



Civil society influence on local HIV policy making in Karnataka, India

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CIVIL SOCIETY INFLUENCE ON LOCAL HIV POLICY MAKING IN KARNATAKA, INDIA

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A thesis in fulfilment of the requirements for the degree of
Doctor of Philosophy



School of Public Health and Community Medicine

Faculty of Medicine

The University of New South Wales

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ORIGINALITY STATEMENT

‘I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.’

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ABSTRACT

Civil society has played a significant role in improving the health of poor and marginalized communities. Civil society organizations (CSOs) have been at the forefront of HIV prevention, treatment, care and support, and the promotion of rights of people living with HIV/AIDS (PLHA). In India, where approximately 2.1 million people live with HIV/AIDS, civil society has played a critical role in the response to the epidemic.

Conducted in the south Indian city of Bangalore between 2009 and 2010, this qualitative study aimed to explore the influence of civil society on local HIV policy making in Karnataka, India, with a particular focus on the role that PLHA play in civil society and in local HIV policy processes. The research sought to explore the relationships between civil society and the government and to understand the dynamics of HIV policy development in a multi-stakeholder environment. The study was structured in two phases, both drawing on data collected through participant observation, in-depth interviews, document reviews and fieldnotes.

Results indicated that civil society engaged in HIV/AIDS in Bangalore comprised diverse actors enmeshed in complex relationships influenced by identity politics, power relations, and trust and accountability issues. The relationships between civil society and the government were often characterized by hostility and fraught with frustration and sometimes fear. Despite such relationships, many CSOs were inextricably linked to the government due to funding partnerships. Findings revealed that notwithstanding the presence of significant barriers, PLHA attempted to maximize their opportunities for participation in civil society.

Local HIV policy making in Bangalore occurred behind closed doors, was dominated by the government and failed to adequately acknowledge the diversity of local community experiences, in particular that of PLHA. Policy participation was limited to a few governmentalized CSOs whose boundaries with the government were blurred. Failure to acknowledge local civil society's experiences has contributed to dissatisfaction with HIV policies and hostile relationships between civil society and

the government. Transparent, inclusive and participatory policy processes which consider local contexts can lead to improved local HIV policies that cater to community needs and better uptake of these policies by civil society and vulnerable community members.

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LIST OF ACRONYMS

AAP	Annual Action Plan of the KSAPS
ACT UP	AIDS Coalition to Unleash Power
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BHAF	Bangalore HIV/AIDS Forum
BMGF	Bill & Melinda Gates Foundation
CIDA	Canadian International Development Agency
CBO	Community Based Organization
CSO	Civil Society Organization
DAPCU	District AIDS Prevention & Control Unit
EC	Executive Committee of the KSAPS
FSW	Female Sex Workers
GB	Governing Body of the KSAPS
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People living with HIV/AIDS
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
KHPT	Karnataka Health Promotion Trust
KSAPS	Karnataka State AIDS Prevention Society
MSM	Men who have Sex with Men
MSW	Male Sex Workers
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NGO	Non-Governmental Organization
NHMRC	National Health and Medical Research Council

NSP	Needle & Syringe Program
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission of HIV
PWID	People Who Inject Drugs
STI	Sexually Transmissible Infection
TAC	Treatment Action Campaign
TRIPS	Trade Related Intellectual Property Rights
TSU	Technical Support Unit of the KSAPS
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNSW	The University of New South Wales
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
WTO	World Trade Organization

CHAPTER 1: THESIS OVERVIEW

1.1 Introduction

This chapter provides a brief overview of the research topic and background to the study presented in this thesis. The research aims and objectives are then clarified. In addition, the structure of the thesis and the significance of the current study are discussed.

1.2 Subject of the Research

This thesis explores the influence of civil society on local HIV policy making in India, drawing on the state of Karnataka as a case study. In particular, the study focuses on the participation of people living with HIV/AIDS (PLHA) in civil society and in local HIV policy processes. Although there are various definitions, civil society is commonly viewed as consisting of organizations and groups that are private, non-state and not-for-profit. These groups may be self-governing and voluntary in nature (Salamon, Sokolowski & List 2003). Civil society organizations (CSOs) have become increasingly influential in global, national and local policy and program processes. Since the early 1990s, there has developed an emergent sphere of social and political participation in which groups, social movements and individuals engage in dialogue and debate with local, national and international government bodies (Anheier, Glasius & Kaldor 2001). These groups have been recognized as providers of relief and promoters of human rights and are increasingly being viewed as important contributors to the economic, civic and social infrastructure that are essential for a minimum quality of life for people (Salamon & Anheier 1997; Fukuyama 1999), particularly those belonging to poor and marginalized communities.

Many experts have noted a recent shift in health governance to give a greater profile to non-state players in public health (Kickbush 2000; Lee & Dodgson 2000). Non-governmental and community based organizations (CBOs) have been at the forefront of HIV prevention, treatment, care and support and the promotion of rights of PLHA. Globally, civil society groups have filled gaps in national policy and programmatic

responses to the epidemic which were often developed by governments that were dismissive of the epidemic in its early stages (Rau 2006). In relation to HIV/AIDS, civil society groups, including affected communities were involved early in influencing politicians and bringing community needs to their attention. The involvement of the gay community in the United States in articulating their concerns and mobilizing affected communities and the development of groups such as the AIDS Coalition to Unleash Power (ACT UP) during the 1980s are early examples of community involvement in HIV/AIDS. The need for participation of PLHA in the response to HIV/AIDS was first formally articulated in the 1983 Denver Principles, which delineated the rights and roles of PLHA in responding to the epidemic (NAPWA 2009). These were later promoted as the Greater Involvement of People living with HIV/AIDS (GIPA) principle (United Nations 1994). Since then, there has been global recognition of the need for participation of PLHA in civil society and in planning, implementing and evaluating HIV-related activities (United Nations 1994; UNAIDS 1999, 2007).

The first case of HIV was identified in India in 1986 (Simoes et al 1987; Solomon & Ganesh 2002). India's HIV epidemic is said to have the 'denominator problem': HIV prevalence is low, but with the country's high population, this translates into a large number of PLHA (Doshi & Gandhi 2008). Current estimates suggest that adult HIV prevalence in India is approximately 0.27%, with nearly 2.1 million people living with the infection (NACO 2013). According to India's National AIDS Control Organization (NACO), the primary routes of HIV transmission in the country are unprotected commercial sex, unprotected sex between men and injecting drug use (NACO 2013). HIV prevalence among 'high risk' groups, namely female sex workers (FSW), people who inject drugs (PWID) and men who have sex with men (MSM) is higher compared to prevalence in the general population; consequently India's HIV epidemic is categorized as a concentrated epidemic (NACO 2013). HIV prevalences in these high-risk communities in India are 5% among FSW, 9% among PWID and 7% among MSM (UNAIDS 2012). Six high-prevalence states account for over two thirds of the HIV burden in India (NACO 2010b, p.3). Karnataka, the study site, is one of these high prevalence states, with an estimated adult HIV prevalence of 0.63% (NACO

2012b, p.24). Estimated HIV prevalence among vulnerable communities in Karnataka is 9.6% among FSW, 3.6% among PWID and 17.6% among MSM (NACO 2009).

To control and mitigate the HIV/AIDS epidemic in India, the Government of India constituted the NACO in 1992 (NACO 2006, p. 1). The NACO is responsible for the development of the National AIDS Control Program (NACP), which governs the national and state-level HIV/AIDS prevention, treatment, and care and support activities. Subsequently, state-level subsidiaries of the NACO were developed in each Indian state. The government body responsible for HIV/AIDS in Karnataka is the Karnataka State AIDS Prevention Society (KSAPS), which was initiated in 1997 (KSAPS 2012). The state AIDS prevention societies are autonomous, decentralized entities that implement the NACP. They are governed by a Governing Body and an Executive Committee (EC) with representatives from government departments, civil society and the private health sector, and headed by the Chief Minister and Principal Secretary for the Ministry of Health and Family Welfare respectively. In Karnataka, the EC is the entity responsible for the development of local HIV policies.

In addition to the NACO and its state subsidiaries, local, national and international CSOs are engaged in HIV prevention, treatment, and care and support in Karnataka and elsewhere in India. This research focuses on the influence of civil society, and in particular PLHA, on local or state-level HIV policies in Karnataka (the terms local and state-level are used interchangeably in this thesis). The thesis illustrates the ways in which CSOs, PLHA and vulnerable communities and the government interact to shape local HIV policies in the state of Karnataka. In addition, the thesis highlights the nature of relationships and interactions within civil society and between civil society and the government.

1.3 Research Aims and Objectives

The overall aim of the study was to explore the influence of civil society engagement in local HIV policy making in India, with a particular focus on the role that PLHA play in civil society and in local HIV policy making. The qualitative study was conducted in two phases over a 15-month period, and the results of Phase I were used to inform Phase II.

