

CHAPTER—VIII

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DISCUSSION AND CONCLUSION

AIDS is the leading infectious cause of adult deaths in the world. Within two years of its first appearance in 1981, AIDS has spreaded to 60 countries and later on to all the countries across the globe. The current revised estimate suggests that globally 33.2 million (30.6 – 36.1 million) people are living with HIV/AIDS in 2007 (UNAIDS 2008). Out of this, 30.8 million (28.2 – 33.6 million) are adults, 15.4 million (13.9 – 16.6 million) are women and 2.1 million (1.9 – 2.4 million) are children under 15 years (UNAIDS 2008). More than 25 million people have already died. AIDS is now considered not only as a health problem, but also as a developmental and security threat. Although AIDS epidemic began in USA more than 25 years ago, up to 95 percent of new HIV infections now occur in developing countries, which are unfortunately also least equipped to effectively respond to the challenge. It is now well recognized that the epidemic is affecting developed and developing countries differently. AIDS in developed countries is now a chronic disease and a manageable health problem. In developing countries, however, AIDS is destroying societies, nations and communities. The antiretroviral treatments that have increased longevity of patients in industrialized countries are unfortunately beyond the reach of those in the developing world. The disease is, therefore, widening the gap between ‘haves’ and ‘have nots’, between rich and poor nations, thereby presenting a new ethical and human rights dilemma.

In India, the first HIV infection was reported in 1986 and within a short period of time, it has evolved as one of the most serious public health problems across the country. The current revised estimate suggests that 2.5 million (2.0-3.1 million) people are infected with HIV/AIDS in India (NACO/HSS 2006). This is equivalent to approximately 0.36 percent of the adult population (prevalence rate for males is 0.43% and for female is 0.29%). Maharashtra, Tamil Nadu, Karnataka, Andhra Pradesh, Manipur, Mizoram and Nagaland are declared as high prevalence states, where the HIV infection rate has crossed one percent in antenatal women. Similarly, Gujrat, Goa, Pondicherry and West Bengal are placed in moderate prevalence states category. The HIV infection rate has increased 5 percent or more among the high-risk groups in these states. The remaining states are placed in low prevalence category.

where HIV infection rate is below one percent among antenatal women and below 5 percent among high-risk groups. NACO has also identified 156 districts as high prevalence districts and out of which four districts are in West Bengal (NACO/HSS 2006). Like other countries, in India too, NGOs were first to respond to HIV/AIDS. Later on, after the establishment of NACO, it has involved NGOs as partners in the National AIDS Control Programmes.

It is true that there is a long history of NGO activities in India. But the phenomenal growth of NGOs has taken place during late 1970s and 1980s. There are numbers of factors responsible for it. Major among them are implementation of SAP as prescribed by the World Bank and IMF; and influence of INGOs as well. Thus, state's inability coupled with funding support from international donor agencies and other INGOs provided the impetus for the expansion of NGO sector in India. It has been found from the previous studies that NGOs are varied in terms of size, capacity, levels of operation and services provided. They carry out various programmes pertaining to income generation, education, welfare of the weaker sections, health and so on. Especially in the field of HIV/AIDS, NGOs perform different activities. They provide clinical services, counseling, awareness, advocacy, care and support as well as conduct research. In India, some of the prominent NGOs engaged in HIV/AIDS care are SHALOM in Manipur, SAHARAN in Delhi, DMSC in West Bengal, Lawyers Collective in Mumbai, MASUM in Pune and Seva Mandir in Udaipur. But, there is little information on the characteristics, distribution and activities of such NGOs at the all India and state levels. In order to get some insights into these aspects, this study has been conducted on NGOs in HIV/AIDS care in West Bengal. The reason for selecting West Bengal is that it is placed in moderate prevalence states category where HIV infection rate is more than 5 percent among high-risk groups: four districts are declared as high prevalence and four districts as moderate prevalence districts as well. Besides it, West Bengal is one of the five states where Government of India initially started National AIDS Control Programme with the help of WHO in 1987. The review of literature suggests there are few studies done on NGOs in health care at the state level and these include Maharashtra (Duggal, Gupta and Jesani 1986), Andhra Pradesh (Baru 1987), Assam (Sarkar 1998) and West Bengal (Sarkar 2005). But, similar studies are not conducted on NGOs in HIV/AIDS care at the state level. In this context, the present study has tried to understand the case of West Bengal with regard to HIV/AIDS care. It has made an effort to get a state level overview of such

NGOs, to understand their distribution and contributions as well as future trends of such NGOs in the context of globalisation.

