TLMTI Responses to the UN on the Status of Adherence to A/HRC/29/5 for India

# Introduction

## The Leprosy Mission Trust India

**The Leprosy Mission Trust India** (TLMTI) [www.tlmindia.org](http://www.tlmindia.org) is the largest Non Governmental Organization (NGO) in India working with and for men, women and children affected by leprosy for over 140 years ( since 1874), in the areas of **health, education, sustainable livelihoods, community development, advocacy** and **research**. TLMTI has 14 Hospitals, 6 Vocational Training Institutes, a Media Centre for media advocacy and communication, a state of the art Immunology Research Laboratory, 5 small residential facilities (Snehalayas) for the care of elderly leprosy disabled people, and various community based development projects spread over 9 leprosy endemic areas states in the country (Chhattisgarh, Maharashtra, Uttar Pradesh, West Bengal, Delhi, Tamil Nadu, Bihar and Andhra Pradesh). TLMTI also supports the National Leprosy Eradication Programme (NLEP) in 4 states.

TLMTI’s core focus remains Leprosy, but realizing that development is the key to tackling the issues of leprosy, TLMTI has expanded its target population to include people affected by leprosy, people living with disabilities, and other marginalized groups in the same communities (like rural poor women, tribals etc), working with them for their inclusive development, and working in partnership with the local, state and national government and other national and International development organizations. TLMTI programmes are in the domains of **Health**; **Sustainable Livelihoods & Empowerment**; **Advocacy & Communications**; **Research & Training** with the domain support of **Finance**; **Human Resources**; **Internal Audit & Risk Management,** **Learning & Development** (knowledge management; monitoring & evaluation; project development) and **Resource Mobilization** for programme effectiveness*.*

TLMTI is also an integral part of ILEP India. It has been working tirelessly to bring back the focus on leprosy issues in India both with the GoI and other organisations working on leprosy and disability in the country.

# Responses to the Questionnaire

1. **Are you aware of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010(resolution 65/215)? If yes, how did it come to your attention?**

Yes TLMTI is aware about the Principles and guidelines document of the UN. TLMTI learnt of the resolution as the organization is present in 33 countries and this document was immediatlly shared globally among all organizations working in the feild of leprosy. Also while the organization started a project called ‘CALL (Challenging Anti Leprosy Legislation) Project’, this document was used as a key guideline through which the project worked on and since then has been promoting the same through its work in India.

2. **What mechanism has the Government (Federal or State level) put in place to disseminate the Principles and Guidelines to its citizens? e.g. translation into national and local languages; media; or any other mechanism?**

Although the UN resolution was adopted in the year 2010, in which India also participated and accepted, the Government has done nothing concrete within its own mandate to disseminate the Principles and Guidelines document. It is not available either in text or a web-link in either of the concerned central ministries, the Ministry of Social Justice and Empowerment (MSJE) and the Ministry of Health and Family Welfare (MFHW) under which leprosy falls.

Additionally, the document was not referred to by either the MSJE established Sudha Kaul committee that drafted the initial Rights of Persons with Disabilities Bill, 2011 (RPD) or by MSJE or other concerned officials in the various edited versions of the said Bill in the preceding two years. This happened despite the fact that leprosy cured is a reconginsed category of disability under the existing legal structure on disability under the Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act, 1995 (PwDs Act, 1995), which was being reviewed to be replaced by the new bill to bring the main disability legislation in line with India’s international obligations on the subject matter of disability. The only UN document referred to and relied upon in the process of the RPD Bill has been the United Nations Convention on the Rights of Persons with Disabilities, 2007 (UNCRPD).

It was through our efforts in our representation to the Standing Committee on the RPD Bill in 2014, which was charged with reviewing the provisions of the RPD Bill by the Parliament that a reference was drawn in our representation to the Principles and Guidelines document. However, the report of the Standing Committee on the RPD Bill does not make any direct reference to the Principles and Guidelines document in its final document.

