

A Report on Human Rights Status Concerning those affected by Leprosy in Nepal for the Universal Periodic Review of the United Nations

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Leprosy, a chronic infectious bacterial disease, predominantly affects skin, peripheral nerves and eye with long-term consequences of loss of sensation and progressive tissue degeneration resulting in physical and mental disability and deformities if treatment is delayed. Leprosy has existed from the middle ages, often with terrifying and inimical stigmas such as “a curse from God” and “being shunned as an outcast”. Outbreaks of leprosy were the earliest pandemics in recorded history, predominantly in Europe in the 11th century. Today, newly diagnosed leprosy cases remain significantly high on a global scale, as WHO reported 208,619 new cases detected in 2018 from 159 countries, the highest leprosy burden being in the South-East Asia region¹. In Nepal alone, leprosy almost broke the WHO elimination status with its elevated prevalence rate of 0.99 in the fiscal year 2018/19, as every two hours and forty minutes, a new leprosy case was detected. Out of 77 districts in the country, 17 districts have been thus categorized as high leprosy endemic districts².

Leprosy still remains a critical and stigmatizing condition in Nepal, and thousands of people affected by leprosy have attested to being discriminated against. Stigma towards leprosy was reported in around 52% of communities when de Stigter et al. conducted a study in 300 community members in eastern-Nepal in 2000, and revealed that stigma/discrimination is significantly high towards people with leprosy³. Due to the existing stigma towards leprosy, people are reluctant to seek support when initial symptoms such as skin patches and/or nodules appear, causing a delay in diagnosis which leads to the increased incidence of disabilities/deformities. Significant numbers of citizens affected by leprosy are unable to effectively perform their duties as per demand due to psychological status and disability, they even face discrimination and physical abuse which further restrict them from carrying out their normal day to day activities. A person pseudonym (Yalram K. C.) was compelled to resign from the Nepal army due to leprosy.

Leprosy has significant impacts on various aspects of life in Nepal, including social interactions, marriage and family, opportunity and employment, and ultimately social status. It is important to note that opportunities in Nepal are predominantly contingent on social status of an individual. As an example, a case study showed that a 45-year person affected by leprosy from Ramechap (pseudonym) said, “My wife rejected me due to leprosy and I can not go outside as freely as I could before I had leprosy. I can not participate in as freely in social events as before. I emotionally feel down and frustrated with my life”⁴. This is a clear example of human rights violations, with a myriad of discrimination issues. Another example, Bhatu Tamang, a 48-year-old male from Nuwakot district of the mid-hill region was diagnosed with leprosy when he was just 10 years old, and when growing up he was told to stay in the corner of a cowshed. Everyone around him felt uncomfortable, due to his condition, which resulted in no one visiting him besides his own mother. He only came for treatment after losing all his toes and fingers. When his mother passed away, his brother exclusively sold all the family property, and deprived him from any property rights. Since then, he has been living with hand-to-mouth condition at Khokana leprosarium.

Another case study revealed the compromised rights of education due to leprosy in a 19-year-old female, Paniya Yadav, from eastern Terai Nepal. She was diagnosed with leprosy when she was just 13. She said that after having leprosy, her school headmaster told her not to come to school as she could spread the disease to other students. He also suggested to her better to get married. Her friends also teased her and avoided coming close to her. Eventually, she dropped out of school and never went

back. She got married at the age of 18 with a man who was also affected by leprosy because she thought that he would be more understanding, given that they both have the disease. The couple is now living at the Khokana leprosarium.

Another prominent case study involves a 68-year female Pulti Shahi, who is from the remote Humla district of the far-western-hill region. Since the time she was diagnosed with leprosy, she has been kept in a dark stone cave for eight years. Her neighbors and her own brother forced her to be in the cave despite her brother being the chief of village development in the community. He attempted to justify his actions by blaming social pressures and the need to preserve his dignity. Pulti said, "Why should I live at home, if the community and my own people did not like my presence? Therefore, I went to that scary cave." After a long time, the government authority (including armed forces) rescued her and brought her to Anandaban hospital for treatment. She has been living at Khokana leprosarium since then, and no relatives have visited to date.

A somewhat different case study involves the life of 36-year Sharmila (pseudonym). When her husband came to know that she had leprosy, he did not allow her to enter their room. He abused her physically and mentally. He was not even willing to recognize their son because he did not accept their son as his own. As a result, she went to her parents' home, and even there, she faced much discrimination by her in-laws. Her in-laws did not allow her to sit near by their children. Eventually, her husband remarried because of her leprosy. Her husband was not even willing to make her son's citizenship registration. Both mother and 13-year-old son have been living in the Khokana leprosarium, however her husband has never made any concerns towards them till date.

Results from a focus group discussion with International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal members including 14 (8 males & 6 females) affected by leprosy, revealed that all study participants had a significant degree of self-stigmatized and agony to introduce themselves as leprosy affected to others, even though they are completely free from active disease after undergoing proper therapy. The study revealed that around 28% attempted suicide at least once in their lifetimes, 36% faced physical abuse, and 21% feared to get married due to being shunned. All felt there is no equal human rights situation for leprosy in Nepal. A research study led by The Leprosy Mission Nepal (TLMN) also demonstrated a 3-fold (58% vs 20%) higher psychological morbidity in far-western residents of marginalized ethnic indigenous Tharu communities people affected by leprosy compared to general non-leprosy Tharu neighbours.