An exploratory design has been used in the present study. The study has been carried out in four phases. In the *first phase*, names and address of the NGOs engaged in HIV/AIDS care were collected from various umbrella organizations (e.g. West Bengal State AIDS Prevention & Control Society, UNICEF, ACTION-AID and SAATHI's directories of NGOs). Having put all names together, a comprehensive list of 60 NGOs engaged in HIV/AIDS care in West Bengal was prepared. In the *second phase*, questionnaires were mailed to all the 60 NGOs and followed up with several reminders through e-mail and phone. The response was received from 27 NGOs. This was done to collect necessary data to get a state level overview of NGOs in HIV/AIDS care. In the *third phase*, six NGOs (i.e. Durbar Mahila Samanaya Committee, Society for Community Intervention and Research, Bhoruka Public Welfare Trust, Human Development and Research Institute, MANAS Bangla and SPARSHA) were selected purposively based on certain criteria and studied in detail. In each NGO, emphasis was given on historical background, organizational structure, present activities, views of staff, beneficiaries' perception towards the working of NGOs, etc. to understand how far NGOs could contribute to HIV/AIDS prevention, care and support. At the *last phase*, the researcher had discussed informally with few key informants like academicians, experts, officials from NGOs and WBSAP&CS to know about their views on the impact of globalisation on NGOs working in the HIV/AIDS field. At the end of this phase, the researcher has done necessary literature review to know more about the impact of globalisation in this regard.

Now, the important issues, which have been observed in this study, are being discussed below.

(i) Typology of NGOs

There are different ways to classify NGOs. In order to avoid the complexity, present study has classified the NGOs of West Bengal in terms of their activities into five categories. These include religious organizations, development organizations, research and consultancy agencies, and action groups. The Chapter-V (Part-II) shows that the HIV/AIDS care programmes are mostly carried out by the service organizations, research & consultancy agencies and development organizations.

(ii) Growth and initial activities of NGOs

The Chapter-V (Part-II) shows that NGOs has grown in numbers during late 1970s and 1980s in West Bengal. Most of the NGOs were initially engaged in awareness generation and health related programmes. It is also found that mostly the dedicated untrained social workers, medical practitioners and group of like-minded people have promoted these NGOs. This may raise a question like what was the reason for rapid growth of NGOs during this period. We find the answer in Sarkar's (2005) study on "NGOs in Health Care in West Bengal". The Sixth and Seventh Five Year Plans have given more importance on human resource development and expressed the need for greater involvement of NGOs. At the same time, a paradigm shift was also taking place from welfare approach to development approach at that time. All these led to the growth of most NGOs during late 1970s and 1980s (Sarkar, 2005). With regard to promoters of NGOs, more involvement of dedicated untrained social workers and a group of like-minded people was due to their humanitarian attitude and zeal to do something for the poor people; and involvement of medical practitioners was due to the availability of fund from the government for initiating health care programmes through NGOs.

(iii) Present activities of NGOs

The Chapter-V (Part-II) also shows that most of the on-going programmes of NGOs are related to HIV/AIDS and health. They are also running permanent clinics and organizing training for health workers. Few programmes are related to drug abuse, anti-trafficking of women, community development, etc. So far HIV/AIDS programme is concerned, most of the NGOs (66.7 %) have started this during NACP-II (i.e. in between 1999 and 2006). Most of these programmes are initiated for a particular section of people like women, children, people vulnerable to HIV/AIDS, etc. As a result of this trend, the principle of universality of public health approach gets undermined – since the needs of entire population are not met.