During our interactions with various officials of the government and its quasi-judicial structures like the National Human Rights Commission and parliamentarians of the government, we found that most people within the system were unaware of the Principles and Guidelines document. Even a large majority of disability activists and professionals still remain unaware of the existence of India’s obligation under the Principles and Guidelines document.

A sustained effort has been underway by the organisations working in the area of leprosy in India to highlight India’s obligation under the Principles and Guidelines document such as the conference organized by Sasakawa Foundation in October 2012 in New Delhi and publication and wide distribution of the document by TLMTI. In the past two years, the MSJE has also taken a keen interest in the issue of leprosy and has organised meetings such as the National Conference on Rehabilitation of Persons Affected by Leprosy in collaboration with NGOs where the platforms have been used to create awareness about the Principles and Guideline document as well. Apart from these sporadic efforts, the Law Commission of India, a recommendatory body to the Government on the issue of the laws of the land, has of its own accord mentioned and referred to the Principles and Guidelines document in its Report Nos. 249 & 256, wherein it has relied on India’s international obligation there-under to address the issues of discriminatory legislation and positive measures for persons affected by leprosy.

3. **Have any policies, action plans or any other measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members? Please provide details on measures taken.**

The National Leprosy Eradication Programme (NLEP) under the Ministry of Health and Family Welfare (MoHFW) has come out with a ‘Guidelines on reduction of stigma and discrimination against persons affected by leprosy’. For the purposes of this document, NLEP has identified a close link between stigma and discrimination.

Within this document NLEP has identified the need to create awareness, based on scientific and in-depth knowledge on leprosy as an important means of addressing the existing discrimination and stigma in society. It further emphasis that the material developed should also aim to demystify the existing myths and misconceptions that breed stigma and exclusion. It recommends working with multi-stakeholders in achieving the same, which include civil society, health professionals and hospital administrations, media, celebrities, local level based bodies like the panchayats, religious and community leaders, corporates and the community. The guideline also recommends the use of methods like group counseling and community based rehabilitation (CBR). Another suggested measure is to work in coordination and collaboration of other on-going efforts like the health melas and village health and sanitation meetings. Self-help groups have also been identified as forums from where awareness can be raised. The positive aspects of this guideline include the stress of working in collaboration with multi-stakeholders in the society and reaffirming that the implementing personnel/officers in each region can adopt any other initiatives and means to achieve the goal of reducing discrimination against persons affected by leprosy. However, this document is limited to persons affected by leprosy and fails to include their family members in its scope of application.

In addition to the above guideline, the NLEP also came out with another document focusing on the need and use of IEC for raising awareness on discrimination and stigma against persons affected by leprosy entitled ‘Behaviour Change Communication – Strategy’[[1]](#footnote-1) sometime in the year 2007-2008. This guideline is mainly focused on health related needs. Under this guideline focus is laid of the social marketing approach to be adopted for wide circulation of IEC material for raising awareness for all and empowerment of persons affected by leprosy. The measures for raising awareness and reducing stigma include the involvement of women, women health workers, old-age people with leprosy, community youth, leaders, budding writers and media persons. It also lays emphasis on including persons affected by leprosy in village level gram-sabha meetings, health melas and cultural festivities as a means of reducing stigma and discrimination. The document provides in detail the activities that need to be done at Central, State, District and Block levels to have impact.

However, little is known of the implementation and success of these measures. Similar measures are also being adopted by non-governmental organizations (NGOs) in the field of leprosy. Yet, self-stigma, stigma and discrimination remain an everyday reality for the higher majority of persons affected by leprosy. A recent positive change that has been witnessed at the central NLEP level is the concern and efforts of the newly appointed DDG of the NLEP programme to review the measures being adopted by the government in addressing the concerns of leprosy in view of the fact that the PR rate has remained pretty static since India achieved the elimination mark in late 2005. Some of the acknowledged barriers in achieving early detection of the disease are lack of knowledge about leprosy and its treatment and the fear, self-stigma, stigma and fear of discrimination attached to the condition.

