ROLE OF VOLUNTARY ORGANIZATIONS IN REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAMME (RNTCP) IN DELHI

Dissertation submitted to Jawaharlal Nehru University in partial fulfillment of the requirement for the award of the Degree of

MASTER OF PHILOSOPHY

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2010

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Date: July 21th, 2010

CERTIFICATE

This dissertation entitled, "***Role of Voluntary Organizations in Revised National Tuberculosis Control Programme (RNTCP) in Delhi***" is submitted in partial fulfillment of the requirements for the award of the degree of Master of Philosophy, of Jawaharlal Nehru University. This dissertation has not been submitted for any other degree of this university or any other university and is my original work.

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To my Dearest

Mummy and Papa

Acknowledgement

At the onset, I would like to thank my Supervisor *Dr. Rajib Dasgupta* for his guidance and help that was instrumental in developing a framework for this dissertation. Without his support it would have been difficult to organize my scattered thoughts and materialize this dissertation into reality.

I would also like to take this opportunity to extend a warm and heart felt thanks to our chairperson, *Prof. Rama Baru* and all the faculty members who directly and indirectly shaped my understanding about public health. A special note of thanks to centre for allowing us to use the classroom in the night which helped us to finish our work on time.

My special thanks go to all the respondents from various organizations, who helped me to complete the dissertation. Without your kind cooperation it would have been impossible to finish this work within a short period.

I also wish to thank *Dinesh* and *Ganga* for all their help in the documentation centre as well as all office staff of CSMCH for always assisting in whatever way possible, always with smile. I would also like to thank JNU library and VHAI staff for the help with materials.

I thank, *Kaushik, Smitha* and *Rohini* for their continuous support in the night during the dissertation writing. My other friends *Cherry, Rupa, Kanhayia, Swalih, Ramaya, Philangum, Jacob, Sabina, Dr. Kamlesh, Dr. Anuradha, Dr. Soa and Dr. Atanu* also deserve special thanks for their support especially during the first two semesters for the happy times spend in the campus. Apart from that I would also like to thank to my all other friends *Deepak, Dinesh, Shashwath and others* for their friendship and constant encouragement.

A special word of appreciation is due to my editors *Dr.Munish, Atreyee, Lakshmi, Reshma, Susrita,* and *Ranveer* for giving their invaluable time as suggesting various inputs to the work. I would also like to thank to my all seniors and juniors for their constant support.

Above all, words are inadequate to express my feelings towards my parents, uncle, and aunty who have been instrumental in providing encouragement for this piece of work. Love to my sisters and brothers for their love and encouragement.

Anil Kumar Gupta

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List of Abbreviations

ACSM	Advocacy, Communication and Social Mobilization
AIDS	Acquired Immunodeficiency Syndrome
ARI	Annual Risk of Infection
ARTI	Annual Risk of Tuberculosis Infection
ART	Antiretroviral Therapy
BCG	Bacilli Calmette - Gurin
CTBC	Community-Based TB Care
C and DST	Culture and Drug Susceptibility Testing
CP	Continuous Phases
CSWB	Central Social Welfare Board
DFIT	Demine Foundation India Trust
DMC	Designated Microscopy Center
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment Short Course
DTP	District Tuberculosis Program
CSWB	Central Social Welfare Board
DFIT	Demine Foundation India Trust
EPI	Expanded Program of Immunization
HIV	Human Immunodeficiency
ICMR	Indian Council of Medical Research
ICSSR	Indian Council of Social Science and Research
ICORCI	Institute of Communication, Operation Research and Community Involvement
IEC	Information, Education, Communication
IP	Intensive Phase
IUAT	International Union against Tuberculosis
KAP	knowledge, attitudes and practice
LT	Lab Technician
MDG	Millennium Development Goal
MDR	Multidrug Resistance
MDR-TB	Multidrug-Resistant Tuberculosis

MoU	Memorandum of Understanding
MO	Medical Officer
MoHFW	Ministry of Health and Family Welfare
NGO	Non-Governmental Organization
NHP	National Health Policy
NRL	National Reference Laboratory
NTP	National Tuberculosis Control Programme
NSP	New Sputum Positive
NSS	National Sample Survey
NTI	National Tuberculosis Institute
PPM	Public–Private Mix
PPP	Public–Private Partnerships
PPs	Private Practitioners
SCC	Short-Course Chemotherapy
SRL	Supranational Reference Laboratory
STO	State TB officer
TB	Tuberculosis
VOs	Voluntary organizations
W H O	World Health Organization
XDR	Extensively Drug Resistant

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CHAPTER - 1

CONCEPTUAL AND METHODOLOGICAL FRAMEWORK OF THE STUDY

1.1- Introduction

Tuberculosis (TB) has been recognized and continues to be a major public health problem globally. It is a very old disease which has probably been known since the Stone Age. Traces of tuberculosis lesions have been found in the lungs of 3000 years old Egyptian mummies.[1] It has always been one of the major killer diseases all over world especially during the 19th century. During this period tuberculosis contributed to large number of deaths in the Western parts of the world experiencing industrialization. However, very little was known about the diagnosis, course of disease, its causes and treatment. This disease had no universal name due to lack of understanding about it. It was referred to by various names such as phthisis, consumption, scrofula, asthenia, tabes, bronchitis, hectic fever, gastric fever and lupus and many more. Johann Schonlein pioneered the use of taxonomy 'tuberculosis' in 1839.[2] During that period there were no proper regimes or measures to treat tuberculosis.

In India, first open air sanatorium was established in 1906 to treat tuberculosis patients.[3] It was the earliest phase of institutional management of tuberculosis. The basic purpose to establish the sanatorium was to isolate the patients in order to control the transmission of the infection. Until 1912 tuberculosis was never given a priority. It was only in 1912 that the Government of India appointed a committee under Dr. A. Lankaster to undertake an in-depth assessment of the situation and realize the enormity of the problem.[4] Due to the absence of effective treatment for TB, the government's efforts at combating the disease were at best half-hearted. However this era saw active presence and role of Voluntary

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[1]Tuberculosis Association of India, (2001), 'General Information on Tuberculosis: Discovery of Tuberculosis', 52nd TB Seal Campaign.

[2]ibid

[3] Singh, M.M. (2007), Tuberculosis Association of India, Role in TB Control (2007), 58th TB Seal Campaign.

[4] ibid

Organizations (VOs) and philanthropic societies in addressing the issues of tuberculosis holistically. [5]

Tuberculosis has always been a 'killer diseases' in India and still continues to be a major public health problem. It is a major cause of morbidity and mortality with an estimated one third of world's population being infected with TB. In 2006, nearly 9.2 million new cases and 1.7 million deaths were reported due to TB. India accounts for one fifth of the global incidence. Nearly 40 percent of the Indian population is infected with the TB bacillus. Each year around 1.9 million new cases of TB occur in the country, of which about 0.8 million are infectious new smear positive pulmonary TB cases. A nation wide study on Annual Risk of TB Infection (ARTI) conducted in 2002-2003 which estimated that in India ARTI is 15 percent i.e. 75 new smear positive pulmonary TB cases are expected per 10,000 populations annually. Every day more than 5000 population develop TB disease and nearly 1000 people die of TB meaning 2 deaths every 3 minutes.[6]

Multi Drug Resistance (MDR) and Extensively Drug Resistant (XDR) tuberculosis has lead to increasing the complexity of effective treatment of tuberculosis. By several small studies, it is estimated that the prevalence of MDR-TB in the country is at around 3 percent among new cases and 12 percent among treated case and the prevalence of primary tubercular infection in children is also very high, nearly 3.4 million children are suffering from TB and another 94 million are at risk.[7]

The disease also causes severe socio economic stress on the ailing population. The economically weaker sections of the society and the individual during their youth are often affected by TB increasing their vulnerability manifold.

Individuals that are most hard hit by this disease fall into the age group of 15 to 54 years which accounts for the period wherein they are most productive. Gender disparity is also seen as the disease affects a larger proportion of females in

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[5] Singh, M.M. (2007),*op cit*

[6]Government of India (2009), *'TB India - 2009: RNTCP Status Report'*, New Delhi: Ministry of Health and Family Welfare.

[7] Varinder, S (1995), LRS institute of TB and Allied Disease, New Delhi, HFM, Jan-Feb 1995, p.27

comparison to males, with 50percentof females being affected before they reach the age of 34 years.

In India the economic burden induced by TB can be accounted to mortality due to TB than morbidity. According to RNTCP study in 2009, the finding shows that on an average each TB case incurs an economic burden of around US$ 12,235 and a health burden of around 4.1 DALYs. At the same time in case of India the average burden has been approximated to US$ 67,305 and around 21.3 DALYs. There have been several studies conducted to estimate the extent of economic loss caused due to TB. Many such studies reveals that TB has lead to creation of debt trap due to average loss of potential earning of approximately 20-30 percent of the annual household income along with three to four months of loss in productive work time. India accounts for an approximate loss of $23.7 billion annually in the form of direct and indirect costs.[8]

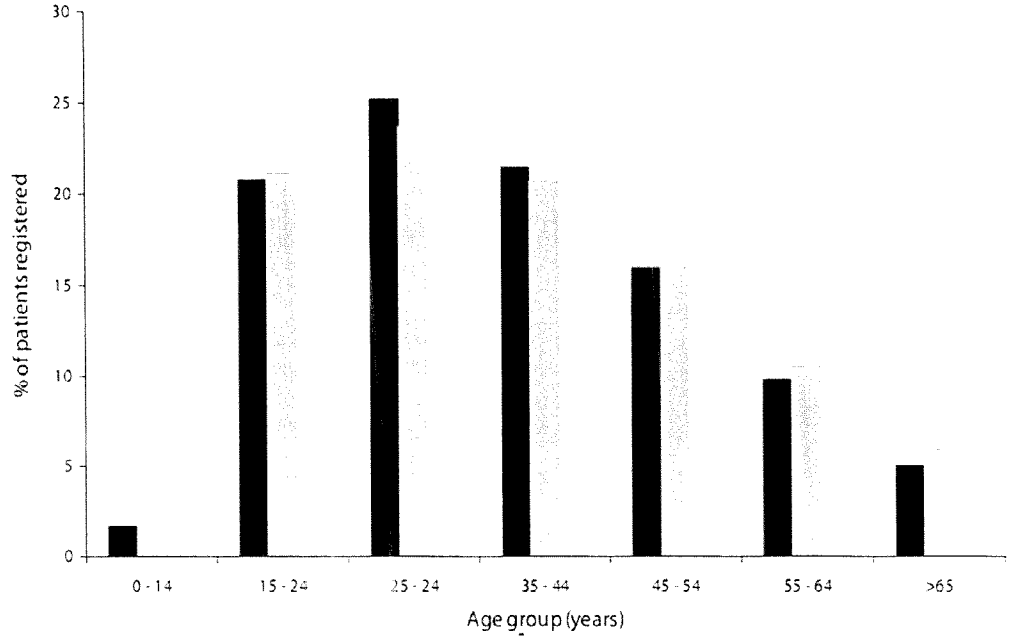

Figure: 1 Year wise, Age wise comparative distribution of NSP cases

(Source: TB India 2010: RNTCP Status Report)

[8] Government of India, (2010), '*TB India - 2010: RNTCP Status Report*' New Delhi: Ministry of Health and Family Welfare.

The situation is really complex in India because TB excessively affects the young men and women in their prime years and ultimately leading them to a slow and destructive death. As figure one reveals, the number of NSP case notification is maximum in the productive age group of 15- 44 years.

To combat tuberculosis, Government of India launched the National Tuberculosis Control Programme (NTP) in 1962. The framework of the programme was well designed to address the problem in a holistic manner. The treatment was also designed, keeping in the mind people's perception, needs and context. Despite its sound design; the performance of the NTP of India has been poor. The literature revels that there were different reason such as improper implementation and service delivery, inadequate funding at the central and state level, managerial weakness, unreliable diagnostic tool, poor administration and lack of systematic information and recording[9] recognized by the different scholars and workers in the field of tuberculosis for the failure of the NTP. The programme review also showed that only 30 percent of patients were diagnosed and, of these, only 30 percent were successfully treated.[10]

In addition to these factors, literature also cited that a large number of tuberculosis patients approached VOs and PPs for treatment where commonly incorrect regimen was administered on them.[11] Private health service provider/ agencies were not following the standard regime because of their isolation from the programme. There were no organized efforts to involve these sectors in the NTP. The participation of VOs was restricted to grant-in-aid for running TB hospital and supply of anti-TB drugs[12]. Thus based on the findings and recommendations of the 1992 review, Government of India launched the Revised National Tuberculosis Control Programme (RNTCP) in the country. The programme recognizes the importance of the other sectors and initiated collaboration with

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[9]Banerji, D. (1997), *'Serious Implications of the Proposed Revised National Tuberculosis Control Programme for India'* New Delhi: VHAI and Nucleus for Health Policies and Programmes.

[10]Chauhan, S. L. and Agarwal, S. P. (2005), 'Revised National Tuberculosis Control Programme', in Agarwal, S.P. et al (eds.) *"Tuberculosis Control in India"* New Delhi: Ministry of Health and Family Welfare.

[11] ibid

[12]Rangan, S. *et. al.* (1995), *Non-Governmental Organization in Tuberculosis Control in Western India*, Mumbai: Foundation for Research in Community Health.

them to ensure the provisioning of the standard regime (DOTS) to those patients who were reporting to the private sector or charitable and non profit health care organizations.

Even though, the involvement of VOs in provisioning of tuberculosis services and other health programme is not new, they have a long history and presence in the provisioning of the health care services. They have continuously been acknowledged for their significant role in health programmes. In the current scenario there exists a wide range of VOs, those engaged in micro to macro level interventions. They are heterogeneous in nature. These organizations are like – Tuberculosis Association of India, Indian Medical Association, Indian Red Cross, National Society for Prevention of Blindness, Hind Kushth Nivaran Sangh, and Christian Medical Association of India. Beside its various service organization like – Lions Club, Rotary Club, as well as certain religious societies like- Arya Samaj, Sanatan Dharam Sabha, and Ramakrishna Missionary also working for the welfare of the society. Universal access to health services is every individual's right and it is the state's responsibility to provide these health services to entire population. However in a vast and diverse country like India where it is not easy to provide health (which also have very large agenda) care services to entire population. Therefore it becomes imperative and necessary that all the stakeholders should engage collectively in provisioning of the health care services throughout the country.

The social dimension or non medical factors of tuberculosis cannot be ignored or overlooked. Factors such as urbanization, overcrowding, economic constraints and psychosocial elements have greatly contributed towards in making millions at risk and susceptible to the disease. These factors associated with the illness may also influence the motivation level of the patient with regards to the completion of treatment. Based on the studies conducted in different countries provide evidence that certain social factors as a major influence for the failure of tuberculosis programme.[13]

[13]Karyadi, E. (2002), 'Social Aspects of Patients with Pulmonary Tuberculosis in Indonesia', *Southeast Asian Journal Tropical Medicine Public Health,* Vol. 33, No. 2.

Tuberculosis is a disease that contributes towards creation of social medical poverty trap especially for the poor and the marginalized section. Stigma is also associated with this disease. Once affected, the tag of being contagious befalls the TB affected people resulting in them being outcastes and ostracized from employment and society. It affects the social relations of the patients such as restriction from social contact with friends, loss of partner, missing the chance of marriage, negative attitude from relatives.

The people affected from tuberculosis have to spend more on their illness which are both monetary and non monetary in nature. For example it affects the quality time devoted for child care. It also has negative impact on occupation of the suffering population. The attitude and perceptions of the affected individuals towards tuberculosis has an important role in control of the disease.

All these factors are interrelated and help in the spread of the disease; directly and indirectly. In India's context where majority of the people are living below the poverty line, these factors are critical from the point of controlling the spread of tuberculosis. Therefore community participation evolves as an important component in the control of tuberculosis. The RNTCP broadly focuses on the community participation in provisioning of the tuberculosis services and to ensure the community participation and social mobilization, the involvement of the VOs becomes necessary.

Apart from these factors, the new emerging challenges such as Human Immune Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) and MDR make the management of tuberculosis more complex. For the urgent management of the tuberculosis, in 1993, the WHO raised alarm about TB, and said that TB is becoming a global epidemic. Then million of dollars are being channelized to propagate and make DOTS strategy universal and most effective. The initiatives of these international agencies have had significant impact on the national and local levels. These also resulted in huge flow of fund and varied research was conducted in the India. However, despite such recent surge of interest, most of the work is still confined to understanding quantitative aspects such as studying effect of PPM in addressing the issue of tuberculosis rather than the role and function of the VOs in control of tuberculosis. In the context of Delhi city, there are limited

studies that have traced the emergence and role of VOs in tuberculosis programme. The increasing number of VOs in tuberculosis programme raised a question as to reasons behind the increasing number of VOs in tuberculosis programme.

The philosophy of these VOs was to provide services to the needy people without the intention of profit. Their activities were based on charity and were of philanthropic nature. Thus, before collaboration with the tuberculosis programme, it is important to understand the philosophy of the organizations because the philosophy of the organizations influences the nature of the work they engage in. It also can influence the purpose of the organizations. Over time the approaches of the organizations in provisioning of the services have also changed. Thus it is also important to understand the strategy used by the organization in provisioning of the tuberculosis services and the transformation in nature of collaboration within the programme.

1.2- Scope of the study

Last two decades has seen a tremendous growth in the number of VOs working in the field of health especially health care services. As a result, these organizations are getting more prominent in government programs and polices. The basic assumption of this collaboration is, to enhance the community participation in programme and to provide quality services to inaccessible areas. Similar trend is seen in tuberculosis programme also.

In 1997, Government of India launched DOTS strategy under the RNTCP. The programme was implemented with the concept of Public-Private Mix (PPM) and was mainly considered the only collaboration between the national TB programme and the private health sector, through the involvement of private hospitals and Public Practitioners (PPs). In the later years, the concept of PPM in TB gained a broader meaning and was conceived as a strategy to diagnose and treat TB patients reporting to all sectors of health care under the DOTS strategy through a mix of different types of service providers. During the period of 2000 to 2003, many models of public-private collaboration in the RNTCP came up in different places such as Delhi, Kannur, Kollam (Kerala), Mumbai, Meerut (UP) and

Teagardens of the North-East.[14] The result of these initiatives reveled that, achieving the global targets for case detection would be difficult if the other sectors (VOs and PPs) continued to be ignored by the program planners.[15] Thus inspired by these collaborations, the Central TB Division published guidelines for the participation of the NGOs and PPs in the year 2001. There were five schemes under this guideline. Under this scheme new emerging challenges such as HIV/AIDS and MDR cases were not covered. So in the year of 2008, the Government of India again launched a new scheme with the collaboration of VOs and PPs. In this scheme, a wide range of VOs got opportunity to work with the participation of government.

But due to diversity in nature and objective of VOs, the role of these organizations is not clear. As of now, more than 2500 VOs are working in collaboration with the RNTCP programme. The growth and increasing tempo of competition among these organizations for the fund and program have raised many questions. These questions are: What are the rationals behind the emergence of the VOs in tuberculosis programme, what is the nature of collaboration in RNTCP of these organizations, what are the roles and functions of the organizations and what are the strategies being used by the organizations to improve the performance of the programme.

1.3- Framework of the study

The RNTCP functions within the general health services. From last three decades a wide number of VOs began work within the TB programme. The collaboration within this large system has affected the development and function of the TB programme. Therefore, it is necessary to explore the emergence and role of VOs in TB programmes. Till date no study has been done to understand the rationale behind the emergence of the VOs in TB programme.

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[14]Agarwal, S. P., Sehgal, S., and Lal, S. S. (2005), 'Public-Private Mix in the Revised National TB Control Program', in Agarwal, S. P. *et.al.* (eds.), *Tuberculosis Control in India*, New Delhi: Ministry of Health and Family Welfare, p-136

[15]The Centre for Health Research and Development, 'Involvement of Private Practitioners in the RNTCP - The Rationale, Problems Encountered and Likely Operational Models', *Health Administrator*, Vol.: XV, Numbers: 1-2, pg. 61-71 (http://medind.nic.in/haa/t03/i1/haat03i1p61o.pdf)

The current investigation is an attempt to understand the concept and philosophy of the VOs, and their role in health services. The study would also sketch the role of different international, national and local VOs in TB. The attempt is also to find out the changing nature of engagement of these organisations as envisaged in RNTCP. The emergence of selected VOs and the pattern of their involvement with TB programme have also been studied. Then the investigation moves towards the programmes run by the selected organizations and the strategies used by them.

1.4- Methodological Framework of the study

The present study seeks to understand the emergence and role of VOs in health services, specifically in RNTCP. There is a wide range of VOs working with the government in the provisioning of the services to the community. The study has classified the VOs in to four types. This classification covers a range of VOs working in different level from gross root level to international level. This classification provides a holistic way to understand the role of VOs at various levels.

1.4.1- Research Questions

The review of diverse literature on VOs, tuberculosis program and role of VOs in tuberculosis program raised a number of questions. These questions are:

1. What are the historical backgrounds of VOs?
2. How did these organizations begin working in the field of health?
3. What is the nature of collaboration of the organizations with the Government?
4. What are the transformations that have taken place in the nature of involvement of the VOs in government run tuberculosis programme ?
5. What is role of the VOs in the tuberculosis program?
6. How do they play a role in information, education and communication, case finding and case holding?
7. What are the major challenges faced by the organizations when working in the field?

8. What are the major resource limitations faced by these organization when working with tuberculosis patients?
9. What are their financing patterns?

The above questions raised many issues which needed to be explored while the studying the role of VO within the health program. On the basis of such questions and keeping in the mind the availability of information, the objectives of the present study have been drawn.

1.4.2- Objectives of the study

The broad objective of the study is to explore the emergence of VOs in health services and its role in tuberculosis program. It also explores the transformation in nature of collaboration.

Specific objectives:

1. To understand the concept and role of VOs in health services.
2. To explore the role and function of VOs in RNTCP.
    - In health education and awareness
    - In case finding and holding
    - In management of defaulter and relapse cases
    - In community mobilization
3. To understand the transformation in the nature of involvement of VOs across NTP and RNTCP.

1.4.3- Study design

The present study explores the role of VOs in RNTCP programme. The study also explores the emergence of these organizations in tuberculosis programme. The study follows an exploratory method with qualitative research paradigm to achieve the objectives of the study.

1.4.4- Selection of study area:

For the purpose of this study Delhi was chosen as the study area as it is one of the six states in India where the DOTS was introduced. Delhi is the national capital territory of India. It is a growing city and has an area of 1483 sq km. with a population of 17 million. The density of population is about 9390/sq km. The national territory is divided in nine districts and 27sub-division.[16] There are large numbers of VOs involved in provisioning of the health services in Delhi. In which 86 VOs are involved in RNTCP.[17] The state has 24 Chest Clinics along with a network of 180 Designated Microscopy Center (DMCs) each covering a population of one lakhs and 580 DOT centers, where the facility of drug distribution is available.[18] The organisations chosen for this study were from four different geographical areas of Delhi.

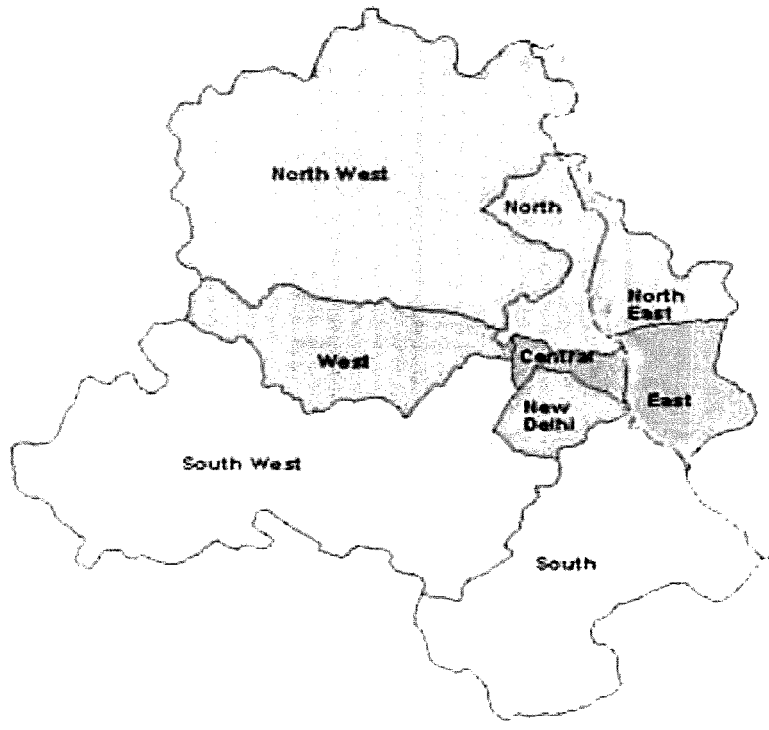

Figure- 2: Delhi Map *(Source: www.cultureholidays.com/.../images/delhi-map.jpg)*

[15]Government of NCT of Delhi (2006), *'Delhi Human Development Report: Partnerships for Progress'*, New Delhi: Oxford University Press.

