Rights-based approach for change!

Positive changes in the lives of people affected by leprosy through a rights-based approach to social inclusion and development

IMPACT ASSESSMENT OF CHALLENGING ANTI-LEPROSY LEGISLATION (CALL) PROJECT

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CALL 4 Change CAMPAIGN

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TABLE OF CONTENTS

LIST OF ABBREVIATIONS

CALL	Challenging Anti-Leprosy Legislation Project
CBO	Community-Based Organisation
CG	Chhattisgarh
CMO	Chief Medical Officer
DFID	Department for International Development
HRLN	Human Rights Law Network
ILEP	International Federation of Anti-Leprosy Association
MDT	Multi-Drug Therapy
MGNREGA	Mahatma Gandhi National Rural Employment Guarantee Act
MLA	Member of Legislative Assembly
MP	Member of Parliament
NGO	Non-Governmental Organization
NLR	Netherlands Leprosy Relief
NSS	Naya Savera Sangathan
PAN	Permanent Account Number
PIL	Public Interest Litigation
PRI	Panchayati Raj Institution
RTI	Right to Information
SHG	Self-Help Group
TLMEW	The Leprosy Mission England and Wales
TLM	The Leprosy Mission
TLMTI	The Leprosy Mission Trust India
UN	United Nations
UP	Uttar Pradesh
UDHR	Universal Declaration of Human Rights

GLOSSARY

Aadhaar Card	Aadhaar is a 12 digit individual identification number issued by the Unique Identification Authority of India on behalf of the Government of India. Each Aadhaar number will be unique to an individual and will remain valid for life. Aadhaar number will help the holder access services like banking, mobile phone connections and other Govt and Non-Govt services.
Anganwadi	Centres started by the Central government in 1975 as part of the Integrated Child Development Services to combat child hunger and malnutrition. A typical Anganwadi centre in a village also provides basic health care, including contraceptive counselling and supply, immunisation, nutrition education and supplementation, as well as pre-school activities.
Antyodaya Anna Yojna (AAY)	This scheme, launched in 2000, is aimed at providing food-based assistance to identified destitute households or an individual within a particular social group. They are provided with a ration card (Antyodaya card) to enable them avail a food-grain quota at a subsidised price. Each household is entitled to 35 kilogrammes of wheat or rice or combination of both every month. The food-grain is pegged at Rs 2/- per kilogramme for wheat and Rs 3/- per kilogramme for rice. A Fair Price Shop - designated local ration shop - dispenses this quota. Its dealer cannot charge card-holders more than the pegged price.
Gram Sabha	All adult residents of a village, who come together in joint meetings to discuss issues affecting the community
Indira Aawas Yojna	A housing scheme for the rural poor, launched in May 1985 as a sub-scheme of Jawahar Rozgar Yojna. It has been implemented as an independent scheme since 1 January, 1996. The scheme aims at helping rural people below the poverty-line (BPL) belonging to Scheduled Castes/Tribes (SCs/STs), freed bonded labourers and other eligible categories in construction of houses and upgrading existing unserviceable kutcha houses by providing assistance in the form of a full grant.
Jan-Dhan Yojna	A programme for ensuring access to various financial services such as basic savings bank account, access to need based credit, remittances facility, insurance and pension to the excluded sections of society i.e., vulnerable & low income groups
Kala jatha	A folk theatre form
Nagar Palika	Urban local municipal body
Nirmal Bharat Yojna	A programme to ensure sanitation facilities in rural areas with broader goal to eradicate the practice of open defecation.
Panchayati Raj Institutions	Institutions at the village, block and district levels for decentralised and participatory local self-government
Pehchaan Patra	Identification document
Sarpanch	Village head
Soochna Kendra	Information Centre

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Nikita Sarah
Head – Advocacy and Communication

Chapter 1

Introduction

Context

Discrimination by others and self stigmatisation on the basis of a disease - leprosy - has historically rendered people affected by leprosy and their family members social outcasts. They were shunned by their loved ones due to lack of a medical cure and ignorance about the disease. More often than not, fearing the stigma that was attached to the disease and believing that they are responsible for their fate and to escape being ostracised by their family and community, they left their homes.

They sought refuge in urban centres which provided them with a certain anonymity, becoming part of the urban poor, with the additional disability of being affected by leprosy. They set up colonies on the fringes of cities, far away from probing eyes, seeking solace in their isolated togetherness and deriving the strength to survive from each other.

They suffer a range of deprivations and are subjected to different kinds of discrimination. There are strong attitudinal barriers that prevent people affected by leprosy and sometimes even their family members from participation in society. They have become so used to the idea that they are not capable of working and not welcome to participate in society, that they do not even consider that such opportunities are available to them.

> “Shopkeepers used to wash the money that we would give” -
>
> Balamani, a woman affected by leprosy as her husband suffered from the disease, Ramganga, Bareilly, UP.

Genesis of the project

The Leprosy Mission (TLM) is the world's oldest NGO working on the issue of leprosy and with people affected by leprosy - providing treatment, facilitating social integration and advocating for their rights. The Leprosy Mission Trust India (TLMTI), a member country of The Leprosy Mission (TLM Global Fellowship), was established 140 years ago. TLMTI's work with people affected by leprosy includes running hospitals, providing vocational training, providing technical support on leprosy, undertaking research and advocating for the rights of people affected by leprosy.

Building on its expertise and experience on leprosy-related issues, TLMTI initiated a rights- based project for the empowerment of leprosy-affected communities so that they can individually and collectively become advocates for their own cause, assert their rights, end their marginalisation and pull themselves out of poverty, thereby owning the entire process.

'Challenging Anti-leprosy Legislation' (CALL) project was initiated with the twin objectives of:

1. empowering leprosy-affected communities to assert their right to equality and equal opportunity and fight against discrimination,
2. and creating awareness amongst media, legislators and civil society to create a climate for repealing discriminatory legal provisions and lobbying with law-making authorities for achieving this.

> "It's ironic that I have been living in the leprosy colony but had no information on leprosy disease. Through TLM, I am informed on leprosy and have also learnt about self-care"-

Ashish Sam, Gandhi Kusht Ashram, Ramganga, Bareilly, UP.

CHALLENGING ANTI-LEPROSY LEGISLATION (CALL) PROJECT

CALL is a project of TLMTI with a rights-based approach to advocacy. It is a five-year project (started in June 2010, and ending in March 2015) funded by the UK Department for International Development (DFID), and co-funded by TLM England & Wales, and TLM Netherlands.

Goal:

People affected by leprosy and their family members are empowered to claim equal rights and be included in the development process.

Expected outcome:

To reduce social and legal discrimination faced by people affected by leprosy and their family members.

Outputs:

- People affected by leprosy and their family members and the general community have the capacity to advocate for the rights of the target group.
- Cases of discrimination are taken up by 'networks of the target group', members of Panchayati Raj Institutions, Members of Legislative Assembly (MLAs), Members of Parliament (MPs) and lawyers, at state and national level to repeal/amend anti-leprosy legislations.
- State level and national level authorities review existing policies and practices relating to anti-leprosy legislation and equality for the target group.
- Significant improvement in media coverage in India on leprosy-related human rights issues.
- Civil society organisations and grassroot government workers are more aware of leprosy-related human rights issues, and are better able to advocate for change in legislation and implementation of United Nations (UN) Resolution 8/13.

Beneficiaries

- Primary beneficiaries: People affected by leprosy and their family members with whom the project is working with in Chhattisgarh and UP.
- Secondary beneficiaries: People affected by leprosy and their family members who have benefited from legislation, policy change and stigma reduction throughout the country.

Scope of intervention

- The Project is implemented in three areas of the country:
    - at national level, in Delhi
    - at state-level:
        - in seven districts in Chhattisgarh (Bilaspur, Champa, Durg, Korba, Mahasamund, Raigarh, Raipur)
        - in five districts in UP (Allahabad, Bareilly, Moradabad, Rae Bareilly, Sitapur)

Overview of impact assessment report

The objective of this publication is to analyse the impact of the project, share the results of using a rights-based approach and the lessons learned in the process.

Empowerment of people affected by leprosy will lead to their social integration and is an effective poverty reduction strategy. The second chapter will address the importance of a using a rights-based approach and empowerment of people affected by leprosy. The project methodology and the rationale behind it will be discussed in the third chapter. The successes and challenges faced by the project in implementing a rights-based approach with one of the most marginalised communities will be analysed.

The results and impact of the project will be analysed in the fourth chapter. Quantitative data will be presented while qualitative analysis will be done through life stories. The issue of sustainability of the impact achieved will also be addressed.

One of the objectives of this impact assessment is to analyse the strengths and weaknesses of the strategies adopted. The fifth chapter will identify the lessons learnt at programmatic level in pursuing the rights-based approach for the empowerment of people affected by leprosy and their family members.

The last chapter will present concluding remarks, future interventions that are required to further strengthen the CBOs and recommendations for future rights-based projects based on the learnings from CALL. Practical tips will assist in the planning and implementation of future projects by TLMTI, and will also help other organisations working with excluded groups wanting to use a rights-based approach.

Methodology

This report draws upon the understanding developed through a baseline survey conducted at the beginning of the project and data collected periodically by the project staff pertaining to the outputs sought to be achieved. Instances of discrimination collected through the questionnaire method have provided an insight into the processes that have resulted in the marginalisation of people affected by leprosy and their family members, thereby depriving them of their basic human rights. Success stories collected by the field staff throughout the project period from all the project sites in the states of UP and Chhattisgarh, which are available on the project's Facebook page and blog, and case studies from UP documented by Sarika Gulati towards the end of the project have been used in this report. The quantitative data has been provided by the project team.

Field visits to select project sites – Barabanki, Sitapur and Bareilly in UP, and Bilaspur, Durg and Champa in Chhattisgarh – were undertaken as part of the impact assessment. Detailed conversations with the project staff in both the states provided an insight in to the various dimensions of the project, especially the challenges faced in the implementation of the rights-based approach, and how they were overcome. Group interactions and one to one discussions with key community leaders who are members of community based organisations (CBOs), select members of the general community living in villages in the vicinity of the project sites and staff of partner non-governmental organisations (NGOs) provided valuable inputs to study the impact of the project.

Claiming her self

Eleven years ago Shamim Banu came to Gandhi Kusht Ashram in Bareilly, UP with her husband. Her father was affected with leprosy and required her attention. Although her father died, she continued living in the leprosy colony with her husband. She is illiterate and has never worked outside to earn a living. Her husband has been the sole earning member in the family.

Her husband left her a year ago. She was fifty-four. Unlike many people living in the leprosy colony, she did not want to beg. “Here, a lot of people live on charity. I feel ashamed to beg and want to earn my livelihood with respect,” she says.

Shamim Banu has been associated with CALL project since 2011. She has attended meetings and training session on human rights in Bareilly. In her husband’s absence she received a lot of support from CBO members in the colony. They advised her to open a small shop just outside the leprosy colony.

She took a loan of Rs 3,000 and invested Rs 2,000 from her savings in the shop. Although she earns just enough to survive on daily basis, Rs 50-100 per day, she feels contented and happy that she is self-dependent.

Source: Sarika Gulati’s compilation for CALL

Chapter 2

winds of change

What did the project seek to address

India contributes 58% new cases of leprosy to the world, with 127,000 new cases detected in 2013-14. CALL aimed to address issues of legal and social discrimination of people affected by leprosy at the national level, while working intensively in the states of UP and Chhattisgarh. These two states have been selected because Chhattisgarh has the highest leprosy prevalence rate (2.3/10,000) whereas UP has with highest number of people affected by leprosy. Within these two states, colonies in select districts were identified for implementing the project.

Socio - legal reality of people affected by leprosy

People affected by leprosy and their family members are routinely deprived of their fundamental rights. This apart, there are certain laws that contain provisions that discriminate against them. Social exclusion and legal discrimination have converged to produce multiple disabilities - social, legal, economic and physical. These include:

- absence of equal opportunity to access the rights to health, education and employment
- precarious living and absence of land tenure in some colonies making them vulnerable to forced eviction
- absence of basic rights to water, sanitation and electricity in some colonies
- absent/inadequate social security and inability to access social security due to lack of required documents/certificates
- inability to prove identity in the absence of any proof of identification, like voter's card/ration card results in the violation of the most basic of rights - the right to vote
- absence of livelihood opportunities has traditionally pushed people affected by leprosy and their family members towards begging, which is criminalised under different state laws and renders them liable to penal consequences

United Nations shows the way

With the advent of a cure for leprosy in the form of Multi-Drug Therapy (MDT) in the early 1980s, leprosy can now be cured. In fact, after administering the first dose of MDT, the patient becomes non-infectious. This has also resulted in a significant reduction in the number of newly detected cases of leprosy. Social perception, although it has been changing gradually over the years, still needs to be addressed to bring about legal and policy change. Greater awareness is required to put an end to the remaining social stigma. Similarly, discriminatory laws need to be repealed and enabling provisions need to be enacted to provide access to all their rights by people affected by leprosy.

Despite the fact that leprosy as a disease has been scientifically and medically proven to be curable and manageable, people who once had leprosy and their family members continue to be deprived of their fundamental rights and do not have equal access or opportunity in matters relating to education, employment, marriage and other aspects of their lives. Recognising the gravity of the problem, the United Nations Human Rights Council (UNHRC) unanimously passed Resolution No.8/13 (Annexure 1) in June 2008, to end discrimination against people affected by leprosy and their family members.

The resolution reiterates the principles of human rights enshrined in the Universal Declaration of Human Rights (UDHR) and states that all persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedom detailed in international law, conventions, constitutions and laws. It also calls upon all governments to take effective measures to eliminate all forms of discrimination against people affected by leprosy and their family members, including raising awareness.

This resolution is an important development and an effective standard in the fight against the socio-legal consequences of leprosy.

Pursuant to this Resolution, the UN Human Rights Council Advisory Committee submitted a 'draft set of Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members' (Annexure 2), in August 2010. The Principles and Guidelines call on governments to abolish discriminatory legislation and remove discriminatory language from official publications, to provide the same range and quality of health care to persons affected by leprosy as to those with other diseases, and to promote social inclusion. The UN Resolution, though not binding on states, is a powerful advocacy tool for ending discrimination and for realisation of rights of people affected by leprosy.

CALL is rooted in these Principles and Guidelines framed by the UN, which finds resonance in India's Constitution too, under which every citizen is guaranteed fundamental rights considered necessary to live a life with dignity and develop to the fullest extent possible. Article 14 provides the right to equality. The right to life under Article 21 includes the right to live with dignity. Moreover, this right has been expanded in scope by the Supreme Court to include the right to livelihood, right to shelter and the right to a clean environment.

While significant efforts have been made over the years by individuals like Mother Teresa and Baba Amte towards rehabilitation of people affected by leprosy, CALL is unique in that it aims to empower individuals to become advocates in their own cause while advocating for changes at the macro level to end discrimination.

Project design

The basis of the project is the acknowledgement that development for people affected by leprosy and their family members will come only through a coordinated effort for their empowerment, and advocacy to change discriminatory laws, policies, practices and attitudes.

A baseline survey was conducted at the beginning of the project, wherein 3,849 people affected by leprosy in UP and Chhattisgarh were interviewed using a structured questionnaire. This survey found that while stigma associated with leprosy has reduced among the general population, people affected by leprosy were found to be suffering from self-stigma and low self esteem. They are unaware of their rights, and continue to live in isolated colonies that came up decades ago when leprosy was not curable and stigma attached to the disease was very high.

Therefore, the project was designed to focus on capacity-building of people affected by leprosy to change their attitudes and perceptions about their situation and to empower them to advocate for their rights and entitlement as citizens, while targeting community attitudes to promote further inclusion.

