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NLEP-guidelines on reduction of stigma and discrimination against
persons affected by leprosy

I. Introduction

Leprosy is an age old disease. As there was no known remedy for the disease in the earlier days, the viciousness of the disease, disfigurement and disability caused by the disease resulting in making the affected persons suffer heavily, led to a number of myths, misconceptions, apprehensions and inhibitions in the minds of people. This resulted into developing such a high degree of stigma against the disease, that the community wanted to avoid all contact with such persons. The leprosy affected persons were forced to leave their home and live in segregated areas. This is the only disease where the sufferer had to live in separate colonies, villages and even in distant islands.

Even after segregation, the societies and the Governments made discrimination to the persons affected by leprosy. A number of such discriminatory laws were framed against such persons. At present, the situation has changed to a great extent. Now there is cure for leprosy and patient can live in their home during treatment. Because of early treatment, deformities and disabilities have reduced. Many discriminatory laws have been repealed all over the world. Yet, there is discrimination against the person affected by leprosy, which need to be removed from the Public mind, so that these persons can lead normal life like any other human being.

II. Objective

This guidelines aims to:

- Provide at one place, the facts about stigma against leprosy, its various determinants and types
- Indicate intervention strategies to be followed under NLEP
- Suggest line of action to be taken by the states/Uts

III. Types of 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 refers to unfavorable attitudes and beliefs directed toward someone or something, which may be broadly grouped as:

- **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 the sufferer feel themselves. This usually is due to reduced self-esteem (“ I am no good”, “ no one will want to marry a person affected by leprosy like myself”), feeling hopelessness (“ I can no longer do anything”) and feelings of guilt or self –blame (“It is probably my own fault that I have developed leprosy”)
- **Enacted stigma:** denotes actual occurrences of discrimination (e.g. divorce, denying someone access to public transport) or negative behavior (e.g. gossiping)
- **Institutional stigma:** is stigma or discrimination which is part of institutional arrangements or policies. This includes separate clinic arrangement for people affected by leprosy, insufficient arrangements for confidentiality, laws sanctioning divorce or social exclusion. Man-made barriers (e.g. buildings without elevators, sidewalks without ramps) may also be seen as part of the same category, as they exclude people with disability.

IV. Determinants of stigma

- (i) **Lack of knowledge:** knowledge about etiology & curability, spread of the disease and whether it is hereditary or not, counts for irrational behavior. Even educated and respected persons can become victim of misconception about leprosy
- (ii) **Attitude:** Attitudes are powerful determinant of stigma. 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. Community attitudes are part of a cultural belief and value system. 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.

- (iii) **Fear:** Fear is a major driving force of stigma. People fear mainly two things: deformity and social exclusion. 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.
- (iv) **Blame and shame :** people affected may be blamed for having the condition as 'being their own fault' or "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 with 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.

V. Discrimination

Discrimination is the treatment of an individual or group with partiality or prejudice. Discrimination is often defined in terms of human rights and entitlements in various spheres, including healthcare, employment, the legal system, social welfare, and reproductive and family life.

Stigmatisation and discrimination : Stigmatization reflects an attitude, but discrimination is an act or behavior. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatizing thoughts. Stigma and discrimination are linked. Stigmatised individuals may suffer discrimination and human rights violations. Stigmatising thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.

VI. Intervention strategies

Stigma associated with the disease is very deep rooted, evolved through centuries of misconceptions and myths. **The process of achieving the acceptance of the leprosy patients in the community along with social status culturally acceptable in the absence of disease/ill health condition should be treated as stigma reduction.** The strategy to reduce stigma in leprosy have to be mainly through :

Spreading awareness: 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. However, mere information and education, to all and 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.

Following steps may help in this regard –

1. **Developing understandings & concepts based on scientific knowledge:** knowledge and fear interact in unexpected ways that allow stigma to continue. Although most people have some understanding of Leprosy, many lack in-depth or accurate knowledge about Leprosy. For example, many do not understand that leprosy cannot spread through the wounds they may have; wounds are not due to the direct effect of the disease; anesthesia is the primary cause of their wounds and so on. Involvement of experts from Medical College and research organization like JALMA (ICMR) should be useful
2. **Preventing iatrogenic stigma:** Non discriminatory behavior of health workers/medical officers while examining and treating e.g. dressing the ulcers and counseling can help in preventing stigma. Integration of leprosy services into general health care practicing 'no isolation –no discrimination' policy in wards or OPDs, should be strictly followed.

- 3. Involving communities/societies:** 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 & Community Based Rehabilitation (CBR). Strategies to reduce stigma must involve active participations between all three i.e. affected people, Health care provider/educator and the community, based on sense of human dignity, equality and acceptance of leprosy affected persons by the community.