Phase I was exploratory, the specific objectives of which were to:

1. Understand the nature and constituents of civil society engaged in HIV/AIDS in Bangalore
2. Capture the realities and voices of PLHA and members of vulnerable communities in relation to their experiences of participation in civil society
3. Identify local HIV policy making agencies and mechanisms and the context in which they work.

Phase I was also conducted to ensure that the next phase of the study was rooted in the community's realities and developed using their narratives. The specific objectives of Phase II were to:

1. Explore the relationships between civil society and the Karnataka State AIDS Preventions Society (KSAPS) and the ways in which the two entities interact and participate to shape local HIV policies
2. Understand the ways in which HIV policies are constructed in a multi-stakeholder environment, consisting of the KSAPS, diverse CSOs, PLHA and members of vulnerable communities.

To achieve these objectives, this research explored the following research questions:

1. How do approaches, dynamics and collaborations within civil society influence the development of local HIV policies?
2. How do civil society and the Karnataka State AIDS Prevention Society interact and negotiate to develop local HIV policies?

1.4 Structure of the Thesis

This thesis is presented as eight chapters. The chapters introduce the study topic, illustrate the study design, present the results and discuss their implications.

Chapter 1 contains a brief introduction of the current research, its aims and objectives, and a discussion of the structure and significance of the study.

Chapter 2 presents a review of the literature on global civil society, and civil society engagement in health, policy making and HIV/AIDS. The genesis of civil society is first explored; definitions of civil society and its constituents are then discussed. The chapter presents examples of civil society's engagement in health, policy making and HIV/AIDS, to illustrate the nature of its influence in these areas. In addition, the chapter highlights the participation of PLHA in civil society through a discussion of the GIPA principle.

Chapter 3 is concerned with the HIV epidemic in India and in the research setting, Bangalore in the southern state of Karnataka. The government's response to the HIV epidemic since the detection of the first case of HIV is briefly described. The work of the KSAPS is introduced, highlighting the role of the EC, the main local HIV policy making body in the state.

Chapter 4 gives an outline of the research methodology. The criteria for site selection are discussed, followed by a description of the sampling and recruitment process and the data collection methods that were utilized, namely participant observation, in-depth interviews and document review. The chapter also identifies the ethical issues that arose during the study. Strengths and limitations of the study are discussed.

Chapter 5 presents the results of Phase I of the study. The chapter identifies the range of CSOs and vulnerable communities that constitute civil society engaged in HIV/AIDS issues in Bangalore. Participant narratives are presented to illustrate the dynamics within civil society, the relationships between CSOs and the KSAPS and the perceptions of CSO members regarding the NACO's policies and programs. The nature and types of participation of PLHA in civil society are also identified. The chapter ends with a discussion of the ways in which these results were utilized to inform the second phase of the study.

Chapter 6 contains an exploration of the everyday realities of communities vulnerable to or living with HIV/AIDS in Karnataka. Factors that cause vulnerability to the HIV infection are first described. The heterogeneity of civil society in Bangalore, as

revealed by study findings, is highlighted. In addition, the ways in which civil society members interacted and collaborated are explored. Themes surrounding issues of power, trust, accountability and leadership are brought to the fore.

Chapter 7 presents study findings related to local HIV policy making in Karnataka. Through an exploration of the KSAPS EC and its role and operations, this chapter reveals the local HIV policy making context, policy actors, process and content.

Chapter 8 summarizes the main findings of the study. It then integrates and draws on all the preceding components of the study in a discussion of the implications of the study findings. Directions for future research are offered.

1.5 Significance of the Study

Despite a significant expansion of research, the not-for-profit sector remains the ‘lost continent’ on the social landscape of modern society (Salamon, Sokowloski & Anheier 2000). Ghaus-Pasha (2004) argued that there is a paucity of quantitative and qualitative information on civil society, particularly in the context of developing countries. Civil society has been instrumental in the fight against HIV/AIDS in India. However, aside from annual reports and media stories of civil society influence, their impact on HIV policies and services has neither been adequately documented nor analyzed – a significant gap in knowledge. The policy role of civil society gained more importance in India as the NACO and its state-level subsidiaries sought to promote greater collaboration with CSOs in an attempt to ensure greater participation of communities and CSOs in HIV policy making and programming. Studies in other countries, such as Thailand, Brazil and South Africa, have illustrated the positive influence of civil society in shaping HIV policies and programs (Biehl 2007; Oliveira-Cruz, Kowalski & McPake 2004; Tantivess & Walt 2008). With CSOs gaining more attention in policy discourse and developing innovative ways of influencing change, similar studies in India are of value in understanding whether civil society participation has had a lasting and positive influence on HIV policies, services and on health outcomes of PLHA and if so, which methods of engagement and participation have proved most effective. Such research, particularly in developing countries with bureaucratic governments and local CBOs, would be a valuable tool in guiding the

work of civil society groups. This study aimed to address these gaps in literature and understand the ways in which civil society influences local HIV policies, with attention being paid to the participation of PLHA in civil society and in local HIV policy processes.

The HIV epidemic in India is heterogeneous in terms of routes of transmission and geographical spread. The nature of the epidemic, including HIV prevalence and routes of exposure, varies across and within states and districts. Given this scenario, developing local responses and policies to HIV is crucial, yet little research has been conducted on the topic to date. This study attempted to shed light on the ways in which local, state-level HIV policies are developed, the key actors involved in this process and the contextual factors that influence local HIV policy making. The relationships between policy actors, process and context are crucial in policy development (Kingdon 1995; Lewis 2005; Walt 1994; Walt & Gilson 1994). In addition, the study sought to understand the nature of the relationship between civil society and the government, in particular the KSAPS. Understanding the nature and dynamics of this relationship is critical to negotiating the boundaries between these entities and optimizing scope for collaboration.

The current study also aimed to understand the nature of civil society in Karnataka, including the types of CSOs involved and the nature of relationships between them. This researcher attempted to go beyond the term 'civil society' and identify the actors involved, the ways in which these different actors interact and the resultant influence on HIV interventions and policies in Karnataka. In doing so, the study was intended to unpack the complex relationships and power differentials that exist within civil society engaged in HIV-related activities. The researcher also strove to give voice to the multiple actors involved in civil society, to illustrate their lived experiences in relation to their participation in civil society. The research expands upon earlier research on PLHA participation in civil society and contributes to the literature on meaningful participation of PLHA.

CHAPTER 2: CIVIL SOCIETY ENGAGEMENT IN HEALTH & HIV/AIDS

2.1 Introduction

This chapter begins with a description of the genesis of global civil society followed by a discussion on the various definitions of civil society and its diverse constituents. The definition of civil society adopted for the current study is introduced and elaborated upon. The chapter then explores civil society engagement in public health and specifically, global health policy making. Further, the participation of PLHA in civil society is discussed using the GIPA principle.

2.2 Global Civil Society

This section provides an overview of global civil society through a discussion of the genesis of civil society and its common definitions. This section also identifies the multiple constituents of civil society.

2.2.1 Genesis of Civil Society

The concept of civil society dates back many centuries in Western philosophy, with its roots in ancient Greece (Ehrenberg 1999; Ghaus-Pasha 2004). It originally revolved around the understanding that men and women lived in distinct spheres bound by a range of human relations. Initial concepts of civil society emphasized that political power and affiliation made civil society possible (Ehrenberg 1999), with active citizens shaping societal institutions and policies. Early concepts of civil society did not recognize it as distinct from the state. Civil society was a type of state characterized by a social contract agreed among individual members of society wherein all members of society were governed by laws, based on principles of equality (Kaldor 2003). The modern idea of civil society is said to have emerged in the late 17th and 18th centuries through the influence of political theorists such as Adam Ferguson (Anheier, Glasius & Kaldor 2001), John Locke (Khilnani 2001) and George Hegel (Seligman 1992), who developed the concept as a domain separate from but parallel to the state. During this era, civil society was a means to promote the idea of human equality and a rights-based society. The Scottish enlightenment thinkers

emphasized the significance of capitalism as the source for a rights- based society and individualism. Adam Ferguson in his book, *An Essay on the History of Civil Society*, noted that civil society required men to take an active interest in the government (Anheier, Glasius & Kaldor 2001). Ferguson's work was furthered by Hegel who proposed the concept of civil society as being a purely public activity separate from, yet symbiotic with, the state (Hegel 1991; Seligman 1992; Anheier, Glasius & Kaldor 2001). Hegel proposed that civil society and the state were separate yet interdependent, with the state playing the role of a mediator. While previous thinkers promoted civil society as positive, others such as Karl Marx held a negative view of civil society (Anheier, Glasius & Kaldor 2001). Marx equated civil society with bourgeois society, one in which everyone pursued their own selfish interests and became alienated from others (Marx 1975). Another important 19th century thinker, de Tocqueville, in his study of democracy in the United States, promoted the idea that the voluntary sector was necessary to provide a check on state power, particularly as the state took over more functions of daily life and the country's resources (Anheier, Glasius & Kaldor 2001). As a consequence, civil society developed as a powerful set of associations and institutions with an intricate relationship with the state.