Studies identified at least 14 laws with discriminatory provisions prohibiting people affected by leprosy from contesting elections, obtaining driving licenses, travelling in trains and allowing the disease as a ground for divorce (A list of such laws is given in Annexure 3). Along with empowerment of affected communities, the project simultaneously focused on working towards influencing law and policy changes by spreading awareness and sensitising key stakeholders - general community, law and policy-makers (MPs and MLAs), duty-bearers (the State represented by officials at different levels), members of Panchayati Raj Institutions/local self-government, religious leaders, TLMTI staff, members of the International Federation of Anti-Leprosy Association (ILEP), NGO workers, grassroots health workers and the media.

Myths and fears overcome by advocacy

Jugdha is a sixty-year old widow who lives in Asodhar village in Sitapur District, UP. A mother of two, she contracted leprosy after her son's birth. Gradually her condition deteriorated and she lost her fingers and toes. The stigma of the disease was a major hindrance for her younger son's marriage. Jugdha decided to live just outside the house in the thatched roof, as her daughter-in-law did not want her living inside the house.

She is provided her daily meals but is otherwise shunned by her family. CALL staff visited the village in 2011.

After several visits and counselling of the Gram Pradhan (Village leader), a toilet and a hand pump were installed for Jugdha, in 2013. Earlier, she had to walk a long distance to fetch water and was dependent on her son and daughter-in-law.

CALL team continues to talk to the family so that the discrimination can be addressed and she can once again become an integral part of the family and everyday life in the village.

Source: Sarika Gulati's compilation for CALL

Chapter 3

shift from welfare to rights

> “A lot of people come and give us in kind. But CALL project, by giving us information and a direction, has strengthened us to assert our rights” -
>
> **Pawan**, a CBO leader from Diprapara Colony, Durg, Chhattisgarh.

A sizeable number of people affected by leprosy resort to begging for their livelihoods, especially those with disability and those who are old. The colonies where they live are recipients of charity – from those who donate food, money and dry ration, who consider it their religious duty and a means of redemption from sins committed.

CALL symbolises the shift in TLMTI’s approach from a service delivery organisation to advocating for change, using the rights-based approach. The project was designed to empower people affected by leprosy so that they can advocate their rights themselves. The project addresses key barriers to stigma reduction (legal, social norms and misconceptions about leprosy).

The methodology adopted involved:

- formation of CBOs by capacity-building of the community members to facilitate collective action
- capacity-building of members of CBOs
- creating awareness about leprosy and the rights of people affected by leprosy among the general community, Panchayati Raj Institutions, local bodies, duty bearers, media and legislators
- actively lobbying with key stakeholders to respect the rights of people affected by leprosy and to repeal discriminatory laws
- facilitating participation of the target group in gram sabha submitting memorandums by the leprosy advocacy network and CBOs to government authorities and political parties for their rightful needs, and follow up for accessing them
- facilitating accessing of government social welfare schemes by the affected communities
- documenting cases of discrimination in order to publicise them and to challenge discriminatory policies and practices
- facilitating participation of duty-bearers, parliamentarians, lawyers, human rights activists, etc, in community/project meetings

Key processes

Capacity-building

The project aimed at empowering the affected communities to unite and advocate for their rights and entitlements at local, state and national-levels. This was done through capacity-building of the affected communities by training them on their rights and entitlements, and on the skills required for advocacy. The object of this exercise was to facilitate formation of leprosy advocacy network and CBOs, with rights-based approach for collective action.

Persons who could provide leadership were identified to become members of CBOs. Intensive group training followed on (i) leadership and motivation and (ii) organising and advocacy. Orientation on human rights and information on entitlements, strategies and tools like use of memorandum, right to information, identification of appropriate duty bearers were imparted to the CBO members through regular trainings.

The CBOs were encouraged to work with key stakeholders in order to repeal discriminatory legislations, discriminatory policies/practices and government orders that stand in the way of achieving equality, poverty reduction and social inclusion.

Creating awareness

The project aimed at sensitising the general community, including members of non-governmental

CBO takes up the issue of imminent eviction faced by neighbouring colony

CHINHARI is a Community-Based Organisation (CBO) of people affected by leprosy, in Champa, Chhattisgarh, with 14 members. Its name is an acronym for Chhattisgarh Innovative Holistic Alliance for Rightful Identity.

The members of the CBO recently addressed a press conference at Champa. Mr Naveen Kurre, President of the CBO said, “The purpose of our CBO – CHINHARI, is to raise issues of the leprosy colonies and bring them to the notice of government authorities, so that people living in leprosy colonies will have dignity and a better life. Recently we have taken up the housing issues of our neighbouring colony at Akaltara and visited the Champa district collector.”

Source: Facebook page - CALL for Change Campaign

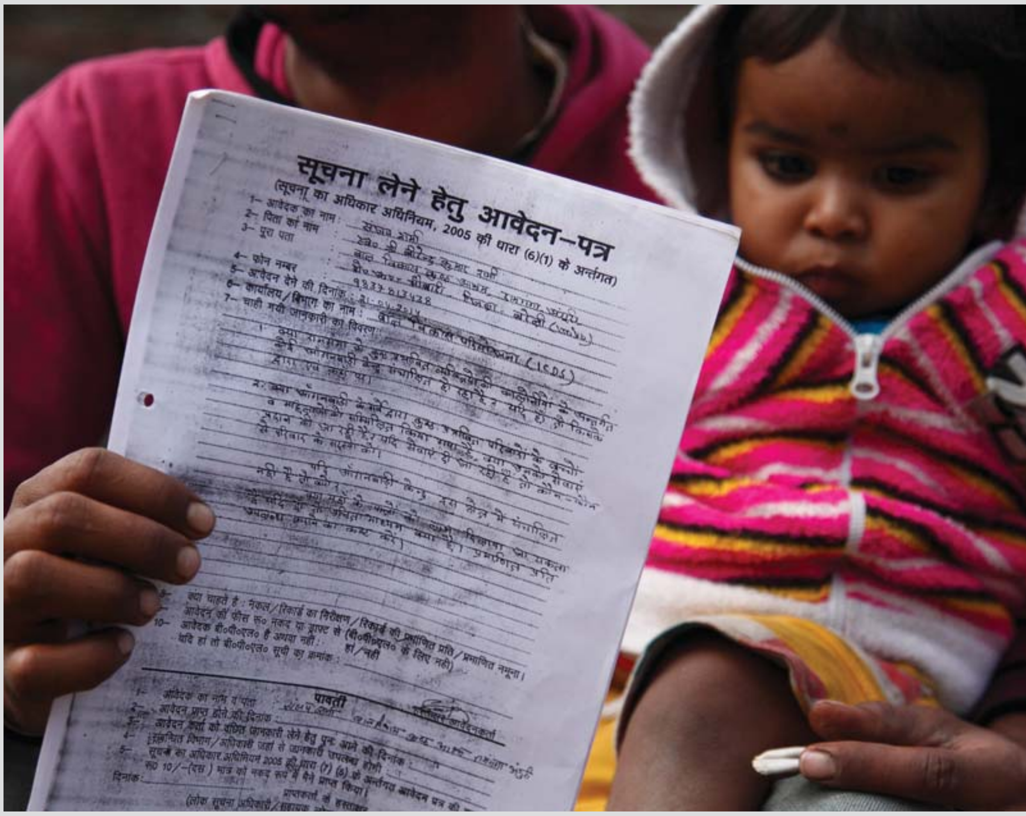
Holding the government accountable

Through CBOs, the project has sensitised the community to be more socially aware, access government social welfare schemes, seek their rights and be self-dependent. Group leaders from Ramganga leprosy colony (Bareilly district in UP) filed an application under Right To Information Act to seek information on Anganwadi Centre in their colony.

Within a month, they got a response from the Child Development Programme Officer of the UP Government informing them that as per government records, an Anganwadi Centre existed in this leprosy colony, but in reality it was non-functional.

As a result of efforts by the group leaders, the government Health Department has started providing services to pregnant women and children in Ramganga leprosy colony. Seven pregnant women started getting antenatal care, immunisation, food supplements and nutrition and health education. Also, 12 children have started getting supplementary nutrition, health check-up and immunization.

Source: Facebook page - CALL for Change Campaign



organisations (NGOs), members of other CBOs, members of self-help groups (SHGs), members of Panchayati Raj Institutions (PRI), religious leaders, legislators and journalists, on rights and entitlements of the target group, and legislations discriminatory towards the issues confronting people affected by leprosy.

In order to reach out to as many people as possible, both affected and from the general communities, the following tools were used very effectively for dissemination of information material on leprosy:

- canopy tent method
- Posters at religious places
- Magic shows in villages
- Folk art, like kala jatha in villages
- Rallies
- Festivals - used as occasions to bridge the gap between general and affected communities

> "Earlier we faced discrimination. Now we get invited to weddings and other functions and we all eat together. Marriages are also taking place with persons from outside any colony" -
>
> **Ibrahim**, CBO leader, Sitapur, UP.

Challenges faced

Some of the challenges that were faced in the implementation of the project and the strategies that were adopted to overcome them are:

Enabling social inclusion

"Recently, on my daughter's marriage, few of my relatives insisted that I invite the people from the leprosy colony a day before and not on the auspicious occasion. I did not agree. I do not believe in discriminating people on the basis of their caste or disease. As a village leader, when we ask for votes, we do not discriminate amongst people. They are our voters and have also selected us without bias." – Ishakh, Anguri Thakuran village Sarpanch, District Bareilly

Ishakh is the Sarpanch (village head) of Anguri Thakuran village from Bareilly district in UP. He is fifty-nine and has been working as a village head for four years. CALL's intervention in Bareilly district started in 2010. The project involved all the stakeholders to sensitise them on leprosy and the challenges faced by the leprosy-affected families. Although Ishakh has grown up seeing the leprosy colony, his understanding has increased through regular CALL meetings.

Ishakh feels that the project through various activities has created awareness on leprosy and shared information on their rights with the community. This has certainly benefited his village and reduced the stigma attached to leprosy.

Over a time span of 4 years, Ishakh has provided work under the Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA) in Ashishi Nagar leprosy colony to dig a pond, allocated one house under Indira Aawas Yojna in Bal Vikas leprosy colony and built a toilet for the same. He further plans to build 10-15 toilets for 6 leprosy colonies under the Nirmal Bharat Yojna in the coming year.

Source: Sarika Gulati's compilation for CALL

- **The mindset of the affected people themselves, who treated the disease as a curse and did not think change was possible**

  This was overcome by tapping the youth to be change-makers in their community. They were trained in human rights, advocacy, communication about the disease itself, so that they can be informed themselves, and in turn clear misconceptions through their advocacy.

- **The charity mindset**

  Progress has started to be made in this regard. CBO leaders and members are becoming instrumental in counselling people to give up begging. This is, however, a gradual process and can be achieved only over a period of time if people are enabled to take up alternative livelihood. The dependence on begging as a means of livelihood has not prevented those who beg, from becoming empowered CBO leaders! This process of empowerment will eventually make them look for alternate livelihoods.

- **Resistance from many senior residents and leaders of colonies who believed that donations would stop**

  Patience and consistent engagement with such people

"We had to face a lot of challenge to start work in the colony. The very first time we were not allowed inside the gates of Sambhal leprosy colony. Only after several visits, families started taking interest and listened to us. Earlier, there were lot of old residents who feared that donation will stop coming from outside. Now the younger generation in the leprosy colony have taken up the leadership and they want to be more self dependent" -

Vinay Singh, Capacity-building officer, CALL, UP.

who were resisting the intervention helped in overcoming their resistance and in winning them over, so they could recognise that they were people with rights rather than subjects of charity.

- **Negative perception held by the media of NGOs which receive funding from abroad**

  This was overcome by consciously keeping the community members in the forefront, with the project staff facilitating the process. The community was also actively encouraged to use the media to highlight their problems.

- **Staffing issues like high staff turnover in CALL, and difficulties in working with partner NGOs**

  In the initial years, the focus was on empowerment of all residents in colonies that were selected for implementing the project through capacity-building. After undergoing training, 'leprosy advocacy networks' were formed by willing residents and this process identified people who could provide leadership. The mid-term evaluation identified issues that needed to be addressed, such as, high staff turnover, withdrawal from the project by partner NGOs and the vast geographical spread of the project sites. These were overcome by focusing on select colonies, identified based on willingness and leadership, for facilitating formation of CBOs and their capacity-building. Advocacy group leaders who had been identified earlier became instrumental in CBO formation. Well trained and able CBO leaders were expected to play the role of partner NGOs and work towards capacity-building of the residents of colonies. Lack of field staff was overcome by frequent visits to the project sites by project team members in both the states.

The most important results of the project will be presented in this chapter. The positive impact includes increased access to Government of India's social welfare schemes, increased self esteem and empowerment, improvement in availability of basic services and increased social acceptance and participation.

Welfare to Rights!

Rambha Mehar hails from Toshgaon village of Mahasamund district. She is married to Chamru Mehar. Presently she resides in Indira Leprosy Community located in Raipur, the capital of Chhattisgarh. Rambha was a victim of discrimination after having contracted leprosy in her village. She was expelled from her family and village on the mistaken grounds that leprosy is a highly communicable disease and moreover a cause for untouchability. Thereafter she took refuge in Sothi Ashram in Champa and lived there for a long period. She received treatment from a Government Leprosy Hospital, Champa. She was on medication for over ten years. Later, she with her family began residing in Indira Dham Leprosy Community.

For a major part of her life she and her family were dependent on begging for their livelihood. But a life changing experience happened when they attended one of the trainings conducted by the CALL project team in 2010. The training led to them developing a dislike towards begging and a desire was kindled to live a life of dignity. Supported by the regular interactions with the self-help group initiatives of TLMTI in Raipur, she decided to start a business of selling rice. Later on she started a small scale grocery shop on a hand cart. Presently she owns and runs a shop in the community that serves as a means of livelihood for the family. Rambha is happy with the upward mobility that she experienced in her life and the prosperity with which she has been blessed. She has also been able to transcend the disconnect with her family and village and occasionally visits her native place and her relatives. She hopes that many more persons affected by leprosy shall start living a dignified life as she does.

Source: CALL's Chhattisgarh team

Chapter 4

results and impact

Ravi Das, thirty-six, is originally from Benaras, UP. He came to Radha Krishna Leprosy Colony in Ramganga, Bareilly, UP thirteen years ago after his father got affected with leprosy. A year and a half later his father died. Since he had no support, he started living by begging.

In 2010, CALL started their project in Ramganga in six leprosy colonies located close to each other. CALL facilitated the formation of a CBO and Ravi Das is one of the members.

After several counselling sessions within the CBO, Ravi Das decided to work for a living. He bought a rickshaw two years ago with his savings and took some loan from neighbours and friends. His earning improved and so did his self esteem. He recently got married and continues to be an active support for others in the colony. He has a Voter's ID Card, Smart Card and PAN Card. He has also applied for Ration Card and Aadhaar Card.

"Earlier I used to earn Rs 40-50 per day from charity and lived a life of a recluse. Now I earn Rs 200-250 per day and look forward to coming home to my family," he says

Source: Sarika Gulati's compilation for CALL

The project has facilitated formation of the following among the affected communities:

- Advocacy groups in the States of Chhattisgarh and UP. Advocacy groups consist of the beneficiaries (primary beneficiaries) who are members of the CBOs, beneficiaries from leprosy colonies in the districts where CBOs

Emergence of well trained community based organisations (CBO)

CALL project has been working in the 6 colonies of Ramganga for 4 years. In June 2014, a thirty-member advocacy group, Naya Savera Sangathan (NSS), was formed in the leprosy colony. ‘Naya Savera’ means a ‘new dawn’.

