

ENDING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN PEOPLE'S REPUBLIC OF CHINA

Submitted for the consideration of the 13th Pre-Session of the CRPD Committee

Submitted by:
International Federation of Anti Leprosy Associations (ILEP)

(The submission may be posted on the OHCHR website)

This submission is made by the International Federation of Anti-Leprosy Associations (ILEP), a federation of 13 member associations working in leprosy-related activities in 69 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members. Persons affected by leprosy¹ play a significant role in organisational decisions through the operation of a high-profile Advisory Panel and through interaction with country-based people's organisations.

Website: www.ilepfederation.org. Email officer@ilepfederation.org. Phone +41 22 940 3412

1. Leprosy has seriously influenced Chinese people mentally and physically for over 2,000 years. In recent decades the country has made remarkable progress in leprosy control. Since 2013, the number of new cases of leprosy in China has decreased to less than 1,000 per year.
2. China's achievements and experiences on leprosy prevention and treatment have provided a beneficial point of reference and important contributions for the world to eliminate leprosy. In his congratulation letter to the 19th International Leprosy Congress in 2016, President Xi Jinping said that China would take stronger measures in this field and actively promote progress and innovation in leprosy in order to achieve the goal of eliminating leprosy in China as soon as possible, as well as to make contributions to the leprosy world as a whole.
3. As new case numbers have reduced, China has entered the stage of eliminating the damage caused by leprosy. Caring about the people affected by leprosy, and enabling their integration into society, is gradually becoming the focus of leprosy prevention. The numbers are large. In one province, for example, there are about 20,000 people affected by leprosy of whom around 10% are spread between around 70 leprosy villages. 90% live in the general community: some are cared for by their children and relatives in their home while others face severe life challenges because of their serious disabled situation and lack of care by their children.
4. **People affected by leprosy in leprosy villages are getting older and older, gradually losing the ability for self-care.** According to one provincial survey, 85% people affected by leprosy aged over 75 are suffering from Grade-2 disability (that is, visible impairments due to leprosy). It is difficult for this group of persons to access disability services, and they suffer from a lack of accessible facilities. As time passes, there will be more and more elderly people without self-care

¹ Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

ability. In addition to the lack of care from nurses and relatives, it is more frequent for geriatric illnesses to affect this group of people. Besides, most hospitals have moved to the counties or been merged into related chronic illness stations, which leads to the low frequency for doctors to come to these villages. Villagers find it hard to get treatment at any time and especially in emergency.

In accordance with Articles 9, 20 and 26, the Government is asked to ensure:

- a. That people affected by leprosy-related impairments are provided with assistive devices, wheelchairs, crutches, protective shoes and cataract surgery for free**
- b. That handrails, ramps, accessible toilets and other accessible facilities are built in all the leprosy villages, and that obstacles and barriers to accessibility are removed**

In accordance with Article 25, the Government is asked to ensure:

- c. That persons with leprosy-related disabilities receive the same range, quality and standard of free or affordable health care as provided to other persons with disabilities**
- d. That on-duty medical staff are made available in leprosy villages to provide medical service such as wound care and general health care to those in need.**

5. **Villages containing few people are left alone and helpless.** Due to the deaths of elderly residents, village populations are reducing. In one province, 30 leprosy villages have a population fewer than ten, and some have only one resident left. Occupants of such villages are lonely and helpless and need much more aid from society than before. In the past, people in these villages could help one another because there were enough people there. However, most of them are now in their 70s or even much older with more and more serious disability from leprosy as well as various kinds of geriatric illnesses.
6. In some places, villagers are prohibited from leaving the village unless specific permission is granted from the relevant government department. Volunteers are prohibited from visiting without an official application letter approved, with a red stamp, by local government. Moreover, some people in leprosy villages have no ID cards and, as a result, they are deprived of basic rights such as rural insurance policy coverage, other social welfare benefits, and liberty of movement.

In accordance with Articles 18 and 28, the Government is asked:

- a. To remove any restrictions on entry and exit from leprosy villages**
- b. To ensure that all villagers have the necessary ID cards to which they are entitled**
- c. To ensure an adequate standard of living for all occupants of the leprosy villages, including adequate food, clothing, housing, electricity and clean water**

7. **Policies of reconstructing and merging villages are not effectively implemented.** Most leprosy villages were built in the 1950s or 1960s and were intentionally established in isolated locations. The focus was on building a medical environment. Many buildings have become shabby or even dangerous, without any maintenance for a long time. As noted above, the occupants are facing the aging problem and 32% cannot take care of themselves. The environment of these villages cannot meet the living demands of elderly people with disability.
8. Therefore, in 2007, the Chinese government invested 220 million yuan to construct new leprosy villages and to improve the medical and living conditions for people affected by leprosy living in hospital. The plan typically involved merging every 8-10 existing leprosy villages into one newly

constructed village.² However, this plan has not been implemented effectively. In many places the newly constructed buildings are not fit for living because they are not designed based on the needs of this group and lack basic facilities of water and electricity. There have been no arrangements or financial provision to enable villagers to move. This has been an empty gesture without consideration to truly meet the needs of people affected by leprosy. As a result, very few villages have been successfully merged since 2009.

