'Behavior Change Communication –Strategy' for NLEP

Strategic components –

1. Rationale for proposed strategy
2. Objectives
3. Targets & Priority
4. Plan for IEC / IPC / BCC – Central level & State level
5. Innovative process of communication
6. Role of partners
7. Time frame
8. Indicators for monitoring

1. Rationale for proposed strategy

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 empathies 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.

Discrimination, and specially 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. Simply, 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.

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 program is developed and executed.

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.

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 persons. These steps would help to retain the momentum of IEC efforts so as to achieve and sustain the program goal

2. **Objectives** –

- To develop **effective communication** vis-à-vis the target audiences and take on the task of effectively delivering the same, specifically cover clients, health providers, influencers and the masses.
- To compliment and **support the detection and treatment** services being provided through the General Health Care System, making it more acceptable to the population so that delay in reporting for diagnosis and treatment is reduced and better patient compliance in taking MDT course is achieved
- To strive to **remove stigma** surrounding leprosy and prevent discrimination against leprosy affected persons.
- Active **participation** of communities & clients is developed through various means of communication.

3. **Targets and priorities –**

The following persons / groups are main target to receive IEC/BCC services -

- Community - at large and selected communities where stigma is more deep rooted.
- Leprosy Affected Persons
- General Health Care Staff
- Local NGOs and Community Based Organizations (CBO)
- Disabled Peoples Organizations (DPOs)

As per objectives of this strategy the priorities are as follow –

- Leprosy Affected Persons are to be empowered to fight against discriminations and for improved health seeking behavior. They are to be informed about all provisions for them and counseled for better compliance.
- Communities in endemic pockets and inaccessible areas are informed & encouraged for self reporting at early stage and participate in NLEP. Level of prevailing awareness and stigma varies from place to place, needing various need based IEC strategy.

- Partners, policy makers and administrator are encouraged to develop 'self care groups' and 'Community Based Rehabilitation' through advocacy meetings.

- GHC-staff, general practitioners and other service providers are oriented to scientific facts and means to improve quality of services and non discriminatory behavior thus preventing iatrogenic stigma. ASHA, AWW and volunteers should also be included in service provider group for IEC purpose.

4. Plans for IEC / IPC / BCC activities –

Activities for communication to change behaviors can be designed on principles of social marketing. Social marketing is a distinct marketing discipline that has evolved since the 1970s. Its focus is on influencing behaviors that will improve social outcomes such as improving health or preventing injuries. Unlike marketing theories that aim to promote a certain brand of commercial product, its general intent is to improve people's quality of life. As such, it is a useful approach for public servants tasked with achieving behavioral change.

Social marketing is a practical approach that integrates the insights from individual, interpersonal and community theories and evidence. Typically, the approach aims to change both the individual and the environment around the individual. The changed behavior of individuals and the changed environment interact, gradually establishing new social norms.

4.1 Inter personal communication - The effective way to deal with difficult challenge of stigma removal is to embark on intensive inter-personal communication (IPC) with the target groups.

- **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. Group discussion especially with the women folk should be organized to motivate them for self reporting and provide correct knowledge about leprosy

- **Old Leprosy Peoples' association** usually old age people face more stigmas due to economic dependence than others. These individuals 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 recognition, 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 or others 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 massages remains high**.**

- **Awareness within the affected persons:** some healing therapies for leprosy affected persons shall aid these persons 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 can be organized where patients and villagers will participate together.

- **Health camps** in the village where leprosy affected persons as well as others are treated together and the villagers could observe the normal behavior of doctor with the patient.

- **Cultural program** for leprosy awareness through regional folk arts. Street theatres, folk music, puppet show, dance theatre, rallies and house visits are to be organized for 'difficult to reach populations' and highly stigmatized population groups.

- **Community feast** organized during any local fare where leprosy affected persons also can serve food

- **Advocacy meetings** can be organized to reduce stigma & discrimination. Non discriminatory behavior of service providers is to be demonstrated.

- **Sensitization of the media persons** during above mentioned programme activities 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

- **Door to door contact and counseling** - training 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.