According to Ashish Sam, an active member of advocacy group, ‘Before CALL, there was no unity in the leprosy colony. CALL informed us on our rights and gave us training on formation of advocacy group. NSS is CALL’s initiative to bring us together on a common platform. Now we realise the significance of working as a collective. Today if we have to go to the MLA or Sarpanch, we go through NSS and our work is implemented more efficiently. Earlier we did not have enough information on the government welfare schemes. With the formation of Soochna Kendra (Information Centre), we are now aware of new welfare schemes that can benefit us.

An information Centre was also setup in August 2014 in the leprosy colony that informs people of the new government social welfare schemes and facilitates to access them. So far NSS has been able to facilitate in getting 126 Aadhaar Cards, 52 Pan Cards, 38 Voter IDs, 86 Zero Balance Account, 82 Jan Dhan account, 21 Birth Certificates, 7 Income Certificates, 12 Cast Certificate, 122 Ration Cards, 28 Smart Cards, 15 Pension, 3 Handicap Certificates. 1 Indira Awas, 5 Rail Pass and 5 Old Age Pension.

Source: Sarika Gulati’s compilation for CALL

are not formed and beneficiaries living outside leprosy colonies, among the general community (secondary beneficiaries).

- CBOs for primary beneficiaries, based in leprosy colonies in both the States.

Thus armed with information, skill and confidence, CBOs have begun addressing immediate issues that confront their colonies. They have discovered the 'magic of the written memorandum' for getting government officials and elected representatives to act upon their demands to solve their concerns. They also use the Right to Information Act to hold the duty bearers accountable when they fail to perform their duties. More than anything else, they now realise the importance of collective action to resolve their problems and to get the state to act!

Number of members of leprosy advocacy network
(as on 31st March 2015)

Total:	4,956 (2,609AM : 2,021AF : 157CM : 169CF)
CG:	2,852 (1,439AM : 1,303AF : 61CM : 49CF)
UP:	2,104 (1,170AM : 718AF :96CM : 120CF)

AM: Adult Male; AF: Adult Female; CM: Child Male; CF: Child Female

Number of CBOs*
(as on 31st March 2015)

Total:	24
CG:	13
UP:	11

* The list of CBOs is given in Annexure 4

> "After being educated under the project, we now know that availing of ration under the PDS is not a charity by the state; it's our right and we have to fight for it" -
>
> **Pawan**, CBO leader from Diprapara Colony, Durg, Chhattisgarh.

Number of Memorandums Submitted by CBOs

Total:	157
CG:	76
UP:	81

Issues raised in the memorandums: Repairing of boring pump in colony, renovation of colony pond, ration card, electricity, health and sanitation, construction of road, water, toilet, renovation of houses, ownership of houses, Aadhaar card, pension card, Rashtriya Swasthya Bhima Yojna (RSBY) card, houses under Indira Awas Yojna, need for dustbin, voter ID card, tricycle, wheel chair, disability certificate, domicile certificate, sewing machine and medicines.

CBO gets municipal water connection for its colony

The CBO in Diprapara Colony, in Durg, Chhattisgarh put up their demand for municipal water supply in their colony. Based on their demand, the government has installed a water connection in the colony. Before this connection, members of the colony had to struggle to get water for their daily needs. 350 people affected by leprosy, living in this colony have benefited from this water connection.

"The project has taught me the importance of many signatures to get our work done", says Pawan, CBO leader from Diprapara Colony, Durg, Chhattisgarh, who was already active in his colony even before the project.

Source: Facebook page: CALL for Change Campaign

Some of the achievements of the CBOs are:

- lanes and common areas in the colony concreted with panchayat funds (Champa, Bareilly)
- electricity connection has been authorised and a survey has been carried out (Bareilly)
- Anganwadi established (Bareilly)
- toilets constructed (Champa, Durg, Sitapur)
- funds sanctioned for a community hall in the colony (Durg)
- water supply in the colony (Durg)

> "I am unable to walk long distance and there is still a lot of social apathy attached to leprosy in the village. I could never avail any services for my five children outside the leprosy colony. With CALL's effort, my two and a half year old son Suraj is regularly getting immunization and food supplements from Anganwadi at my doorstep" -
>
> **Mayadevi**, Ramganga Leprosy Colony, Bareilly, UP.

Increased self esteem and empowerment

At the beginning of the project many of the beneficiaries lacked confidence in their own capabilities. Ignorance about the disease which had resulted in their marginalisation had also led them to stigmatise themselves. Through support from CALL their self-esteem has grown along the way.

Now they meet government officials and elected representatives to place their demands before them. They know that they too have rights and are capable of asserting themselves. With increased awareness about the disease and their rights, self stigma has reduced. Inter-mingling with the general community has increased. This is evidenced from marriages being conducted with persons from outside the colonies, invitations to attend festivals and functions in nearby villages and people from nearby villages attending functions in the colonies.

> "Earlier we used to vote in panchayat elections, but did not know that the panchayat also had duties towards us" -
>
> **Mayadevi**, Ramganga Leprosy Colony, Bareilly, UP.

Breaking away from tradition

Naresh Pal, a leader of Swami Vivekanand Kusht Ashram in Bareilly District, got his nineteen-year-old daughter Tara married to a family outside the leprosy colony. The groom's parents had no objection and wanted Tara as their daughter-in-law. The marriage ceremony was performed in the leprosy colony and all the residents were part of the wedding. "The CBO members gave me the courage to find a suitable match for my daughter. We are all the same and my daughter has an equal right to get a good life partner", he says.

Similarly, the granddaughter of Dwaraka Prasad Gurre, a senior leader of the Champa colony and a guiding force behind the CBO, got married to a boy from the nearby village. According to him, discrimination has reduced to a great extent from when he was young and came to the colony as he had leprosy

When Pawan, a CBO leader's father expired, the residents of his native village agreed to his cremation in the village as per his last wishes.

CBOs, armed with knowledge about the disease and their rights, intervene in cases where a person who contracts leprosy is abandoned by his/her family. CHINHARI, a CBO from Champa, Chhattisgarh has taken up such cases and counselled the families. Gulabi was left in the colony by her family after she contracted leprosy. On CHINHARI's intervention, she is now back with her family.

Improved access to fundamental rights and social security entitlements

Health is a priority for people affected by leprosy. CBOs have been able to realise the right to health to some extent. In Sitapur, UP, the CBO led by Ibrahim, has been able to ensure a regular supply of bandages and medicines from the government for the people affected by leprosy in the colony (Ibrahim administers the dressing himself). CHINHARI in Chhattisgarh has been able to get a weekly medical clinic in their colony.

The right to vote has become a reality for many of the beneficiaries with the acquisition of the voter's card. Access to social security entitlements has vastly improved as is evident from the table on the following page.

> "I have benefited a lot from CALL. I came to know about the family planning scheme from CALL. Today I have voter ID card, Aadhaar card, ration card and disability certificate. *Pehchan Patra* (identification card) is important to exercise my right to vote and also to open a bank account. My wife and I save Rs 2,000 as we are able to access the benefits" -
>
> **Rajesh**, Kusht Ashram Sewa Samiti, Sambhal, Moradabad, UP.

A beginning towards right to health

There are about 3,000 people affected by leprosy living in Ghogranala colony, in Champa, Chhattisgarh. Under the CALL team's guidance, they formed a community-based organisation (CBO) to collectively fight for their rights.

Many of the people affected by leprosy living in this colony have ulcers, and need bandages and other medicines for general illness. At present, there are no medical facilities available. The CBO submitted memorandums to the District Collector and the Chief Medical Officer (CMO) of Champa to look into this, and provide facilities for general check-up, medicines and bandages to the people living in this colony.

The CMO replied, informing that the government will provide them facilities for general check-up; medicines and bandage every Thursday in their colony. The Block Medical Officer of Bamhinidh Community Healthcare Centre organised a free medical camp at the colony, with the active support of the CBO. Most of the people affected by leprosy living in this colony benefited through the free medical camp.

Source: Facebook page: CALL for Change Campaign

Social Security Entitlements Availed* (as on 31st March 2015)
Total: 17,301 (7,532AM : 8,041AF : 868CM : 860CF)
CG: 12,236 (5,110AM : 6,079AF : 539CM : 508CF)
UP: 5,065 (1,962AF : 2,422AM : 329CM : 352CF) *AM: Adult Male; AF: Adult Female; CM: Child Male; CF: Child Female* * The detailed break up of entitlements availed under the different social welfare schemes is given in Annexure 5

Suresh Chandra Sahu provides rations under the public distribution system (PDS) to six leprosy colonies in Ramganga (Bareilly district). His shop in Tanda was easily accessible for the inhabitants living in the colony. A year and a half ago, Suresh Chandra Sahu had to leave the shop and move to Anguri Thakuran village. Although it was not much of a distance, the railway crossing on the way to the village made it difficult for elderly leprosy-affected people to fetch rations.

The CBO members of the leprosy colony called a meeting with Suresh Chandra Sahu. Through discussions and mutual consent it was decided that he would provide a drop facility for those who are elderly and are unable to collect their ration.

Source: Sarika Gulati's compilation for CALL

Increased participation in the political process

Participation of the members from the affected communities in Gram Sabha meetings has increased as seen from the table on the following page.

With the right to vote becoming a reality for many after being successful in getting

> "Earlier we were not called for *gram panchayat* meetings. Now we attend *gram panchayat* meetings as a collective and discuss our issues. Naya Sevara Sangathan has given us a new identity in the village" -
>
> **Ashish Sam**, Naya Savera Sangathan, Ramganga, Bareilly, UP.

themselves enrolled on the voter's list and getting a voter's card, the residents of colonies cannot be ignored by politicians. Some CBOs, like CHINHARI, Champa, Chhattisgarh and Naya Savera Sangathan, UP are in the forefront in political participation. A member of the former is an elected member of the *Nagar Palika* (Urban Municipal Body), while a member of the latter is a member of the Block Development Committee.

Participation in Gram Sabha
(as on 31st March 2015)

Total	403 (293AM : 110AF)
CG	197 (148AM : 49AF)
UP	206 (145AM : 61AF)

AM: Adult Male; AF: Adult Female

Increased awareness

Effective use of the media - print, electronic and social media - has helped in the issues and concerns of people affected by leprosy being written about in newspapers in both the states where the project was implemented. Regular press conferences and media briefings, where community members and project staff were present, have helped in sensitising journalists to the lives of a hitherto marginalised community, previously apprehensive of being shunned by all.

Electronic media too has been effectively utilised to spread awareness about leprosy and discriminatory laws. Radio jingles, TV spots and documentaries have contributed in sensitising the *aam admi* - common man. Social media, blog, IEC material have all been part of the media strategy.

Now, CBOs know the importance of the media for highlighting their problems and some have started approaching journalists on their own, as and when the need arises. For example, the Brahma Vihar Kushth Sewa Samiti colony, Bilaspur, Chhattisgarh, gets flooded during the monsoon. During one such flood the CBO invited the media to cover the situation, which resulted in relief supplies for the colony. Naya Savera Sangathan, Ramganga, Bareilly, UP facilitated a radio programme on leprosy and rights of people affected by leprosy in which many from the colonies spoke.

Number of supportive articles in print media
(as on 31st March 2015)

Total	306 (94 news items published 306 times & 5 newsletters)
CG	44 news items published 131 times
UP	47 news items published 169 times
Delhi	3 news items published 6 times

Number of supportive radio/TV broadcasts
(as on 31st March 2015)

Radio jingles	4 that were broadcast 735 times
CG	549
UP	186
TV broadcast	12
CG	9
UP	3

Number of press conferences
(as on 31st March 2015)

Total	45
CG	21
UP	24

Identification of new cases of leprosy

This is an unexpected impact of spreading awareness amongst general communities. After a magic show in UP or a *kala jatha* in Chhattisgarh, there have been instances of people coming up to the project team and consulting them on whether the spots on their skin are an indication of leprosy!

An enabling legal and policy framework

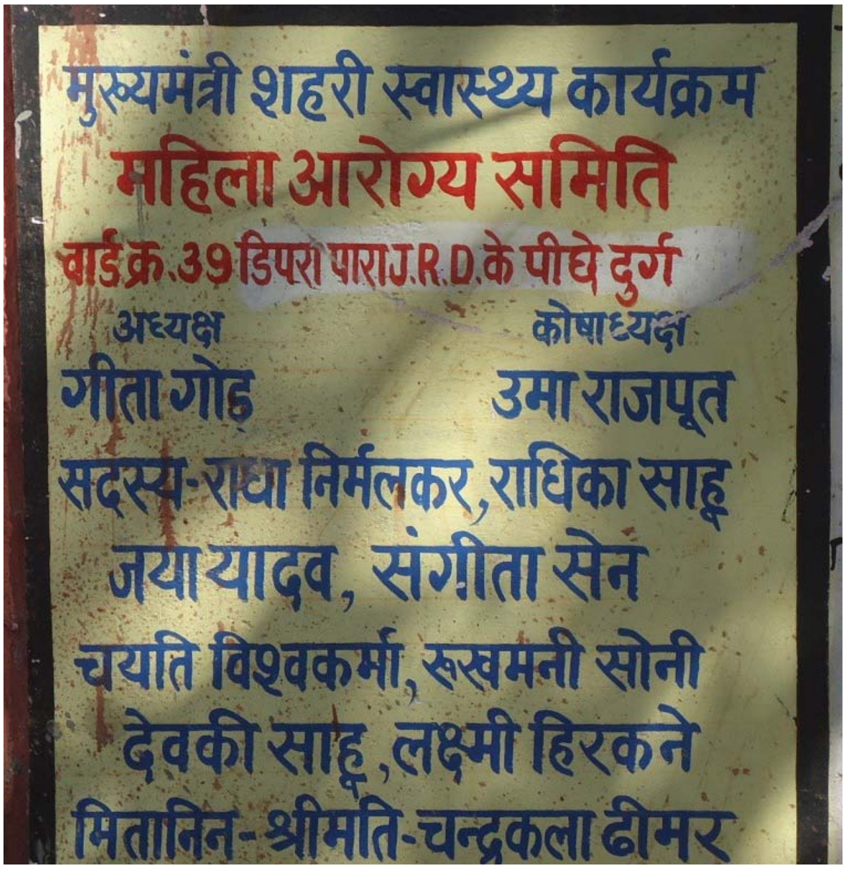
A beginning has been made to not only repeal the discriminatory laws and policies, but to create an enabling framework wherein people affected by leprosy can get equal opportunity to realise their potential to the fullest extent and extricate themselves out of poverty. A process of constructive dialogue has started between the project team and the Law Commission of India, based on which the latter will recommend an overarching legislation on entitlements for people affected by leprosy, which will over-ride existing discriminatory legislation.

Efforts are also on to amend the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. to incorporate enabling provisions for people affected by leprosy. These processes involving law reform are bound to go on well beyond the project period and will hopefully yield the desired results in the long run.

In the short term, through advocacy by the CBOs, facilitated by the project team, 4 government orders have been issued (Annexure 6):

- An order was passed by UP State Road Transport Corporation to the effect that people affected by leprosy with 40% disability can use public transport free of charge.
- A nodal officer has been designated in all police stations in UP, who will address human rights violation issues of people affected by leprosy.
- Chief Medical Officer of Champa district, Chhattisgarh has issued a letter dated 1st December 2014 to provide free medical service at Ghogranala leprosy colony, once a week.
- State Leprosy Officer of UP has issued a letter dated 2nd December 2014 to all District Leprosy Officers (DLOs) to provide health facilities in leprosy colonies.
- Further, the Chief Minister of UP has in principle agreed to raise the pension amount for people affected by leprosy from Rs 300 to Rs 2,500 per month, and made an announcement to this effect on January 30, 2014 (World Anti-Leprosy Day). This will be implemented in the coming budget period.

These are no mean achievements for a group which been hitherto voiceless, and invisible to policy makers!