Recommendations:

Participation in social and cultural activities:

It is highly recommended that the newly reformed federal government system of Nepal sets mechanisms and actions to increase public knowledge surrounding leprosy. Awareness with factual information and scientific knowledge regarding leprosy should be given in the active public areas such as schools, offices and businesses, movie theatres and public transport networks via various tools and techniques such as pamphlets or leaflets, sketched wall diagrams, newspaper, FM, radio and televisions and social media. Importantly, active participation of people affected by leprosy should be guaranteed for the leading and representing in the public awareness campaigns. The grassroot level local government to national government of Nepal should allocate adequate budget to give opportunities encouraging to those affected by leprosy to involve in all social and cultural activities, removing the fear of stigma and discrimination.

Access to healthcare:

Due to the federal transition in the health sector, leprosy knowledge is not mainstreamed within healthcare provision in Nepal. Most of the new healthcare staffs have not received proper leprosy training yet and often misdiagnose or miss cases of leprosy when they see them, and so patients may not get the appropriate treatment fast enough. Furthermore, there is insufficient leprosy expertise within the country and most young health staffs have been losing interest in leprosy so that treatment is not available to people who require intensive ulcer care, reconstructive surgery and eye care. The government of Nepal should ensure the provision of essential leprosy knowledge and trainings within the healthcare community so that people affected by leprosy can receive early diagnosis and treatment, preventing major consequences such as subsequent disabilities. Each local level health post in rural

municipality should be equipped and capacity built up for leprosy diagnosis (Slit Skin Smear Test) for early leprosy diagnosis. Further, the government should provide enough funding for the training of medical professionals so that they can perform specialised treatments, such as the treatment of ulcers or reconstructive surgery or eye care. The government should expand the leprosy active case detection, contact tracing and leprosy-post exposure prophylaxis activities in leprosy endemic districts to find out the hidden cases in communities and provide those with adequate and free healthcare access.

Access to education

Experiences and case studies in Nepal have shown that many children affected by leprosy and the adults affected by leprosy face many difficulties in accessing education in schools and higher colleges and universities. Due to the fear of being discriminated against in schools, many pupils affected by leprosy quit before they complete their education, and sometimes they are also pressured by teachers and fellow students to terminate. Many children with leprosy disability are rejected from schools or colleges because the school fears that they will not be able to integrate with the other pupils and/or because most of the educational systems such as schools, colleges and universities still do not have the appropriate facilities to allow a person with disabilities to access their buildings. The government of Nepal should ensure that no person affected by leprosy and no person with disabilities should be turned away from the education system of Nepal. Where school facilities are not sufficient to allow access to buildings, the government and collaborating stakeholders should dispense the appropriate funding available so that accessibility requirements can be met.

Legal discrimination:

People affected by leprosy are also discriminated against in the legal system. Point C. of the Section 71 (2) (Marriage not to be concluded) of the Chapter 1 (Provisions Relating to Marriage) of Part 3 (Family Law) of the "National Civil (Code) Act, 2017 (Nepal)"⁵ which was passed on 17 August 2018 states that a marriage is void if one of the partners fails to declare that he or she is suffering from leprosy or certain other severe diseases, such as HIV. Leprosy can be easily treated with multi-drug therapy and early treatment averts most disabilities and reduces existing stigma towards leprosy. Most people affected by leprosy in Nepal are raising their voice and asking: is it truly necessary to mention leprosy in the National Civil Code Act, 2017? Despite the nation's strides towards reducing leprosy discrimination, such legislation has a contrary effect and enhances agony and self-stigma, stigma, discrimination and human rights concerns towards leprosy.

Offensive terminology

The terminology 'leper' and the provisions for "leprosarium" are deeply derogatory and offensive for persons affected by leprosy. The government of Nepal should immediately repeal the use of the derogatory and offensive terminology such as "leper" and "leprosarium" from the legal and formal documents or amend all legislation at the union or state level, and any subordinate legislation, that discriminates specifically against people affected by leprosy. Khokana leprosarium should be renamed with a respectful name improving the dignity and overall quality of life of those residents.

Implementation of positive measures

All stakeholders should raise awareness of these existing leprosy related misconceptions and superstitions, and put in place measures and mechanisms to establish an environment where people affected by leprosy are no longer looked down upon and discriminated against. All levels of governments systematically collaborating with UN Agencies, NGOs and the private sector should ensure appropriate implementation of the UN *Principles and Guidelines for the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members* and promote inclusion and empowerment of leprosy affected persons and their family members. Similarly, the government should prioritize activities and interests towards empowering the leprosy community through free education and capacity building opportunities, free healthcare services, improving overall quality of life and enforcing policies that protect human rights for those affected by the disease. Now is the time to finally transform our mentality towards leprosy via mass awareness, potential measures and interventions, as well as holding policymakers accountable when they stray away from enforcing law that protects human rights.

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