

**WORKSHOP 10: SOCIAL ASPECTS**

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The Workshop, composed of social scientists, clinicians and leprosy programmers, deliberated on the comprehensive meaning of the social aspects of leprosy. After reviewing reports of earlier workshops on social aspects of leprosy and considering concurrent workshops on health education and rehabilitation at this Congress, the group identified the role of social sciences in leprosy as the focus of the Workshop.

The contribution of the social sciences extends to all aspects of leprosy control, including transmission, treatment, training, health services delivery, health education, and rehabilitation. The Workshop reaffirms that leprosy control also includes the prevention of associated deformities. For the purpose of leprosy control, the social sciences include disciplines of anthropology, economics, psychology, history, sociology, philosophy, linguistics, political science, and law.

**Policy statement.** The major social issues in the area of leprosy that need to be addressed and are of critical importance to policy planning are: a) acknowledging the fact that leprosy is as much a social problem as a medical one; b) viewing leprosy control to be a comprehensive activity that deals not only with the prevention and control of infection but also related to prevention and treatment of deformities and ulcers with a view to change the deformity image of the disease; c) aiding the psychological and socioeconomic rehabilitation of the leprosy patient in society; d) the establishment of integrated medical and social support systems; e) involvement and participation of

nonleprosy professionals and institutions in the provision of medical, social, and rehabilitation services for persons with leprosy; f) the fuller participation of the person with leprosy and paramedics in the development of control programs; g) the provision of humane care for persons with severe disabilities, in the institutions, away from the streets, to cut down the transmission of social prejudice against leprosy; h) the integration of the leprosy control program with primary health care, realizing the stigmatizing effect of a vertical program; i) increase the participation of social scientists in the planning and evaluation of leprosy programs; j) evaluation and collation of existing studies to provide a comprehensive data base for social scientists working in this area, with a view to improving the reliability and quality of data available to planners; k) dissemination of research results to generate greater awareness about utilization of social science research in leprosy control; l) better utilization of research ideas and findings in developing relevant training, educational and communication programs; and m) identification of lacunae in the information pertaining to the understanding of leprosy by the community and health services, and the types of studies that could supply such information.

**Research.** The Workshop reviewed the social science publications related to leprosy and noted the theoretical and methodological limitations of many of these studies. As a result, the research results have been of little practical significance. Furthermore, it was also noted that a majority of past re-

search on the social aspects of leprosy had not been conducted by trained social scientists.

The group strongly advocated a need for scientific rigor in terms of research design, methodology, data collection, and analysis of research data. This would result in increased scientific reliability and validity, thus facilitating effective use of research results in leprosy control.

The role of a multidisciplinary research team was emphasized. This team should include social science researchers and leprosy programmers at all levels from field leprosy workers to policy planners.

The dissemination of research results was identified as a critical issue. These issues need to be: a) clear, b) easily accessible, and c) translatable in order to be of value in leprosy control.

Research in other areas of health, disease, and illness is a valuable source from which social scientists in the field of leprosy could benefit. For example, extensive research on compliance-improving strategies to hypertension and diabetic regimens would be of importance. The group agreed on the need for detailed background papers from sources. These "state-of-the-art" papers would include an annotated bibliography and would form the basis of further leprosy-related scientific enquiries.

The group recommended that a centralized documentation center of social science and leprosy be established, preferably as part of the World Health Organization leprosy archives in Geneva.

**Research priorities.** The priorities of social science research on leprosy include: a) those having an immediate relevance to better leprosy control, e.g., improved patient treatment compliance; b) the differential impact of monotherapy and multidrug therapy (MDT) on the patient's, community's, and health worker's concept of cure; c) the study of social epidemiological factors related to the transmission of leprosy should be conducted by multidisciplinary teams of

social scientists, epidemiologists, and other researchers; d) the study of the social environment which creates fear because of the prevalence of ulcers and deformity, resulting in nonparticipation by the community in leprosy control programs; and e) the study of the concept of "a person with leprosy" in the historical context.

**Research areas.** Areas needing study include: a) health beliefs, behavior and practices of the community, health providers and patients; b) impact of MDT on the community and health services; c) impact of existing health systems (vertical and integrated) on the health functionaries and their relative efficiency; d) the diagnosis, treatment and rehabilitation problems of women; e) patient and family self-stigmatization and low self esteem; f) status of leprosy health personnel in the entire health care system; g) effective communication between health providers and patients; h) legislation regarding leprosy; i) cost effectiveness of various approaches in leprosy control programs; j) concept of "cure" among patients, community and health providers under monotherapy and MDT; k) semantic problems associated with various aspects of leprosy; and l) organizational structures of control programs in governmental and non-governmental sectors.

**Training.** The training for social scientists needs to include an orientation to the various problems of leprosy control. The group also emphasized the need for special training in social science research methodology for other leprosy workers who may form part of the multidisciplinary research team. Special funding should be made available for training to attract social scientists to the field.

**Conclusion.** Social science insights aim to provide scientific understanding of the process of change that is brought about in behavior, attitudes, and practices of various sectors of society toward leprosy, including the health services sector.