4. **What measures have been taken (Federal or State level) to modify, repeal or abolish discriminatory laws, policies or practices, including terminating forced segregation, in order to eliminate discrimination against persons affected by leprosy and their family members? Is freedom to choose where to live ensured for persons affected by leprosy and their family members?**

The Lepers Act, 1898 was a law created to deal with the provisions for segregation of people affected by leprosy from the general community. This central legislation had to be adopted by each State and Union Territory separately to become enforceable in its own jurisdiction. Thus, in case of its repeal, each State and Union Territory that adopted the same has to repeal is also which the Central Government has to repeal the primary Lepers Act, 1898. As per the available information, the primary central Lepers Act of 1898 still remains in force but some States and all the Union Territories have repealed their individually adopted Acts. These States and Union Territories include Gujarat, Assam, Nagaland, Meghalaya, West Bengal, Tamil Nadu, Tripura, Punjab, Karnataka, Orissa, Himachal Pradesh, and Maharashtra, and in the Union Territories of Delhi, Andaman and Nicobar Islands, Lakshadweep, Dadra and Nagar Haveli and Chandigarh[[2]](#footnote-2).

In 2014, after the present government came to power, the Law Commission of India, a recommendatory body to the government on the issue of laws was asked to look into all laws of the land and suggest removal of obsolete and anarchic provisions and legislations. Under this process, in its Report No. 249 “Obsolete Laws: Warranting Immediate Repeal” (Second Interim Report), October 2014 the Law Commission of India recommended the repeal of The Lepers Act, 1989 from the central statue book as well as from all those States, in which it was still in existence. In making this recommendation the Law Commission referred to India’s obligation under the Principles and Guidelines document as well. This report was taken up in the Lok Sabha[[3]](#footnote-3) under the title of The Repealing and Amending (Fourth) Bill, 2015 on 27th July 2015 and the Lepers Act was part of the repeal list. Although, the Bill was passed by the Lok Sabha it remains pending to be introduced in the Rajya Sabha[[4]](#footnote-4) before it can be finally passed. As of yet the present Bill and repeal of the Lepers Act remains pending[[5]](#footnote-5).

Additionally, since 2011 there have been four efforts to address the issue of discriminatory provisions in various laws. The Juvenile Justice (Amendment) Act, 2011 struck down a provision under its law that allowed for a juvenile affected by leprosy to be removed to a leprosy colony. The issue of this provision had been highlighted in a previous advocacy effort to address such laws when a comprehensive petition on the issue of empowerment and inclusion of people affected by leprosy was filed before the Rajya Sabha Committee on Petitions[[6]](#footnote-6) in 2008. A follow up of this petition had taken place in the year 2010 but since then nothing much happened on it.

The other step has come about in the process of creating a new legislation on disability to replace the existing PwDs Act, 1995, which is the primary law on the subject. This effort is being undertaken by the central government. Although the last finalised version of this proposed legislation entitled RPD Bill, 2013 did not contain any provisions addressing discriminatory provisions in other laws except for stating that the provisions of this law will be in addition to other laws in existence[[7]](#footnote-7), the Standing Committee suggested otherwise. It has clearly recommended that any provisions in any other laws that are inconsistent and negates the spirit and objective of the proposed legislation should be deemed repugnant, when the bill becomes law. This recommendation if accepted will have an immediate effect and impact on all direct and indirect discriminatory provisions against people affected by leprosy in other laws.

With reference to people affected by leprosy there is also a negative recommendation in the committee report, which relates to the housing of people affected by leprosy. Herein the committee has suggested the creation of separate housing for people affected by leprosy if they face discrimination in the general community. In the particular recommendation at point 22 it states that, “Specific efforts should be made by the Government to provide housing to leprosy cured people who may not be allowed to live in other colonies on the grounds of discrimination by the society.” However, it still remains to be seen what all recommendations would be accepted and incorporated before its presentation to the Cabinet from where it will be sent for consideration to become a law in both the houses the Parliament. The reviewed draft is yet to be presented before the Cabinet.

