

CHAPTER-II

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REVIEW OF LITERATURE

Voluntary organizations, now popularly known as non-governmental organizations (NGOs) embrace a wide array of agencies within and across different countries of the world. NGOs are simply agencies or groups, which are different from government bodies. However, NGOs are distinctive in containing a voluntary component and because they don't operate for profit. Most commonly, NGOs are defined as voluntary and non-profit organizations working towards the development and amelioration of suffering with non-self serving aims and free from state control in managing day to day affairs (D. Rajasekhhar 2000). NGOs are funded through individual and corporate donations, levies imposed on members or grants from international and government agencies. Hence, the following terms usually come up: NGOs, Voluntary Organizations (VOs), Community Based Organizations (CBOs), Peoples Organizations (POs), Public Service Contractors (PSCs), and Non-Profit Organizations (NPOs). The first term, NGO, is the most widely used as the umbrella organization within which other terms can be included depending on the scale of operations (Korten 1990).

The term 'NGO' applies to diverse organizations that work together outside of government to address a need, advance a cause or defend an interest (Brodhead and O'Mally 1989). NGO encompasses a whole range of organizations that differ in size, function and geographical location. Thus, the term can be used to describe small, locally based and loosely established voluntary and largely grass-roots types of associations, as well as large national and even transnational voluntary associations with formal constitutions employing hundreds of staff. However, World Bank defines NGO as "private organizations that pursue activities to relieve suffering, promote the interests of the poor, protect the environment or undertake community development" (World Bank 1987; Mercer et al. 1991). Based on a close scrutiny of goals, relationships among various organizations and operational methods, it was deduced that NGOs play two broad roles in society: (1) operational roles and (2) educational and advocacy roles. Operational NGOs are more central to international responses in the post-cold war world. They have the responsibility of fund raising. The rendering of services is central to most NGO budgets. While the target of operational NGOs is

beneficiaries or victims in case of emergencies, the educational and advocacy NGOs seek to influence citizens, and through public opinion, bear fruit in the form of additional resources for their activities as well as new policies, better decisions and enhanced international regimes. These NGOs help to reinforce various norms promoted through public education campaigns. This heightened awareness among public audiences in turn helps hold the state accountable for their international commitments (Gordenkar and Weiss 1996).

In increasing numbers, NGOs have voiced their concerns in international discourse about numerous problems of international scope. NGOs assumed a central role in activities involving human rights, complex humanitarian emergencies, the UN relationship, the global environment, the international women's movement, operational coalitions and state relations, and AIDS. They also bring local experiences to bear on international decision making (Gordenkar and Weiss 1996). The NGO expansion, dubbed as "barefoot revolution" can be attributed to several external and internal factors. A declining faith in the capacities of governments to solve the interrelated problems of social welfare, development and environment, lead to the global upsurge of organized private activity through a non-profit sector. The non-profit sector has grown increasingly important in its efforts to provide alleviation of societal problems and injustices and the promotion of democratic values through out the world in recent years. This sector has also become a major economic force with sizeable expenditures and multiple levels of paid and volunteer employment. NGOs make up the sub-set of non-profit sector involved in development work (Salamon 1995). In the beginning of 1980s, several developed and developing countries started thinking of privatization, liberalization and withdrawal of state from social sector programmes like education, health, nutrition, etc. Because these countries were facing the problem of BOP (Balance of payment), reduced their budgets in social sector and started taking loan from International Monetary Fund (IMF) and World Bank (WB) for the survival of country's economy. During the implementation of IMF and WB's programme, an understanding was developed that investment in public sector was wasteful and therefore, the emphasis on NGOs was better. It was assumed where government failed to reach out to the marginalised sections and created gap, NGOs could bridge the same (Sarkar 2005). The end of cold war was perhaps most important influence on NGO expansion. The end of cold war also brought it with the end of ideological and social orthodoxy. UN practitioners and diplomats became less

reluctant to interact with NGOs, opening up new avenues of communication and cooperation within the decision making process. The UN became a forum of governments and NGOs. They also contribute advanced knowledge on issues such as gender, human rights, environments, AIDS, relief assistance and community development (Gordenkar and Weiss 1996).

In India, VOs or NGOs have a long history. It is clear that NGO is legacy of the colonial system and its growth in independent India is very steady to reinforce the development process. Health care and education were prominent among the initial concerns of many NGOs in the 1950s and 1960s. However, NGOs have increasingly moved into projects directly targeted at alleviating poverty and attempting to raise the incomes of the poor. Thus, projects aimed at increasing the farmers' incomes became fashionable in 1970s. A different trend was also emerged in the 1970s, where the emphasis was not so much on service delivery or development programmes, but on organising the poor with a view to enabling them to exercise greater influence over decisions affecting their lives. This 'empowerment' approach has its roots in the view that literacy can often become a means by which the poor can reflect on the causes of their poverty and find ways to tackling them (Chandra 2005). In 1980s, new concerns came to the fore such as gender and environment, with social forestry and soil conservation prominent among the environmental concerns. These reflect an increasing concern about how projects affect the wider setting in which the poor live. This extension of interests comes from 'innovation' – another characteristic that NGOs emphasize. The 1990s have witnessed yet more changes in the nature of NGO activities. Work in the areas of gender and environment has been widened, deepened and integrated under the umbrella of 'sustainable development'. There are two reasons for this. First reason stems from a concern with cost recovery and the desire among the NGOs (especially Northern NGOs) to transfer the recurrent costs of project management to the community following the withdrawal of the support agency. This is based on the belief that development interventions can be sustained over longer term only if community assumes ownership of the project or programme. A second reason for the interest in sustainability is bound up with the desire to avoid promoting dependence on an external agency. This is based in part on NGOs' not wishing to be perceived as benevolent patrons, especially when external dependence simply replaces the influence of locally dominant elites without addressing the structural reasons for such dominance.

Therefore, it is found that NGOs have been around us for a long time and involved in performing various developmental and welfare activities. At the same time, there was widespread skepticism outside NGO circles about the potential of NGOs in development. This has now diminished. However, there are many contradictory views about the comparative advantages and weaknesses of NGOs. These views range from quasi-denial of NGOs' effectiveness to hyperbolic exaggeration. One way of assessing the impact and effectiveness of NGO interventions is to attempt to isolate those features of NGOs, which place them in a comparatively advantageous position. But it is not an easy task to come to any firm overall conclusions about either the factors, which characterize the uniqueness of NGO interventions, or the degree to which NGOs have succeeded in their tasks. There are four main reasons for this. The first is simply a lack of data. For all the evidence provided, the extent of reliable evidence upon which judgments have been made and are made still remains minute in comparison with both the absolute numbers of NGO interventions and the very different types of project embarked upon. The second is that there still seems to be confusion in the eyes of both the general public and the agencies over claims and assertions about the comparative advantage of NGOs and the evidence, which is available. The third is the growing realization that a range of both complex and external factors plays a powerful role in influencing the outcome of NGO intervention in very different social, economic and political contexts. Finally, the lack of an agreed method of assessing the performance of NGO projects and programmes create a handicap in judging the impact (Chandra 2005).