The idea of civil society was neglected in the mid-19th century as political philosophers focused on the social and political consequences of the industrial revolution (Carothers 1999). However, after World War II, the concept became popular again through the writings of Antonio Gramsci, who described civil society as a crucial sphere of struggle and independent political activity (Carothers 1999). Gramsci was the first to promote the concept of civil society existing between the state and the market (Anheier, Glasius & Kaldor 2001), as a non-state, non-economic social interaction tool for revolutionary struggle. This idea grew popular in the 1960s among people disenchanted with Marxist ideas about civil society (Khilnani 2001) and the authoritarian state in Latin America and central Europe (Anheier, Glasius & Kaldor 2001). For these groups, civil society became the 'power of the powerless' (Cohen & Arato 1994; Havel 1985) and a potential means of overthrowing authoritarian regimes and furthering the people's interests. The Gramscian idea of civil society as a tool to question state powers gained international momentum in the 1960s, with groups increasingly valuing the need for international solidarity and voicing people's concerns

in global forums. The concept was resurrected in the 1970s by the Polish Worker's Movement (Seligman 1992), the Latin American left-wing intellectuals in the 1970s and 1980s (Anheier, Glasius & Kaldor 2001), and in the 1990s due to a renewed interest in civil society as democracy was promoted, opening a space for participation of CSOs. In addition, increased attention focused on the gaps in social services created by structural adjustment and reforms, particularly in developing countries (Ghaus-Pasha 2004).

Anheier, Glasius and Kaldor (2001, p.14) argued that between the years 1980 and 2000, the idea of civil society “spread like wildfire”, being taken up by social movements and non-governmental organizations (NGOs) (Kaldor 2003). There has since been a rapid increase in the number of individuals involved in the international non-government sector, forming a global civil society which encompasses diverse groups acting across borders, beyond the reach of governments (Keane 2001), with citizens of one country actively supporting citizens in another (WHO 2014). Global civil society transcends national boundaries and addresses international and at times, local issues. This, Chandhoke (2002) argued, has been aided by the information revolution increasing capacity to collect, collate and publicize information on development issues. Chandhoke also stated that civil society was increasingly globally recognized as a moral authority capable of ethical and legitimate political intervention. Structural changes during the 1990s, particularly globalization, have also been attributed to the increase in influence and visibility of CSOs. Anheier, Glasius and Kaldor (2001) stated that civil society ‘feeds’ on and also reacts to globalization. These authors explained that globalization provides a foundation for the growth of civil society and that there appears to be a strong positive correlation between areas of ‘thick globalization’ and clusters of civil society. Their research found that global civil society was heavily concentrated in north-western Europe, particularly Scandinavia, Austria, Switzerland and the United Kingdom, and that 60% of secretariats of international CSOs were based in the European Union. This same area is the most densely globalized in terms of concentration of global capitalism as measured by the presence of transnational corporations (Anheier, Glasius & Kaldor 2001). At the same time, civil society has also developed as a response to globalization, which has deepened exclusion and led to uneven distribution of resources (Anheier, Glasius &

Kaldor 2001). Many groups that have been excluded or denied access to the benefits of globalization have organized in social movements as a consequence (Anheier, Glasius & Kaldor 2001; Kaldor 2003).

2.2.2 Definition of Civil Society

The term ‘civil society’ is used widely in contemporary academic, political, economic and social discourse. The meaning of the term, however, is fluid and reflects the differing interpretations of various disciplines and discourses.

Hodgson (2004) stated that models of civil society are adopted depending on one’s academic and political leanings and paradigms. Seligman (1992) argued that the idea of civil society is defined by one set of principles and practices by liberal thinkers and another by their conservative critics. Different thinkers emphasize different aspects of civil society and draw on historical sources to determine the contemporary usage of the term. Key definitions of civil society are presented in Table 1.

Table 1: Common Definitions of Civil Society

<p>... a sphere of social interaction between the household and the state which is composed of structures of voluntary associations and networks of public communication following the values of trust, reciprocity, tolerance and inclusion (Veneklasen 1994)</p>
<p>... constitutes a mix of voluntary associations with the market and form an environment for providing welfare (Green 1993, 2000; Schechter 2000)</p>
<p>... a sphere of social interaction between the economy and the state, composed above all of the intimate sphere, especially the family (Cohen & Arato 1994; Jareg & Kaseje 1998)</p>
<p>...a sphere in which people can freely organize into groups and associations and engage in uncoerced human association or voluntary activity (Deakin 2001; Walzer 1995)</p>
<p>...an ‘uncoerced free association’ of law-abiding individuals and institutions in open societies and economies (Raymond et al 2004; Walzer 1995)</p>
<p>... a set of autonomous associations that develops a diverse and pluralistic network which amplifies the collective voices of members of civil society as a partner in governance and the market (Connor 1999)</p>
<p>...a set of institutions that performs functions of inculcating morals and values that facilitate social cohesion or enable people to act as good citizens who are aware of their civic duties (Etzioni 1995, 1996)</p>

A common feature of most definitions of civil society is that it is a sphere *distinct from the market and the state, yet it forms associations with both these entities* (Cohen & Arato 1994; Green 1993, 2000; Jareg & Kaseje 1998; Schechter 2000; Veneklasen 1994). In addition, most definitions of civil society are unanimous in insisting that it is *composed of people who have common interests entering into voluntary associations* (Connor 1999; Deakin 2001; Green 1993, 2000; Raymond et al 2004; Schechter 2000; Veneklasen 1994; Walzer 1995). A key similarity among all the definitions of civil society is that it is *constituted by individuals associating freely and building networks and other forms of social communication*.

Cohen and Arato (1994) and Jareg and Kaseje (1998) defined civil society as a sphere of social interaction between the economy and the state, composed of the intimate sphere, especially family, as well as voluntary associations and social movements. The concept of freedom within civil society was discussed by Deakin (2001) and Walzer (1995), who defined civil society as the sphere in which people can freely organize into groups and associations and engage in ‘uncoerced human association’ or ‘voluntary’ activity. According to this definition, the defining feature of association within civil society is that it is voluntary and without pressure or interference from others. This idea was supported by Almond and Verba (1965), Hirst (1994), Keane (1998), Putnam (2001) and Putnam, Leonardi and Nanetti (1993), who argued to varying degrees that voluntary association within civil society is the source of the civic virtue that is necessary for a healthy democratic society. Walzer (1995) and Raymond et al (2004) also referred to civil society as the ‘uncoerced free association’ of law-abiding individuals and institutions in open societies and economies irrespective of its economic rationale or role. Similarly, Connor (1999) discussed civil society as a set of autonomous associations resulting in a diverse and pluralistic network. He argued that civil society consists of a range of local groups with specialized organizations and linkages between them to amplify the collective voices of people as a partner in governance and the market.

Civil society is also discussed in the literature in terms of its ability to instil values and morals in people. Etzioni (1995, 1996) defined civil society in normative terms as

institutions that perform functions of inculcating morals and values that facilitate social cohesion or enable people to act as ‘good’ citizens who are aware of their civic duties. Popple and Redmond (2000) portrayed civil society as a moral community in which citizens are responsible, access their rights and engage with their duties. This concept of civil society therefore involves instilling ethical and moral ideas and balancing the conflicting demands of individual interest and the public good.

As indicated in Table 1, while there are several commonalities between different definitions of civil society, the role of the state and market in civil society is contested. Veneklasen (1994) argued that civil society is the interaction between the family and the state, yet the role of the state in building and maintaining this interaction is not delineated. This definition largely overlooks the role of the market in civil society, which other definitions discuss at length. Contrary to the definition proposed by Veneklasen (1994), Green (1993, 2000) and Schecter (2000), following the ideology of Adam Smith (1776), argue that the economy is central to civil society. They asserted that civil society institutions constitute a mix of voluntary associations with the market and form the appropriate environment for providing welfare to citizens. These authors emphasized that civil society is a sphere in which the state’s participation is minimal. While the definitions presented by Veneklasen (1994), Green (1993, 2000) and Schecter (2000) emphasize the relationship between civil society and either the state or the market, Hodgson (2004) argued that a unique feature of civil society discourse is the emphasis placed on engendering a partnership between the state and the civil society. Similarly, Giddens (1998) contended that the partnership between civil society and the state will enable each to facilitate and act as a means of keeping a check on the other. Kendall (2000) suggested that voluntary activity, which is pivotal to civil society, is at the heart of the partnership between the state and civil society. Connor (1999) also highlighted the notion of a partnership between civil society, the state and the market. One of the core features of civil society therefore, is the partnership between its members and other stakeholders, mainly with the state but also the market.

While some authors have emphasized the relationship between the state and civil society, others such as Makumbe (1998) defined civil society as a set of institutions

whose members are engaged in non-state activities. In addition, Ikelegbe (1999) discussed civil society as being distinct in its independence from the state, and its goals and activities being underlined by popular struggles. Civil society has also been defined as a force to counter state hegemony, a pressure on the state and a social base to set limits and controls on state institutions (Bratton 1992; Keane 1988; Makumbe 1998). The relationship between civil society and the state, whether viewed as a partnership or antagonistic in nature, has been widely debated. This interplay also forms a critical aspect for consideration while studying civil society and its roles.

