

Strategic Framework For Reduction Of Stigma & Discrimination

“SOCIAL INTEGRATION” OF THE LEPROSY AFFECTED PERSONS WITH THE COMMUNITY.....”

Introduction

Leprosy is a disease, which still strikes fear in the societies as a mutilating, disfiguring, contagious and incurable disease. Because of the horrifying nature of the enigmatic physical disfigurement and since no cure was discovered until the 20th century, leprosy has, for centuries, been a highly stigmatizing disease. Though leprosy is not a disease of the poor, yet it affects poor to a much greater extent because of their social and economic vulnerability. The stigma attached to leprosy leads to loss of employment even before manual labor becomes more difficult due to disability, which often results from late or no treatment. It also leads to exclusion from society, causing physical and emotional distress.

Even to this day, when leprosy is completely curable with MDT (multi drug therapy), some parts of India uphold the belief that leprosy is a divine curse, a punishment of the past sins, and a result of immoral sexual behavior. These beliefs reinforce the image of the '*leper*' as being physically and morally unclean, to be blamed for contracting the disease and therefore to be ostracized. The repulsive physical image, the fear of infection and the belief that it is incurable are the root causes of the inhuman treatment that is often meted out to those who have leprosy.

At all levels of society, leprosy often makes women more vulnerable, socially and economically, than men. Hence gender equity needs equal focus besides reducing stigma and discrimination. Mere information and education, to the sundry about the signs and symptoms of leprosy and its curability, shall not work. It is imperative to break the barrier between persons affected by leprosy and the rest of the society, by appealing to peoples' emotions and their ability to empathise with those they feared and shunned. NLEP workers also had to face such barriers and this is what led to a paradigm shift, of looking at this problem with a new perspective.

Attempts to reduce stigma have been tried in different conditions around the world. With specific reference to leprosy, few attempts like community involvement in leprosy control activities, counseling to individual patients, apart from integration of leprosy services with general health care, have shown some impact on certain categories of populations. However, there has been no comprehensive attempt to reduce stigma based on scientific interventions addressing the total community with specific reference to leprosy. It is therefore high time a culturally acceptable stigma reduction programme is developed and executed. This framework is an effort towards this objective.

What is Stigma?

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception, or reasonable anticipation of an adverse social judgment about a person or group.

Stigma is not just a matter of using the wrong word or action. Stigma is about disrespect. It is the use of negative labels to identify a person living with physical and mental illness. Stigma is a barrier. Fear of stigma, and the resulting discrimination, discourages individuals and their families from getting the help they need. Leprosy affects many problems like avoidance, negligence, separation, torture and less respect in society etc. because of which they hide their disease.

The distressing prospect of having a stigmatized condition, which is further associated with stigmatized status in society, may be an inducement to ignore or conceal it and forego the kind of help that one might readily acknowledge as useful if the condition were affecting someone else.

Although denial may relieve the anxiety that follows from stigma, denial is a problem when a treatable condition remains untreated and progresses to cause unavoidable suffering.

Different categories or types of stigma-

- **Felt stigma** refers in particular to the negative attitudes the community felt or perceived by those with a stigmatized condition internalized (or self-) stigma refers the way people who are (or perceive themselves to be) at the receiving end of stigma. This usually includes reduced self-esteem (“I am no good”; “no one will want to marry a person affected by leprosy like myself”), hopelessness (“I can no longer do anything”) and some times feelings of guilt or self-blame related to the stigmatized condition (“ it is probably my own fault that I have developed leprosy”).
- **Enacted stigma** denotes actual occurrences discrimination (e.g. divorce, denying someone access to public transport) or negative behavior (e.g. gossiping).
- **Institutional stigma** is stigma or discrimination which part of institutional arrangements or policies. This would include separate clinic arrangements for people affected by leprosy, mental illness or HIV/AIDS, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion on the basis of a health condition. Man-made barriers (e.g. buildings without elevators, sidewalks without ramps) in the environment may also be seen as part of the same category, as they exclude people with disability and require higher level advocacy-type interventions.