Unfortunately, there is a meagre literature on the NGOs working in various issues and situations in India. The role of NGOs in HIV/AIDS care is one of such unexplored areas of social science discipline. In this regard, Baviskar writes, "Systematic studies are required to say anything with confidence about them. In absence of such studies, our understanding of NGOs will remain vague, superficial and hazy" (Baviskar 2001). It is found that there are only few NGOs who are exclusively working in the HIV/AIDS field. Most of the NGOs engaged in health sector are running HIV/AIDS programmes in India. Therefore, in order to understand and find out the trends of research in NGO sector, it is worthwhile to examine the existing literature on NGOs in health care as well. Considering the available literature, the review, in two parts, has focused studies on health care and NGOs response to HIV/AIDS.

Studies on NGOs in Health Care

Duggal, Gupta and Jesani (1986) conducted a study on “*NGOs in Rural Health Care*” at the behest of ICMR to gain a deeper insight into the role and functioning of many different types of NGOs in Maharashtra, a state having the largest number of such agencies. The study brought out the target variation between the aims and motivation of the various NGOs as well as their different approaches, which vary from the running rural hospitals to community participation and conscientisation. An interesting finding of the study was that NGOs had neglected the socially and economically backward districts as compared to their better concentration in the average and highly developed districts of Maharashtra. This highlighted the need to pay more attention to the deprived masses of backward districts.

Baru (1987) made a study on “*Factors influencing variations in health services*” in Andhra Pradesh. The study was limited in two well-developed districts (Krishna and Guntur) as well as two backward districts (Medak and Mehbub Nagar). It considered public, private and voluntary sector providing health care services. With regard to voluntary sector, study explored that growth and distribution of voluntary agencies were skewed in favour of well-developed districts.

The Ford Foundation has been engaged with NGO programmes in India since the 1970s. In order to systematically analyze documents and disseminate the experiences of NGOs implementing health and family planning programme in India, it initiated a project in 1986. Under the project, twelve case studies, entitled ANUBHAV were published. Each case study included details regarding the NGO i.e. genesis of the project and its evolution, its organizational structure, staffing pattern, funding and cost structures, the range and mode of service delivery, institutional relationships with the government and other institutions, community participation, information systems and programme impact. The lessons of these projects were shared with NGO policy planners, researchers and donors (Pachauri, 1994). Based on these documented case studies (published in ANUBHAV series) many scholars have given many interpretations. For instance, Peter Berman and Priti Dave (1994) point out that NGOs show a high degree of creativity and innovation in developing varied source of financing to reduce dependency and enable them to sustain their programmes. Their health programmes operate as efficiently as public services and provide supplementary support rather than substitute services. They suggest further

development of voluntary sector financing, which may reinforce overall health care intervention. Rajesh Tandon (1994) studied the ANUBHAV projects in order to know the nature of community participation in health. He suggested a policy framework in promoting effective community participation for better health in India.

Bhattacharjee (1996) has completed a study on “*NGO Approaches to Health and Development in India: Strategies and Sustainability*”. He observes in order to achieve appreciable and sustainable results; an NGO will have to make long-term commitments to the community. He observed that NGOs could overcome different of its problems through financial stability. But dependence on government or donors will affect their role as a pressure group. Therefore, they will have to generate their own funds. Increasing the number of pay clinics can do such generation of fund. The NGO then will become a channel to redistribute money from rich to poor.

Dr. Sunil Mishra (2000) analyzed 14 action research projects of the Population Foundation of India. The Population Foundation of India was established in 1970. It had either supported or itself commissioned around 320 projects. The Foundation selected 14 action research projects carried out by voluntary organizations during 1995-96 for the case study and qualitative evaluation. Main purpose was to assess the effectiveness of the NGOs in bringing about the desired changes in the individual and community value systems. Among the 14 projects, three were related to infant mortality and fertility, three were pertaining to integrated health, family planning and development; four to reproductive health and family planning in urban slums among industrial workers; another three to reproductive health and family planning and the remaining one to family planning; through rural medical practitioners. Dr. Sunil Mishra brought together all the 14 case studies (evaluation report) of action research projects in a volume and analyzed the dynamics of social change, the factors that led to success and the problems. He found that NGO could work as catalyst of change. A concern for community participation as well as a need for mass education, under an NGO was, very crucial to bringing about an attitudinal change in health behaviour.

Varma (2001) in his article on “*Reproductive and sexual health of adolescents: An NGO experience.*” describes a particularly successful initiative in the mobilization of target group. He provides background of an NGO operating in Delhi, and then sets out to describe the experience it had in implementing a reproductive and sexual health programme for adolescents. Varma concludes by describing briefly the lessons learnt, which cover the importance and applicability of research with

intervention in developing an effective design; community development approach; addressing the environment along with the individual; and the role of adolescent development.

Gupta (2003) in his article on “*Contribution of NGOs in implementing population policy*” has analyzed the role played by NGOs in implementing the government’s national population policy in Bangladesh. He has noted that the target oriented, heavy-handed approach to population control, with an element of coercion, created an adverse impact. Gupta has also discussed population and empowerment of women; contribution of NGOs, and IEC strategies adopted by NGOs in handling population policy. He has emphasized that in the ultimate analysis the challenge of the population explosion will be met only if it is understood in proper perspective, particularly by the political leadership. He has concluded by noting that NGOs’ major contribution has been the sensitisation of various stakeholders, especially in bringing home the realisation that the family welfare programme needs to be linked with sustainable development, empowerment of women, and social and gender equity.

Vishnu and Sudarshan (2003) examine the case of Karuna Trust and Vivekananda Foundation a public sector–voluntary organisation partnership for primary health care services. They discuss the four key aspects of partnership between the public sector and NGOs: participation in health policy, effects of decentralisation; partnerships out of services; and quality assurance activities. They describe the case background profile and context followed by policy and political environment and the legal framework and go on to the work in the area of reproductive and child health. Their work highlights the constraints of the partnerships. Notable among them are: people with vested interest even attempted to withdraw control of the health centres from the NGOs through a resolution passed by the *zilla parishad*; there were huge financial implications, as the finance sharing between the government and the NGO was in the ratio of 75:25 as against the 90:10 agreed in the partnership terms; and unnecessary bureaucratic constraints interfered the smooth operations of these NGO run PHCs. The article also lists policy implications. There must be explicit, transparent and adequate policy mechanisms, which ensure the involvement of all stakeholders in the partnership process. There is also a need for coordination across various government departments and implementing agencies for the smooth transition of handing over, thereby preventing undue bureaucratic delays.

Gomez (2004) examines the feasibility of the government's partnership with NGOs in reproductive health in Mexico. In 1995 the Mexico government began to develop policies on establishing collaborative agreements with civil society organisations and currently working together. He analyses whether the conditions exist in Mexico for successful partnerships between the public sector and NGOs in reproductive health. In-depth interviews were carried out with key informants in the public sector of national and state level, and the NGO sector in six states in Mexico. Partnerships were found to be an option for the provision of reproductive health services in geographical areas where the population is under-served, and for services the government does not provide. While the contribution of NGOs to the reproductive health field is recognized at least at the federal level, there are still very few public agencies that collaborate with NGOs, and agreements are often limited to short-term financing of projects. Gomez-Jauregui concludes that the future of NGOs in Mexico will depend largely on their ability to obtain funding from within the country. More effective mechanisms are needed by the government to generate resources for health care. The government must recognize the specific contribution of NGOs, including inputs of social capital and creation of community networks, and must share decision-making more equitably with NGOs for partnerships to succeed.