[17] Government of India (2006), *'TB India – 2006: RNTCP Status Report'*, New Delhi: Ministry of Health and Family Welfare.

[18] Dhingra, V. K *et. al.* (2009), 'Tuberculosis Mortality Trends in Delhi after Implementation of RNTCP', *Indian Journal of Tuberculosis*, 56:77-81.

1.4.5- Sampling

As discussed above the universe of the study is VOs which is providing TB services in Delhi. Study has considered those VOs who are providing the tuberculosis services with the collaboration of RNTCP. Purposive sampling method was used to identify the organizations. To explore different levels of VOs from the grassroot level to the international level, organisations in Delhi were categorized accordingly. Ten VOs were narrowed down on the basis of the objectives of the study, the nature of the organizations were based on the working period of these organisations. These organisations were then contacted over the telephone and through personal meetings. Four different types of VOs agreed to participate in the study. These organizations were '*Ramakrishna free Tuberculosis Clinic' a missionary organization, 'Damien Foundation India Trust (DFIT)' an international organization, 'Delhi Tuberculosis Association of India' a state run organization,* and *Samarpan a grassroot level organization*. To understand the role of these four VOs, each organization was taken as a case study in which four key informers were interviewed.

Table - 1.1: No of Respondent at a glance

VOs	Respondent			Total
	Programme coordinator	Medical Doctor	Health Visitor/DOTS provider	
Ramakrishna Free TB Clinic	1	1	1	3
DFIT	1	1	1	3
Delhi Tuberculosis Association of India	1	1	1	3
Samarpan	1	1	1	3
Total	4	4	4	12

As table one depicts that four Programme coordinator, four medical doctors, and four health visitors/DOTS providers totally twelve respondent were interviewed. Apart from this, three informal interviews were done by the expert personnel who are working in the area of tuberculosis. Out of three, two respondents were government officer while one was experienced medical doctor who is working volunteer in an organization. Thus total 15 interviews were conducted.

1.4.6- Pilot study

An initial visit was carried out to understand field area, nature of the VO, and their role in the TB programme. After this, a pilot study was undertaken with the objective to validate the tool, which was a semi- structured questionnaire. An organization was chosen for this pilot study. During the pilot study the schedule was also administered to check its reliability. This pilot study helped to omit some non relevant questions and to add few more.

1.5- Source and Tools of data collection

The study used predominantly primary data and secondary data was used to supplement the arguments. Keeping in view the objectives of the study, qualitative data was collected from primary sources. Secondary data were collected through different literature such as WHO reports, government's report, NGOs report, books, newspapers, articles and annual report, journals, dissertations, thesis, web sources etc. For the primary data case study, informal interviews of key informants of the organizations and other experienced persons were interviewed. Three kinds of data was required as mentioned below-

- Data related to their philosophy, nature and reasons for emergence in tuberculosis.
- Second kind of data required was about their nature of collaboration in programme and role and functioning in RNTCP.
- Third kind of data was related to financing pattern, performance and relationship with government.

For the data collection, following techniques were used.

1.5.1- Case Study Method

A case study is an in-depth comprehensive study of a person; a social group, an episode, a process, a situation, a programme, a community, an institution or any other social unit.[19] Case study method was used to get the information related to emergence and role of VOs in RNTCP. It is a single unit of study in which four key informers were interviewed from each VO, to understand their views regarding organizations, their role in organizations, philosophy behind the emergence in TB programme, organizations approach in case finding and case holding, defaulter management, different strategies used for IEC activities, financing pattern in program, major problems faced by the organization in control of tuberculosis and relationship of the organizations with government. To get these information following tools were used.

a) *Interview Schedule*

Unstructured interview schedule were used to collect the data regarding history and nature of organization, their philosophy behind the emergence in tuberculosis program, role and function of the organizations in RNTCP, funding pattern, problem faced by the organizations in management and control of tuberculosis.

b) Construction of the Tool

The interview schedule was developed on the basis of literature review which showed certain gaps in studying the emergence and role of VOs in tuberculosis programme. The study was developed to address certain specific question related to the gaps which came out from the review of literature and these questions were incorporated in the interview schedule. Apart from that other published qualitative research studies and expert consultation was also done to finalize the schedule.

c) Tool Testing

Pre-testing of the schedule was done and necessary modifications were made before proceeding for the data collection. The reliability was also checked. To

[19] Krishnaswami, O. R. and Ranganatham, M. (2006), *Methodology of Research in Social Sciences*, Mumbai: Himalaya House Publishing.

test the reliability of the tool same questions were asked in different ways, two or three times; during the pilot study.

1.5.2- Observation Method

Observation may be classified on the basis of the situation in different ways such as participant, non-participant, direct and indirect observation, controlled and uncontrolled method.[20] In this study non-participant method was used to see the role of DOTS provider/health visitor in provisioning of the DOT services, awareness generation, and patients provider interaction.

1.6- Data Analysis

In the present study, qualitative analysis was done. For the first objective the secondary data was used. To achieve the second objective, data related to VO's, rational behind their emergence in TB programme, their role and function in provisioning of the TB services were analyzed. In this regards, data were analyzed under different themes. Narrations were used to substantiate these arguments. The themes were divided as given below-

1. Emergence of the VOs in TB Program
2. Nature of the Involvement and Transformation
3. Role of VO in Case Finding and Case Holding
4. Role of VOs in Health Education (IEC activities) and Community Mobilization
5. Major challenges faced by the organizations
6. Relationship of VOs with government
7. Performance of the Organizations
8. Allocation of funds to VOs

[20]Krishnaswami, O. R. and Ranganatham, M. (2006), *op cit*

1.7- Conceptual Clarity

The term VO is used differently by different authors, academicians, and professionals. VOs are those organizations which have volunteers to engage themselves in service without the object of profit earning. It has the character to promote public welfare or social improvement in some special regards. Member of such bodies work together for a common end and registered under the Society Act. These agencies are also known as NGOs and used interchangeably. Although there are technical differences between VOs and NGOs, this study does not go into the details of that, here the term VOs are used as an umbrella term which includes all kind of non-profitable organization such as "Private Voluntary Organizations (PVOs)," "Non Governmental Organizations (NGO's)," "Voluntary Organizations," "Non Governmental Development Organizations," and "Non Political Organizations." working for the welfare of the society.

The study explores the emergence and the role of the VOs in RNTCP. Here the term emergence is used to understand, what is the reason behind the working in the field of the tuberculosis? Is there is any philosophical reason behind it or they are doing it for funds from the donor agencies or for their survival.

The terminology 'transformation' is used in this study to understand the shifting in the nature of the collaboration with the RNTCP.

1.8- Limitation of the study

The present study has some limitation of a single investigator doing research work for an M.Phil dissertation. Beside, there are few other points which could be kept in the mind while going through the dissertation.

1. The study was intended to generate data of qualitative nature and as a consequence a wide coverage of the VOs was not possible. It is not representative of the all the VOs, as the sampling was purposive.

2. It is very difficult to engage with VOs and get into the intricacies of their work. The study involved collecting some information particularly with respect to reason behind the emergence of the organization and their funding pattern which was difficult to obtain.

3. The study seeks to understand the emergence and role of VOs in RNTCP and explore only on the providers' point of view. It does not look the beneficiary's point of view.

1.9- Chapterization

The organization of all the five chapters gives a holistic way of understanding of the dissertation, connectivity and continuous flow of all the chapters. The structure and Chapterization of the dissertation is as follows

Chapter one, titled Conceptual and Methodological Framework, gives an overview of the dissertation, including rational behind the study and framework of the study. The chapter also includes the methodological framework, which is adopted for the study. The methodology also includes the conceptual clarity, and limitations of the study.

Chapter two, titled History of VOs in Health Services in India, begins with the concept and definition of the VO, difference between VOs and NGOs, philosophy of the VOs based on the review of the literature. The chapter also discusses the role of VOs in the programme and policy with the some reflection of VOs in Five Year Plan.

Chapter three, titled the Tuberculosis Programme: The role of International, National and local VOs, explores the role of VOs from 1900 to till now. It also explores the effort done by VOs at international, national level and local level. Then the discussion moves on to the strategy used by the government in RNTCP programme to collaborate with the VOs and NGOs for the provisioning of the tuberculosis services. After that the chapter reviews the guidelines developed for the collaboration of NGOs/PPs.

Chapter four, titled Emergence and Role of VOs in RNTCP, is divided under seven themes. Data are interpreted under each and every theme. Narration is used to understand the emergence and role of the VOs and their role in control of tuberculosis. The chapter also explains the strategy used by the organization for the case finding and case holding.

Chapter five, titled as Discussion and Inferences, begins with discussion of the VOs in health services. Then the chapter gives insights into the role of VOs in RNTCP on the basis of the data analyzed under the themes divided in chapter four.

CHAPTER - 2

CONCEPT AND HISTORY OF VOs IN HEALTH SERVICES IN INDIA

In this chapter; efforts have been made to conceptualize the term used in this dissertation and to understand the concept of Voluntary Organization (VO) and types of VOs. Later on the chapter explores the rise of VOs in health services and their role in policy and programme with a reflection of VOs in five year plans. The time frame under consideration in this chapter is the period from 20th century till date.

2.1- Voluntary Organization: Concept and Definition

Nowadays the act and degree of voluntarism has received growing attention in sociology, psychology and other social sciences[1]. The use of the term voluntarism sounds new but the spirit of voluntarism is perhaps as old as humankind. From the beginning people used to help the needy, poor, sick and helpless. In those days the nomenclature of voluntarism was not in existence. It is the action of people working for the betterment or for a particular cause of others without the intention of any kind of incentive for their time and services. It is conceived as an altruistic activity, intended to improve quality of life of the people. The term voluntarism is derived from the Latin word 'Voluntas' which means will. The will includes all forms of impulses, passion, appetites or desires and determinations."[2] These people can work individually or with a group of people. These group of volunteers come together to form VO. VO has played an important role in social history.

A number of definitions of VO have been given by different scholars from different disciplines, but there is widespread dissatisfaction and disagreement with the definition of VOs. The term VO is used differently by different researchers, scholars and academicians, such as charity, civil society, non-government organization (NGO), trust etc.

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[1] *Cited in,* Marnik, D. G. and Zeger, D. (1995), 'Theory and Methodology, The Attrition of Volunteers', *European Journal of Operational Research,* 98, 37-51.

[2] VHAI, (2000), *Dimension of Voluntary Sector in India; CAF's Validated Database,* New Delhi: VHAI, Charities and Foundation India.

As per World Bank definition NGOs are ' private organizations that pursue activities to relieve suffering, promote the interests of the poor, protect the environment, provide basic social services, or undertake community development'[3]

Bourdillon (1945) defines that "VO is the product of the blood, sweat and toil of a few individuals who are known for their persistent efforts for achievement of their sincere aspiration."[4]

Michael Banton (1968) an anthropologist, argued that, it is a group organized for the pursuit of one interest or of several interests in common. Usually, it is contrasted with voluntary groups serving a greater variety of ends, such as kin group, castes, social class and communities."[5]

Inamdar (1987) says, VO in development to be of durable use to the community, has to nurture a strong desire and impulse for community development among its members, to be economically viable, to possess dedicated and hard working leadership and to command resources of expertise in the function undertaken."[6]

According to Lord Beveridge (1979), a VO, properly speaking, is an organization where its workers are paid or unpaid, governed by its own members without external control[7].

On the basis of above definitions, it can be said that VOs are those organizations which have volunteered to engage themselves in service without the object of profit earning. It has the character to promote public welfare or social improvement in some special regards. Members of such bodies work together for a common end. These organizations are independent in nature and controlled by

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[3]World Bank website *"Nongovernmental Organizations and Civil Society/Overview." http://wbln0018.worldbank.org/essd/essd.nsf/NGOs/home> Accessed June 8, 2001*

[4] Bourdillon, A.F.C (1945), *Voluntary Social Service: Their Place in Modern State*, London: Methuen, p. 104

[5] Banton, M (1968), *Anthropological Aspect, Voluntary Associations, International Encyclopedia of Social Sciences*, Vol 16, London: Collier Macmillan, p- 358

[6] Inamdar, N.R (1987), 'Role of Voluntarism in Development', *The Indian Journal of Public Administration*, Vol. XXXIII, No. 3, pp. 421- 422

[7] Beveridge, W (1979), '*Voluntary Action in Changing World*', London: Bedford Square Press.

those who have formed themselves or by board of management. These agencies are also known as non-governmental organizations.

The term VO and non-government organizations (NGOs) are used interchangeably. There is a technical difference between VOs and NGOs hence, the use of these terms interchangeably is incorrect

2.2- Difference between Voluntary Organization (VO) and Non-Government Organization (NGO)

VOs and NGOs are terms which differ widely in their objectives, methodology, style of functioning, motives, legal status, socio-political orientation, ideological definition, economic strength etc. They are just opposite to business and cooperative and trade association. VOs are essentially non- profit and non-partisan organizations. They are largely independent of the government and are characterized primarily by humanitarian or cooperative rather than profit making objectives. The quintessence of VOs in voluntarism and their sprit of voluntarism stem from varied sources such as e.g. love for humanity, charity, welfare of the needy and active destitute etc. VOs are controlled and administered by an association of citizens rather than any influence from the government.

The term NGOs, has acquired wide acceptance internationally. The United Nation nomenclature of the NGOs refers to any international organization not established by the inter-governmental agreement including organization which accepts members designated by government authority provided that such membership does not interfere with the organization's free expression of view. NGOs are different from the market induced organization's and other organization's of the state. The term NGO in India has been used to denote a wide spectrum of organizations which may be non-governmental, formal or informal, non profit or profit oriented bodies, with a global status and registered under special act like companies act, societies registered act[8].

[8] Handbook for NGO's: An encyclopedia for Non-Government organization and Voluntary agencies. Incorporating; Government AID Scheme and Facilities. Project Proposal and implementation funding agencies and other Day to day work, New Delhi: ANABHI publication.

Hence it can be said that the VOs are a subset of NGOs. In other words all VOs are NGOs but all NGOs cannot be VOs. The most important feature of a VO is that they are formed voluntarily, are willing to work on behalf of others, are independent, are not for profit, not self serving.[9]

2.3- Types of Voluntary Organization

The task of understanding the classification of VOs is very challenging because of the diversity in role, size, and legal status, source of funding and working philosophy of the VOs. Professionals of different arenas such as scholars, researchers and academia have given different typology of VOs. Literature reveals the difficulty in placing many organizations in to category defined by different social scientists. In his paper 'A Comprehensive Analysis of Health and Welfare Organizations' Raymonds W.Winstein discussed the difficulty in defining the typology of VOs.[10].s

World Bank classified VOs in to two types that are Operational VOs and Advocacy VOs. Operational VOs are concerned with design and implementation of development related projects while Advocacy type of VOs defend or promote a specific cause.[11]

Bhose S.G.R. (2003) classified the VOs on the basis of different functions in the programmes. He classified the VOs in to eight types.[12]

1- Charity VOs

   This is the earliest form of the VO. The purpose of this kind of an organization is to provide help to the needy people. Organisations working with a religious point of view fall under this category.

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[9] VHAI, (2000), *op cit*

[10] Winstein, R.W. (1997), 'A Comprehensive Analysis of Health and Welfare Organizations', *The Pacific Sociological Review*, Vol. 20, No. 1, pp. 79-104

[11] Ghosh, B. (2009), 'NGOs, Civil Society and Social Reconstruction in Contemporary India', *Journal of Developing Societies,* 25; 229

[12] Bhose, S.G.R (2003), *NGOs and Rural Development: Theory and practice,* New Delhi: Concept Publishing Company, pp. 45-49

2- Relief and Rehabilitation VOs

The VOs which are working for relief and rehabilitation come under this type. This kind of an organization works with areas affected by natural disasters, epidemic disasters, war and other kind of man made disasters.

3- Service provider VOs

These kinds of VOs are working for the social welfare of the society. They provide different kinds of services such as mobile clinic, hospital, and school etc. to the poor and marginalized sections of the society. These organizations work in those areas where government finds itself ill equipped to work.

4- Economic development VOs

This type of VO works for the economic betterment of the poor. The philosophy of these VOs is; economic growth of the poor will raise their social and human development. These organizations get grants from the government and implement income generating programmes for poor and marginalized.

5- Social development VOs

The organization which is working for the different social aspect of the community comes under this category. They try to create awareness among society because they believe that social awareness and people's participation will result in development.

6- Empowerment VOs

These kinds of VOs work for the empowerment of the community. These VOs bring up the issues such as drinking water, economic activities, literacy, adult and non-formal education, injustice etc.

7- Network VOs:

These kinds of VOs work to create linkage with other VOs for the provisioning of services. In the period of 1980s there was a remarkable development of these kinds of VOs. In essence they work as liaison NGOs.

8- Support VOs:

These VOs are newly emerging ones which provide different kinds of support to grass root VOs operating in local settings. They help to strengthen the capacity of the grass root organisation to function more effectively and with greater impact.

Another Classification of VOs as stated by David Korten[13]distinguishes VOs in to four types on the basis of the Development Strategies. These types are relief and welfare organizations, community development organizations, sustainable systems development organizations and people's organization.[14]

The above classification of VO gives clear-cut understanding of difficulties in classification of VOs. The present study has categorised the VOs in to four types; charity and religious VOs, developmental VOs, service provider VOs and lastly community based VOs.

2.4- Historical Perspective of VOs

India has a long history and tradition of voluntary action. These voluntary groups provided services to the sick, needy and poor and have played a critical role in promoting and facilitating health and education services. The main role of VO was in reaching out and mobilizing people and developing their insight into ground level problems. The main target group of these organizations were the deprived and exploited community. There were different forms of organisations working for the welfare of the society. Their success attracted national and international attention towards them.

Up to nineteenth century the genesis of the voluntarism was in the form of charity, philanthropy and relief activities. But the voluntary efforts were limited in those days. Mostly kings and the chiefs used to provide free kitchens during famine and shelter to homeless. This kind of voluntary work was due to belief in the *Dharma Shastra*. Prior to nineteenth century the main institutions were family kinship,

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[13] *Cited in* Sarkar, A.K. (2005), *NGOs The New Lexicon of Health Care*, New Delhi: Concept Publishing Company, p-40

[14] http://www.caledonia.org.uk/ngotypes.htm

caste and the village community who were providing the facility and services to the needy people.

The first half of the nineteenth century was the era of social reform movement. In this period some people like Raja Ram Mohan Roy, Ravindra Nath Tagore, Dayanand Saraswati, and Swami Vivekananda were fighting against the rigid social evils like *Sati Pratha*, child marriage, prohibition of widow remarriage and the caste directed practice. During this period the VO was based on 'Reformist approach'[15]. The efforts by these reformers gave impetus to the growth of VO during this period.

This period saw the shift of Christian missionary in to voluntary action and growth of number of indigenous VOs in India. Other religious organizations like Muslims and Sikhs also came forward to protect the interest of their community.[16]

The second half of the nineteenth century was the period of institutionalization of social and religious movement. And a large number of reform associated organizations in different part of the country were attracting many people to voluntary work. Due to their religious passion people were interested into socially oriented activities. During these period religious organizations set up a number of educational institutions, health facilities, and other charities. Christian missionaries also established schools and hospitals. During the period of freedom struggle there was an increase in the number of VOs with different professionals such as doctors, lawyers and teachers becoming part of the freedom struggle, in response to the call of Mahatma Gandhi. He appealed to all these professionals to devote their time for the betterment of the society and for these people health work was not separate from overall development.[17] Many of these organizations came into existence in response to major disasters and crisis, with the aim of

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[15] Sudhir, P. K. (1995), *Voluntarism and Development: A Social Science Focus on Health,* Unpublished Thesis, Centre for Study of Social System, JNU, New Delhi.

[16] Jasni, A. *et. al.* (1996), *NGOs in Rural Health Care*, Mumbai: The Foundation for Research in Community Health.

[17] Sharma, M. (1996), 'The Voluntary Community Health Movement in India: a Strengths, Weaknesses, Opportunities, and Threats (SWOT) Analysis', *Journal of Community Health*, Vol. 21, No. 6.

providing emergency relief and rehabilitation.[18] In the beginning of the twentieth century along with charity and religious organizations, many large businessmen also started to participate in charitable work.

After independence the major task in front of the newly independent country was to ensure the all round development especially in the rural areas across all sectors. To give proper emphasis for the development-oriented activities the then government launched the Community Development Programme.[19] This program was influenced by the experiments of the non-governmental organizations'. Till mid sixties the nature of the VOs was charity oriented but after that the focus shifted to developmental work. During this period Green Revolution was spread in to the countryside with the help of second (Private) and third (VOs) sector. This success inspired VO to puling into development work[20].

Another shift that had taken place in the history of VOs in the era of 1980s was the emphasis on 'advocacy'. This period saw an involvement of magnanimous organizations of developed countries, working for the development and welfare of poor people in developing countries. During this period many developed and developing countries decided to introduce privatization, liberalization and limit the role of the state in social sector programmes. Several third world countries who were in the crises due to the balance of payment, cut down their budget in the social sector and started thinking loans from international funding agencies and World Bank (WB)[21].

A new shift in philosophy of VOs was seen in the period of 1990s. In this period the philosophy of development changed to 'People-centred-development'[22]. For this purpose the active role was played by the self help group and autonomous group and the VOs were working as a catalysts and facilitator in the process.

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[18] Patal, V. and Thara, R. (2003), '*Meeting the Mental Health Need of Developing Countries, NGOs Involvement in India*, New Delhi: Sage Publication.

[19] Jasni, A. *et. al* (1996), *op cit*

[20] Jasni, A. *et. al* (1996), *op cit*

[21] Sarkar, A.K. (2005), *op cit*

[22] Elements of People-Centered Development, http://www.mercyworld.org/projects/mgc/2004/pdfs/brief-040601.pdf, accessed on 2nd Feb. 2010

The past fifty years have seen a very rapid growth in profile, size and range of activities in VOs. Some kind of changes have taken place since independence such as change in degree of professionalization of organizations activity, in source of funding (National and International) patters and in secular origin of the VOs. This development in VOs inspired the professionals to participate towards social activities and professionalization of organizations started. This professionalization showed the way to organizations to work on issues pertaining to health and organizations began to fulfill gap in health care provision, focusing on under-served populations.[23]

Simultaneously there were many movements taking place in India which have great impact in genesis of VOs in India. Some of these movements have been briefly discussed below:

The Christian Missionaries movement

In the colonial period around eighteenth century, the European were converting the natives of Hindustan to the Christian religion[24]. By the side of conversion of religion of Hindu Natives in Christian, they started charitable work and fight against social problems. A huge number of school, hospitals, literacy center, vocational tanning center etc were started in this period. In fact it was the starting of the voluntary action on the part of the missionaries. In the period of 1947 there were decreasing pattern seen in these institutions but after independence many Christian missionary have promoted VOs to serve the vulnerable people.[25]

Movement against Casteism:

The other factor in the endorsement of the VOs was movement against Casteism. During the period of 1870s and onwards, there were many organized societies initiated cast movement in different part of the India. For instance Satya Sodhak Samaj (1873) in Maharashtra, Non-Brahmin movement in the south and Arya Samaj etc started fight against the oppression of the lower castes. These

[23] Jasni, A. *et. al* (1996), *op cit*

[24] Basu, (1985), *cited in* Sarkar A .K (2005), *op cit* p-104

[25] Sarkar A .K. (2005), *op cit* p-104

organizations were divided in two types on the basis of approach in fight against casteism. One group was following the Gandhian approach and second was non-Gandhian. Gandhian group never followed inter-cast marriage or taking food with higher cast people moreover the approach adopted by this group was based on the Hindu point of view and made an attempt to transform them at individual level .The Non-Gandhian group was against Hindu social order and caste system. Similarly different other societies also emerged after the independence to fight against Casteism. These societies took the form of large VOs who were working for the welfare of the lower caste.