Leprosy Associated Stigma & Discrimination

No disease has been more closely associated with stigma than leprosy, and it has become a metaphor for stigma. When the family or community knows that a person has leprosy

he/she suffers economic and social losses, as well as participation restrictions in the community.

The impact of leprosy stigma explains some paradoxical preferences in the utilization of health services. Although the availability of nearby health facilities is usually considered an indication of their accessibility and responsiveness to needs, concerns about disclosure of the condition may make nearby health services for leprosy too close for comfort.

It is high time that we look beyond the integration of leprosy in the general health care, access to health care and the fundamental right to health etc. It is imperative that we focus specifically on the scourge of discrimination.

Discrimination against leprosy affected people has certain distinctive features- the misunderstanding of the nature of the disease or the psychological, emotional responses towards it that are often described as stigma and which result in discrimination.

Many people still think that leprosy is a disease easily transmitted through touching, that if you are affected, the treatment is not perfect and the deformities will follow. This image of leprosy has been around for centuries, and it persists even today, even among well-educated people.

The most obvious instance, which has been observed, is that in some cases hotels were not willing to allow leprosy-affected people to stay. Usually they discriminate, and hotels were afraid that other patrons would be unhappy.

Determinants of stigma

Determinants of stigma may be – lack of knowledge, negative attitudes, perceived fear of infection and blame & shame. Knowledge about etiology & curability, spread of disease and whether it is hereditary counts for irrational behavior. Community attitudes are part of a cultural belief and value system. Attitudes are often defined in terms of beliefs (evaluation), affects (feelings) and behavior tendency. Attitudes are learned responses and are manifestations of past experiences. These are socially shared. Our natural tendency is to pay more attention to confirmatory than to discrepant information. An event or experience will bring change in attitude if it presents opportunities that have not been presented before. Attitudes are powerful determinant of stigma. A better understanding of what attitudes are and how they may be modified will in the fight against stigma.

Fear is a major driving force of stigma. People fear mainly two things: deformity and social exclusion, or more generally, the negative social consequences of leprosy. The latter would include diminished marriage prospects for children or other relatives and reduced earning capacity.

Fear can be deeply ingrained and may be associated with the risk of transmission of the disease or with the notion of 'perceived impurity' of the person affected. Fear to touch a

person affected by leprosy is often seen even in doctors and other health workers who are not used to working with leprosy.

People affected may be blamed for having the conditions as 'being their own fault' – "they must have done something very bad to be punished in this way". People are ashamed of having leprosy, often, this is a reason for people to conceal the diagnosis as long as possible. It is a reason for people to abandon their own family, because they fear their presence will have serious negative effects for the family.

Behavior of people who feel stigmatized is also strongly influenced by prevailing attitudes and beliefs, since they themselves are members of the same community and culture. People who live the perceived threat of stigmatization or who have experienced actual discrimination often internalize these feelings and start behaving accordingly. They may vary from withdrawal from public gatherings or moving away to a different area, to submissive, 'unworthy behavior' –the role of how the community would expect a leprosy patient to behave. Actual acts of discrimination should be a priority target for intervention.

Causes of Stigma

- **Physical dimension:** Discussions with key informants revealed that patient's appearance such as deformity, shabby look, foul smelling ulcers are the main reasons of stigma. There have been instances where people have lost all their fingers and spent the rest of their life outside their house. No member of the family was willing to sit or speak with them either. The entire community ostracized them, including the family, till the person was alive. Normalcy in the relations was restored after the person's death.
- **Threat of communicability:** The foul smell of the ulcers and the shabby look of the leprosy patients hampered their communicability and acceptability within the community.
- **Threat of social avoidance:** Even those who have overcome the above causes may not establish contact with leprosy patients due to threat of avoidance, separation, and negligence by society, as a result of many traditional customs, which are in vogue since long. These customs are very strong in the community and very difficult for someone to go beyond them.
- **Self-stigma:** The patients with patches generally hide their disease due to fear of ostracism and create self-stigma. There are many examples where patients have left their villages without being abandoned either from their family or society.
- **Uniform education:** Lack of actual knowledge and a feeling of untouchability about leprosy is the main cause of stigma and the leprosy programme have all the way emphasized on the uniform performance of education activity and did not address to the specific needs of the communities.