Tikku (2004) has conducted a study with respect to NGOs in three north Indian states. The research examines the functioning of NGOs and their role in combating nutritional and health problems prevalent among children, adolescents and women in Delhi, Haryana and Rajasthan. The NGOs also dealt with other related areas to supplement and complement their main focus on health and nutrition. However, not many of them were involved in tackling endemic and emerging diseases like jaundice, TB, malaria, dengue and HIV/AIDS/ STD, which should be given more emphasis. It was found also that there is no proper mechanism for obtaining and analyzing information on health and nutritional services provided by voluntary organisations. Each state should have a district-wise database on nutritional and health services provided by NGOs. Lack of coordination/support from government departments, and inadequacy and or untimely release of budgets were among the other problems cited.

Mercer et al. (2004) through their article on "*Effectiveness of an NGO primary health care programme in rural Bangladesh: Evidence from the management information system*" looks at the effectiveness of an NGO primary health care

programme in rural Bangladesh. It is based on data from the programme management information system reported by 27 partner NGOs from 1996 to 2002. On the basis of a crude indicator of socio-economic status, the programme is poverty-focused. The data indicate that relatively high coverage has been achieved for reproductive and child health services. There is good service coverage among the poorest one-third and others, and the infant and child mortality differential has been eliminated over recent years. A rapid decline in infant mortality among the poorest from 1999–2002 reflects a reduction in neonatal mortality of about 50 per cent. Allowing for some under-reporting and possible misclassification of deaths to the stillbirths category, neonatal mortality is relatively low in the areas covered by the NGOs. The lower child and maternal mortality for the areas covered by these NGOs combined, compared with estimates for Bangladesh in recent years, may at least in part be due to high coverage of reproductive and child health services. Other development programmes implemented by many of the NGOs could also have contributed. Despite the limited resources available, and the lower infant and child mortality already achieved, there appears to be scope for further prevention of deaths, particularly those due to birth asphyxia, acute respiratory infection, diarrhoeal disease and accidents. Maternal mortality in the NGO areas was lower in 2000–2002 than the most recent estimates for Bangladesh.

Sarkar (2005) made a study on “*NGOs in Health Care in West Bengal*”. The study shows that there is plurality among NGOs in terms of their emergence, basis of initiating programme, approach, type of service, promoter’s background, source of funding, organizational set up, nature of activity etc. In West Bengal NGOs prefer to work in socio-economically developed areas and can’t continue work in the community for long time due to financial unsustainability. The study shows a high-degree of dependence on national and foreign funds that influences priorities of the NGOs. They focus primarily on preventive and promotive services with little emphasis on curative services. Thus NGOs generate ‘demand’ for care but there is little effort to provide services to address their needs. Ultimately people, having received the awareness from NGO, go to public and private sector for better curative services. This kind of trend proves that health services provided by the government and private sectors are complementary for NGOs of West Bengal. The study suggested that there is need to integrate the services of government, private and NGO sectors in providing better health care.

Mugisha et al. (2005) in the article on “*Are reproductive health NGOs in Uganda able to engage in the health SWAp?*” has tried to explore the ability of reproductive health (RH) NGOs in Uganda to survive in the context of SWAp (sector-wide approaches) and decentralisation. The authors argue that contrary to perceptions that this may increase NGOs’ financial vulnerability, a SWAp and a decentralised system may actually provide an opportunity that should be embraced by NGOs to enhance their sustainability and effectiveness by reducing their current dependency on donors’ funding. The article discusses the systemic weaknesses of many NGOs that currently make them vulnerable, and observes that unless these are addressed, such NGOs will lose their space in the SWAp and decentralisation arena. The authors suggest that NGOs need to recognize the opportunities that participating in public-private partnerships through a SWAp can offer them for long-term and significant funding. They need also to develop their capacity of proactive participation in a SWAp and decentralised context by becoming more entrepreneurial in nature, through reorienting their organisational philosophies, and strategic planning and budgeting so as to be able to partner effectively with the public sector in accessing funds made available through health sector reform.

Studies on NGOs response to HIV/AIDS

The review of the studies on NGOs response to HIV/AIDS is divided into two parts – namely (A) studies conducted in other countries and (B) in India.

(A) Studies conducted in other countries

Aldaba, Fernando T.; Josefa P. Petilla (1997) made a case study on “*Governance and HIV: Government - Civil Society Interface: An Aspect of Governance Critical to an Effective Response*” in Phillipines. There exists a dynamic inter-relationship between good governance, a successful government organisation (GO) - civil society organisation (CSO) interface, and an appropriate response to the HIV/AIDS epidemic. This case study specifically examines three examples of interface: the Philippine National AIDS Council (PNAC) at the national level; and Olongapo City AIDS Foundation Inc. (OCAFI) and Inter-agency HIV/AIDS Network (IHAIN) in the province of Palawan at the local level. The study also looks into another interface which it considers crucial to the success of the HIV/AIDS response -

the interface between Pinoy Plus, the sole organisation of people living with HIV/AIDS (PLWHA) in the Philippines, and GOs and NGOs. The conclusions from the three examples of interfaces reveal that the HIV/AIDS epidemic requires a multi-sectoral and collaborative response. There should be openness and humility, tolerance of other's ideas, and parties must be frank and comfortable enough to make and receive criticism. Finally the interface must extract commitment from members and must be inspirational, motivating others to emulate the successful partnership. A successful interface is able to strengthen and energize the active participants to the interface. Good governance is eventually strengthened by increasing examples and models of collaborative efforts between government and civil society and by expanding such responses to issues other than HIV-AIDS.

David Wilkinson and team (2000) made a study on “*An evaluation of the Ministry of Health/NGO Home care programme for people with HIV/AIDS in Cambodia*”. Cambodia had one of the fastest growing epidemics in Asia, but has also had an active government and NGO response. In 1998, the Cambodian Ministry of Health established a partnership with a group of NGOs to develop and deliver home care in Phnom Penh and in Battambang Province. The findings clearly show that home care has an impact at a number of levels. This has reduced the suffering of people with HIV/AIDS, improved their quality of life and that of their caregivers increase understanding of HIV/AIDS helped to empower the poorest by providing social and economic support. The findings have also shown that the cost of delivering home care compared favorably with outpatient services and with home cares services in other countries.

