EVOLVING PERSPECTIVES FOR VOLUNTARY AGENCY/ NGO ACTION IN TB CARE AND CONTROL*

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Early historical roots

Organised voluntary action in the health field in India had emerged by the turn of this century. It was possibly a response to the appalling health conditions of people resulting from growing impoverishment, frequent famines and epidemics. It was superimposed on traditional forms of voluntarism in Indian society and was influenced by the freedom movement.

By the time TB received official recognition in 1910 as a problem of magnitude, the voluntary sector had initiated micro level action. In keeping with knowledge available then, sanatoria were started by Christian Missionaries, Philanthrophic individuals and trusts. The first open air sanatorium was started in 1906 in Tilonia, Rajasthan. Significantly it catered primarily to girls from orphanages and schools.

Efforts were isolated, not linked together. There was particular focus on the poor and indigent, who then comprised more than 80% of the population. These initiatives set the trend for a strong service delivery and pro-poor orientation in the anti TB efforts of volags.

Some voluntary groups developed mechanisms of meeting regularly. The severity of the TB problem and difficulties in dealing with it, were discussed. The need for a larger level assessment of the problem, for preventive measures, and health education was urgently felt. It is interesting that Dr. C. Frimodt Moller of Union Mission TB Sanatorium, Madanapalle in the early 1920s spoke of ‘Home Treatment’ as being necessary for tackling TB in India. Close contact with the realities of TB and TB care in the field, on the basis of which suggestions are made, has been a strength of the voluntary sector.

The Bengal TB Association was the earliest group formed to combat TB around 1929. The King George Fifth Thanksgiving (Anti Tuberculosis) Fund in 1929 and the King Emperor’s Anti TB Fund in 1934 were largely voluntary efforts started with official patronage of the Vicerine. The Funds were built on local Indian contributions.

The Tuberculosis Association of India (TAI) formed in 1939 was the first coming together at national level of the voluntary sector. It comprised mainly of medical professionals with experience/ specialization in TB and was specific disease oriented in focus. A close relationship with the Government was established through TAI’s governing structure. Thus a second important trend of being complementary to the official health authority was laid down. The State however hardly responded to the problem of TB because of preoccupation with

diseases like cholera, plague, small pox and partly because of the staggering magnitude of the problem and a lack of clear conception as to what should and could be done to combat it” (CHEB 1960). In fact, after the Second World War there was an effort to transfer responsibility for care of army personnel with TB to the voluntary sector.

The TAI set up a model TB Centre at New Delhi in 1940, a sanatorium at Kasauli and pioneered several training programmes. The section of TB in the Bhore Committee Report (1946) was drawn up by members of the TAI. This gave a national perspective and plan for TB control. It drew on the experience of organized home treatment tried from the early Forties by Dr. Sikand at the New Delhi TB Centre

**Post Independence changes**

The key change after Independence was the Indian government’s Constitutional acceptance of responsibility for the health of its citizens. Tuberculosis control measures were given importance by the political leadership. The Chairman of the Technical Committee of the TAI become the first Adviser in Tuberculosis to the Government of India. A national level BCG campaign was suggested by the Technical Committee of TAI, which becomes the think tank for TB. **Thus during this important period the voluntary sector played a crucial role of placing TB on the national agenda and gave content and direction to the national control programme.**

Collaboration was established with the international Tuberculosis Campaign to initiate The Mass BCG campaign, and later with WHO and UNICEF.

Several large studies were initiated by the TB Unit of the Government of India. These were undertaken by the I.C.M.R., the newly established TB Research Centre, and the National TB Institute (NTI), in collaboration with WHO and others. These led to a new understanding of the problem of TB and its distribution, and to a new approach to control integrated with the general health service. The initiatives and responsibility for TB control was now taken by the government sector. **The National Tuberculosis Programme (NTP) was launched in 1962.**

**New Developments**

During the Fifties and Sixties, dispensaries, health centres, hospitals and some TB Sanatoria were set up by voluntary agencies. Their general medical work also involved TB treatment.

By the early Seventies, there was growing concern in several parts of the country that general health services, particularly rural, were not growing or functioning properly. In the NTP which was integrated with the above, there were frequent complaints of shortages of drug supply, staff vacancies, absenteeism and poor quality of services. TB case finding and case holding was much lower than expected.

The TAI over the years had expressed its concern about this and conducted brief independent studies in two States. Then playing a more pro-active role, it raised the issue at the highest level with the Health Minister, Dr. Karan Singh.
Thus the voluntary sector kept in mind the interests of the widely dispersed and unorganized TB patients and articulated these interests at policy making levels. They were openly critical of Government effort. The government responded by asking the I.C.M.R to conduct an independent review.

In the meantime several other groups and formations also because articulate regarding the continuing problem of TB. This was inevitable as anyone working at grassroot level was confronted with the problem of TB.

The Voluntary Health Association of India (VHAI) a national federation of State Voluntary Health Associations was formed in 1974. Peripheral member institutions were faced with a double problem of TB and a poorly functioning NTP. VHAI organized state and national meetings, interacted with NIT, published training material and most importantly, studying the issue of production, distribution and supply of anti TB drugs. This opened a Pandora’s box of political economy issues, which were pursued by them and the All India Drug Action Network.

The Medico Friend Circle, another national network of people interested and involved in health problems and issues of the majority impoverished people in the country, also took up TB as an issue, with a national meeting, interaction with NITI and concerned academicians, publication of critical papers etc.

Grassroot service voluntary organizations involved in medical and health work in India were estimated to be about 4000 in number. They were finding it increasingly difficult to get funding for TB programmes during the Eighties when drug prices also began to increase. However those who had a particular interest in TB managed to raise funds and ran very successful low cost programmes. This was an important field witness when there was general pessimism that TB control was an intractable problem in India and much blame was laid on defaulting patients.

Unfortunately other than brief, transitory interaction, there was no sustained coming together among the major voluntary sector groups in India. At the national level TB appeared to receive priority by being put on the Twenty Point Programme. However the budget was not increased adequately, the drug production/distribution system continued to respond to market forces and family planning/welfare and other vertical programme continued to plague the general health services. While targeting supposedly increased case finding, particularly in peripheral health institutions, achievements of cure, a crucial component, continued to be elusive. International interest in TB was at its lowest.

Voluntary sector effort, though with a widened base and a broader perspective, seemed to be ineffective in bringing about any major policy change during this period. It would be instructive to try and understand why this was so.

The most recent wave of global interest in TB control has been sparked by its link with HIV/AIDS and the emergence of MDR TB. The WHO has declared TB a global emergency in 1993 and has been actively promoting its strategy as the revised National TB Control Programme.
This is supported by multilateral donor agencies like The World Bank and bilateral donor agencies. Forms of subtle and not-so-subtle conditionality’s are being attached to large loans that are being offered to the health sector as part of the ‘human face’ of structural adjustment. While government health sector personnel are totally convinced of this approach, sections of the voluntary sector have been more analytical and critical in approach. The VHAI and the Nucleus for Health Policy have submitted a critique and an alternative approach. The voluntary sector would do well to safeguard the short and long term interests of the TB patients, particularly the poor, who do not have access to the private sector. The sustainability of a programme that covers the entire population, the development of an accountable, effective programme that helps solve the problem and does not worsen it, is of paramount importance.

The WHO and World Bank have identified the voluntary sector or NGOs as being important in playing a role in health in general and in TB control. However both they and the government would prefer a docile, dutiful lot who would do as they are told. However, it is up to the voluntary sector to carefully study the situation, not just the technical content of the programme and problem, but the broader socio-political-economic context, in which, it functions and to redefine their own role.

References

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