

## COMMUNITY INVOLVEMENT IN LEPROSY CONTROL: REDISCOVERING THE FORGOTTEN PARTNER

Leprosy control in India has made impressive gains especially in the last few years. While many are basking in the high glory of achieving the much-wanted goal of reining in prevalence and accomplishing the much awaited-for integration, a few in the fringe-view feel underwhelmed and point at a few failed obligations. One of them is community involvement. Policy makers while mapping policy positions have all along given not enough attention to the concept. It remains very much a dream.

Community involvement is the Top ten fodder on sale in public health malls. Unfortunately it has the least fascination for the window-shopping public health managers: it is not their primary orbit. Let us not forget that the avowed aim is to dispense service, not to align with the public at large. Our inability to expand the social rim of the public health programme is an intentional predicament. It is born out of stark ignorance, flawed perception of public capabilities and paternalistic attitude. It is time to awaken the managers out of a passive relation to the public.

The story is that it is great to have the community in the stakeholders' checklist and ready to tick off during elaborate discussion parades but it is more often than not regarded as politically not just correct, for no justifiable reason, to seek their active participation in the programme. We are certainly missing an opportunity.

The natural history of leprosy is littered with several events where at each point, individuals in the community may be willing and ready to help each other in their hour of need. They are hamstrung by lack of adequate knowledge and appropriate guidance. For example, a person with a patch may go to a general practitioner. If he is trained to suspect leprosy he can refer him to a Government centre for management. This requires that all the GPs in an area are



identified and trained to deal with such cases. Since majority of common public seek the help of a local GP when they become sick, their participation in the programme is crucial for early diagnosis and treatment of leprosy. Take another scenario. A person with a patch may not suspect leprosy. What if there is somebody in the village who is trained and is co-opted to direct the affected to the right place for help? Plausibly, he can also be the disseminator of correct information and the agent to recalibrate contrarian attitude through persuasive arguments at village gatherings. Health

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Update is published quarterly in the months of January, April, July and October by ILEP-INDIA as part of its CME Programme to keep the field staff abreast of the development in the field of leprosy.

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**Community involvement in leprosy control: rediscovering the forgotten partner - Contd. from page 1**

workers because of their myriad responsibilities and hodgepodge abilities in communication are not the best in metastasizing meaningful messages successfully. Whereas, a volunteer interlocutor will have less difficulty in nudging his neighbours into action. This is more cost-effective than the frenzied effort from public enterprise directed at the community through mass-media-transmitted messages. Mass media-initiated actions are, unfortunately, more popular with the establishment than the volunteer-mediated initiatives because the latter is more labour intensive and less visible even though they are known to produce sustainable effect.

The second event where public can play decisive role is in helping and guiding a leprosy-affected person complete the treatment. There are many Primary Health centres in rural India which are not easily accessible to populace for various reasons. In such areas assisted drug intake through community volunteers will certainly help in ensuring completion of treatment. In addition to ensuring proper supervision of drug-intake even in impossible situations it provides an opportunity for free publicity about the curability of leprosy.

The third critical area is in the care of persons affected with leprosy-related deformities. The principal focus of the programme all along has been to detect and cure leprosy and therefore has been more rhetorical than real in reaching the unfortunate few with residual consequences of leprosy. The hundreds and thousands of such affected persons stand as a constant reminder of our flopidity. It is in this neglected domain that a public mandate is required. Self-care by individuals with deformity is a highly labour-intensive activity which needs constant support and guidance from family and neighbours, to awaken them from passive resignation, and take their minds away from the debilitating reminder of their disability through constant practice. It is possible to establish social watch guards to assist the disabled in overcoming their obstacles and reshaping their ordeals into opportunities.

Finally it is important to realize that in a democracy it is imperative that the public are made an important patron by establishing health committees at every important administrative level and offering membership to them. It should be the responsibility of these committees to engage as many people from the society as possible for various simple tasks that would make the programme gain further traction.

