

# Laying the Groundwork for Change

Socio-economic empowerment workshops serve as catalyst for action

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It was in 2005 that WHO Goodwill Ambassador Yohei Sasakawa suggested to IDEA India President Dr. P. K. Gopal that he conduct a survey of leprosy colonies in India. To date, the survey has yielded a list of about 700 colonies in different states.

This led to a chain of socio-economic empowerment workshops across India, attended by representatives of various colonies in each state. It was the first opportunity for persons affected by leprosy to meet their brothers and sisters. This motivated them to unite and coordinate their efforts to better the quality of their lives.

To borrow the words of Jawaharlal Nehru, India's first prime minister, it represented "an awakening," stimulating persons affected by leprosy to unite and fight for their human rights. Goodwill Ambassador Sasakawa addressed many such meetings.

In his speeches, Mr. Sasakawa always encouraged participants to develop a network and work together for their rights as citizens of the country. At each workshop, participants chose their own leaders, and nominated one from their number to be the state representative to the National Forum of People Affected by Leprosy, inaugurated last year as an all-India network.

The workshops proved an encouraging experience for all concerned as they spoke their mind about discrimination, the sad compulsion of begging, the lack of employment opportunities for the leprosy disabled and even their educated children, and government apathy in the face of demands for basic civic amenities.

In short, the workshops put the following points before society and the government.

1. Persons affected by leprosy should be brought under the wing of the Ministry of Social Justice and Empowerment at the central level as well as in all states, as they now need social and economic rehabilitation.
2. Persons affected by leprosy have been treated as social rejects (suffering more rejection than



Participants at recent SEE workshop in Raipur

scheduled castes, or SCs) from time immemorial, and so the constitutional provisions for SCs should be extended to them and their children (especially those living in leprosy colonies).

3. The social justice ministry should establish a special commission for persons affected by leprosy, to be headed by such a person.
4. The National Human Rights Commission of India should have a special unit for persons affected by leprosy at both central and state levels to deal with cases of human rights violations.
5. Persons affected by leprosy should not have to pay court fees when filing a case, at any level.
6. Of the 3% of jobs reserved for disabled persons, 1% should be reserved for persons affected by leprosy. Training centers for the disabled should admit persons affected by leprosy, too.
7. All families of persons affected by leprosy should be given Below Poverty Line (BPL) status automatically, and all provisions should be extended to them.
8. A uniform pension scheme for persons affected by leprosy should be declared nationwide by the central government (currently pensions vary from Rs. 200 in Bihar to Rs. 1,000 in Delhi) to check migration to greener pastures.
9. Persons affected by leprosy and their families, who are presently occupying governmental or semi-governmental land or housing, should be given title to it. In cases where eviction is unavoidable, they should be given alternative accommodation, free of charge.
10. The majority of persons affected by leprosy live in dilapidated housing. They should be given houses under an appropriate housing scheme, such as the Indira Awas Yojna, away from established colonies, if possible.
11. Under Sarva Shiksha Abhiyan, a program for the universalization of elementary education, the government should give directives to establish in each colony a school and a center for Integrated Child Development Services (ICDS).
12. There should be free education for children of persons affected by leprosy at all levels.
13. The majority of disabled persons affected by leprosy are now elderly. The social justice ministry should allot special funds for NGOs that are ready to establish old-age homes for them.
14. Municipal boards or corporations should provide urban-based leprosy colonies with all civic amenities, including electricity, water supply, roads and public toilets. ■