Interventions required may be at five levels –Viz. intrapersonal, interpersonal, community, organizational/institutional and governmental level. Stigma reduction programs should use a combination of approaches. Promising interventions are empowerment, counseling, contact with affected persons and education.

VII. Situation in other countries

Stigma and discrimination against person affected by leprosy is a world wide phenomenon. The fight against the problem is now on. Situation in a few countries are as below:

Srilanka: The country launched a professional, powerful and broad based advertising campaign aimed at changing the public image of leprosy. The campaign was launched on a big scale and in big time fashion, which resulted in changing the image of leprosy from one of fear and despise to one of hope and cure.

Thailand: In Thailand, the social attitudes were strongly coloured by the religious notion of leprosy - incurable, brought by sinful acts. Even among health workers, it was known as “the disease of social loathing”. Thailand’s highly revered king, Bhumibol Adulyadej, established a leprosy foundation and urged the public not to treat victims as outcasts.

A strong Buddhist faith with its compassion and mercy for those who are less fortunate, staunch government commitment, backed by dedicated NGO support has changed this “disease of social loathing” not to another sanatorium but to the past.

Venezuela: The country used a successful 3 pronged plan to reduce leprosy burden and stigma. The first two were on effective case detection and treatment. The third strategy was on stepping up public health education to reduce the stigma of leprosy, spread the word that it was now just another curable disease, and thus encourage spontaneous self-reporting at an early stage.

Vietnam: Vietnam's comprehensive health education was so successful that, by the early 1980s, discrimination against leprosy patients and their families had virtually disappeared in many villages, raising the possibility that patients, previously isolated in the country's 27 leprosaria, could be openly treated in their homes. "The social wounds caused by centuries of stigma and discrimination are like wise largely cured.

Benin: Benin, a small country with a population of just over 6 million, had 20 leprosaria - an indication of the especially sever stigma attached to the disease. They had strong traditional religious customs that considered leprosy as embodiment of evil, curse inflicted by nature's darkest forces. Benin took some drastic steps to control the disease and its consequences. Integration of general health care services; complete national coverage become the goal of this country. The result, some of the leprosaria were eventually phased out as homes for the slowly dying and completely transformed and the rest serve the general population as primary health care centers.

In India, over the years, with the introduction of MDT and IEC campaigns, the stigma and discrimination against persons affected with leprosy is gradually coming down ; but still there is lot of scope for innovative interventions to eliminate stigma and discrimination , so that persons affected with leprosy are fully integrated with society.

VIII. Suggested line of action under NLEP

1. The National Rural Health Mission carries out various Health related IEC activities including for leprosy. The State and District Programme Officers will coordinate with the respective NRHM IEC cell to incorporate all communication strategies in the NRHM activities.
2. Develop strategy with the involvement of the following six groups of persons as partners to fight stigma against person affected with leprosy

- (i) **Civil societies** : It is crucial to identify the political and the prestige structures and work through their leadership to create a climate conducive to bring in changes in the mindset of all people. The cases of PAL facing stigma / discriminations are taken to them, problem is discussed and various options to solve the problem are analyzed to implement.

In the past, during the modified leprosy elimination campaigns, valuable input was received from the leaders of the civic society including Panchyati Raj Institution and Municipalities, which ultimately gained leprosy elimination in India at national level.

Proper advocacy efforts to involve the civic society at large will be useful only if action is taken at all levels i.e. National, State, District and Local.

- (ii) **Social activist** : Leprosy patients are receiving support and strength from a large number of national and International NGOs working in different parts of the country. They are working over the years not only for treating the leprosy disease but also to remove the stigma and rehabilitate them. Partnership with these organization in our fight to remove stigma and discrimination will be invaluable.

There are also organization like the Bharat Scouts and Guides, Gayatri Pariwar, Faith Based Organization (religious groups) and many others who are socially engaged for the upliftmen of the persons affected by leprosy.

There are many celebrities like Actors, Artist, Musicians, sport persons who are involved in social upliftmen activities and would like to support the persons affected by leprosy also, free of charge. Messages through such persons have greater meaning to their fans.

- (iii) **Health service providers** :

- All Health service providers whether in the Govt. or outside are equally important. People not only listen to what they say but also observe their actions minutely and follow the same.
- Private practitioners of all system of medicines are very close to the community and are good source of spreading awareness.