Chillag K. et al (2000) made a study on “*Factors affecting the delivery of HIV/AIDS prevention programs by community-based organizations*”. The Community based organizations (CBOs) play a frontline role in HIV/AIDS prevention activities. CBOs face formidable challenges to effective delivery of HIV prevention services including client characteristics such as homelessness and CBO characteristics such as limited resources and staff turnover. Despite these obstacles, CBOs are generally well positioned to deliver services to specific high-risk populations because they understand their local communities and are connected to the groups they serve. This qualitative study illustrates that structural, socio-cultural, organizational, and individual client factors both facilitate and act as barriers to delivery of HIV

prevention services. These challenges and successes helped to identify critical technical assistance needs.

Roy, C.M. and Cain R. (2001) in their article on "*The involvement of people living with HIV/AIDS in community-based Organizations: contributions and constraints*" paid attention on this neglected aspect. An important feature of the social and organizational response to the HIV epidemic has been that many people living with HIV/AIDS have demanded to have a say in the development of policies and the delivery of services. Surprisingly little attention has been paid in the literature to this involvement. This paper is based on a participatory action research project that involved 70 people with HIV/AIDS in 15 focus group discussions. Findings from the study show the complexities of translating organizational commitments to involve people with HIV/AIDS into practice. This paper outlines the organizational contributions of people with HIV, and examines the difficulties and obstacles to their meaningful involvement. The paper concludes with a discussion of the challenges of user empowerment and with recommendations for policy and practice.

UN-NGLS (United Nation - Non Governmental Liaison Service) has been publishing its "*Voices from Africa*" series for the best part of a decade now. Written entirely by African activists, practitioners and professionals, the series is designed to provide an opportunity for Africans to share their work, concerns, ideas and views with an international readership and help shape a more positive and balanced picture of African realities. The 10th series, focuses on the theme of "*NGO response to HIV/AIDS: Country Experiences*" and has been prepared for the Special Session of the UN General Assembly (UNGASS) on AIDS in New York in June 2001. This series included few country experiences from Africa, some of them are being discussed below.

1. Marie Rose Sawadogo (2001) has discussed about Burkina Faso in her article on "*Private and Community-based HIV/AIDS Approaches in Burkina Faso*". Burkina Faso is the third most affected country in West Africa with an adult prevalence rate of 6.5%, and there is no sign the epidemic has stopped its spread. The country's population is vulnerable to HIV/AIDS because of poverty, high internal and external migration, weak health services, low levels of school enrolment, and certain traditional practices and beliefs regarding women. The impact of HIV/AIDS is increasingly visible in all sectors of society and in the daily life of each citizen. Initial response to HIV/AIDS in the country came essentially from the government, which

set up a national control programme to tackle the epidemic in 1987, with development partners readily providing assistance. Civil society was slower in responding, and the first AIDS control associations came into being only in the early 1990s. One of these earlier groups is the Private and Community-based HIV/AIDS Control Initiative (IPC), set up in December 1994 under the legal responsibility of Plan International as a liaison agency for the London-based International Alliance Against HIV/AIDS. The IPC is now an autonomous NGO in Burkina Faso. A cornerstone of its work was a campaign in 1996 to raise public awareness about HIV/AIDS. Early awareness efforts in the country had centered on IEC campaigns, but this approach was considered inadequate in bringing about changes in attitudes and behaviour.

Although it is difficult to evaluate the actual impact of associations working on HIV/AIDS issues in Burkina Faso, a number of lessons have been learned. Sustained investment in associations and additional financial resources are needed to consolidate them and broaden responses to the disease. Other needs include developing “relay associations” to increase responses to HIV/AIDS; building the training capacity of NGOs; improving administrative procedures; instigating leadership training sessions; intensifying resource mobilization efforts; improving impact evaluations; increasing the profile of AIDS and of people living with the disease; and better sharing of experiences among community-based associations and organizations to improve skills and involve a community’s leading actors. IPC believes that the close link between association members and the communities they target will increase their ability to identify needs and appropriate responses. The main hurdle to active participation by association members is the voluntary nature of the work. In addition, the failure of donors to provide institutional support to community-based organizations and the lack of access to funds, materials, and technical and human resources poses many other problems.

2. Leiliane M’Boa, Aristide Kacou, Mariette Wandandi, Samuel Lijalem Hassan, Victor Kamanga, Dora Ofobrukmeta, Regina Clement Akpan, Anne Fiedler and Esther Guzha in their article on “*NGO and Community Responses to HIV/AIDS*” narrated the case studies of few NGOs in Congo, Malawi, Nigeria and some other countries. In the Democratic Republic of the Congo, about one million adults and children are infected with HIV/AIDS. In July 1994 a non-governmental group, the People Affected by HIV/AIDS Organization (PAHO), was launched to provide assistance to infected and affected persons, help them come to terms with the disease.

and lead valued lives. The first stage of PAHO's work is to gain these people's confidence and help them understand that they are full human beings with rights and duties. Fieldworkers who visit beneficiaries in their homes tactfully perform this groundwork. The second stage involves the organization of information sessions at which people living with HIV/AIDS describe their experiences to groups of 30 to 50 people with whom they feel secure and accepted. This encourages them to speak frankly and openly about their seropositivity. This process of realization helps ensure that people living with HIV/AIDS will adopt more responsible behaviour and reduce the spread of AIDS. It also awakens caution in others by warning people about the AIDS epidemic through personal experience and example. In its work, PAHO draws on the skills available in local institutions such as the Society for Women and AIDS in Africa (SWAA/Congo), National AIDS Control Programme (PNCS), National AIDS Coordination Office (BCC/SIDA) and the World Health Organization's then Global Programme on AIDS. PAHO has a total of 35 active members; with 250 beneficiaries including 75 women living with HIV, 20 HIV-positive men and 25 children, and 130 AIDS orphans.

Malawi is one of the world's poorest countries where the situation is grim with high rates of HIV infection. Although AIDS is under-reported, the National AIDS Control Programme (NACP) estimated a total of 265,000 cases in the country between 1985-1998 and some 400,000 AIDS orphans. One of the major concerns is access to treatment for the disease. Most citizens in Malawi, faced with low income and a hand-to-mouth existence, have no access to treatment. This must also be viewed against a background of inadequate health facilities, drug supplies and medical personnel in public hospitals. Growing demand for health services due to increased illness is also exerting further pressure on an overburdened infrastructure. Founded in 1997, the Malawi Network of People Living with HIV/AIDS (MANET+) is an umbrella group for people living with AIDS (PLWHA) and HIV/AIDS community-based organizations. It has 30 HIV and AIDS support groups across the country. The network is based on the principle of Greater Involvement of People Living with HIV/AIDS (GIPA) is a critical component to ethical and effective national responses to the epidemic. MANET+ has been working to improve access to treatment in Malawi by advocating for a stronger medical infrastructure, training of medical personnel and health care workers in the use of antiretroviral, negotiations for subsidies from suppliers or reduced prices of antiretroviral drugs, legislation enabling

parallel importing and compulsory licensing, and a national drug policy and management programme.