One cannot expect the establishment to plunge into the orbit and take the public cohort into the programme fold. Grand intentions alone are not enough to guarantee successful insertion. It requires acuity of challenging actions which can best be provided by Non Governmental Organisations. They should be the catalysts to bring about the change, to look beyond the horizon, open the established mindsets to see the world that they want and conjure up all possible avenues to reach there. There are several well-meaning NGOs whose large reservoir of goodwill can be drawn to bring about the much needed change. Giving the community the position, a standing that makes them feel important and noticeable, that rekindles the dormant pastime, is a promised option that needs constant, passionate, pursuit despite the turndowns from the doubters.

What the programme is what we choose. Very rarely we make the right choices. Choice is however a matter of convenience. Many policy makers do not believe that embedding the community in the programme is a good choice because of the hidden fear that it may rationalize their inadequacy and ineptitude. They are not right in their belief. When public is involved in making the informed choices success is guaranteed. It is the right choice with the right consequence.

# NLEP Programme Review and Planning Workshop for North Eastern States

A workshop was organized at Gangtok Sikkim on 6<sup>th</sup> and 7<sup>th</sup> December 2007, for the North Eastern States, with the objective of programme review and planning for the year 2008-09. The meeting was attended by Dr. Joshi, Deputy Director General (Leprosy), teams under the State Leprosy Officer from six out of eight states viz. Arunachal Pradesh, Assam, Meghalaya, Manipur, Nagaland and Sikkim. Mizoram and Tripura could not attend the meeting. In addition to the GOI, WHO and ILEP India senior officials, Representatives of different ILEP organizations assigned to support North Eastern states viz. The Leprosy Mission (TLM), Italian Leprosy Relief Association (AIFO) and Swiss Leprosy Relief Association (ALES) also participated. Dr. Rajan Babu, ILEP Co-ordinator highlighted the participation of ILEP in the programme.

The common challenges and issues brought out during the presentations of State Leprosy Officers are as below:

- Training programmes need improvement.
- Assistance should be provided to the state for the DPMR implementation, giving stress on home based self care. Surgery is only the last component.
- Line listing of back log of disabled cases should be done by the states and then ask for assistance from ILEP.



- Female proportion of cases unbelievably low.
- Advocacy is not very good. Keeping the programme away from decision makers will not help.
- IEC – very loose term used. Innovation in IEC required with some new messages. Need guidelines on counseling.
- MDT stock management is not optimum.
- ILEP should be proactive in advocacy work.

The states prepared the draft action plans in consultation with the respective ILEP member representatives supporting the states.

## Memorandum of Understanding (MoU) between Government of India and ILEP

A Memorandum of Understanding (MoU) between Government of India and ILEP Members active in India was signed by Dr. P.L. Joshi, DDG (Leprosy) and Dr. G. Rajan Babu, ILEP Co-ordinator-India (Representative) on 24th October 2007 at Nirman Bhavan, New Delhi. The MoU was signed in presence of Mr. Debasish Panda, Joint Secretary, Ministry of Health, Government of India; Mr. Rigo Peeters, President of ILEP; Dr. P. Krishnamurthy, Secretary, DFIT; and Dr. D.M. Thorat, DADG (Leprosy). This Memorandum of Understanding provides the formal framework for collaboration between Government of India and ILEP Members active in India for the period starting from date of signing MoU to 31<sup>st</sup> March 2012. The guiding principles of ILEP support to NLEP are: sustaining quality leprosy control activities (in line with WHO global strategy); ensuring ownership of programme by general health care system and synergizing resources for efficient leprosy control.

