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Editorial

VOLUNTARY AGENCIES AND LEPROSY CONTROL IN INDIA

Introduction

Health is essentially a matter for the individual. No health service, however wide and efficient, can keep a country healthy unless its people are conscious about their health needs. This underlines the basis for community participation in health programmes, particularly in the eradication of leprosy.

The past decade has witnessed a great expansion in the facilities for leprosy control in India, but in spite of a more than 14-fold increase in expenditure on leprosy eradication, since the inception of the National Leprosy Control Programme (NLCP), it has not been possible to make an impact on disease incidence.[1] The rapid increase in infrastructural facilities has not been commensurate with the utilization of services by the large masses of suffering people. Lately, the importance of initiating a qualitative change in the NLCP, by generating mass participation of the professional people as well as the rural population, through involvement of voluntary organizations (VOs), has been recognized as a national policy.[2] The present paper briefly traces the growth of voluntary leprosy control agencies in India, delineates their contribution to its control and outlines their expected role in its eradication.

Development of voluntary organizations in leprosy

Voluntary organizations have been playing a pioneering role throughout the history of leprosy control in the country. The first known leper asylum was established in Calcutta early in the nineteenth century followed by another in Varanasi. Mission to Lepers, started in 1875 at Chamba, had been by far the biggest single agency engaged in any leprosy work. The establishment of Indian Council of the British Empire Leprosy Relief Association in 1925, renamed as 'Hind Kust Nivaran Sangh' in 1947, laid down the foundations of organized leprosy work in India.

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The first organized efforts for leprosy control in the non-governmental sector were initiated in 1951 in the form of services through outpatient clinics in villages by the Gandhi Memorial Leprosy Foundation, Sevagram, funded by the Gandhi Memorial Trust. This was also the period when dapsone was introduced, for the first time, in the control of leprosy. Thus, the strategies of leprosy control in the country were laid down, with the focus changing from the patient in the control area to the entire population. Intensive health education campaigns and house visits, to firstly identify leprosy patients and secondly bring them under treatment, characterized the strategy of the Gandhi Memorial Leprosy Foundation.

After 1951, there occurred an extensive expansion in voluntary services for leprosy patients all over the country. Presently about 100 VOs are actively engaged in leprosy relief.

International agencies have also contributed significantly to strengthen voluntary efforts for leprosy control in India. From a small beginning in 1894 in Ambala, the Leprosy Mission has developed into a widespread organization. It operates 32 centres of its own besides providing aid to 42 hospitals devoted to leprosy care programmes.[3]

The German Leprosy Relief Association joined India's fight against leprosy in 1957 by starting Chettipatty Leprosy Relief Rural Centre in Tamil Nadu. The Damien Foundation, Brussels, was the first purely voluntary agency to enter into an agreement with the Government of India to function in co-ordination with the national control programme. The International Federation of Anti-Leprosy Associations (ILEP), undertakes to support field as well as research projects of a wide international network of member associations. In India alone, it was financing 172 projects, in 1984, through the agency of 14 member associations.

With a view to providing a common platform for voluntary institutions to discuss their problems, share experience and mobilize public participation for promoting voluntary effort, a federating body, in the form of the National Leprosy Organization (NLO) India, formed in 1965.

Role

Significant as the services of VOs are in leprosy relief, their capacity to organize social measures to alleviate human suffering, and their sensitivity and responsiveness to the needs of the people, render them just as suitable for supplementing governmental effort towards leprosy control in the fields of rehabilitation, health education and enlisting community support.

Rehabilitation in leprosy must be total. In addition to measures designed for restoring the physically handicapped, it should aim at relieving financial distress caused by the incapacitating effects of the disease and establishing programmes for economic self-reliance. Many social workers have experienced that the

formation of a nucleus for cooperative development with active involvement of patients as beneficiaries, can ensure a higher degree of economic success than bureaucratic governmental schemes. In the light of this, a cooperative sector with community resources can be visualized as a self-sustaining leprosy care system.

An inescapable necessity for promoting economic well-being will be to restore disrupted social relationships of leprosy patients. The social distance expressed as exclusion from community gatherings, both religious and ceremonial, can be effectively eradicated only through the creation of a suitable environment divested of ignorance, superstition and prejudice against the disease. Experience in providing services under the NLEP has revealed that baseless fear acts as a great deterrent in organizing rehabilitative services. The situation is further aggravated by a close relationship of the disease to poverty, overcrowding and insanitary conditions.

While recently new drugs have radically altered attitudes of many people towards leprosy, these must be reinforced through persistent and sustained health education campaigns. Since the government have the exclusive use of mass publicity and educational agencies such as the radio and the TV, the non-governmental organizations can supplement this effort by judicious use of press, group and individual education. The ultimate aim would be to explain to the people the true nature of leprosy in order to create confidence and build a rational attitude towards its sufferers.

Contributions

The VOs engaged in leprosy have their own specific objectives functioning mainly at the community level. In recognition of the great potential of these institutions, the Directorate General of Health Services, Government of India, has evolved a mechanism for annual meetings with them with a view to establishing communication and an exchanging of information, and also to understand the nature of their work.