In accordance with Articles 19 and 30, the Government is asked to implement the plan to merge leprosy villages and hospitals with careful consideration of the reality of each situation. The Government should:

- **Ensure that, in merging the villages, the will of people affected by leprosy is the basis of the final decision**, respecting the villagers' opinions, understanding their needs and focusing on their living and spiritual needs. Villages should be gradually merged according to their needs, recognizing that some will resist moving due to their relationship with the hometown as well as the habits of living there for a long time, whereas others will respond positively to moving to a new place. In addition, logistic and administrative issues should be considered so as to release the former workers' worries.
- **Make proper arrangements for the land, houses and other property assets** in the closed villages, and use any profits on sale for the living and medical needs for the moved villagers.
- **Inform villagers clearly about the subsidies available from local governments.** Consideration should be given to the living and medical fees of people affected by leprosy who move to other places being covered by the former departments of civil affairs and health care.
- **Repair the villages from which people are not willing to move and provide them with more funding and more executive and medical workers**, in order to guarantee the quality of life and health of people affected by leprosy living there.
- **Close leprosy hospitals with few occupants, poor transport links and poor living or medical conditions, and encourage the occupants to move to neighboring leprosy hospitals with good living and medical conditions**
- **Establish pilot programs to help transfer disabled elderly people without family in communities, who are currently occupants of leprosy hospitals, to comprehensive nursing homes in the general community.**

9. **There is a lack of caregivers in leprosy villages.** Most people affected by leprosy who live in leprosy villages continue to be isolated from family without children or relatives. It is an urgent issue to take care of these elderly people but, because of the lack of money, it is difficult to hire workers to nurse them or do cleaning. There is still some discrimination against leprosy in the society, and this adds to the difficulty of finding people who are willing to offer service in these villages. Even where villagers do enjoy service from volunteers or hired caregivers at present, it is still a serious problem to care for the occupants, especially those who are sick, because volunteers and hired caregivers lack expertise about medical nursing and the consequences of living in such villages for a long time.

In accordance with Articles 5, 8 and 19, the Government is asked to:

- a. **Recognise the efforts by people affected by leprosy in the villages to care for themselves and at the same time care for one another over many years**
- b. **Increase the financial provision to hire government health staff who are able to nurse and care for the disabled people.**

² Notice of the National Development and Reform Commission on the Approval of the Construction of Leprosy Villages Forwarded by Ministry of Health (No.56, 2007). The initiative involved numerous provincial departments including the Health Department, Development and Reform Commission, Department of Finance, and Department of Civil Affairs.

- c. **If health care workers refuse to work in the villages on account of their attitude to leprosy, work with the non-government organizations which are active in the frontline of serving leprosy villages.**
 - d. **Take positive steps to build awareness of leprosy in the health system and combat negative attitudes towards persons affected by leprosy.**
10. **Many people affected by leprosy would like to go back to leprosy villages because of the poor living conditions after departure.** As noted in section 3 above, typically around 90% of people affected by leprosy, most of them severely disabled, have returned to the general community. In 2011, to meet the needs of these and other people affected by leprosy, eleven departments including the former Ministry of Health initiated the Plan for Eliminating Damages of Leprosy in China (2011-2020), proposing goals and corresponding measures with special focus on the disability of and discrimination on people with leprosy. The intention was to further perfect the system of leprosy prevention and treatment at all levels throughout China.
11. However this system also has not been implemented effectively. The people who returned to the general community, especially those with physical or sensory impairments, are facing major difficulties in daily life. Some non-government welfare organizations, who provide services for these people, have discovered through their work that many of these people apply to go back to the leprosy villages because of their poor physical conditions as well as the lack of guaranteed services. It is extremely difficult to deal with this situation. Many of those who left the villages now live in different regions so it is not easy to visit them or get the latest information about them. But it is a common situation that people affected by leprosy who are outside the villages are finding it difficult, whether to continue living in the community or to go back to the villages.

In accordance with Articles 5 and 19, the Government is asked:

- a. **To ensure that people affected by leprosy have the opportunity to choose their place of residence and where and with whom they live, and are given the necessary information to enable an informed choice.**
 - b. **To ensure that people affected by leprosy living in the general community have equal rights of access to public services and social welfare services, and take action to correct any instances of discriminatory practices by local government personnel**
12. As described above, in a number of cases, clearly established and well-intended Government plans and policies have been poorly implemented or not implemented at all.

In accordance with Article 4, the Government is urged to establish an accountability mechanism to evaluate the effectiveness and the implementation of leprosy-related policies in every level of government.

13. The UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members were adopted by the Human Rights Council in 2010. They broadly mirror the CRPD and provide a valuable roadmap for countries seeking to reduce anti-leprosy stigma and promote the human rights of persons affected by leprosy.

The Government is urged to adopt and implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.