Under the mandate of the Law Commission to review obsolete and archaic laws, a team from TLMTI approached the Commission with a request to also look at the other existing discriminatory provisions in law, both of direct and indirect nature. The Law Commission took up the matter and created a working group on the subject and came out with a very comprehensive report on the subject of people affected by leprosy. The report having number 256 is entitled *Elimination Discrimination Against Persons Affected by Leprosy*, April 2015 and provides for both substantive provisions as well as removal or suitable amendment of discriminatory provisions from other operational laws. At the end of the report is annexed a draft Bill dealing with both aspects within the report. The same has been presented to the present Minister of Law for further action. The last known position on Report 256 is that it was sent to the Ministry of Health and Family Welfare for their opinion. A serious advocacy effort is now needed to ensure that the government takes up this report and passes the draft bill annexed thereto at the earliest.

There is no specific set mechanism to ensure that people affected by leprosy do not face discrimination with regard to their choice of residence. From our field experience we know that there are people affected by leprosy living peacefully in the general community and we also know of cases where people affected by leprosy hide the fact of their disease and fear that if their condition becomes generally known they will have to face discrimination. However, in such cases the presumption of discrimination stems from the person’s perception without an actual basis of having faced discrimination. In case discrimination happens a person affected by leprosy can access the existing judicial and quasi-judicial structures available in the country. However, no such examples of cases are known to us and therefore there is little knowledge of how such situations will be dealt with at that level on intervention. Hopefully, if the recommended definition of discrimination by the Standing Committee on the RPD Bill is accepted then it will cover such instances of discrimination under its ambit in legal terms. However, it is needless to say that the implementation of it will have to be judged in the course of time.

5. **Which is the terminology originally used in your native language in respect of persons affected by leprosy? Please also provide, aside from the specific terminology in your native language, a translation of it in English. Are there any popular myths associated with persons affected by leprosy? Please provide a short description.**

Traditionally, the word *kodhi* is used in Hindi, which is the official language of the country. In literal translation it means leper. The term *Kusht* is used for leprosy. Apart from this, the term leprosy-cured has been used in the Persons with Disabilities Act, 1995 for people that will fall within the ambit of that law.

There are many myths associated with leprosy such as:

* It is due to past sins of the person or their family members
* It is a curse from God
* It is because of bad ‘karma’
* Leprosy is hereditary
* It spreads by touch
* It is a disease of the poor
* Leprosy is not prevalent now
* You get leprosy due to immoral sexual behaviour[[8]](#footnote-8)
* Leprosy infection spreads through food and water
* Leprosy is incurable

6. **Are those affected by leprosy and their family members being consulted with and/or actively participating in the decision-making processes that deal with matters related to them?**

There are many Disabled People’s Organisations (DPOs) in India, especially in every State with an organized structure at the national level. There are also DPOs of persons affected by leprosy such as the Association of People Affected by Leprosy (APAL), International Association for Integration, Dignity and Economic Advancement(IDEA), Hind Kusht Nivaran Sangh (HKNS). Slowly this form of organized formation of persons affected by leprosy is increasing but there is a long way to go to achieve active participation by them.

Due to the deep rooted sense of self-stigma the general participation level of persons affected by leprosy remains low with the government agencies on issues affecting them. However, with sustained programmatic interventions, for example in TLMTI’s recent project on Challenging Anti-Discriminatory Legislation (CALL) the participation of persons affected by leprosy improved in gram-sabhas and panchayats in the project areas.

For example, the participation of persons affected by leprosy is extremely negligible in the larger disability movement in India, which is currently an important platform for raising concerns, advocating on issues and influencing the government for needed actions. In comparison there is better participation of persons affected by leprosy in meeting organized specifically related to leprosy issues by the organizations working in the field of leprosy.