What Are the Effects of Stigma?

If one becomes ill he would go to a doctor. Once he gets better, he would expect to get on with life as usual. But it's not that easy for people who suffer from illnesses like **Leprosy**,

Tuberculosis or HIV/AIDS. Often, they can suffer from persistent rejections and exclusions by ill-informed members of the community. Some people have been denied loans, health insurance and jobs because of their history of health issues. Consequently, these people lose their self-confidence and may develop further anxiety or debilitating depression. On top of the issues they are already facing. As such treatment by the society, sometimes becomes so unbearable that many take their own lives.

What Can We Do?

All of us have times when we feel depressed, anxious or angry. We might even have a series of bad days, where we think that nothing will ever go right for us and the world is against us. For a physically or mentally ill person, these feelings do not go away.

So the answer lies in education and understanding. If you know someone who seems very emotional, down or upset, then lead by example; show compassion and understanding, and encourage them to seek help. And if you're suffering silently yourself, take comfort in the fact that you're not alone and that there is still hope.

True rehabilitation is meaningful only when an afflicted person can go back to his village, his home and resume his life from the point he had left.

What should human kind learn from the way people affected by leprosy have been treated?

Discrimination, and in particular discrimination against a particular category of people, is the worst kind of human rights violation. Such categorizations are a creation of human mind. Disease is a condition of being human. It could happen to anyone. Simple because some people have suffered from leprosy, they are put in a certain category and treated miserably. This is thoroughly against the concept of human rights that should be enjoyed by all human beings, whatever their situation is and wherever they are.

The Approach That Was:

Health Education

When so much of the incidence of a disease is hidden because of fear and stigma, the health system has to inform people about its cause, symptoms and cure and motivate them to seek both diagnosis and treatment. Such education also aims at reducing stigma and the social cost that accompanies it. Although drugs to combat leprosy were available, since 1950's, but due to long-drawn treatment very few could sustain the interest till treatment completion. The major breakthrough came with the introduction of MDT (multi drug therapy) in the 1980's, with the assurance of sure cure after short-term treatment, which reinforced the importance of health education making it more convincing.

Soon the need for a transition from health education to information, education and Health education in leprosy was primarily a substance of mass communication and publicity, in which the information giver and receiver were distanced from each other. No attempt was made to modify the frightening image of leprosy look like any other communicable disease, which is curable and treatable. Instead, fear was used to urge people to seek early diagnosis and treatment communication (IEC) was felt, which involved the use of information to promote a two-way communication, a drift from the earlier approach of - *teacher/superior to learner/inferior relationship*. The new approach included promotion of people's participation in the development process.

IEC for and in Case Detection

Case detection is both a means and an end of IEC in leprosy elimination. Detection is the first step in the process of treatment, cure and elimination, which is the target of all programmes; many methods of IEC are employed for accomplishing this aim. Detection, when demonstrated in public not only informs and educates the masses, but is also a powerful tool for reduction of stigma and community participation. The traditional method of case detection in the NLEP was the general survey. This was done through health education rather than IEC, with information being presented to a passive community in a teacher-learner relationship.

Public Awareness

The new approach involved public awareness and spreading the message that fear of leprosy was ill founded, as a mere contact with leprosy affected person did not pass on the disease. *Residential camps* were organized in which the community saw patients and service providers living and eating together. They could see services providers cleaning patients' wounds and ulcers, massaging and exercising their disabled hands and feet– thus making physical contact non-threatening. Patients were taught self-care practices and in the course of the camp their limbs became suppler. They shared their life's experiences with others and the commonality of their suffering helped to heal emotional wounds. Skin care camps were run concurrently, so that people could see and learn the signs and symptoms of leprosy and also how to distinguish them from other disease. Hence, a holistic approach of combining education, training and treatment, gave patients their dignity, changing perceptions of them from objects of disgust, revulsion and pity to individuals who participated in their own treatment and rehabilitation. These camps unlocked the fear of leprosy and gave it space to breathe into the open. The camps were deliberately made festive occasions, celebrating its curability. Many leprosy-affected persons who had been rejected by their families were reunited with them and returned home.