In Nigeria, Life Link Organisation (LLO) is a non-governmental, non-profit group founded in May 1994. It works in selected prisons in five states of Lagos, Kano, Abuja, Edo and Oyo—on reproductive health issues related to the prevention of sexually transmitted infections (STIs) and HIV/AIDS. LLO's mission is to provide health and psychosocial services by disseminating information, and providing education and counselling by well-trained personnel. Its activities target four groups: prisoners, prison staff, their wives, and youth. So far LLO has reached more than 8,200 people with its HIV/AIDS education programmes. LLO is the only group in Nigeria that has targeted prison communities with HIV/AIDS prevention and control programmes. Initially, certain authorities could not understand why HIV/AIDS education was needed in prisons. Prison communities are vulnerable to HIV/AIDS for several reasons. Homosexual practices exist among certain inmates; blood-contaminated instruments such as razor blades can be shared; and some prison guards can be exposed to high-risk behaviours because they are regularly transferred from one post to another but are unable to take their wives. LLO had to be persuasive with cogent reasons and facts. It also had to be tolerant, persistent and patient in order to convince those who were antagonistic. Before the starting of education programme, knowledge of HIV/AIDS and STIs was low. Today a good number of prison community members are well informed about HIV/AIDS and STIs, and unsafe homosexual practices have been reduced in prisons where HIV/AIDS prevention activities have been carried out. The prisons now carry out HIV/AIDS prevention programmes in collaboration with the National Action Committee on AIDS (NACA) and the State Action Committee on AIDS (SACA). Trained peer health educators at each location have formed Anti-AIDS Clubs to ensure the continuation of the programme. There are now 16 clubs in the prison communities with whom LLO works, and each has a minimum of 25 members.

3. Brian Williams, Eleanor Gouws, Janet Frohlich, Catherine Campbell and Catherine MacPhail narrated the experiences of South Africa in the article on "*Lessons From the Front: NGOs and the Fight Against HIV/AIDS in South Africa*" It is another article from "*Voices from Africa*", 10th Series' published by UN-NGLS. South Africa has experienced successive epidemic waves of HIV/AIDS. Today about five million people are infected in the country. As the epidemic matures, up to one

million people a year may die and by 2010 one million children will probably be orphaned by AIDS. The National AIDS Convention of South Africa (NACOSA) was formed in 1990 to bring together government, the private sector, trade unions, political groups, AIDS activists and NGOs. They would work together to define principles and determine strategies for intervention. NACOSA was also given a mandate to develop a National AIDS Plan. The article examined two community-based projects: one is in Hlabisa, which is the largest rural district of South Africa's nine provinces and the other is in Carletonville, a major industrial centre in Gauteng. It is about 700 kilometers from Hlabisa, but linked to it by men who live in Hlabisa and migrate to Carletonville to work in the mines.

The **Hlabisa** Project covers about 3,000 square kilometres and is home to some 215,000 predominantly Zulu-speaking people. Homesteads are widely scattered and people depend on subsistence farming, migrant labour and pensions. Hlabisa has a well-developed health service including a 430-bed hospital, 13 fixed primary health care clinics and a mobile clinic service. The South African Medical Research Council (MRC) has conducted research in the area since the early 1990s, and this has led to substantial improvements in community health care. In 1991 community-based, directly observed therapy (DOTS) was introduced through volunteers and community health workers who now manage 90% of tuberculosis patients. Rural society is highly complex and involves a range of cultural norms including attitudes toward polygamy, the importance of traditional forms of governance, and low levels of education. As a result of this diversity, scientists working on HIV/AIDS and related health issues in Hlabisa have developed good communications with the community. The *Inkosi* (Chief) and his *Izinduna* (Counsellors) eventually hosted a community meeting in Hlabisa in 1997. A Community Advisory Board (CAB) was also elected by the community to promote partnership among researchers, research participants and community members. Community educators, appointed by the CAB, were employed to raise awareness of HIV/AIDS among young people, encourage appropriate STI treatment-seeking behaviour, provide support for people living with HIV, prepare the community for participation in vaccine trials, and inform the community of research findings. Programmes for home-based and paediatric AIDS care were also introduced. In this way it has been possible to bridge the gap between the community and research workers and ensure that the rights and dignity of the community are

protected. The community of Hlabisa has benefited from research into community-based health care provision, but the epidemic continues unabated.

The **Carletonville** Project has been given the name *Mothusimpilo*, or “working-together-for-health.” It was set up to develop a sustainable community-based intervention and evaluate the impact on behaviour, sexually transmitted diseases and HIV in Carletonville, the biggest gold mining complex in the world. About 70,000 migrant mine workers, drawn from rural areas in South Africa and neighbouring countries, live in single sex hostels without their wives or families. In addition about 200,000 people live in the historically white town of Carletonville, the historically black township of Khutsong, and several smaller settlements in the area. The intervention was initially targeted at sex workers and mine workers since it was felt that they were at highest risk. The intervention has two main aims: first, to ensure that all health services in the area—public, private and mine-based—provide syndromic management of STIs while working closely with traditional healers; second, to develop effective and sustainable community-based peer education and condom distribution. Periodic presumptive treatment for women at high risk was subsequently added. Efforts were also made to ensure that the main stakeholders were involved in the design, management and implementation of the project. In addition to the locally based Carletonville AIDS Committee, these included the national and provincial departments of health, mine management and unions, various research organizations, and the principal donors namely DFID (UK) and USAID. In many areas the project has been very successful. Women at high risk in what are locally known as hotspots (informal settlements close to mine shafts where alcohol and sex may be obtained) have developed an active and very effective programme of peer education. This has been extended to women at high risk living in Khutsong. Peer education among mine workers has been less successful, partly because the industry is unwilling to allow men time off work to be trained. Some of the schools in the area are developing their own AIDS programmes with the support of project staff. There is also an effective home-based care project running in Khutsong, but it remains short of funds and support.

4. Milly Katana in her article on “*NAP+, The People’s Own Voice*” discussed about the role of NAP+. Since 1994, NAP+ has taken up the challenge of living in communities where people living with HIV/AIDS (PLWHA) face varying degrees of hostility. Its mission is to improve their quality of life by forming and strengthening

networks and associations of PLWHA. NAP+ works through the four sub-regional groupings in Southern, Eastern, Western and Central Africa. These sub-regional groups support the central secretariat based in Nairobi (Kenya) in coordinating efforts of the network. However the strongest links are still the country networks or associations, and individuals in countries where no networks or associations have yet been established. The country networks and associations maintain autonomy to implement activities that respond to the needs of the local membership and communities.

People living with HIV/AIDS across Africa have benefited from the efforts of NAP+ in different ways. First, through supporting the formation and strengthening of support groups and networks, PLWHA realize that there is still something they can control. When support groups or networks are created, members share their experiences of living with the disease, discuss their challenges and set priorities to enhance their survival. It is not until one finds a similar “species” that he or she can realize there is hope for tomorrow, and he or she needs to take some action concerning their life. In an effort to meaningfully involve PLWHA in all issues affecting their lives, NAP+ and its affiliate national networks and associations have encouraged their members to train as AIDS and family counsellors, clinical officers, organizational development experts, professional social workers, journalists, managers, teachers and nurses. NAP+ has encouraged its members to live as role models and to give HIV/AIDS a human face. This has a far-reaching impact on prevention. PLWHA not only preventing any further spread of HIV in communities through self-preservation, but also giving hope to other community members who may be infected with HIV but are not sure of steps to take in order to stay alive. Role modeling is done at both country and regional level. In countries where PLWHA have publicly been on the frontline of prevention, efforts are now paying off. For example, Uganda is registering a downward trend in new infections. This is particularly attributed to, among other factors, the efforts of PLWHA who have engaged in countrywide mobilization efforts. NAP+ through its networks and associations, have formed strong lobbying and advocacy groups to improve their quality of life. Such a movement is sweeping across sub-Saharan Africa, from South Africa to Mali, from Cameroon to Ethiopia. The issues under consideration range from family stigma and discrimination to access to care and treatment. There are considerable achievements in this area, although a lot of work still needs to be done.