(iv) District wise distribution of NGOs

In the Chapter-V (Part-I), district wise distribution of NGOs in HIV/AIDS care in West Bengal has been discussed. This has clearly brought out the fact that 50% of total NGOs are situated in Kolkata and its adjacent areas (i.e. Howrah, Hoogly, North and South 24 Parganas). Out of the total NGOs implementing targeted intervention programmes (TIPs), 43.5% NGOs situated in these districts and implementing 46.7% of total TIPs in West Bengal. It means NGOs prefer to work in socio-economically

developed areas. The similar trend was found in the study of Maharashtra (Duggal, Gupta & Jesani, 1986), Andhra Pradesh (Baru, 1987), Assam (Sarkar, 1998) and West Bengal (Sarkar, 2005). This kind of trend has an implication on the principle of universality, accessibility and availability. As a result of this kind of approach, HIV/AIDS care services do not reach to all areas and sections of society. For example, there is no full-fledged TIP in Bankura, Malda, Paschim Medinipur and Uttar Dinajpur districts. This lack of attention might have led to increase in HIV infection rate as NACO (2008) identified Uttar Dinajpur, Purulia and Burdwan as high prevalence and Medinipur (Purba and Paschim) as moderate prevalence districts.

(v) Target groups addressed by NGOs

The Chapter-V (Part-I) has discussed about the target groups addressed by NGOs in HIV/AIDS care. It is found that almost half (46.7%) of the total TIPs are for sex workers and 28.3% for truckers. However, the coverage of high-risk groups like IDUs (11.7%) and MSM (3.3%) are comparatively less. This may be the cause of increasing trend of HIV infection among the IDUs and MSM in West Bengal as indicated by NACO (2008). However, most of the NGOs have been working in both urban and rural areas by adopting institutional as well as community-based approaches.

(vi) Problems faced by NGOs

NGOs have been facing various problems in the implementation of HIV/AIDS programme. The Chapter-V (Part-I) shows that majority of them have identified indifferent attitude of people due to stigma (96.3%); wrong policy of WBSAP&CS/NACO (96.3%); inadequate infrastructure to meet the demands of HIV/AIDS victims (55.5%); fear of victims to be exposed and to be socially boycotted (33.3%); and staff related problems (33.3%). NGOs have also pointed out about the apathetic attitude of government health personnel, inadequate finance and ART related problems. Case studies in selected NGOs (discussed in Chapter-VI) have also supported these views. It is surprising that NGOs are not hesitant to point out the defects in the donor's (i.e. WBSAP&CS/NACO) policy.

(vii) Suggestions of NGOs for effective implementation of HIV/AIDS

In Chapter-V (part-II), various suggestions given by NGOs for the effective implementation of NGOs have been discussed. Majority of NGOs (92.5%) think that stigma related problems could be overcome through mass awareness and counseling. With regard to financial problem, 74% of total NGOs have asked for financial support to meet the needs of target population. Other suggestions include developing network

among the NGOs in HIV/AIDS care in West Bengal; bringing necessary change in the existing policy of NACO; opening of more ICTC and ART distribution centers; and simplification of MIS and Reporting system. These suggestions are justified and important. Most of these issues are considered and taken care of in NACP-III (2007-2012).

(viii) Organisational Set-up

Case Studies, in Chapter-VI, bring to our notice that there is a variation in organizational structures of NGOs. For instance, SCIR, HDRI, SPARSHA and MB have very simple or flat type of organizational structures. But BPWT and DMSC have very complex or hierarchical organizational set-up and both the organizations have very wider coverage. While BPWT tries to reach all sections of community, DMSC has adopted an integrated approach for the sex workers and their children. As a result of this kind of plurality, it is understood that all NGOs do not contribute equally. However, all of these six NGOs are working as per the guidelines of WBSAP&CS/NACO.

