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PROMOTION OF COMMUNITY PARTICIPATION;  
THE ROLE OF NON-GOVERNMENTAL AGENCIES

by

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In the last few decades, considerable success has been achieved by many advanced and prosperous countries in containing the monster of tuberculosis. This led the late Dr Harley-Williams to write his "Requiem for a Great Killer". But alas for the less fortunate developing countries, the "Great Killer" is still very much alive.

The havoc and misery this killer causes has roused the conscience of leaders of communities in practically every country. It has brought the realisation that something must be done if this senseless loss of life and enormous socio-economic distress and drain is to stop. This realisation led to the formation of tuberculosis associations everywhere.

The immediate aims of these voluntary tuberculosis associations are (1) to educate, mobilize and stir public opinion and create consciousness among the community of the danger of tuberculosis and (2) to impress upon governments and official agencies that, unlike other health problems, tuberculosis needs special measures for its control, a special structure of basic health services, a planned control programme and a good deal more money than is usually allocated to it.

As time and experience advanced, new concepts and new techniques have been adopted for the control of tuberculosis in developing countries. This is largely due to the pooling of knowledge, experience and research by WHO and the International Union against Tuberculosis.

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It is now recognized that in order to control tuberculosis, a definite, integrated and far-reaching plan has to be prepared taking into account the epidemiology of the disease and the circumstances prevailing in any particular country. It is also accepted that in such a control plan, non-governmental agencies have an important and distinctive part to play. Their voluntary character enables them to perform certain duties and functions which, if undertaken by governments, would be regarded as suspect. Non-governmental agencies can thus take up a number of activities to supplement the measures undertaken by governments. Indeed the nature of the disease is such that the active collaboration of the community becomes necessary at practically every stage of a control programme.

The prevention and control of tuberculosis is undoubtedly the responsibility of governments. This responsibility cannot be discharged without the active support and co-operation of the community. It is therefore necessary for tuberculosis associations to maintain close contacts with government authorities at all levels.

Dealing with the specific tasks that tuberculosis associations can perform, these can be classified under the following categories.

#### Health education

For the promotion of health generally, a background of health education is regarded as a necessity. In developing countries, where the proportion of illiteracy is high, this becomes a dire necessity. This is an area in which tuberculosis associations can do a great deal of useful work. Health education with particular reference to tuberculosis serves the dual purpose of helping to prevent disease and creating an awareness of the problems posed by tuberculosis. It mobilizes public opinion in favour of anti-tuberculosis measures.

Health education is closely connected with publicity. The organization of both these activities requires talent of a high order. It is therefore suggested that:

1. Tuberculosis associations should form two separate committees at the national level, one for health education and the other for publicity. These committees should be composed of experts — health educators and publicity men — and should be responsible for the creation and production of all health education and publicity material. These committees should keep in touch with available forms of information media - press, radio, television, films - obtain editorial comments, arrange frequent appearances on radio and television, produce and exhibit suitable films on tuberculosis. Centralizing these activities will ensure uniformity of approach to each problem and eliminate confused and contrary thinking.

2. Tuberculosis associations should employ fully-trained and properly paid full-time health educators at the district level in order to cover both urban and rural areas in their districts. They should be amply supplied with material produced by the health education and publicity committees and should be equipped with slide and film projectors to give visual education in schools, colleges and other groups in cities and particularly in villages. These health educators should co-ordinate their activities with other official and non-official agencies to avoid duplication and overlapping.

#### Prevention

It is important to make the utmost use of the most potent weapon against tuberculosis — BCG vaccination. The success of a BCG campaign depends on the whole-hearted co-operation of the community. Ground for acceptance of BCG vaccination has to be prepared both in urban and rural areas by tuberculosis associations. While massive health education and publicity campaigns will form a background, certain specific measures must be taken.

1. Voluntary workers should be sent in advance to areas to be covered by BCG teams. These workers should contact leaders of the community and village elders in those areas to obtain their co-operation.
2. At least two volunteer workers should be attached to each BCG team to facilitate their work and act as liaison men between them and the people to be vaccinated. The target for each BCG team should be 100 per cent vaccination of all eligible members of the population. This is not impossible to achieve if full co-operation of the community is forthcoming.

#### Treatment organization

Ambulatory chemotherapy is now accepted as the best method for treatment of tuberculosis in developing countries. Its success depends, among other factors, on the duration of

treatment and the regular ingestion of drugs by the patient. This needs careful supervision and follow-up. Tuberculosis associations can play a vital role here by providing auxiliary health visitors to help in checking and following up patients defaulting in treatment. These health visitors can at the same time bring to treatment centres the patients' relatives and close contacts for examination and other suspicious cases for assessment. These services should be organized by the tuberculosis associations both at urban and rural centres by employing paid workers to be attached to all treatment centres. The money and effort spent in ambulatory treatment will be utterly wasted unless it is ensured that the patient is taking his treatment for the required duration and is having the drugs regularly as prescribed.