Shaping Community Participation

IEC accomplishes the task of information, education and communication, but even a *two-way* communication between the health provider/educator and patient/or community is not enough. It has to be translated into active participation between all three. A number of factors act and react on each other in the process, the most important being a sense of human dignity and equality, the acceptance of leprosy affected persons by the community

and the stepping down of the health educator from the podium of a teacher. This concept of a *trialogue* was replicated in few states, which included people from all classes and castes of local society. Soon, people who had been instrumental in ostracizing the leprosy-affected persons were roped in. A change of attitude in such persons was the strongest demonstration of the need to accept patients into the community. They provided an example of the community organizing itself to break its own social and cultural taboos.

Those who initially maintained a distant approach came closer and some even joined the campaign realizing the unnecessary pain and agony they had afflicted on their less fortunate fellow beings. The bonding that resulted between the patients, service providers and community members, made many to pledge themselves to work towards eliminating leprosy. This involvement of patients and communities also resulted in their participation in case detection among themselves, so further strengthening awareness and removing fear. Training therefore was not confined to NLEP and general health care staff but was extended to a wide variety of community partners – members of women and youth groups, village leaders, anganwadi workers, school children, elected rural and urban representatives, NGOs and social service organizations.

In this process of community mobilization a variety of communication methods inventively came to occupy centre-stage viz. street theatres, folk music, dance theatre, rallies and house visits. The content of the information was changed from frightening images of people disabled with leprosy to positive images of healthy cured persons sharing their experiences about the curability of leprosy.

Ensuring Better Services

Preparing the community to deal with leprosy required uninterrupted drug supplies and treatment services. Provision of colour-coded blister calendar packs and patient cards, mobility for leprosy supervisors and other infrastructure facilitated is providing greatly leprosy services. Comprehensive methods of programme monitoring were tried out over the years, finally resulting in the introduction of a simplified management information system, developed in collaboration with the World health organization (WHO).

Capacity Building

Developing the capacity of staff at all levels to carry out their tasks has been a major component of the of the programme. The aim was to promote learning rather than just teach, and in addition to providing technical training on all aspects of leprosy, emphasis was on programme implementation aspects. It helped people to analyse their own work situations, identify problems and find solutions for them. This was initiated with the community participation approach and was particularly effective in relation to leprosy workers and supervisors. A group of people who were held in low esteem, both by the community and themselves, grew in confidence, ability and stature. It also promoted team training, thereby increasing understanding of each others' roles within the NLEP teams.

Integration with the General Health care System

Promoting integration was an objective towards which the programme worked steadily. The chief role of advocacy and persuasion was played by **CLD and NLEP** partners. It promoted activities and studies to demonstrate to decision makers and field staff that

integration need not be a threat to any group. It could be handled with careful planning and implementation, along with a system for early recognition of problems and corrective actions. The partners played a role in persuading international agencies such as the World Bank about the need to integrate in order to reach the goal of elimination. The experience with integration from the DANLEP-supported states showed that ideally, the functional and structural aspects of integration should be planned with the involvement of all the stakeholders and that consensus building was important in this process. The process is still on going.

The Elimination Goal

In 1992, India adopted the WHO goal of eliminating leprosy as a public health problem by 2000, elimination being defined as a prevalence rate of less than one case per 10,000 population. In terms of actual numbers, this translated into reducing the number of leprosy cases by 95% from about two million cases in 1992 to 1,00,000 by 2000. Though the goal could not be reached by 2000 at the national level, yet 9 out of 35 states and the union territories did achieve the elimination target. The goal of elimination at the national level was finally achieved in December 2005.