Gandhian Movement

The idea of this movement was reconstruction of society through social struggle. His movement during 1920s and 30s aimed at the welfare of all human beings and creation of a stateless and classless society by means of 'Swaraj' and 'Sarvodaya'. In this regard, Gandhi started various programmes like Khadi and village industries, abolition of untouchability, village sanitation, basic education, tribal labor welfare, women welfare etc. The movement wanted to make village communities self reliant, self sufficient and free so that they would stand up for their own rights. In 1938 by the help of 'Shanti Senas' he made his movement strong. It was the most systematic attempts toward development of moral and spiritual value among the people. Another aspect BHOODAN was initiated by Visnoba Bhave in 1951 after the death of Gandhi Ji. The objective of this movement was to effect a voluntary transformation in the distribution of lands in rural India according to the principle of equality. This nature of movement promoted voluntary sector in India.'[26]

Women's Movement:

The status of women was an issue of great concern during nineteenth century. In the year of 1920s, in India first time a women's organization at the national level came in the existence to fight for the status and right for the women. The movement came after the formation of All India Women's Congress (AIWC). The

[26] Dayal, P. (1986), '*Gandhian Approach to Social Work*', New Delhi: Sage Publication.

aim was to address the issues of gender inequalities, 'Sathi' practice, women's atrocities, female infanticide, higher maternal mortality, etc. The organization was also in support for freedom movement.[27] As a result a number of VOs came in to existence to address these issues such as Self Employed Women's Association (SEWA) came in existence in 1972 and were addressing the issue of gender discrimination at the work place, unequal wages and the domestic lever. Later on the women's movements emerged as the space where many of the debates around sexual rights come to the forefront[28]. Thus different kinds of VOs emerged who were addressing the issues of women's health.

Environmental Movements

A range of VOs also came from the environment movements. The environmental movements were addressing the issue of ecology sustainability based on people's initiative. The ecological movement, chipko movement and green movement are the outcome of people's movement for the sustainability of the natural resources.

All above discussed social movements were normally anti-authoritarian and were grassroots in nature. There was no participation of political parties.

2.5- Reflection of Voluntary Organizations in Five Year Plans: A Brief Analysis

After the independence India initiated Five Year Plan in 1951. The assumption behind it was that the state would take the responsibility to eliminate the poverty, ignorance, disease and inequality of opportunity. The planners took into consideration the available resources, made adequate provisioning of the social welfare services, and prioritising of different developmental programs. In these plans the role of VO was recognized effectively.

In the First Five Year plan VOs were taken in to consideration as a social service agency. Thus social service agencies provided workers to help village Panchayats and cooperative societies. It was recognised in the First Five Year Plan that these

[27] Kartar, S. (1977) *cited in* Sarkar, A .K. (2005) *op cit* pp-109-10

[28] Rao, M.S.A. (2002), *Social Movement in India*, New Delhi: Manohar Publication.

organizations will help in training of workers and their service could be availed in specific area. It was felt that VOs could be better in rural areas for the construction and repair of sources of water supply, roads and sanitation works for which state has no resources. In the national advisory committee for public cooperation it was recognized that VO would play an important role in national plans. They were expected to develop their own activities and work accordingly. In this plan mostly VOs were engaged in the training of midwives, dais and health workers and establishing of large number of maternity and child health centres.

In woman and child welfare, social education and community mobilising, it was realised that public cooperation through VOs could give valuable results. The Planners admitted, 'It is necessary to coordinate the programmes of various VOs. Such coordination calls for a common approach and a cooperative outlook on the part of the organisers of voluntary social work'.[29]

Public participation in the work of VO was appreciated in the Second Five Year Plan. As stated by the plan 'by harnessing voluntary effort and local manpower resources, physical targets in the Plan can be supplemented in many fields and even greatly exceeded'[30]. This statement was inspired by the two organizations which were working in those days that were 'Bharat Sewak Samaj' and the 'Kasturba Gandhi National Memorial Trust'. In this period the premise of VOs was social welfare. Central Social Welfare Board (CSWB) established state level social Welfare Advisory Board in order to reach to the local NGOs and release funds. But in second five year plan, VOs did not have broader role in programmes and policies. It was limited only to social welfare. In this period, the CSWB was set up with the object of assisting VOs in organizing welfare program for women, children, and the handicapped. But their potential was not recognized in policy planning and implementation.[31]

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[29] Government of India (1951), *First Five Year Plan (1951-56)*, New Delhi: Planning Commission. http://www.education.nic.in/cd50years/15/8p/82/8P821301.htm accessed on 3ed Jan 2010

[30] VHAI, (2000), *op cit*

[31] Lalitha, N. (1975), *Voluntary Work in India*, New Delhi: NIPCCO.

During the Third Five Year Plan there were gradual increments in VOs in quality and quantity both. During this period they were engaged in flood control, anti-water logging and irrigation. There work based on technology. Rural industries and health was the main focus. It was the period when individual cooperation got institutionalized and Nation Advisory Committee for public cooperation lost its credibility. This plan acknowledged, 'it is essential that the help of VO labour organization and other association in various fields of national life should be sought, on as large a scale as possible and integrated in to the practical programme of work adopted in each area'[32]. The role of VOs recognized in the displaced tribal, resettlement and rehabilitation of the people also.

In fourth plan the focuses was on support and strengthen the VOs to build up their capability for continuous work. The Family Planning and Child Welfare Program was underway in partnership between VO and *Panchyti Raj*. A study was also set up by the Commission on Social Welfare. This Commission made several recommendation concerning grants to VOs.

In Fifth Five Year Plan financial assistance was given to VOs providing medical care and implementation of family planning program. VOs started to conduct experiment, like youth against famine, and involvement of youth in development work.

Sixth Plan was on same theme of social welfare. The area of voluntary work was extending in energy sources, water management, soil conservation, disaster management and nutrition. Seventh plan is seen as emergence of VOs in planning and implementation of program and policy. They were free to plan their own schemes and follow the methodology they thought best in provisioning of the service and reduction of poverty"[33]. They were offering grants in aid to help set up income generating unit for needy women. Regarding health, Union Ministry of Health and Family Welfare launched many scheme for realising fund to VOs like scheme for improvement of medical services, improvement of hospitals in rural or

[32] Government of India (1961), *Third Five Year Plan*, New Delhi: Planning Commission, p-393

[33] Roy, S. (1987), 'Voluntary Agencies in Development – the Role Policy and Programs', *The Indian Journal of Public Administration,* Vol. XXXIII, No. 3, pp. 454-464

urban areas, promotion and development of voluntary blood donation program, special health scheme for setting up small hospitals/ dispensaries in rural area only.

The key goal of Eighth Plan was socio-economic development. It was believed that the association of VOs could be cost-effective in the integrated development of rain fed areas, watershed management, and agricultural extension. VOs made a tremendous contribution in raising and promoting the small family norms by motivation and education of women, provisioning of the antenatal and postnatal care. The role of government has shifted from service delivery to facilitating VOs to fill the gap in social services. VOs were participating effetely in decision making, and accountability from the state.

The Ninth Five Year Plan was almost silent on VOs. It has been realised that the VOs are actually complementary in nature. Both the government and voluntary sector are to work on a reciprocal basis. In this plan there was liberty to each ministry to allocate funds to VOs for various projects and programmes.

2.6- Role of VOs in Health Services since 1900s

All these above discussed development and movements had impact on health. It was resulted a similar kind of voluntary action on health. In modern times, Christian missionaries initiated the tradition of running charitable dispensaries and hospitals[34]. Much later, Hindu charitable organizations like Ramakrishna Mission also opened charitable dispensaries. But at this time the character of VO was ambiguous.

In the period of 1920s and 30s voluntary action in the health field was influenced by the Gandhian ideology. The first of voluntarism was guided by a humanist concern and an anti-colonial and nationalistic sprit. The concern of the ill health and communicable disease was created among the intellectuals and medical

[34] Mukhopadhya, A. (1987), 'Health For the Millions', *Voluntary Health Association of India Bulletin*, vol. XIII, No-516.

professionals[35]. This resulted in the formation of voluntary bodies like the Hindu Kustha Nivaran Sangh and the TB association of India. The Indian Medical Association was also born out of voluntary effort by nationalistic minded doctors. These doctors were inspired by the welfare state movement of United Kingdom and socialized health service of Soviet Union[36].

In All India medical Conference at Lahore in 1929, Dr. B.C. Roy in his presidential period had called for an organized voluntary effort by the Indian medical association. He stated that the current situation of the health of the country is very bad. 'The death rate is very high, infant mortality rate is very high, the prevalence of disease like cholera, small pox, plague, and dysentery is also very high. If we want to do any thing extra, we have to form VO for social services, for giving aid during epidemic, for the medical inspection of school children, for raising sanitary consciousness among the mass.'[37]

A scheme for improvement of medical services launched by government seeks to provide medical care to rural and highly density slum population of the country. The objective of this scheme was to encourage VOs to provide improved medical services to rural and high density slum population in the country. A program 'Special Health scheme for Rural Area' was launched by the Ministry of health and family welfare. The main purpose the scheme was to encourage the VOs in setting up a new hospitals/ dispensaries in rural area where the existing medical care facilities are inadequate.[38]

State has never denied its responsibilities towards public health. Distinct literature reveals that in the mid nineteenth government accepted the responsibility of health care of people but the centre of attention was predominantly on urban areas with the curative services. Rural areas were getting attention during epidemic. It was

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[35] Pattnaik, S.K. (1988), *Voluntarism and Development: A Social Science Focus on Health*, Unpublished M.phil Dissertation, Centre of Social Medicine and Community Health, JNU, New Delhi.

[36] *ibid*

[37] Banerji, D. (1985), *Health and Family Planning services in India, An epidemiological, Socio-Cultural and Political Analysis and a Perspective,* New Delhi: Lokpaksh, p-15.

[38] Mohanty, M. and Singh, A.K. (2001), *Voluntarism and Government Policy, Programme and Assistance,* New Delhi: Voluntary Action Network India (VANI), p. 105.

only 1946 when urban and rural areas got equal importance through the concept of community based primary health care by Health Survey and Development (Bhore committee) on public health.[39] To get the participation of people in promotion of health and education the committee emphasised the role of VOs in health services.

The period late fifties and throughout the sixties is the witness of economy crises in India, and government failed to meet the growing challenges poverty and ill-health. A large number of VO came into being to fill in the void. Government data also revels that, during this period approximately fifty percent health services were provided by the VOs.[40] This initiate a process of experimentation with new approaches and a search for methods beyond curative medical model to meet the needs of the masses.[41]

There were different approaches used by the different international organizations to meet the challenges of third world countries such as communicable disease, population growth and health status of the populations. To meet these challenges different vertical program were launched. The roles of VOs in these programmes were recognized.

To control the population of third world country, a technology oriented family planning programme was launched in sixties. Before the family planning programme VOs were also active in birth control movement. After the launching of the government programme the role of VOs in control of population became ambiguous. The role of VOs in programme was 'covert the family planning programme from a routine government programme in to the people's movement'[42],[43]

[39] Sundar, P. (1994), 'NGO Experience in Health, An Overview', in Pachauri, S. (1994), *Reaching India's Poor: Non-Governmental Approach to Community Health*, New Delhi: Sage Publication, p-309.

[40] Pattnaik, S.K. (1988), *op cit*

[41] Sharma, M. (1996), *op cit*

[42] *Cited in,* Banerji, D. (1985), *op cit* p- 07.

[43] *Cited in,* Gupta, J. and Duggal, R. (1986), '*NGOs in Health Care*', Bombay: Foundation for Research in Community Health (FRCH), Vol. 1.

In the period of 1970s several organizations took the challenge of translating the concept of equity, social justice, community participation and integrated development, embodied within the primary health care approach. But the Government failed to get desired results and provided space for VOs to proliferate in their programs and policies.[44]

In the period of 1980s a study group on the health status of the people was jointly setup by the Indian Council of Medical Research (ICMR) and Indian Council of Social Science and Research (ICSSR). This group reported that the mortality rate of women and children's' was high although the epidemiological data shows that, many diseases like smallpox and cholera had been cured. The group committee reported that several disease arising due to poverty, malnutrition, bad sanitation, lack of safe water supply and inadequate drainage, housing and low level of immunity were still prevalent among poor. The family planning programme was also far from success and health education was inadequate. There were critical problems of infrastructure and health personnel. During those periods there was lack of involvement of community in deciding which felt need to be meet first and how. The training of the health personnel was also inadequate, medical professional were trained only in western medicine and used to stay only in urban areas. There was stress on maternal and child health rather than women's general health. Over all health was seen as a separate entity rather than one component of general development.[45]

There were some problem like gap between planning and implementation, people were unaware about government services, some organizational problems like lack of proper referral system, dual administrative control, lack of evaluation and monitoring system46. Though government was main actor in provisioning of the services during this period but simultaneously VOs or NGOs were also acting in welfare of the society. Mostly VOs were engaging with the problems directly.

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[44] Pachauri, S. (1994), *op cit* pp-14-15.

[45]ICMR and ICSSR, *cited in*, Sundar, P. (1994), 'NGO Experience in Health: An Overview', in Pachauri, S, *Reaching India's Poor: Non-governmental Approach to Community Health*, New Delhi: Sage Publication, p-309.

[46] Government of India (1983), '*National Health Policy'*, New Delhi: Ministry of Health and Family Welfare.

They were using community health approach to reach the community. This approach was joining commitment and close involvement with the community at the grassroots, targeting of the poor and disadvantage and organizational involvement.[47]

This involvement of community at the grassroots and targeting marginalize section, VOs has built up a right body of knowledge and practice to identify the poorest in the community and their involvement in development process. Due to these reasons there is an increasing trend of involvement of VOs in health services.

The National Health Policy of 1983 opined that, to improve the health services of the country there is a need to stabilization of population. The policy emphasised on the need for "securing the small family norms through voluntary efforts and moving towards the goal of population stabilization"[48].

In 1978, the Alma-Ata conference was held under the joint sponsorship of the WHO and the UNICEF fixed a goal of 'Health for All by 2000 A.D' (WHO/UNICEF 1978). This conference recommended alternative approaches to meet the basic health needs of the third world people. In this declaration it was mentioned that we have to achieve the target- infant mortality rate below 60 per thousand live births, prenatal mortality to 30 per thousand live births, crude death rate to nine, maternal mortality rate below two hundred per hundred thousand live births, life expectancy at birth to 64, and net reproductive rate one. These goals look unachievable without the help of second and third sectors. The conclusion drawn by the report goes strongly in favour of VO[49].

Throughout the world, voluntary sector has important role in provisioning of the primary health care in adverse situations. The Seventh Five Year Plan and National Health Policy emphasise on the importance of voluntary sector to achieve the health care goals.

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[47] Pachauri, S. (1994), *op cit*

[48] Government of India (1983), National Health Policy, op cit, p-4.

[49] Sarkar, A. K. (2001), *Non-Government Organization a Study of West Bengal*, Unpublished Thesis, Centre for Social Medicine and Community Health, JNU, New Delhi.

The National Health Policy (2002) recognized that the major national disease control programme can not be effectively implemented merely through government functionaries. Taking in to consideration, the experience of last two decades the policy emphasized the importance of VOs in provisioning of the health services. It is stated that 'NHP 2002 will address the issue related to implementation of the services and suggested policy instrument for the implementation of public health programmes through individuals and institution of civil society.'[50]

The role of VOs is not only limited in provisioning of the services. Their role is also recognized in all stages of research cycle development. It helps in making good policy, knowledge production and in priories the felt need of the community. VOs are generally looked up as experience holders in health research for development.

The role of VOs is recognized in the level of policy implementation. Ministry of Health and Family welfare involved the NGOs and voluntary agencies in various programs and policy as supplement. The credibility of these second and third sector agencies is to bring the change in social and personal attitude, perception and behaviour of the community. The role of these sectors is not only to supplement health and family welfare services provided by the government, it also helps in the bringing up the communication gap between the people and the government.

A number of National Health Programmes like National Anti Malaria Program, National Leprosy Eradication Program, RNTCP, National AIDS Control Program, National Cancer Control Program and Drug De-Addiction Program launched by the MoHFW with the collaboration of various ministries of government like Ministry of Social Justice and Empowerment, Ministry of HRD etc. In these programs the financial assistance was made to VOs to undertake different kind of survey, education, awareness, treatment and provide services especially to the weaker sections of the society.

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[50] Government of India (2002), '*National Health Policy*', New Delhi: Ministry of Health and Family Welfare, p-15.

It is also mentioned by Thaneswar Bir'[51] in his book, that MoHFW launched several programmes with the contribution of VOs within which VOs have a major contribution in five major programmes, namely, National family planning programme, National Blindness Control Programme, National Leprosy Control Programme, National TB Control Programme, and National AIDS Control Programme. This dissertation mainly focuses on one of the scheme of RNTP which illustrate the role of VOs within the governmental schemes. The following chapter explores the relevant literature on the role of these organizations especially in control of tuberculosis. It also tries to see, what were the international and national efforts that have been done by the VOs to combat tuberculosis? It also made an attempt to explore the role of these organizations in policy implementation, case finding and case holding, community mobilization, monitoring and supervision.

[51] Bir, T. (2006), *Health Sector Reform in India, Perspective and Issues*, New Delhi: Arise Publication and Distributes, Vol-1.

CHAPTER - 3

TUBERCULOSIS PROGRAMME: THE ROLE OF INTERNATIONAL, NATIONAL AND LOCAL VOs

Tuberculosis Programme:

The Role of International, National and Local VOs

The previous chapter explains the concept of voluntarism and the role of the VOs in health services. It also analyzes the role of VOs in five year plans with respect to health services. As discussed in the previous chapter, VOs have an important contribution in provisioning of the health services in the remote areas and the community of the urban slum areas. This chapter explores the role of VOs in the tuberculosis programme. This includes the international, national and local efforts that have been done by the VOs to combat tuberculosis, scheme launched by the government agencies to collaborate the VOs in the provisioning of the tuberculosis services, and role of the VOs in case finding and case holding, community mobilization, monitoring and supervision.

Tuberculosis is one of the most ancient diseases and a cause of great suffering for human beings[1]. It is a major public health problem not only in India, all over the globe. 'It is a potentially fatal contagious disease that can affect almost any part of the body but is predominantly an infection of the lungs. It is caused by a bacterial microorganism, the Tubercli Bacillus or Mycobacterium Tuberculosis. Although TB can be treated, cured and can be prevented if persons at risk take prescribed drugs, scientists have never come close to wiping it out. Few diseases have caused so much distressing illness for centuries and claimed so many lives.'[2]

Although TB bacilli had been discovered over a century back (1882) by Robert Koch and drugs were available for more than 50 years but still it is a major cause of morbidity and mortality.[3] In 1912, the government of India appointed a committee under Dr. A. Lankaster to undertake an in depth assessment of the situation and

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[1] Daniel, T.M. (2006), 'The History of Tuberculosis', *Respiratory Medicine*, Vol-100, PP, 1862-1870.

[2] Medical encyclopaedia, http://www.answers.com/topic/tuberculosis accessed on 22nd Aug 2010

[3] Singh, M.M. (2007), Tuberculosis Association of India, Role in TB Control (2007), *58th TB Seal Campaign*.

enormity of the problem. At that time there was no effective treatment for TB and government efforts at combating the disease were half-hearted. At that time VOs and philanthropic societies were actively involved with this problem[4].

3.1- Journey of Voluntary Organizations (VOs) in Control of Tuberculosis from 1900 till now

From last two century, it is seen that VOs have an important role in control of tuberculosis and there is an increasing trend of collaboration with VOs within the program and policy. From the period of 1900 the role of these organizations has gain a broad meaning in the tuberculosis programme. Taking into consideration of these increasing trends of collaboration of the VOs in the programme, it is important to understand the efforts made by the international and national VOs in control of tuberculosis.

3.1.1- Tuberculosis Control: An International Voluntary Effort

From the beginning there were many international initiatives taken by international VOs in different countries. The first international conference on international medicine was held in Paris in 1867. This conference noted that tuberculosis is the most important issue in these times. Hence they projected that they should organize the meeting where they could exchange their views. The next international conference on tuberculosis held in Paris in 1888. It was the first international conference on tuberculosis. It also recommended tuberculosis in major problem and it should be controlled. During the period of 1888 to 1898 there were four conferences held in Paris specifically addressing TB[5]. All these conferences recommended that tuberculosis should be controlled. For this purpose Central Tuberculosis Bureau was formulated in Berlin in 1902. This bureau adopted double Red Cross as a symbol of the fight against the tuberculosis.[6]

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[4] Singh, M.M. (2007): *op cit*

[5] http://www.theunion.org/about-the-union/history-of-the-union.html accessed on 24th Aug 2010

6 Becklake, M. R. (1995), 'International Union Against Tuberculosis and Lung Disease (IUATLD): Initiatives in Non-Tuberculous Lung Disease', *Tuberculosis and Lung Disease*, 76, pp-493-504.

This bureau joined the Voluntary National Association and Sanatoria Movement to form a federation. But this bureau became dysfunction during First World War. Again in the period of 1920 this bureau reconstituted in Paris and again suspended during the Second World War. The delegates once again gathered during the 1946 in Paris and motivated the World Health Organization (WHO) to focus on tuberculosis.[7] The first Expert Committee of WHO met in Paris in August, 1947 and the tuberculosis section was established at the WHO secretariat to help governments for the development of effective control programmes. This control program was based on BCG vaccination and case management and since then, case management became central technical strategy for tuberculosis control.[8]

'The period of 1890 to 1900 is the period when anti-tuberculosis organizations were established in Canada many European countries.'[9] After the First World War, in 1920 International Union against Tuberculosis (IUAT) established in Paris with the help of 31 country's delegates.[10] This organization started playing an important role in setting up National Tuberculosis Associations in different countries.

During the period of Second World War tuberculosis control was not in the priority although it was a major killer disease. By early 1946, a Danish VO (Danish Relief mission) in Poland gave the attention to tuberculosis and said that 'tuberculosis is a major public health problem and local facilities are completely inadequate to cope with disease'.[11] But the problem was that, at that time (After WWII) government was not organized, lack of spare parts and reliable electric

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[7] Billo. N. *et. al.* (2009), 'International Union Against Tuberculosis and Lung Disease: past, present and future', *International Health*, PP-117-123.

[8] *Cited in* Raviglione, M. C. and Pio, A. (2002), 'Evolution of WHO Policies for Tuberculosis Control, 1948–2001', *The Lancet*, Vol. 359.

[9] Rouillorl, A. (1982), 'The International Union against Tuberculosis: a General View', *Bull International Union against Tuberculosis*, 57(3-4): 196-201.

[10] Becklake, M. R. (1995), 'International Union Against Tuberculosis and Lung Disease (IUATLD): initiatives in non-tuberculosis lung disease', *Tubercle and Lung Disease*,76, pp-493-504.

[11] International Tuberculosis Campaign (1951), '*Final Report of the International Tuberculosis Campaign, July 1, 1948- June 30 1951*', Copenhagen: ITC.

power made X-ray impossible.[12] So as a result it was thought mass vaccination against TB with Bacilli Calmette-Gurin (BCG) vaccination would be good in prevention of disease.

The literature shows that Denmark is also known as an important contributor in control and prevention of tuberculosis[13]. It is the first country where VOs played a significant contribution in prevention of tuberculosis, although in Denmark tuberculosis death rate is said to be the lowest in the world. The Danish Relief Mission started the movement against tuberculosis and gradually the State took over complete responsibility.[14]

A remarkable voluntary initiative was taken by the UNICEF and the Danish Red Cross on the European continent. Infact, it was the first voluntary effort in the form of collaboration of two organizations in the control of tuberculosis. This collaborative effort was to make available the BCG vaccination on the scale never before attempted, represented a lasting contribution for the welfare of the European childhood and adolescence and will contribute to very large degree in speeding up the recovery of the war-sic countries. Mr. Jahannes Holem was the director of this project. This voluntary effort was based on tuberculin testing followed by the BCG vaccination.[15]

Although in most of the countries the TB control is a state responsibility, the presence of the strong and influential TB Association shows the commitment of the voluntary effort for TB management and control. For e.g. the Canadian Tuberculosis Association, UK National Association for the Prevention of Tuberculosis, National Tuberculosis Association of America etc plays a very important role in research and support services. Most of these association acts as a strong research and advocacy body which carry out research independently from the state and also initiating various welfare programmes like support group, health education, supplementing govt effort etc. More over these associations do not take

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[12] Comstock, G. W. (1994), 'The International Tuberculosis Campaign: A Pioneering Venture in The Mass Vaccination and Research', *Clinical Infectious Disease*, vol.19 No.3, pp 528-540.