CBO, Diprapara, Durg, Chhattisgarh rids itself of the shackles of the past by dropping the term 'kushth' from the colony's name

Issues impacting sustainability

The key question to ask about sustainability in a rights-based project is: how empowered are the beneficiaries of the project to continue to assert their rights without the project team acting as a facilitator?

The CBOs are key to sustainability of the impact achieved during the project period and to continue with advocacy for change. Collective leadership is critical to sustainable actions and putting systems in place.

The project has addressed issues of sustainability in its implementation by ensuring that the project team acts only as facilitators, while CBOs take the initiative. Further, some systems and tools have been developed to support CBOs to become more sustainable, like the self-assessment tool kit for CBOs (Annexure 7), which is already being used by the CBOs. However, there are several variables that will determine sustainability of the impact of the project and the achievements:

- **Collective leadership of CBOs -** Where educated youth are in the forefront, experience of success during the project period will keep them motivated.
- **Level of empowerment of CBOs -** The CBOs are at different levels of empowerment due to inherent reasons like capability of members and quality of leadership. Therefore, many CBOs will benefit from continued hand holding till they find their feet.
- **Existing leadership prior to the project -** CBOs which are led by persons who had assumed leadership and were already working for betterment of their colony even before the project have good chances of being sustainable.
- **Livelihood concerns -** Ability of the CBOs to address livelihood concerns of the community and explore avenues for earning a living will play a decisive role in sustaining the achievements of the project.
- **Outcome of ongoing law reform process -** A positive outcome of the ongoing process of law reform and a resultant enabling legislation will contribute greatly to the sustainability of the project's impact.

Life was fairly comfortable for 40-year-old Pooja Devi, who belongs to Korba district of Chhattisgarh. She has studied up to eighth standard, was married and has five children. However, life turned tumultuous when she was diagnosed with leprosy in 2007, when she was 33. Fearing social isolation, her husband, Sevakram Chouhan, asked her to leave the village. She had to leave everything behind – even her children – and took refuge in Brahma Vihar leprosy colony in Bilaspur, about 120 km from her native village.

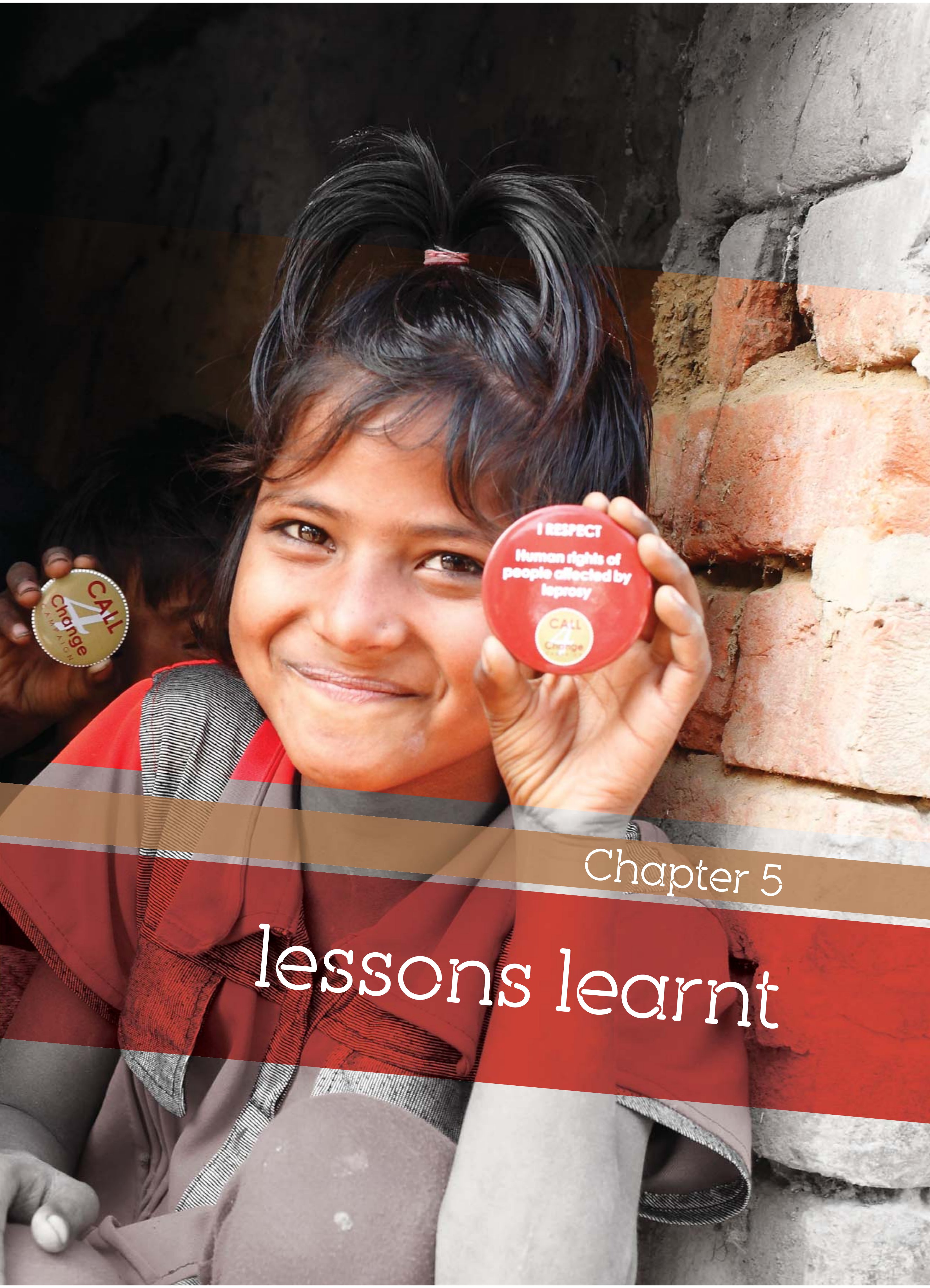
Leprosy had already left its brutal, indelible marks on her body. Her both hands were clawed, left eye was affected with lagophthalmos (inability to close the eyelids), and ulcers deformed her right leg. She underwent corrective surgeries in various hospitals, and has regained her functions, to some extent.

At this time, CALL staff started a human rights awareness campaign in her colony, and Pooja Devi showed much interest. She became very active in coordinating training programmes and mobilising others in the colony. When CALL facilitated a Community-Based Organisation (CBO) in her colony, colony members elected her as the president. Human rights training galvanised Pooja Devi to take up issues of people in the colony. She has already become a catalyst for change. So far, through her efforts, 20 people got the benefits of the Antyodaya Anna Yojna (AAY) scheme; 15 people got an old-age pension, and 30 people got smart cards for accessing health benefits. She is busy gathering information on other government social welfare schemes so that people in her colony can access them all. The CBO is registered, under the Societies Registration Act.

No doubt, Pooja Devi is weighed down by her problems – disability, lack of proper income, stigma and most importantly, inability to live with her children. But she is uniquely motivated. As the president of the CBO, she has great plans for the colony. Her vision for the colony includes – good quality, permanent houses in place of the huts which get inundated during monsoon rains; medical facilities in the colony; potable water; paved roads inside the colony; sustainable livelihood opportunities.

Source: CALL's blog: LEPROSY RIGHTS TODAY


I RESPECT
Human rights of people affected by leprosy
CALL 4 change CAMPAIGN
CALL 4 change CAMPAIGN
CALL 4 change CAMPAIGN



Chapter 5

lessons learnt

The project design involving a two-pronged strategy of empowering the affected communities to assert their rights through capacity-building on one hand, and advocating for law and policy reforms on the other, is an effective way of implementing a rights- based project. There have been many valuable insights that have been gained during this process. While the strengths of the project need to be identified, it is equally important to acknowledge the shortcomings as the purpose of this report is to assist in the planning and implementation of future projects by TLMTI and other organisations. The lessons learnt during the project implementation are presented below.

Rights-based approach works even with the most marginalised groups

One of the biggest contributions of the project has been that it has addressed the issues and concerns of people affected by leprosy within a framework of rights, however challenging this may have been with a group that has traditionally been the recipient of mostly private charity. The rights of the affected communities are seen to be grounded in the fundamental rights guaranteed to every citizen and the UN standards as contained in the UN Resolution No. 8/13 and resultant Principles and Guidelines (A/HRC/15/30).

Empowered communities are best placed to assert their rights and hold the state accountable for performing its duties, with the project team playing the role of facilitators. The micro - macro approach built into the project design - of empowerment of communities and advocating for change and an enabling legal and policy framework - is an effective and sustainable strategy for the realisation of rights of an extremely marginalised group.

Capacity building is the key to empowerment

“Why do you remain poor?” This was a key question that was posed before the CBO leaders through a game at a training exercise. It was meant to provoke the group to think and to motivate them to act for themselves. Information about the disease, their rights, social security entitlements, tools to hold the state accountable have together worked wonders for the morale of CBOs.

Systems for the sustainability of CBOs have been initiated. While a few are already registered under the Societies Act, the remaining are in the process of being registered. They have been trained in organisational management and have drawn up by-laws for their functioning.

However, capacity-building of the target community, i.e. people affected by leprosy, has to start from an early stage of the implementation of the project.

Need for patience and perseverance

The biggest challenge that the project faced was the mindset of the target community who have been living on charity. In the beginning, not all residents in colonies were receptive to the project’s goal of empowering them to advocate their own cause. The transition from charity to rights needs patience and perseverance on the part of the project team. Further, this change will be gradual and cannot be achieved in a hurry.

Need for transition from availing of benefits under different schemes of the state to assertion of rights

In a rights-based approach, while it is important to address the immediate concerns of the community, which is what the CBOs are doing, it is also important to develop a strategy for advocacy on ‘right to work’ and ‘right to equality’ for complete empowerment to become a reality. The CBOs are empowered enough to work towards accessing entitlements under different state schemes and in procuring necessary documents towards this. Now, they need to be gradually directed towards expanding their horizon to include a positive assertion of their fundamental rights to complete the process of social integration and reduction in poverty.

Livelihood needs have to be addressed

Livelihood concern has emerged as a primary concern of the communities. Breaking free from the traditional mind set of reliance on charity and begging for a living will need a carefully thought out strategy to address the livelihood needs of the people. The project has achieved this to some extent by enabling CBOs to build linkages with organisations that work specifically on livelihoods like Sasakawa Foundation and the Association of People Affected by Leprosy (Formerly, National Forum India). Some CBOs, like the one in Sitapur, UP, led by the dynamic Ibrahim, have initiated livelihood projects in their colonies, such as, poultry and fish farming. Incorporation of the need for the project to facilitate development of livelihood opportunities by the communities in the project design would have strengthened the communities better.

Networking with human rights organisations working on other issues is required

Building linkages and networking with other organisations working on rights of persons with disability, women, children, dalits and minorities is necessary for two reasons:

(i) to integrate and mainstream the issues and concerns of people affected by leprosy so that organisations working on other issues concerning similarly marginalised groups are aware of the need to address leprosy when they come across instances during the course of their work, and

(ii) to utilise the experience and expertise of organisations working on other issues for working

Livelihood is paramount

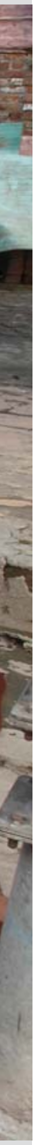
A leprosy colony in Sambhal, Moradabad, UP is located on the fringe of a cemetery and consists of eight families. The families mostly depend on charity, as they do not have any other source of livelihood.

CALL started working in Sambhal leprosy colony two years ago. A sixteen member Community Based Organisation (CBO) has been formed in the colony. The CBO also has a joint account and a saving of Rs 30,000. With CALL's facilitation and the CBO's efforts, 13 people in the colony have started getting disability pension of Rs 300 per month, 14 have bank accounts and Aadhaar Cards, 2 have bought a life insurance policy, 3 women have availed the facility under Janani Suraksha Yojna for institutional delivery and one family has availed the facility of family planning from the government hospital. CALL has also linked them with Association of People affected by Leprosy (APAL), funded by Sasakawa Foundation. The colony will soon be receiving Rs 1, 75,000 from Sasakawa Foundation to start their income generation units.

With their collective efforts, the colony received Rs 1,900 for tin roof repair that was damaged by the winds. The CBO has also given a memorandum to the Sambhal Sub-divisional Magistrate (SDM) for construction of toilets and room repairs in the colony. Looking at their progress, Netherlands Leprosy Relief (NLR) approached the CBO to provide support for their children's education.

Today, the CBO has gained enough strength and direction that they can seek their own rights, fight discrimination and lead their life with dignity.

Source: Sarika Gulati's compilation for CALL



with the people affected by leprosy, as in addition to being that, they are also women/children/dalits/minorities/persons with disability/elderly, etc.

Importance of sharing experience and reflection within the project teams and amongst CBOs

Integrating a process of learning and reflection between state level project teams would have contributed further to the effectiveness and impact of the project. Equally important is the need to expose the CBOs to each other's work so that they can learn from each other. For example, the CBO in Ramganga, Bareilly, UP, forced the administration to get a special machine for taking hand prints of persons with disability for making Aadhaar card, since some people had missing fingers and could therefore not give finger prints. This they did by collectively boycotting the camp that was set up for making Aadhaar cards and by demanding that the need of people affected by leprosy should be catered to. The administration had to listen to this collective voice and a camp for persons with disability using a special machine was set up. This would be a valuable learning for CBOs who are struggling to get Aadhaar cards made for persons with disability.

Use of judicial and quasi-judicial mechanisms

The judicial process should be used to seek redress for all acts of omission and commission by the state and its agencies in respect of the violation of rights of the affected communities. Also, alternate mechanisms, such as, the Right to Information Act, National/State Human Rights Commissions and other Commissions with mandates pertaining to specific groups like Scheduled Castes, women, children and minorities needs to be used to tackle injustice.

Importance of ongoing primary research and documentation

The project has initiated documentation of cases of discrimination that can be used in advocacy for law and policy reform. They also conducted a large baseline survey to collect primary data. Apart from this, ongoing primary research into the lives of people affected by leprosy would have provided greater understanding to the project team about their vulnerabilities and concerns. This would have helped in planning strategies for advocacy at the policy level.

Importance of trust and mutual understanding in working with partner NGOs

Change in government regulations necessitated alteration of the Memorandum of Understanding (MoU) with the partner NGOs. Earlier the NGOs used to be given payment in advance for their activities under the project. This practice had to be discontinued and the MoU had to be changed to provide for reimbursement of expenses incurred instead of advance payment. This was not acceptable to the NGOs who then withdrew from the project. Change in the terms of the MoU could not have been avoided as the change in government regulations could not have been anticipated. However, based on mutual understanding with some NGOs in UP, the project was able to get the NGO to commit one staff member for field activities, whose expenses would be reimbursed. This shows that greater trust and understanding of each other may have led to acceptance of the changed terms of MoU and prevented the other NGOs from withdrawing.

Importance of an ongoing assessment of the project to facilitate course correction

A mid-term evaluation was conducted by a team of two external and one internal evaluators in 2013, wherein areas for improvement were identified. Based on the recommendations of the evaluators, course correction was adopted to maximise the impact of the project and to achieve the project outcomes. These steps included:

- Focussing on CBO formation in select colonies only, as the geographical spread in the both the states was making the monitoring of the project difficult, especially given the inadequate staff strength, reduction in the number of partner NGOs in UP and withdrawal by all the partner NGOs in Chhattisgarh.
- Focussing on improved capacity-building of CBO leaders by engaging advocacy consultants who conducted intensive training sessions for CBO leaders and members on leadership, motivation, organisation development and micro planning. Apart from this regular monthly training sessions were conducted by the project team.
- Developing advocacy skills of CBO leaders and members on writing of memorandums, use of the right to information (RTI) and identification of appropriate duty bearer for resolution of a particular issue.
- Improving the advocacy at the national level by utilising the opportunity provided by the Law Commission of India to engage in a constructive dialogue with it for legislating an enabling law for people affected by leprosy based on positive discrimination and affirmative action by the state.