Similar to the genesis of national-level civil society, global civil society also grew from a disenchantment with states and as a means to promote and protect human rights and demand action on national and international concerns and override . Transnational civil society groups came together to address diverse issues such as landmines, HIV/AIDS, climate change and human rights (Kaldor 2003). The concept of civil society suggests the existence of a social sphere, a global civil society that is beyond national, regional or local societies (Anheier, Glasius & Kaldor 2001). A number of the definitions of civil society discussed above also describe global civil society. For example, global civil society groups tend to be *distinct from the market and the state, yet it forms associations with both these entities* (Cohen & Arato 1994; Green 1993, 2000; Jareg & Kaseje 1998; Schechter 2000; Veneklasen 1994). In addition, global civil society is mostly *composed of people who have common interests entering into voluntary associations* (Connor 1999; Deakin 2001; Green 1993, 2000; Raymond et al 2004; Schechter 2000; Veneklasen 1994; Walzer 1995).

Connor (1999) raised the point that while civil society comprises autonomous associations, in contemporary situations, civil society is not always entirely independent of other forces such as funding agendas and political situations. Further, Hodgson (2004) proposed the notion of ‘manufactured’ civil society. Manufactured civil society refers to groups that are developed and funded, at least initially, through government initiatives or funding bodies (Hodgson 2004). The term is used to describe such initiatives because they have not developed organically but have been constituted by specific agendas of the state or funding agencies. These groups are accountable to and must meet targets set by the state and donor agencies. While it has

been recognized that civil society operates optimally when groups develop organically (Anheier & Themudo 2004), there has been a significant increase in the number of manufactured civil society groups. Deakin (2001) discusses concerns about state involvement in building civil society, highlighting concerns that while voluntary groups have always had to abide by state regulations, the funding partnership approach may change the nature and character of these groups, potentially even corrupting them. This raises questions about whether ‘manufactured’ groups should be considered as ‘true’ members of civil society and the resultant impact of the role played by the state in civil society formation.

While the definitions of civil society are varied, there is a general consensus that civil society is non-official and non-governmental. CSOs are traditionally not part of the state system and do not seek control of government offices. For the purposes of this study, HIV-related civil society is defined as *entities that are voluntary, non-state and not-for-profit and engaged in HIV/AIDS programs*. The thesis focuses on civil society and in particular, how it manifests and relates to HIV/AIDS. This includes CSOs, grassroots and community-based groups working on HIV/AIDS, and networks of PLHA and vulnerable communities such as FSW, MSM, PWID and transgender people. However, in stating that civil society is defined as non-state and non-market for the purpose of the current study, it is important to acknowledge that many CSOs in Karnataka receive government and corporate funding and therefore may not be completely devoid of state or private influences. The following chapters explore the interplay between civil society and the state in Karnataka and the ways in which this interplay may influence local HIV policies.

2.2.3 Constituents of Civil Society

The term ‘civil society’ is the collective noun, while civic groups, associations and organizations are the individual elements within civil society. Civil society, known variously as the ‘non-profit’, ‘non-governmental’, ‘voluntary’, ‘independent’, or ‘third’ sector includes a wide array of institutions and groups, ranging from large registered formal bodies to informal local networks. Much literature on civil society uses the term NGOs synonymously with civil society and many argue that these organizations are at the heart of civil society. This, however, is a common misconception. Carothers

(1999) argued that at the core of the current enthusiasm regarding civil society is a fascination with NGOs, which have been multiplying in recent years. NGOs form only one constituent of civil society though they may play a vital role in initiating people's participation and empowerment and influencing policy making and program development. In addition to NGOs, civil society comprises groups such as the media, professional associations, faith-based organizations and corporate social responsibility divisions of large companies.

The Johns Hopkins Comparative Nonprofit Sector Project, which studied the not-for-profit sector in more than forty countries, developed the International Classification of not-for-profit organizations to determine the exact constituents of civil society (Salamon, Sokolowski & List 2003). The project identified twelve categories of CSO activity which included 'service' functions such as education and research, community development, health care and social services, and 'expressive' functions such as civics and advocacy, arts and culture, and other categories including environmental protection, business, labour and professional representation. This classification has made it possible to draw distinctions between different types of CSOs.

As illustrated by the various definitions in Table 1, civil society comprises associations that exist outside the state and the market. CSOs can include 'traditional' unitary groups such as the Catholic Church and other religious groups, modern organizations such as hospitals, human rights organizations, mass movements, advocacy and action groups, political parties, trade unions, professional associations and community based groups. Smaller community-based organizations are perhaps more numerous, yet less visible to outsiders. Civil society also incorporates associations that exist for other purposes. Many of these, such as student groups, are advancing social or political agendas; others, such as cultural organizations and informal community groups, facilitate community expression of artistic, cultural, ethnic, spiritual and social sentiments (Anheier, Glasius & Kaldor 2001; Carothers 1999; Kaldor 2003; Salamon, Sokolowski & List 2003).

The diversity of membership of CSOs also reflects diversity in the objectives of civil society. Civil society includes conformists, reformists and radicals (Antonio 2007;

Scholte 1999). Conformists attempt to uphold and reinforce existing norms; professional associations and research foundations often fall into this category. On the contrary, reformists are those civil society entities that attempt to change existing systems, particularly government initiatives and policies. Human rights groups, relief organizations, academic institutions and consumer groups often promote reformist agendas. Some factions of civil society may also be classified as radicals, including associations that aim to transform the social order. These associations are frequently called social movements and may include environmentalists, feminists and other groups that oppose the state, industrialization, patriarchy or militarism (Antonio 2007; Scholte 1999).

This section briefly traced the evolution of global civil society. In addition, the various definitions of civil society, their commonalities and points of dissimilarity and the diverse constituents of civil society were discussed. The next section focuses on civil society's engagement in health, and in particular, its influence on health policy making.

2.3 Civil Society Engagement in Health

Collaboration and partnerships between groups from different sectors have been central to public health practice since the mid-19th century (Beaglehole et al 2004). The importance of civil society was first highlighted through the Alma Ata Declaration in 1978, which promoted "Health for All by the Year 2000" (Jareg & Kaseje 1998). It had become clear that primary health care goals could not be achieved solely by the state; therefore, the role of civil society, particularly CSOs that worked closely with communities, became pivotal to the Declaration and its implementation. However, the lack of inclusiveness of civil society in primary health care was a major constraint and policy makers took more than a decade to understand the crucial role of civil society in facilitating the implementation of primary health care (Jarege & Kaseje 1998).

Additional emphasis was placed on civil society in 1986 with the Ottawa Charter for Health Promotion, which recommended mediation between different sectors of society for the pursuit of health. Baum (1997) argued that the mission of civil society is analogous to the aims of the 'new' public health; promoting social life and calling for

highly developed civil and political participation. The new public health is an integrated approach to protecting the health of individuals and communities, with a focus on equitable access to health services and creating linkages required for the provision of health services, with community participation and collaboration between health and other CSOs (Baum 1997; Beaglehole et al 2004; Lawn et al 2008; Tulchinsky & Varavikova 2010). The concept of new public health also incorporates health systems leadership, political engagement in public health policy, community partnerships and multidisciplinary approach to address all determinants of health, along-side primary, secondary and tertiary prevention and health systems management (Beaglehole et al 2004; Tulchinsky & Varavikova 2010).

Civil society therefore became an inextricable component of the new public health. The concept of CSOs being key players in the development sector was emphasized following the Millennium Development Goals in the year 2000. In addition to reducing poverty, improving access to health and education, combating HIV/AIDS and ensuring environment sustainability, the Millennium Development Goals include a goal to develop a global partnership for development. This goal urged the formation of global partnerships between governments, civil society, the private sector and foundations to develop pro-poor development strategies in a participatory manner (United Nations 2008). More recently, civil society has been instrumental in developing the post-2015 development agenda through groups such as the UN-Non Governmental Liaison Service (NGLS) (United Nations 2013).

The recognition of civil society as a crucial partner in primary health care and a simultaneous disenchantment with the state's ability to provide high-quality health care drove greater engagement of civil society within the health sector (Jareg & Kaseje 1998). Three key arguments exist for civil society's growing force within the health sector (Jareg & Kaseje 1998). The first is the acknowledgement that the global environmental, health and social crises can only be tackled through responsibilities and actions shared between civil society and the state. The second is that in recent years, global civil society has become more influential in addressing the causes of ill health due to better access to media and electronic communication. Lastly, Jareg and Kaseje argued that the significant increase in the number of people worldwide who are

becoming well-informed about health issues and as a result, wanting to become involved in the health sector, has also contributed to the growth of civil society.