7. **What measures have been taken at the national level to ensure persons affected by leprosy enjoy fully and equally rights with others regarding the rights of citizenship; obtaining identity documents; the right to vote; the right to stand for elections; the right to serve the public in any capacity or other civil and political rights?**

Technically, persons affected by leprosy are allowed equal rights to citizenship; various identity documents and the right to vote, but in reality acquiring these are not as easy for them. For many living in leprosy colonies, the foremost barrier in accessing such documentation is the proof of residence as in most of the 850 leprosy colonies in India, the people living there have no rights to the land and houses they stay in. Additionally travelling several times to various government offices for availing the necessary documentations are very difficult for persons affected by leprosy with issues of finance of travel, accessibility and attitudinal barriers that they face.

One very important identity document for persons with disabilities (PwDs) is the Disability Certificate that is issued under the PwDs Act, 1995, which entitles them to the benefits and schemes for PwDs under the various laws, rules, policies and schemes of the land. Although leprosy-cured is a specified category in the PwDs Act, 1995 wherein loss of sensitization is also included, the disability certificates are issued under the category of physical or visual or multiple disability category. Moreover, the certification board usually does not include a leprosy expert and usually does not take into account loss of sensation. Moreover, the entire process of going through the examination and certification procedure is very cumbersome, leaving many who should be entitled to it without an access to the same.

As for the rights to stand in elections, these are curtailed under six Municipal and Panchayati Raj Acts of the States of Rajasthan, Andhra Pradesh, Orissa, Chhattishgarh and Madhya Pradesh at present. Even the Supreme Court of India had upheld this discriminatory provision of not allowing a person affected by leprosy to stand for public office[[9]](#footnote-9). The question of enjoying an equal right to participate in political life has been addressed in Report No. 256 of the law Commission and it has clearly recommended the need to do away with such provisions that inhibit a person affected by leprosy to contest elections. It remains to be seen whether this recommendation of the Law Commission will be accepted and acted upon by the concerned central and state level governments.

In TLMTI’s experience of supporting persons affected by leprosy in availing such documentation, it found that on request and facilitating proper response, the government officials have also willingly come to the leprosy colony to take applications en-mass for the residents of the colony.

There was an effort to create accessible voting booths during elections as a result of the advocacy carried out in this regard by the larger disability movement in India. However, apart from this no specific measures have been put in place to provide easier access to such processes especially for persons affected by leprosy.

The RPD Bill, 2014 which is in the pipeline also affirms these rights for all persons with disabilities including those affected by leprosy. However, it remains to be seen what shape the Bill will take as it gets passed into a law and how will it be implemented.

8. **What measures have been taken to ensure persons affected by leprosy enjoy equal rights with others with regard to the rights to work and education; establishing a family; access to public places, including hotels, restaurants; and buses, taxis, trains and other forms of public transport; access to cultural and recreational facilities; access to places of worship or any other economic, social and cultural rights?**

Again in the existing system most of these rights per say are guaranteed to all persons including persons affected by leprosy but they still fall through the cracks of the generalised provisions in their application and implementation. As of now there are barely any specific measures for persons affected by leprosy.

Under the PwDs Act, 1995 there is a provision for 3% reservation in employment within the government sector, for specified categories of PwDs. Under this persons affected by leprosy share 1% reservation along-with persons with physical disabilities including persons with cerebral palsy. In the RPD Bill, 2014, which remains pending consideration this reservation has been increased to a total of 5% but herein also persons affected by leprosy are sharing 1% of it along-with persons with locomotor disability including cerebral palsy and muscular dystrophy.

