

FIGHT FOR SELF-RESPECT AND DIGNITY

FIGHT AGAINST STIGMA AND DISCRIMINATION

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*“My heart is not thinking about the difficulties,
but just thinking about the future.”*

---Fire Lily

SITUATION AND PROBLEMS

For many centuries, leprosy was considered as a disease of human rejection and exclusion from society, always associated with stigma and discrimination. There have been misconceptions about the disease. A large number of people were abandoned by their families and communities. People who have experienced leprosy are not only facing physical challenges, but are also facing great challenges in terms of social, economic and psychological difficulties.

After the very effective cure of leprosy, MDT, was discovered and introduced in 1980s, many patients were rapidly cured of the disease. However, many of the cured persons are still living with social, economic, physical and psychological challenges.

In the last 50 years, there were approximately half a million people diagnosed with leprosy in China. Over 400,000 of these individuals have been cured with the number of active cases is now less than 6,000 individuals. At present there are nearly 250,000 people affected by HD still living and facing great difficulties due to the stigma and discrimination by people who do not understand HD. More than 10% of these people are living in leprosy hospitals and villages isolated from the communities due to the social stigma and physical disability. According to our survey in Guangdong and Yunnan, more than 70% of these people are illiterate, never having had a chance to go to school due to the disease and poverty. About 20% of these people are unmarried. Among the married people, 46.28% of them were married with another person who had experienced of leprosy. The average income of the people is less than RMB 100/month, about US\$ 12.00. About 60% of these people have eye problems, 60% have serious hand deformities and 50% have plantar ulcers.

ESTABLISHMENT OF IDEA AND HANDA

Due to the high level of stigma associated with leprosy, persons disabled due to leprosy did not come forward openly to fight against the injustice done to them, or to claim their human rights. For a long time, there was no initiative from the persons affected by leprosy to join together, to create a common platform to work for their own improvement, to voice their needs, problems and opinions. In 1994, the first organization of the people affected by leprosy, the International Association for Integration, Dignity and Economic Advancement, IDEA, was established in Brazil. It is best described as the process through which individuals affected by Hansen's Disease are empowered -- psychologically, socially and economically. They were encouraged and started to take an active part in fighting against the disease, especially against the stigma and social discrimination.

HANDA Rehabilitation and Welfare Association, a branch of IDEA in China was established in 1996. It initiated its activities in Guangdong province in 1996 and, as of 2001, has expanded to four other provinces. It now has more than 3000 members, who are mainly people affected by leprosy, as well as some individuals who have been involved deeply in improving the situation of people affected by this disease.

HANDA is a partnership.

HANDA is an opportunity.

HANDA is a forum for discussion.

HANDA is a network of support.

HANDA is a pathway of hope.

“HANDA gives me a good chance and the feeling like I have a family.”

---Yang Qian Mei

PUBLIC EDUCATION AND ADVOCACY

The ignorance and misunderstanding about leprosy is still the biggest obstacle for the people to regain dignity and integrate into society. Advocacy can serve an important role in generating a better understanding and promote a modern image of the disease and the people it affects. The words of the people and their experience make a profound impression and promote a better awareness of their lives and the needs of someone affected by leprosy today. Participation in forums and workshops provide an opportunity to share views with others and encourages self-confidence and dignity. It may bring some discomfort and unease in the beginning as they are trying to reintegrate themselves into society, but it helps with their own psychological healing. An important role of HANDA is to provide a forum for the individuals and the community, to fight against the stigma and discrimination. This is accomplished by:

- A. Provide forums where individuals affected by leprosy can meet with concerned government agencies and local and provincial government in order to obtain their rights as citizens.

More than six meetings or workshops were held in three different provinces. There has been participation by a diverse level of government officials. These included: governors, directors of Public Health and Civil Affairs bureaus, community leaders from the provincial level to the county level. These individuals were invited to participate in the workshops so that they could directly discuss the problems and needs with the people affected by HD. Changing the attitude of the government officials is a priority of advocacy.

- B. Publish and distribute information about the disease and the people it affects, especially those books, poems and other articles written by the people HD affects personally.

The HANDA newsletter is edited by people who have had HD. It has been a great forum to present HANDA's work and for the people to express their ideas and opinions. It has been distributed to most leprosy related organizations and parties in Guangdong and in other provinces.

"No Misery In The World" is an autobiography of 400,000 words written by Mr. Lin Zhi Ming, a person affected by HD. It was published in 1999 with the support of IDEA, the Sasakawa Memorial Health Foundation and the Guangdong Provincial Public Health Bureau. The book gives the real story of the people affected by HD, presenting that they are human just like you and I, but facing greater difficulties because of an illness they happened to contract. The book has brought a lot of attention to the HD community. All the largest newspapers in Guangzhou and Hong Kong have published articles about Mr. Lin, his book and other people affected by HD as well.