Civil society engagement in health has also arisen from the push to include consumer participation in health policy and service development, in an attempt to close the gap between those who plan and provide health services and those who access them (Aronson 1993; Hambleton 1988). Loewenson (2003) argued that the participation of CSOs in health develops new political, financial, institutional and technical resources to promote health. Green and Matthias (1995) proposed that changes in perceptions of donor agencies led to the growth in the non-governmental sector during the 1990s. Growing disillusionment, particularly among donor agencies, with the governments of developing countries and their failure to deliver acceptable levels of health care was a key factor in the growth of civil society and the private sector. In addition, the belief within some donor agencies that the private sector was more efficient than the state in service delivery and the lack of democracy in decision-making in governments of the South, are commonly stated to be other reasons for the increase in influence of the not-for-profit sector.

Within the health sector, civil society continues to be called the 'third' sector and constitutes not-for-profit health initiatives with the 'first' sector being the state's primary health system and the 'second' sector being the realm of the private, for-profit health providers (Jareg & Kaseje 1998). One of the most established roles that civil society plays in promoting health is that of facilitating and providing relief and rehabilitation in humanitarian emergencies (Ghaus-Pasha 2004). CSOs have recently broadened their activities to include income generation programs, micro-credit and education, all of which contribute to the promotion of health. Their success in doing this is partly due to their advantage in identifying and accessing marginalized communities and addressing their needs and concerns. At local, national and international levels, civil society is involved in advocating for the health needs and rights of excluded communities, building their capacity, advocating for change in health policies and agendas and providing services within the private and public health systems.

The specific contributions of civil society to promoting the health and well-being of resource-poor communities have been well-documented (Acharya & Thomas 2001; Doyal 2004; Etemadi 2000; Field & Gregory 2000; Gwatkin 2002; Kutzin 1995; Putney 2001; UNFPA 1998). Field and Gregory (2000) argued that CSOs can effectively support the health needs of these communities due to their commitment to values of social justice and human rights and their ability to reach communities that are poorly served by the state, which may include poor rural and urban communities, women, refugees and the internally displaced. Acharya & Thomas (2001) in a study of ten CSOs working with low income groups in Ahmedabad, India, found improvements in school attendance and literacy levels, immunization and mortality rates due to civil society interventions. Doyal (2004) illustrated how civil society can encourage women in resource-poor communities to become involved in health care and to demand their health rights; this has resulted in women assuming greater responsibility for health care and taking collective action to defend their well-being (Hale 1996; Parveen & Ali 1996; Theobald 1999). Similarly, Etemadi (2000) found that health indicators such as child malnutrition rates, use of oral rehydration and immunization rates improved in areas characterized by civil society health service interventions in Cebu city in the Philippines. Marked reductions in maternal mortality rates due to maternity outreach services provided by CSOs were also reported in Bangladesh, Ghana and India (Kutzin 1995). The United Nations Population Fund (1998) also noted country examples of civil society groups improving reproductive health in resource-poor communities through provision of services and information, influencing policies and raising the visibility of women's health issues.

2.3.1 Civil Society Influence on Health Policy Making

In addition to grassroots impacts, civil society is also increasingly playing a role in influencing global economic and health policies, strengthened by global networks such as the People's Health Movement and the World Social Forum. During the 1990s there was an increase in CSOs networking across national borders, thrusting critical issues onto international platforms. The strength of global CSOs was first visible at the Earth Summit in 1992, which was attended by approximately 2,400 civil society members (United Nations 1997). Similarly, many international CSOs participated in the 1994 World Population Conference in Cairo and took responsibility of setting the

agenda for discussions on human rights standards and development proposals (Chandhoke 2002). One of the major international victories for civil society was the campaign to pressurize governments to draft a treaty to ban the production and export of landmines, which led to the signing of the Mine Ban Treaty in 1997 as well as the International Campaign to Ban Landmines being awarded the Nobel Peace Prize (Chandhoke 2002). Another visible success of CSOs was the 1999 protest involving approximately 700 organizations and 40,000 students, workers, CSO members, religious groups, and representatives of business and finance sectors during the third ministerial meeting of the World Trade Organization (WTO) in Seattle; this protest was aimed at blocking policies relating to unsafe work conditions and exploitation of the poor working people and environmental degradation caused by the relocation of industries to developing countries (Chandhoke 2002). The scale of people's mobilization and intensity of the protest by global civil society marked the first time that single-issue groups converged into a movement to challenge the world trade and financial system. Other global successes included improved mechanisms for debt reduction in low-income countries and the Doha Ministerial Declaration on access to essential medicines (People's Health Movement et al 2008).

Despite these successes at a global level, it is necessary to acknowledge civil society's limitations in addressing health policy concerns. Global protests and policy advocacy efforts to date have attempted to limit damage caused by decisions which would have affected the health conditions of people, particularly those in developing countries (for example, the WTO ministerials) or to limit the impact of adverse decisions such as the Trade Related Intellectual Property Rights (TRIPS) Agreement. Civil society has not succeeded in completely overturning detrimental decisions or changing global agendas. When civil society has played a role in completely blocking decisions, the effect has often been temporary (People's Health Movement et al 2008). Protests during the WTO ministerials have not changed its agendas or negotiation processes (Third World Network 2002). Similarly, the potential benefits of the Doha Declaration on access to essential medicines were reduced by the ensuing imposition of conditions on the provisions of the Declaration and the bilateral trade agreements on intellectual property that surpassed those of the TRIPS agreement (People's Health Movement et al 2008). In addition, Wallace (2003) argued that most global campaigns are limited to

attacking specific aspects of global issues and policies and do not question the roots of the paradigms used to develop them. Other limitations of global campaigns include the lack of coordination between various not-for-profit organizations and the increasing reliance of these organizations on their funding agencies. Overcoming these limitations to bring change in global health and development requires coordinated action by global civil society.

In discussing the role of civil society in promoting equitable health policies, it is essential to review its interactions with the state. Nyang'oro (1993) described three types of interaction between civil society and the state. Groups that detach themselves from the state (known as the 'exit' option) and develop parallel political, health and economic systems form the first type, an example of which is the community-based health care movement of the '70s and '80s (Jareg & Kaseje 1998). Other groups engage with the state (known as the 'voice' option) to address social issues, corruption and inadequate policies to ensure that the state meets minimum obligations to its citizens (Nyang'oro 1993). The third form of interaction describes those groups that oscillate between the exit and the voice options according to their circumstances, known as the 'straddling' option (Nyang'oro 1993). Although civil society groups may adopt any of the three forms of interactions with the state at various points in time, often their main role might be to assume responsibility for service provision due to the poor functioning of the state.

Bangser (2000) argued that the policies and actions of many governments and donor agencies neglect the 'agency' of the poor to create lasting social change and therefore fail to promote the participation of the poor in agenda-setting. Bringing to the forefront the issue of people's social exclusion is one of the critical means of overcoming the damaging effects of social and health inequity (Evans et al 2001; Loewenson 2000, 2003), an ongoing campaign in which CSOs are actively involved. Therefore, a key role of civil society in promoting equitable health policies is to raise and strengthen the voices of the poor and promote their participation in health agenda-setting. CSOs often reach populations that may be poorly served by the state. Involvement of CSOs in social mobilization to change or implement health policies and campaigns have been illustrated in areas of road safety, tobacco control,

reproductive and maternal health and HIV/AIDS (Ellevset 1999; Kickbush & Quick 1998; McKee et al 2000; Partnership for Health Reform 2000; Salojee 2001). In addition, examples of CSOs promoting the involvement of communities in health services to make government health systems more accountable to the public have been noted internationally (Etemadi 2000; Loewenson 2000; Mittlemark 2001; Raghuram & Ray 1999). Global advocacy campaigns such as the People's Health Movement, the Global Campaign for Microbicides, the International AIDS Vaccine Initiative and the Global Week of AIDS Action are also examples of raising the voices of communities experiencing poor health, deprivation and HIV/AIDS to influence global policy making and agenda-setting.

Articulating the values of equity in health is central to the shaping of pro-poor health policy (Evans et al 2001). A strong civil society is viewed as a prerequisite to refocusing health care systems towards social welfare and protecting health rights (Isaacs & Solimano 1999). Raymond et al (2004) discussed the ways in which civil society promotes health values and rights, namely through facilitating relationships between health providers and those accessing services, promoting individual associations with larger groups working on health and providing open information and competing ideas to people. While global civil society has been instrumental in influencing health policy agendas, national and local civil society groups have had similar successes. Recently, national and local CSOs worldwide have been involved in promoting the rights of PLHA and vulnerable communities, particularly with respect to the right to treatment, of which the Treatment Action Campaign (TAC) in South Africa is a prime example (Treatment Action Campaign 2012). The TAC had a pivotal role in the South African government's decision to provide Antiretroviral Therapy (ART) to PLHA in the country (Friedman & Mottiar 2005). Similarly, in Thailand, civil society groups have been instrumental in improving the availability of affordable generic medicines to PLHA by challenging the practices of the multinational pharmaceutical industry and governments of industrialized nations (Ford et al 2004; Tantivess & Walt 2008).