[13] Brimnes, N. (2007), 'Viking against Tuberculosis: The International Tuberculosis Campaign in India 1948-1951' *Bulletin of the History of the Medicine,* 81 (2), 407-430

[14]Comstock, G. W. (1994), *op cit*

[15] Comstock, G. W. (1994), *op cit*

grant or subsidy from the state so that they can act as independent organization free from government regulation and red tapism and put forward their concern freely and without any barrier.[16]

In the period of late nineteenth century the first VO was established in the city of London, consisting of same celebrities of that time under the patronage of then Prince of Wales. The main activities of this organization was to look after the families of the patients admitted in sanatoria and to look after the patients and rehabilitate them, if necessary, after discharge from the sanatoria to supplement the official setup. Similar organizations came up in different countries very soon.

3.1.2- Control of Tuberculosis: Efforts by National Voluntary Organizations

The voluntary effort in India can be divided in two forms, one is in the form of institution in which provide services for treatment and cure like voluntary hospitals and sanatoria etc. Second aspect of the voluntary effort was looking after the socio-economic need of the patients and their families during treatment and rehabilitation.

3.1.3- Contribution of Voluntary Effort in the Formulation of Tuberculosis Institution

The fundamentals of the anti-tuberculosis movement in India are based to some extent on the experience gained in other countries in the field. It is new phenomena in India. A tuberculin survey was conducted by the Dr. Lankester on behalf of the government for several years. The survey report published in 1921. Due to the high incidence of TB infection, he recommended that the government should work closely with the VOs/Non-Governmental Organisations (NGOs) and support their activities. This will help in fill the vacuum between government and people in terms of services.[17] And as a result the voluntary effort stared in India and India became the member of the IUAT in 1929.[18]

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[16] Benjamin, P.V. (1955), 'Non-Official Anti-Tuberculosis Movement', *Indian Journal of Tuberculosis*, Vol. II, No-2.

[17] http://ntiindia.kar.nic.in/docs/nti_annals/pages/ANNALSThegenesis_22.htm, accessed on 25th Aug 2010

[18] Benjamin, P.V. (1955), *op cit*

In India the institutional cooperation with the non state actor was initiated with the set up of King George V Thanksgiving (Anti-tuberculosis) Fund in the period of 1929. This was set up as an all India fund dedicated for TB control activity and also specialized Medical Education programme on TB for doctors was organized through the fund money[19].

The next stage in the movement was when in 1937 Lady Linlithgow issued a public appeal for an anti-tuberculosis fund on behalf of the government. As a result, nearly a crore of rupees was collected from which five percent of this money was retained by the centre and the balance was distributed to the Provinces and States. With the help of this five percent direct donation and King George V Thanksgiving (Anti-tuberculosis fund), the Tuberculosis Association of India was formed in February, 1939. The provinces and States, which received money, started their tuberculosis association. The Bengal Tuberculosis Association which was established in 1929, however, was maintaining dispensaries in Calcutta and Howrah and helping poor patients.[20] [21]

3.1.4- Sanatoria movement

In India first voluntary effort in tuberculosis control started in the form of sanatorium. The basic assumption of this effort was to keep the patient in isolation; it will not transmit the infection. It was believed that tuberculosis was not present in the mountains due to the climatic factors and hence led to establishments of sanatoria in the hilly regions of Italy and Rome. This doctrine said, "Pure *air, pure water, pure foods were essential for healthy living.*"[22]It was the beginning of the 'Sanatorium Movement' which was organized in England. In the absence of chemotherapy, rested fundamentally on a balance diet fresh air and regulated exercise if possible in an environment of unspoiled nature. The first open-air sanatorium was started in the period of 1906 in India, near the city of

[19] Benjamin, P.V. (1955), *op cit*

[20] Benjamin, P.V. (1955), *op cit*

[21] Singh, M.M. (2006), *Tuberculosis Association of India, Role in TB Control*, 57th TB Seal Campaign.

[22] Dubos, R.J. (1952), '*The White Plague: Tuberculosis Man and Society*', Boston: Little Brown and Company.

Ajmer at Tilonia. It was started by Christian VO. The second came up at Almora in 1908 for isolation and treatment of patient[23] and followed by the Maharashtra, UP and Bengal. One of the VO based in Bombay administered by a Parsee Trust set up a sanatorium in the Simla at Dharampur in 1909. It was first non-missionary sanatoria.[24] [25]

It is the government's responsibility to provide the medical care to all people, protect the patient's family and establish institutions and trained personnel. But these tasks are not possible without the cooperation of the community. To get the cooperation of community the role of VOs is very important. Tuberculosis Association of India has initiated to participate in anti-tuberculosis work.

The first organizational effort came in Delhi in 1940s when domiciliary treatment was being tried by the New Delhi Tuberculosis centre. Care and after care committee was started in several localities. They helped the patient's family financially for the supplement of the nutrition; sustain the family look after other need like vocational training for some family members, rehabilitation of the patient etc. The basic assumption behind this was not to eliminate poverty but to make sure that poverty did not obstruct the patient's treatment.[26]

The organization started to provide training to doctors and health visitors during the period of 1947. Institution was also engaged in organizing the annual conference of the TB worker, evolving standardisation of method of diagnosis and treatment. They were also involved in stimulating the anti-tuberculosis movement.

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[23] Kumar, P. (2005), 'Journey Of Tuberculosis Control Movement In India: National Tuberculosis Programme To Revised National Tuberculosis Control Programme', *Indian Journal of Tuberculosis*, 52:63-71.

[24] Agarwal, S.P. *et. al.* (2005), 'The History of Tuberculosis Control in India: Glimpses through Decades' in Agarwal, S.P. and Chauhan, L.S., *Tuberculosis Control in India*, New Delhi: Ministry of Health and Family Welfare.

[25] Pamra, S.P. (1995), 'The Role of Voluntary Organizations in Tuberculosis Control', in Chakraborty, A.K. *et. al.* (eds), *Urban Tuberculosis Control: Problems and Prospects*, Mumbai: The Foundation for Research in Community Health, p. 61.

[26] Pamra, S.P. (1990), *New Delhi Tuberculosis Centre:1940-1990, Golden jubilee Souvenir*, New Delhi: New Delhi Tuberculosis Centre, pp 1-6.

The diploma course in tuberculosis is the outcome of these efforts done by the Tuberculosis Association of India.[27]

Further the contribution was continuing in control of tuberculosis. The New Delhi tuberculosis clinic has been developed, with the help of UNICEF as the training and demonstration centre. The Tuberculosis Seal Sale Campaign was also started for health education among communities and to collect money.[28]

The second aspect of voluntary effort in tuberculosis control was socio-economic and rehabilitation support to the tuberculosis patients. Because tuberculosis is a disease of poverty, it mostly affects those who are living in unhygienic conditions and do not have sufficient food, and work in close contact in worse conditions. For instance, if the victim is the breadwinner of the family then malaise has to be borne by the entire family and thus the sustenance of the family becomes difficult. So the second aspect of voluntary effort was to provide socio-economic support to the family.

When the anti-tuberculosis drugs became available, government was not responsible to provide free of cost drugs to the patients because of the cost factor. At that time VOs were playing an important role in providing the free drugs to the patients who were unable to afford the cost of the drugs. This kind of philanthropic work was being performed by the VOs at that time and it became very important factor in success of New Delhi tuberculosis centre in domiciliary treatment trial.[29]

3.1.5- BCG Campaign in India

From the 1920s Bacillus Calmette Guerin (BCG) vaccination was used as a preventive measure in European countries. It was the only measure used as prevention and control of tuberculosis and was considered as an operationally and economically feasible method in the control of tuberculosis. In India Dr. J. Frimodt Moller introduced BCG

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[27] Benjamin, P.V. (1955), *op cit*

[28] Benjamin, P.V. (1955), *op cit*

[29] Pamra, S.P. (1990), *op cit*

vaccination for the first time in 1948[30] and in 1951 the mass BCG campaign started, and total 65 million children were vaccinated, 165 million tuberculin tests were administered.[31]

In 1950s the UNICEF and WHO collaborative action on TB resulted in the BCG vaccination Production unity in Guindy Chennai. Also the indigenous production of Streptomycin and Para-Amino Salicylic Acid (PAS) was first introduced in 40s followed by Thioacetazone and Isonicotinic Acid Hydrazide (INH) in 50s. The drug trials for these were also carried out in various places by different physicians like Dr. Sikand from New Delhi TB Centre, Dr. Sen from Calcutta in 1952, Dr. Frimodt Moller from Madanapalle in 1953, and Dr. Sikand & Dr. Pamra from Delhi in 1956 on a controlled no of patient. The BCG vaccine produced by the Guindy Unit also helped India to launch mass BCG vaccination programme.[32]

Dr. P.V. Benjamin was the moving force behind the introduction of the mass BCG campaign in India and setting up of the Mahtauli TB Hospital. It is now known as Lala Ram Saroup Institute of TB and Allied Diseases. He was the member of health planning in the Planning Commission and played an important role in development of Tuberculosis Research Centre (TRC) in Madras. It was earlier called as Tuberculosis chemotherapy Centre and National Tuberculosis Institute (NTI) at Bangalore.[33]

During the period of mid 1960s there was a world wide debate and controversy on the preventive effect of BCG vaccination. This debate was the outcome of the different number of studied done in different countries. This study shows the protection value of BCG varying from zero to eighty. In India it was felt that it is necessary to undertake a field trial study to see the preventive value of BCG. In 1968 government of India decided to conduct a field trial study in Chingleput district of Tamilnadu where BCG vaccination was previously not offered. The results showed the

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[30] Kumar, P. (2005), 'Journey of Tuberculosis Control Movement in India: National Tuberculosis Programme to Revised National Tuberculosis Control Programme', *Indian Journal of Tuberculosis*, 52:63-71.

[31] Agarwal, S.P, *et. al.* (2005), 'The History of Tuberculosis Control in India: Glimpses through Decades, in Agarwal, S.P. and Chauhan, L.S. (2005), *Tuberculosis Control in India*, New Delhi: Ministry of Health and Family Welfare.

[32] Kumar, P (2005), *op cit*

[33] Mahadev, M. and Kumar, P. (2005), *Glimpses of Tuberculosis Program and Research in India-Yesterday, Today and Tomorrow,* Bangalore: National Tuberculosis Institute.

ineffectiveness of BCG against Pulmonary TB, the wider implications became evident as the BCG campaign had already ensued. But, despite this it was decided to continue BCG vaccination in children as a part of the expanded program of immunization (EPI) to provide protection during childhood against TB[34].

3.2- Formulation of National Tuberculosis Program (NTP) and Role of Voluntary Organizations

Before the National Tuberculosis Program, the available tool for tuberculosis control was BCG vaccination, chest radiography and sputum microscopy and ambulatory domiciliary chemotherapy. The BCG vaccination was used for prevention, chest radiography and sputum microscopy was for diagnosis and ambulatory domiciliary chemotherapy was for treatment of the disease. But the problem faced by the country was the application of these tools on a wider canvas. There was a need for systematic approach to apply these tools on mass scale. So for development of tuberculosis control program, government of India established a National Tuberculosis Institute (NTI) with the help of WHO in 1959 in Bangalore.[35]

The build-up a national program for tuberculosis, NTI started in the right earnest by collating all the available data on tuberculosis and commissioning studies to fill in the existing gaps in knowledge about different aspects of the disease to develop nationally applicable, socially acceptable and epidemiologically sound National Tuberculosis Program. As a result India launched National Tuberculosis Program in 1962. The program was inspired by the study done by the National Tuberculosis Institute (NTI) Bangalore, Tuberculosis Research Centre (TRC) Madras and Delhi . The finding of the study was that, the prevalence of the tuberculosis is not only prominent in urban areas but also in rural areas. It was proved by the National Sample Survey (NSS) and other studies that there is no need of active case finding. Hospital

[34] Baily, G.V.J (1980), 'The Efficacy of BCG Vaccination-A Brief Report of the Chingleput BCG Trail', *NTI News Letter*, Vol. 17, pp. 108-18.

[35] Agarwal, S.P, *et. al.* (2005), *op cit.*

based treatment is not needed and home based treatment has equal effect on control of tuberculosis.[36]

Considering the tuberculosis problem as a problem of suffering, and of the availability, accessibility and affordability of the general health services for TB patient, provided the basis for the integration of NTP with general health services. Thus, NTP was planed as an integrated programme, which would "sink or sail" along with the general health services.[37]

This program was operating through the District Tuberculosis Program (DTP) which was the backbone of the NTP. The DTP was including government's all level hospital and other institutions like dispensaries, health unit, CGHS hospitals, local bodies religious missionaries, VOs and private charitable societies. The activities of DTC were case finding and treatment. The treatment was domiciliary based.[38]

The VOs had very significant role in the control of tuberculosis before the NTP, because there were no specific effective measures for that and government had no program for the control of tuberculosis. During the period of late 70s the availability of the drugs and diagnosis facilities in government hospitals reduce the role of these organizations. Hospitals and sanatoria were having very miner role to play. But it does not means that VOs had no role to play. Some charitable organizations such as Ramakrishna Mission, Tuberculosis Association of India (TAI), Delhi Tuberculosis Association, Bengal Tuberculosis Association etc were working for the control of tuberculosis and betterment of people. But their role was ambiguous. Within the NTP, VOs were not having the define role to play.

This ambiguity of the VOs raised the question in what way the VOs can supplement government effort. This was the transformation in role of VOs. The organizations during this era were working especially in the area of health education especially for information education and communication (IEC) activities, and started to work as to

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[36] Uplekar, M. and Rangan, S. (1999), *Tackling TB the Search for Solution*, Mumbai: The Foundation for Research in Community Health.

[37] Banerji, D. (2003), 'A Social Science Approach to Strengthening India's National Tuberculosis Programme', *Indian Journal of Tuberculosis,* 40, 61.

[38] Kishore, J. (2006), *National Health Programme in India National Policies and Legislations Related to Health*, New Delhi: Century Publications.

supplemental government effort. They were engaged in providing the information to community regarding facility provided by the government. In other words they stared to do empower the patient and legislative work.[39]

3.3- Evaluation of Revised National Tuberculosis Control Program (RNTCP)

The availability of the anti-tuberculosis drug and successful trial of short course chemotherapy it was possible to reduce the duration from 12 months to six months during the period of NTP. This was start of a new era in control of tuberculosis. There were lots of studies done in those days to see the effectiveness of the program. A pilot study was done by Tuberculosis Research Centre, Chennai in 1983 to access the feasibility of the sort-course chemotherapy. In this trial 18 district of county were covered. Later on in 1986 a field trial was done by TRC and NTI, on the basis of these successful trials, Government of India agreed to introduce short-course chemotherapy on 252 districts.[40]

But these interventions were not very effective as there was an only a slight improvement in the control of tuberculosis cases in the country. Some evaluation studies were also done by different agencies such as Indian Council of Medical Research (ICMR), the Institute of Communication, Operation Research and Community Involvement (ICORCI), and . These evaluation studies explicitly presented the difference between expected and actual achievement.[41]

In 1992 a comprehensive review done by a committee of national and international expert, also determined that the program had not achieved the desire result.[42] To strengthen efforts to combat new emerging challenges like TB-HIV co-infection and MDR, the government of India adopted Revised National Tuberculosis Control Program in 1993 in the form of DOTS. This program makes a call to all health sectors to fight against tuberculosis. The underlying principal of this program is TB can be controlled by early detection and effective treatment of

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[39] Pamra, S.P. (1995), *op cit* pp. *63-64*

[40] National Tuberculosis Institute (1993), *Year Book on NTP in India 1992,* Bangalore: NTI

[41] Agarwal, S.P, *et. al.* (2005), *op cit*

[42] Arora, V.K. and Sarin, R. (2000), Revised National Tuberculosis Control Programme Indian Perspective, *Indian Journal of Chest Disease Allied Sciences*, 2000; 42 : 21-26.

infectious pulmonary TB cases who act as the sources of infection. Thus the basic curative as well as preventive strategy is the treatment of infectious TB patients until cure. The priority for treatment were newly diagnosed, sputum-positive pulmonary tuberculosis cases, as they are the main sources of infection and are more likely to die unless effectively treated. The political and administrative commitment ensures the provision of organized and comprehensive TB control services were emphasized.

3.3.1- Objectives of Revised National Tuberculosis Control Program

The Goal of the RNTCP is to decrease mortality and morbidity due to TB and reduce the transmission of infection until TB ceases to be a major public health problem. The goal is achieved through the following objectives:

I- "Emphasis on the cure of infectious and seriously ill patients of tuberculosis, through administration of supervised short course chemotherapy, to achieve a cure rate of at least 85.

II- Augmentation of the cases finding activities to detect 70 percent of estimated cases, only after having achieved the desire cure rate."[43]

The above mentioned objectives of RNTCP are to be attained through the strategy of DOTS. DOTS which is now the internationally recommended strategy of choice for TB control has the following five components-[44]

1- Sustained political commitment to increase human and financial resources and make TB control a nation-wide activity integral to national health system;

2- Access to quality-assured TB sputum microscopy for case detection among persons presenting with, or found through screening to have, symptoms of TB (most importantly prolonged cough).

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[43] Banerji, D (1997), '*Serious Implications of the Proposed Revised National Tuberculosis Control Programme for India*', New Delhi: Voluntary Health Association of India and Nucleus for Health Policies and Programmes.

[44] Government of India (2005), '*Revised National Tuberculosis Control Program, Technical and Operational Guidelines for Tuberculosis Control*', New Delhi: Ministry of Health and Family Welfare.

3- Standardized short-course chemotherapy to all cases of TB under proper case management conditions including direct observation of treatment – proper case management conditions imply technically sound and socially supportive treatment services.

4- Uninterrupted supply of quality-assured drugs with reliable drug procurement and distribution systems.

5- Recording and reporting system enabling outcome assessment of each and every patient and assessment of the overall programme performance

3.3.2- The Strategy used in RNTCP to control of Tuberculosis:

To achieve the objective of any program there is a need of some strategy. Taking in to consideration of above objectives the program adopted some strategies in control of tuberculosis. These strategies are given bellow:

Strategies Relating to Case-finding:

Case finding is the most important factor in control of tuberculosis. The program emphasized the passive case finding method to detect the new sputum cases. To identified the positive cases correctly, a better technology of diagnosis was important so programme stress on diagnosis of patient and the diagnosis is based on sputum examination and the quality of diagnosis will be improved by provision of binocular microscopes, uninterrupted supply of good quality laboratory material, proper training and supervision, three sputum smears for diagnosis, establishing quality control with a cross checking mechanism at every level.

Strategies Related to Treatment and Case-holding:

It is also an important component in control of tuberculosis. Short course chemotherapy will be given every diagnose patient as per RNTCP treatment guideline. The intensive phase is directly observed through DOTS providers and continuation phase properly supervised by observing the intake of the first dose of the medicine during the weekly drug collections. The empty foils of comb packs also will be checked at the time of collection of next dosages.

Strategies Related to Operational Management:

Operational management is important for success of any programme. So strengthening at every level will be done by providing necessary manpower, equipment and training to facilitate monitoring, supervision and training. A Tuberculosis Unit (TU) will be established at the sub-district in an existing community health centre (CHC)/Block Primary health centre (PHC)/Taluk hospital which function as the managerial unit of the programme for 0.3 to 0.5 million populations and comprise of a Senior Treatment Supervisor (STS) and a Senior TB Laboratory Supervisor (STLS). This team will be responsible for implementation and supervision of all facets of the programme in their area. Maintenance of the records and preparation of progress reports was also done by the TU. The team will be under supervision of one of the medical officers in position at the TB Unit who shall be designated as MO-TC.

Strategy for Other Key Areas

Other strategy also adapted to control of tuberculosis. A health information network also will be developed for the regular monitoring and evaluation of programme activities. To spread the awareness regarding TB in the community an effective Information education and Communication (IEC) strategy will be develop through expert group and awareness will be spread regarding the symptoms and sign of TB in the community."[45] [46]

3.4- Public Private MIX (PPM) Model in RNTCP:

Providing the Legitimacy to Voluntary Organizations

VOs have been working in the field of the tuberculosis for many decades till now. In the beginning VOs were providing psychosocial and economical support with the tuberculosis services to patient and their families. After that they started to work with the collaboration of government. Although RNTCP program was

[45] Sarin, R. and Dey, L.B.S. (1995), 'Indian National Tuberculosis Programme Revised Strategy', *Indian Journal of Tuberculosis*, Vol. 42, No-2, pp. 95-100.

[46] Arora, V.K. and Sarin, R.(2000), 'Revised National Tuberculosis Control Programme Indian Perspective', *Indian Journal of Chest Disease Allied Sciences*, 42 : 21-26.

designed for implement through public health services under state governments. But to cover whole population program started to collaborate with second and third sector organizations on the basis of PPM concept. PPM concept has gone through various stages. Earlier it was used as in connection of TB program with other sector. Later this concept evolved and acquired a broader meaning as a strategy to diagnose and treat TB patient from any sector of health care under the DOTS strategy through different type of service providers.[47] WHO defines PPM as 'strategies that link all entities within the private and public sectors (including health providers in other governmental ministries) to the national TB programme for DOTS expansion'.[48]

Thus Public private mix (PPM) has been recognized as an important component in the RNTCP. The purpose of public private mix-DOTS (PPM-DOTS) '.....is to effectively link the national TB programme and all public and private health care providers presently out of realms of national TB programme efforts so as to provide standardized treatment to all TB patients in the country.'[49] Thus till 2009 there were more than 2500 NGOs[50] are working with the collaboration of VOs. The figure one reveals the state wise number of the VOs working with the collaboration of the Government. States with less than 50 VOs have not been mentioned in the figure.

Thus on the basis of PPM-DOTS strategy, in the period of 2000 and 2001 Government of India developed guidelines for NGO and private sector to make equal partner for the RNTCP implementation.

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[47] Agarwal, S.P. *et.al.* (2005), 'Public-Private Mix in the Revised National TB Control Programme', in Agarwal, S.P. and Chauhan, L.S., *Tuberculosis Control in India'*, New Delhi: Ministry of Health and Family Welfare, p. 136.

[48] *Cited in,* Agarwal, S.P. *et.al.* (2005), *op cit,* p. 136

[49] Government of India, (2008), '*Revised National Tuberculosis Control Program, Revised scheme for NGOs and Private providers*, New Delhi: Ministry of Health and Family Welfare.

[50]Government of India, (2010), '*TB India 2010 – RNTCP Status Report'* New Delhi: Ministry of Health and Family Welfare.

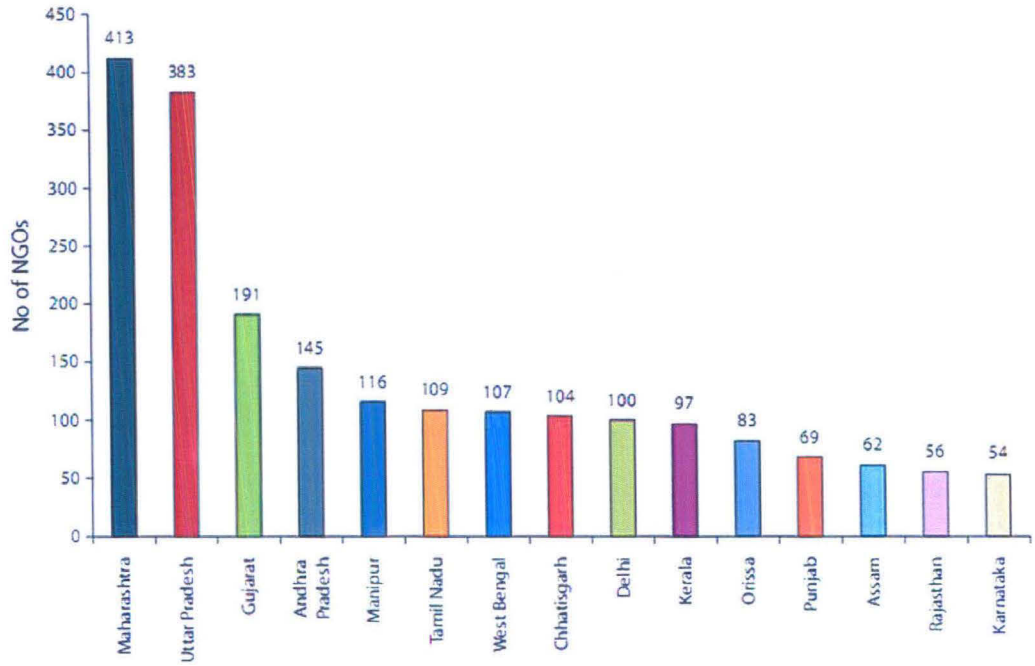

Figure – 3.1 Number of VOs in India in RNTCP: State wise Distribution

(Source: Government of India, (2010)

On the basis of these guidelines government of India made a call for VOs/NGOs to collaborate within the RNTCP in five schemes. These schemes were:'[51]

1- 'Scheme 1: Health Education and Community Outreach: In this scheme it was mentioned that VOs/NGOs will sensitize, train volunteers, disseminate information, provide counseling to patients, families; orient & advocate key groups, develop and revise IEC material according to local context.