Two benefit concerts have been held in Guangzhou for the people affected by HD. These were not only a way to raise funds for the people but, more importantly, it was a good way to make people aware of the activities of HANDA and give the public a better understanding of the disease.

The news media, including many important newspapers and TV stations, have been very helpful to HANDA. They have produced many news stories about HANDA's activities and the people we work with.

- C. Representation by people affected by HD in international forums where they can share their views with medical professionals and have a say in their own care and treatment.

Participation of the clients in professional forums is not only important for the outcome of these gatherings, it is also of considerable encouragement to the people themselves and greatly helps in improving their dignity and self-confidence. More than 22 people affected by HD have attended different international forums in 6

countries. They have shared their views and ideas with other participants, which have benefited both professionals and those personally affected by HD.

SOCIAL AND ECONOMIC EMPOWERMENT

For a long time people affected by HD have been isolated and discriminated against by the community and society. Their poor social and economic situation, which is caused by the isolation and discrimination, becomes one of the main barriers that prevents individuals from integrating back into society and regaining their self-esteem and self-confidence. Economic Projects are extremely important to empower those who have to earn enough money to put food on the table and support their families. This in turn increases self-esteem because they are supporting themselves and not being a burden on society. Breaking free of this cycle of poverty is critical to encouraging self-respect and subsequent acceptance in the community. Improvement of a person's economic situation usually means the improvement of their social status and self-confidence.

With the support of organizations and individuals, HANDA has provided opportunities for people in more than 10 counties in four provinces to start micro-economic development projects. More than 300 people have been involved in the projects that have been helping them not only economically, but also socially and, most importantly, psychologically.

It is important that all of the projects are managed by the people themselves. They make their own decisions on what they are going to do, how to do it and how to deal with the revenues, etc. This is important to ensure the success of the project and is an important way to empower and enable them to have more self-confidence and increased self-support.

***“We have to rely on ourselves, not on others.
Relying on the welfare is only a short-term relief.
It can never bring us self-esteem and the dignity.
To reduce the stigma, we have to use our own hands,
even though they may have disabilities,
to become self-supporting and self-dependent.”***

Mr. Ma Tie Xi

EQUAL OPPORTUNITY

Because of the stigma and misunderstanding, most of the people who have had the disease have been denied their rights. They lost the right to study, lost the right to participate in many community activities, and the right to seek work wherever they can. Poor education and no skills are obstacles for their reintegration into society and their self-development. It is important to provide opportunities for education and skills

training, especially for the young people. This will enable them to promote their self-confidence and regain their place as self-supporting and contributing members in society. Skills Training Programs and Children's Educational Scholarships are two approaches whereby HANDA is trying to provide equal opportunities to those affected by HD.

Skills Training Programs:

· The sewing school and the quilt project have provided people with the opportunity to acquire sewing and handicraft skills, which are put into practice by making goods that are sold to the public. One hundred and seven participants have graduated from 12 classes in the school. Twenty-five graduates are still working in the HANDA quilt project; 22 now work in clothing or shoe factories; 2 are running their own tailoring business; 25 work in factories other than clothing; 10 are running small business other than tailoring; and 23 graduates are jobless or farming at home.

Summary of Sewing School Graduates

No.	Present Employment	No. of people
1	Work in the HANDA quilt project	25
2	Work in a clothing or shoe factory	22
3	Run a small tailoring business	2
4	Work in a factory other than clothing	25
5	Run a business other than tailoring	10
6	Jobless or farming at home	23
Total		107

· In 2000, The First Electrical Appliance Maintenance and Repair Workshop was held in collaboration with the Guangzhou Disabled Person's Federation, which was a great first step on the road to integration with other community organizations. Fourteen people from 6 provinces graduated from the workshop and passed the examination for Electrical Appliance Repair held by the State Labor Bureau and received the license of Junior Electrical Appliance Repair Worker. The Second Workshop started on 20th September and will be completed in December of this year. Twenty students from two provinces are attending the workshop.

· One Basic Small Business and Personal Finance Management Workshop was held in 1999 in order to improve the management skills of the people who are managing or planning to manage their own economic empowerment project. Fourteen people attended the workshop. Most of them now are working on their own projects and one is even working in the HANDA office as a cashier and bookkeeper.

