NGOS RESPONSES TO HIV/AIDS PROBLEMS IN INDIA AND SOUTH AFRICA
CHAPTER-IV
NGOs RESPONSES TO HIV/AIDS PROBLEMS IN INDIA AND SOUTH AFRICA

4. 1 NGOS Responses to HIV/AIDS in India

4. 1. 1 Introduction

Non-Governmental Organisations (NGOs) has been associated with HIV/AIDS since day one. Prevention, care and awareness generation on HIV/AIDS were their main focus and areas of exploration, NGOs carry forward the various governmental policies and programmes on HIV/AIDS which are customise and then vividly implemented as per local reality. This aspect of working strategy seems to be an effective tool in dealing with HIV/AIDS.

The National AIDS Control Programme aims to reduce the spread of HIV/AIDS in India, and to strengthen its capacity to respond to HIV/AIDS on a long term basis. Globally, NGOs are the primary players in leading a country’s responses to HIV/AIDS from the grassroots level. Their flexibility and innovative approach enables NGOs to access constituencies that the state apparatus sometimes finds difficult to reach. They often represent realistically the needs of even the most marginalised and vulnerable populations. In this manner, the NGOs help complement and supplement the efforts of government to put in place an integrated, holistic and comprehensive response. The National AIDS Control Organisation (NACO) of India sees NGOs as its primary allies and critical partners in undertaking targeted interventions among high risk groups; disseminating the school AIDS education programme; delivering counselling services as well as providing care and outreach services for the people living with HIV/AIDS, and in general, NGOs are significantly contributing in evoking the community response to HIV.¹

There is a transparent and viable system in place to ensure that the NGOs selected for the participation and partnership should enjoy the trust of the targeted community, besides having a relevant and appropriate skill with a credible track record. The National AIDS Control Programme has been decentralised taking into consideration the significant role of NGOs.

Each Indian state has its own Technical Advisory Committees (TAC), set up by that particular state’s AIDS Control Societies; NGOs are usually selected by TAC. These committees examines and scrutinise the application and project designs of NGOs and also subsequently monitor and evaluate the programme within the framework of the guidelines drawn up by NACO in respect of each intervention. The SACS provide financial assistance and sustained technical support in project implementation.²

The National AIDS Control Organisation supports NGOs at the state levels, who opt to run a telephone counselling service at a dedicated toll free number such as 1097, primarily and solely for HIV/AIDS counselling. All relevant information, education and communication activities are disseminated through this number via pre-recorded information. Option is also provided to the users for a manual response to specific queries. Information seeking ranges from basic information on HIV/AIDS to the diverse and most common routes of transmission as well as areas of services available for any personal anxieties. One of the primary reasons for the popularity of this service is that the callers are able to get quality information and still maintain anonymity.³

NGOs and CBOs in the development sector have designed and implemented innovative programmes based on the needs at community level. Government has been responsive, but now needs to further expand access to these services. And slowly but surely, the government is succeeding in forging inter-sectoral links that will mainstream HIV/AIDS prevention and control with broader concerns. A clearly defined National AIDS Control Programme has enabled the National AIDS Control Organisation (NACO) to become among the most trusted names in the field of HIV/AIDS in India. At the core

² Ibid.
of this programme lies a deeply ingrained sense of social responsibility that aims to reduce the spread of HIV infection in the country and to strengthen India’s response to HIV/AIDS on a long term basis. For any organisation, partnerships form an effective indicator of not only the direction it is taking but also the contribution it is making in its chosen field. The National AIDS Control Organisation works closely with NGOs, CSOs and other organisations across the country through its 38 State AIDS Control Societies (SACS), and finds that these partnerships have served to multiply the effectiveness of HIV/AIDS programmes in India over the past few years. Moreover, pulling in the state resources into one direction and aligning inputs have demonstrated tangible results in building awareness and motivating safer practices and behaviour patterns.\footnote{Ibid.}


The second phase of the National AIDS Control Programme (NACP-II) began from 1999 and ended in March 2007. It was during this second phase of NACP that the importance of NGOs role was felt. The main focuses of the second phase of NACP were: Targeted interventions for high risk groups; Preventive interventions among the general population, and the involvement of NGOs line department (such as Transport, Police and Education) and other sectors.\footnote{National AIDS Control Organisation (2007), \textit{Independent Evaluation of the National AIDS Control Programme-II}, New Delhi, [Online: web] Accessed 24 December 2007, URL: http://www.nacoonline.org/upload/Finance/Independent%20Evaluation%20of%20NACP-II.pdf.}
Presently, the third phase of National AIDS Control Programme (NACP-III) is running for the time period of 2007-2012. NACP-III provides an integrated package of prevention, care and support as well as treatment with the aim of reducing HIV incidence by 60 per cent in the high prevalence states and by about 40 per cent in the vulnerable states. For the sake of NGOs and CBOs involvement, the NACP-III uses behaviour change communication, it has also committed in extending the existing infrastructure for care, support and treatment, by developing guidelines and training modules for health care personnels and services. Improvement of medical care and quality for the people living with AIDS is set as one of its aim. It has further planned to decentralise its activities from the state to the district level and also ensured the involvement of various government departments and the private sector in its efforts to contain the HIV menace in India. During the five-year period of NACP-III, it is estimated that the financial resources required for the various HIV/AIDS programme in India such as prevention, treatment, care and support will be about Rs. 11,600 crore. NACP-III therefore has the multi-disciplinary contribution that includes nationwide consultation with various national stake holders, NGOs, as well as international development partners.7

4.1.2 Aims and Objectives of NGOs in the HIV/AIDS programme

Most of the NGOs in the developing countries emerged as consciously created civil bodies to deal with the problems of economic underdevelopment, health and gender issues along with the environment concerns in the recent times. They may originate from within the country or from without as part of the globalising trend. Whatever the original aim of these organisations, they have to adjust their ‘aims and objectives’ as per the ongoing demands and preferences of a particular country or the international agencies to which they are attached. Nevertheless, NGOs receive more funds from foreign donors than national donors. For instance, in the Latin American countries, 43 per cent of the total funding for NGOs dealing with HIV/AIDS are from international agencies, while only a meager 9.4 per cent comes from the government side and the remaining 46.9 to 4.7 per cent is jointly provided by the international agencies and the national government,

the rest 42.2 per cent is incurred by the NGOs themselves from their own resources. These aids are bestowed with the expectation that the NGOs will target their policies and programmes to the highest risk groups such as: Men having Sex with Men (MSM); Commercial Sex Workers (CSWs); People Living with HIV/AIDS (PLWHA) and adolescents.\(^8\)

The case in point is Manipur for instance, were funding from various agencies always has some strings attached to them, which is also applicable to NGOs everywhere in India, if they get aids from donor agencies. Likewise, when Rapid Intervention and Care (RIAC) Project was launched in November 1998, the aim intended were to bring about a more effective and quick control of the spread of HIV/AIDS in the state in collaboration with 12 partner NGOs. Under this project, 3 targeted groups are mentioned: the truck drivers; the women at risk (CSWs, women IDUs, women quarry labourers, spouses of IDUs, HIV/AIDS patients) and MSM. This means that the various NGOs working in collaboration with MACS (Manipur State AIDS Control Society) and the other donor agencies are obliged to work within that framework.\(^9\)

Thus, NGOs as aid machines are prone to interference from the donor agencies as well as the local powers. This open secret of unethical and sleazy engagements arouse deception in the minds of the general people towards NGOs and other similar organisation, and the latter see them as bogus which do not have genuine interest for the betterment of those suffering or affected by HIV/AIDS.\(^10\)

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4.1.3 Participation of NGOs and Other Sectors in HIV/AIDS Control

There are more than 933 NGOs working in the field of HIV/AIDS in India at local, state and national level. They cater to targeted interventions among the high risk group and vulnerable sections such as women and children, NGOs are directly involved in extending care, treatment and prevention to the people suffering from HIV/AIDS.11

NGOs have massively taken up to drive the general awareness campaigns as well as care for AIDS orphans. The resource needed by NGOs comes from various quarters, they are partly funded by the center or state government and partly the funds come from the international donors, corporate funding and local contributions.12