2- Scheme 2: Provision of Directly Observed Therapy- NGOs can identify, train and supervise volunteers who will provide DOT. The DOT provider is also responsible for ensuring collection of sputum during treatment and for default retrieval.

3- Scheme 3: In-Hospital Care for TB patients- The established and experienced NGOs provide in hospital care for TB patients who require such care. The hospital performs AFB smear microscopy and follow-up sputum examination of patients on treatment to those who live in areas covered by the RNTCP.

[51]Government of India (2001), *op cit*

4- Scheme 4: Microscopy and Treatment Centre- the NGO serves as a microscopy & treatment centre and is designated as such by RNTCP. The NGO provides Acid Fast Bacilli (AFB) microscopy & TB treatment service free of charge.

5- Scheme 5: TB Unit Model– Under the scheme, NGO provides full services for microscopy, treatment, direct observation, defaulter retrieval, recording and registration as earmarked for TB Unit.'[52]

After 7 to 8 years of implementations a decline in the uptake of the scheme under formal agreement was observed. It was felt that there is a need to revise scheme for better collaboration of VO and PPs. The new initiatives such as DOTS plus, TB- HIV collaboration were not covered under the previous scheme. The social support component required for successful completion of long Duration treatment of MDR TB was not there. It was also felt that previous collaboration did not have the any specific scheme to cover migrants and slum dwellers."[53]

Therefore, the Central TB Division conducted a three day Consultation on Revision of NGOs/PPs Guidelines in January 2008 in Delhi. There were 60-70 participants in this consultation from government, non-government and other different sectors. The present scheme is more feasible and provides better opportunity to local VOs/NGOs to collaborate in RNTCP. Today the programme involves more than 2500 non - governmental organizations (NGOs), more than 25,000 private practitioners (PPs), 260 Medical colleges and 150 corporate houses'[54]. The number of the VOs is continuously increasing. The data reveals that in 2003 there were 800 VOs were providing tuberculosis services[55] where in 2008 the number of VOs is 2500.

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[52] Dhingra, S. (2001), 'Role of Non-Governmental Sector in Revised National Tuberculosis Control Programme', *NTI Bulletin*, 37, 1-4, 22-23.

[53] *Ibid*

[54] Government of India, (2008), '*Revised National Tuberculosis Control Program, Revised scheme for NGOs and Private providers*, New Delhi: Ministry of Health and Family Welfare.

[55]Government of India, (2003), '*TB India 2003*', New Delhi: Ministry of Health and Family Welfare, pp. 16-46

3.5- Towards new Government-VOs collaboration: Revised Schemes for NGOs/PPs

This scheme provides a great opportunity to all type of VOs to work with RNTCP. There are 10 schemes under which VOs/NGOs can collaborate.[56]

1- ACSM Scheme: TB Advocacy, Communication, and Social Mobilization

It is a very important component in control of tuberculosis. It is assumed that improvement in ACSM (advocacy, communication, and social mobilization) will help in Mobilization of local political commitment and resources for TB, in improved case detection and treatment adherence, in empower people and communities affected by TB and reduced stigma and discrimination against persons and families affected by TB. The role of the NGO/VOs in this scheme is to plan and undertake a series of ACSM activities in consultation with the District Health Society and these plans should be based on the need assessment, programme performance, and should be linked to work plan submitted at the time of signing of MOU. The NGO and VOs is also expected to reproduce good quality communication materials, ideally using prototype materials obtained from the District / RNTCP website, which can be adapted for the local language and context if necessary. For this purpose a total Grant in aid of Rs. 1, 50,000 per 1 million (10 lakhs) populations per year will be provided. If a larger population is covered with a larger series of ACSM activities, then RNTCP support for the scheme would be scaled up on a pro-rata basis.

2- SC Scheme: Sputum Collection Centre/s

In RNTCP diagnosis through sputum smear microscopy is the backbone of the program. So to increase equity and accessibility of TB health care delivery services, sputum collection should be as close and convenient to patients as possible. In current scenario there are 12,000 Designated Microscopy Centres (DMCs) in the entire country, but there are still areas where Designated Microscopy Centres (DMCs) is not available. So under lying assumption of this scheme is that, VOs or non-government organizations/private provider supported

[56] This section drawn largely from the article, Government of India, (2008), *op cit*

sputum collection centres can be established to provide ease of accessibility to patients.

Under this scheme the role of NGOs/VOs ranges from Sputum collection from TB suspects referred from outpatients of the same facility, the surrounding community, and other facilities linked in the vicinity and to collect diagnostic and follow up sputum specimens following RNTCP guidelines. Moreover it has to be ensured the adherence to guidelines on sputum collection in order to obtain good quality sputum samples. The accuracy of recording in lab forms and dispatch lists, labelling, recording and packaging of samples, too has to be ensured.

There also has to be a mechanism for transportation (via Transport Scheme or via general health system), and also that there is timely communication of sputum results back to referring providers and NGOs should procure standardized kits for transportation.

For this purpose a total reimbursement of Rs 60,000/- per annum per sputum collection centre, lump sum has been established. In which Rs 3000 are allocated for facility cost and Rs. 2000 for service cost.

3- Transport Scheme: Sputum Pick-Up and Transport Service

Transportation is very important to send the sample of sputum to respective place. So under this scheme the role of NGOs/VOs is to coordinate with the assigned Sputum Collection Centres and the DMCs, transport samples safely to DMCs periodically, convey the results in dispatch lists and forms to the Sputum Collection Centres and maintain travel log book. For this purpose a total Grant in aid Rs 24,000 per annum (for a maximum of 20 visits per month) are provided to organization.

4- DMC Scheme: Designated Microscopy cum Treatment Centre (A & B)

Under this scheme, VOs/non-governmental organization can collaborate in two ways one is Designated Microscopy and Treatment Centre for a NGO/Private lab and second one is Designated Microscopy Centre - Microscopy only.

Under the scheme Designated Microscopy and Treatment Centre for a NGO/Private lab it is recommended that the NGO/private facility provides AFB microscopy and TB treatment services free of charge and method of sputum collection and examination and providing anti-TB treatment will be as per RNTCP guidelines. The NGO/private facility will be responsible for ensuring the treatment or referral and follow-up treatment of all patients placed on treatment. The organization will also provide antibiotics, free of cost to all sputum smear negative case for two weeks before they are sent for X-ray examination.

The NGO/private facility must ensure that, in addition to a trained laboratory technician, there is a qualified Medical Officer (MO) trained in the RNTCP. For these purposes the government (RNTCP) will provide annual Grant in aid of Rs 1, 50,000.

Designated Microscopy Centre - Microscopy only

This scheme is basically for private practitioners who have its own laboratory. Under this collaboration they provide services under RNTCP guideline and patients are not charged for AFB microscopy. The required materials are provided by the Government itself.

All sputum microscopy and health facility including records must be follow according to RNTCP guideline. LT should also preserve slides for cross checking by STLS as per quality assurance protocol of RNTCP and all diagnosed TB patients must be informed of the availability of free services and referred to Government MCs or DOT centres for categorization and treatment. It is also organizations responsibility to pass on the result of microscopy to their respective place within one day. They are also responsible to prepare a monthly report which will be collected by STLS during his visits to the microscopy centre. The fund allocation for this purpose is Rs 25 per slide.

5- LT Scheme: Strengthening RNTCP diagnostic services

There are many RNTCP designated microscopy centre where the influx of patients is very high and due to lack of proper resource centers are not properly functioning. So insure the effective and uninterrupted functioning the guideline

made a call for those VO/ NGOs who will work under the public sector (e.g. health department of the state/centre, medical colleges, other public sector health facilities like ESI, public sector undertakings, etc). The recruitment of the LT and maintenance of the centers will be in the hand of collaborating organizations. But the supervision and guidance of the LT will be in hand of DTO and the local STLS. This support by the NGO should be provided to address short term human resource constraints, usually not exceeding 3 years. Every effort should be made by the local RNTCP programme manager to address in the longer term this human resource constraint through the government health system and initiatives/projects that target health system strengthening.

The role NGOs/VOs under this scheme is to recruit a suitable laboratory technician, to maintain person on payroll and regular salary payments, in supervision and monitoring of laboratory technician performance (with District RNTCP), including conduction of performance appraisals and in cases where this activity will be funded by the NGO, the responsibility of resource mobilization will lie with the NGO. For this the Grant in aid is as per RNTCP contractual Lab Technician salary, and 5 overhead, and recruitment cost reimbursement equal to one month salary.

A partner NGO or RNTCP has to bear the recruitment cost, salary and overheads and the salary of the laboratory technician should be at par with the existing approved salary of such cadres of RNTCP staff. The gross amount payable by RNTCP to a partner NGO, if it is a RNTCP funding, will be worked out on the basis of the prorated salary(s) of laboratory technician(s) for the period of support and adding to it a recruitment cost of a month's salary (only for new recruits) and an overhead cost equaling 5 of the overall salary. For instance if the RNTCP salary for LT is Rs.6500 for a month the amount payable to each laboratory technician per year to the NGO will be Rs.88, 400.

6- Culture and DST (Drug Susceptibility Testing) Scheme: Providing Quality Assured Culture and Drug Susceptibility Testing Services

This scheme provides the space to VOs/NGOs for the collaboration in establishing a national wide network of quality assured sputum / specimen culture and drug susceptibility testing (C and DST) laboratories for the diagnosis and follow up of multi-drug resistant TB (MDR-TB) patients. This scheme will provide help to non-governmental sector in development of well functioning mycobacteriology laboratories.

The roles of VOs/NGOs in this scheme are to maintain adequate infrastructure, equipment, and appropriate staff for the fully functioning of laboratory at all times. They are also administering to keep records and make co-ordination with the respective NRL (National Reference Laboratory) and State TB Officer (STO) for external quality assessment of the laboratory.

Grant in aid in this program is based on per decided number as per DOTS-Plus implementation plan.

7- Adherence scheme: Promoting treatment adherence

It is recognized that VOs or Non-governmental organizations are providing the health services in the community from the beginning. They are easy accessible and has good rapport with community. These organizations also have capacity to provide excellent treatment support, counselling for patients, and can contribute to public health oriented activities in TB treatment, namely address verification and default retrieval. So this scheme used the decentralization process with the VO/ non-governmental organization to make treatment maximally accessible and acceptable to patients.

In this program the role of VOs are very broad. Under this scheme they are engaged in DOT services, awareness generation and counselling services for the patients and families.

Under DOT services the following activities should be done by the VO that is given below:

- Identify, train, and supervise volunteers who will be providing DOT.
- Provide RNTCP treatment to patients at a time and place accessible and acceptable to patients.

- Ensure that treatment is provided strictly as per RNTCP policy, free of charge to patients for any service rendered
- Ensure that DOT providers maintain records as per RNTCP policy
- Ensure the collection of follow up sputum specimens
- Organize medical care for side effects at appropriate health services
- Facilitate payment of RNTCP DOT provision honorarium at current rate to community DOT providers
- Assist in providing continuity of care for referred or transferred patients.

In awareness generation organizations are supposed to conduct IEC activities related to treatment adherence, including community meetings and patient-provider meetings. They are also accountable for creating awareness and linking the patients with the existing welfare schemes for entitled patients.

The counselling services for patients and families are also important. Under this scheme VOs are also recommended to provide emotional support, information on symptoms, disease, and duration of treatment, importance of DOT adherence, side effects, and referrals. The role of NGOs is also in services and referrals for substance abuse harm reduction.

The Grant in aid for NGOs supervising DOT services is Rs 40,000 for every 1 lakh population per annum, pro-rata for population served. (For example, if 5, 00,000 population treatment services were supported with all services, Rs 2,00,000 per annum would be reimbursed.)

Grant in aid for DOT- the RNTCP provide Rs 250 for Cat I, II, and III patients to the individual volunteer for each patient. The amount is given after the cured or treatment completion. For Cat four Rs 2500 per patient {Rs 1000/- for intensive phase (IP) and Rs 1500/- for continuation phase (CP)} is given to the individual volunteer for each case.

8- Slum Scheme: Improving TB control in Urban slums

The urban growth is rapidly increasing with the population of urban slum dwellers and they are suppose to very close to health services but due to inadequacies in the urban public health delivery system their accessibility is very low. They are migrant and living in worst condition. The urban poor women are more vulnerable

to get disease. They are mostly engaged in manual work. So taking in to consideration of these factors to cover whole population RNTCP make this scheme.

The role of VOs/NGOs in this scheme are to organize IEC activities in slum population for TB and service awareness, counsel patients for completion of diagnostic process, treatment initiation, treatment adherence, information regarding pending migration, and default prevention, conduct address verification for patients, address special needs of patients, such as drug abuse, alcohol abuse, facilitate sputum collection and transportation to DMCs, provide DOTS as per RNTCP guidelines, retrieve patients who have interrupted treatment, and inform RNTCP staff regarding patients for whom retrieval efforts are not successful and facilitate communication to RNTCP staff regarding impending migration of patients, so that appropriate referral or transfer can be arranged.

An Rs.50, 000 per 20,000 populations per annum (pro-rata for slum population size) are being provided as a Grant in aid. It includes facility cost, remuneration for the worker, and cost of sputum transportation and administrative cost.

9- Tuberculosis Unit (TU) Model

This model envisages that VOs under the scheme, are supposed to provide the stipulated RNTCP services of a TU. A TU covers approximately a population of five lakh. VOs have to follow the prescribed RNTCP guidelines. This type of collaboration is only being considered in the areas, where the governmental infrastructure is not sufficient to ensure effective RNTCP implementation. One VO/non-governmental organization can apply for more than one tuberculosis unit but must meet all eligibility criteria for each TU.

NGOs in this program are supposed to provide full services for microscopy, treatment, direct observation, defaulter retrieval, recording and registration, supervision, et al. The NGOs should ensure fulfilment of all general functions of the Tuberculosis Unit. It is of great significance that the NGO carefully maintains RNTCP records and submits quarterly reports to the District TB Officer in the stipulated manner and in a timely fashion.

The Grant in aid for these activities is given in two instalments. The different amount is released for different activities these are given below:

The Grant in aid provided for operationalizing a TU has two basic components i.e. one time Grant for start up activities and an annual Grant in aid for meeting the running cost. In start up activities maximum of an amount of Rs. 1.5 lakhs are provided for the development infrastructure and Rs. 50,000 for training of multipurpose workers, supervisors and other staff. For annual Grant in aid a maximum of Rs. 5.3 lakhs provided. Out of this Rs. 3.0Lakh is earmarked for programmatic and administrative purpose. Rs. 1.8 lakhs are under personnel head for remuneration for staff and Rs. 50000 is given for distributing incentives for DOTS patient. In the following illustrations the Grant amounts and Grant heads were shown as per government directives.

Table: 1 Start-up Activities (one-time grant only)

Item	Amount (in Rs)
Civil works for up-gradation of microscopy centres (up to Rs 30,000 per microscopy centre)	Rs.1,50,000*
Funds for training of multi-purpose workers and other staff	Rs.40,000 #
Funds for training of multi-purpose supervisors and related staff	Rs.10,000
Sub-total available for one-time assistance	Rs.2,00,000

Source: Government of India, (2008), 'Revised National Tuberculosis Control Program, Revised scheme for NGOs and Private providers, New Delhi: Ministry of Health and Family Welfare

Table: 2 Annual Grant-in-Aid

Annual Grant-in-Aid	Amount (in Rs)
Personnel (NGO to ensure full-time, mobile staff to serve as Senior treatment Supervisor & Senior Tuberculosis Laboratory Supervisor)	Rs.1,80,000
Honoraria for directly observed treatment (@ Rs 250/patient with an assumption that 25% patients will be with the Community volunteers)	Rs 50,000
General Support (to cover all administrative and technical costs of running the programme, including ensuring the presence of an MO of the TB Unit, book-keeping, getting the accounts audited annually By a chartered accountant, POL and maintenance of vehicles, phone calls, faxes, photocopying, accounting expenses, etc.)	Rs. 3,00,000
Amount available for annual assistance	Rs. 5,30,000

Source: Government of India, (2008), 'Revised National Tuberculosis Control Program, Revised scheme for NGOs and Private providers, New Delhi: Ministry of Health and Family Welfare

10- TB-HIV Scheme: Delivering TB-HIV interventions to high HIV Risk groups (HRGs)

This program covers those populations who are in high risk. It is the target intervention program which is based on the pillar of community ownership. These NGOs could be covering a number of very localized geographical areas in case of brothel based commercial sex workers and community care centres or huge geographic areas focusing smaller but more challenging populations like street based sex workers.

Under the proposed scheme NGO would undertake delivery of '*Comprehensive TB Care for HIV high risk populations*' which includes all of the following components such as intensified TB Case Finding, to make patient friendly approach for Diagnosis and treatment categorization, undertake address verification before initiation of TB treatment, treatment delivery through appropriate community DOTS provider. VOs are also intended to follow up of the patient and also undertake patient's retrieval action in case of treatment interruption. Monthly meeting with DTO and NGO and outreach activities like community capacity building, community involvement in TB services, and advocacy with PLWHA network for TB control are also completed by NGO. The Grant in aid for this program is Rs 1, 20,000 per NGO per 1,000 target group population.[57]

3.6- PPM in RNTCP: Evidence from Field

The above mentioned scheme is more feasible to VOs and provides better chance to grass root VOs to work with government in control of tuberculosis. But it is important to see whether this collaboration is effective or not. Is it cost effective and how it helps in case identifications? There are a less number of studies who focus the effectiveness of this collaboration in control of tuberculosis.

A pilot project was undertaken in Delhi and Hyderabad to access the effectiveness, cost and cost effectiveness of PPM-DOTS. In Hyderabad project was undertake in Mahavir where PPM-DOTS strategy has been in effect since 1995 and Delhi project PPM-DOTS was implemented in for 18 month, starting January 2001. Both project covered a population of around 500000 people. The geographical area covered by the both project was on Tuberculosis Unit (TU). In both place the responsibility of implementation of PPM-DOTS was in private hand - Mahavir charitable hospital in Hyderabad project and the Delhi medical association in Delhi project. The budget, drugs and other materials were provided by the public sector. The major difference between the two projects was whether DOTS in the private sector is work as a supplement or substitute of DOTS in the public sector. In Delhi DOTS in the private sector was supplement of DOTS in the

[57] Government of India, (2008), *op cit*

public sector while in Hyderabad DOTS provided by the private sector is the substitute of public sector. To see the effectiveness, cost and cost effectiveness two measures were assessed – the number of case detection and the number of case successfully treated. Some statistical methods were used to see the average cost per patient treated and average cost per patient successfully treated and to compare the effectiveness, cost[58] and cost effectiveness, public sector cost per patient treated and successfully treated were used.

It was found that PPM-DOTS project can achieve a large increase in the number of cost 26 percent more cases were detected in Hyderabad with compare to public sector while in Delhi 47 percent increases found in case detection and the successful treatment was more that WHO target of 85 percent. In the context of cost it was found in Delhi and Hyderabad both places the cost per patient treatment was much cheaper as compare to public sector. The average cost per patient successfully treated PPM-DOTS project was near about 50 percent less compare to public sector. The study concluded that PPM-DOTS can be an effective affordable sector effective approach to improve TB control in India[59].

A study was done by Zafer Ullah, *et.al.* (1996) in Bangladesh. This study was carried out as part of the process of developing a locally appropriate public private partnership model in the NTP in Bangladesh. The main objective of this study was to see the government and NGO collaboration mechanism, and policy environment within which the collaboration is being nurtured and developed. In this study NTP was taken as case study for government NGO collaboration. For this purpose both primary and secondary data were used to address the research objectives. It was found that there is an increasing trend of government collaboration with NGOs in implementing TB control program. The study

[58] The average cost per patient treated and the average cost per patient successfully treated are sometimes confused. In the former, total costs are divided by the total number of patients treated. In the latter, total costs are divided by the total number of patients successfully treated, which is always lower than the total number of patients treated. (For Reference-World Health Organization (2004), *'Cost and Cost Effectiveness of Public – Private Mix DOTS : Evidence from two pilot project in India'*)

[59]World Health Organization (2004), *'Cost and Cost Effectiveness of Public – Private Mix DOTS : Evidence from two pilot project in India'*, Switzerland: Stop TB Deportment

indicates that government–NGO collaboration is an effective way of improving access to and quality of TB and other health care services[60].

Another study done by Deepak Karki *et. al.* (2007) in Nepal to evaluate the feasibility, effectiveness and costs of public-private partnerships (PPPs) for TB control. For this a PPP was developed in Lalitpur municipality. The objective of the study was to assess and report on the costs involved in the PPP scheme in tuberculosis. It was found that PPP scheme to treat TB patient is very effective. Paper concludes that treating TB patient in PPP scheme has low additional cost. It also increases the case notification rate and maintaining a high success rate[61].

A study done by Dick, J. *et. al.* to see the effectiveness of the group of volunteers who is involved in voluntary health worker project (Operation Elsies River) in enhancing adherence of notified TB patient to tuberculosis treatment. It was cohort study including with 351 TB patients (203 children and 148 adults). It was seen that, child group was more adherent to TB treatment than adult. The supervision option provided by the volunteers did not significantly improve the adherences of adult patients to anti tuberculosis treatment.[62]

To control tuberculosis, case finding is very crucial. VOs even have limited resources but can handle active case finding in urban and rural area by setting up sputum collection centre or microscopic centre so that the patient does not have to go long distance looking for diagnosis. Taking in consideration of these factor government started collaboration with VOs. Study revels that is an effective collaboration in control of tuberculosis.

A study done in Meerut district (Uttar Pradesh) to evaluate the contribution of public-private collaboration between the Indian TB program and the private health sector (including non government organization and private providers) to TB case

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[60] ZafarUllah, A.N et al (2006), 'Government-NGO collaboration: the case of Tuberculosis Control in Bangladesh', *Oxford University Press in association with The London School of Hygiene and Tropical Medicine*, pp-143-155

[61] Karti, K.D. et. *al.* (2007), 'Cost of a successful public-private partnership for TB control in an urban setting in Nepal', *BMC Public Health,* 7:84.

[62] Dick, J. (1966), 'Planning and Practice, Tuberculosis in the Community: 2 The perception of member of a Tuberculosis health team towards a voluntary health worker program', *Tubercle and Lung Disease,* 77, 380-383.

detection and treatment out comes. For this district TB register were reviewed. It was found that new smear positive case detection rate was 103/100,000 population. It was exceeded from national target. This target was achieved due to collaboration of private and NGOs. 29 percent cases were detected in private sector. From all microscopic centre 16 percent centre were operated by the NGOs and 12 percent were operated by the private health facilities. Another interesting result was that the treatment outcome was more in NGOs but there was no significant difference between NGOs and public private outcomes. Thus this study concludes that public private collaboration can be successful implementation implemented at the district level in India, and have the potential for substantial contribution to TB control effort in India."[63]

A study was conducted by LRS institute of tuberculosis and respirator disease during the period of 2003 by V.K.Arora, K.Lonnroth and Sarin to investigate the impact of public-private partnership DOTS program on tuberculosis case detection. The study was conducted in New Delhi. Two area were selected one was intervention area and second was control area. Regression analysis was used to analyze the data. The result revels that there was a significant positive no of increase in case detection in intervention are as compare to control area. The study indicates that public-private partnership is feasible way to improve TB case detection."[64]

Study related to ACSM shows that it have a very powerful role in tuberculosis control. According to the expert consultation on communication and social mobilization in the consideration of available treatment and exiting infrastructure, the better response in tuberculosis control program can be achieve through ACSM intervention. This intervention of ACSM can be most effective in improving in case detection and treatment adherence, combating stigma and discrimination, empowering people effected by tuberculosis and commitment and resource mobilization.

