

Demystifying Leprosy

A workshop explores ways to familiarize people with the true nature of the disease.

Transforming a government program to eliminate leprosy into a people's movement was the goal of the National Consultation Workshop on Advocacy Strategies for the Elimination of Leprosy held in New Delhi June 4-5.

Organized by Dr. S.D. Gokhale (International Leprosy Union), the two-day event brought together an eclectic mix of participants tasked with formulating a strategy for demystifying leprosy and bringing about the social rehabilitation of those affected by the disease.

"Killing the bacillus is not enough. We need to change mindsets," said Dr. Gokhale.

One starting point is people-centered advocacy, defined by Dr. Amitabh Behar (National Centre of Advocacy Studies) as "a set of organized actions aimed at influencing public policies, societal attitudes and socio economic processes that enable and empower the marginalized to speak for themselves."

He outlined several steps for effective advocacy, including identifying and framing the issues, mobilizing interested parties, forming and sustaining networks and alliances, and getting media involved.

For Razia Ismail Abbasi (India Alliance for Child Rights), the issue was why such a workshop was necessary in 2004, 20 years after she had become involved in a similar campaign to change attitudes toward leprosy, and despite the proven effectiveness of multidrug therapy in the interim. The reality, she said, is that leprosy is "not just a bacillus that a combination of drugs can defeat; it is as much a social condition with the power to irrevocably afflict a life."

Where the role of media was concerned, there

was general agreement that the broadest possible definition of the term be used, to allow messages to be targeted and delivered in the most appropriate format.

Shamsher S. Bahadur (The Leprosy Mission Media Center) said that TLM campaigns were coordinated across a whole range of media, and use a "building-block system" in accordance with specific local conditions. The resulting media mix features a combination of mass media (radio and television), interpersonal communications (use of influential community figures), music, theatre, posters, billboards, leaflets, T-shirts, badges and keyrings. In particular, interpersonal communications plays an important role in areas where hardly any mass media are available.

Among the mass media, radio was seen as having the broadest reach, although, as Julian Parr (BBC World Service Trust) pointed out, people only listen to what is local, in their language and has relevance to their lives. Given India's profusion of



Seeking ways to change mindsets

'SOCIALLY RESPONSIBLE' MEDIA

In December 2003, 80,000 copies of a booklet entitled *Together We Can Eliminate Leprosy* were distributed with *The Times of India* in Bihar and Jharkhand. In an area with a high rate of illiteracy, the idea was to target the educated decision-makers who form the paper's readership and who have an influence on society and a positive role to play.

Explains Gautam Chatterjee of Times Response, who worked closely on the project, "First you have to reach the reachable, and then, through them, those who are not easily reached."

Aimed at the lay person, the 16-

page booklet gives an overview of the leprosy situation at the global and national levels, contains messages from the chief ministers of Bihar and Jharkhand, and deals with both the medical and social aspects of the disease. It was produced in conjunction with the WHO, with technical input provided by the National Leprosy Eradication Program (NLEP).

Even among the educated, many



people do not have a clear understanding of the disease, says Chatterjee's colleague, Harnam Shankar. "The upper classes have a perception that leprosy only affects the ignorant, who need to be quarantined. We wanted to generate awareness among them, try and sensitize them, and so influence people down the line."

Although *TOI* was publishing something on leprosy for the first time, it has previously produced booklets on hepatitis B, polio and HIV/AIDS, and also compiled a directory of