- In the Medical Colleges / District Hospitals, not only the Dermatologist but other departments like Medicine, Surgery, Orthopedics, Plastic Surgery, Physiotherapy, Microbiology, community medicine etc. are equally important partners.
 - Hospital managers and superintendents can support the fight against the stigma and discrimination by their making the system working without identifying the persons affected by leprosy as a separate group to deal with.
- (iv) Community / Opinion Leader :** Communities action in leprosy manifest in different ways :
- By not discriminating against or ostracizing the leprosy affected and enabling them to perform their ascribed social roles without restriction.
 - Community participation in case detection and referral.
 - Community ensuring regularity of treatment by the patients.
 - Helping cured persons in their struggles to earn a livelihood.
 - Community accepting a cured leprosy patient.
- Community action is transforming action when it is Supportive, Purposive and nurturing.
- (v) Corporate sector :** Some industries and jobs are especially suited to or useful for leprosy patients. Certain trades like Smithy, Garment making, Carpenter and Crafts allow people to work from their home and mainly visit the centre only for using the mechanism.
- (vi) Media :**
- Media persons are directly involved in spreading awareness, be it Television, Radio or Print Media. Advocacy for the media is essential on continuous basis.
 - Writers whether they are well known or new entrants need advocacy so that they can write positive things on this issue.
 - Folk artist groups and performing artist like in Theatres have large followers and can be strong partners in spreading the positive messages.
 - State level media coordination committees can be of great help in planning activities in the state.

3. Utilise the Village Health and Sanitation Committee Meeting on “Health Day” to spread specific messages for Behavior Change Communication (BCC) through some of experts in the above groups
4. Develop and use effective, attractive and impressive communication of destigmatizing messages through different Media agencies.
5. During “Health Mela”, organize care and concern camp with triologue and dialogues with the aim of combining services (Diagnosis, POD care) with BCC. Such camps organized jointly by community and health department with the purpose of demonstrating in discriminatory behavior and zeroing distances along with providing services and educating the people have been found to give strong impact.
6. Women mobilization for sensitizing about the disease and utilizing their services for awareness generation in villages can be very helpful to reduce stigma
7. Prepare and implement non-discriminatory behavior guidelines for service providers which includes institutions and individuals. Separate leprosy clinic room in PHC/CHC/SDH/District Hospital to be closed down immediately.
8. Empower the people affected by leprosy to over come discrimination by supporting ‘self care group’ in leprosy colonies. Involve the “ Lok Doots” appointed by the National forum of persons affected by leprosy, wherever needed.
9. “Sasakawa India Leprosy Foundation” have a number of schemes to support the persons affected by leprosy and their children. Coordinate with the Executive Director, SILF, 228, Jor Bagh, New Delhi-110003, ph (011) 42403160, website www.silf.in , and support such initiatives.

These are only a few suggested line of actions. The programme officers at State/Districts may feel free to work out and implement measures to reduce stigma against leprosy and remove discrimination against person affected by leprosy.

IX. Key Messages :

1. **Human Rights issue** : All human beings are born free and equal in dignity and rights. This also includes persons affected with leprosy (PAL). Any legal, social & economic discrimination against PAL is violation of human rights.
2. **Early reporting to health centre for diagnosis & treatment** : Undetected adults with leprosy transmit the disease to children and adolescent. Therefore, the community should know the importance of reporting to Health centre in case of any suspicion of leprosy.
3. **Use of words like 'Leper'** : Words like 'Leper' or 'Kodhi' are used to define people by their disease, which are very humiliating to the persons affected by leprosy. Such words must be eliminated from our vocabulary, for which education should begin from the school level. The Lepers Act 1898 was repealed by the courts in 1983, therefore such use is also unlawful.
4. **Self Respect** : Persons affected by leprosy should be encouraged to overcome their shame and sense of helplessness and take a proactive role in preventing and solving the Physical, Social, Economic and Psychological problems they face.
5. **PAL helping other PAL** : Persons affected by the disease can provide effective support to the programme in the fight against stigma and discrimination, if asked for to help as Counselors, Teachers, Spokespersons and Lobbyists.
6. **Positive Slogans** : These may be
 - (i) No deformity among new cases (Not Prevention of Deformity)
 - (ii) Cure without the need for care (Not care after cure)
 - (iii) Detect early, give MDT and prevent need for rehabilitation (Not community based rehabilitation)
7. **Caution to prevent** : Never start treatment for leprosy unless the diagnosis is confirmed – thus one can prevent pushing a person and family to the world of stigma and discrimination.
8. **Educator not preacher** : Provide useful Health education but do not try to preach.
9. **Cause of the disease** : Leprosy is caused by a Bacteria "Mycobacterium Leprae" and not because of any past sin or curse.
10. **Spread of the disease** : Untreated leprosy patients are the only known source for M. leprae. It is transmitted from a leprosy affected to a susceptible person via mainly the respiratory tract (droplet infection). The major sites from which bacilli escape from the body of an infectious patient are the nose and mouth. Nose appears to be the major port of entry of the bacilli. Leprosy is not spread by skin contact.