· Two Leadership Empowerment Workshops were held in Jiangxi and Hubei separately. It was a good opportunity for the people to share their experiences and ideas with others, including several government officials. It was a good chance for the people to gain

useful information and knowledge to assist them in their economic activities. Extremely important was the fact that everyone could experience and be affected by the HANDA's spirit of self-support and self-esteem and become an active HANDA member in their own activities. The third workshop will be held in Wenshan, Yunnan province from 20-26 December of this year.

“We are not less intelligent than others. We have sound minds and wisdom. However, we lost many opportunities to be educated and to develop ourselves due to leprosy.”

---Mr. Shi Yin Chun

Educational Scholarships:

HANDA started this project in 1998. Since then, 275 children were granted scholarships and were able to restart or continue their schooling. Due to the stigma of HD and their poor economic situation, many children of the people affected by HD are unable to go to school. It is a priority to give this basic right of education to these children. The Educational Scholarship Project was especially designed for these children, to assist them in claiming their right to an education, just the same as anyone else. HANDA truly believes that with a good education the children will be able to break the cycle of poverty and finally be able to fully integrate into society

PHYSICAL REHABILITATION

More than 60% of the people affected by HD face some kind of physical challenge, especially the elderly. Severe physical impairments as a result of HD seriously affect the quality of their lives and are one of the main barriers to full integration into society. Physical rehabilitation projects and projects to upgrade living conditions are also important in improving the people's self-confidence and dignity.

Individuals affected by leprosy can greatly aid in the effort to promote self-care and the prevention of disabilities. Those who have personally experienced the disease have important insights into barriers to the prevention of disability, the consequences of lack of attention to self-care, and the means by which self-care and prevention of disability programs can best succeed.

1. The Foot Care project, started in April, 2000, addresses wound care combined with the use of special protective shoes. Self-care techniques are difficult for the people, so their active involvement in the project is promoted. Some people were also trained to be technician to make protective shoes and even prostheses. About 400 people affected by leprosy who have plantar ulcers have been treated and fitted with protective shoes in 10 leprosy villages or hospitals in Guangdong. A significant effect has been seen in the

improvement of the condition of their feet and their quality of life. This shows that the involvement of the people themselves in the project is the key to success.

2. The Eye Project was started in 1996 with one nurse and one eye doctor part time. Now it has been implemented in more than 25 HD villages in Guangdong, Jiangxi and Hubei provinces. More than 1,500 eye operations have been carried out. Saving someone's eyesight has to be one of the most important projects in order to improve the living quality of the people, especially those with disabilities in their hands or feet.

3. Upgrading living conditions and facilities is a great need, especially for those with disabilities and the elderly. The Communal Kitchen project is one of the ways to protect hands, feet and eyes and prevent them from getting worse. It also helps the people to lead a little easier life. Since 2000, three public kitchens have been built in different leprosy villages where now the elderly can now enjoy their old age with a little more peace.

NETWORK OF SUPPORT

An international network of support is important in order to provide a secure environment in which individuals are willing to take possible risks as they identify themselves as being a person affected by leprosy. When they choose to become an active part of the process of challenging the stigma – psychologically, socially and economically -- the traditional negative image of leprosy is transformed into a positive message of hope and triumph.

HANDA is a platform not only for seeking support from the government, international and national NGOs and the community, but also encouraging the mutual support between people themselves. It is partnership rather than charity. Successful stories and personal victories against the disease are always a great encouragement to others. This is much more valuable than relief or welfare.

***“Wanting to get the respect by others and improve social status,
first of all you have to be economically independent.
If you can be economically independent,
you will find you are a valuable person in society.”***

--Mr. Wang Shao Huai

CONCLUSION

- 1) Handa is basically a process through which individuals affected by HD are empowered -- psychologically, socially and economically, which is important in their quest for self-respect and dignity. These individuals should be regarded as partners rather than patients.
- 2) The stigma associated with leprosy will only be eliminated when those who have personally experienced this disease have regained their self-confidence.
- 3) An important component of empowerment is the promotion of forums, in which individuals who have the experience of HD, can share their wisdom in order to educate, inspire and guide the general public, health professionals, government officials, non-governmental organizations, fundraisers and future generations.
- 4) Public education and fundraising strategies can aid in empowerment by emphasizing ability rather than disability and by promoting dignity through partnership.
- 5) Overcoming poverty and becoming self-supporting through an economic improvement project are important steps in regaining self-confidence.
- 6) Persons affected by leprosy have an important role to play in the planning and implementation of social and economic empowerment projects.
- 7) Providing opportunities for education and skills training, especially for children and young adults are extremely necessary in order to end the cycle of poverty and social exclusion.
- 8) Individuals affected by leprosy can greatly aid in the effort to promote self-care and the prevention of disabilities.
- 9) An international network of support is critical in order to provide a secure environment for people to take an active part in the process of challenging the stigma.