(ix) Nature of Programme activities

In Chapter-VI (Part-II), nature of programme activities of the six selected NGOs has been discussed in detail on the basis of eight requisite criteria. These are: (a) objectives of the programme, (b) components of programme, (c) programme execution process, (d) people's participation, (e) monitoring and evaluation, (f) source of funding, (g) innovative components and (h) local cooperation. Some commonality is found in six NGOs as all of them are implementing the programme as per WBSAP&CS guidelines. But they differ from each other, as each of them working with different target groups. It is found that the programmes of all six NGOs under the study suffer from one or more problems. Some of the problems are common in all the programmes under the study. For instance, lack of timely disbursement of fund by WBSAP&CS, no funding provision for addressing the general health problems of target groups and for meeting traveling expenditure of Peer Educators. In every NGO, there is some internal mechanism for monitoring and evaluation of the programme. At the same time, each NGO's programme has got some positive aspects and innovative components too. But, all the programmes are fully dependent on the funding agency i.e. WBSAP&CS. Therefore, all the programmes under the study are less sustainable. This kind of trend expresses that NGOs can't contribute in the community for a long time.

(x) Extent of People's Participation

The Chapter-VI (Part-II) has discussed people's participation on the basis of their participation in need identification, beneficiary selection, programme planning, programme implementation, resource contribution, and monitoring & evaluation. It is found that comparatively people's participation is better in CBOs like DMSC, MB and SPARSHA. In SCIR and BPWT, beneficiaries don't have scope to participate in programme planning, monitoring and evaluation. However, they participate in the evaluation of external team (i.e. WBSAP&CS/NACO) by providing information. Beneficiaries of all six NGOs do not contribute financially except the registration fees. But, they physically participate in the programmes of NGOs, provide physical infrastructure (e.g. chair, table, etc.), control public gathering, arrange refreshments for resource persons, etc. However, they have no right of getting a programme sanctioned that they need, which is seen as management level affairs. Thus, top-down approach of public sector is very much present in NGOs too. Government funding may be one reason of replicating this in NGOs.

(xi) Innovative Components

In Chapter-VI (Part-II), innovative components of each selected NGOs have been analyzed in detail. It is found that comparatively CBOs like DMSC, MB and SPARSHA are better than remaining three NGOs. These CBOs have got a team of committed and dedicated staff members, most of whom are selected from among the target groups that they serve. All six NGOs under the study are having strong networking with government, private and other NGOs. Especially, their networkings with pathological laboratories help the beneficiaries to avail the concessions. DMSC, SCIR and SPARSHA have made provisions for the vocational training of their respective target groups. These arrangements help in the rehabilitation of marginalized groups like CSWs, IDUs and PLWHA. DMSC and SCIR also run schools for the children of their respective target groups, which has helped to win the confidence of their respective beneficiaries. Having own blood testing facility and ICTC is an added advantage respectively for BPWT and DMSC, as beneficiaries are getting such facilities from the respective NGOs. World Health Organisation has declared the Sonagachi Project of DMSC as 'Model Community Based Project for Sex Workers' in the world for its peer-based approach.

(xii) Sources of Funding

India has adopted “Three Ones” principles as suggested by UNAIDS. These principles include one national AIDS control authority, one national strategic framework and one national monitoring and evaluation system. Therefore, all funds are routed through NACO and from NACO to State AIDS Control Societies. The Chapter-VI shows that there is plurality in sources of funding – self-generated resources, state government, central government and foreign funding agencies are the main sources. So far as HIV/AIDS programmes are concerned, NGOs are receiving fund from WBSAP&CS. However, some research activities are funded by bilateral and international funding agencies. As all NGOs are dependent on WBSAP&CS for funding, it is less likely that programmes would be sustainable in absence of such external funding. NGOs have also complained about the inadequate and irregular flow of funding.