Information supplied by 88 VOs operating in leprosy control in India revealed that they provided services to a population of 590·00 lakhs spread over areas with great variation in the leprosy prevalence rate (1·1–32·0 per 1000). They were all geared to control activities through survey, education and treatment. Up to March 1986 a total of 8·40 lakh patients had been detected; of which 6·88 lakh were under treatment by 82 participating VOs in SET activities.[4]

Most of the VOs are multifunctional in nature, rendering curative as well as rehabilitative services, besides organizing the training of medical and health auxilliaries. With a bed strength of 19,000 in 1985 in 70 VOs, these institutions had rehabilitated about 36,000 physically handicapped patients in addition to providing vocational training to another 21,782.[5]

An idea of the contribution made by voluntary organizations can be obtained

Table 1. Leprosy services being provided by government and voluntary sectors as on 1.9.1986.

Activity	Voluntary sector	Government sector	Total
1 Population covered	59·00	400·00	459·00
(in millions)	(11)	(89)	(100)
2 Leprosy cases on record			
(in millions)	0·84	2·50	3·34
3 Leprosy cases under treatment			
(in millions)	0·68	2·38	3·06
4 Leprosy cases discharged	0·18	2·22	2·40
after cure	(4)	(96)	(100)
5 Rehabilitation of leprosy cases			
Medical	36,000	8,000	44,000
Vocational	21,782	7,000	28,782
6 Training			
(a) No. of training centres	12	32	44
(b) Annual training capacity			
Medical Officers	121	119	240
	(50)	(50)	(100)
Paramedical staff	575	1765	2340
	(25)	(75)	(100)
(c) No. trained so far			
Medical officers	1978	2529	4507
	(50)	(50)	(100)
Paramedical staff	7225	22,326	29,551
	(20)	(80)	(100)
7 Annual budget (Rs. in	180·00	420·00	600·00
millions)	(26)	(74)	(100)

Figures in parenthesis represent percentages.

from Table 1 which compares their services with those provided by the National Leprosy Eradication Programme.

Recognizing the wealth of expertise in the voluntary organizations and their contributions towards leprosy control, the Government of India introduced a scheme of financial assistance to these agencies in the form of grants-in-aid. The scheme envisages that the interested voluntary organizations would approach the Ministry of Health for grants as governed by conditions laid down. The number of voluntary organizations availing the grants-in-aid during the past 5 years is shown in Table 2.[6]

Starting as a scheme of financial assistance, the government's partnership with VOs has steadily grown over the years. Voluntary activities now converge,

Table 2.

Year	No. of VOs	Amount (Rs. in millions)
1980–81	32	3·1
1981–82	39	3·5
1982–83	44	3·1
1983–84	44	3·5
1984–85	49	5·1
1985–86	56	5·5

by and large, on NLEP goals. As requested by them, their performance was subjected to an independent evaluation along with that of the National Leprosy Eradication Programme in 1986 and their expertise was also made use of during this evaluation. The quality of work carried out at these institutions was found to be very satisfactory, as assessed by the members of the Evaluation Team visiting eleven of the VOs in randomly selected districts.[7]

Some of the voluntary organizations have developed material to aid in training medical and paramedical staff working for leprosy eradication, while others have developed prototypes of educational material for public and leprosy patients.

Of the 44 leprosy training centres undertaking training of medical and paramedical staff in the programme, twelve function under the VOs; their output thus far being 1978 medical workers and 7225 trained paramedical workers. Acting as referral centres some of these institutions provide services in: confirmation of diagnosis; guiding the treatment in such cases that fail to respond to prescribed treatment; managing complications and reactions; undertaking surgical correction of deformed patients; and providing vocational training to the disabled.

Fifteen highly endemic districts with a population of 44 million and an estimated caseload of 0·6 million are under varied phases of multidrug therapy (MDT). The activities in one of the above districts are under a voluntary organization. MDT guidelines developed by the government in consultation with the voluntary organizations is followed by voluntary organizations as well.

The voluntary organizations have been advised by the Leprosy Eradication Programme Headquarters to initiate multidrug therapy to the hospitalized cases who could be given regular treatment for the prescribed duration. The voluntary organizations are also identifying together with the programme personnel to detect dapsone refractory cases and putting them under multidrug treatment.

NLEP has an extensive network of services provided by the government. These inputs need to be converted into desired outputs in terms of quantitative

targets by involvement of VOs and through people's participation. While most VOs do work within the overall objectives of the NLEP, creation of specific roles with a view to supplementing each other's efforts will make the programme much more purposeful. The professional associations can mobilize a vast medical and auxiliary manpower to provide the necessary technical support. Unfortunately at the present moment, there is no standing mechanism for interaction between the government and non-governmental agencies. The two meetings of VOs organized by the Ministry of Health in October 1985 and October 1986 were steps in the right direction. But this partnership needs strengthening and put on a far more permanent basis.

Following the announcement of the Government of India to eradicate leprosy by the turn of the century, there has been widespread international interest in the National Leprosy Eradication Programme. Bilateral agencies like SIDA, DANIDA have come forward with financial support and cooperation. In addition, the already existing international organizations provide substantial financial, material and technical support. Thus, the resources of several agencies converge on the single focus of leprosy eradication. It must be ensured that these efforts become mutually supportive with a clear understanding and appreciation of each other's role. It can be facilitated by establishing a consortium or other similar mechanisms to develop linkages between various agencies at the national and state levels. Such a mechanism will ensure imaginative utilization of all existing facilities, exploitation of total professional and para-professional manpower both under the health services and the non-governmental bodies towards the goal of leprosy control.

In conclusion, it may be stated that the voluntary organizations and the NLEP are working in close cooperation with mutual trust and understanding. The government is keen in strengthening this relationship further to achieve the desired long-term goal of arresting leprosy in all cases in the country.

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