There has also been a government order for employment of persons cured of leprosy titled O.M. NO. 14-11/65-ESTT.(D) on the subject: “Rehabilitation Assistances to Cured Leprosy Persons in Central Civil Services in Class III and Class IV posts” dated 2nd March 1965 passed by the Ministry of Home Affairs, New Delhi. As per this order and many following orders reiterating the same more than 200 persons affected by leprosy had been identified for employment in the Railways. Yet even today, they are fighting to get their jobs. After having approached the Supreme Court on many occasions, their petition is currently being heard in the High Court of Delhi[[10]](#footnote-10), wherein a final judgment is still awaited. None of the Petitioners has yet got the promised for jobs and some of them have even passed away in this long drawn battle.

A similar provision for reservation in higher education exists in the existing PwDs Act, 1995 which likewise has been increased to 5% in the proposed RPD Bill, 2014. Under the reservation section in higher education there is no segregation of the reserved percentage between the various categories of disabilities.

Under transportation, the Indian Railways Act provides for a discretionary power with the railway officer to remove anyone from a train if he feels the person is suffering from a contagious disease. Although the provision does not have any direct mention of leprosy as one such category, there is a tendency that it may be used against a person affected by it as the general understanding of leprosy and its curability remains very poor. At an individual State level, The Maharashtra State Transport has been providing leprosy cured persons with 75% concession on their buses, which is a welcome form of affirmative action. However, its limitation to only leprosy cured and only in its own transport buses is limiting in its scope and benefit.

Overall, there is rampant violation of these rights of persons affected by leprosy due to their lack of knowledge of these rights and the forums for their redressal and at times the means and will of pursuing the violation. Adding to that is a host of attitudinal and structural barriers mixed with the silenced acceptance of the age-old norms and practices of segregation and exclusion in society.

9. **What actions have been taken to promote and protect the human rights of (a) women; (b) children; (c) the elderly; (d) members of other vulnerable groups who have or have had leprosy, as well as their family members? Please provide details.**

There are no specific measures to protect and promote the human rights of the multiply marginalised sections within persons affected by leprosy. The report of the Standing Committee on the proposed RPD Bill, 2014 has clearly recommended the re-inclusion of the specific chapters on women with disabilities and children with disabilities in the bill. If this recommendation is accepted by the GoI, then women and children affected by leprosy will also get covered by it.

There are no specific measures to promote and protect the human rights of the family members of persons affected by leprosy. The first time that such a need has been acknowledged and addressed has been done by the Law Commission in its Report No. 256 in line with the Principles and Guidelines document. It remains to be seen what shape these recommendations will finally take. The other proposed measure where family members will be covered on the grounds of their association with a PwD is under the provisions on Non-Discrimination under the RPD Bill, 2014 as recommended by the Standing Committee Report on the said Bill.

10. **What actions have been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons?**

The Law Commission of India in its Report No. 256 has recommended the removal of discriminatory and labeling language i.e the term *leper* from all government communications and documents. It has clearly stated that, “… the use of the term leper is derogatory and contributes to the stigma associated with the disease. Therefore, the Law Commission recommends that such a term should be removed from the statute book and all government records to curtail the perpetuation of the stigma associated with the disease. The need for the removal of the term leper under State beggary prevention laws has been recognised by the Rajya Sabha Committee on Petitions in its Hundred and Thirty-First Report and its Hundred and Thirty-Eighth Report.”

Furthermore, this recommendation finds mention in section 7 of the draft Elimination of Discrimination of Persons Affected by Leprosy Bill, 2015 (EDPAL, 2015) that is annexed with Report No. 256.

Currently, this report is pending consideration for action by the GoI.

11. **Have Governments drafted and/or adopted a national action plan to implement the Principles and Guidelines? Please attach a copy. Has a national committee been established? Please provide some details as to its mandate, size and composition of members.**

We are not aware of any action plan having been made and adopted by the GoI to implement the Principles and Guidelines document or of any committee having been established for the same.

12. **What major obstacles, if any, have Governments faced in implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members?**

As the GoI has not done anything specific till date to implement the Principles and Guidelines document, we cannot comment on this question.