(xiii) Staff's views

The Chapter-VI (Part-III) highlights the views of selected staff members of six NGOs under the study on different issues related to HIV/AIDS. These issues are (a) stigmatization, (b) ethical issues, (c) violation of human rights, (d) major barriers encountered, (e) major reasons of spreading HIV/AIDS, and (f) future AIDS scenario and role of NGOs. It is found that no staff members of six NGOs are affected by HIV/AIDS related stigma because of the nature of their jobs. But staff members of DMSC, MB and SPARSHA are affected by prevailing social stigma related to CSWs, MSM and PLWHA respectively. It is to be noted that most of the staff members of these three organizations are selected from among the respective target groups. However, staff members of all the six NGOs have admitted the existence of HIV/AIDS related stigma in the society and have suggested awareness programmes, counseling, sex education at school level, etc to reduce it. With regard to ethical issues related to HIV/AIDS, majority of the selected staff members of six NGOs are aware and always practice them. With regard to the violation of human rights of PLWHA, all staff members have said that they would protest against such incidences. On the issue of preventing such incidences occurred in government run hospitals, while staffs of SCIR and BPWT suggested more training, staff members of DMSC, MB, SPARSHA suggested exemplary punishment for the guilty health personnel. Surprisingly, majority of staff members of HDR1 did not make any comments. The selected staff members of all the NGOs have talked about ignorance, fear of exposure

and stigmatization, indifferent attitude of the people towards AIDS, migration and drug addiction as major barriers encountered in implementing the project. Most of the staff members of SCIR, DMSC and MB are optimistic about the future AIDS scenario in our country. They think that the situation would be under control, if government continues its effort by involving all stakeholders. On the other hand, staff members of BPWT and SPARSHA think that situation will be out of control, if government did not change its policy. Surprisingly, majority of staff members of HDRI have not expressed their views in this regard. However, all staff members of the six NGOs are of the opinion that NGOs would play a key and more effective role in combating HIV/AIDS in future too.

(xiv) Perception of Beneficiaries towards the working of NGOs.

The beneficiaries' perceptions towards the working of six selected NGOs under the study have been discussed in Chapter-VI (Part-IV). Out of eleven groups, eight groups have expressed positive perception and few members of remaining three groups have shown dissatisfaction. By and large, beneficiaries have better perception towards the working of respective NGOs. The HIV/AIDS programmes of the respective NGOs are satisfactory to the beneficiaries. These NGOs have helped them in improving their health status and awareness level on various HIV/AIDS related issues. These programmes include more preventive services and less curative services. Out of the six NGOs, SPARSHA only runs HIV/AIDS Care and Support services for PLWHA. So far as anti-retroviral medicines (ART) are concerned, it is distributed by the government through a very few ART distribution centers in West Bengal. Majority of the beneficiaries use these NGOs as a stepping-stone for better referral health services and to avoid the indifferent attitude and apathy of the health personnel in government run hospitals.

(xv) Impact of Globalisation on NGOs in HIV/AIDS Care.

The Chapter-VII has thoroughly discussed about the impact of globalisation on NGOs in HIV/AIDS care. Globalisation, like other spheres, has affected both positively as well as negatively to the NGOs in HIV/AIDS care. The impact of globalisation is discussed in terms of networking, sustainability of funding, future demands of services, etc. It is found that globalisation has reduced states' capacity to fulfill its social responsibility towards the people, which has created a space for the NGOs. Thus, globalisation has helped in the growth of more NGOs and made them active throughout the world. Globalisation has also helped to strengthen the networking at

the national, regional and international level not only among the NGOs working in HIV/AIDS field, but also with NGOs working in the other fields. It has also brought together NGOs of the North and of the South. But at the domestic level, such networking is missing among the NGOs in HIV/AIDS care in India as well as in West Bengal. Similarly, NGOs have been playing advocacy role successfully at the international level; but at the local level, NGOs are not able to play advocacy role properly because of their dependency on external funding resources. They can't raise their voices against the policies of the donors. With regard to financial sustainability, considering the increasing number of multilateral, bilateral and private philanthropic donors and their increasing contributions to HIV/AIDS, it is expected that financial sustainability will be continued in future too. At the same time, new avenues for funding must be explored in order to achieve the goal of universal access to HIV/AIDS prevention, care, support and treatment by 2010. However, the policy of getting quick outcome in terms of quantity within a limited period may not have societal impact in the long run. So far as the future demands of services are concerned, NGOs will have to cope up successfully with the side effects of ART related problems; as increased access to ART will increase both the life span of PLWHA and their numbers gradually. In brief, governments, donors and civil society, as were in the past, will have to remain at the forefront of efforts to move towards universal access to HIV prevention, treatment, care and support by 2010.