The importance of NGOs participation are recognised and appreciated by NACO. NGOs show an expertise in providing required care and counseling, they bring with them the experience of community level work, thereby enhancing the people's participation by invoking an interpersonal approach, which largely benefits the governments HIV/AIDS programmes.13

NGOs and civil society organisations in India have made a significant contribution in the prevention, treatment, care and support services to the people living with HIV/AIDS in India. They are working in the field of preventive or targeted interventions for high risk groups, care and support services and in general awareness campaigns on HIV/AIDS. They work from the grassroots level both at the local, state and national levels. Civil Society Organisations and NGOs play a crucial role in preparing communities to take ownership of the programme, and thereby enhance the scope of dealing with the HIV/AIDS. Their participation has immensely benefited the national HIV/AIDS programme because they bring with them their experience of community level work in enhancing people’s participation. Hence NGOs and other civil society organisation are part and parcel of India’s HIV/AIDS programme.14

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11 Ibid.
12 Ministry of Health and Family Welfare (2001), n.3.
13 Ibid.
The involvement and participation of NGOs/CBOs and other sectors in the National AIDS Control Programme are realised by the government of India as an important group in the following manner: Setting up of plate form at the national and state level for NGOs involvement in the decision and policy making; Apart from the NGOs involvement in the conventional areas of awareness, care and counselling of people living with HIV/AIDS, their participation in the provision of medical facilities including home based care and establishing community care centers were expected; Government has extended to undertake training and capacity building programmes for the NGOs so that the responsibilities to tackle the HIV/AIDS will be better up; There are periodic updating of guidelines issued by NACO to NGOs, which will facilitate better participation and accountability of NGOs; States governments are also addressing the need and participation of NGOs by mobilising government officials; Counselling services in the villages and the distribution of good quality condoms in the STD clinics across the country are being delegated to the NGOs; Government of India is providing incentives and support for the formation of self-help groups among the HIV infected person, the service which are relied on NGOs. Hence, to achieve these goals, NGOs participation is highly appreciated and motivated. See figure 4.1 regarding the working relationship between the government and the non-government organisation.


NGOs were one of the foremost groups that has reacted and responded tough against HIV/AIDS. Today there are numerous NGOs associated with HIV/AIDS in India.
They are working tirelessly and ensures that the resources mend for taming HIV/AIDS be implemented fully. The care and support to people living with HIV/AIDS, generation of awareness as well as educating people are the basic tools NGOs have taken up. Due to ever increasing HIV/AIDS cases in India as well as various loopholes in the public health care services, the NGOs have joined hands with government in providing support to people living with HIV/AIDS along with community outreach prevention. NGOs and Civil Society Organisations (CSOs) as well as other similar organisation provide instant care and support needed by the people living with HIV/AIDS and their family. They have integrated various governmental policies and programmes on HIV/AIDS within their other developmental programmes. Many NGOs and CSOs are associated in changing the negative attitudes of people and the misconception about HIV/AIDS. They are instrumental in advising safer sex and the promotion of community based intervention; NGOs are also educating the school children through educational sessions on HIV/AIDS and sexuality.

4.1.3.1 NGOs HIV/AIDS Preventive Interventions

One of the most significant components of National AIDS Control Programme of India is the preventive and targeted interventions. Because the preventive and targeted interventions provide a comprehensive and integrated approach for HIV prevention among the marginalised and vulnerable populations, such as Commercial or Female Sex Workers (CSW/FSW), truck drivers, Injecting Drug Users (IDU), Men Having Sex with Men (MSM) and migrant workers. NACO, in partnership with CSOs/NGOs, provides HIV prevention services to these groups at a place and time where they can be most effectively accessed.

Assessing the capability and effectiveness of NGOs and CBOs in reaching the targeted interventions, the government has further expanded their involvement in the

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fight against HIV/AIDS in India. In 2006 more than 1000 NGOs and CBOs were involved in various HIV/AIDS programmes. Under NACP-III, NGOs involvement were further scaled up and seek their active participation in providing home based care services as well as their role in addressing stigma and discrimination associated with HIV/AIDS.¹⁸

The intervention for HIV/AIDS prevention among women and children as well as the empowerment of women are largely taken up by various NGOs in India. They have generated awareness, provided information and strengthen Indian women’s capacity and capabilities. NGOs have setup a broad framework focusing on women, such as; empowerment of women, addressing the problems of HIV/AIDS among women and children, employment of need based approach and HIV/AIDS prevention from the view point of reproductive health.¹⁹

India’s prime organisation, the National AIDS Control Organisation (NACO), sees NGOs as its primary allies and partners. To date NACO and the NGOs are working together and have undertaken a number of targeted interventions among high risk groups. Dissemination of school AIDS education programmes, counselling services, care and outreach services for people living with HIV/AIDS are the various joint activities undertaken by NACO along with NGOs. NGOs work at the grassroots level; they take seriously the wants of most marginalised and vulnerable sections of the society. In this way NGOs fulfill the expectations of the marginalised masses, Therefore, NGOs not only compliment but also supplement the effort of the government to put in place an integrated response.²⁰

Given the severity of HIV/AIDS situation in India, dealing with AIDS indeed need a concerted cooperation and support between the government, NGOs, donors and

the international health community. The growing miseries of AIDS therefore has brought about a wide range of caretakers and care givers, who work in close allies with the government within general masses, private hospitals, NGOs and community based facilities. The response of NGOs on HIV/AIDS in India is presently quite appreciable; these organisations have extended a valuable presentation programmes and policies of government and contributed immensely in fighting the HIV/AIDS menace. NGOs have therefore demonstrated their commitment, by investing appropriate economic and human resources, which over a period of time have helped in setting trends that have been institutionalised in the HIV/AIDS programmes and policies.²¹

In India though NGOs response on HIV/AIDS were in the fore front, yet it emerge very slowly, because of the lack of resources and experience, as well as it took time to recognise their potentiality and capability, both by the public and by the government. As the epidemic advanced, however, both well established and newly organised NGOs were among the first to react and respond, promoting the need for the people living with HIV/AIDS to have a better access to public health care facilities and information about AIDS. They have mobilised impressive efforts for training, education and other supportive services related to HIV/AIDS,²² were as the government officials and politicians were slow to react, in fact some of the bureaucrats and politicians at the helm even denied the existence of HIV/AIDS problems in the general level.²³

During the initial periods of HIV/AIDS cases in India, the World Health Organisation’s (WHO) Global Programme on AIDS (GPA) began to assist and advice the countries to draw up their national plans and prevention policies on HIV/AIDS. Indian NGOs were neither asked by the government during the planning and documentation period of HIV/AIDS programmes and policies nor were they invited during the foundation of National AIDS Committee and National AIDS Control Programme in the 1980s. A 1989 resolution of world Health Assembly overwhelmingly admitted and

²³ Snow, Melissa (2004.), n.20.
supported the importance of NGOs in the global fight against HIV/AIDS. There are also a number of companies that contributes in the HIV/AIDS prevention in India. More than 700 companies have signed and put forward their support and commitment to the Confederation of Indian Industry’s (CII) HIV/AIDS policy that caters and facilitates the prevention, care and treatment not only within the companies but also communities. Some 2000 companies have initiated workplace HIV/AIDS programmes.

4.1.3.2 Networking of NGOs and other Partnership Forums

The NGOs, CSOs and other community based organisations are accepted as a very important partner in the National AIDS Control Programme of India. Civil society organisations including NGOs, CBOs and FBOs like Red Ribbon Clubs, Network of People Living with HIV/AIDS (PLHA), private sector organisations, business houses and international agencies are contributing tremendously for HIV prevention, treatment, care and support services in India.