Importance of engaging with senior and inspirational members of the existing movement of people affected by leprosy

The project has actively engaged with senior persons who have been in the forefront of the movement advocating for the rights of people affected by leprosy. These people are key stakeholders who have themselves faced the brunt of legal and social discrimination and are familiar with the background and the history of the movement. They command respect in the affected communities and are in a position to influence not only the advocacy networks, but also the law and policy makers.

A little information can work wonders!

Indira Dharma Dham Kusht Seva Samiti in Mowa, Raipur, Chhattisgarh was set up for people affected by leprosy in 1985 in the name of Mrs Indira Gandhi, the then Prime Minister. 185 people affected by leprosy from different parts of the country live in this colony.

CALL staff, in 2011, informed people in the colony about Government of India's Basic Services to the Urban Poor (BSUP) scheme, under Jawaharlal Nehru National Urban Renewal Mission (JNNURM). Under this scheme good quality houses with in-house basic services are being provided to city slum-dwellers, free of cost. CALL staff encouraged the inhabitants of this colony, who by that time had become members of the advocacy group facilitated by the Project, to submit a memorandum to Raipur Municipal Corporation for providing such houses. After much follow-up by the advocacy group, the municipal corporation sanctioned construction of 256 houses in a four-storied building complex in this colony, in September 2013.

The Government has sanctioned Rs 9.70 crores for the development of the colony and the construction of houses would be completed within 18 months. People affected by leprosy living in a nearby colony – Ganga Kusht Seva Samiti – also would be allotted houses in this housing complex.

"God has brought CALL staff to us; otherwise we would never have known about this housing scheme. But for CALL, we would never have got the courage to demand our rights. Now, we also can live like others in decent houses," says Smt Shakun Bai, leader of the advocacy group.

Source: CALL's blog: LEPROSY RIGHTS TODAY

A step towards life with dignity

CALL project staff while orienting advocacy groups of people affected by leprosy on various social welfare schemes, informed them of Nirmal Bharat Abhiyan scheme, and encouraged them to access this scheme. CALL staff in UP identified six families of people affected by leprosy living in Asodhar village (outside the leprosy colony, with the general community), in Khairabad block, Sitapur district, and brought them under the umbrella of the Community-Based Organisation (CBO) facilitated by the Project in Khairabad leprosy colony. CALL staff found that none of the six families had access to toilets and used to defecate in the open, endangering their health and security. These families were encouraged to apply for toilets under Nirmal Bharat Abhiyan scheme. They applied in January 2014, and with the rigorous follow-up by the CBO, all the families got financial assistance of Rs 10,000 each, and they have constructed toilets near their houses.

This has brought about a significant change in the lives of people affected by leprosy in Khairabad, as they have become more equipped to claim their rights and entitlements and live like others, with dignity.

Source: CALL's blog: LEPROSY RIGHTS TODAY

Chapter 6

conclusion

> “We do not fear approaching any government official now. We know whom to approach for the problem at hand. The project has given us direction by giving the necessary information on our rights. We submit written memorandums and take a receipt. Officials respond positively and listen to us” -

A common opinion expressed by many CBO leaders and members during field visits to select project sites for conducting this impact assessment.

Guided by the UN Resolution on ending discrimination against people affected by leprosy and the resultant Principles and Guidelines, and rooted in our Constitutional guarantees, CALL project seeks to address the socio-legal consequences faced by people affected by leprosy. The project draws upon TLMTI’s experience and expertise gained over several years of providing treatment to leprosy patients and working with them and their family members on issues confronting them. In fact, TLM’s name proved to be an effective entry point into the colonies.

The project makes a conscious shift from service delivery to a rights-based approach. The goal of the project - “People affected by leprosy and their family members are empowered to claim equal rights and be included in the development process”, was sought to be achieved by empowering the affected communities, and simultaneously working towards creating a conducive environment for legal and policy level changes by spreading awareness and sensitising the key stakeholders.

The impact of the project can be seen among communities in colonies where intensive work was carried out. This is borne out by CBO leaders and members, ranging from the youth to the not so young, educated to the illiterate, exuding confidence in their ability to assert their rights! During the field visits undertaken for this impact assessment, it was also observed that colony residents are enforcing accountability on the part of their CBO leaders by questioning them about applications made for

availing certain entitlements. The CBOs in turn are empowering the colony residents by encouraging them to take necessary steps to avail of entitlements, while guiding them and stepping in only when difficulties arise.

The ripple effect created by a receptive media willing to engage with and highlight the issues raised by people affected by leprosy has contributed to the positive impact of the project. Further the cooperation of government officials when approached by CBOs for their entitlements under government schemes has helped to bolster the morale and confidence of the CBOs.

While issues of sustainability have been addressed while implementing the project, the efficacy of CBOs will be determined by their ongoing performance. Hand holding for at least three more years is required for regular monitoring of CBOs and to help them to raise funds. Livelihood is a primary concern for people affected by leprosy, and working towards facilitating opportunities for earning a dignified living should be the next step towards complete empowerment. This will enable the affected communities to break out of the cycle of impoverishment that is the result of decades of deprivation/ stigmatisation and lack of equal opportunity to realise their potential and aspirations.

Processes have also been initiated under the project for law and policy reform to provide for affirmative action by the state to help realise the rights of people affected by leprosy. The outcome of these efforts will determine the creation of an enabling legal and policy framework which will have a positive impact on the empowerment of the beneficiaries of this project. In fact, all the affected communities in the country will benefit from such changes

Some future interventions are required to strengthen the CBOs and take them to the next level of development. These include:

- formation of an umbrella federation at the state level of all the CBOs
- formation of human rights defenders network and legal network
- establishment of legal cell in TLM hospitals in the vicinity of the project sites
- tapping ongoing projects of TLM, like Self-help towards Holistic Community Developement Project (SHCDP) to facilitate addressing livelihood concerns by CBOs
- linkage with other networks and movements, going on across the country

Recommendations for future rights-based projects

Every rights-based project will be unique and the design and implementation will depend on the target group that the project seeks to work with. Every project should provide the space for ongoing reflection and consequent modifications when required. However, some broad recommendations can be advanced based on the learnings from CALL project.

Project design

- A rights-based project should be designed by including the affected communities right from the project formulation stage to its completion. This participatory design can be used to support Participatory Action Research (PAR) for an ongoing meaningful and effective engagement with the community and other stakeholders.

- A rights-based project should be designed such as to incorporate a two-pronged strategy of empowering the affected communities to assert their rights through capacity-building on one hand, and advocating for law and policy reforms on the other.
- Formation of CBOs and their capacity-building should be an essential component of a rights-based project seeking to empower the target communities
- The project design should provide for mechanisms to ensure sustainability, such as, registration of CBOs, so that they can raise funds and function as independent organisations after the project period.
- The project design should provide for formation of support structures to strengthen CBOs, such as, a federation of CBOs and networks of lawyers and human rights defenders.
- A rights-based project with marginalised and impoverished communities should envisage addressing livelihood concerns by the people themselves to enable them to pull themselves out of poverty.
- Ongoing primary research and documentation should be a key component of the project so that the understanding and knowledge gained during implementation of the project can be used for effective advocacy.

Project implementation

- Project staff should play the role of facilitators with CBOs taking the lead for asserting rights and advocating for change.
- Proper attention needs to be paid to the quality of training that will be imparted for capacity-building of CBO members. The emphasis needs to be on motivation, leadership and skills, with appropriate training material being used. The nature of the training should be based on the Training of Trainers (ToT) format.
- Capacity building of CBOs should be an ongoing process throughout the project period.
- In a rights-based approach, while it is important to address the immediate concerns of the community through micro planning, it is also important to develop a strategy for advocacy for rights that will help the members of the target group to eject themselves out of poverty and realise their full potential as individuals.
- Networking with human rights organisations working on other issues and effective use of the media should be essential components of macro level advocacy
- Judicial and quasi judicial processes should be used to seek redress for the violation of rights of the target communities.

TLMTI is blessed with its indefatigable efforts for close to a century and half. And has made remarkable strides in leprosy cure, stigma removal, community interface, media engagement and legislative mechanisms.

The work needs to go on until the stigma remains and until the affected communities are able to lead a fulfilling life, on their own terms based on equity and justice.

The support of the nation and the international community is sought towards this dream.

An inspiration for the young CBO leaders

It all started in June 1965, when seven men and eight women settled in a patch of government land, in the backyard of Bhilai city, in Durg district of Chhattisgarh. They all had a common yoke to share – they were all affected by leprosy, and were cast out of their native villages due to the stigma of leprosy. There was a 29-year-old person among them – Shri Vishwanath Ingle, from the neighbouring state of Maharashtra.

In 2005, after TLMTI started a self-help group (SHG) in this colony, Ingle got the SHG registered with the Government of Chhattisgarh. He applied and got patta (land ownership) from the government for their colony. After the formation of the SHG, 20 women from the colony, under Ingle's leadership, approached the District Collector and requested for training to set up a weaving unit in the colony, under the government's Rural Livelihood Scheme. Their advocacy worked, and the collector immediately made arrangements for their training at the district headquarters, in weaving, and sanctioned Rs 50,000, for training and other needs. With TLMTI's active support, 20 women from the colony underwent three-month training in weaving. With the help of Sasakawa-India Leprosy Foundation, 23 looms were installed in the colony, and 30 women are presently working on these looms. The modus operandi is that the government will supply the SHGs with raw materials and the SHGs will weave dhari and kambal and other items on job work basis, and the government will pay them for the job work.

Presently, there is work only for five months in a year, and the SHG is advocating with the government to provide work for all the 12 months. It is encouraging to note that each woman earns Rs 10,000 every month from weaving. There are men from the colony who operate self-owned auto rickshaws, and work as security guards in nearby offices.

Asha Deep Colony doesn't have the stereotypical 'leprosy colony' look. According to Ingle, there are 51 men and 71 women living in this colony now. They have decent, well-maintained houses with all civic facilities; and there is an aura of 'well-being' around the colony. The children from the colony have good education, and many of them are well-placed. There are two medical doctors, five girls working in the computer software sector, 15 to 20 children pursuing university education.

Ingle is not resting on his laurels. He is still continuing his crusade. Because of his efforts, the state government has sanctioned Rs 9.5 lakhs to start a tailoring institute in the colony. The institute will soon come up on the first floor of the main building in the colony. Girls from the colony will be trained here. Ingle has a clear succession plan for the colony, as well. There are two to three women who are active and trained under Ingle, who are ready to take forward the success story scripted by Ingle.

Source: CALL's blog: LEPROSY RIGHTS TODAY

Shri Vishwanath Ingle, a person affected by leprosy living in Asha Deep Leprosy Colony, in Bhilai, Chhattisgarh

Annexures

ANNEXURE – 1

Human Rights Council

Resolution 8/13. Elimination of discrimination against persons affected by leprosy and their family members

The Human Rights Council,

Recalling the provisions of the Universal Declaration of Human Rights, including Article 1 that all human beings are born free and equal in dignity and rights, and that they are endowed with reason and conscience and should act towards one another in a spirit of brotherhood,

Recalling also the provisions of the International Covenant on Economic, Social and Cultural Rights, including article 12,

Taking note of the work of the Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health,

Noting the report of the Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health (A/58/427), in which he reported that persons affected by leprosy and their family members often suffer stigma and discrimination born of ignorance and prejudice,

Recognizing that more than 16 million people affected by leprosy have been cured worldwide since the 1980s and that leprosy as a disease has been scientifically and medically proven to be curable and manageable,

Recognizing also that tens of millions of people and their family members still suffer from leprosy not only as a disease but also from political, legal, economic or social discrimination and ostracization due to society's lack of knowledge and misguided notions, such as leprosy being incurable or hereditary, and that the issue of leprosy is not only a matter of medicine or health but also one of discrimination that can give rise to a clear violation of human rights,

Taking note of the previous work done by the Commission on Human Rights and its mechanism on discrimination against persons affected by leprosy and their family members,

Encouraging States to share best practices on combating discrimination against persons affected by leprosy and their family members and also on their efforts to achieve full recovery from and manage this disease,

1. *Affirms* that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all basic human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws;

2. *Calls upon* Governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members, including awareness-raising;

3. *Requests* the Office of the United Nations High Commissioner for Human Rights to include the issue of discrimination against persons affected by leprosy and their family members as an important matter in its human rights education and awareness-raising activities;

4. *Also requests* the Office of the United Nations High Commissioner for Human Rights to collect information on the measures that Governments have taken to eliminate discrimination against persons affected by leprosy and their family members, and, if extra-budgetary funding is available, to hold a meeting to exchange views among

relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and programmes, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members, and to transmit a report to the Council and the Human Rights Council Advisory Committee;

5. *Requests* the Human Rights Council Advisory Committee to examine the report referred to in paragraph 4 above, and formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and to submit it to the Council for its consideration by September 2009;

6. *Decides* to consider this issue based on these reports submitted to the Council in September 2009.

28th meeting
18 June 2008

[Adopted without a vote.]

ANNEXURE – 2

United Nations' Resolution No. A/HRC/15/30

Principles and Guidelines for Elimination of Discrimination against People Affected by Leprosy and their Family Members.

I. Principles

1. Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.
2. Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.
3. Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end:
   a. No one should be denied the right to marry on the grounds of leprosy;
   b. Leprosy should not constitute a ground for divorce;
   c. A child should not be separated from his or her parents on the grounds of leprosy.
4. Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.
5. Persons affected by leprosy and their family members should have the right to serve the public, on an equal basis with others, including the right to stand for elections and to hold office at all levels of government.
6. Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated on an equal basis with others in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.
7. Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.
8. Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth. Persons affected by leprosy and their family members who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.
9. Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

II. Guidelines

1. General

1.1 States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy. To this end, States should:

(a) Take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination;

(b) Ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.

1.2 States should take all appropriate measures to achieve for persons affected by leprosy and their family members the full realization of all the rights enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

1.3 In the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to persons affected by leprosy and their family members, States should consult closely with and actively involve persons affected by leprosy and their family members, individually or through their respective local and national organizations.

2. Equality and non-discrimination

2.1 States should recognize that all persons are equal before and under the law and are entitled, without any discrimination, to the equal protection and equal benefit of the law.

2.2 States should prohibit all discrimination on the grounds of a person having or having had leprosy, and should guarantee equal and effective legal protection to persons affected by leprosy and their family members.

2.3 Specific measures which are necessary to achieve de facto equality of persons affected by leprosy and their family members shall not be considered as discrimination.

3. Women, children and other vulnerable groups

3.1 In many societies, leprosy has a significantly adverse impact on women, children and other vulnerable groups. States should therefore pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

3.2 States should promote the full development, advancement and empowerment of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

4. Home and family

States should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy.

5. Living in the community and housing

5.1 State should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community.

5.2 State should identify persons affected by leprosy and their family members living in isolation or segregated from their community because of their disease, and should give them social support.

5.3 States should enable persons affected by leprosy and their family members to choose their place of residence and should ensure that they are not obliged to accept a particular living arrangement because of their disease.

5.4 States should allow any persons affected by leprosy and their family members who were once forcibly isolated by State policies in effect at the time, to continue to live in the leprosariums and hospitals that have become their homes, if they so desire. In the event that relocation is unavoidable, the residents of these places should be active participants in decisions concerning their future. States should, however, improve living conditions in those leprosariums and hospitals. With due regard to the wishes of the persons affected by leprosy and their family members, and with their full participation, States should also design, promote and implement plans for the gradual integration of the residents of such places in the community and for the gradual phasing out of such leprosariums and hospitals.