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[63] Sehgal, S. *et. al.* (2007), 'Public-Private mix TB Activities in Meerut, Uttar Pradesh, North India: Delivering DOTS via Collaboration with Private Providers and Non-Governmental Organizations', *Indian Journal of Tuberculosis*, Vol.-54, pp-79-83.

[64] Arora, V.K, *et. al.* (2003), 'Improved Case Detection of Tuberculosis Through a Public-Private Partnership', *Indian Journal Chest Disease Allied Sciences*, 46 : 133-136.

The support of community organization and community leader is necessary because this community based organization involving community health worker (CHWs) which are more accepted by community. Community people often listen to them carefully and do not show aversion to them.

The above discussion shows that the International, National and Local VO plays three distinct role in the TB programme. Most of the international VOs were involved in policy and programme formulation and development at a multi country level and often the country specific details were not taken into account. They were mainly engaged in advocacy, institution and skill development. The national level VOs were mainly engaged in provisioning of TB care services and raising awareness among the community. These organization helped filling up the gap developed by the limitation of public health services, where as the local VOs were mainly engaged in outreach and very localised service delivery.

This phenomenon was changed with the RTCNP. The RNTCP provided more space to the National and Local VOs in implementing programme in partnership with the Government at various levels. The participation of VOs in service delivery and programmes has increased by many folds. As discussed above, different studies were conducted in different part of the country which reveals that, VOs have significant role in the case finding, case holding, and provisioning of the services. These studies also reveal that the provisioning of the tuberculosis services is also cost and cost effective.

CHAPTER - 4

EMERGENCE AND ROLE OF VOLUNTARY ORGANIZATIONS IN RNTCP COMMUNITY

Emergence and Role of Voluntary Organizations in RNTCP

It is envisioned in the constitution that all citizens shall be provided access to health services but in country like India which has 28 states and more than a billion populations it is not easy to provide services to all. Thus it becomes necessary to work with all stake holders for the provisioning of the health services. Voluntary Organizations (VOs) have been working as a supplementary to the government. They are providing the services where government faces some limitations for execution of its policies and plans. Most of the VOs have their limitations in resources while provisioning for the services. In the arena of tuberculosis control there are certain defined areas where VOs can be involved to provide the services to the population. Taking these factors into consideration, this chapter analyzes the issues on the basis of collection of datasets. These datasets were collected from the four organizations which were covered under the study.

The aim of this chapter is to analyze the role of VOs in RNTCP based upon the interviews taken with the respondents of four VOs. There were in all twelve respondents from a four VOs. This chapter makes an effort to understand the various issues such as emergence of the organizations in tuberculosis program, current programs run by the organizations and the transformation in nature of collaboration within tuberculosis programme. It also examines the strategy that is being used by the organizations for awareness generation, new case finding and case holding; the challenges faced by the organization in control of tuberculosis and relationships between government and VOs.

4.1- Emergence of the Voluntary Organization in Tuberculosis Program:

Some reflections

It is interesting to know how these organizations have got involved in working with TB. While tracing involvement of these organizations the question to be asked is, *why are these organizations taking interest in working in the area of TB?*

While discussing about the reason behind the emergence of the organization, different kind of responses emerged from different organizations.

Ramakrishna Mission is a religious organization working for the betterment of poor and homeless people. The organization serves the people, particularly the poor by providing homes for destitute orphans and old people and through hospitals and dispensaries covering the whole country. The organization provides all kind of medical services in all the locations that they work in, except two places 'Ranchi TB Sanatorium' and 'Ramakrishna Free TB Clinic' where they provide exclusive TB services. Ramakrishna Free T.B. Clinic was established in 1933 and is the first T.B. institution in Delhi As stated by the in-charge of the Ramakrishna free TB clinic that during the initial period when the clinic was being established, huge number of the people were dying due to tuberculosis (in fact, they are still dying in large numbers); therefore, the organization initiated work in the field of tuberculosis. The genesis of the Ramakrishna free TB Clinic was the result of the electrifying words of Swami Vivekananda:

> *"I consider that the great national sin is the neglect of the masses and that is one of the causes of our downfall. No amount of politics would be of any avail, until the masses in India are once more well educated, well fed and well cared for .....If we want to regenerate India, we must work for them."*
>
> ***(Swami Vivekananda)***

The emergence of Ramakrishna Free TB Clinic is based on the philosophy of Swami Vivekananda. One another organization, Damien Foundation India Trust which is also working in the same area, is also a part of the study, but has different reason of emergence. Demine Foundation India Trust[1] is well known organization in the field of leprosy. The organization operates in different parts of country. It is an internationally funded organization working with a large number of workers. As the prevalence of leprosy came down, funding for the organization through the external donors reduced. The organization started to work in the field of tuberculosis since 2002. In response to the question regarding the reason for the shift of focus of the organization the project co-coordinator, responded that

> *"Previously the organization was working only in the field of leprosy. When the prevalence of leprosy came down and there was staff to spare. To manage*

[1] Damien Foundation Indian Trust is the Indian chapter of Demine Foundation which is working in field of leprosy and tuberculosis.

this staff the organization started to work in the field of tuberculosis. 50% of leprosy staff is now working in the field of tuberculosis. And this was not the only reason; tuberculosis was and still is, a major public health problem and a big challenge."

The nature of funding had changed the priorities of the organization. For getting a continuous and adequate supply of funds from the international donors, the organization started to work in the field of tuberculosis. In response to the question as to why the organization started to work in the field of tuberculosis it was stated that the causative organism is the same for both Leprosy and Tuberculosis I,e; *Mycobacterium,* the organization started to work in the field of tuberculosis in addition to Leprosy. Moreover, a large health workforce was in danger of being made redundant so a platform was ready to launch TB services.

Another organization which was studied was a state level organization working only in the field of tuberculosis namely, 'Delhi Tuberculosis Association of India'. Started in 21st march 1939, this organization emerged after the appeal of '*Lady Linlithgow'* for anti-Tuberculosis funds on the behalf of the government. As a result nearly a crore of rupees were collected out of which five percent of total amount was for retaining the centre and the balance was distributed to provinces and state for the foundation of state associations. Each of the state used that money for the formation of state tuberculosis association and thus Delhi Provincial Tuberculosis Association of India registered under societies registration act XXI of 1860. Apart from tuberculosis, no other health program is run by the organization. Following was said by the senior treatment supervisor in response to the question of the reason(s) behind emergence of organization,

"When the organization started to work, at that time tuberculosis was a big problem in the country. There was no effective medicine available during that time. It was highly stigmatized disease. People and even family members of the patient were behaving very rudely with TB patients. Then it was realized that there is a need of awareness in the community. Thus the organization started work for the awareness generation."

The last organization observed was Samarpan. It is gross root organization which started work recently in the field of tuberculosis. The organization came out in the period of 2004. In the beginning, the organization was working in the field of eye care services with the help of 'Venu Eye Institute and Research Centre' and was also involved in primary health care, malnutrition, blindness control, reproductive

and maternal and child health services, vocational training health education, and legal awareness and women empowerment. In all these programmes, the main focus of the organization was on the eye care program because this programme was collaborated and funded by the government. After the eye care project which was funded by the government ended, the organization did not have any government funded project and was working for the welfare of the people without any financial assistance from the government or other donor organizations. In the period of 2008 they got an opportunity to get involved in tuberculosis program. Thus the organization started to work in the field of tuberculosis. As stated by the director of the organization,

> *"When the eye care program was finished we were working without any government financial assistance. We were not getting any donation or fund from any other sources. For our survival there was a need of financial assistance and then we got the opportunity to get government fund with the collaboration of RNTCP under Public Private Partnership."*

However when it was asked to the Director of the organization as whether they were interested in other programs also, a positive response was found.

All the four organizations which has been discussed above, have been working in the field of tuberculosis ranging from 6 years to 75 years. There have been many reasons why these organizations concentrated in this area. Although the reasons for working in TB programs of these organizations can not be generalized yet it provides an understanding of why these organizations are working in the field of tuberculosis.

As discussed above, from all four organizations; some organizations have their own philosophical reasons for their emergence in the tuberculosis while some organizations are working for survival and utilization of their present resources while some organization are working with the assurance of greater availability of financial resources thus making them economically viable.

4.2- Transformation in Nature of the Involvement

The VOs are working in collaboration with the government and have been providing the services for a long time. But as time went by, the nature of the organization also underwent a change. To understand the transformation in nature

of the collaboration, it is necessary to understand these organizations' previous programmes and what kinds of transformation have taken place over the years. This section also deals with the question of how the organization started to collaborate with the current programmes run by the government and what activities within the program are run by them presently.

4.2.1- Ramakrishna Free TB Clinic

Ramakrishna free TB clinic is a district chest clinic working as a Tuberculosis Unit (TU)[2] with the collaboration of RNTCP. It is the only VO which is working as TU in Delhi and providing all kind of tuberculosis services such as diagnosis, treatment under DOTS strategy in urban slums and as well as the area surrounding them. It covers more than 6 lakhs population in more than 50sqkms area of Karol Bagh.

The major role of the organization is to provide microscopic examination services to all the population in the area. It is found that there are five microscopy examination centers functioning in different part of the Karol bagh and provide the diagnostic services.

Another important role of the organization is provisioning of tuberculosis services with DOTS strategy, to population coming under TU. Different kind of strategy is being pursued by the organization to facilitate the services. There are eleven DOTS centres functioning under Ramakrishna free TB clinic. The activities in these centres are based as per the RNTCP guidelines.

The organization conducts various IEC/behavior change control (BCC) activities as per the norms over and above the prescribed norms to create more awareness among the population. The organization maintains all the records and documents related to the Microscopy and DOT centres under its operation, as per the surveillance requirement of RNTCP. The surveillance of all centres is done by the Chief Medical Officer of Ramakrishna free TB clinic and government District Tuberculosis Officer (DTO).

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[2] The detail of the scheme is given in chapter three on page number- 25

In response to the question as to how was the programme functioning in collaboration with the government, it was mentioned by the in-charge of the organization that

> *"We are working in the field of tuberculosis since 1933 and providing the services to near about 5 lakhs population. We are also working in health awareness activities. When the government launched the scheme of collaborating with NGOs/PPs, we approached to government and on the basis of our infrastructure and coverage area the government authorized us as a TU."*

Over the years, right from its inception in 1933, this organization had different strategical shifts in their interventions in TB control. This was mainly due to the shifting policies of the ruling government(s). In the initial period, this organization was working independently without any financial assistance from government. During 1949, they opted for a grant from the government for the purpose setting up infrastructure facilities for the provision of inpatient services. Thus some fund was provided by the government to setup some observation beds for critical cases to be treated under the supervision of specialist doctors. As a result, observation beds were raised from 16 in 1949 to 24 in 1951. When free hospital admission facilities were offered by Rajan Babu Tuberculosis (R.B.T.B.) Hospital of Municipal Corporation of Delhi (M.C.D) in 1985, government withdraw grant, which forced this organization to discontinue their inpatient facility. In 1993-94 there was a pilot-study for RNTCP in Delhi. The result attracted Ramakrishna Mission to implement RNTCP. It managed to get the drugs from M.C.D. and started DOTS here from January 1996. On 28th October 1998, RNTCP was officially launched in the organization and started working as District T.B. Centre.

In 2001 when government of India launched a scheme of collaboration with VOs and private practitioners for Tuberculosis control, Ramakrishna free TB clinic collaborated in RNTCP under the scheme of Tuberculosis Unit (TU). It was the first VO in Delhi which started working under the TU model in collaboration with the RNTCP. Again in 2008, government launched a revised scheme for the collaboration of NGOs and PPs. It was mentioned in the scheme that those VOs that are already a part of the scheme have to sign again the Memorandum of Understanding (MoU). Under this scheme the organization again collaborated as a TU under the scheme nine.

4.2.2- Damien Foundation India Trust (DFIT)

DFIT is an organization which is providing the tuberculosis services to a large chunk of population of Delhi. The organization is working as a Designated Microscopy Centre (DMC) under the scheme four[3], which provides all kinds of tuberculosis services such as diagnosis, treatment and is also engaged in case finding, case holding, IEC activities etc. There are ten DMCs functioning under DFIT which covers a population of ten lakhs.

It was stated by the coordinator of the programme in response to a query, how the programme of collaboration with the government was initiated as--

> *"In the beginning we met the State TB officer and expressed our desire to begin our work in the area of TB. The state TB officer gave us brief information about five schemes that were being implemented at that point of time. We realized that the fourth scheme 'microscopy and treatment centre' covered all the services under RNTCP. They asked us that which area we would be interested in; to which we stated the desire to have a unit close to our office. We were granted permission to work in the in the area we asked for with the DMC scheme"*

The organization started to work in field of tuberculosis since 2002. After some months of the initiation in the tuberculosis, the organization collaborated with RNTCP programme as a DMC. In the beginning there were two DMCs working under the organization. Then again in 2003, the organization approached to the state TB office and on the basis of performance of the organization, got the permission of three more DMCs. These all five DMCs were working under a TU named as Deen Dayal Upadhyay (DDU) hospital. After the successful implementation of the DMCs the organization were inspired to expand the area of coverage. In the year 2004 the organization approached to state TB office for the five more DMCs and got the permission for it. One interesting observation was: The programme coordinator reported that when they met the state TB officer they asked them as to how may DMCs they wanted. The coordinator agreed, thus the organization got five new DMCs. At the present there are ten DMCs functioning under the scheme four.

4.2.3- Delhi Tuberculosis Association of India

[3] The detail of the scheme is given in chapter three on page number- 21

The scenario of Delhi Tuberculosis Association of India is entirely different from other organizations. The collaboration between government and Delhi tuberculosis association of India is the unique example of PPM model. This model of collaboration helps in control of that section of population which is more vulnerable for disease and is difficult to cover under the defined schemes for VOs/NGOs and PPs.

In the beginning, the objective of the organization was to generate health awareness among community, to provide medicine to the poor and to facilitate as many ancillary services to the people in connection with tuberculosis programme. Currently the organization is also working for awareness generation and providing the DOTS to the destitute population by the DOT centre in mobile vans. It also has sputum microscopy facility in these vans. It is reported by the secretary of the organization that, the mobile DOT centre goes to Chandni Chawk in front of the Shishganj Gurudwara early in the morning three days a week. There is *Langar*[4] *service* (charity meals providing free food to all who come there) service in the Gurudwara. The organization provides the diagnostic and treatment services to the destitute population of the area.

The role of the organization is also vital in control of tuberculosis as it provides its services to hundreds of destitute, who indeed are responsibility of the state, but where the government lacks the facilities to tackle this serious menace in such areas. The uniqueness of the organization lies in its structure. Most of the staff is retired government officers and they are working voluntarily. An interesting observation in this organization is the organization's DOT centre in the mobile van. In government program there is no such scheme existing. In response to question of how was the programme of collaboration with the government initiated, it was said by the honorary secretary of the organization that:

> "*When I was in the meeting with the state officer, he proposed to provide the DOT services to destitute. Although there is no such program for these people but we can do it for the betterment of the street based people.*"

[4] Launger is a kind of community feast in which religious people use to provide food to the people. In this process there is no discrimination in the poor and rich. Every one sits in a queue and gets food.

In response to the question whether they were interested to work with other schemes it was said by the secretary that--

> *"If you will see, Delhi is ranked as number one in RNTCP and the provisioning of the tuberculosis services in Delhi is better than the other states. We have limited resources and we are doing better. We do not think there is need to work in other programmes. Many VOs are working in the field of tuberculosis. They cover the area where we are not working so we do not want to work with other schemes."*

Delhi tuberculosis Association of India has gone through different phases from its inception. The organization has changed the nature of its work as per the requirement of the time. Initially, the focus was on awareness raising programmes. After realizing that people were aware of disease but were unable to access services or purchase medicines because of their poor financial conditions, organization shifted its attention to provision of medical services. At present they are involved in the provisioning of DOT services with a mobile unit and as well as conducting program for awareness. It was reported by the honorary secretary (a medical doctor) of the organization:

> *"It is necessary to change the strategy for the betterment of the people. When people were not aware then we were trying to aware them. When they became aware then we started to help those people who were unable to purchase medicine. When government started to provide medicine to Tuberculosis patients then we started to provide financial support to tuberculosis patients and their families. We are also distributing blankest to poor people in the winter and working for their social upliftment."*

4.2.4- Samarpan

Samarpan is working in the area of Zakhirarabad as a DOT centre under adherence scheme[5]. The organization covers the population of around 30,000. The major role of this organization is to provide DOT services to the patient at a time and place according to their convenience. The organization is also responsible for collection of follow up sputum samples. Apart from this, awareness generating activities are also done by the organization.

[5] For the detail of the Adherence scheme please refer chapter three page number-23

A contradictory note observed during the field visit was that the organization is providing DOT services with very limited resources and falls short of justifying the purpose of the scheme. They are not at all able to cover whole population and also not involved in all activities which are mentioned in scheme. For example during the field visit it was found that the health visitor of the organization was engaged in the other health programmes and was not available at the DOT centre during the DOTS day. The purpose of the scheme is suffering here.

In response to a question about how was the collaboration with the government programme initiated, the in-charge of the organization reported that:

> *.....We saw the advertisement in the paper that the organization who are registered under the Society Act they can collaborate in the RNTCP program and can function as a DOT centre. Then we went to Moti Nagar chest clinic and talked to the DTO. He told us that we can provide only one scheme that is 'Adherence scheme'.*

Samarpan is a newly developed organization working in the field of tuberculosis. The organization started to work in collaboration with the government since 2009. Therefore, no major transformation has taken place in the nature of the collaboration of the organization. Although, they have been working in the field in others areas of health but there were no specific program run by the organization except eye care services. In the process of providing eye care services in the community they identified TB patient on the basis of the symptoms of the patient and they were referred to nearby DOT centre. Based on these few referrals the organization presented data showing that they have been working for the betterment of tuberculosis patients.

4.3- Role of Voluntary Organization in Case Finding and Case Holding

VOs have very important role in case finding and case holding. It is a key component in control of tuberculosis. Different kind of strategies such as active and passive case finding was being used by the organizations for the maximum case finding and case holding. As seen in the previous chapter, the study reveals that there is significant role of VOs in case finding and case holding. It also plays a significant role in the management of the defaulter and relapse cases.

4.3.1- Case Finding

The term "case finding" is defined as, 'an organized effort to discover as many cases of tuberculosis as possible, in the entire community, year after year, till the disease ceases to be a public health problem.'[6] In other words it is a strategy to find out the sick cases which is essential for the eradication of the disease. Hence for the control of tuberculosis, the maximum number of new case finding is important and it depends on coverage of the population. A study conducted by Banerji and Andersen (1963)[7] in Tumkur district in south India, reveals that people are aware about tuberculosis but the services of the tuberculosis are out of the reach of the community. Thus for the maximum case finding the services should be as close to patients as possible. As it is seen previously (literature cited)[8] that, VOs are more close and acceptable to the community and are able in providing the services at gross root level. They are more competent in mobilizing the patient to approach the DOT/DMCs centres.

It was found that out of four, three organizations were using passive case finding method to identify new cases. Patients with complaints approached the clinics either through referral or directly. These referral patients could be made by the private doctors, public health services, or from other health institutions. On the other hand, the organization 'Samarpan' is using active and passive case finding. In passive case finding method, patients with complaints approach whereas in active case finding organizations reach out to the probable cases.

All organizations are organizing the community meetings to make people aware and motivate them, to come in centre for the diagnosis if they have symptoms related to tuberculosis.

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[6] Jagota, P. (1998), 'Case-Finding Policy for National Tuberculosis Programme', *Indian Journal of Tuberculosis*, 45, 3.

[7] Banerji, D. and. Andersen, S. (1963), 'A Sociological Study of Awareness Symptoms among Persons with Pulmonary Tuberculosis', *Bulletin World Health Organization*, 29:665-683.

[8] To see the reference please refer chapter two page number-18, Pachauri, S (1994), *op cit*

For maximum case finding the team members of the organization make contact with community leaders and motivate them to send the symptomatic patient to DOT centre. These community members help us in identifying of new cases.

Apart form these efforts, an Out Patient Door (OPD) is run by the each and every organization and they find out the tuberculosis patients on the basis of the symptoms shows by the patient. It also helps in new case finding.

The diagnostic tests conducted for confirmation are sputum examination and X-ray. It is found that out of four, three organizations have facility for the diagnosis while one organization has to send the sputum to referral microscopic centre for the examination of the sputum. The tests are conducted for all patients by the organization without any cost to them. It was found that the diagnosis was done according to RNTCP guidelines.

Among these four organizations, Samarpan proposes to carryout an additional strategy for case finding. Within this strategy, they target that they will find out three cases in every visit. But the actual implementation seems to be vague and the field work appears mostly on paper. It was observed that the organization is engaged in different activities and does not have adequate infrastructure and human resource to cover this area. The health visitor of the organization is also engaged in different activities. It was observed by this researcher during his field visit that the DOTS provider/health visitor was not available during the assigned days for DOTS provision.

Out of the four, one organization 'Delhi Tuberculosis Association of India' was using snowballing technique to find out new cases. The members of the team motivate those patients who come for the treatment to find out other person(s) who have cough for last two weeks or more. It was also found that the mobile DOT centre of the organization goes to Chandni Chawk in front of the Gurudwara early in the morning. There is *Langar* process in the Gurudwara. The destitute population comes for it. They screen patients from that population on the basis of symptoms and collect sputum for the diagnosis. On this way they are trying to find out maximum number of TB cases.

Another organization, DFIT; organizes health camps in each DMCs in collaboration with government and other NGOs. These camps are run by a team of 7 to 10 people. In the course of these health camps symptomatic TB patients are identified and their sputum samples are collected. Based on these collections new cases are identified. It is reported by the medical officer in-charge that approximately 1000 people participate in each health camp among which, approximately five to six cases are detected positive.

4.3.2- Case Holding

Case finding will have no meaning unless it is followed by effective case holding activities. This means that every case of tuberculosis diagnosed must be treated as effectively and fully until cured. Treatment of the tuberculosis is not only the handing the drug to patient. It includes management of the patient aspect also. It means to ensure not only the regularity of the drug collection but also consumption by every patient[9].

Drug availability is important for the case holding. It is found that the availability of the drugs is not a problem for the VOs except Samarpan. In fact the unavailability of the drugs in Samarpan is not due to unavailability of the drugs in RNTCP but is because of ineffective drug inventory. To get the drug Samarpan has to go through different stages to collect the drugs. First of all they send the sputum samples to the tuberculosis unit for the diagnosis. After diagnosis of the disease patient has to go TU to consume the drug under DOTS strategy. After that the health visitor of the organization goes to TU to collect the drug box. And after that the organization starts to provide the drug to the patient. The whole process takes 10 to 15 days. This results in an increased number of defaulters.

The discussion here raises a point of concern. If the decision making power rests with some other organization as is evident from the functioning of Samarpan then how can we expect a functioning PPM/PPP model in RNTCP. The issue needs to be looked into and is certainly a bottleneck in an otherwise smooth functioning of the programme.

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[9] Mohanty, K.C. (1998), 'Prevention and Control of Tuberculosis' in Pande, N.J., *Respiratory Medicine in The Tropics*, Delhi: Oxford University Press, p. 254.

It was observed in all four organizations that for the case holding they provide drugs at patients' home. For this purpose they make a community DOTS provider who had taken the treatment earlier from the organization and now has been cured. The community DOTS provider goes to the patients' house who, are unable to come to the DOT center and makes the patient to consume the drug in front of him. But here the problem is that these community DOTS providers are uneducated and do not have adequate training. So they are unable to understand the philosophy behind the DOTS and they just provide the drugs to the patient and do not force them to take medicines in front of them.

Treatment completion is also important factor in case holding. Though the course of the treatment has been reduced, but it is still a very big challenge to the physicians as well as social scientists. To ensure the completion of the treatment the community participation as well as family support is important. It was found that, to ensure the participation of the community and family for completion of treatment, the team goes to the community to mobilize community members to come forward for treatment. They also visit patients' home and talk with patient and patient's family to support for the completion of treatment.

