

# Leprosy and the Community

## WORKSHOP ON THE PROMOTION OF LEPROSY WORK IN INDIA, AUGUST 1975

Closer co-ordination between government and voluntary agencies in India in leprosy control has been encouraged through a Workshop convened by the National Institute of Public Cooperation and Child Development, with the cooperation of the National Leprosy Organization (India), the Hind Kusht Nivaran Sangh, The Leprosy Mission and the Gandhi Memorial Leprosy Foundation. The main objectives of the Workshop were to review the needs and programmes of government and voluntary agencies in India; discuss the role of government and voluntary agencies in this field; suggest ways and means of streamlining existing programmes; and evolve a strategy for maximal cooperation at all levels. Background and discussion papers were presented by experts in various aspects of the subject. The Report of the Workshop includes the following conclusions and recommendations.

1. There was a general appreciation of the efforts of the Government and Voluntary Organizations in the field of leprosy control. However, the Workshop took a serious view of the fact that so far only one third of the existing cases have been recorded for treatment and only about 50 per cent of the population in the endemic areas have been covered by the National Leprosy Control Programme. It recommended that in order to ensure effective interference with the transmission of infection, all the existing cases of leprosy should be brought under treatment, and the entire population in the hyper-endemic and moderately endemic areas should be covered by the programme as quickly as possible in order to ensure effective case detection in the early stages.

2. The Workshop recommended that the prevalence and incidence rates of leprosy should be studied through systematic surveys in both the covered and uncovered areas of the country. More precise knowledge about these rates is necessary to assess the need for the services in different regions and the impact of the programme in the areas covered by it.

3. Arrangements should be made for hospitalization of infectious, sulphone resistant and refractory cases in order to contain the disease. Adequate provision should be made for hospital beds and expansion of facilities like physiotherapy, reconstructive surgery and occupational therapy.

4. At present DDS is the sheet anchor in the treatment of leprosy. However, it has been found that some patients are developing DDS resistance and sensitivity to the drug. Therefore there is urgent need to provide alternative drugs and make them available at a reasonable cost in adequate quantity to ensure their regular supply.

5. As leprosy control services have to be provided on a very extensive scale, the

ultimate objective should be the integration of leprosy work with the general health services in the country. The existing institutional structure at different levels should be utilized for providing them in areas where they are needed.

6. At present the medical courses at graduate level do not impart sufficient knowledge about leprosy. This is responsible not only for relative ignorance of an average medical graduate about this disease but also his unwillingness to work in leprosy control programme or to handle leprosy patients in the general hospitals. The Workshop strongly recommended that the curricula of medical colleges should be suitably revised to impart adequate knowledge about leprosy to the students and interns to inculcate in them a positive attitude towards leprosy work. It was further recommended that facilities for training in reconstructive surgery, which is an attractive field of study, should be expanded in the medical colleges. This would ultimately strengthen the existing facilities for this specialized service in the hospitals and facilitate effective rehabilitation of leprosy patients.

7. While expanding the leprosy control programme it should be ensured that properly trained medical and para-medical workers in adequate numbers are available for running the programme. In fact, the training of workers should precede the opening of Leprosy Centres. Arrangements should also be made for the in-service training of the existing staff wherever necessary. The curricula for the training of para-medical workers should be suitably revised to include social welfare, health education and rehabilitation procedures. Refresher courses for existing leprosy workers and general health workers should be organized.

8. The Workshop recommended that the work of Leprosy Control Units should be adjudged on the basis of the following criteria: (i) Case detection by total population surveys every 3 years with at least 90% coverage; (ii) Not less than 80% of infectious cases brought under regular treatment; and (iii) Deformity index in newly detected cases should come down year by year and should not ideally be more than 5% of cases in 10 years.

9. The Workshop emphasized that in a comprehensive leprosy control programme, the measures which would help prevent the development of deformities should be given as much importance as the efforts to help the patients make the maximum use of their residual capacities to become useful members of the community. The former would ultimately make rehabilitation easier.

10. The leprosy patients have psychological resistance to rehabilitating themselves, and their own family members and the people in the community also do not accept them as normal human beings. These problems need to be tackled through programmes of individual counselling of the leprosy sufferers and education of the family members and the community in general. But the Workshop emphasized that any programme which helps leprosy patients become economically productive and independent is likely to be far more effective in their rehabilitation than efforts to change the attitudes alone. Therefore programmes of economic rehabilitation should be given due weightage.