Moreover, Forum of Scientist, Academic forum, Literary personalities, Artist, Film stars, Sports personalities, Models, Cleric, Musicians, Yogis and many more have come forward and contributed in taming the HIV/AIDS epidemic in India. Medias, Movies, Plays, TV and Radios are the other parameters through which awareness about HIV/AIDS are propagated massively in India. These were not possible without the valuable help extended by the NGOs, Community Based Organisations (CBOs), Civil Society Organisations (CSOs), Faith Based Organisations (FBOs), as well as volunteers, alert communities and institutions. The prevention campaign and the care and support services in the remote areas of India were made possible with the active participation of these organisations; many of these organisations have already taken up mainstreaming


26 UNDP (2003), n.22.
their activities and other allied services for the benefit of people affected by HIV/AIDS in India.\textsuperscript{27}

The involvement of NGOs in dealing with HIV/AIDS is a significant milieu and a paramount step for reducing the HIV/AIDS incidence and prevalence in India. NACO officials maintain that involving NGOs brings more people within the fold, since discrimination, stigma and ignorance keeps most of the marginalised masses away from seeking treatment and counselling, it is therefore NGOs which will play an activist role in raising awareness and encourage people to come to the voluntary testing centers.\textsuperscript{28}

Tamil Nadu, the worst hit state of India have managed to contain the number of infection from growing, the Tamil Nadu AIDS Initiative (TAI) with the Support of Bill and Melinda Gates foundations and the simultaneous launch of \textit{Avahan}\textsuperscript{29} scheme had made it possible to reduce the number of HIV infection and sets model for the other Indian state to emulate.\textsuperscript{30}

The participation and involvement of NGOs/CBOs and other sectors in the war against HIV/AIDS epidemic cannot be ignored. The list of NGOs working in the field of HIV/AIDS are ever increasing, the response extended by these sector are therefore very appreciable and effective. NACO’s thumps up signal to the various national NGOs participation to exterminate HIV/AIDS in India is a welcome sign which indicates that India indeed woke up to drive away the deadly menace, and it will not be far away when we count the number of infections on our finger tip. The response extended by Indian NGOs in tackling HIV/AIDS in India is widely appreciated. In many communities suffering from HIV/AIDS throughout India, the most credible source of support were the numerous NGOs involvement in the vast array of health and development issues in the grass root levels. In recognition of such appreciable responses, the UNDP has supported a pilot initiative in order to identify and demonstrate ways of generating relevant and

\textsuperscript{27} International HIV/AIDS Alliance (2005), n.15.
\textsuperscript{29} Avahan is a multi-year HIV prevention program funded by the Bill and Melinda Gates Foundation on HIV/AIDS. In India it is implemented by the Indian branch of Population Services International.
sustainable local responses to the HIV/AIDS by accruing local experience and expertise throughout India.\textsuperscript{31}

All the Indian NGOs related to HIV/AIDS are governed by the Indian Network of NGOs on HIV/AIDS (INN). It is a platform that brings together around 300 NGOs in sharing of professional concerns and needs, as well as joint action for advocacy and service to those most affected by the challenge. The need for such a space and network was felt over a decade ago, in the midst of national confusion and lethargy toward clear indications of the crisis awaiting India. A small group of activists met in 1992, to organise stronger network and mutual support within the civil society. After a gestation period of two year, it led to the First National Convention of INN in Ahmedabad. In 1994 INN was formally formed with an elected governing council. Experience over the past has vindicated the vision which led to INN. Working informally and on shoestring budget, INN has a strong track record of exchange and mutual support in key areas of HIV/AIDS awareness and control. The annual INN conventions have served as major opportunities, as well as building morale within a sector besieged by indifference and ignorance. An example of INN’s catalytic role was the invitation to the Network to hold its 2003 convention in Madurai. The invitation reflected the need of sharing experiences of India on a floor in Tamil Nadu where the first case of HIV was identified and since then both Government and NGOs remained active to bring a visible change in the campaign against HIV/AIDS in India.\textsuperscript{32}

Several mobilisation and advocacy priorities have emerged through the National Conventions. This sort of convention also provided the opportunity to share important new developments in HIV/AIDS prevention and care such as: The trials of microbicides and the female condom in India; Status of vaccine development in India and the programmes on voluntary counselling and testing; as well as the prevention of HIV from Mother to Child Transmission in India. Technical materials have been translated into local languages to help spread such awareness. Such conventions and conferences offer a

\textsuperscript{31} UNDP (2003), n.22.
valuable resources for tracking India’s growing experience in the sector. INN partners overseas have actively supported the exchanges that take place during the INN conventions. Major input in INN convention at Madurai was by Care International of USA and the World Bank.33

There are many countries that provides a significant bilateral assistance to India to fight the HIV/AIDS epidemic, these countries are: United States, Britain, Australia, The European Union, Japan, The Netherlands, Sweden and Canada.34

4.1.3.3 NGOs Participation in Government’s Policy Making

Non-governmental organisations have made a significant contribution in the health sector by their innovative approach in the areas of public health, family welfare and in arresting the spread of communicable diseases especially HIV/AIDS. It is essential to continue to encourage the involvement of voluntary sector in HIV/AIDS. The national AIDS control programme has recognised the importance of NGOs and other civil society organisations, particularly their contributions in the programme for providing community support for people living with HIV/AIDS and their families as well as for providing the required care and counselling services. NGOs bring with them their experience of community work in enhancing people’s participation by adopting an interpersonal approach with sensitivity and thus benefit the HIV/AIDS programme immensely.35

The Government of India and several state governments have been encouraging NGOs involvement in various development sectors over the years. The collaborative models of NGOS are available in the sectors of Education, Women and Child Development, HIV/AIDS and Natural Resource Management amongst others. The collaborators are as partners in primary health care for over two decades and more recently in the area of Reproductive and Child Health (RCH).36

33 Ibid
Government enhances a large scale involvement and participation of NGOs and other civil society organisations the following manner: Involvement of NGOs at the policy making level through regular interaction and adequate representation at the State level bodies; Extending their participation to new areas like provision of medical facilities to home-based care, opening of community care centers apart from the conventional areas of awareness, counselling, and targeted interventions among high-risk groups; Greater efforts to take training and capacity building programmes for the NGOs to empower them to take up these additional facilities; Adopting local level monitoring and guidance through District Collector, Joint Director of Health Services and Deputy Director of Health Services; Independent evaluation of the NGOs intervention which will enable in planning for the sustainable implementation of the programmes, periodical evaluation takes place once in three years subsequently to analyse the track records of NGOs performances; Enhancing community participation to create an enabling environment and an ownership of the whole HIV/AIDS prevention activities in the District and the State level; Encourage networking and periodical updating of guidelines issued by NACO for involvement of NGOs to facilitate greater participation of NGOs and for better accountability.37

As per United Nations, the level of NGOs and civil society organisations involvement varies from the mandate and organisational structure of UN based organisations. Some organisations can work directly with NGOs, but others route their programmes through the government. It was suggested that there should be greater documentation of NGOs and their work to facilitate their involvement in HIV/AIDS programme in India. There is also an urgent need to delineate the interface between NGOs and Panchayati Raj Institutions (PRIs). The comparative advantage and the role of the NGOs in relation to the activities of the PRIs need to be clarified. NGOs do have a vital role in initiating pilot projects and innovative interventions for widespread replication by the government. For instance, the involvement of NGOs in India’s polio eradication drive have been successful in maintaining the momentum of the programme

37 TANSACS., n.35.
and it was suggested that this could be used as a model for collaboration with NGOs at the field level in various other sectors including HIV/AIDS.\(^{38}\)

### 4.1.3.4 NGOs Participation in Government's Policy Implementation

To be an equal development partners, one of the prerequisite for non-governmental organisations or civil society organisations is the existence of a policy framework that recognises their relevance, role and right to implement the governmental policies, for instance: Conduct independent activities (without the pre-approval of the government, including the receipt of foreign funds); To meet and express opinions; To approve self-governance mechanisms as well as to engage in advocacy and monitor the work of the government. Full participation of NGOs in all development processes must be institutionalised. It should not be something like needs driven or ad-hoc, rather it should take place throughout the entire process, including during the policy development, implementation and monitoring phases.\(^{39}\)