It was found that for the case holding, all organizations put stress on education and information of patients and family members. Regular motivation and follow up is also being used by all the four organizations through which treatment completion is optimized. Motivation is an ongoing process which takes place every time the patient visits the DOT centre.

Defaulters' management is also important component in case holding. To manage the defaulter cases, DOTS provider identifies the patient's address and visits his/her home for the confirmation of the address before starting the treatment. In any case, if patient does not come to DOT centre to consume the medicine, the same day or next day health visitor/ DOTS provider goes to patients' home and provides the drugs to the patient. If any patient refuses to take medicine they convince the patient to consume the medicine and if he/she is not ready to take it, then DOTS provider goes to the patient's house with senior treatment supervisor.

If both fail to motivate the patient then they visit the patient house with District tuberculosis officer (DTO).

During the interview it was found that most of the members report that major cause of the defaulting is lack of knowledge about the treatment regime. Meaning that patients do not understand the importance of regular treatment, a sort of blame game wherein the patients were blamed by the organization members.

4.4- Role of Voluntary Organizations in Health Education (IEC activities) and Community Mobilization

Health education and community mobilization have been two important pillars on which most of the public health programmes get their sustenance. Good IEC goes a long way in making a program successful. But to achieve that a lot of skill and patience is required which sadly the public sector staff is lacking. Here the role of VOs becomes crucial with their host of field workers and counselors and educators, they come in handy for this type of job. The basic idea is to make people understand the complexities of the disease and the adherence to the treatment schedule. Once people are cognizant of the whole details, further treatment and follow up becomes all the easier.

4.4.1- IEC activities

Health education has been identified as a key element in control of tuberculosis. The objective of the health education in control of tuberculosis is to educate the patient to complete treatment, identify the people at risk and educate to ensure treatment, informed the community as well as patient about free health services, to educate about symptom and the need of testing and early diagnosis for prevention. Literature from the studies done by the Arora and Mittal[10] recognized that without the participation of community and substantial social mobilization, to achieve the desire global target of 70% smear positive case detection rate and 85 percent

[10] Arora, V.K. and Mittal, A. (2007), '*Community Mobilization: Role of Non-Governmental Organizations*', 58th TB Seal Campaign, New Delhi: Tuberculosis Association of India.

successful treatment is not possible. For community participation and social mobilization, effective IEC (Information, Education and Communication) activities are very important. Because VOs are very close to community they can implement the IEC activities in effective manner. It is also found that to enhance the quality of IEC activities, organizations are collaborating with other organizations too. Different strategy was also used by the organizations to enhance the efficacy of IEC activities. It was stated by the in-charge of the Ramakrishna free TB clinic:

> *"People get bored to see the same kind of materials so we started to collaborate with Kathputali Kala. Kathputali Kala is an organization which organized the puppet show in our DOT centers. We found that the number of the participants is increased gradually. People watch this with a keen interest. In this program we focus on symptoms of tuberculosis, diagnostic process, treatment procedure etc".*

Number of programs does not have importance; important is, how many participants are participating in the programmes. It was found that to improve the number of the participant; half of the organizations organize animation movies for the awareness regarding TB in schools and slum areas.

All four organizations have different kind of activities for raising awareness in the community. It was observed that all four organizations arranged different kinds of program such as community meeting, public meeting, animation film shows, public talks, patient-provider meetings, awareness camps and community volunteers' meetings, health promotion camps etc. Printed material, pamphlet, browser and other materials to raise awareness also distribute by the organizations. Delhi Tuberculosis Association of India which provides DOT services to destitute populations organizes movie screening in some areas where this floating population spends their nights.

In response to the question as to what are the activities being undertaken during community meeting, it was reported by the all organizations that,

> *"Under this activity they go to their defined areas and community, where some people are already getting treatment from the defined DOT centre. They hold intensive discussions with the community and make them aware about the disease, symptoms and how they can get rid of it".*

Similarly, all organization organizes public meetings, but there is a difference in the frequency of the meetings. Some organizations are arranging the public meetings twice in a month and some are once in a month.

Another activity, health promotion camp is organized by the all organizations. It was found that under this activity the DOTS provider visits in their defined area six days in a week and educates and talks with people about tuberculosis and other health related issues such as cancer, tobacco, health and hygiene practices, nutrition food, eye care and family planning.

Another special program is being organized by the DFIT. The organization has started a new type of IEC activity from January 2009 onwards. During the DOTS day, after undertaking the treatment of continuous phase (CP), intensive phase (IP) patients are asked to sit in the DOTS center, two CP patients educate five IP patients and they explain the importance of the regular treatment, about the improvement after IP and what are the problems they faced and how to solve these problem during the IP course. They explain, after the completion of the full IP course how they became negative from positive and how they improved their health. A maximum of five group talks were held daily among these groups between IP and CP patients in the center. It was said by the medical officer of the Damien Foundation Indian Trust that these kinds of group talks improved the conversation, patient were getting regular treatment and the defaulter rate was reducing. The same type of IEC was discussed in the weekly meetings and started at all nine other DMC's from January 2009 onwards.

4.4.2- Community mobilization

Community mobilization is a process or strategy, which aims to create an environment with the help of key persons of the community for the behavioral modification and desired social change. The program recognized the need of the principle of the community mobilization. The principal of community participation will help in control of tuberculosis and will play a significant role in achieving the twin goals of the United Nations 'Millennium Development Goal' (MDG) for tuberculosis. The targeted goals of the MDG for tuberculosis are to reveres the incidence and reduce the prevalence rate of tuberculosis by 50% by

2015[11]. It is understood that the VOs are usually closer to community than the formal health care sector and they are more acceptable than government. They can play an important role in community mobilization. Their interaction will be more effective and can provide services effectively, which is ranging from increased community awareness to data collection recording and reporting. VOs can help in 'support to community' for TB treatment. It is entirely different from 'support to TB patients'. The community support provides all kind of support such as awareness, transport support and food supplement. It is found that all organizations are providing the counseling and working for the community mobilization through community meeting, and IEC activities.

One of the observations was that the participation of the community in the community volunteer meeting has increased. It was found that in the year 2008, there were 210 people participating in the community meetings organized by DFIT. In the same year after three months, the number of participants of the community was 285. While the data of community participation in the community meeting from other organizations was not readily available; but from the interviews of the staff it was learned that the number was on an increase. Due to lack of data from all the sources it is difficult to say about a definite increase in the number of participants and thus comment about the role of VOs in community mobilization.

4.5- Major Challenges Faced by the Organizations

Working in the field of tuberculosis has been a major challenge for these organizations. All four organizations have established themselves in this field after overcoming various difficulties. The difficulties these organizations have faced fall within a continuum of awareness rising to providing services. To control the spread of tuberculosis these challenges should be taken under consideration during implementation of program and policy. While working in collaboration with the government these organizations have faced challenges such as MDR, HIV-TB dual co-infection, poverty and malnutrition etc.

[11] World Health Organization (2006), '*The Millennium Development Goals Report*', Geneva: WHO United Nation

It is reported by all the organizations that MDR is a major problem in current scenario. The treatment of MDR cases takes more than18 to 25 months. It makes very bad the condition of the patient. It also has side effects so patient does not continue the treatment. It increases in the number of defaulter. It was found that out of four organizations only one organization (Ramakrishna Free TB Clinic) has facility for treating MDR cases while other organizations refer the patients to respective DOT centres.

HIV is the most potent risk factor for the progression of TB infection to active disease. Individuals infected with M.tuberculosis have approximately 10 percent life time risk of developing active TB, compared to 60% or more in persons dually infected with HIV and TB. It is observed that all four organizations are facing the HIV/AIDS TB co-infection as a major hindrance in control of tuberculosis.

Another problem faced by all the four organizations is stigma attached with tuberculosis. It was said by the project coordinator of DFIT that although stigma is reducing but still is a major obstacle in control of tuberculosis. The main problem in diagnosis of TB as reported by secretary of one of the organizations and echoed similarly is:

> *"People hide their symptoms behind the garb of superstition and blind beliefs because of social stigma attached to this disease. They dropout the moment they are investigated for the disease as they do not want to be told as suffering from TB".*

In the control of tuberculosis poverty and malnutrition is also a big handicap, reported by all four organizations. It was reported by the all four organizations that most of the TB cases in their centres belong to low socio-economic status. Although tuberculosis is not completely a disease of the poor, yet there is a well recognized association between poverty and TB.

Some other problems in control of tuberculosis such as literacy, overpopulation, alcohol and smoking are faced by the Ramakrishna free TB clinic. It was found that all the organizations covered in the study reported that, diabetes is another hindrance in control of tuberculosis. It is newly emerging problem in the control of tuberculosis.

Alcohol consumption is one factor which plays a significant role in treating Tuberculosis. Alcoholism is a social construct as well as a behavioral problem which has strong psycho-somatic repercussions. Consumption is seen more in low socio-economic group which is more vulnerable to contact disease. Alcoholism leads to absenteeism at work and family quarrels. Besides it also leads to irregular treatment and defaulters. Alcohol also leads to micronutrient deficiency and loss of appetite. This has significant impact on recovery process and cure. Thus a vicious cycle forms of alcohol consumption, irregular treatment, malnutrition and relapse. These are the cases who are prone to develop Multi Drug resistance and have poor prognosis. This significantly affects the treatment and programme outcomes.

Overcrowding and illiteracy also is a challenge reported by the organizations. Most of the respondents reported that in slum areas there are six to seven people living in a single room. If any family member gets TB he/she can infect the other members also.

It was found that out of four organizations, one organization reported that they are not getting community support in the fight against tuberculosis. In response to the question, why people are not participating in control of tuberculosis? Project coordinator said,

> *"Community does not participate in the program, may be because of lack of awareness or due to social stigma. It also may be because people do not have time from their day to day activities".*

Other Problems:

The satisfaction of the organizations' member plays an important role in performance of the organizations. During the interview it was observed that some staff people were not satisfied with their salary and honorarium. It was reported by the Health visitor of Samarpan that,

> *"Government is providing only Rs. 250 per case after the completion. Till date there are only 10 cases found. One case takes 8 to 10 month for full cure. It means that after 8 to 10 month health visitor will get only Rs 2500 if all cases will be on hold. How can one survive on this amount?"*

One interesting fact is that the DOTS provider who is a government employee is getting more than Rs. 20,000 while contractual staffs are getting only Rs. 6500; this huge disparity in the amount reduced the motivational level of contractual staff. DOTS provider of Ramakrishna said:

> *"..... The money which government gives us is not sufficient for survival. We need to do extra work after this work. Those who are employed in government do less work and get more salary than us. That is why we lack interest in our the work"*

It is evident from the above statement that the health visitor gets a salary of Rs. 6500 per month. It is very less as to the cost of living. They are also comparing their services from government employees. It affects the motivational level of the contractual staff. In his study Smith et. al.[12] measured the satisfaction level in work and retirement and found that for the satisfaction, staffs are comparing their salary from other organizations. If they are getting fewer amounts than other organizations, it affects the motivational level of the staff.

4.6- Relationship of Voluntary Organization with Government in term of Funding and Accountability

Government of India with collaboration of second and third sectors launched RNTCP to address the problem of tuberculosis. The collaboration with other sectors is aimed to cover the entire population and those patients who report to the other health sectors and get the services close to them which were not possible in the earlier programme. The relationship between all these organizations needs to be efficient and harmonious in the interest of patient's care. The relationship of these organizations has great impact on functioning of the programme. So, for the smooth functioning of the programme, it is important to see the relationships in term of funding and accountability among these agencies while working for TB control.

When it was asked to all four organizations whether there was any problem in getting the funds, the response was that getting the grant in time is never a problem. The

[12] *Cited in* Sarkar, A.K. (2005), *NGOs The New Lexicon of Health Care*, New Delhi: Concept Publishing Company.

pattern of funding is on annual basis. Some organizations send the annual plan of action and budget and on the basis of that government provides the fund. Some organizations get fund according to fixed grant-in-aid as decided by the RNTCP. Thus the funding is based on the nature of the organization and type of collaboration.

Accountability is another component which is very important in establishing relationship among the organizations. In the literature the term accountability is defined in two ways[13], firstly in terms of responsibility as to whether the assigned and decided work has been done according to the defined standards, and secondly; in the terms of the financial accountability which means whether the allocated money is utilized for the given purpose. It is important from this researcher's point of view, to explore both aspects of the accountability. It provides holistic view in understanding the relationship of VOs with government in the context of accountability.

In the context of responsibility given to the organization, it was found that all organizations reported achieving the targets and the standards given by the government in controlling tuberculosis. All the organizations claimed that they were performing much better than government organizations in spite of their limited resources.

While discussing with the organization about financial accountability, different opinions were found. The in-charge of the Ramakrishna free TB clinic mentioned that, they have two kinds of evaluation system i.e. internal evaluation and external evaluation. The accounts are audited by Chartered Accountant (internal) every year apart from the audit conducted by the government auditors (external).

Delhi Tuberculosis Association of India and Samarpan finalize their accounts through the audits conducted by chartered accountants, while DFIT, apart from the audits by chartered accountants also has to undergo audits by their funding agencies.

4.7- Performance of the Organizations

[13] Coid, D. R., *et. al.* (2002), 'Partnership with Health and Private Voluntary Organization: What are the issues for Health Authorities and Boards?', *Journal of the Royal Institute of Public Health*, 117, 317-322.

The performance assessment of organizations was crucial to evaluating the level of their participation in the program and collaboration with the government. Annual data were used to see the contribution of organizations in tuberculosis control. The data from Ramakrishna Free TB Clinic reveals that, the treatment outcome of new sputum positive case is increasing every year except in year 2007. Total cases on DOTS year wise from 2000 to 2009 were1131, 1347 1255, 1476, 1628, 1672 1659 1757 2018 and 1937 respectively; New Sputum Positive (N.S.P) cases year wise for the same periods were 419, 496, 412, 521, 569, 540, 559, 534,612 and 557. The sputum conversion rates after three months were 88 to 93 percent. The treatment outcome of the organization is continuously increasing. It was 79 percent in 1999 and became 90 percent in 2009. The organization also conducts research on tuberculosis and has internal assessment process to evaluate the performance of the organization.

Data from DFIT also reveals that in the period of 2008 a total 820 cases were found new sputum positive in both TU in which 732 cases were cured. Out of 820 cases only 27 cases were defaulter. Annual data of 2009 attribute that, there were 35684 patients attended the OPD in both TU, in which 1202 cases were found positive. In these 1202 cases, 834 were new sputum positive cases. The organization has achieved 87.7 percent new sputum positive cases, which is more than national target and cure rate of the organization was 89.3 percent. The conversion rate of the organization was 89.4 percent.

As per Delhi Tuberculosis Association of India's record, in the year 2009 there were 1032 patient examined by the organization of which 80 cases were found positive. Only 24 patients completed the treatment and became cured which is 30 percent of total cases examined. The defaulter rate of the organization was 17.5 percent (14 cases) as the organization provides the DOTS service to homeless and street based population.

The performance of the Samarpan was not up to the mark. It is found that in the year 2006-07 there were only 26 people referred to the DMC for the sputum examination and in the year 2008-09 the organization provided the services only to 12 patients. Till now there were only 18 patients in record.

The table 4.1 depicts the activities and strategy taken by different organizations for the control of tuberculosis. It also reveals the NSP cases and conversion rate of the organization with the area of coverage.

Table 4.1 –Profile of the VOs at a Glance:

No	Name of the organizations	Approaches to Tackling TB	NSP Cases (2009)	Conversion rate (After three months)	Population coverage by the organization
1	Ramakrishna Free TB clinic	Diagnosis, treatment, case finding, case holding and IEC activities	557* (97.2%) **	90%	More than six lakhs population with five microscopy centre and eleven DOT centres.
2	DFIT	Diagnosis, treatment, case finding, case holding through multiple health worker	834* (87.7%)	89.4%	Ten lakhs population with ten DMCs
3	Delhi TB Association of India	IEC activities, Diagnosis, treatment through DOT centre in mobile van, case holding and networking with the local level VOs.	80* (-----)	------***	Area covered Chandni Chawk (no define population)[14]
4	Samarpan	Treatment, case finding, case holding and IEC activities	12* (70%)	------****	Thirty thousand population with one DOT centre

(*) shows the number of the NSP cases per year
(**) shows the percentage of the NSP targeted achieved
(***) conversion rate could not be derived from the data provided
(****)Low No. of cases prevented getting substantive conversion rates

4.8- Allocation of funds to VOs

It was found that three organizations (Ramakrishna free TB clinic, Delhi Tuberculosis Association of India, and Samarpan) are getting RNTCP funds.

[14] Delhi Tuberculosis Association of India provides DOTS services to the destitute population. It is difficult to quantified the population covered by the organization.

While one organization, DFIT was not willing to receive fund from the RNTCP. DFIT is providing other kind of support from the RNTCP in the form of drugs, and diagnostic materials. Two organizations (RKM and Delhi TB association of India) are also getting fund through donation. One additional fund is also raised by the Delhi TB Association of India through selling TB seals. One organization totally depends on international funding. The organization Samarpan is entirely based on government funds.

RNTCP provides an approximate annual budget of 25, 00,000 for the implementation of the TB services. It covers civil work, laboratory material, Honorarium of contractual staff, IEC publicity, equipment maintenance, miscellaneous expanse, contractual service etc. Out of this amount some amount (data not provided by the organization) are allocated by Ramakrishna Mission for the free TB clinic which includes additional man power, electricity, water and other infrastructure. While DFIT is getting an approximate Rs 70 lakhs/year for the provisioning of the tuberculosis and leprosy services both. The data related to how much money is being spent on tuberculosis could not be found.

Another organization, Delhi TB association of India is generating approximately Rs 20 lakhs/year from donation, TB seal selling and RNTCP fund for the proper implementation of tuberculosis services. While Samarpan, is getting only approximately Rs 13,000/year from the RNTCP fund for DOT services. Apart from that the DOTS provider of the Samarpan is also getting Rs 250 after the completion of the one case and Rs 400 goes in favor of VO.

DISCUSSION

This study explores the rationale behind the emergence of VOs (those selected) and their role in controlling tuberculosis in the state of Delhi. It provides evidence on the interests of the organizations and the ways in which the funding patterns change the nature of the work of these organizations. It also probes into the ways in which organizations are involved in different kinds of activities in control of tuberculosis. Qualitative method was used to achieve the objectives and the results were based on observations, interaction, interview and discussions with VO personnel. They provided a way of understanding the emergence of VOs and their role in tuberculosis control programme. Secondary and primary literatures were used to understand the role of VOs in RNTCP programme. The dissertation begins with the conceptualization and definition of VOs followed by their role in health services and five year plans. Subsequent discussions (Chapter III) review the international and national level initiatives of the VOs. Chapter four explores the role of selected VOs in RNTCP programme. The organizations were selected on the basis of the purpose of the study and geographical areas.

The term voluntarism is defined by different professionals in different ways. There is no common consensus on definition of voluntarism. Operationally in this dissertation, the term voluntarism is defined as 'those organizations which have volunteered to engage themselves in service without the objective of profit earning and intended to promote public welfare services or social improvement in some special regards. Members of such bodies work together for a common end. These organizations are independent in nature and controlled by those who have formed the organization or by a Board of Management. On the basis of the different definitions discussed in chapter two and based on the operational definition, the study has classified the VOs into four types - these are Charity and Religious VOs, Developmental VOs, Service Provider VOs and Community based VOs.

5.1- Historical Perspective of VOs

The rise of VOs has a glorious history. In the twenty first century the significance and role of VOs received attention from different disciplines. As discussed previously, from the ancient period, people were willing to provide help to the indigent people. During this period, the philosophy of the VOs was centered on providing 'relief work' in crisis situations such as flood, war, famine etc. This was considered as an altruistic activity, intended to promote the quality of life of people. During 1970s, main thrust of the organizations was on development work which was done by self help groups that provided services at the field level. This form of voluntarism was institutionally organized and the activities during this period were done by the self help groups. During the 80s, voluntary organizations adopted a new form of working pattern, where emphasis was on 'advocacy'. Another shift in philosophy of VOs was seen in 1990s. In this period the philosophy of development changed to 'People-Centered-Development'. Self help groups, autonomous groups and the VOs played an active role, working as catalysts and facilitators in the process. The literature on historical analysis of VOs reveals that voluntarism can be divided into two terms – one, conventional voluntarism and second, modern voluntarism. Modern voluntarism is significantly different from the conventional voluntarism in form, content, role, approach and impact. Previously voluntarism was aimed at providing charity, relief and philanthropic work which were done by the kings and other elites of the period. These philanthropic works were inspired by the religious, generous and altruistic thoughts. Conventional voluntarism was based on ideology while modern voluntarism is based on idealism. The aim of modern voluntarism is to do developmental work for social justice while the nature of conventional voluntarism works is philanthropic.[1]

Literature from different areas shows that there are various socio-political and cultural factors that have great influence on the rise of VOs in welfare services.

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[1] Nawani, D. (2000), *Role and Contribution of NGOs to Basic Education*, New Delhi: National Institute of Educational Planning and Administration.

Literature shows that the drastic growth of VOs was due to several factors - state neglect in dealing with issues concerning the welfare of the common man, development thinkers and intellectuals, in their desire to create alternative institutions, and called for people's participations in their own development[2].

5.2- VOs in Health Services

As we have seen before, during the pre-independence period there were different factors such as the Christian missionaries, Caste-based movements, Gandhian movement, Lions club etc. which had impact(s) on the health sectors. Apart from these and much later, different religious and charitable organizations also came into existence. The participation of VOs in the health sector ranges from support in policy making and implementation to actual field based service delivery. They have glorious history of involvement in specific disease control programmes such as leprosy, tuberculosis, family planning etc. Different kinds of national and international VOs were formed in the period of 1920s and 30s. Most of the National Organizations were inspired by the Gandhian ideology and guided by the humanitarian concern. In 1929, Dr. B.C. Roy called for an organized voluntary effort to improve the health status of the people. During this period the health situation of India was alarming.

By mid twentieth century the focus of the government got restricted to urban areas. It was the 'Bhore Committee' of 1946 that emphasized on the need for attention on rural areas and made a call for VOs to meet the health needs of the country. Their recommendation emphasized the role of VOs in community participation in the field of health and education. Thus government launched special schemes for the rural and high density slum populations of the country. Another programme, 'Special Health Scheme for Rural Area' was launched by the MoHFW, the main objective of which was to provide better health servicers to entire population with the assistance of VOs. After independence, different vertical programmes on leprosy, family planning, tuberculosis etc. were launched

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[2] The section is discussed in the chapter two. For full reference please refer the chapter two, page number. 14.

by the help of International VOs. These programmes recognized the role of VOs in providing of the health services.

An increasing number of VOs were seen in the period of 1970s and 80s. In these decades many international VOs of developing countries started participating in service provision programmes towards development and welfare of poor people. The organizations were also interested in indentifying the needs of the community. As discussed in chapter two, a study done by ICSSR and ICMR revealed that during the 1980s there was scarcity of human resources apart from lack of quality infrastructure, resulting in substandard functioning of health services. The community participation in government programmes and policies were also very low. During these periods, VOs worked very effectively and were involved in community mobilization. 'Community Health Approaches' were used by the organizations to reach the community. In 1978, Alma-Ata Conference fixed a goal 'Health for All by 2000 A.D'. The International Health Assembly recommended a goal that was to be achieved if the member countries hoped for a better and healthy populace. The assembly recommended that the desired goals cannot be achieved without the help of VOs. Consequently, in 1983 the National Health Policy (NHP) was launched which emphasized the significance of the VOs in population stabilization initiatives. The policy was inspired by population control movement carried out by the VOs. The review of the role of VOs in health programmes as discussed in chapter two reveals that there are several health programmes in which the contribution of VOs is considerably huge, tuberculosis programme being one of them.

5.3- PPM: A Strategy to Share the Responsibility

VOs have historically been pioneer in TB care. In the beginning, to improve the efficiency of the services especially in tuberculosis the VOs and the government were seen to be working parallel. However one witnessed instances where VOs and the government collaborated for the betterment of tuberculosis patients. Apart from these international efforts, national level initiatives such as development of the sanatoria, and formulation of state TB association and so on were also done by

the VOs. VOs were active in providing tuberculosis services when there were almost no measures for treatment. Organizations such as Ramakrishna free TB clinic, Delhi Tuberculosis Association of India etc. were involved in preventive, promotive and curative services. After the implementation of National Tuberculosis Programme the role of VOs turned less significant. This does not mean that their roles were insignificant rather; it means that, this period saw a transformation in nature of services provided by the VOs. During these periods the VOs were actively involved in preventive services such as awareness generating activities. The organizations were also involved in the providing the socio-economic support to TB patients and their families.