5. Moses Chingono discussed about the transport sector on his article on *“AIDS Education and Prevention in Zimbabwe’s Transport sector”*. The National Employment Council for the Operating Transport Industry (NECTOI) is a non-profit statutory body in Zimbabwe established in 1985. NECTOI represents the interests of 2,500 employers through the Transport Operators Association and the Zimbabwe Rural Transport Organisation, and between 70,000-100,000 employees through the Transport and General Workers Union. The Council has equal representation from employers and employees. NECTOI incorporated an AIDS education and prevention programme in its activities in 1992 as a result of the heavy toll exerted upon the industry by the AIDS epidemic, which threatens to cripple the country’s entire transportation workforce. The programme, designed to promote behaviour change and responsible behaviour, is divided into three phases. Phase-I began in 1992 to promote and design specific programmes for individual transport operators. During this phase, company-based awareness programmes were conducted for all employees including Senior Managers. NECTOI recruited, selected and trained company-based health facilitators whose task was to coordinate AIDS education activities in their workplaces. The employees themselves selected the peer educators. This phase was fully funded by NECTOI, with additional technical and material support from the Swedish International Development Authorities (SIDA). The outreach phase began in Phase-II when it was realized that the more mobile employees of the transport industry were difficult to reach. This phase, funded by AIDSCAP through Family Health International (FHI), ran from 1995 to July 1998. The project covered three major transport routes through Zimbabwe linking the capital city Harare to border posts leading to Mozambique, Zambia, South Africa and Botswana. Along these routes, 21 truck stop sites were identified for the outreach programme. Phase-III, funded by the Norwegian Agency for Development Cooperation (NORAD), has been running since January 1999 and has as its objectives to strengthen NECTOI’s capacity to sustain workplace-based interventions throughout the transport sector.

NECTOI offers a range of services including peer education training in which workers’ representatives learn to offer ongoing informal education to co-workers; condom distribution; short presentations of factual information about HIV/AIDS; development, production and distribution of literature and posters; STI diagnosis and treatment at existing company-based clinics; counselling services; and voluntary HIV testing. In addition to 70,000-100,000 transport company employees, the programme

also benefits their spouses, family members and social contacts, as well as their communities. NECTOI develops, produces and distributes sector-specific information, education and communication (IEC) materials for use by transport companies. Materials include posters, charts, and booklets in three local languages, t-shirts, caps, bags, newsletters, license disk holders, peer education carrier bags, and weekly radio programmes on popular channels. NECTOI has managed to reach commercial sex workers and gain their confidence and trust. This has been very difficult given the reluctance of this group to provide information to outsiders. As a result of its activities, NECTOI has noted significant successes in terms of an increase in demand for condoms and IEC materials; significant sexual behaviour change and establishment of an open communication channel between commercial sex workers and health authorities. Good and effective planning, professional implementation, and strong networking with local health programmes have brought about the success in NECTOI's programme. The adult education principles employed by project staff also promoted community participation and yielded good results. At the same time, the programme faces significant constraints. There continues to be unmet demand for condoms and IEC materials, as well as a lack of incentives for peer educators, which results in low morale. It is also difficult to carry out regular follow-up visits because of the distance between project sites.

Horizons (2002) published a Research Summary on "*Greater involvement of PLHA in NGO service delivery: findings from a four-country study*" Seventeen NGOs in Burkina Faso, Zambia, India and Ecuador participated in this study, which examines the ways in which people with HIV/AIDS (PLHA) are involved in NGO programmes and service delivery. The study identified four distinct types of PLHA involvement. These are namely access to services, inclusion, participation and finally involvement, where PLHA take part in management, policy making and strategic planning. The study concluded that PLHA involvement strengthens NGOs as well as enhancing the lives of PLHA. But it is distinct from public disclosure and visibility, and requires a supportive environment. The study recommended ways in which NGOs can create a supportive environment in order to improve their own work and approaches.

Jocelyn DeJong (2002) in his book entitled "*A Question of Scale: Expanding NGO Impact in HIV/AIDS*" discussed about the specific challenge of deliberately increasing the scale of HIV/AIDS prevention, care and support programmes in

developing countries. AIDS activities initiated by non-governmental organisations (NGOs) have been highly influential on thinking and strategies found within the HIV/AIDS sector. Yet despite their proliferation, NGOs often experience particular difficulties in increasing the scale of their activities to reach larger numbers of people, to have an impact at levels higher than the “community” and to address the broader social determinants of HIV/AIDS. Perceiving the urgent need for NGOs to expand the scale of their activities in the face of an escalating epidemic, Horizons and the International HIV/AIDS Alliance launched an initiative to examine the nature of the challenge to scale up in the context of HIV/AIDS internationally. This publication was prepared as part of this initiative. While the focus of the publication is on the activities of non-governmental organisations, it recognizes that increasingly NGOs are engaging in partnerships with governments, academic institutions and other organisations in their quest to widen the impact of their activities. The publication consists of three main sections. The first provides a background to and definitions of the term “scaling up” and describes contrasting perspectives to defining this term within the field of HIV/AIDS. In section two, drawing on the existing broader experience of scaling up development programmes, a typology of these processes relevant to HIV/AIDS is proposed. Substantial attention is paid to some of the risks inherent in the scaling up process, as cautionary tales for those interested in embarking on it. The publication also analyses the varied obstacles to scaling up programmes, both in general and how the sensitive nature of HIV/AIDS and diversity of contexts complicate the process. The third section examines the institutional implications of scaling up and the many internal dimensions that must be taken into consideration to prepare for scaling up. The publication concludes with some discussion of the relevance of the arguments made here for both donors and AIDS-support organisations.