Stakeholders themselves cannot be token participants, but must truly reflect the constituents they are intended to represent. For example, civil society representatives at the table must include broader participation than national or international NGOs. NGOs or CSOs have the responsibility to ensure that local and community based groups, including representatives of vulnerable and marginalised populations have a voice. Appropriate mechanisms, such as a transparent election process of representatives should be in place. The provision of relevancy, transparency and on-time information to all the stakeholders, regarding the process and progress in a continuous manner is the key to their meaningful participation. It remains difficult for NGOs and other non-state actors to gain access to information during critical periods of decision making. Information often arrives too late and incomplete, particularly regarding funding levels, sources and channels. Commitments to transparency made by donors and aid recipient countries are

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insufficient, if they don’t include the systematic disclosure of financial information to NGOs or CSOs as well as to the general public.40

4. 1. 4 NGOs and the State AIDS Prevention and Control Societies

National AIDS Control Organisation provides leadership to HIV/AIDS Control Programme in India by implementing a wholesome National Plan within a single monitoring system. Though the State AIDS Prevention and Control Societies (SACS) implement the NACO’s programme at state level, but they have their functional independence to upscale and innovate.41

SACS are autonomous and decentralised. Each State AIDS Prevention and Control Society has a governing body, its highest policy making structure, headed either by the minister in charge of health or the chief secretary. It has on board representatives from key government departments, the civil society, trade and industry, private health sector and the Network of People Living with HIV/AIDS (PLHA), who meet twice a year. It approves new policy initiatives, annual plan and budget, appoints statutory auditors and accepts the annual audit report. For better financial and operational efficiency, administrative and financial powers are vested in the Executive Committee and the Programme Director. Functions of SACS are: Medical and public health services; Communication and social sector services; and Administration, planning, coordination, monitoring, evaluation as well as finance and procurement.42

With the setting up of District AIDS Prevention and Control Unit under NACP-III, there will be an increased emphasis on improving coordinated functions at state level for supporting the implementation of HIV/AIDS programme in the district level.43

NGOs play a pivotal role in the prevention of HIV/AIDS as they work closely with people who engage in high-risk behaviour. The aim of NGOs is to educate the

40 Ibid.
42 Ibid.
43 Ibid.
vulnerable groups engaging in high risk behaviour and to promote safe sex, by intervening at the grassroots-level. NACO and the SACS maintain a healthy relation with NGOs and CSOs and support them in their HIV/AIDS awareness and campaign programmes. NACO and SACS mostly depends on the effort of NGOs and CSOs for providing counselling, testing, treatment and care services to the people living or affected by HIV/AIDS.44

For the sake of discussion in this thesis regarding the participation of NGOs in the State AIDS Control Society in India, the case study is referred from the state of Tamil Nadu. Tamil Nadu, which has over a period of time, has evolved into a transparent and an open system that lends support to the activities of the NGOs. Today, the number of NGOs supported by Tamil Nadu AIDS Control Society (TANSACS) is about ninety eight, which is the highest in India.45

Broadly there are two types of organisations which are supported by TANSACS. The first group comprises NGOs or CBOs who undertake intervention projects. The second group includes organisations of People Living with HIV/AIDS, with a focus on activities related to care and support, as well as it aims in reducing HIV/AIDS impact. As a part of its policy of transparency, TANSACS places advertisements in newspapers inviting NGO proposals. The selection of NGOs involves three stages: (1) Scrutiny of the proposal by the NGO Advisor and the Technical Advisory Committee (TAC); (2) A pre-sanction field inspection by the Zonal Officer; (3) Approval by the Executive Committee. All the proposals from NGOs are appraised by the NGO Advisor and the TAC. Proposals recommended by the TAC are inspected by Zonal Officers who make field visits to verify the working of the NGO, their capability and the community’s perception of that particular NGO. After field inspection, the proposals along with the field inspection reports are presented to the Executive Committee of TANSACS.46

Based on approval by the Committee, funds are disbursed to the NGOs in installments after signing the necessary agreement. TANSACS periodically inspects the

45 TANSACS (2004), n.35.
46 Ibid.
NGOs to monitor the progress made. All NGOs are required to present a progress report to TANSACS. Intervention programmes are aimed at promoting safe behaviour by providing vulnerable and marginalised groups with access to condoms, counselling and STD treatment services. The groups identified for intervention programmes are industrial workers, truck drivers, commercial sex workers, migrant labour, prison inmates, domestic help, students, street children, Youth and Adolescent, and Men having Sex with Men (MSM).  

TANSACS has developed working relationships with NGOs to ensure that the HIV/AIDS situation is properly and adequately addressed in the appropriate manner. Periodically, Trainings are provided to the NGOs and data’s are received electronically from them. During these sessions, clarifications were provided on proposal guidelines, identifying target population and preparing a project proposal for grants. This gives confidence to NGOs and built bridges between the NGOs and TANSACS. Presently all the 29 districts in Tamil Nadu are covered through NGO grants.  

To establish a good rapport with NGOs, TANSACS appointed an NGO Advisor who is easily accessible to the NGOs. The NGO Advisor provides them with information, advice and promotes participation. There are three NGO members in the Technical Advisory Committee, as well as in the Executive Committee, one of whom represents positive people. Every year, open house meetings are conducted with NGOs during which the Hon’ble Health Minister interacts with the NGOs. TANSACS also conducts sessions where NGOs can share their experiences and benefit from each other’s insights and experience gained in the field. Training programmes on preparation and management of a project are held, apart from workshops and seminars for NGOs. Research Studies are funded by TANSACS relating to HIV/AIDS.  

Through NGOs, TANSACS provides support for the following activities: Counselling; STD treatment; Condom promotion; Treatment for opportunistic infections; Home and community based care and support for the people living with HIV/AIDS. The

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47 Ibid.
48 Health and Family Welfare Department, Government of Tamil Nadu., n.44.
49 Ibid.
continuous efforts in improving awareness levels and regular advocacy have created an environment for people living with HIV/AIDS (PLWHA) to come out in the open to disclose their status and unite to form an organisation to promote their cause. With the help of TANSACS, the Indian Network of Positive People (INP+), the first of its kind in the country, was started in Chennai and is networking positive people across the country. At present 7 PLWHA network are supported by TANSACS.50

Within the State, the Tamil Nadu Network of Positive People has also been promoted with the assistance of TANSACS. To address specific issues and problems faced by the HIV positive women, a Positive Women's Network has also been started in Tamil Nadu. TANSACS has employed two positive persons in the society to demonstrate its empathy with the cause of such persons. NGOs are also required to engage at least one positive person in their project funded by TANSACS. Thus TANSACS is involving NGOs, more actively and successfully in various care and support programmes.51

4.1.5 Constraints and Challenges

Indian NGOs have come a long way, their contributions in dealing with the HIV/AIDS epidemic are immeasurable, NGOs are working with dedication and sincerity, they work hard and have network that covers whole of India. Their campaign strategy are rather uniquely localised to suite the prevailing customs and culture of India, this makes the AIDS awareness drive much more effective and result oriented campaign.52

However, NGOs are facing a lot of problems and challenges in their endeavour to tackle the HIV/AIDS menace. India is a multi-faceted country, be it religion, custom, culture, language, race or ethnicity. It is also geographically a distinct place and climatically a diverse region. Given this ground reality about India, any policies and programmes needs a careful framework. Time and again it urgently calls for several rounds of modification and re-configurations of policies to suite a particular region or communities. These all exercise therefore needs ample resources at their disposal. Many

50 TANSACS (2004), n.35.
51 Ibid.
a time NGOs have to counter communication and infrastructural problem, they are not able to manage the economic and human resources, they have to shed many important time and resources to re-do or un-do the work in order to localised their policies and campaign programmes. Most importantly the NGOs have to always integrate themselves to the religion and customary sensitiveness of India.\textsuperscript{53}

Non-Governmental organisations or civil society organisations as well as other similar organisations have made a very positive contribution in India’s health sector by their experience and innovative ideas. Because of their concerted effort the spread of communicable diseases has been significantly reduced in India which in other words has helped in reducing the incidence and prevalence of HIV/AIDS. It is therefore important for the government to extend its support and encouragement to the NGOs and CBOs.\textsuperscript{54}