2.3.2 Social Capital and Civil Society

A concept closely related to civil society and often used in conjunction with it, is that of social capital. Social capital is acknowledged as a poorly defined, contested topic

(Woolcock 1998) which is nevertheless gaining momentum in relation public health (Wakefield & Poland 2005). This section briefly discusses the notion of social capital and its interface with in relation to civil society participation in health and HIV/AIDS.

Wakefield & Poland (2005) discern three distinct constructions of social capital: communitarian, institutional and critical. From a communitarian perspective, social capital is most commonly defined as the *networks, norms and social trust that facilitate cooperation for mutual benefit* (Putnam 2001; Putnam et al 1993). According to Putnam (2001, p.vi), social capital consists of the “bonds of community” that enrich people’s lives. He argues that societies with high levels of interpersonal trust, social norms and networks that emphasize reciprocity are more likely to experience positive economic, political and social development.

Evans (1996, p.1121), in describing the institutional construction of social capital, highlighted its significance in state-civil society relationships and states that “social capital is formed by making some who are part of the state apparatus more thoroughly part of the communities in which they work”. Evans (1996) suggested that synergies between government officials and citizens can achieve more together than either party can separately. In this view of social capital, the role of state and civil society organizations is emphasized and well-resourced, strong public institutions are seen as developing, and developing from, social capital.

The critical view of social capital, outlined by Bourdieu (1979, 1986), described it as *resources linked to the possession of durable networks of acquaintance and recognition*. Bourdieu (1986) asserted that social capital is seen as a resource that individuals and groups can use as leverage to achieve particular goals that may or may not be beneficial to others; Bourdieu highlighted that social capital can be used to reinforce the power of affluent social groups and elite social networks to exclude people from participating and gaining the benefits of memberships to these networks. The most commonly used definition of social capital within civil society discourse is that of Putnam.

From the definitions of civil society (presented in section 2.2.2) and those of social capital discussed above, it can be seen that a number of commonalities exist between social capital and civil society. These include concepts of cohesive networks, civic associations, social norms, collective voices, trust, reciprocity and inclusion. Civil society is a source of social capital (Fukuyama 2001) and participation in civil society can contribute to building individual and group social capital. Fukuyama (2001) highlighted that trust, networks and civil society are all epiphenomenal to social capital, arising as a result of social capital but not constituting it entirely. Further, he (Fukuyama 2001) stated that an abundance of social capital produces a dense civil society, which is a necessary component of modern liberal democracy. Putnam (2001) stated that civil society includes mainly groups whose activities engender networks, norms and trust, all of which are at the heart of social capital. Further, Putnam argued that CSOs are rich environments for building social capital, in which individuals learn civil skills and work together, and that where there are dense networks of civic participation, social capital is high (Putnam 1993).

Within the health sector, social capital has been linked to community integration and public participation, both of which are critical components of civil society engagement in health. Social capital theorists suggest that individual health and development outcomes are better achieved through community participation and action (Lomas 1998; Muntaner, Lynch & Smith 2001; Welshman 2006). People are more likely to adopt health-enhancing behaviors if they engage with communities characterized by trust, reciprocity, a positive community identity and high levels of involvement in community organizations and networks (Baum 1999).

Social capital has been linked with lower mortality rates (Kawachi et al 1997), improvements in child health (Drukker et al 2005), mental health (De Silva et al 2004) and high levels of self-reported health (Miller et al 2006). Although there is limited research on social capital and civil society participation within the field of HIV/AIDS, there is evidence that when social network and support aspects of social capital are strengthened, desirable HIV-related outcomes are achieved (Campbell, Williams & Gilgen 2002; Gregson et al 2004). Pronyk et al (2008) illustrated experimentally that social capital can be created exogenously and this can then have positive influence on

health and HIV indicators among communities. Membership to some groups and not others has been linked with lower HIV risk (Gregson et al 2004). Participation in civil society initiatives, through group memberships, has been reported to have a significant influence on HIV-related knowledge (Campbell & MacPhail 2002). Similarly, Campbell and Mzaidume (2001), in their micro-qualitative study of a female sex worker-led peer education program in South Africa, illustrated that social capital can be built in communities with low social capital to prevent HIV infections through participation in local decision making, building trust and common identities and shaping community dynamics. Particularly in India, there is indirect evidence of the role of community association and organization in the Sonagachi Project in Kolkata, on sex workers' gaining HIV prevention information and advocating for health care (Jana et al 2004). Sivaram et al (2009) found that in Chennai, India, social capital indicators, in particular membership in civil society organizations and collective action, were associated with reduced fear of HIV transmission, lower levels of feelings of shame and judgement, and low levels of discrimination against PLHA.

It must be noted that a number of critiques to social capital have been raised. Dasgupta (2000) noted that while social capital is a private good, it is pervaded by both positive and negative externalities. For example, internal group cohesion is a positive aspect of social capital, however, this cohesion may be at the cost of treating outsiders with suspicion, hostility or hatred (Baum 1999; Dasgupta 2000). Fukuyama (2001) highlighted that groups such as the Ku Klux Klan achieved high social capital, however also produced significant negative influences on the larger society.

In relation to public health, some authors highlight that the concept of social capital is vague and indiscriminate (Baum 1999; Fine 1999; Foley & Edwards 1999; Woolcock 1998), and that the process by which social capital is developed and maintained have not been clearly identified (Hayes & Dunn 1998). Labonte (1999) asserted that the concept of social capital is merely a repackaging of well-established health promotion and community development concepts that have been long practiced and researched. Pronyk et al (2008) acknowledge that not all social capital promotes health. For example, membership to a club that promotes negative behaviours can limit an individual's health-related choices. These authors (Pronyk et al 2008) also highlight

that irrespective of social capital, environmental and individual factors can lead to negative behaviors. Social capital may also be linked to unequal and exploitative power relations (Bourdieu 1986; Campbell & Mzaidume 2001) and may even enhance negative behaviours (Williams, Campbell & Macphail 1999). Campbell (2001) argued that while health workers and international development agencies seek latent and pre-existing indigenous sources of social capital within communities, the ambiguities regarding the positive and negative effects of social capital and potential links between social capital and unequal power relations, remains under-researched and under-theorized. Sceptics of social capital argue that a focus on social capital presents an easy way for policy makers and development agencies to place the onus of better health outcomes on communities, rather than on the necessary strategies to reduce income and health inequalities (Gordon et al 1999; Muntaner & Lynch 1999).

Despite these critiques of social capital theory, it is largely believed that social capital can make a significant contribution to public health theory, research and policy (Baum 1999; Campbell 2001; Pronyk et al 2008). Social capital concepts are utilized in the subsequent analysis chapters to highlight issues of trust, power and reciprocity.

2.3.3 Barriers to Civil Society Growth

Though the majority of information on civil society contributions to improving the health of the poor and marginalized is positive, there have also been reports of minimal impacts. For example, Ahmed (2000) highlights that the reach of CSOs can be limited and his study indicated that all the CSOs in Bangladesh together reached only 10-20% of landless households in the country; their resultant impact on poverty reduction was minimal. In Tanzania and Zambia, benefit incidence analysis indicated that the initial economic status of people aided by the civil society health sector was actually higher than that of patients in government facilities (Gwatkin 2002); therefore, the people most in need of support were being overlooked. In his case study of CSO interventions in northern Ghana, Mohan (2002) found that local CSOs created their own fiefdoms in the communities in which they worked and that the process of strengthening civil society was in fact undermining efforts towards decentralization of decision-making. Such studies highlight the potential for civil society to overlook the needs of the poor and vulnerable resulting in further marginalization of these communities.

Several barriers to civil society's aims to improve the health of poor and marginalized communities have been identified. These include poor leadership and legal authority, the internal politics of CSOs, unstable funding, donor dependency and poor mechanisms for monitoring and scaling up interventions carried out by CSOs (Nathan, Rotem & Ritchie 2002; Osmani 2000). One of the key inhibitors to civil society's impact on the health concerns of disadvantaged groups is that people from higher income groups, predominantly men who may promote their own interests and the perceived needs of their constituents, often dominate the leadership of CSOs. These leaders may also be unwilling to confront the state or funding agencies to voice the needs and interests of poor communities (Gomez 2000). Similarly, Holzscheiter (2011) argues that CSO representational politics at times promote the voices of the most powerful within vulnerable communities while the most vulnerable and 'voiceless' remain under-represented. Holzscheiter (2011) asserts that CSO representational practices in global institutions must be constantly evaluated, to determine the extent to which the direct and meaningful involvement of vulnerable communities is ensured in policy making and program processes. In addition, political and organizational power (Taylor 2002) which can determine CSO interventions and which communities are engaged with, can inhibit the growth of civil society. Lewis (1999) argued that organizational issues manifest in poorly designed programs that are inadequate to improve the health status of poor communities. A study of CSOs working with the urban poor across nine cities in Chile, India and South Africa found that the internal weaknesses of CSOs markedly decreased their willingness to challenge the state to address the needs of the poor and undermined their ability to advocate for the interests of the poorest communities (Mitlin 2000). Such inability to address the needs of the poor and marginalized can damage the trust community members have in CSOs. This is also a significant constraint to the growth of civil society (Fukuyama 2001; Tonkiss 2000).