6. Participation in political life

States should ensure that persons affected by leprosy, and their family members, enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others. Voting procedures must be accessible, easy to use and adapted to accommodate any individuals physically affected by leprosy.

7. Occupation

States should encourage and support opportunities for self-employment, the formation of cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labour markets.

8. Education

States should promote equal access to education for persons affected by leprosy and their family members.

9. Discriminatory language

States should remove discriminatory language, including the derogatory use of the term “leper” or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language.

10. Participation in public, cultural and recreational activities

10.1 States should promote the equal enjoyment of the rights and freedoms of persons affected by leprosy and their family members, as enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

10.2 States should promote access on an equal basis with others to public places, including hotels, restaurants and buses, trains and other forms of public transport for persons affected by leprosy and their family members.

10.3 States should promote access on an equal basis with others to cultural and recreational facilities for persons affected by leprosy and their family members.

10.4 States should promote access on an equal basis with others to places of worship for persons affected by leprosy and their family members.

11. Health care

11.1 States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as that provided for persons with other diseases. In addition, States should provide for early detection programmes and ensure prompt treatment of leprosy, including treatment for any reactions and nerve damage that may occur, in order to prevent the development of stigmatic consequences.

11.2 States should include psychological and social counselling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.

11.3 States should ensure that persons affected by leprosy have access to free medication for leprosy, as well as appropriate health care.

12. Standard of living

12.1 States should recognize the right of persons affected by leprosy and their family members to an adequate standard of living, and should take appropriate steps to safeguard and promote that right, without discrimination on the grounds of leprosy, with regard to food, clothing, housing, drinking water, sewage systems and other living conditions. States should:

(a) Promote collaborative programmes involving the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living;

(b) Provide or ensure the provision of education to children whose families are living in poverty by means of scholarships and other programmes sponsored by the Government and/or civil society;

(c) Ensure that persons living in poverty have access to vocational training programmes, microcredit and other means to improve their standard of living.

12.2 States should promote the realization of this right through financial measures, such as the following:

(a) Persons affected by leprosy and their family members who are not able to work because of their age, illness or disability should be provided with a government pension;

(b) Persons affected by leprosy and their family members who are living in poverty should be provided with financial assistance for housing and health care.

13. Awareness-raising

States, working with human rights institutions, non-governmental organizations, civil society and the media, should formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members. These policies and plans of action may include the following goals:

(a) To provide information about leprosy at all levels of the education system, beginning with early childhood education affirming, inter alia, that leprosy is curable and should not be used as grounds for discrimination against persons who have or have had leprosy and their families;

(b) To promote the production and dissemination of “know your rights” material to give to all persons recently diagnosed with leprosy;

(c) To encourage the media to portray persons affected by leprosy and their family members with dignified images and terminology;

(d) To recognize the skills, merits and abilities of persons affected by leprosy and their contribution to society and, where possible, to support exhibitions of their artistic, cultural and scientific talents;

(e) To encourage creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents;

(f) To provide information to social leaders, including religious leaders, on how addressing leprosy in their teachings or written materials may contribute to the elimination of discrimination against persons affected by the disease and their family members;

(g) To encourage higher education institutions, including medical schools and nursing schools, to include information about leprosy in their curricula, and to develop and implement a “train the trainer” programme and targeted educational materials;

(h) To promote implementation of the World Programme for Human Rights Education and to incorporate the human rights of persons affected by leprosy and their family members into the national human rights education programme of each State;

(i) To identify ways to recognize, honour and learn from the lives of individuals forcibly isolated by their Governments for having been diagnosed with leprosy, including oral history programmes, museums, monuments and publications;

(j) To support grass-roots awareness efforts to reach communities without access to traditional media.

14. Development, implementation and follow-up to States’ activities

14.1 States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights field and related fields, and representatives of government.

14.2 States are encouraged to include in their State party reports to the relevant treaty bodies the policies and measures that they have adopted and/or implemented with regard to the elimination of discrimination against persons affected by leprosy and their family members.

ANNEXURE – 3

Laws in India that are discriminatory towards people affected by leprosy

The Right of Participation in Political Life

There are certain State laws governing elections at local levels such as Panchayati Raj that still provide for prohibition on the rights of people affected by leprosy to stand and contest in elections.

Name of the Acts:

- Andhra Pradesh Panchayati Raj Act, 1994
- Chhattisgarh and Madhya Pradesh Panchayati Raj Act, 1993
- The Rajasthan Panchayati Act, 1994
- The Rajasthan Municipality Act, 1959

Discriminatory Provision: Disqualification from contesting election and holding a public office on the grounds of having leprosy.

Comment: Such provisions are highly discriminatory towards all persons affected by leprosy, cured or not, for the following reasons:

- Open discrimination on the grounds of a disease;
- Violates the right to equality and political participation;
- Restriction on the right to participate in the political process, which is also ensured by the various International documents; and
- Similar provisions in the Orissa Municipality Act have been amended.

Action Needed: Amendment of the Acts to ensure removal of the impugned section/provision in the law.

The Right to Marriage and Family Life

All laws related to matrimonial issues in India still contain provisions that provide for a virulent and incurable form of leprosy as a ground for divorce. Such a provision needs to be immediately amended, as it clearly discriminatory towards persons affected by leprosy.

Name of the Acts:

- Hindu Marriage Act, 1955 [Section 13 (1) (IV)]
- Dissolution Of Muslim Marriage Act, 1939 [Section 2 (VI)]
- Indian Divorce Act, 1869 [Section 10]
- Indian Christian Marriage Act, 1872 (The divorce of Christian spouses is governed by the Provisions of the Indian Divorce Act, 1869)
- Special Marriage Act, 1954 [Section 27 (g)]

Comment: The above-mentioned ground for divorce in the above mentioned Acts is not only discriminatory against people affected by leprosy but also redundant now, because

- Leprosy is curable;
- The provisions in effect takes away the affected person's social identity attached to their marital status, which in the Indian society is an integral part of the individual's identity;
- It has the power of withdrawing essential support of a family structure in a situation of having been diagnosed with an age old disease, which carries not only a heavy burden of social stigma and but also self-stigma for the person. This leads to a situation of clear discrimination, segregation, isolation and deprivation of confidence, dignity and support;
- It is violative of the person's right to protection from discrimination and right to dignity and life;
- The UN Resolution on leprosy (A/HRC/15/30) clearly states that any marriage and divorce law that provides for leprosy as a grounds for divorce should be suitably amended; and
- It also violates the rights of life, equality and non-discrimination as enshrined under Articles 1; 3; 7; 16 and 25 of UDHR, Principles 1; 2; 3; Guidelines 1 (General); 2 (Equality and non-discrimination) and 5.3 (Living in the community and housing) of the UN Resolution's No. A/HRC/15/30 and Articles 3 (General Principles); Article 5 (Equality and non-discrimination); Article 10 (Right to Life); Article 17 (Protecting the integrity of the person); Article 19 (Living independently and living in the community) and Article 23 (Respect for home and the family) of the UNCRPD.

Action Needed: Amendment of the Acts to ensure removal of the impugned section/provision in the law.

On the point of divorce, it is also submitted that we are not aware of cases where people have resorted to using this ground, as the usual practice is of abandonment/compulsion to silently leave home and family on the affected person.

Another Indian law that hampers the right to family life is the ***Hindu Adoption and Maintenance Act, 1956***, which provides for a form of legal separation from a person affected by leprosy by his/her family.

Discriminatory Provision: Section 18 (2) (c): "A Hindu wife shall be entitled to live separately from her husband without forfeiting her claim to maintenance, (c) if he is suffering from a virulent form of leprosy."

Comment:

- Leprosy is no longer an incurable and virulent disease;
- On being diagnosed with a disease such as leprosy, the person's first point of support is his/her family and making the disease a grounds for withdrawing that much needed support is discriminatory; and
- This provision attracts the non-discrimination clause guaranteed under Fundamental Rights and other international documents.

Action Needed: Removal of this section from the stated Act.

Right to Employment

Economic empowerment for people affected by leprosy is a crucial need, which must be actively supported and facilitated by the State.

Name of the Act:

Industrial Disputes Act, 1947 [Sec 2]

Discriminatory Provision: The authority to terminate service on the ground of continued ill-health.

Comment: Although this section does not mention leprosy as a grounds for termination per say, it may be indirectly used against an employee having or having been cured of leprosy due to the social stigma attached to the condition.

- A person being diagnosed with leprosy and under-going treatment may be likely to develop reactions, which require prolonged in-patient treatment;
- A person having been cured of leprosy but having loss of sensation in hands and feet may be prone to develop repeated ulcers, which if not treated and cared for in time, may also require in-patient treatment and even in some cases amputation;
- A person affected by leprosy is also so highly self-stigmatised by his/her condition that he/she may not find it easy to approach the judicial/;quasi-judicial mechanism for redress; and
- A person with leprosy may in most likelihood not have the economic capacity to approach and pursue a judicial/quasi-judicial form of legal redress.

Action Needed:

- A safeguard of the right to lien (return to work) needs to be added into the law;
- A stringent punitive clause should also be built into the law in-case it is proved that the termination was due to the person's condition of having leprosy; and
- A similar right to lien should also be incorporated in the Rights of Persons with Disabilities Bill, 2014.

Right to Inclusion

In the States of Maharashtra, Gujarat and Karnataka there is a law which legally allows for segregation of persons affected by leprosy. This Act is also applicable in Delhi.

Name of the Act:

Prevention of Begging Act, 1959

Discriminatory Provision: Medical Examination and detention of leprosy patients and lunatics.

(1) Where it appears to the Chief Commissioner that any beggar detained in a Certified Institution under any order of a court is of unsound mind or a leper, the Chief Commissioner may, by an order setting forth the grounds of belief that the beggar is of unsound mind or a leper, order his removal to a mental hospital or leper asylum or other place of safe custody, there to be kept and treated as the Chief Commissioner directs during remainder of the term for which he has been ordered to be detained or, if on the expiration of that term it is certified by a medical officer that it is necessary for the safety of the beggar or of others that he should be further detained under medical care or treatment, then until he is discharged according to law.

(2) Where it appears to the Chief Commissioner that the beggar has ceased to be of unsound mind, or is cured of leprosy, the Chief Commissioner shall, by an order, direct to the person having charge of the beggar, if still liable to be kept in custody, to send him to the Certified Institution from which he was removed or if the beggar is no longer liable to be kept in custody order him to be discharged.

(3) The provisions of section 31 of the Indian Lunacy Act, 1912, (IV of 1912) or (subject to the provisions of sub-section (2) of section 14 of the Lepers Act, 1898 (III of 1898) shall apply to every beggar confined in a mental hospital or leper asylum under sub-section (1) after the expiration of the period for which he was ordered to be detained;

and the time during which a beggar is confined in a mental hospital or leper asylum under that sub-section shall be reckoned as part of the period for which he may have been ordered by the court to be detained:

Provided that where the removal of a beggar due to unsoundness of mind or leprosy is immediately necessary, it shall be open to the authorities of the Institution in which the beggar is detained, to apply to a court having jurisdiction under the Indian Lunacy Act, 1912 (IV of 1912), or the Lepers Act, 1898 (III of 1898), as the case may be, for an immediate order of committal to a mental hospital or a leper asylum until such time as the orders of the Chief Commissioner be obtained in the matter.

Comment: This provision is discriminatory and violative of the rights and dignity of a person affected by leprosy due to the following reasons:

- Leprosy is completely curable now, and the first dose of MDT makes people affected by leprosy non-infectious. Therefore, there is no need to detain or segregate them;
- A similar provision in the Juvenile Justice Act has been amended in 2011;
- Due to the close co-relation of poverty and leprosy, old-age stigma and segregation practices and
- low skills, many people affected by leprosy are forced to live on begging. Such persons can easily come within the purview of such a law and face harassment situations by enforcement and judicial agencies, who may have little understanding of the social construct of their socio-economic realities; and
- Application of the Leper's Act, 1898 also needs to be done away with, if still in force in any part of the country as it is anarchic and antiquated and highly discriminatory.

Action Needed: People affected by leprosy need to be removed from the purview and application of this section by a way of amendment.

Name of the Act:

Mumbai Municipal Corporation Act, 1888

Discriminatory Provision: Section 421 of the Act requires information to be given of existence of dangerous disease or continuous pyrexia of unknown origin to the Executive Health Officer by the medical practitioner for prevention of spread of the disease.

Comment: As there exists a lack of knowledge regarding leprosy even amongst medical practitioners, there is a danger that a person affected by leprosy who turns up for diagnosis, treatment or ulcer care may be reported as having a dangerous disease under the stated provision.

Action Needed: An explanation to this section that leprosy is now a curable disease and should not be regarded as a dangerous disease for the purpose of this section.

Appropriate use of Language

Language is a significant medium of communicating not only information but also socio-cultural perceptions. Its use has a strong influence. Bearing this in mind, an effort needs to be made to discourage the use of the term 'Leper', as it carries very visual and negative connotations with reference to people affected by leprosy. This also acts as a hamper to the efforts of their inclusion and affects their sense of dignity and honour as human beings.

Name of Act:

Prevention of Begging Act, 1959

Comments:

- The derogatory use of term 'leper' reinforces the already strong stigma against leprosy, and contributes to the heartbreaking ostracism of people affected by leprosy;
- People affected by leprosy also find the use of this term as hurtful towards them and their sense of dignity; and
- The term 'leper' is considered inappropriate and offensive and needs to be discouraged in strict terms. Additionally, the UN Resolution No. A/HRC/15/30 mandates under Guideline 9 that this word should be removed from all government books. The provision stats that, *"9. Discriminatory language States should remove discriminatory language, including the derogatory use of the term "leper" or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language."*

Action Needed:

- Government order to ban the use of the term in all official publications and communications;
- Amend all laws and policies to remove the term "leper" and replace it with the internationally accepted terminology of "people/person affected by leprosy";
- Allow a similar interpretation for the use of the term 'Leper', as has been done for the term 'Chamar' under Section 3(1)(x) of The Schedule Castes and The Scheduled Tribes (Prevention of Atrocities) Act, 1989 by the Supreme Court of India. ("Calling an SC 'Chamar' offensive, Punishable, Says Apex Court", The Economic Times, August 20, 2008, http//articles.economictimes.indiatimes.com/2008-08-20/news/28488600_1_upper-castes-insult-chamar; Arumgam Servai vs State of Tamil Nadu, 2011 STPL (Web) 403 SC)

Right to Freedom of Movement

Due to the existing myths and fears regarding leprosy that are coupled with ignorance about its curability, people affected by leprosy may be stopped and hindered from travelling with the same freedoms as others on public transport.

Name of the Act:

Indian Railways Act, 1989 [Sec 56]

Discriminatory Provision: The Act gives power to railway authorities to refuse to carry persons suffering from infectious or contagious diseases.

Comment: Although leprosy is not specifically mentioned in the Act, lack of awareness about leprosy on the part of Railway authorities and the society may result in discrimination and segregation of people affected by leprosy.

Action Needed: An explanation to this section to say that leprosy now being curable should not be read into the list of infectious and contagious diseases.