In view of the need to expand the responses to the new challenges thrown by the spread of the disease across the country, it is therefore necessary to update and revise the guidelines for involvement of NGOs in the programme. The experience and the result has been a mixed one so far, while there have been a number of successful programmes undertaken by NGOs for awareness generation, provision of counselling facilities and intervention projects among commercial sex workers and other high-risk groups, there have also been occasions of failures by newly-formed NGOs due to lack of proper perspective. Very few grassroots NGOs are coming forward to participate in the AIDS Control Programme.\textsuperscript{55}

On the government side NGOs have been encountering the problem of structural and other constraints like lack of reciprocation from officials at various levels. There is also a general lack of uniformity in the approach and performance of various state governments as well as an inadequate orientation among government officials towards the role of NGOs in the National AIDS Control Programme. There are delays in handling NGO cases which sometimes leads to decline of interest and withdrawal on the part of the NGOs. Delay in disbursement of funds and over-emphasis on utilisation of finances

\textsuperscript{53} Ibid.
\textsuperscript{55} Ibid.
rather than on impact assessment of the work done are also some of the serious flaws in the system of NGO financing.\footnote{UNDP (2003), n.22.}

Government recognises all these challenges and constraints faced by NGOs and commits itself to large scale involvement and participation of NGOs/CBOs in NACP such as: Involvement of NGOs at the policy making level through regular interaction and adequate representation at the National AIDS Committee; Enlarging their participation to new areas like provision of medical facilities including home and community based care services, opening of hospices et al apart from the conventional areas of awareness and counseling; Government will put in greater efforts to undertake training and capacity building programmes for the NGOs to empower them to take up these additional responsibilities; Guidelines issued by NACO for involvement of NGOs will be revised and updated to facilitate greater participation of NGOs in NACO programmes and for reduction of bureaucratic delays in NGO financing; and lastly, government will encourage networking among NGOs to avoid duplication of efforts in some of the areas.\footnote{Ibid.}

Efforts are being made to identify nodal NGOs in different states for coordinating the work of all the NGOs working in that area. Governments also need to address the problem of motivation among government officials towards involvement of NGOs in the programme. Government will therefore address all these issues to ensure and enhance collaboration between NGOs and the government both at the central and state levels to ensure greater participation of non-governmental sector in the National AIDS Control Programme.\footnote{Ibid.}

There are severe institutional capacity constraints, including managerial, at the national and state levels. These are critical factors to address as the program attempts to scale-up the national response. NACO will require a change in its role and responsibilities to provide the necessary leadership and steering role for a stronger multi-sector response for the next phase in India's fight against HIV/AIDS. The capacities to

\footnote{UNDP (2003), n.22.} \footnote{Ibid.} \footnote{Ibid.}
mount a strong programme are sometimes weakest in some of the poorest and most populated states with significant vulnerability to the epidemic. There is a need for tailored capacity building activities and the introduction of some performance based financing approaches. HIV/AIDS is a great threat to India’s development, localised epidemics within high-risk groups already exist in India, and the virus is spreading to the general population in a big way. India is just a step behind South Africa in the HIV/AIDS. Given India’s large population, a mere 0.1 per cent increase in the prevalence rate means an increase in the number of adults living with AIDS by over half a million persons. Only through an immediate and vigorous action as well as an active participation of NGOs and other similar organisations, that the spread of HIV/AIDS can be prevented from its further growth in India. There is also a high turnover of state level project directors, resulting in limited continuity and variability in performance across states. This puts the expansion of HIV/AIDS programme at risk.\textsuperscript{59}

Moreover, there is a need of better mechanisms to coordinate the donors and clear leadership by the government to reduce the transaction costs. Presently there are more than 32 donor agencies working with NACO in different states and on different programmes in India. Each donor has its own mandate and requirements, as well as areas of focus. The transaction cost to the government as a result of attending to the various demands of the donors is huge. As a result the programme implementations are slow and participants like NGOs lose their interest.\textsuperscript{60} There remains a need for greater use of data for decision making, including program data and epidemiological data. A lot of data that is being generated is not adequately used for managing the program or inform policies and priorities. Results based management and linking incentives to the use of data should be explored.\textsuperscript{61}

Stigma and discrimination against people living with HIV/AIDS and those considered to be at high risk remain entrenched. A lot of this is a result of inadequate knowledge. For instance, more than 75 percent of Indians mistakenly believed they could contract HIV from sharing a meal with a person who has the disease. Stigma and denial

\textsuperscript{59} World Bank (2005), n.10.
\textsuperscript{60} Ibid.
\textsuperscript{61} Ibid.
undermine efforts to increase the coverage of effective interventions among high risk groups such as men having sex with men, commercial sex workers and injecting drug users. Harassment by police and ostracism by family and community drives the epidemic underground and decreases the reach and effectiveness of prevention efforts. Though there is significant increase in awareness, due to efforts by the government and NGOs. But at the same time these gamuts of problems and constraints are reality through which NGOs have to struggle. Hence with the support and encouragement of governments as well as international communities, it is not so much difficult to level off the ground.\textsuperscript{62}

\textsuperscript{62} UNDP (2003), n.22.
4. 2 NGOs RESPONSES TO HIV/AIDS IN SOUTH AFRICA

4.2.1 Introduction

HIV/AIDS, as we discussed in the preceding chapter of this thesis, is a core developmental problem and issues not only in South Africa or in the continent of Africa, but it is a major problem throughout the world. HIV/AIDS threatens the very existence of human being and its civilisation. The situation therefore sensibly and seriously demands for a global effort.

HIV/AIDS has shaken the socio-economic framework as well as the political stability of many nations in Africa. However, with the help of donor countries, UN agencies and CFA (Commission for Africa), it is worth noting that most of these nations which are continuously under the severe grip of HIV/AIDS epidemic have an appreciable tools and resources at their disposal to deal with the HIV/AIDS crisis.  

HIV/AIDS cases in South Africa were first noted in the year 1982. However, discernable policies on HIV/AIDS came to light in 1992, when South Africa’s nodal agency, the National AIDS Coordinating committee of South Africa (NACOSA) endorsed a mandate to develop national strategies on HIV/AIDS prevention and control. This mandate mobilised and unified the provincial, international and local resource to contain the epidemic. In 1999 the South African government prepared an extensive national strategic plan and issued guidelines to the country’s response as a whole to HIV/AIDS. Since then the guidelines become the basis for all the governments’ institutions, Non Governmental Organisations (NGOs), Community Based Organisations (CBOs), Civil Society Organisations (CSOs), Faith Based Organisations (FBOs) and various other local institutions. South African NGOs have adopted the governmental

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64 Co-operative for Research and Education (CORE) and The Institute for Democracy in South Africa (IDASA) define Civil Society as “the sphere of organisations and/or associations of organisations located between the family, the state, the government of the day, and the prevailing economic system, in which people with common interests associate voluntarily. Amongst these organisations, they may have common, competing or conflicting values and interests”.