The International HIV/AIDS Alliance (the Alliance) has published a Policy Briefing on “*Participation and empowerment in HIV/AIDS programming*” in July 2002, which provides an overview of the many lessons that the Alliance and its partners have learned about participation and empowerment in HIV/AIDS work. Meaningful participation and empowerment of affected populations in HIV/AIDS programming increases the impact of prevention and care interventions. Participation requires an investment in the development of appropriate skills, attitudes and behaviours of facilitators. NGOs and NGO support organizations are in a strong

position to support participation of communities in responding to HIV/AIDS. The provision of technical and financial support for this is important. This briefing also discussed about different models of the continuum of participation and empowerment in HIV/AIDS programming. As an example of project level participation, participatory community assessments (PCA) are widely used jointly by Alliance partners and affected communities to develop effective project strategies. PCAs support community members in assessing the local context, identifying needs and resources, and making decisions collectively about how to achieve change. The process helps all concern to develop an understanding of behaviours, attitudes, services, and community norms and values that influence vulnerability to HIV infection. In order to carry out effective PCAs with those most marginalized, it is necessary to identify the relevant groups successfully and then create safe spaces where they feel empowered to participate without fear of discrimination from the wider community. In 2001, partners of the Alliance in Ukraine, along with community members and drug users themselves, carried out 20 participatory community assessments across the Ukraine. They looked mainly at HIV vulnerability and injecting drug-related harm. It has been found that the use of participatory tools increased understanding of the vulnerability among the community people, and specifically injecting drug users. Relationships between drug users, the wider community and NGOs improved, resulting in an increase in volunteers from such groups. The assessment process resulted in a high level of community mobilization, with self-help groups officially registering, securing premises and funding and establishing one of the first harm-reduction programmes in Kiev.

Helmut Kloos, Tadesse Wuhib, Damen Haile Mariam and Bernt Lindtjorn (2003) have reviewed the role of CBOs in their article on "*Community-based organizations in HIV/AIDS prevention, patient care and control in Ethiopia*". This review has provided a preliminary evaluation of the suitability of community-based organizations (CBOs) to contribute to HIV/AIDS prevention, care/support and control programs in Ethiopia. Findings show that the multi-sectoral HIV/AIDS Strategy, the current Health Policy, and plans to strengthen the *kebeles* (communities) facilitate the development of CBOs and programmes and infrastructure through the HIV/AIDS Council, the Ministry of Health and various other governmental organizations. CBOs studied are at different stages of planning and implementing preventive and care/support programs but little is known about their progress, operations and

effectiveness due to the lack of monitoring and evaluation mechanisms. Although most CBOs are either still in the formative stage or in process of carrying out HIV/AIDS prevention programs on a limited scale, their self initiative, their knowledge of and acceptance by the community, and their relative cost-effectiveness render them suitable as owners, advocates and participants in programs. Several organizations and health agents are operating in integrated primary health and HIV/AIDS prevention programs that have a multi-disease, multi-organizational and poverty-reduction focus and use appropriate and promising behavioral change communication methods that may contribute significantly to overcoming social stigma and reduce HIV exposure risk. Recommendations are made for further research towards identifying, promoting, strengthening and up scaling CBOs and programmes to the regional and national levels.

James Putzel (2004) in his paper on “*Governance and AIDS in Africa: Assessing the International Community’s Multisectoral Approach*” analyses the international community’s response to HIV/AIDS in Sub-Saharan Africa. The paper is based on fieldwork undertaken in Uganda, Senegal and Malawi, originally in the context of consultancy work for the Department for International Development (DFID) of the UK government. The paper begins with an exploration of the political and epidemiological dimensions of the crisis. It then outlines the main parameters of an “organizational template” elaborated and imposed on developing countries by the World Bank, UNAIDS and the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM). The template is evaluated based on an assessment of its implementation and focusing on key political issues, including the role of state leadership in organizing a multisectoral response and in mobilizing religious and associational/NGO sectors. The author argues that the organizational template misinterprets the experience of countries that have achieved some success in fighting the virus, and that it is overly influenced by the “post-Washington consensus”, which brings together neoliberal prescriptions with prescriptions promoting popular participation and the defense of human rights. As with religious organisations, the associational sectors (NGOs, community based organisations, or CBOs, and professional associations) have been pivotal players in both Uganda and Senegal’s HIV/AIDS campaigns, particularly in getting messages on behaviour change to communities and in providing counseling, and care and treatment to HIV positive people and people living with AIDS. However, the central state played the leading

role, not only in creating the space for the NGO sector to act, but also in initially mobilizing the sector around HIV/AIDS. The AIDS crisis provides new opportunities for reviving public health sectors and creating an ethos of public service within the public sector and the medical profession, but also forces policy-makers to confront difficult trade offs between individual rights and the public good.

O'Gorman, Patrick & Paul Hardacre (2004) conducted a study on the practices of NGOs working with the injecting drug users (IDUs) in SAARC countries. Asian Harm Reduction Network (AHRN) in collaboration with the United Nations Office on Drugs and Crime, Regional Office for South Asia (UNODC, ROSA) published the report of the study as "*Documentation of Best Practices and Needs Assessment of Service Providers in South Asian Association for Regional Cooperation (SAARC) Countries*". This report consists of two main components. The first component outlines the threats of HIV transmission through injecting drug use in the SAARC countries including India. Many unreached groups of individuals injecting drugs are present in most countries in the region. The combination of high-risk drug taking practices, lack of relevant information and essential services, and mutual distrust between these high-risk population groups and mainstream health and social care services has led to a critical situation in the transmission of blood-borne viruses like HIV. Each country faces a different level of threat. A profile of the situation in each SAARC country is provided. NGOs currently working in drug treatment services are best placed to build bridges with people using and injecting drugs. This report recommends the scaling-up of capacity and services amongst NGOs in each country in the region through a three-part training strategy: (1) training in a holistic approach to street-based outreach, (2) workshops to develop model projects which respond to the needs of people injecting drugs and (3) ongoing training throughout subsequent phases through exchange visits to suggested demonstration sites. The second component of this report captures the current reported capacity of NGOs providing drug treatment and drug use related services in each country. The Directory of Service Providers in the SAARC Region included as Appendix in this report shows detailed information on the capacity and services provided by the listed NGOs. This directory can be used to determine the potential that currently exists. If this potential is harnessed through the strategy outlined in this report, it will become a force to arrest the epidemic of blood-borne viral transmission related to injecting drug use in the SAARC region.

UNAIDS (2005) in its report on “*A scaled-up response to AIDS in Asia and the Pacific*” summarises the AIDS challenge in Asian and Pacific countries. While some countries have already made their decision and begun to scale up effective AIDS programmes, in others there is still hesitation. Using the best available evidence, it discusses the reasons why critical services currently reach only a fraction of those in need. It also outlines the action needed that will allow the region to seize this key moment of opportunity. The report observed that growing political and financial support for AIDS efforts has been accompanied—and in some cases preceded—by stronger civil society engagement. Organizations of people living with HIV and AIDS (PLWHA) are advocating for increased access to treatment and care, and working to alleviate the stigma associated with the disease. In Cambodia, civil society organizations and people living with HIV joined with the national government and international donors to develop a national AIDS treatment plan. NGOs created by former drug users have initiated drug-substitution programmes in India and organized harm-reduction services in South-East Asia. Sex worker advocacy groups have created and expanded programmes in Bangladesh, India, Cambodia and Thailand, while programmes for men who have sex with men (MSM) have emerged in Pakistan, Nepal, the Philippines and Thailand. In some countries, lawyers’ collectives have taken up legal battles to fight instances of discrimination against people living with HIV. Finally, the report makes recommendations for urgent implementation of strategies known to work, by global, regional and national political leaders, by international donors, the UN system, civil society and other key stakeholders in Asia and the Pacific. The report specifically recommended that countries should increase support to civil society organizations’ involvement in national responses by identifying and implementing viable and effective mechanisms for financing, building capacity and promoting coordination of civil society organizations. These include, among others, legal recognition, tax incentives, streamlined contracting regulations, and financial support to build effective and accountable community-based organizations.