In addition to organizational limitations, external obstacles to the work of civil society groups exist. Corporate and state interests can resist the work of groups working towards health equity as well as impede their effectiveness in reaching the poor (Gwatkin 2002; Mudyarabikwa 2000). A study of CSOs involved in urban housing in

Chicago found that despite efforts by poor and marginalized groups to defend their interests, their housing choices were primarily determined by powerful business coalitions that ignored the interests of low-income groups (Ranney, Wright & Zhang 1997). Jarege and Kaseje (1998) identified two main threats to the growth of civil society in the health sector. These are that the agendas of funding agencies such as the government, the UN, the World Bank will be pursued rather than the public interest, and that the sudden input of large amount of resources into communities can impair their capacity for sustained development. Small grassroots organizations, particularly in developing countries that are completely dependent on donor funding, are particularly susceptible to these threats. Spicer et al (2011) found in their study of CSOs engaged in HIV-related work in Eastern Europe and Central Asia that competition for external funding, particularly grants from the Global Fund has created divisions and acrimonious relationships within civil society, hindering their collective action. Their study also found that relationships with the government also hinders civil society participation, with many CSOs feeling like “circus monkeys” rather than credible organizations (Spicer et al 2011, p. 1751). An analysis of the equity impacts of community financing in Benin, Zambia and Kenya found that these schemes failed to protect the poor from the burden of payment for health care. This was attributed partly to the failure to ensure that the voices of poor communities were heard in the decision-making process (Gilson et al 2001).

2.4 Civil Society Engagement in HIV/AIDS

CSOs have been at the forefront of HIV prevention, treatment, care and support, and promoting the rights of PLHA. According to Rau (2006), CSOs recognized various issues related to HIV/AIDS and promoted comprehensive responses to the epidemic well before governments and international agencies. For example, CSOs emphasized the importance of promoting the prevention-to-care continuum at least three years before most donor agencies acknowledged the links between prevention and treatment (International HIV/AIDS Alliance 2002). Similarly, grassroots CSOs lobbied for the inclusion of condoms in Information, Education and Communication campaigns prior to USAID’s decision to provide condoms (Rau 2006). Civil society groups have also been instrumental in raising awareness of HIV/AIDS and reducing the associated stigma and, as noted previously, played a crucial role in establishing universal access

to ART in Brazil (Oliviera-Cruz, Kowalski & McPake 2004) and Thailand (Tantivess & Walt 2008). In addition, PLHA and other vulnerable community members also provide a more nuanced understanding of the illness, and their engagement in the HIV response has contributed to ‘de-technifying’ HIV/AIDS and focusing on the rights of key affected communities (Vielajus & Haeringer 2011).

2.4.1 The GIPA Principle

The GIPA principle is rooted in the human right to participation, first articulated in the 1948 Universal Declaration of Human Rights (United Nations 1948, Article 27, paragraph 1). Community participation is also central to the Alma Ata Declaration on Primary Health Care (World Health Organization 1978) and the 1986 Ottawa Charter for Health Promotion, which promotes strengthening community actions and advocates public participation in health matters (World Health Organization 1986). The need for participation of PLHA in the response to HIV/AIDS was first voiced in the 1983 Denver Principles, which delineated the rights of PLHA and their role in the HIV response (National Association for People with AIDS [NAPWA] 2009). Similar principles of PLHA participation and self-empowerment were reiterated and reinforced by the Montreal Manifesto at the International AIDS Conference in 1989 (AIDS ACTION NOW! & ACT UP 1989). This was followed by the 1994 Paris AIDS Summit, where 42 countries declared their commitment to:

Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community based organizations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments. Section IV.1 (United Nations 1994)

The signatories, national governments, also committed to:

Fully involve non-governmental and community based organizations as well as people living with HIV/AIDS in the formulation and implementation of public policies. Section III (United Nations 1994)

This commitment became known as the GIPA principle and was endorsed by 189 member countries of the United Nations in 2001 as part of the Declaration of Commitment on HIV/AIDS (UNAIDS 2001, Article 33). It was subsequently reaffirmed in the 2006 Political Declaration on HIV/AIDS, adopted by 192 countries (United Nations 2006). The GIPA principle was developed with two purposes: to acknowledge the involvement of PLHA and to create a space for PLHA to actively participate in responding to the HIV epidemic (UNAIDS 1999). At the individual level, PLHA involvement was envisaged to improve their sense of self, decrease isolation and improve health through access to better information, testing and treatment (UNAIDS 2007). At the societal level, identifying PLHA as equal partners in the fight against the epidemic sought to contribute to reducing the stigma and discrimination they face (UNAIDS 1999).

Despite the logic and rationale behind the GIPA principle, evidence suggests that implementation of the principle has been limited. In 1999, UNAIDS (1999) declared that the principle remains idealized and far from being a reality. Research on the implementation of the GIPA principle indicates that greater involvement of PLHA leads to increased feelings of personal empowerment (Collins et al 2007; Roy & Cain 2001, Solomon, Guenter & Stinson 2005), improvement in the quality of life of PLHA (Cornu 2003) and increased credibility of organizations working on HIV (Collins et al 2007; Roy & Cain 2001; Stephens 2004). Despite these benefits, considerable barriers to participation of PLHA and insufficient involvement of PLHA at all levels of CSO functioning and in CSO and government policy making processes have also been noted.

2.4.1.1 Definition of Greater and Meaningful Involvement Unclear

The implementation of the GIPA principle remains uneven in part due to the lack of definition of ‘greater’ involvement. UNAIDS proposed a pyramid of PLHA involvement, with the levels of involvement increasing from PLHA participating as a ‘target audience’ who are beneficiaries of and provide feedback to HIV programs, to ‘contributors’ who are involved “marginally” in HIV programs, ‘speakers’ who participate as spokespersons for HIV campaigns, and as ‘implementers’ who act as peer educators and outreach workers. The higher levels of PLHA involvement include the ‘experts’ who participate at the same levels as professionals in the design, adaptation and implementation of programs, and at the apex of the pyramid are ‘decision-makers’, PLHA who participate in decision and policy making processes (UNAIDS 1999). Existing research demonstrates that PLHA continue to participate in civil society at the ‘target audience’, ‘contributors’ and ‘speaker’ levels rather than at ‘expert’ and ‘decision-making’ levels (Chakrapani & Abraham 2010; Cornu 2003; Magaz & Hardee 2004).

Through consultation with PLHA in Ecuador, Burkina Faso, India and Zambia, Cornu (2003) defined the stages of PLHA involvement as ‘access to services’, ‘participation’ and ‘greater involvement’. The ‘greater involvement’ stage represented the most meaningful contribution, in which PLHA had the skills to cope with stigma and discrimination and were able to influence program design and implementation (Cornu 2003). While Cornu’s model provides a good platform for clarifying the definition of meaningful involvement, it also implies that participation at decision-making levels is most meaningful. This may lessen the recognition of efforts of PLHA who participate as volunteers, peer counsellors and peer educators, which has been found to be of substantial direct benefit to HIV prevention and care (Hilfinger et al 2009; Roy & Cain 2001).

‘Greater’ involvement was more recently replaced in literature by the term ‘meaningful’ involvement of PLHA. This amendment reflected a shift in focus to the empowerment of PLHA and sought to promote them as equal partners in change (UNAIDS 2007). However, this change in terminology has not resulted in more extensive uptake of the GIPA principle, possibly in part due to uncertainty in the

definition of ‘meaningful’ involvement. Such a term is subjective and interpreted in different ways among PLHA and across diverse contexts; to whom the participation should be ‘meaningful’ remains unstated.

2.4.1.2 Barriers to PLHA Participation

The social, cultural, economic and legal contexts within which the HIV epidemic thrives significantly influence the implementation of the GIPA principle. These contexts create significant barriers to the meaningful involvement of PLHA. Fear of stigma and discrimination is perhaps the most important barrier to their involvement in civil society (Cain et al 2014; Collins et al 2007; Magaz & Hardee 2004; Paxton & Stephens 2007; Poindexter & Lane 2003; Stephens 2004). Another key obstacle to meaningful involvement in civil society is the superficial and tokenistic involvement of PLHA in HIV-related activities, noted by Paxton (2005), Paxton & Stephens (2004) and Roy & Cain (2001). Feelings of ‘over-participation’, where PLHA feel they are being asked to be involved in too many activities, and long-term involvement resulting in burnout, particularly among women living with HIV, have also been reported (Roy & Cain 2001).

