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COMMUNITY PARTICIPATION AND SOCIAL ASPECTS

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Leprosy control is probably unique among the disease control programmes from the point of view of the size of social and behavioural problems which it encounters for its implementation.

The main problem is historical and finds root in the distant past when the diagnosis of the disease meant social rejection, isolation, loss of status and of economic resources in addition to crippling complications, disfiguration and disability.

Up to a very recent past therapy and rehabilitation were not possible and an irrevocable prognosis of continuous deterioration was the rule.

In many cases and in many countries this situation has not substantially changed. The stigma of the disease is therefore still very strong and involves the communities and, to a much larger extent than expected, the medical profession itself. It is, in fact, very true that the main obstacle to an effective leprosy control programme is the limited knowledge of the disease as well as the substantial prejudices among the medical profession itself. The reluctance to abolish forcible isolation of the leprosy patients often stems from responsible medical authorities.

Such limited knowledge of the disease and the ensuing prejudices are obviously more evident among the communities. Such situation is more acute the lower the general educational level of the communities, and often is reinforced by traditional beliefs and practices. Studies on the nature and reasons for prejudice have not been systematically carried out and this renders more difficult to implement a strategy of behavioural change in the communities.

The objectives of the behavioural change desired can tentatively be defined as follows:

<u>Subject</u>	<u>Problem</u>	<u>Objective</u>
Patient	lack of awareness of disease	* obtain awareness
	fear of the disease	* reduce fear
	lack of confidence in therapy	* induce confidence
	refusal of examination	* acceptance of examination
	refusal of drugs	* acceptance of treatment
	irregularity of drug taking	** defaulters retrieval
	fear of isolation	** abolish isolation
	economic loss	**** rehabilitation - economic measures for social integrati
Community	rejection of lep. patients	* acceptance
	refusal of examination	* induce acceptance
	ignorance of the disease	* improve knowledge
	ignorance of the therapy	* health education
	lack of participation and cooperation	**** incentives and demonstrations
Medical Profession	ignorance of epidemiology of leprosy	*** continuing medical education
	ignorance of therapy	*** refresher courses
	fear of infection	*** induce confidence

NOTES.

- * Health education of the public
- ** Epidemiological surveillance
- *** Professional educational meetings
- **** Social work

It may be assumed that patient cooperation as well as community participation can be influenced to a certain extent through a sustained effort towards health education. It should be noted that the basis for an effective health education effort is still lacking and more intensive studies of all social and behavioural aspects have to be implemented. Results therefore may be more difficult to obtain than one would expect.

The abolition of isolation, the establishment of peripheral primary health care drug delivery systems, measures to develop the economically backward communities and the demonstration of the efficacy of the combined therapy may be of great help in inducing confidence in the programme and on the proposed strategies.

The community participation should manifest itself by voluntary submission to clinical examination as evidenced by the more frequent diagnosis of early signs of the disease, increased referral of suspected cases and lack of rejection of diagnosed cases.

With the introduction of the combined therapy of leprosy, the community participation becomes an essential element of the revised strategy as it aims at improving acceptance of case detection, early diagnosis and regular administration of the drugs.

While no forecasts can be made on the extent of community participation to the revised strategy for control, it may be appropriate to establish indicators of community participation to evaluate the efficacy of the educational measures taken.