11. The Workshop identified 2 distinct groups of leprosy sufferers from the point of view of their rehabilitation needs. The first group consists of those who can be helped to regain their capacity to do some productive work and can live with their families as earning members. They need vocational training and economic assistance to become independent. The other group consists of those for whom there is no hope to earn their own subsistence. They need a monthly allowance from an outside agency and therefore the Government should help

them with programmes of social assistance. The rehabilitation programmes should be so designed as to cater to the needs of both these groups.

12. The Workshop considered education of the community about the medical and social aspects of the problem of leprosy as one of the most important components of a sound programme for its control and rehabilitation. The masses need to be informed about the nature of the disease to remove the wide-spread ignorance, prejudices and fears about it. Suitable efforts in this direction would not only help prevent spread of infection but also facilitate the rehabilitation of leprosy patients. Scientific lessons about leprosy should be included in the school curriculum from the primary stages. In addition, the mass media like the newspapers, radio and TV should be fully utilized for disseminating scientific information about leprosy and making people aware about their responsibility towards leprosy patients.

13. The Workshop felt that it was neither possible nor desirable to draw a very rigid line between the responsibilities of voluntary organizations and Government in the field of leprosy control and rehabilitation. However, considering the strengths and limitations of these 2 agencies, it was recommended that the primary areas of government concern should be research, policy formulation, training, massive control programmes, financing and evaluation, and those of voluntary concern should be health education, public cooperation, dissemination of information on policies and programmes, welfare and rehabilitation of patients, etc. in addition to leprosy control work.

14. The discussion in the Workshop revealed many gaps in the information of representatives of voluntary organizations about the Schemes of the Central Government under which voluntary organizations can get financial assistance for extension of hospital facilities, purchase of equipment, rehabilitation programmes, etc. It was recommended that the concerned Departments at the Central and State levels should circulate their Schemes as widely as possible and evolve ways and means to ensure that the information reaches the organizations in time so that they can avail themselves of the assistance, and the funds provided in the budget do not lapse.

15. The Government Scheme for Leprosy Control Unit, SET Centres including the voluntary SET Scheme should have an element of flexibility so that they can be adapted to local conditions. It was specially stressed that if the norms given in the SET Scheme about the population to be served by a Centre are observed rigidly in tribal or hilly areas, which are sparsely populated, the very purpose of the Scheme is likely to get defeated. Therefore, the Workshop recommended the Government to make suitable modifications in the Scheme considering the special problems in hilly and tribal areas. Similarly, necessary flexibility should be introduced in the terms and conditions attached with various grant-in-aid Schemes.

16. The Workshop recommended that the State Governments should constitute Leprosy Advisory Committees on the lines of the Central Leprosy Advisory Committee which is already in existence. The Committee should consist of representatives of Government and voluntary organizations, leprologists and social workers. It should function as a forum for discussion on problems of leprosy control and rehabilitation, an instrument for coordination at the State level and an expert body to advise the Government. A sub-committee of this body should provide technical guidance to voluntary organizations in the State.

17. The Workshop recommended that there should be more active and

effective communication between the Centre, the State and the field agencies for better implementation of Control programme and optimum utilization of available resources. This should be followed up by frequent dialogues, regional meetings, State level conferences and visits by the representatives of the Centre to the States. The Workshop further felt that at the meetings of Central and State Ministers of Health, adequate time should be allowed for review of work done in the field of leprosy.

18. In order to cope with the rapid expansion of the Leprosy Control Programme, Leprosy Cells at the Centre, State and District levels should be adequately staffed and equipped in order to ensure effective programme management. More specifically, Leprosy Officers at Centre and States should be given adequate administrative support so as to enable them to discharge their supervisory and field monitoring responsibilities more effectively.

19. The Central Health Ministry may issue firm guidelines about the minimum qualifications and experience of Leprosy Control Work needed for the post of State Leprosy Officer and Para-Medical Supervisor.

20. In order to attract and retain qualified medical personnel in leprosy control work Government should offer adequate incentives in terms of special remuneration and facilities, as well as priority in selection for Post-graduate courses to Medical Officers engaged in leprosy work.

21. The Workshop considered the need to bring about greater coordination among Voluntary Agencies functioning in the field of Leprosy Control Work. This is specially necessary in order to organize mutual aid and assistance through agencies best suited to provide specific types of help needed.

The Workshop, therefore, recommended that Hind Kusht Nivaran Sangh national headquarters should take the lead in providing coordination and serve as the Central coordinating agency, without merging the independent identity of cooperating organizations.