#### Rehabilitation

To assist cured tuberculosis patients to return to their normal or near-normal life in a state of usefulness is the aim of rehabilitation. Rehabilitation of the tuberculosis patient should begin from the time he is diagnosed. He should be made to understand that, because of the length of his treatment, he may not be able to return to his former employment and his productivity is likely to diminish. He should be taught simple skills requiring little exertion as early as possible so that when he is cured or becomes non-infectious, he should be able to earn a living. For this purpose, sheltered workshops on the lines of cottage industries and according to the requirements of each area should be set up in many parts of each country. Help from government and private industry should be sought in setting up these workshops.

Tuberculosis associations should also be able to negotiate with governments and with private industrial and commercial concerns that a certain percentage of the jobs available with them should be reserved for non-infectious tuberculosis patients.

#### Isolation homes

In practically every district of a developing country will be found innumerable chronic, incurable and highly infectious cases. To leave them unattended is to increase the pool of infection.

Although in many countries, it is the statutory duty of municipal bodies to isolate all infectious cases, this duty is more often than not ignored in the case of tuberculous patients.

This state of affairs calls for urgent action on the part of tuberculosis associations. They should see to it that wherever it is obligatory on the municipal bodies to isolate infectious cases, the obligation is honoured. Where no such obligation exists, steps should be taken to make it obligatory.

Isolation homes should be run as economically as possible. The cost should be borne by local and municipal bodies. The associations could help by getting donations from the community.

#### Legal enactments

It should be recognized that governmental action in a democracy does not precede public opinion. It is therefore the function of tuberculosis associations to rouse public opinion and create an atmosphere of acceptance among the people before legal enactments are made.

No gigantic public-action programme can be expected to become on-going and complete within the time limits imposed, without the enforcement of some legal enactments. The tuberculosis control programme is no exception. The following legal enactments are suggested:

1. Tuberculosis must be made a notifiable disease. Local bodies must assume certain responsibilities for providing diagnostic treatment and isolation facilities within the frame-work of the control plan.
2. BCG vaccination for all eligible members of the population must be made compulsory.
3. Full treatment facilities shall be given free of charge to all tuberculous patients by official treatment centres.
4. All employing agencies such as government, industry and business shall give 4 per cent of their jobs to cured tuberculous patients who have been declared fit for work by the district tuberculosis officer.
5. Any person contracting tuberculosis while in service shall get from his employer leave for one year on full salary.
6. A special tax called TB Tax shall be levied.

These and other suitable legal enactments will help to speed up the control programme. The TB Tax will bring in the much needed finance required for the implementation of the programme.

### Conferences and seminars

Conferences and seminars held from time to time are a most valuable means of imparting information on the latest researches in treatment techniques and on socio-medical aspects of tuberculosis. They provide an opportunity to physicians and surgeons specialising in tuberculosis, socio-medical and social workers to get together to exchange information and ideas, discuss common problems and evolve new and better methods in fighting tuberculosis. Conferences generate enthusiasm and confidence and a determination to continue the fight with greater vigour. Their value cannot be over-estimated.

It is suggested that tuberculosis associations should organize at least one local conference every year for the benefit of everyone, including the government, participating in tuberculosis programmes to review the progress made during the year, to rectify any mistakes or omissions and to plan new measures that may be necessary. A seminar should be organized every second year dealing with the scientific aspects of the problem, researches in new treatment techniques, evaluation of new drugs, epidemiological changes, surveys and evaluation of BCG campaigns, etc. etc. Experts from other countries should be invited to these seminars.

From the foregoing, it is obvious that in the tuberculosis control programme the community can participate effectively in so many different ways and that its participation is essential for the speedy attainment of the objectives of the control programme.

Here a note of caution is necessary. Community participation to be effective has to be intelligent and well-informed. The anti-tuberculosis movement has now reached a stage where a greater knowledge of the problems posed by tuberculosis and of the measures adopted for its control is necessary on the part of tuberculosis associations and their workers. Social service in the field of tuberculosis is no longer a matter for the amateur. It is a highly specialized activity.

It is suggested that responsible officers and workers in tuberculosis associations should make a careful and thorough study of the problems of tuberculosis control. For their voluntary and paid field workers, they should organize courses of short duration every year to reorient them and instruct them in their duties. Only then will tuberculosis associations be able to make a meaningful and significant contribution to the control of tuberculosis in their respective countries.