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guidelines and set their own strategic and operational plan into a local reality within the purview of government policies.\textsuperscript{65}

NGOs response to HIV/AIDS in South Africa increasingly began since 1990s. Today, there are numerous NGOs working at provincial, local and national levels, their contributions are wide ranging and are appreciable and effective.\textsuperscript{66}

NGOs are presently emerging as a powerful force and tools in containing and taming the HIV/AIDS epidemic. The most vulnerable sections of South Africa have been mostly taken care of by the NGOs with their wide variety of localised programmes. The African Medical and Research Foundation (AMREF), one of the prominent institutions engage in HIV/AIDS is working to build national resources in South Africa, which will strengthen the local communities, support people living with HIV/AIDS and helps community groups and other NGOs. AMREF in alliance with Ford Foundation has played an important role in drafting a new strategy which aims to slow down the prevalence of HIV/AIDS in South Africa in the coming years.\textsuperscript{67}

NACOSA has strongly recommended and supported the South African NGOs for their support and care for the families and children affected by HIV/AIDS. NACOSA advocates that NGOs play a key role in mobilising community support, due to their localise work with community structures. The South African National AIDS Council (SANAC), which coordinates the various HIV/AIDS related activities in South Africa too has advise the South African government to give more weightage and priorities to NGOs and CBOs. In 2001 government of South Africa has set up the AIDS Communication Test (ACT) by launching \textit{Khomanani} campaign\textsuperscript{68} as well as a campaign called \textit{Love Life} to generate awareness about HIV/AIDS through Medias.\textsuperscript{69}

In 2003 South Africa launch a comprehensive operational plan to check the HIV/AIDS pandemic, under this plan the government has paid more attention on

\textsuperscript{65} United Nations Economic Commission for Africa (2005), n.63.
\textsuperscript{66} \textit{Ibid}.
\textsuperscript{68} It is a media campaign to educate people about the dangers of HIV. Khomanani means ‘Caring together’. This campaign is made in several South African languages.
prevention, care, support and treatment to the infected and affected masses as well as the South African government have ensured that those who are not affected by AIDS will remain, as it is. This comprehensive plan is basically in tune with South Africa’s famous plan known as the five year National Strategic Plan, which was launch in the year 2000 for the term period that extends from 2000 till 2005. South Africa’s HIV/AIDS policies in fact are largely guided by this strategic plan of 2000-2005. During this period South Africa’s expenditure on HIV/AIDS appreciably rose from a mare 30 million Rand in the year 1994 to over 3 billion Rand during the year 2005 and 2006. This plan therefore resulted into high levels of awareness, stabilisation of HIV prevalence rate, reduction of sexually transmittable infections, inclusion of Anti Retroviral (ARV) treatment, availability of Nevirapine drugs, behavioral changes among the youth as well as among the women.

Most importantly the comprehensive plan has brought about the creation of much needed infrastructure that supported and sustained the counselling, testing, care and treatment throughout South Africa. The 2003 comprehensive plan in fact strengthens South Africa’s national health system and catalyst to an overall active multi-sectoral participation involving all spheres of society such as: NGOs; CBOs; CSOs and FBOs.73

In order to successfully implement the comprehensive plan under the National Strategic Plan, a well known platform called Partnership Forum has been launch in South Africa, this partnership forum includes the government, non government, UN agencies,

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70 Rand is the name of South Africa’s currency, it is denoted by letter ‘R’ it is also noted as ZAR (South Africa Rand), 1$ converts to approximately R7.47 and 1R is equivalent to approximately 5.96 Indian Rupee.

71 It is an antiviral drug used in the treatment of AIDS; an adverse side effect includes liver damage and suppression of bone marrow.

72 Nevirapine is a Non-Nucleoside Reverse Transcriptase Inhibitor (NNRTI) drugs used for treating AIDS and HIV. It is especially prescribed for women to prevent mother to child transmission (MTC) of HIV/AIDS.


There are a number of NGOs, CBOs, CSOs and FBOs working in the various activities of HIV/AIDS in South Africa. These organisations play many essential and important roles in South Africa, such as relief work, welfare services, income generation, self help schemes, training and technical assistance, promotion of faith based human rights, advocacy, lobbying, networking, democracy education and community development. They work in close proximity as well as complementation with the government in dealing with the HIV/AIDS pandemonium in South Africa.\footnote{Ibid.}

4.2.2 Involvement of NGOs in South Africa

UNAIDS, WHO, AMREF, KAISER, BMW, Clinton Foundation, Gates Foundation et al are some of the prominent international agencies and NGOs present in South Africa. Some of the well known and significant local NGOs, CBOs, CSOs and FBOs involve in South Africa are highlighted as well as briefly discussed for the sake of this thesis, because the role played by the NGOs in South Africa exemplifies the paramountcy of how in the event of dangerous posed by the epidemic be dealt with.\footnote{The Centre for AIDS Development, Research and Evaluation (CADRE), (2002), [Online: web] Accessed 19 November 2007, URL: http://www.cadre.org.zalBAC/BAC_pdf/Prov_Audit.pdf.}

4.2.2.1 Basic Income Grant (BIG) Coalitions

Basic Income Grant (BIG) was founded in the year 2001 with a sole aim to develop a common platform for the introduction of universal income grant in South Africa. This network has extended a valuable help and support to the people who are marginalised and unemployed in South Africa. With the BIG coalition’s effort, a minimum of 100 Rand per month were made available to South Africa’s poorest households. The programme in essence therefore provides and guarantees a minimum level of income as well as an equitable economic development that importantly promotes
the welfare and stability of families and communities suffering from HIV/AIDS in South Africa.\textsuperscript{77}

4.2.2.2 Gender AIDS Forum (GAF)

It is a Durban-based organisation that engages itself for the rights and issues concerning women in South Africa. GAF encourages and supports the greater participation of woman in the governments HIV/AIDS policies and decision making, which magnifies their power, rights and access to information and resources. GAF is an instrumental in putting the women’s issues on top of the national agenda in South Africa.\textsuperscript{78}

4.2.2.3 Hospice Association of South Africa

Hospice is dedicated to the terminally ill patients. Basically their focus was on cancer and pain relief, however since HIV/AIDS has become a major health issue in South Africa, their emphasis shifted to HIV/AIDS patients, were they provide quality health care and give these patients an opportunity to live and die with dignity. This is achieved by means of providing home and community based care services, education, training and counselling of community caregivers.\textsuperscript{79}

4.2.2.4 Joint Civil Society Monitoring Forum (JCSMF)

This conglomeration of organisations was established in 2004. JCSMF includes the organisations that work in the similar areas such as in the field of HIV/AIDS and community development. Some of the well known organisations associated with JCSMF are: AIDS Law Project (ALP); Centre for Health Policy (CHP); Institute for Democracy in South Africa (IDASA); Medecins Sans Frontiers (MSF); Open Democracy Advice Centre (ODAC); Public Service Accountability Monitor (PSAM); Southern African HIV

\textsuperscript{77} \textit{Ibid.}


Clinicians Society (SAHCS); UCT School of Public Health and Family Medicine; Treatment Action Campaign (TAC).  

The JCSMF basically assist in monitoring the proper implementation of the 2003 operational plan as well as the various HIV/AIDS policies and programs. They ensure that the management, treatment and care mend for the people living with HIV/AIDS are meted dutifully and satisfactorily. JCSMF’s main objectives therefore are to provide the government and public an accurate up to date assessment of the programme’s implementation. It acts as an early warning system for the problems and extends valuable help in solving that problem. They have made a constructive rapport with the national and provincial health departments, and had already made a remarkable impact by monitoring the government’s policies, such as the rollout of Antiretroviral and Nevirapine drugs. JCSMF thus remain a critical conscience to the government of South Africa.  

4.2.2.5 Life Line  

Life Line is a telephonic counselling service, that provides 24 hour SOS counselling with confidentiality and anonymous services to the people seeking help related to HIV/AIDS. Life Line offers training, counselling, and outreach programmes which are easily accessible by communities and individuals as well as other organisations.  