4.2 Information spread through mass media remains important component as out -reach of electronic media is increasing and large number of people are informed in short time. The content of the information should be changed from frightening images of people disabled with leprosy to positive images of healthy cured persons sharing their

experiences about the curability of leprosy. Such messages if came through the various programmes shown by Regional television will have to be the acceptance.

Mass Media Activities being carried out by **Central Leprosy Division** directly are: Kalyani and Non-Kalyani (TV Spots & Radio Spots) and News paper advertisement on Leprosy day

Kalyani program has already been merged with other health programs similarly Non-Kalyani program can also be merged with these programs.

Awareness Generation - Certain level of awareness has developed in the communities due to the persistent efforts in communication during last decade. However continuous efforts are needed to cover the till now uncovered areas. Coverage will have to move from high risk centric to general community at large and high stigmatized population groups in particular.

- **Advertisement through local newspapers**, posters, wall writing
- **Community Newspaper** if available should be utilized for spreading such messages. This would give them a sense of oneness and ownership of the program
- Through **community radio listening** followed by discussions shall help to dispel myths and misconceptions
- **Health Melas** organized under NRHM are good platform for leprosy awareness stalls.s

4.3 GHC staff is to be equipped with **IPC & counseling skills**. Needy cases are counseled and target persons / groups are addressed properly by GHC staff so that the objectives are achieved at the earliest.

4.4 Other activities include -

- Hoarding
- Posters and exhibitions.
- Wall painting
- Rallies (including banners etc.)
- Quiz
- Folk Shows
- IPC / advocacy meetings for Influencers/ opinion leaders

4.5 Implementation of IEC

Central Level

- The Centre will provide leadership and develop core messages, mass media and advocacy events. Detailed planning, choice of communication channels and monitoring should be decentralized to ensure local relevance and wide reach of information.

State Level Activities

The states and districts will base their specific strategies on the core framework and messages, and will encourage local adaptation and innovation to reach all possible groups with the most appropriate communication tools. NRHM infrastructure on IEC will be utilized for maximum benefit.

- Inter-sectoral coordination at the State level would be needed for the effective implementation of the IEC strategy, through NRHM mechanism At the State level, various departments e.g. Health, Education, Panchayati Raj, ICDS Department would contacted for providing effective linkages.
- The state have to get IEC action plan prepared by the districts as per local needs. And develop the state plan on IEC.

District Level Activities

At the District level a 'Advisory- cum-Monitoring Committee' or district coordinating Agency (DCA) need to be formed to prepare implementation plan in association with other health departments under NRHM and to carry out the activities jointly. Necessary instructions and leadership from the district collector to all the concerned departmental heads in the district for their active and effective involvement in favor of the leprosy awareness and stigma reduction will be very useful.

- Support should also be taken from the local MLAs and MP who will provide necessary backup for generation of people's movement in favour of leprosy.
- The DCA will also coordinate with various other agencies in respect of development of location specific media, develop functional linkages with other key stake holders like the Self help groups, community based organizations etc, develop feedback and provide necessary modifications.
- The DCA members can be identified from among the local NGOs., teachers training institute, community polytechnic or the local degree college.

Block Level Activities

-The Medical officer, block PHC will be the coordinator of IEC activities in the block.
-He may draw support from the Block Development Officer, Block Extension Educator, local NGOs, Panchayat leaders, teachers etc.

- Banners, posters and hoardings could be placed at the venue of the **Community Group Meetings.**
- Leaflets, broachers, posters could be used to disseminate information on leprosy, myths and misconceptions during the **Focused Group Discussions.**
- **Cultural sensitivity:** It has been characteristic of the development of IEC activities for NLEP that communities should be involved in a **bottom-up approach** this will help to reduce the distance between service providers, patients and communities. For example,

special initiatives should be taken to decrease social distance between tribal communities and non-tribal service provides, targeting the latter to increase their understanding and tolerance of cultural variation.

- **Community participation:** Community involvement in planning and implementation of IEC activities foster a **sense of ownership of the program at the local level**. Social mobilization is based on direct dialogue with the community to understand and explore existing concerns and possible social conflicts with relevance to diagnosis and treatment. Ideally, this will create a self-supporting and sustainable system for voluntary reporting of people with Leprosy symptoms. Only by creating a shared understanding that MDT is a sure cure for leprosy in spite of these factors, and that cure of leprosy is necessary for individuals, the active involvement of communities in demanding MDT drugs and RCS services can be ensured.