New Dimensions of Strategic Framework

The dimensions of stigma, constituting a framework for assessment, include consideration of the following points:

- Reluctance to disclose the problem
- Exclusion or rejection from school, work, social groups and activities
- Blame and devaluation
- Diminished self-esteem
- Social impact on family
- Ability to marry and impact on existing marriage
- Compare stigma for different health problems and in different settings

While developing any strategic action plan for reduction in stigma and discrimination against leprosy affected persons, situation a _____ should be corrected and keeping the above points in mind.

Focus and approach to Interventions to Mitigate Stigma

Focus	Approach
Health problem	<ul style="list-style-type: none"> ● Public health to control the disease ● Early recognition and treatment for cure or disability prevention
Stigmatizes	<ul style="list-style-type: none"> ● IEC and social marketing to enhance compassion and reduce blame

	<ul style="list-style-type: none"> • Correct misapprehensions of risk
Emotional impact	<ul style="list-style-type: none"> • Counseling • Peer support groups and therapeutic communities
Social policy	<ul style="list-style-type: none"> • Advocacy, lobbying, and legislation • Research support

The stigma and discrimination mitigation strategy shared make an analyses of the above key focused areas and approaches to address them should be worked art.

The Challenges Ahead: What needs to be done – A big question?

Every program that aims at development needs to change behaviour. Barriers to behaviour change have to be broken down before making any progress in the program. And every intervention to bring about behaviour change involves communication. Once the motive to change behaviour has taken root in the individual and community, it has to be sustained. Resistance, as a result of either social inequities or stigma, has to be dealt with.

The initial stage of IEC in leprosy program involved treatment compliance and completion. Subsequently with a decline in prevalence, the focus shifted to early voluntary seeking of treatment. As of now, with the elimination of leprosy having been achieved, it has to be sustained and initiatives for “*Leprosy Free India*” to be taken. To accomplish this mission the following challenges need to be addressed:

- **The urban challenge:** Special IEC strategies and campaigns to reach urban audiences comprises a key feature of the strategy that should soon be implemented in identified urban areas.
- **Other special groups:** The high rates of leprosy in some districts in low prevalence states and the extremely high rates in some districts in endemic states indicate the need for area specific and target group specific focus in the years to come. Special efforts will have to continue to reach the poor and marginalized –women, tribal communities and hard to reach groups through customized IEC in focused areas. An integral aspect of program’s IEC strategy is to reduce stigma towards women affected by leprosy, by empowering them to seek treatment and motivate them for self-reporting. Equally vital is to enhance the access of tribal groups to services and information, in order to counter the myths and misconceptions.
- **Early detection/POD counseling:** The disaggregated analysis of data indicates a fairly high proportion of multibacillary cases. While this could due to various epidemiological factors, it is also possible that these cases are not being detected in time. Hence, the IEC component on early voluntary reporting and treatment will have to continue. Although deformity rates have come down dramatically, the high proportion of multibacillary cases calls for strengthening self-care and counseling for the prevention of disability.

- **Focus on providers:** The program's IEC strategy has addressed the need to motivate providers; nevertheless they have received less attention than other target groups. In the post integration period, the focus will have to include improving quality of service delivery by motivating providers especially the new entrants in the system and counseling patients. Appropriate strategies and tools – such as non-monetary recognition in local events- needs to be developed and implemented to recognize the contribution of the providers.
- **Advocacy:** With the goal of the program having been achieved the task ahead is even more daunting. This success will have to be sustained at all levels. This will help strengthen the image of the program that influencers have, and motivate people associated with the program at all levels. A significant advocacy task remains at the district level: the continued involvement of state/district/block and village level administrators and influencers remains a crucial and significant achievement of the program goals.
- **Sustainability:** The IEC experience in the leprosy program holds valuable lessons for other programs. In many ways, the leprosy program has been part of the collective experience that has shown the way for other health programs, namely polio, RCH, HIV/AIDS, TB, in which communication is a key component. IEC has become an integral part of service delivery, is an achievement the leprosy program justifiably can be proud of. At the same time, the way ahead hold some challenges. These include addressing hard-to-reach groups and finding more cost effective and sustainable methods to implement IEC, focus on public awareness, devising a complain mechanism, remedial and redressal measures and last but not the least generate awareness within the leprosy affected person. These steps would help to retain the momentum of IEC efforts so as to achieve and sustain the program goal of elimination.

