barely hear. Ms. Gao rolls over, sits up, smiles and grabs Circle's hand and holds it in her lap. It's clear they have a warm friendship. All of the villagers Circle saw that day greeted him with wide smiles.

Circle cups his hand and shouts into Ms. Gao's ear again.

"How old are you?"

She shakes her head. "I'm not sure, 91 or 92."

"When did you come here?"

"A long time ago."

"How old were you?"

"About 20," she says, and lies back down.

Circle turns to his visitors and says Ms. Gao has more than a hearing problem. "She can barely see. All she sees is shadows." 

This case was made possible by the generous support of the Board of Directors of the Centre for Asian Philanthropy and Society.

QUANTITATIVE INDICATORS

Financial

Planned budget or income versus actual expenditure for the fiscal year	Budget in 2014: approx. CNY 4 million or USD 644,654 Expenditure in 2014: approx. CNY 4.3 million or USD 609,038 (1 USD = 6.02 CNY)
Income composition by source: individuals, corporations, events, trusts, other (please specify)	Individuals: 31%; corporations, 60%; events, 1%; other, 8%
Income composition: domestic versus international	Domestic, 24%; international, 73%; other, 3%
Did you achieve cost recovery? Yes/No	Yes

Personnel

Staff retention rate (number of employees who remained during the year, divided by the total number of employees, multiplied by 100)	76%
Turnover rate (number of employees who left during the year, divided by total number of employees, multiplied by 100)	24%
What is the board composition?	15 members: 11 men; 4 women
Board member occupational sectors?	Busines, media, service recipients, other
Frequency of meetings?	4 x year
How many employed staff?	23
How many staff members have attended some non-profit or management training course? If training was organized, please answer the following:	10 staff have attended training in NGO project management or project sharing organized by such groups as: Beijing Capacity Building and Assessment Center
What topics were covered?	China Social Sector Development
Basis of selection of staff chosen for training?	
Provider of training -- internal department or outside vendor? If outside vendor, please give name	

Quantitative Indicators Continued

Organizational

Do you publish an annual report?	Yes
How many sites/locations do you operate in?	Multiple sites in Chinese provinces that vary by year, but mainly in Guangxi, Yunnan and Guangdong provinces
Do you measure results? Yes/No	Yes
If yes, what are your results measurement indicators?	Number of activities, participants and service hours
Do you measure activities? Yes/No	Yes
If yes, please give examples of indicators in such categories as: awareness-raising, training and capacity- strengthening	Physical rehabilitation; mobile prosthesis workshop; socio-psychological rehabilitation; skill training
Do you measure impacts by effect of outcomes? Yes/No	Yes
If yes, please give examples such as: reduction in prevalence of ill-health, improved economic empowerment, choice, access, change in policy priorities, enactment of new legislation	Increased social and economic integration; improved self-confidence; improved public understanding of leprosy and reduction of prejudice; disability prevention and improved physical function
What types of outreach do you use (e.g., radio, print, postal, community bulletin boards, social media, or others)	Radio, newspaper, social media, pamphlets
Do you regularly meet with government representatives? Yes/No	Yes
If yes, on a scale of 1-3 how close is government relationship? 1 = not close; 2 = somewhat close; 3 = very close	Closeness of relationship = 2