The major emphasis of MoU is on the thematic areas of support to build the capacity of General Health Care system to carryout quality leprosy services in an integrated approach and to sustain leprosy control activities. The thematic areas of support includes strengthening the planning, monitoring and supervision (including disease surveillance); support to Disability Prevention and Medical Rehabilitation (including referral system); operational research and Socio-economic rehabilitation and community participation. Each state government will draw an action plan with ILEP state



**Signing of MOU between GOI and ILEP**

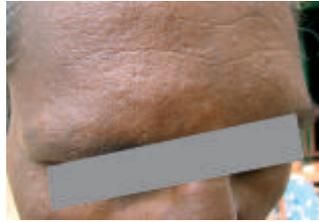
L-R: Dr. G. Rajan Babu, ILEP Co-ordinator-India (Representative), Mr. Rigo Peeters, President of ILEP & Dr. P.L. Joshi, DDG (Leprosy)

coordinator of the respective state in consultation with all the ILEP partners working in the state, describing the objectives of the collaboration, respective responsibilities and contributions.

At the national level, support is provided in the form of provision of National Consultant (DPMR), Data entry clerk and Office Assistant; production of learning material on DPMR; support to State Leprosy Officers review meeting; developing NLEP web-site; developing strategic document on behavioral change communications; provision of technical inputs for independent evaluations of NLEP.

## Out of darkness into light

Mr. Shivadas (Name changed) from Nalanda district in Bihar was a shoe maker by profession. Two years back he went for fishing. A snail (according to him) bit him in the leg. Even though there was severe bleeding, he did not feel any pain. He was taken by his uncle to a local ayurvedic doctor who treated him for one year. He used to get medicine once a month for which he spent Rs.500/- per



See Pic. 1 & Pic. 2 in page 8

month. The doctor died. Three months later the village leader saw him and took him to the PHC where diagnosis of MB leprosy was made. Patient had infiltration on the face, back of the arm and buttocks. He had thickening of both ulnar and both LPN. There was anesthesia in the sole and both the feet but no ulcers. Patient was diagnosed as MB leprosy and MDT was started at the PHC.

## All is well that ends well

Mr. Upendra (Name changed) in Gaya district of Bihar went to Surat in search of livelihood. A few months later he noticed redness & shininess of the skin on the face, ear, back. People noticed the abnormality in the ears and told him about it. He was advised by his neighbour to go to a doctor. He refused



See Pic. 3 in page 8

because some body told him that if he went to Government doctor at the PHC, his ears would be cut. When he came back to the village in Washirganj, Gaya, PHC staff living in the village took him to the PHC and got the treatment started for him. He is responding well to MDT.

## So near yet so far

Mrs. Kamala (Name changed) belongs to Rajgir, a town in Nalanda District of Bihar. 3 years back she had a patch on the right cheek. She went to the local doctor who said it was leprosy in reaction. He treated her for four months. She did not find any improvement. Her maternal uncle who visited her told her that treatment was available for her disease at the local primary health centre. She was taken by her husband to the PHC where treatment with MDT was started. For first six months all the three drugs (Rifampicin, Clofazimine, and Dapsone) were given and for the subsequent six months Dapsone was excluded from treatment for no apparent reason. She was released from treatment after one year of MDT. Skin smear at that time was negative. Three months after stopping MDT she had severe ENL reaction for which she was given steroids by physician at the PHC. The reaction subsided. A few month later she had



See Pic. 4 in page 8

the reaction second time. She went to a local dermatologist who started steroids again which was continued for one year. During this period she had consulted two dermatologists and one of them advised her to go to All India Institute of Medical Sciences at Delhi. Her maternal uncle took her to a famous private hospital in Tamil Nadu. After extensive lab investigation including skin smear which was positive (2.75) she was put on Rifampicin 600 mg once a month, Clofazimine 300 mg once a month and 50 mg daily and Ofloxacin 200 mg twice a day. She was asked to take the treatment for one year. She spent almost Rs.25000/- for this. She came to the PHC again. We saw her. She was in ENL reaction with extensive lesions on the upper limb, lower limb and the back. She had cushingoid features. Nerves were normal. The lady had 3 children, last child was five years old.