Suggested Stigma & Discrimination Reduction Strategies

1. Inter-mixing of patients and public

- **Women mobilization** we should take the confidence of females as well as head of the family in community. Women health workers/volunteers should be employed for awareness campaign in villages to reduce stigma.
- **Old Leprosy Peoples' association** usually old age people face more stigmas due to economic dependence than others. These patients can be groomed as Peer Educators and used to disseminate the information on leprosy among other members, and also reporting the cases to Primary Health Centres. For this they could be given some kind of honoraria, which would act as an incentive for more such people to come forward and support the community.
- **Complain mechanism** will help the leprosy affected persons to register or lodge a complain through a *toll free* number in case of discrimination at the workplace, family or society level. Besides the use of IVRS (interactive voice recognition system) will help people to acquire information on leprosy on this toll free information.

- **Remedial & redressal measures** should be built in IEC campaigns so that the credibility of IEC messages remains high.
- **Awareness within the victims** some healing therapies for leprosy affected persons shall aid these patients to build positive vibes and regain their lost confidence. These classes could be organized by the NGOs, CBOs in collaboration with other local level functionaries and govt. departments.
- **Village level meetings** village leaders should allow patients in different meetings, they should co-operate with patients and help them in their needs. Gram sabha meetings can be organized where patients and villagers will participate together.
- **Health camps** in the village where leprosy patients as well as others are treated together and the villagers could observe the normal behaviour of doctor with the patient.
- **Cultural program** for leprosy awareness through regional folk arts
- **Common feast** be organized during any local fare where patients will serve food
- **Public Garden** where community people come for enjoyment will be maintained under the charge of leprosy patients to take care of it.

2. Awareness Generation

- Sensitization of the media persons, so that they write positive about leprosy affected persons, service providers
- Motivate the youth to come forward and educate the community about leprosy. Scouts and Guide, NYK volunteers, NCC cadets can take the lead role.
- Inviting budding writers to write positive and motivational stories on leprosy
- Collaboration with the Department of Social Justice & Empowerment to help Leprosy affected persons get equal opportunities
- **Door to door contact and counseling** - training five or six volunteers within the community and educating them on various issues of leprosy, who in turn will educate the entire community. Advocacy of old age persons, religious leaders and motivating them to carry forward the message to other members of the community, as these people have more stigma. Organize group counseling and group meetings in the village.
- Advertisement through local newspapers, posters, wall writing
- Propagating the concept of *Community Newspaper*, among community members highlighting their meetings or other activities. This would give them a sense of oneness and ownership.
- Through community radio listening followed by discussions shall help to dispel myths and misconceptions
- Showing dramas, cinema, puppet shows on leprosy during local festivals to establish practical example of mixing
- Group discussion especially with the women folk to motivate them for self reporting and provide correct knowledge about leprosy

Interventions are needed at five levels, the intrapersonal, interpersonal, organizational/institutional, community and governmental/structural level. Stigma

reduction programs should use a combination of approaches. Promising interventions are empowerment, counseling, contact with affected persons and education. Activities to reduce stigma can be grouped into 4 as given below-

1. Spread the demystifying messages and its interpretations, mainly regarding nature of disease, whether hereditary, whether leprosy cases are touchable, role of immunity in occurrence of leprosy, what is burnt out case and so on.
2. In discriminatory behavior of health workers / medical officers while examining and treating e.g. dressing the ulcers and counseling.
3. Community counseling, Group meetings and discussions using live case stories, incidences and involving Leprosy cases in discussion. This can be clubbed with developing “self care groups” and involving community in treatment provisions & CBR.
4. Integration of leprosy services into general health care practicing ‘no isolation – no discrimination in wards or OPDs.