

Book Review

Social Science Research and Social Action for Better Leprosy Control

Editor: D H Srinivasan

This book is a record of an attempt made in India to help leprologists and social scientists work together to solve the extramedical problems of leprosy. Sponsored by the Indian Association of Leprologists, this workshop consisted of 30 Indian leprologists and social scientists from different disciplines and took place over 2 days in March 1991 at Karigiri, India.

While some leprologists think social science research 'a waste of time from a practical viewpoint', Dr Srinivasan in his introduction feels that co-operation between leprologists and social scientists can and must be established if we are to deal effectively with the problem of leprosy in all of its dimensions.

Papers presented included subjects like 'Problems of leprosy and leprosy control', 'Social sciences and social action for leprosy control', 'Self concept and coping with illness', 'Patient-health service contact in the context of NLEP', and 'Towards developing social action for comprehensive leprosy work in local community systems'. The report also includes background information on leprosy, a short introduction to the research methods and concerns of social scientists and a bibliography on social science research between 1979 and 1990 taken from 3 of the main leprosy journals.

Participants at the meeting concluded that many of the problems confronted by the National Leprosy Eradication Programme (NLEP) in India are because it operates on a 'biomedical' perception of leprosy, while society and patients have a 'biosocial' view of the disease. For these reasons health education, imposed from the top down on passive recipients, has not been successful in changing society's and patients' negative views of leprosy and persuading them to co-operate with professional staff in leprosy control programmes.

On the other hand, experiences in several Indian districts have shown that when patients and community members are involved by leprosy workers as equal participants in the process of identifying and solving leprosy-related problems, their views of the disease and their level of co-operation with the programme changes for the better.

Because of this positive experience in 'social action', the participants in the meeting urged that NLEP staff should be trained to promote similar community and patient involvement elsewhere in order to eradicate fear and a sense of despair, and to encourage voluntary reporting, prevention of deformities, rehabilitation and integration. Likewise, social scientists were encouraged to become involved in more practical 'action-research-action' schemes. Together with medical scientists, they would jointly define problems, design research programmes and carry them out as partners.

This report on the workshop is a timely one and helps to bring to the forefront a number of issues which are being thought about and acted on in many parts of the world: (1) leprosy is the cause of at least as many psychosocial problems as physical ones; (2) nonmedical problems are often more important to patients and to members of their communities than medical problems and certainly effect the success or failure of medical treatment; (3) to solve these nonmedical problems in a systematic way, we need the input, co-operation and leadership of others outside the medical field who are affected by or have experience in dealing with the problems we are facing. These are not

only the wide array of persons covered by the term 'social scientists' but also patients, family members, and the leaders of the medical and socioeconomic institutions whose support we need to solve our problems.

Perhaps the time has come to put as much effort into planning and implanting practical, efficient programmes on the social side of leprosy as on the medical side. The Indian workshop is certainly a sign that concern is growing that we need to do much more than we are now doing. It also provides some practical proposals for action.

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