(B) Studies conducted in India

Creating Resources for Empowerment in Action (CREA), New Delhi published a series of annotated bibliographies on Reproductive Health Research in India carried out during 1990-2000. These bibliographies are part of the Gender and Reproductive Health Research Initiative’ sponsored by the Ford Foundation. Six areas of concern in

reproductive health were identified of which HIV/AIDS was one. The designated team searched on each of these research areas. Accordingly a team comprising Dr. Vimala Nadkarni, Anita Rego and Deeksha Vasundhra prepared annotated bibliography on HIV/AIDS along with a critical review paper, which looked at the content gaps, methodological issues and ethical concerns in the research. This has culminated into inviting proposals for future.

The annotated bibliography lists 126 studies carried out during 1990-2000 on HIV/AIDS. State wise 33 studies were conducted in Maharashtra, 21 in Delhi, 13 in Tamil Nadu, 12 in Karnataka, 8 in West Bengal, and 5 each in Andhra Pradesh and Uttar Pradesh. It indicates 77% of the studies conducted in the above mentioned seven states only. Numbers of study conducted in the remaining states were below five and even no study was conducted in few states. Seven studies were conducted involving more than one state. City wise 21 studies were conducted in Delhi, 17 in Mumbai, 11 in Chennai, 10 in Bangalore and 8 in Kolkata. It means most of the studies were conducted in urban areas. Surprisingly numbers of study conducted in Andhra Pradesh (5), Manipur (4) and Nagaland (1) are comparatively less in spite of their high HIV infection rate. There were six studies conducted in other countries.

Medical Practitioners, Social Scientists, funding organizations, government organizations and individuals have researched the two-decade long epidemic widely. The existing research on HIV/AIDS in India has been grouped under the following categories and presented in Table-2.1.

Table-2.1: Research on HIV/AIDS in India during 1990-2000

<i>Sl. No.</i>	<i>Themes of Research</i>	<i>No. of Studies (%)</i>
1.	Understanding and response to HIV/AIDS	42 (35.0%)
2.	Safer sexual practices and other modes of risk reduction	18 (15.0%)
3.	Biological and societal vulnerabilities to HIV/AIDS	15 (12.5%)
4.	Economic impact of HIV/AIDS	03 (02.5%)
5.	Disclosure, stigma and discrimination	06 (05.0%)
6.	Mental health issues including substance abuse	13 (10.8%)
7.	The rights of positive people	01 (00.8%)
8.	Prevention programmes and interventions	15 (12.5%)
9.	Mixed themes	07 (05.9%)
	Total	120 (100%)

K.S. Rao, R.D. Pillai and R.R. Rao conducted a study on “*Awareness of AIDS/HIV among voluntary organizations in Andhra Pradesh*” during 1988-91. The aim of the study was to assess the knowledge about transmission of AIDS, misconceptions and safe sexual behaviour among voluntary organizations. A structured questionnaire was administered to different voluntary organizations in Andhra Pradesh after conducting 27 AIDS/HIV health educational programmes for them. The majority of the participants were aware about AIDS/HIV and the associated aspects. Ignorance (61%) was reportedly higher among the rural youth even after the health education session. It is found that post intervention had a significant impact on knowledge gain.

Asthana S. and Oostvogels R. (1996) in an article on “*Community participation in HIV prevention: problems and prospects for community-based strategies among female sex workers in Madras*” examined problems and prospects for participation in HIV prevention strategies among commercial sex workers (CSWs) in Madras. Based upon the experiences of a pilot project established by the Tamil Nadu State Government AIDS Cell and WHO, they found that the organization of the commercial sex trade in Madras is not highly conducive to collective action. Identifying the factors that have frustrated attempts to promote community-based strategies in the city, the paper suggests that this approach is unlikely to succeed unless there are significant changes to the institutional arrangements that keep sex workers in a position of subordination and exploitation.

Paul and Gopalakrishnan (2003) investigated the *impact of training on knowledge of functionaries of NGOs* regarding mode of transmission and prevention of STIs including HIV/AIDS. This study began with the research mission of ascertaining the present level of knowledge of NGO functionaries dealing with MCH issues and their training requirements. They adopted a cross-sectional study design, using percentages and chi-square tests as the method of statistical analysis. They came up with the following results. Almost all representatives of NGOs were aware that HIV infection has emerged as a new threat. A majority of them were aware that use of condom during intercourse could prevent STDs, but could not relate this with HIV/AIDS prevention. They also were of the view that avoiding sex with multiple partners could prevent HIV/AIDS. The major sources of information on HIV/ AIDS were newspaper and TV. A major lacuna in knowledge, which needs to be substantiated, includes use of disposable/sterilised needles for preventing HIV/AIDS.

mother-to-child transmission of HIV, complications of STDs, need for partner's treatment in STDs, and concept of window period for HIV detection.

From the above review, it is clear that NGOs/CBOs are at the forefront in the battle against HIV/AIDS and have so far played a significant role. AIDS activities initiated by NGOs have been highly influential on thinking and strategies found within HIV/AIDS sector. In this context, associations/networks of PLWHA are also crucial, as their involvements strengthen NGOs as well as improve the quality of PLWHA's lives. Yet despite their proliferation, NGOs experience particular difficulties in increasing the scale of their activities to reach large number of people, to have a greater impact at higher level than "community" and to address the broader social determinants of HIV/AIDS. Besides this, other issues that need to be considered include the difficulties of many NGOs to integrate their activities with those of other NGOs, the government and the communities; and the generally weak IEC methodologies and instruments that were not often appropriate for local needs and realities. The review also indicates that the relative effectiveness of different NGOs/CBOs in different communities depends on many factors associated with individual organizations, their communities and collaborations with and support by other community or outside organizations. Strong government support and commitment will be crucial in scaling up the existing community-based prevention and patient care programs to a truly national multi-sectoral HIV/AIDS programme by building on available models, starting with existing capacities and building them through learning by doing, by giving the highest priority to prevention, by promoting accountability and improving fiscal sustainability, among others. Key components for the success of the HIV/AIDS programme include strong partnerships, selection of the right personnel, adequate and appropriate training, support from community leaders, a supportive supervisory system, participatory reviews and monitoring, consistent technical and financial support and an active Home Care Network.

However, such studies on NGOs response to HIV/AIDS are not found in India. The objective of a large percentage of studies in India is to assess the level of knowledge about HIV/AIDS. It is also seen from the above review of literature that few state level studies on the role of NGOs in health care were conducted (Duggal et.al 1986; Baru 1987; Sarkar 2005). There is no doubt on the fact that NGOs play a key role in combating HIV/AIDS. But no such state-level study on the contribution of

NGOs in HIV/AIDS prevention and care was undertaken in India so far. Thus, it is pertinent to explore and examine the NGOs response to HIV/AIDS in detail.

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