It is clear from the review done in the chapter three; major role of VOs in tuberculosis programme can be seen after the implementation of RNTCP which was adopted in the period of 1993 in the form of DOTS. The programme was started to technically authorize the VOs in the providing of the tuberculosis services. While attempting to understand the role of VOs in connection with the programme, it is important to understand both the nature of the organizations as well as the socio political contexts in which they place themselves within the programme and policy frameworks. During the period when RNTCP was launched the country was undergoing Health Sector Reform and a large number of VOs from the developed countries were moving towards third world country to improve the health status of the third world countries. It was the era of mushrooming of the VOs in the health services and there was an increasing trend of the involvement of the private sectors with the public sector in the name of PPP (Public Private Partnership)/PPM. Same trends were also seen in the RNTCP. Government of India used PPM concept as an involvement of the private sector in the RNTCP. But after some time the concept acquired broader meanings and was used as strategy in the RNTCP.

In 2001 government of India launched a collaborative scheme for NGOs/PPs for the control of tuberculosis on the basis of PPM model. In this programme there were five schemes where VOs could be involved in control of tuberculosis. This assumption was based on the studies done on health seeking behavior which

showed that more than half of the TB patients first approach the private health sector. Thus to cover the whole population under DOTS it was important to work with the cooperation of all other sectors. This collaboration was based on the PPM model. In this scheme the PPM model was used as a strategy while before it was used as a component. Again in 2008 government of India lunched a revised scheme for the collaboration of the VOs in RNTCP. Under this there are ten schemes in which VOs can collaborate. This revised scheme provided a better chance to all kinds of VOs to collaborate with RNTCP.

Before the RNTCP, nature of collaboration between the government and VOs was at a very informal level based on specific need and task. There were no well defined programme areas where VOs could work or form a partnership. After the implementation of the RNTCP, the government started to collaborate with VOs in a formal manner. To understand the role of VOs in RNTCP, primary data were collected from those organizations which were selected for the study and working in collaboration with the RNTCP. The collaboration with VOs in RNTCP programme depends on the concerned organization's work experience, infrastructure, human resources and coverage areas. All the four organizations covered under this study are different in nature, form, and composition. Ramakrishna free TB Clinic is a faith based and service providing organization having very large infrastructure and covering fairly large catchment area. The DFIT is an International developmental VO with funding from international agencies. This organization has good infrastructure and provides services to large chunk of population. Delhi TB Association of India which is a service providing organization has limited resources and provides the DOTS services to a small population, but covers a large population and geographical area for IEC activates. The other organization, Samarpan is a gross-root level local organization having a limited resource base, and the services provided by them are limited in terms of population and geographic coverage.

5.4- Reflections on Emergence of the VOs in TB programme

A review of the emergence and growth of the VOs is telling of the shifts in the philosophy on which the organizations are based. It is possible to see from this dissertation that of the four organizations that come under the purview of the study, some have philosophical reasons for their emergence in tuberculosis programme while some others work *for* the international fund for their survival. The literal meaning of voluntarism is 'will' that includes all forms of impulses, passion, appetites or desires and determinations. The philosophy of VOs is to provide the services to the needy without the objective of profit earning. The people involved in such voluntary work ought to have internal motivation to work for the betterment of the community and do not have any interest in returns. As discussed in chapter four, the concern behind emergence of 'Ramakrishna Free TB Clinic' which is functional over the last seventy years, was to provide the tuberculosis services to the patients. The organization is now working in collaboration with RNTCP. They get funds from RNTCP to run TU, while for infrastructure and rest of the facilities such as water, electricity etc. the fund is mobilized by the organization locally. 'Delhi Tuberculosis Association of India' is the other organization that has been working in the field for the last 70 years, with a commitment on services provision to TB patients. An analysis of the other two organizations shows that the very purpose behind the interest of DFIT in tuberculosis is to sustain the international funding. After the decline of leprosy rates the staff of the organization happened to be in surplus and the international funding began to fall. For the survival of the staff there was a need for continuous future funding. Tuberculosis being a major killer disease, with the bacteria of leprosy and tuberculosis being from the same family of mycobacterium, and with both diseases having chronic nature and requiring prolonged treatment, a shift to tuberculosis seemed reasonable. Thus the purpose behind the emergence of this organization in the area of tuberculosis is not only the sustainability of the organization but also an effective utilization of their large network and resources. The organization has large network and human resources that has an acceptance in the community.

'Samarpan' started to work in the field of tuberculosis since 2004. The basic motive and interest of the organization in the field of tuberculosis is to obtain government funds.

The analysis reveals that they work in the area not owing to any commitment to the cause, but to ensure their own survival. The organization thus shows tendencies to swing on to other programmes for its survival if and when required. Here commitment came after survival.

The analyses of all four organizations show that the nature and the work of the organizations are not exactly similar. Whereas the emergence of the some of the organizations is for funds, the emergence of the some others is to provide better services in a particular area. These imply that it is most crucial for the State to understand the philosophy that guides the emergence and the politics of an organization while collaborating in programme and policy.

Another issue is that the nature of work of VOs has not being taken into account while developing a framework for collaboration. This has resulted in a haphazard sort of collaboration with organizations and institutions which are ill equipped or ill suited to carry out the work for which they been asked to do. For example, the organization which was working in other health programmes such as family planning abruptly started to work in the tuberculosis programme despite their lack of experience in tuberculosis. Sometimes even their workers are also not trained in tuberculosis. This mis-match results in avoidable handicaps in smooth functioning of the program which should be the hallmark of any successful health initiative. Therefore it is highly desirable that the collaboration should be done or made on the basis of nature of work of the organizations and their relative competence to initiate work in other related fields of health provision. For example, if any organization is working in the field of HIV/AIDS they should collaborate under the scheme of TB-HIV scheme of intervention to high risk group for HIV infection. This type of collaboration will be helpful in effective service delivery to the patients and it will serve the purpose of the collaboration.

Accountability of the government officers in supervising the VOs with which collaboration is done is an important issue that needs to be discussed. As per the guidelines, it is mentioned in the programme document that the DOTS provider should visit the place where VOs are working and inspect whether or not the organization has

proper infrastructure and human resource. It was found during the course of field work, that the government officials do not visit the place where VO is functioning. Two organizations reported that there were no visits by the government officers during the period of their work in the field. Without visiting the field and without understanding the structure and function of the organization, it becomes nearly impossible for the government employees to understand the scheme(s) under which the government and VOs should collaborate resulting in failure to give adequate responsibilities to VOs. It was observed that out of four, one organization does not have adequate infrastructure and has insufficient human resources. The staff who have been involved in the field of health for the last ten years still lack basic information regarding tuberculosis and the components of the DOTS programme as they were not fully sensitized before starting the work in the field. Thus, it was observed that the purpose of collaboration with the VOs got adversely affected due to lack of adequate homework by government employees before doling out the carrot of government funding to these organizations, resulting in the failure of the whole programme and its implementation. This was noticed in the field work observation of Samarpan, which was a failure in terms of serving the purpose of the collaboration (Till the time of data collection, there were only 18 cases with the organization, although Zakhirabad is a slum area and is more vulnerable to TB).

5.5 – Reflections on Role of VOs in Programme Aspects of tuberculosis

5.5.1 - Role of VOs in Management of tuberculosis

The importance of need based collaboration and the role of VOs in addressing specific issues regarding TB can be seen through the working of Delhi Tuberculosis Association of India. Delhi Tuberculosis Association of India has historically been working for awareness generation in entire city of the Delhi. The target group of the organization was mostly destitute population. When the Delhi government wanted to address the problem of TB in this population group, they collaborated with Delhi Tuberculosis Association of India under a special scheme based on the local situational analysis. This scheme is not a part of the national guidelines for NGOs/PPs collaboration. Because of the homeless status and migratory nature of the population, the completion of the

treatment for the target population turned out to be a big issue. The case holding for completion of DOTS and defaulter management is the biggest obstacle for the scheme. However the access to treatment ensured by the organization for the targeted population has resulted in conversion of infectious cases to non- infectious to a certain extent.

Samarpan is a VO working with the collaboration for RNTCP in Zakhirabad area. This is a local Community Based Organization with very limited human resources and infrastructure and operates an Out Patient Door (OPD) service in that area. Even though there is a government facility in the locality, it is interesting to note that Samarpan gets at least 60 to 70 patients a day seeking general health services from its OPD clinic. However, since the organization does not have the required facilities to address the problems of patients, the question remains why people utilize the services of a facility run by VO more than that offered by a nearby government centre. The reason for this may be attributed to the fact that the people of Zakhirabad locality find the facility run by Samarpan more accessible as compared to the government facilities. The irresponsibility shown by the government in providing prompt services and people's positive attitude towards service delivery by the VOs influences the success of the VOs. The collaboration with VOs in the areas where people have low or no faith in the government system may increase the case detection and treatment adherence as the VOs will supplement and complement the government effort. But the data collected from Samarpan reveals that although there are 60 to 70 patients reporting for general health problems, only 18 cases were found smear positive in the organization since collaboration. It may be because the organization started working in the field of tuberculosis recently and the number of cases could have increased after some time.

5.5.2- Role of VOs in Case Finding and Case Holding

There is significant role of VOs in case finding and case holding. The areas covered by the organizations mostly belong to very poor population. The NSP case detection rate of all organizations is approximately 90 to 95 percent. All organizations are using approximately the same strategy such as follow up of patients, education, keeping records of information about the patients and their family members, home visit by health visitor etc, for case finding and case holding. Some organizations use active case

finding method for the new cases. It was found that the new case detection rate of all organizations was higher than the set target in the programme and these targets were achieved through using the above mentioned strategies. A study done in Delhi reveals that, there was a significant increase in the number of case findings. The study indicates that 'public-private mix' is a feasible way to improve TB case detection.[3]

Data related to strategy used by the organizations reveals that some organizations are using the 'target oriented' strategy. The strategy that is being used is not appropriate in the context of tuberculosis program as it increases the false case detection. This was a major problem in NTP.

Different strategies such as health camp, community interaction meeting, and awareness generation camp in the high prevalence area were used by the organizations. It helps in the identification of maximum number of the case identification. To identify the cases, sputum examination and x-ray methods were used by the organizations.

There is a significant role of VOs in case holding also. An examination of the role of VOs in case holding also shows that there is a significant contribution of VOs in case holding. The strategy being used by the VOs here is health education. Apart from that, all four organizations are providing drugs to the patients at their homes, if in any case patient is unable to come to the DOT centre. All the four organizations were using community DOTS providers for delivering drugs to patients located in its defined areas. This proved to be a successful strategy in case holding and management of the defaulter cases. It was also felt that it has been more useful in dealing with some of the social factor related to TB such as stigma.

Another approach used by the all four organizations to ensure adherence to treatment is interaction with the patients. It was realized that the DOTS doctor and Health Visitor of the organizations attempts to talk to those patients and their family members who were irregular in consumption of drugs.

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[3] Arora, V.K, *et.al.* (2003), 'Improved Case Detection of Tuberculosis Through a Public-Private Partnership', *Indian Journal Chest Disease Allied Sciences*, Vol. 46: 133-136.

Attitude of the provider is a very important factor in success of DOTS. Direct observation does not have any affect without the good interaction between patient and providers. In other countries such as China, the government provides incentives to enhance the patient-provider interaction. During the field work, the DOTS provider/ health visitor in some organizations were found commanding the patients to visit the centre. This goes against the spirit of DOTS. A TB patient requires moral and psycho-social support during the course of treatment. The DOTS provider or drug provider should have a caring attitude rather than an imposing attitude. It affects the motivation level of the patients and works as a hindrance in case holding. A controlled trial study was done in Pakistan, in which it was concluded that DOTS with direct observation of treatment by health worker, family members or self administered, gave similar outcome.[4]

The role of voluntary organizations is also important because there is a geographical difference in the prevalence of the disease and it is not possible to design separate program for different places. Voluntary organizations have flexible rules and regulations. They can afford to give priority to different areas and give more emphasis on the high prevalence areas. This results in increased case finding. The literature from different studies also reveals that after the collaboration with voluntary organizations the number of new case identification has increased.

5.5.3- Role of VOs in IEC activities

IEC is an important component in tuberculosis programme. The main purpose of the IEC activities is to provide a better understanding of TB and its cure among the community, improve the quality of care provided to TB patients and to reduce stigma about the disease in the community. The organizations conduct various IEC activities as per the norms and also at times over and above the prescribed forms to create more awareness among the population. There is difference in strategy that is being used by the organizations in IEC activities. For example DFIT is conducting an interactive session between the patient who is in IP and CP. The patients who had gone through it

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[4] Wally, J.D. (2001), *cited in* Kishore, J. (2006), *National Health Programmes of India: National Policies and Legislation Related to Health* , New Delhi: Century Publication, p-97.

told about the importance of the treatment adherence and problem faced during the treatment. They also talked about the importance of full course treatment. It was seen that some patients leave the treatment after two or three months because after two months the patient becomes non-infectious. The symptoms disappear and the patient thinks that they are cured. Thus the interaction between IP and CP patients helps in case holding also.

Apart from these efforts all organizations are conducting community meetings, public meetings, doctor patient-interactions, awareness generating camps etc. to make the IEC activities attractive. Some organizations are using some distinct methodology such as organization of animation movies in the school and the community and DOTS centre, organization of puppet shows in the community and other slum areas. Pamphlets and handouts are also being distributed in the community and other needy areas for the awareness.

The activities taken by the organizations help in case finding, case holding and reduction in stigma. It can be said that the IEC activities done by the VOs were effective. Because the organizations are very close to community so they are more acceptable in the community.

In the control of tuberculosis community involvement in the programme is very important. The success of the programme is based on the successful involvement of the community in provisioning of the DOTS. Significant level of involvement of the community can be ensured through VOs. The study reveals that, involvement of community can contribute in improving RNTCP performance[5]. To ensure the community participation in provisioning of the DOTs, all organizations are organizing community talks and public meetings.

5.6- Relationship with the government:

For the success of any collaborative programme, the smooth relationship between VOs and government is very important. As discussed in chapter four, the relationship of VOs

[5] World Health Organization (2003), '*Community Contribution to TB Care: Practice and Policy Stop TB Department*', Geneva: World Health Organization.

with government is seen in the terms of funding and accountability. This study found that getting funds from the government was not a problem but it does vary on the size and nature of the organization. For example, Ramakrishna free TB clinic send their own action plan to the government and then the fund is allocated to the organization accordingly. But other organizations are getting fund as per guidelines. Thus the funding pattern is based on the nature and previous work and credibility of the organization.

The second term used in the study is accountability. The study found that most of the organizations are achieving the target and the standard given by the RNTCP. In the context of proper utilization of the fund, it was found that the auditing of the fund was done by the Chartered Accountant in each VO.

Another point that emerged during discussion with expert personnel was that there is a difference in the nature of the VOs and government. VOs are flexible in their functioning, but that does not mean that they are not working as per the norms as laid down in the programme. Here flexibility means that the VOs put their trust in provisioning of better services and for that they are using methods which do not always adhere to the government norms. On the other hand the government has certain strategy and they follow those rules strictly. This contradiction in nature some time creates friction between the government and the VOs. Another thing is that authoritarian attitude of the government employees some times causes impediment in the smooth working of the program.

5.7- Collaboration with VOs: Divergence of views

It is important to discuss how and why the government formed collaboration with the four above mentioned organizations. This discussion is based on empirical observations made on selected organizations and on the information gathered from experienced personnel working in the field.

Initiation for collaborations was made by either of the parties in each case. It was found that all the other organizations except 'Delhi TB Association of India' approached the government for collaboration. Collaboration was based on past credibility of the

organizations. The target group of Delhi TB Association was the destitute population of Delhi. Taking into consideration the organization's nature, potential and its targeted population, the government launched a special scheme for destitute population. Based on the outcomes of the IEC activities of the organization that covered the entire city of Delhi, the scheme offered to cover the destitute populations of Chandni Chowk.

The story of Ramakrishna free TB clinic is entirely different from other organizations. The organization has been working in Karol Bagh and its periphery, providing services to a population of about six lakhs. Since 1998 the organization has been working as a district chest clinic and in 2001 with the collaboration of RNTCP it started to work as a TU. The credibility and goodwill of the organization, and the vastness of the population that it covered (five lakhs was the minimum mandate to set up a TU) allowed the organization to work with government in the scheme of TU. But the two other organizations, DFIT and Samarpan cover the area where government was already providing the services. In the year 2002 DFIT got the permission to work in the area of Qutub Vihar and Vikas Vihar Kakraula and covered the population of two lakhs. In the next two years the organization got permission to open ten DMCs, covering a population of ten lakhs. Similarly the area covered by Samarpan was earlier covered by the 'Motinagar Chest Clinic'.

Here the question that needs to be asked is, when health itself is a state subject, where the government has already been providing services, and then what was the need to allot the work to the VOs. There can be two reasons - either to provide better and speedy services to the public, or that the government wanted to pitch its responsibility on to the VOs. That is to say that the PPM strategy could have been an easy solution for the government to shift its responsibilities. This possibility can be explained in two ways. One, from the programme perspective, as stated by the government it was by and large vertical despite its assertion to the contrary. The health workers were ill equipped and under motivated to carry out the programme in its earnest, i.e. reaching to the end beneficiary. This led to a serious rethinking in the planning of RNTCP when the services were started to outsource to other health sectors in order to increase peripheral coverage and thus have an effective programme outcome. The PPM mode was an elaboration of the strategy and culmination of rethinking on the part of government

policy makers. By the help of this collaboration government is sharing the responsibility with other sectors. The intention behind handing over the work could be to make the services more effective. This apart, by collaborating with an existing organization, it could also save on setting up the infrastructure for a fresh arrangement. From a different vantage point, one could also say that the government wants to withdraw from their responsibility. The case of Samarpan does represent a case where the government is shedding its responsibilities, as was evident by the remarks of the in-charge of the organization that, after the collaboration public sector personnel have sort of washed off their hands from the area.

Another issue that came across is related with the policy. It is mentioned in the programme document that the organization will provide the DOTS services only to those patients who come under their catchment area only. If any patient is coming who does not comes under their catchment areas, the organization will refer the patient to DOTS center which comes under the patient's area. It was found that the area related to DOTS centre is defined by the government but people are not aware that in which DOT centre they should go. The patients have to run around for identification of their related areas. It takes too much time and in such a situation patients have to suffer and finally most of the patient turn towards private clinics.

Sustainability of the VOs in collaborating in RNTCP is a big question that needs to be answered very clearly. But in the absence of any clear policy directives on part of the government and questions about the continued funding either by government or international agencies, the long term sustainability of VOs is doubtful. Nor is there any assurance about the programme being run in the same mode of PPM in future. As tuberculosis control is a long term plan with uncertainty looming large over the fulfillment of objectives, a lengthy association between the government and VOs cannot be taken for granted. As such, future prediction on feasibility of VOs in the RNTCP is sort of entering into a grey area where the exact role of both the donors and the volunteers is ill-defined. The best that can be said at this juncture is that the collaboration seems to be working and moving towards its defined and /or prescribed objective.

Thus in the entire discussion on the emergence and role of the organizations working for control of tuberculosis it is found that the there is a need of collaboration between the government and the VOs to cover all cases of the tuberculosis under DOTS. The collaboration reveals that there is a wide role played by the organizations in provisioning of the health services. In the case of tuberculosis it is also important to improve the case finding and case holding and case management, treatment compliance and completion, better IEC activities, to ensure the community participation in the programme.

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Role of Voluntary Organizations in Revised National Tuberculosis Control Programme (RNTCP) in Delhi:

Check List for Interview

Check List for the organizations those are working for NTP

Information related to Historical background of the organizations

1- What is the year of registration of the organization?
2- What type of organization is this? (Like- religious, service organization, developmental organization, research organization etc.)
3- Are you affiliated to any association? (like- VHAI, Lions International, any other)
4- What is the reason behind the emergence of the organization? What factor or issues motivated to be organized or to form this agency?
5- Why this organization is working in this field?
6- How this organization came in the field of tuberculosis. What were the initial aim and objectives of this organization?
7- Can you please detail the activities since inception/ what shifts happen and what were the major reasons for the change?

Information related to emergence and Role of organizations in tuberculosis programme

1- When did you start tuberculosis program?
2- Are you aware of NTP? What was the role of your organization in NTP?
3- Organization has institutionalized service or community based service or both?
4- Under health and specific to TB what kind of activities did your organization take up at the initial stage? Was it programme specific or something else? Please elaborate. (Like- services provisioning, awareness generation, training program, permanent hospital etc.)
5- What was the main target group at the time of starting of the organization? (like- children youth, women, aged people, people, below poverty level)
6- Has there been change in target group as compared to earlier stages? (yes/No)
7- If yes, what kind of changes and what has been the major reason?
8- Visualising the initial stage of the programme what changes have undergone during these periods both at the programme level and organization level?
9- Are you aware of RNTCP? What is your organization's role in RNTCP?
10- Please tell me the programs that you have at present in your organization.
11- Under which scheme this organization is working with the collaboration of RNTCP.
12- Can you elaborate, how the collaboration happened with the government
13- Who started to initiate for the collaboration
14- How much time was taken by the government for the collaboration

15- Is their was any inspection done by the government officer of your organization before the collaboration
16- Did the scheme allotted by the government or did they select it on their own.
17- Why do the organizations work only in a particular scheme?
18- Are they interested to work with other schemes also?
19- What are the strategy are being used by the organization to improve the case finding and case holding.
20- What are the activities done by the organizations for the aware generation among the community?
21- What are the other activities done by the organization for the management of the tuberculosis?
22- What is the procedure of sputum collection and how much time does the organization take to send the report.
23- What is the processer to send the report?
24- Do they have adequate human resource and other resources such as infrastructural facility?
25- Do they have the facility for Sputum Culture Susceptibility if no how does the organization handle MDR case?
26- Did the VOs have adequate facilities to send the sputum samples to the diagnostic centre?
27- How is their relation with the government?
28- What are the monitoring and evaluation process?
29- What are the other programmes run by the organization?
30- Can you please detail the activities since inception/what shifts happen and what were the major reasons for the change?
31- What are the major challenges you face in TB programme
    - At the programme level
    - Human resource
    - Finance
    - Response of community
    - Procurement of drugs
    - Other problems

32- What is the community response to these programmes?
33- What effort do you make at the organizational level to facilitate the community and reach to maximum people in need?
34- Can you explain the transformation taken place during these period in term of
    1) Nature of the collaboration within the programme
    2) Institution point of view (funding, multi specialist)

Information related to funding

1- What are the sources of funds of your organization?
2- What problem or barriers do you find in financing?
3- What is your organizational policy pertaining to fund raising?

Check List for the organizations those are working for RNTCP:

Information related to Historical background of the organizations:

1- What is the year of registration of the organization?
2- What type of organization is this? (Like- religious, service organization, developmental organization, research organization etc.)
3- Are you affiliated to any association? (like- VHAI, Lions International, any other)
4- What is the reason behind the emergence of the organization? What factor or issues motivated to be organized or to form this agency?
5- Why this organization is working in this field?
6- How this organization came in the field of tuberculosis. What were the initial aim and objectives of this organization?
7- Can you please detail the activities since inception/ what shifts happen and what were the major reasons for the change?

Information related to emergence and Role of organizations in tuberculosis programme

1- When did you start tuberculosis program?
2- Organization has institutionalized service or community based service or both?
3- Under health and specific to TB what kind of activities did your organization take up? Was it programme specific or something else? Please elaborate. (Like- services provisioning, awareness generation, training program, permanent hospital etc.)
4- What was the main target group at the time of starting of the organization? (like- children youth, women, aged people, people, below poverty level)
5- Has there been change in target group as compared to earlier stages? (yes/No)
6- If yes, what kind of changes and what has been the major reason?
7- Visualising the initial stage of the programme what changes have undergone during these periods both at the programme level and organization level?
8- Are you aware of RNTCP? What is your organization's role in RNTCP?
9- Please tell me the programs that you have at present in your organization.
10- Under which scheme this organization is working with the collaboration of RNTCP.
11- Can you elaborate how the collaboration happened with the government?
12- Who started to initiate for the collaboration
13- How much time was taken by the government for the collaboration
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Information related to funding:

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