**Question : How do you manage this patient?**

**“Our interest in the present overshadows our inclination to learn from the past”**

- Krishnamurthy

# Operational guidelines for Leprosy control activities

(World Health Organisation SEA/GLP/2006.2)

Contd. from October 2007 Issue

## 4.3 How and why are leprosy cases classified?

Leprosy is a very variable disease, affecting different people in different ways, according to their immune response. Those at one end of the spectrum, with a high level of immunity harbour a low number of bacilli and are termed paucibacillary or PB patients. Those with many bacilli in the body are referred to as multibacillary or MB cases. MB patients need more intensive treatment than PB patients – they need three rather than two antileprosy drugs, taken for a longer period. Classification in routine programmes is therefore a practical step which divides leprosy patients into two treatment groups.

A simple clinical rule is now used to divide patients into these two groups. The number of individual skin lesions is counted (this means that the whole body must be examined, including more private parts, to make an accurate count):

PB cases have up to five skin lesions in total.

MB cases have six or more skin lesions.

If a skin smear is done and is positive, the patient must be classified as MB, whatever the number of skin lesions. If the smear is negative, the classification is decided by the number of skin lesions. Other factors like nerve involvement may be considered at the referral level for classifying the disease.

The risk of nerve damage is greater in MB patients. Therefore, classification is helpful in assessing future risk (section 6.1) and in guiding patient care.

## 4.4 What should be done when leprosy is suspected but the diagnosis is uncertain?

Generally, the most difficult cases to diagnose are people who present with one or two pale patches, without loss of sensation or other signs of leprosy. In these cases, there are three options:

- refer: know where to refer cases that are difficult to diagnose; discuss cases with colleagues who have experience of managing leprosy (section 2)
- consider the possibility of another skin disease and treat appropriately
- wait 3 – 6 months and review the skin lesions again; if it really is leprosy, loss of sensation may now be found and MDT can be started.

If there is no loss of sensation in the skin lesions and no enlarged nerves, but there are suspicious signs, such as nodules or swellings on the face or earlobes, or infiltration of the skin, it is important to try and get a skin smear test done. In these circumstances a positive skin smear confirms the diagnosis of leprosy, while a negative result (in the absence of other cardinal signs) would, in practice, rule out leprosy. An alternative diagnosis should then be considered.

In PB cases (in whom the skin smear will be negative); loss of sensation is almost always detected. In MB cases, normal sensation may still be present in a proportion of cases, but these patients often have one or more enlarged nerves and a positive skin smear. Signs of nerve involvement (enlarged nerves or signs of nerve damage, such as numbness, tingling or weakness affecting hands or feet) may occasionally occur without any obvious skin lesions. In such cases, known as neural leprosy, the disease can only be diagnosed by someone with experience of assessing nerve involvement in leprosy.

## 4.5 How can the accuracy of leprosy diagnosis be ensured?

The diagnosis of leprosy is straightforward in the majority of cases; these cases should be diagnosed in clinics as near as possible to the patients' homes and treatment with MDT should be started immediately or at least within a few days.

In some cases, the diagnosis of leprosy is more difficult. As stated above (section 4.4), the most difficult cases are early PB cases with one or two pale patches on the skin; another difficult group (especially if skin smears are not available) are early MB cases with very vague skin patches and no loss of sensation.

The following steps will help to ensure the accuracy of leprosy diagnosis:

- (1) adherence to the criteria for case definition (section 4.2)
- (2) good training about leprosy diagnosis for health workers (section 9.4)
- (3) regular and effective supervision, with on-the-job training (section 9.1)
- (4) clear lines of referral for suspect cases, when the diagnosis is uncertain (section 2)
- (5) availability of appropriate training and reference materials (section 10.1).

The quality of diagnosis should be monitored as part of regular technical supervision. If there are indications of substantial over-diagnosis, a validation exercise on a representative sample of cases can be conducted (section 8.3), in order to understand the magnitude of the problem.

## 4.6 How is disability assessed and recorded in leprosy?

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person.

### Disability Grading in leprosy

Every new case of leprosy must be assigned a Disability Grade, which shows the condition of the patient at diagnosis.

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The grade is either 0, 1 or 2. Each eye, each hand and each foot is given its own grade, so the person actually has six grades, but the highest grade given is used as the Disability Grade for that patient.