ANNEXURE – 4

Name and address of the leprosy colonies where CALL has formed CBOs

District	
Chhattisgarh	
Bilaspur	Bramh Vihar Kusht Ashram, Silpahari Road, Bilaspur, Chhattisgarh.
	Ramshakti (Marimata) Kusht Ashram, Near Railway Locoshed, Bilaspur, Chhattisgarh.
Champa	Hasdeo Ganga Kusht Kalyan Samiti, Prem Nagar, Champa, Chhattisgarh.
	Chinhari Jan Kalyan Samiti, Prem Nagar Ghogranala Champa.
	Gandhi Kushtha Ashram, Tikrapara Ghogranala Champa.
	Jai Jagannath Kushtha seva samity, Ghogranala Oriyapara Champa.
Durg	Kusht Ashram Sewa Samiti, Diprapara, Durg, Chhattisgarh.
	Shri Vivekanand Kusht Mukt Ashram, Kursipar, Bhilai, Durg, Chhattisgarh.
Korba	Unmukt Kusht Ashram, Ward No: 15, Mudapara, Korba, Chhattisgarh.
Raigarh	Baal Samund Kusht Sewa Samiti, Near Hanuman Mandir, Pahad, Raigarh, Chhattisgarh.
	Arunodaya Kusht Sewa Samiti, Jurda, Raigarh, Chhattisgarh.
Raipur	Indra Dharamdham Kusht Sewa Samiti, Mandiget Mova, Raipur, Chhattisgarh.
	Ganga Kusht Sewa Samiti, Behind Govt Hospital, Pandri, Raipur, Chhattisgarh.
UP	
Allahabad	Kusht Rogi Sewa Ashram, Noorulla Road, Karailabagh, Allahabad, UP.
	Om Sai Kusht Ashram, Near Shastri Pul ke Niche, Daraganj, Allahabad, UP.
	Durbal Kusht Ashram, Near Hanuman Mandir, Bandh ke Niche, Daraganj, Allahabad, UP.
Bareilly	Naya Savera Sanghthan, Near Ramganga Ghat Rly Station, Post - Chowbari Badau Highway, Bareilly, UP.
	Asisi Nagar Punernivas Kendra, Near Ramganga Ghat Rly Station, Post - Chowbari Badau Highway, Bareilly, UP.
	Balvikas Kusht Ashram, Near Ramganga Ghat Rly station, Post Chowbari Badau Highway, Bareilly, UP.
	Gandhi Seva Kusht Ashram, Near Ramganga Ghat Rly Station, Post - Sader Cantt, Bareilly, UP.
	Radha Krishna Kusht Ashram, Near Ramganga Ghat Rly station, Post - Chowbari Badau Highway, Bareilly, UP.
Moradabad	Poornabhakti Kusht Ashram, Sambhal Road New District, Sambhal, Moradabad, UP.
Raebareilly	Jai Durga Kusht Ashram, Ahiyapur, Raebarely Road, Raebareilly, UP.
Sitapur	Anjunpur Kusht Ashram, Near RTO Office, Vill - Arjunpur, Khairabad, Sitapur, UP.

ANNEXURE – 5

Detailed break-up of entitlements availed under each social security scheme

Total: 17,301(7,532AM : 8,041AF : 868CM : 860CF)

(AM: Adult Male; AF: Adult Female; CM: Child Male; CF: Child Female)

Chhattisgarh -12,236 (5,110AM : 6,079AF : 539CM : 508CF)

Rashtriya Swasthya Bima Yojna (RSBY) – 1,485 (692AM : 793AF)

Pension card – 1,081(640AF : 441AM)

Ration card – 2,177 (1047AF : 970AM : 80CM : 80CF)

Disability card – 193 (119AF : 71AM : 1CM : 2CF)

Cycles – 9CF

Houses – 1,556 (969AF : 563AM : 10CM : 14CF)

PAN card – 36 (13AF : 23AM)

Bank A/C – 151(63AF : 87AM : 1CM)

Aadhaar card – 640 (274AF : 259AM : 60CM : 47CF)

Voter ID – 71 (32AF : 39AM)

Disability certificate – 42 (22AF : 18AM)

Disability pension – 11 (6AF : 5AM)

Travel pass – 2AM

Water connection – 380 (118AF : 124AM : 73CM : 65CF)

Municipal dustbin – 59 (32AF : 28AM)

Sewing machine – 3AF

MCR footwear – 20 (9AF : 11AM)

Toilet – 973 (478AF : 409AM : 8CM : 78CF)

Paved road – 667 (263AF : 268AM : 117CM : 13CF)

Ekalbatti – 1,870 (896AF : 824AM : 70CM : 80CF)

Janani Suraksha Yojna (JSY) – 2CF

Caste certificate – 4 (2AF : 2AM)

MGNREGA job card – 3AM

Income certificate – 3AM

Sarva Siksha Abhiyan – 58 (23CM : 35CF)

Balika Janani Suraksha Yojna – 1CF

Street light – 190 (64AF : 68AM : 32CM : 26CF)

Shiksha Sanghi Chatrabrithi card – 1CM

Pradhanmantri Jan Dhan Yojna – 236 (133AF : 101AM : 2CF)

Old Age Pension Scheme – 2 (1AF : 1AM)

School dress – 73 (43CM : 30CF)

Borewell – 109 (33AF : 34AM : 20CM : 22CF)

Nal Jal Yojna – 128 (64AF : 64AM)

UP: 5,065 (1,962AF : 2,422AM : 329CM : 352CF)

Ration card – 1,198 (420AM : 533AF : 115CM : 130CF)

PAN card – 273 (190AM : 83AF)

Bank A/C – 378 (135AF : 217AM : 16CM : 10CF)

Aadhaar card – 321(168AM : 120AF : 15CM : 18CF)

Voter ID card – 729 (310AF : 419AM)

Hearing aid – 3 (2AM : A1F)

Tricycle – 26 (5AF : 21AM)

Wheel chair – 1AF

Disability certificate – 425 (186AF : 230AM : 6CM : 3CF)

Old Age Pension Scheme – 109 (51AF : 58AM)

Domicile certificate – 12 (7AF : 5AM)

Solar street light – 355 (102AF : 111AM : 64CF : 78CM)

Rashtriya Swasthya Bima Yojna (RSBY) – 420 (145AF : 181AM : 50CM : 44CF)

Janani Suraksha Yojna (JSY) – 21AF

Disability pension – 267 (115AF : 149AM : 2CM :1CF)

Travel pass – 19 (8AF : 11AM)

Indira Awas Yojna – 78 (38AF : 40AM)

Kanya Vidhya Dhan – 1CF

MNREGA job card – 53 (11AF : 42AM)

Pond construction (under MNREGA) – 66 (19AF : 17AM : 14CM : 16CF)

Sahayata Samooh Yojna – 13 (4AF : 7AM : 1CF : 1CM)

Aam Aadmi Bima Yojna – 1AM

Birth certificate – 8 (5CM:3CF)

Caste certificate – 8 (4CM : 4CF)

Pradhanmantri Jan Dhan Yojna – 9 (6AM : 3AF)

Income certificate – 6AM

Samajwadi pension – 168 (97AM : 71AF)

MCR footwear – 15 (8AM : 7AF)

Widow pension – 6AF

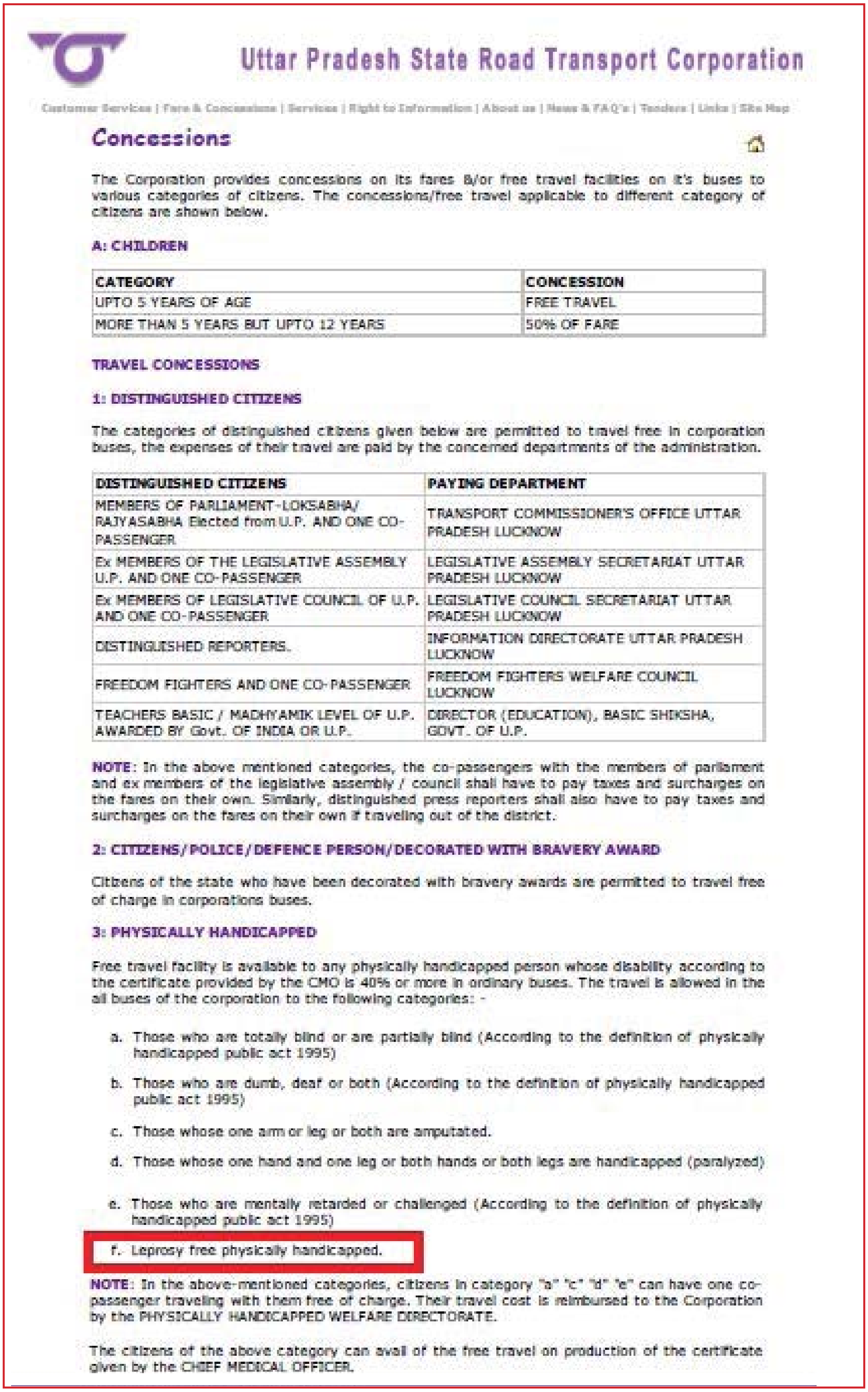
Sarva Shiksha Abhiyan – 58 (23CM : 35CF)

Balika Janani Suraksha Yojna – 1CM

Residence certificate – 1AF

Skill development – 16M

ANNEXURE – 6



Concessions

The Corporation provides concessions on its fares &/or free travel facilities on it's buses to various categories of citizens. The concessions/free travel applicable to different category of citizens are shown below.

A: CHILDREN

CATEGORY	CONCESSION
UPTO 5 YEARS OF AGE	FREE TRAVEL
MORE THAN 5 YEARS BUT UPTO 12 YEARS	50% OF FARE

TRAVEL CONCESSIONS

1: DISTINGUISHED CITIZENS

The categories of distinguished citizens given below are permitted to travel free in corporation buses, the expenses of their travel are paid by the concerned departments of the administration.

DISTINGUISHED CITIZENS	PAYING DEPARTMENT
MEMBERS OF PARLIAMENT-LOKSABHA/ RAJYASABHA Elected from U.P. AND ONE CO-PASSENGER	TRANSPORT COMMISSIONER'S OFFICE UTTAR PRADESH LUCKNOW
Ex MEMBERS OF THE LEGISLATIVE ASSEMBLY U.P. AND ONE CO-PASSENGER	LEGISLATIVE ASSEMBLY SECRETARIAT UTTAR PRADESH LUCKNOW
Ex MEMBERS OF LEGISLATIVE COUNCIL OF U.P. AND ONE CO-PASSENGER	LEGISLATIVE COUNCIL SECRETARIAT UTTAR PRADESH LUCKNOW
DISTINGUISHED REPORTERS.	INFORMATION DIRECTORATE UTTAR PRADESH LUCKNOW
FREEDOM FIGHTERS AND ONE CO-PASSENGER	FREEDOM FIGHTERS WELFARE COUNCIL LUCKNOW
TEACHERS BASIC / MADHYAMIK LEVEL OF U.P. AWARDED BY Govt. OF INDIA OR U.P.	DIRECTOR (EDUCATION), BASIC SHIKSHA, GOVT. OF U.P.

NOTE: In the above mentioned categories, the co-passengers with the members of parliament and ex members of the legislative assembly / council shall have to pay taxes and surcharges on the fares on their own. Similarly, distinguished press reporters shall also have to pay taxes and surcharges on the fares on their own if traveling out of the district.

2: CITIZENS/POLICE/DEFENCE PERSON/DECORATED WITH BRAVERY AWARD

Citizens of the state who have been decorated with bravery awards are permitted to travel free of charge in corporations buses.

3: PHYSICALLY HANDICAPPED

Free travel facility is available to any physically handicapped person whose disability according to the certificate provided by the CMO is 40% or more in ordinary buses. The travel is allowed in the all buses of the corporation to the following categories: -

a. Those who are totally blind or are partially blind (According to the definition of physically handicapped public act 1995)

b. Those who are dumb, deaf or both (According to the definition of physically handicapped public act 1995)

c. Those whose one arm or leg or both are amputated.

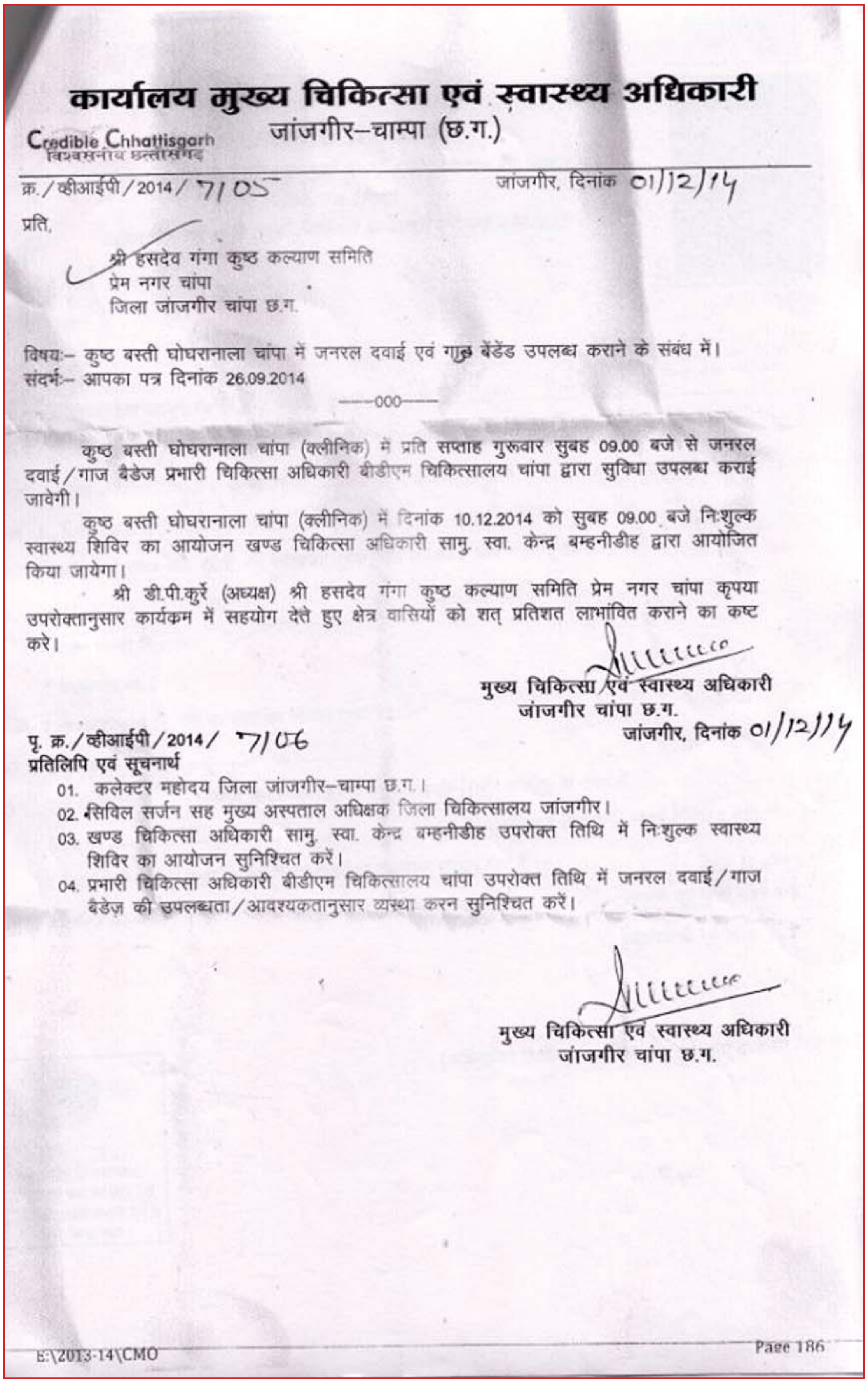
d. Those whose one hand and one leg or both hands or both legs are handicapped (paralyzed)

e. Those who are mentally retarded or challenged (According to the definition of physically handicapped public act 1995)

f. Leprosy free physically handicapped.