13. **In your view, what follow-up mechanisms should be put in place at the national and international levels to effectively implement the Principles and Guidelines?**

* Ask the GoI for a 3 to 5 year action plan on how it plans to implement the Principles and Guidelines document.
* Adopt the recommendations and the draft EDPAL Bill in Report No. 256 of the Law Commission of India at the earliest.
* Launch a Nation-wide awareness generation campaign on leprosy including information on the disease, treatment, discrimination and stigma faced by the persons affected by it and the Principles and Guidelines document.
* Bring back focus on leprosy in its health programmes to improve the current stagnation in the PR rates.
* Ask the UNCRPD committee to include a review of the obligations under the Principles and Guidelines documents for countries like India that are contributing a large percentage of the global burden of leprosy.

14. **Are there any concrete measures taken by Governments at different levels that you can share with us regarding actions taken to eliminate discrimination against leprosy affected persons and their family members in your country?**

The issue of land rights is very crucial for those persons affected by leprosy that are living in leprosy colonies. As these colonies were established on government, railway or individual owners lands, the residents there have no legal rights to the land or their houses and thus live in constant threat of eviction. Moreover, due to the lack of residence proof they are many times denied access to government facilities and schemes. In this regard in some colonies the local governments have issued pattas (land-ownership document) in the name of the residents. This is a positive step for persons affected by leprosy in securing their future.

15. **Please provide identified cases of discrimination experienced by leprosy affected persons and their family members in your country, disaggregated by its different forms, including de facto discrimination.**

There are several cases of discrimination that we come across in our work. One case was faced by our CALL project team in Uttar Pradesh where a local hotel refused to give its premises for organising a workshop for persons affected by leprosy as they would have come and stayed there. This was a clear case based in a sense of prejudice and stigma against persons affected by leprosy.

Discrimination in the health sector for persons affected by leprosy is very common. In a case of Delhi – a female resident of a Delhi leprosy colony who had contracted dengue was refused admission by the government hospital as she was a person affected by leprosy. The doctor who diagnosed her for dengue was unwilling to even touch her. Her life was finally saved when her neighbours gave her financial help to get herself treated in a private hospital which was beyond her own means.

In another case, also in Delhi, a person affected by leprosy who was suffering from multi-organ failure of the liver and kidney and had diabetes was denied admission in GB Pant hospital of Delhi for over a month. This lack of treatment ultimately resulted in his death.

 In another similar case in Delhi a women affected by leprosy who urgently needed dialysis was refused admission by a series of hospitals in the capital on the excuse that the hospital did not have dialysis facility. The family was ultimately forced to take her home after a whole day of running from one hospital to the next where she died due to lack of treatment. These hospitals included GB Pant, Arvind, Ram Manohar Lohia, St. Stephen’s, All India Institute of Medical Sciences and Moolchand.

Another major issue that leads to life-long discrimination for persons affected by leprosy is because of the consequences of delayed treatment as many doctors are unable to recognise leprosy and are also unaware of its treatment and availability of free medication. In one known case, the patient was sent to so many different doctors and institutions to find about out the free MDT drug as he could not afford to purchase the medication of the counter that he gave up on the idea of availing the treatment. And in another case a 14 year old girl was misdiagnosed and given ointments and vitamins for the skin patches. This lead to her developing clawed hands, loss of sensation and loss of the ability to blink her eyelids before she was finally diagnosed and treated. This is a routine story that we hear at our own hospitals of patients who come to us. With leprosy having been removed as a public health issue, the medical knowledge of it is being treated as less important in medical courses now leading to the inability of doctors in recognising the disease in its early stages and providing the correct treatment.