4.2.2.6 Love Life  

Love Life is a consortium of Advocacy Initiatives, Health Systems Trust, Media Training Centre, Planned Parenthood and Reproductive Health Research Unit. Love life works in partnership with UNICEF, the Department of Health, the National Youth  

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80 The Centre for AIDS Development, Research and Evaluation (CADRE), (2002), n.76.  
81 Ibid.  
82 SOS is the commonly used description for the International Morse code for distress signal, such as ...-- -.... It was first adopted by the German government in radio regulations in 1905 and became the worldwide standard when it was included in the second International Radiotelegraphic Convention, which was signed in 1906. SOS does not stand for “Save Our Souls” or “Save Our Ship,” though it was the popular opinions for long time. The otherwise meaningless string of letters was selected because it was easily recognisable.  
83 The Centre for AIDS Development, Research and Evaluation (CADRE), (2002), n.76.
Commission and various other governmental and non-governmental agencies. It is basically engage in educating the youth and adolescent about the misdemeanor of HIV/AIDS in South Africa. Their main focus is to bring in the sexual behavioral changes among the youths and adolescent, primarily to reduce the extent of HIV/AIDS, STDs and teenage pregnancy.\textsuperscript{84}

\textbf{4.2.2.7 National Associations of People Living With HIV/AIDS (NAPWA)}

The primary aim of National Association of People living with HIV/AIDS is the co-ordination of resources and needs of all the people living with HIV/AIDS in South Africa. NAPWA initiates its aims by facilitating the resources of government, international and NGOs to the people living with HIV/AIDS and their families.\textsuperscript{85}

\textbf{4.2.2.8 Planned Parenthood Association of South Africa (PPASA)}

This organisation is a member of the International Planned Parenthood Federation (IPPF). Their network covers whole of South Africa. They focus mainly on education and training in sexual reproductive health as well as HIV/AIDS. They use booklets, pamphlets and posters to train teachers, parents, women, men and adolescent. PPASA offers services, such as education on STD and HIV/AIDS prevention, counselling, treatment and pregnancy test.\textsuperscript{86}

\textbf{4.2.2.9 Society for Family Health (SFH)}

SFH uses marketing and communication approaches as a strategy for HIV/AIDS prevention, treatment and care, SFH have dedicated its resources in providing quality health care service and products. One of its popular and distinguish products is known as \textit{Lover's Plus}, a brand of highly subsidised and good quality condom. This condom is easily available and affordable by the poor's, however they are also freely available in

\textsuperscript{84} Ibid.
\textsuperscript{85} AVERT, n.35
\textsuperscript{86} Ibid.
many areas under the government scheme. These initiatives of SFH proved to be an effective way of preventing both HIV/AIDS, STDs and unwanted pregnancies.\(^{87}\)

4.2.2.10 Soul City

One of the first organisation that has endeavour to campaign on HIV/AIDS in South Africa, it was launch in 1994 with the contribution of various individuals and agencies to educate and alert the masses about the dangers of HIV/AIDS. They used dramas, soap operas, print media, radio, television and adult education to promote HIV/AIDS message across the Republic of South Africa. During the period 1998-2000, the campaign *Beyond Awareness* was launch by using Medias to aware the youth of South Africa.\(^{88}\)

4.2.2.11 South African Catholic Bishops Conference (SACBC)

This faith based organisation (FBO) stands for social justice and fights for the rights and dignity of poor masses in South Africa, they advocates and raise voices on behave of marginalise masses for their rights to access the basic health care and treatment services on HIV/AIDS in South Africa. Such noble initiatives of SACBC and other organisations has made a huge impact, particularly because they have linked their care programmes to treatment initiatives and has been proactive in prioritising the developmental issues in South Africa.\(^{89}\)

4.2.2.12 The South African Red Cross Society

The Red Cross Society of South Africa is mostly engage itself with the victims of violence, education and training of home-based care volunteers, peer counselling, provides first aid and skill training, disaster relief preparedness, community based primary health care and income generation projects for young people. In the context of

\(^{87}\) AMREF (2003), n.67.
\(^{88}\) AVERT (2002), n.69.
\(^{89}\) AVERT (2002), n.69.
HIV/AIDS, the Red Cross Society of South Africa is seriously engaged in assisting HIV/AIDS infected people and their families.  

### 4.2.2.13 Treatment Action Campaign (TAC)

The Treatment Action Campaign was launched to happen simultaneously with the International Human Rights Day on 10th December 1998, under an august leadership of Mr. Zackie Achmat. The main objectives and goals are to ensure and make an urgent availability and affordability of treatment to the people living with HIV/AIDS in South Africa. Within no time, TAC shook the South African government to make the availability of Antiretroviral and Nevirapine drugs to the South African people. TAC therefore became a powerful force and a hope for many South Africans. Because of their forceful pressure, TAC has brought back the hope to South African people and demonstrated the will and ethos of democracy, making people realise that even in a democratic country, there needs an action filled critical engagement with the government to affirm one’s rights.

### 4.2.2.14 Wola Nani

Wola Nani was founded in 1994 with a prime aim of assisting individuals and communities for an easy access to HIV/AIDS care services, Wola Nani has created a viable job opportunities, were an individual or a community can help by themselves. They provide support services such as: Psychological and emotional counselling; Education and training of primary-health and child care; Welfare needs; Peer support; Home visits and health monitoring.

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90 Ibid.
91 Zackie Achmat, a Nobel Peace Prize nominee and an HIV positive himself is known for his campaign to put pressure on government to increase public access to ARVs so much so that he refuse to take ARVs until they were made available to all South Africans. Zackie Achmat said that “the cost of providing treatment and preventive education was ultimately less expensive than the economic impact of an unchecked AIDS epidemic”.
92 AVERT., n.35.
93 The Centre for AIDS Development, Research and Evaluation (CADRE)., n.42.
94 Ibid.
Some of the other well known NGOs, CSOs and CBOs which are supported by CFAs (Co-Financing Agencies), particularly the Dutch CFAs in South Africa are.95

4.2.2.15 The AIDS Foundation Centre (AFSA)

It is supported by ICCO (Interchurch Organisation for Development Cooperation), and was founded in 1988, AFSA was the first organisation to be registered as AIDS organisation in South Africa. This organisation arranges grants and technical support to CBOs. It works in partnership with the networks such as the BIG (Basic Income Grant) coalition and TAC.96

4.2.2.16 The AIDS Law Project (ALP)

This Johannesburg based NGO was launch in 1993 and it is being supported by HIVOS (Humanist Institute for Cooperation with Developing Countries). ALP provides legal services, particularly in the field of legal rights for people living with HIV/AIDS. ALP is one of the most respected and internationally recognised NGO in South Africa; it has set itself with a clear cut goals and objectives to fight HIV/AIDS. It uses a proper legal channels and litigation to promote equal rights and justice for people living with HIV/AIDS and their families. ALPs main focus is therefore on law and policy development for people living with HIV/AIDS. The ALP Director, Mark Heywood, has become a national figure in the South African media.

4.2.2.17 Black Sash

This Durban based organisation is supported by CORDAID (Catholic Organisation for Relief and Development), it was established some two decades back as a forceful militant group to transform the classical approach to social welfare. Today Black Sash is known for addressing vigorously and aggressively the questions and issues of HIV/AIDS in South Africa.

96 Ibid.
4.2.2.18 NISAA

The NISAA Institute for Women’s Development was established in 1994, it is supported by NOVIB (a Dutch Co-Financing Agency) also known as Oxfam NOVIB\(^7\). NISAA’s main focus is in the domain of gender-based violence and HIV/AIDS in South Africa, including all the possible dimensions such as counselling, shelter, outreach, training, and the building of public awareness.

4.2.2.19 St Joseph’s Care and Support Trust

The St Joseph’s Care and Support Trust, which was set up in 1999 is supported by CORDAID (Catholic Organisation for Relief and Development). It is located at Sizanani Village east of Johannesburg. Its main objectives are to mitigate the impact of HIV/AIDS in various towns of South Africa. Capacity building of staff, spiritual and psycho-social support, community and home based care, comprehensive approaches including VCT and ARVs are some of the HIV/AIDS related activities carried out by the St Joseph’s care and support trust.\(^8\)

4.2.2.20 The Sex Workers Education and Advocacy Taskforce (SWEAT)

This Cape Town based organisation is supported by NOVIB. SWEAT is a human right based organisation that fights for the sex workers rights, it is attached to Sisonke movement.\(^9\) Advocacy and lobbying on HIV/AIDS are the part of SWEAT’s outreach programmes which focuses on prevention and protection.

Besides the above local NGOs and CBOs, there are a number of other organisations operating in South Africa, they are either privately funded or are being run with the help of government support. There are many European and American agencies working in the field of HIV/AIDS in South Africa, almost all the known international and UN supported agencies are present in South Africa. Moreover, the local business communities, major corporate house and many other organisations are contributing

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\(^7\) NOVIB stands for “Nederlandse Organisatie Voor Internationale Bijstand”; it is a Dutch organisation for International aid.

\(^8\) The Centre for AIDS Development, Research and Evaluation (CADRE), n.42.