Summarizing, the activities for different target groups covered under this strategy is as follow –

A. **For Community** – dissemination of messages through mass media-print & electronic both, orientation of students & teachers, display of hoardings, posters, exhibition, announcements, group meetings and participation of community key persons in service – camps are common activities.

B. **For Leprosy Affected Persons** (LAP)– information sharing and counseling are the main activities for LAP. Information, regarding leprosy & its consequences, MDT, service provisions and motivational case stories are needed. They are encouraged to come forward to share their experiences with community.

C. **For GHC staff** – selected health providers need to be equipped with communication skills, counseling techniques and how to conduct group meetings & advocacy meetings. They also need to know about developing linkages, supervision & monitoring of IEC activities and instant impact assessment of their efforts.

D. **For NGOs, CBOs** – They need to be informed about program & policies, service provisions through PHC system and Rehabilitation Council of India. They need to promote 'Self Care Groups' and 'Community Based Rehabilitation' through their communication channels. They are given chances to share the models of social marketing used by them in their areas.

E. **For Disabled Peoples Organizations** – Registered leprosy colonies & other such organizations and organizations for disabled not due to leprosy are to be informed about provisions under law PWD –Act & rehabilitation services motivation to regain self esteem, positive case stories and supported to develop self help groups. Advocacy meeting will be required at all 3 levels to promote these activities.

5. Innovative IEC activities – New methods & material should be tried to bring the desired changes in behavior. SMS / messages through mobile phones, internet and use of

toll free helpline can be considered. Messages should be short, interesting, easily communicable, piercing and effective. Cost effective methods & means of communication can be designed. Live versions / quotations, messages from celebrities and true case stories are usually effective. Suggestions from professionals /communication experts can be sought. How to arrange and conduct group meetings or advocacy meetings should be planned in advance. Inclusion of leprosy Affected Persons or persons with experience in IEC activities for leprosy (participatory approach) will help in designing innovative methods of IEC. Activities using 'monologues', dialogues' and 'trialogues' can be designed as per objectives.

6. **Role of partners** –ILEP partners engaged in CBR projects should be encouraged and supported to continue these projects in collaboration with government. CBR department of PMR institutes can provide integrated & sustainable services to Person With Disability (PWD) in collaboration with departments of MOSJE. The main communication methods used here are counseling & advocacy meetings.

ALERT India has tried community volunteers, NCLC has experience of social marketing IDEA India & SILF India used to uplift LAPs and unite them, ILU believes in developing 'Lok Doot & Madhyam Doot. They can contribute in same manner expanding their IEC activities & coverage area

IEC van used by NRHM may also be used for NLEP.

7. **Time frame** –

1. **Orientation training of GHC staff** about IEC strategy, basic principles of communication, implementation & monitoring of IEC activities etc should be completed **by March 09.** A session on communication & counseling has to be included in training manuals.
2. **Coining of messages and preparing new material** should be started and made available **by December 08.**
3. **Coordination meetings and networking** should be started **in 2008** so that the communication channels are developed to provide services.
4. **Group meetings** with Village health committee / Rogi Kalyan Samiti should be started and will remain ongoing process throughout 11th plan period.
5. **Information spread through mass media** will continue with some modification each year / as per need. This can be done **from time to time** through local radio stations (Aakashwani Kendra), Local news papers and regional Door Darshan/TV Kendra.
6. **Street theatre and IPC activities** as per area & population will remain selective for urban, tribal or difficult to approach areas and can be organized from time to time on different occasions.

8. **Indicators for monitoring BCC activities –**

1. New Case Detection Rate and Proportion of Early case detection in voluntary reported
2. Proportion of gr. ii disability among new cases
3. Treatment Completion Rates in predefined areas
4. Number of cases availed Rehabilitation services
5. Number of cases reported / noticed discrimination.
6. Number of cases (under care) developed new disability
7. Number of group meetings (IPC) held.