NOTE: In the above-mentioned categories, citizens in category "a" "c" "d" "e" can have one co-passenger traveling with them free of charge. Their travel cost is reimbursed to the Corporation by the PHYSICALLY HANDICAPPED WELFARE DIRECTORATE.

The citizens of the above category can avail of the free travel on production of the certificate given by the CHIEF MEDICAL OFFICER.



कार्यालय मुख्य चिकित्सा एवं स्वास्थ्य अधिकारी
जांजगीर–चाम्पा (छ.ग.)
Credible Chhattisgarh
विश्वसनीय छत्तीसगढ़

क्र./व्हीआईपी/2014/ 7105
जांजगीर, दिनांक 01/12/14

प्रति,

श्री हसदेव गंगा कुष्ठ कल्याण समिति
प्रेम नगर चांपा
जिला जांजगीर चांपा छ.ग.

विषयः– कुष्ठ बस्ती घोघरानाला चांपा में जनरल दवाई एवं गाज बैंडेड उपलब्ध कराने के संबंध में।
संदर्भः– आपका पत्र दिनांक 26.09.2014

——000——

कुष्ठ बस्ती घोघरानाला चांपा (क्लीनिक) में प्रति सप्ताह गुरूवार सुबह 09.00 बजे से जनरल दवाई/गाज बैडेज प्रभारी चिकित्सा अधिकारी बीडीएम चिकित्सालय चांपा द्वारा सुविधा उपलब्ध कराई जावेगी।

कुष्ठ बस्ती घोघरानाला चांपा (क्लीनिक) में दिनांक 10.12.2014 को सुबह 09.00 बजे निःशुल्क स्वास्थ्य शिविर का आयोजन खण्ड चिकित्सा अधिकारी सामु. स्वा. केन्द्र बम्हनीडीह द्वारा आयोजित किया जायेगा।

श्री डी.पी.कुर्रे (अध्यक्ष) श्री हसदेव गंगा कुष्ठ कल्याण समिति प्रेम नगर चांपा कृपया उपरोक्तानुसार कार्यक्रम में सहयोग देते हुए क्षेत्र वासियों को शत् प्रतिशत लाभांवित कराने का कष्ट करे।

मुख्य चिकित्सा एवं स्वास्थ्य अधिकारी
जांजगीर चांपा छ.ग.

पृ. क्र./व्हीआईपी/2014/ 7106
जांजगीर, दिनांक 01/12/14

प्रतिलिपि एवं सूचनार्थ

01. कलेक्टर महोदय जिला जांजगीर–चाम्पा छ.ग.।
02. सिविल सर्जन सह मुख्य अस्पताल अधिक्षक जिला चिकित्सालय जांजगीर।
03. खण्ड चिकित्सा अधिकारी सामु. स्वा. केन्द्र बम्हनीडीह उपरोक्त तिथि में निःशुल्क स्वास्थ्य शिविर का आयोजन सुनिश्चित करें।
04. प्रभारी चिकित्सा अधिकारी बीडीएम चिकित्सालय चांपा उपरोक्त तिथि में जनरल दवाई/गाज बैडेज़ की उपलब्धता/आवश्यकतानुसार व्यस्था करन सुनिश्चित करें।

मुख्य चिकित्सा एवं स्वास्थ्य अधिकारी
जांजगीर चांपा छ.ग.

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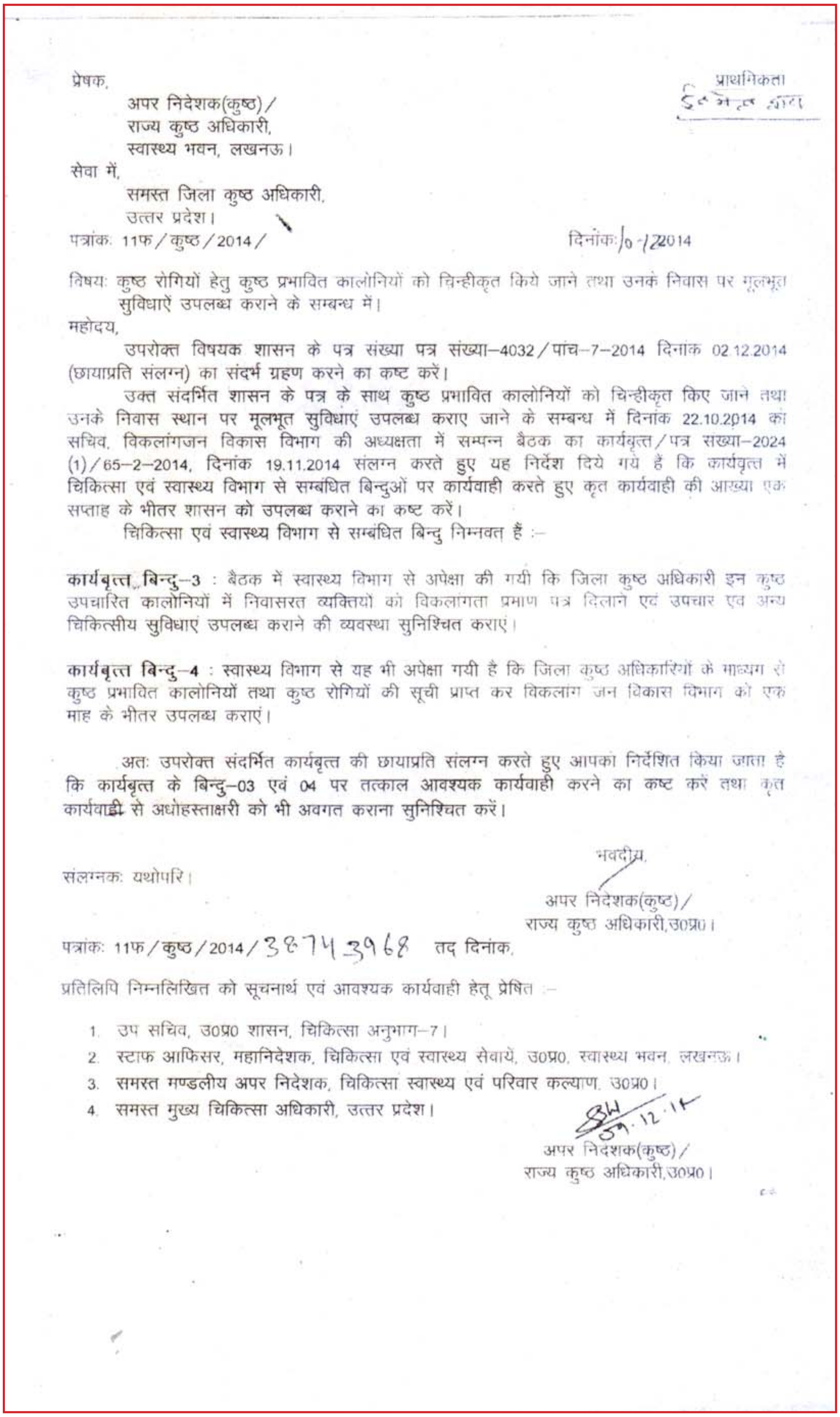
Page 186



प्राथमिकता

प्रेषक,

अपर निदेशक(कुष्ठ)/
राज्य कुष्ठ अधिकारी,
स्वास्थ्य भवन, लखनऊ।

सेवा में,

समस्त जिला कुष्ठ अधिकारी,
उत्तर प्रदेश।

पत्रांक: 11फ/कुष्ठ/2014/

दिनांक:10-12-2014

विषय: कुष्ठ रोगियों हेतु कुष्ठ प्रभावित कालोनियों को चिन्हीकृत किये जाने तथा उनके निवास पर मूलभूत सुविधाऐं उपलब्ध कराने के सम्बन्ध में।

महोदय,

उपरोक्त विषयक शासन के पत्र संख्या पत्र संख्या–4032/पांच–7–2014 दिनांक 02.12.2014 (छायाप्रति संलग्न) का संदर्भ ग्रहण करने का कष्ट करें।

उक्त संदर्भित शासन के पत्र के साथ कुष्ठ प्रभावित कालोनियों को चिन्हीकृत किए जाने तथा उनके निवास स्थान पर मूलभूत सुविधाएं उपलब्ध कराए जाने के सम्बन्ध में दिनांक 22.10.2014 को सचिव, विकलांगजन विकास विभाग की अध्यक्षता में सम्पन्न बैठक का कार्यवृत्त/पत्र संख्या–2024(1)/65–2–2014, दिनांक 19.11.2014 संलग्न करते हुए यह निर्देश दिये गये हैं कि कार्यवृत्त में चिकित्सा एवं स्वास्थ्य विभाग से सम्बंधित बिन्दुओं पर कार्यवाही करते हुए कृत कार्यवाही की आख्या एक सप्ताह के भीतर शासन को उपलब्ध कराने का कष्ट करें।

चिकित्सा एवं स्वास्थ्य विभाग से सम्बंधित बिन्दु निम्नवत हैं :–

कार्यबृत्त बिन्दु–3 : बैठक में स्वास्थ्य विभाग से अपेक्षा की गयी कि जिला कुष्ठ अधिकारी इन कुष्ठ उपचारित कालोनियों में निवासरत व्यक्तियों को विकलांगता प्रमाण पत्र दिलाने एवं उपचार एवं अन्य चिकित्सीय सुविधाएं उपलब्ध कराने की व्यवस्था सुनिश्चित कराएं।

कार्यबृत्त बिन्दु–4 : स्वास्थ्य विभाग से यह भी अपेक्षा गयी है कि जिला कुष्ठ अधिकारियों के माध्यम से कुष्ठ प्रभावित कालोनियों तथा कुष्ठ रोगियों की सूची प्राप्त कर विकलांग जन विकास विभाग को एक माह के भीतर उपलब्ध कराएं।

अतः उपरोक्त संदर्भित कार्यबृत्त की छायाप्रति संलग्न करते हुए आपको निर्देशित किया जाता है कि कार्यबृत्त के बिन्दु–03 एवं 04 पर तत्काल आवश्यक कार्यवाही करने का कष्ट करें तथा कृत कार्यवाही से अधोहस्ताक्षरी को भी अवगत कराना सुनिश्चित करें।

भवदीय,

संलग्नक: यथोपरि।

अपर निदेशक(कुष्ठ)/
राज्य कुष्ठ अधिकारी,उ0प्र0।

पत्रांक: 11फ/कुष्ठ/2014/3874-3968 तद दिनांक,

प्रतिलिपि निम्नलिखित को सूचनार्थ एवं आवश्यक कार्यवाही हेतु प्रेषित :–

1. उप सचिव, उ0प्र0 शासन, चिकित्सा अनुभाग–7।
2. स्टाफ आफिसर, महानिदेशक, चिकित्सा एवं स्वास्थ्य सेवायें, उ0प्र0, स्वास्थ्य भवन, लखनऊ।
3. समस्त मण्डलीय अपर निदेशक, चिकित्सा स्वास्थ्य एवं परिवार कल्याण, उ0प्र0।
4. समस्त मुख्य चिकित्सा अधिकारी, उत्तर प्रदेश।

29.12.14

अपर निदेशक(कुष्ठ)/
राज्य कुष्ठ अधिकारी,उ0प्र0।

ANNEXURE – 7

Challenging Anti-Leprosy Legislation (CALL) Project

CBO Assessment Toolkit

Name of the CBO ______________________________

Date __ / __ / __

SL NO	ASPECT	CATEGORY	RATING	
1.	Regular Meeting	a) No meeting at all	0	1
		b) Meeting fewer times than decided	1	
		c) Meeting as per decision	2	
2.	Attendance	a) Less than 74%	0	2
		b) 75-99%	1	
		c) 100%	2	
3.	Female Participation	a) Less than 10%	0	2
		b) Less than 40%	1	
		c) Above or equal to 50%	2	
4.	Regular Savings	a) Less than 49% members save	0	2
		b) 50-99% members save	1	
		c) All members save	2	
5.	Record keeping	a) No records at all	0	2
		b) Records available, but not properly maintain	1	
		c) Records up to date & properly maintained	2	
6.	Micro Plan	a) Plan not available	0	2
		b) Plan available, but not implemented	1	
		c) Plan available and implemented	2	
7.	Bank Account	a) Not applied for	0	2
		b) Applied for, but not opened	1	
		c) Available	2	
8.	Bank Linkages	a) Not getting loan	0	2
		b) Loan not getting as per demand	1	
		c) Getting loan and properly utilized	2	
9.	Tapping Govt. Resources	a) Not applied	0	2
		b) Applied, but not received	1	
		c) Received and used	2	
10.	Meeting & Activity of CBO	a) Not regular meetings and activities	0	1
		b) Meetings and activities conducted with support of local NGOs	1	
		c) Meetings and activities conducted independently	2	

11.	Leader's Role & responsibilities	a) They do not take responsibilities	0	1
		b) They take responsibilities, but are not effective	1	
		c) They give effective leadership	2	
12.	Supports to other CBO of person affected by leprosy	a) Not interested	0	1
		b) Interested, but do not give support	1	
		c) Give support to other groups	2	
13.	Linkage with other group (Disable, Dalit, women group or any rights-bases group)	a) Not interested	0	1
		b) Linkages are there, not effective	1	
		c) Effective linkage and functioning	2	
14.	Linkage with other Leprosy advocacy groups	a) Not interested	0	0
		b) Linkages are there, but not effective	1	
		c) Effective linkage, and functioning	2	
15.	Advocacy issues (Local, State or National level)	a) No issues	0	0
		b) No effective work on issues	1	
		c) Progressive/effective work on issues	2	

Minimum score - 0

Maximum score - 30

Score Grade

Score	Grade	Current Status
0-5	1	
6-15	2	
16-23	3	
24-30	4	

Web References

http://www.who.int/lep/en

http://nlep.nic.in

http://nlep.nic.in/pdf/Progress%20report%2031st%20March%202013-14.pdf

http://tlmindia.org

http://www.ilep.org.uk

CALL Project's Blog: LEPROSY RIGHTS TODAY
https://leprosyrights.wordpress.com/

CALL Project's Facebook page: CALL for Change Campaign
https://www.facebook.com/tlmindia.CALL
http://www.leprosymission.org.uk

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