\(^9\) Sisonke movement is a nationwide movement launch by sex workers in South Africa, who have organised themselves to fight for their rights.
towards HIV/AIDS prevention and treatment. Academicians, Scientist, Literary figures, Artist, Film personalities, Sports personalities and Models are appreciably responding to South Africa’s HIV/AIDS crisis.100

4.2.3 NGOs Participation in the Policy Initiation and Implementation

The participation of NGOs and other non-state actors in all the developmental activities are still a challenge to the Governments, Donors and Development Partners. A clearly and well defined mechanism on who, how and when to engage should be put in place to function. The questions of cooperation and collaboration as well as the role and responsibilities of NGOs in all the developmental initiatives, such as the Regional Economic Communities (REC), New Partnership for Africa’s Development (NEPAD) and African Union (AU) are critical, if their programmes targeting the rural communities are to succeed.

The participation of NGOs or CSOs are significant in the developmental activities of a country, their importance were also discussed in the context of globalisation and liberalisation during the Cancun conference in Mexico in September 2003.101 Governments should also include the views and suggestions of NGOs before signing any international commitments to ensure that such protocols and agreements are to the benefit of the majority of the people. Since HIV/AIDS is one of the major issues in South Africa, the government must take civil society organisations into confidence and must extend its full support if HIV/AIDS is to be defeated in South Africa.102

Given that there is no cure for AIDS, the government of South Africa has focused its attention on prevention and treatment by promoting public awareness and delivering

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life skills on HIV/AIDS education. The many AIDS awareness campaigns run by the government and NGOs such as Love Life and Soul City are now bearing fruit in South Africa. There is now a high level of HIV/AIDS awareness (around 90 per cent) among youth in South Africa, but the pressing challenge is to ensure that this awareness translates into behaviour change. Educations on HIV/AIDS are made a compulsory school curriculum and are fully implemented by the end of the year 2003 in South Africa.103

Forging partnerships between all the sectors and communities are important in addressing the HIV/AIDS problem. The eight strategies of government of South Africa for strengthening the participation and cooperation of NGOs in the ‘Partnerships Against AIDS’ are: (1) understand and respect the uniqueness of the NGO and CBO sector; (2) redefine the concept of ‘expert’; (3) ensure that people living with AIDS are the key components to drive the response; (4) identify the lessons learned and build on past experience; (5) redefine the concept of NGOs and CBO sustainability; (6) clarify the roles and the responsibilities partners; (7) support ongoing capacity building; and (8) commit to good governance.104

A wide range of NGOs and CBOs have satisfactorily responded to the HIV/AIDS crisis in South Africa. They engage in wide varieties of HIV/AIDS activities such as, awareness raising, research and training, advocacy, education, welfare, health care, orphan care, prevention, counselling, treatment and other related activities. It is NGOs who have driven the campaign for access to treatment, lower drug prices, improved care and more effective policies on HIV/AIDS. NGOs’ relationships with the government of South Africa have come a long way, on one hand the National Association of People Living with HIV/AIDS has received government funding and applaud; on the other hand TAC has been time and again attacked by the government for its protests and litigation over the response to the epidemic.

Overwhelming funds have been channelled by the government and donors for the cause of HIV/AIDS in South Africa. But it has often been difficult for smaller organisations to access such funds, many a time donors have tended to push for particular responses, such as orphanages or high profile prevention campaigns, instead of responding to local needs or priorities. Services have tended to fragment, but in recent years NGOs have come together in coalitions to promote a more coherent response. Directories of AIDS service organisations have been developed and information on funding for HIV/AIDS work has been collated. Bodies such as the Joint Civil Society Monitoring Forum have brought together NGOs, business, government, donors and health professionals to work together in the fight against the epidemic. There have also been more efforts to identify the successful and good practices.105

The HIV/AIDS pandemic is growing rapidly in South Africa, resulting in NGOs and CBOs working across a wide range of issues on HIV/AIDS as well as attending to an ever increasing number of people in need of their assistance. NGOs have been very influential in developing strategies to curtail the spread of HIV/AIDS and extending necessary help to the people living with HIV/AIDS and their families. The NGOs and other civil society organisations have a tremendous positive impact on the lives of many South Africans. NGOs have made it clear and ensured that HIV/AIDS is an integral part of their programmatic focus, with the view that knowledge of HIV/AIDS is the first step towards prevention and cure.106

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4.2.4 Constraints and Challenges

The Non Governmental Organisations and Civil Society Organisations are facing many daunting challenges and obstacle in their endeavour to contain the HIV/AIDS problems in South Africa. Problems are of various kind and nature, NGOs and CBOs are often blamed for their ineffective programmes and policies on HIV/AIDS, many a times their responses are not effectively coordinated, which results into duplication and competition on an already limited and scarce resource. Some of these organisations that have made an attempt to mainstream the HIV/AIDS policies into their programmes are still by and large remain in confusion. They are not able to integrate the HIV policies due to their incapacity to recognise the key elements of HIV and AIDS mainstreaming.

HIV/AIDS has left a significant proportion of NGOs and civil society organisations sick, impoverished and ineffective, which directly undermines the programme impact. HIV/AIDS is also putting the rapport between the NGOs and donors under pressure and jeopardy, at a time when more participation and greater collaboration is essential. Many HIV personnels of these organisations are themselves affected and infected by AIDS. This causes the loss of staff time through illness, family care, funerals and rising costs for medical expenditure which leaves the NGOs and other civil society organisations struggling with increasing overheads and declining output.¹⁰⁷

Most of the time, NGOs and civil society organisations face the financial crunch and constraints. Many CFAs and donor agencies have closed down their South African kiosk, the case in point is the Norwegian Church Aid (NCA) that recently pulled down their South African shutter, these has resulted and force many local NGOs and CBOs to close down the HIV/AIDS programmes. A Durban based NGO called Centre for Public Participation (CPP) has closed down its network recently in 2005. Because of financial constraints, many NGOs and CBOs have now started relying on women volunteers to fight the HIV/AIDS menace in South Africa. However, it is been noted that, until and

unless the volunteers are properly supported, it is likely that poor women in South Africa will continue to remain as an un-empowered masses of society.  

The challenges for South African NGOs therefore are to look and search for viable alternative resources and begin tapping the resources which are locally available. The problems are further hardened because NGOs have to compete for municipal funding, which on the other hand clashes with the governments HIV/AIDS policies to incorporate the development of local communities. In order to solve and counteract such problem, many organisations working towards a similar goal has come under a single umbrella such as the Joint Civil Society Monitoring Forum (JCSMF), which was launched in the year 2004. Though the challenges and obstacles had hampered the NGOs responses to HIV/AIDS in South Africa, yet the work and policies initiated by the NGOs, CBOs, and other organisations in collaborations with the government and the international bodies are appreciable and worth noting. The financial constraints, funding problems and staff sickening are some of the hindering elements which need to be addressed properly and measured accountably.

Keeping in mind the results oriented donor environment in South Africa. There seems to be a desperate need to build an organisational resilience to the disease. This can be achieved by developing certain combinations of interventions, such as staff awareness programmes, creation of appropriate HIV/AIDS organisational policies. However, NGOs need to do much more, given the dynamics of HIV/AIDS problems. They need to analyse the implications of long term human resource and ensure that the costs born for responding to the organisational impact are in line with their financial budgeting, planning, monitoring and evaluation processes. But it has been noticed that such responses are negligible, because many a times though NGOs and CBOs who have HIV/AIDS policies in hand often lacks the resources to implement them. Moreover HIV/AIDS is putting a lot of pressure on the NGOs and CBOs to address vividly the organisational culture, organisational boundaries and gender roles as well as how

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108 HIVOS., n.48.
decisions are made. Such issues have a profound influence as to whether an organisation becomes resilient to HIV/AIDS.\textsuperscript{109}

The policy on HIV/AIDS is widely cited as one of the few examples of an effective national AIDS prevention program anywhere in the world. The Thai experience shows that a concerted cooperation between the government, NGOs and other organisations in the fight against HIV/AIDS can be effective in preventing and reducing the scope of the epidemic.\textsuperscript{110}

\textsuperscript{109} INTRAC., n. 56.