The present study has given many new insights. It has confirmed following two hypotheses. The first hypothesis was developed for the first time in the study of Maharashtra (Duggal, Gupta & Jesani, 1986) and was confirmed by the studies of Andhra Pradesh (Baru 1987) and Assam (Sarkar 1998). The second hypothesis was developed in the study on "NGOs in Health Care: A Study of West Bengal" (Sarkar 2005).

- (i) There is an association between socio-economically developed areas and location of NGOs.
- (ii) Contribution of NGOs varies with the nature of financial sustainability of the programme.

The present study has also developed two new hypotheses. These are:

- (i) CBOs are more effective than NGOs in HIV/AIDS prevention, care, support and treatment.
- (ii) There is a positive correlation between globalisation and NGO response to HIV/AIDS care.

Implication for Social Work

The key findings of the present study demonstrate the relevance of 'Structural Social Work' perspective in HIV/AIDS prevention, control, care and support activities. More specifically, the findings of the study identified the crucial need for a holistic social work practice. There are two-fold goals of structural social work. First, it alleviates negative effects of structural exploitation on the people; and second, simultaneously transforms the social structure through social reforms and social change initiatives. The study illustrates that the selected NGOs have been working to strike a balance between the social care and social change in their battle against HIV/AIDS. It has been demonstrated by their involvement in social care activities such as running drop-in centres, community care centres, clinics and vocational training centres; counseling, etc. for the people infected and affected by HIV/AIDS. At the same time, NGOs have initiated social change activities such as awareness generation programmes, community organization, protest march, and evolving strategies to reduce stigma and discrimination against people living with HIV/AIDS (PLWHA), men having sex with men (MSM), etc. to bring social transformation. Therefore, NGOs are successful instruments and initiators of structural social work practice. Thus, the present study indicates the importance of 'structural social work' as holistic social work practice for empowering the marginalized section such as PLWHA, MSM, CSWs, etc.

The findings and observations of the present study are significant for current social work practice. The different approaches, strategies, programmes and field experiences found in the study are relevant to the body of social work knowledge. These experiences of the study are useful information for the social workers committed to the pursuits of social justice and equality. The successful implementation of structural social work by NGOs in HIV/AIDS prevention care and support will inspire social workers and civil society to take initiatives against the stigmatization and discrimination of PLWHA. The holistic approach of NGOs in HIV/AIDS care raises issues before current social work practitioners to adopt structural social work practice, if they really believe in the core professional values of social justice, equity and commitment to marginalized groups in society. Thus, the present study is the important source material for the social work education to adopt structural social work perspective as model to address the issues of marginalized and promote social justice in the society.

Conclusion

There is plurality among the NGOs in HIV/AIDS care in West Bengal in terms of their emergence, promoters' background, organizational set up, nature of activity, etc. In West Bengal, NGOs are found as suitable means to provide HIV/AIDS prevention, care and support services; but can't contribute much in providing treatment services for PLWHA. People having received the awareness from NGOs and understanding the need of treatment services, go to public sector hospitals especially for HIV test and ART. This kind of trend proves that health services provided by government are complementary for NGOs in HIV/AIDS care in West Bengal. There is a need of more integration and coordination of services of all stakeholders in providing better HIV/AIDS care services. It is also important to note that NGOs in HIV/AIDS care prefer to work in socio-economically developed areas in West Bengal and can't continue to work for a long time due to their external resource dependency. It is expected that major findings of the present study will be worth for the government in formulating appropriate policy and useful to donors and NGOs to be careful in designing, implementing and monitoring HIV/AIDS programmes. The present study suggests that there is a need to initiate further research in the following areas: (a) Role of FBOs in HIV/AIDS care in West Bengal, (b) Comparative study between CBOs and NGOs in HIV/AIDS care and (c) Interface between Government and NGOs with regard to HIV/AIDS care in West Bengal.

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