Grade 0 means no disability found.

Grade 1 means that loss of sensation has been noted in the hand or foot (the eyes are not given a grade of 1). Loss of sensation in the hand or foot means that one of the main peripheral nerve trunks has been damaged by leprosy and this is more common later in the disease than at diagnosis. It should not be confused with the loss of sensation in a skin patch, which is caused by local damage to the small nerves in the skin, and not to the main peripheral nerve trunks.

People with loss of sensation (grade 1 disability) on the soles of their feet, but no other abnormality, are at significant risk for developing plantar ulcers. People with grade 1 disability who routinely use appropriate shoes are protected from ulceration and have far fewer long-term problems with their feet. Therefore, measuring and recording grade 1 disability is an essential step in preventing damage to the feet of people affected by leprosy – it is therefore a key component of quality leprosy services.

Grade 2 means that visible damage or disability is noted.

For the eyes, this includes the inability to close the eye fully or obvious redness of the eye (in leprosy, this is typically caused by either a corneal ulcer or by uveitis); visual impairment or blindness also gives a disability grade of 2.

For the hands and feet, visible damage includes wounds and ulcers, as well as deformity due to muscle weakness, such as a foot drop, or a claw hand. Loss of tissue, such as the loss or partial reabsorption of fingers or toes is a late sign in leprosy, but it also gives a disability grade of 2 for that hand or foot.

### Peripheral level

(1) Check for grade 1 disability by asking the patient for the presence of loss of sensation in the hands and the feet

(2) Look for the signs of visible disability (grade 2):

- Wounds or ulcers on the hands or feet
- Marked redness of the eye
- Muscle weakness – causing:
  - Incomplete eye closure
  - A claw hand
  - A drop foot

(3) Loss of tissue, such as fingers or toes shortened or missing

Any patient showing the above signs should be referred to a referral unit where POD services are being provided. Visible disability should be recorded before referral.

### Referral level

Examine carefully for any disability, recording the full results of the examination in the Patient Record Card for future reference:

#### Eyes

- check the Visual Acuity of each eye separately, using a Snellen chart; if no chart is available, ask the person to count fingers at 6 metres; if the person cannot read the top line of the chart, or count fingers at 6 metres, they are visually impaired and have grade 2 disability in that eye.
- look for an inability to close one or both eyes (lagophthalmos) and check
- for normal strength of eye closure
- look for any redness of the eye

#### Sensation in hands and feet

Check the sensation in the palms of the hands and the soles of the feet, using a ballpoint pen:

- Explain the test to the patient
- Ask them to close or cover their eyes
- Touch the skin very lightly with the ballpoint
- Ask the patient to point to the place you touched
- Test a minimum of four points on each hand and foot
- Note any areas where the pen is not felt

NB: In the palm of the hand, the side with the little finger is supplied by the ulnar nerve. The part with the thumb, index and middle fingers is supplied by the median nerve. The sole of the foot is supplied by the posterior tibial nerve.

#### Check for muscle weakness

The three key muscles are:

- (1) thumb up (tests the median nerve)
  - ask the person to put out their hand, palm up
  - support their hand in your hand
  - ask them to point the thumb towards their own nose
  - test the strength of the thumb to stay in that position
- (2) little finger out (tests the ulnar nerve)
  - ask the person to put out their hand, palm up
  - support their hand in your hand
  - ask them to move the little finger out
  - test the strength of the little finger to stay in that position
- (3) foot up (tests the peroneal nerve)
  - ask the person to sit down
  - support the person's lower leg in your hand
  - ask them to point the foot up to the roof
  - test the strength of the foot to stay in that position

Muscle strength is recorded as “Strong” (S), “Weak” (W) or “Paralyzed” (P):

“Strong” (S) - means that the muscle being tested is of normal strength;

“Weak” (W) - means that the muscle can move, but it is definitely weak;

and

“Paralyzed” (P) - means that the muscle cannot move at all.

To be Contd.

# Different Presentations of Leprosy