In the education system, even with the Right to education Act,2009 in place now, discrimination continues for children from leprosy affected backgrounds. At times it is a direct denial of admission due to the background of the child being associated to leprosy, as happened with a child in the Nagar Nigma School, of the government, in Tahirpur area of Delhi. In this particular case the child was reluctantly admitted after the local MLA intervened in the matter. On other occasions, the admission comes with unjust conditions, which generally include that the leprosy affected parents of the child will never come to school and not participate in the parents teachers meetings either, just in case the other students and their families find out and raise objections. This practice is known to happen in government run school in the Dilshad Garden area of Delhi.

Discriminatory practices have even been noticed in government related services. In India the very poor people are categorized as being below the poverty line and are given a special card called the BPL card, which them entitles them get free food grains from the government. Another card that is routinely issued is the APL card (Above Poverty Line) but the difference is that an APL cardholder is not entitled to free grains. Many persons affected by leprosy who are genuinely entitled for BPL cards are given APL cards instead. Whenever, such persons have gone to the concerned authorities to have the same changed they have been abused and have been given remarks like, ‘these leprosy affected people want everything for free’.

There is a lot discrimination and lapse in dealing with the concerns and complaints of persons affected by leprosy within the government departments. A fine example of this has been the attitude of the Jal Board authority that is responsible for supplying clean drinking water in the biggest leprosy cluster in Delhi in Tahirpur area. For years there was no water supply pipeline in the colony and then an insufficient one was laid in 2006, which was then added to by the colony members by raising money for it. And in this pipeline there is a fault leak from a sewage line because of which the water is unhygienic for consumption. Till date the Jal Board authorities have not addressed the problem and the people residing there are being continually denied their basic right to clean and safe drinking water despite several requests, applications and protests.

A Public Interest Litigation case of Pankaj Sinha vs Union of India & Ors[[11]](#footnote-11) is also pending in the Supreme Court of India, which has raised several issues regarding the prevailing discrimination against persons affected by leprosy and their family members, the under-reporting of new cases, denial of medical care, issue of land rights in leprosy colonies and the need for better awareness on leprosy.

1. <http://nlep.nic.in/pdf/Guidelines%20-%20Strategic%20Framework%20For%20BCC..pdf> – last accessed on 28th December 2015 [↑](#footnote-ref-1)
2. Law Commission Report No 249 (<http://lawcommissionofindia.nic.in/reports/Second%20Interim%20Report%20on%20Obsolete%20Laws.pdf> – last accessed on 28th December 2015) [↑](#footnote-ref-2)
3. The Lok Sabha is the House of Commons in the Indian Parliamentary system [↑](#footnote-ref-3)
4. The Rajya Sabha is the House of Lords in the Indian parliamentary system [↑](#footnote-ref-4)
5. Status of The Repealing and Amending (Fourth) Bill, 2015 on the Parliamentary website (<http://164.100.47.192/Loksabha/Legislation/billintroduce.aspx> - last accessed on 28th December 2015) [↑](#footnote-ref-5)
6. The Rajya Sabha has the power to hear Petitions under its Committee on Petitions process and it can issue recommendatory advice to the concerned departments of the Government of India for further action. [↑](#footnote-ref-6)
7. Section 110 on Application of Other Laws not Barred in the proposed cabinet version of the RPD Bill, 2013 [↑](#footnote-ref-7)
8. Recorded in ‘Behaviour Change Communication – Stragergy’ for NLEP (<http://nlep.nic.in/pdf/Guidelines%20-%20Strategic%20Framework%20For%20BCC..pdf> – last accessed on 28th December 2015) [↑](#footnote-ref-8)
9. Dhirendra Pandua v. State of Orissa, AIR 2009 SC 163 [↑](#footnote-ref-9)
10. W.P. (C) 7457/2010: (*RADHAKANTAPUR LEPROSY ASSOCIATION Vs. UOI AND ORS*) before the Delhi High Court on behalf of 201 leprosy cured person. [↑](#footnote-ref-10)
11. Writ Petition (civil) in the Supreme Court of India, 2014 [↑](#footnote-ref-11)