Gender inequality and marginalization have also been identified as structural barriers to meaningful participation of PLHA, particularly in developing countries (Chakrapani & Abraham 2010; Cornu 2003; Paxton & Stephens 2007). Women who live with HIV face significantly higher levels of AIDS-related stigma than men (Stephens 1999, cited in Stephens 2004) and are more likely to face barriers to participation due to financial dependence on men and domestic and childcare responsibilities (Cornu 2003). Other barriers to participation of PLHA in civil society include lack of medical support and counselling (Paxton & Stephens 2007). Travers et al (2008) and Cain et al (2014) found that engagement of PLHA in some settings was hindered by drug dependence and the availability of food and shelter. In addition, Travers et al (2008) and Collins et al (2007) reported that ‘credentialism’, the idea that only PLHA who have degrees from accredited post-secondary institutions are credible, excluded those without high levels of formal education. Similarly, the professionalization of HIV-related CSOs that look for specific skills and experience for staff and volunteers, who may be reluctant to hire PLHA, was a significant barrier to their participation in CSOs in Canada (Cain et

al 2014). These barriers, which stem from community stigmatization and discrimination, human rights violations, a lack of supportive legislation and societal and organizational attitudes towards PLHA, undermine GIPA implementation.

2.4.1.3 Role of Enabling Environments in Promoting the GIPA Principle

The GIPA principle envisaged supportive environments as an outcome of greater involvement of PLHA. However, supportive environments, in terms of economic, political and psychosocial support and empowerment, are also prerequisites to both greater and meaningful involvement of PLHA, and in their absence, progress towards effective implementation is likely to be limited. Maxwell, Aggleton and Warwick (2008) emphasized the significance of committed resources for encouraging greater involvement of PLHA in England. Their study found that budget availability to facilitate training and participation of PLHA enabled them to participate in service and policy development (Maxwell, Aggleton & Warwick 2008). GNP+ (2008) cited the lack of direct budgets to promote GIPA as an indicator of inadequate application of the GIPA principle. Financial support for PLHA, including support for transportation and childcare to enable them to participate in HIV-related activities, is critical to increasing their participation (NEPWHAN 2010; NEPHAK 2010; NZP+ 2010; Paxton & Stephens 2007).

Stephens (2004) highlighted the importance of enabling political and organizational environments for greater involvement of PLHA and concluded that the GIPA principle is marred by ill-defined policies and legal frameworks. Cornu (2003) emphasized the need to understand the social context in which GIPA is applied, stating that the experiences of PLHA in developed countries cannot be replicated in developing countries that have a higher burden of HIV and more difficult economic and social circumstances such as poverty and a lack of access to treatment, and care and support. Access to life-saving ART and health services are also fundamental prerequisites for effective and greater involvement of PLHA in civil society (Collins 2007; Cornu 2003; Paxton & Stephens 2007). Lack of skill building has been cited repeatedly as a barrier to GIPA (Chakrapani & Abraham 2010; Magaz & Hardee 2004; Paxton 2005; Paxton & Stephens 2007; Poindexter & Lane 2003; Stephens 2004; Travers et al 2008). Furthermore, PLHA have reported that while awareness of their rights and entitlements

has increased, many vulnerable groups lack the ability to negotiate and advocate on their behalf (Paxton & Stephens 2007). These studies highlight the significance of building skills, both personal and institutional, in order to increase the participation of PLHA in civil society.

2.4.2 Global Examples of Affected Community Involvement in HIV Response

As mentioned above, some authors argue that the implementation of the GIPA principle and resultant involvement of PLHA and communities vulnerable to HIV/AIDS has been limited. Nevertheless, a number of national and international organizations continue to attempt improving the participation of key affected communities in the HIV response by mandating their participation in organizational guidelines and by encouraging communities to take control of their health. Some recent examples of the promotion of community participation in the HIV response are briefly presented in this section.

Inclusion of CSOs, PLHA and vulnerable communities has become an integral part of the HIV response and a number of bilateral, multilateral and international aid agencies now insist on the inclusion of these representatives on all grant proposals (UNAIDS 2007). Examples of these include the Global Fund to fight AIDS, Tuberculosis and Malaria, the World Health Organization and the President's Emergency Plans for AIDS Relief (PEPFAR). The Global Fund, which invests in more than 140 countries (GFATM 2014) is a significant promoter of the need to involve affected communities in the fight against HIV/AIDS. It was the first international grant-making organization to invite AIDS-related CSOs and PLHA into its decision-making structure (Jonsson & Jonsson 2012) and requires that key affected populations participate in HIV governance entities, including in the country coordinating mechanisms in charge of developing national proposals for the Fund (GFATM 2011a; Csete 2011). In countries such as Jamaica, the Philippines, Senegal, Nepal and Macedonia, PLHA and vulnerable community members already participate in the Fund's country coordinating mechanisms (Csete 2011; Poteat et al 2011; Trapence et al 2012). Further, the Global Fund is currently promoting the Community Systems Strengthening framework, in an effort to develop roles for PLHA and members of vulnerable communities, CBOs and networks to work in partnership with civil society groups, in the planning, implementation and monitoring and evaluation of HIV-related services (GFATM

2011a). The Global Fund's Strategy in relation to Sexual Orientation and Gender Identities (SOGI) also acknowledges that MSM, FSW, and transgender people face challenges in accessing the Fund's grants and limited access to the decision-making bodies of the Global Fund and promotes leadership, advocacy and partnership with the MSM, transgender and FSW communities (GFATM 2011b). Implementation of the SOGI strategies will also take precedence in the Global Fund Strategy 2012-2014 (GFATM 2011b). Particularly in respect to the participation of MSM, the PEPFAR highlights the importance of using this community to engage with their peers in the community and retain them in health and HIV interventions (PEPFAR 2011).

Similarly, the World Health Organization (WHO) promotes partnerships between government, non-government organizations and people affected by HIV/AIDS for HIV prevention, treatment and care (WHO 2002). In promoting the partnership approach, the WHO (2002) also highlights that full partnership with communities can only be achieved when they are well informed, have the capacity to assess problems and identify solutions; communities need to be facilitated to use their full potential in the response to HIV/AIDS. Here again, the significance of capacity building and enabling environments in promoting greater participation of PLHA and vulnerable communities (discussed earlier in section 2.4.1.3) is highlighted.

Addressing the needs of the most-at-risk populations and affected community engagement is also critical to the recently popularized concept of 'combination prevention' (Kurth et al 2011; UNAIDS 2010; PEPFAR 2011). Combination prevention programs combine behavioural, biomedical and structural HIV prevention strategies at individual, relationship, community and societal levels to address the needs of the populations that are most-at-risk of HIV infection (UNAIDS 2010). Community mobilization, enhanced partnerships and coordination, community capacity building and collective action are key components of the combination prevention method action (PEPFAR 2014; UNAIDS 2010). Reliance on peer educators, who are responsible for data collection and analysis and some aspects of program planning and implementation, was a key success in the Avahan program's approach to combination prevention in the concentrated epidemic in India (Rau 2011). Although community engagement is promoted, the extent to which the involvement of

PLHA and other vulnerable communities, particularly at decision-making levels, is being achieved in combination prevention activities is unclear as the approach is still in its nascent stages.

A number of recent examples support the need for civil society engagement, particularly that of PLHA and communities vulnerable to the infection in improving health, human rights and HIV program and policy outcomes. These examples of positive outcomes at the community level, of affected community participation in the HIV response, include programs such as the Mpowerment Project in the United States, which has established the effectiveness of engaging the MSM communities in the design and implementation of HIV prevention and on the reduction of HIV risk (Hays, Rebhook & Kegeles 2003; Mpowerment Project 2014). Similarly, a recent evaluation of the Networks Project in Uganda, a three-year USAID-funded project designed to increase access to services by PLHA, strengthen organizational capacity of PLHA networks and empower PLHA to deliver HIV-related services, illustrated that the project was able to put into practice the principles of greater and meaningful involvement of PLHA (Kim et al 2012). This was achieved through PLHA groups reaching a large number of people with education and awareness, PLHA being service providers in the community and a reduction in the stigma associated with being HIV-positive and increase in PLHA health seeking behaviour through the engagement of PLHA networks (Kim et al 2012). In Andhra Pradesh, India, a CSO engaged in HIV and human rights-related activities illustrated the ways in which FSW, powerless, marginalized and stigmatized in the country, combined the forces of community empowerment, collective action and networked governance (Braithwaite 2006) to regulate the police force, a powerful state actor (Biradavolu et al 2009). In order to do this, FSW were empowered through collective action and legal literacy to confront improper police action, a crisis intervention team was set up which included FSWs, lawyers, human rights activists, politicians and members of the media (Biradavolu et al 2009). Other key examples are discussed in Chapter 8.

The participation of civil society is promoted by national and international CSOs and there exist a number of successful examples of this participation. However, it must be noted that greater and meaningful participation is not universal and there exist a

number of factors that hinder participation. For example, despite the thrust on civil society within the Fund's policies and strategies, in 2012, civil society's significance has not remained unequivocal; in 2012, the Global Fund's Civil Society Team, a key group in charge of sustaining links with non-state groups at country level was disbanded, raising concerns about CSO influence at country level in governance, oversight and grant implementation (Kageni 2012). This move was a major disappointment for CSOs engaged in HIV-related work worldwide who questioned the Fund's commitment to sustained community and civil society participation. In addition, civil society participation in many country coordination mechanisms, a key thrust of the Global Fund, has been perceived to be tokenistic (Bartsch 2007; Edstrom & MacGregor 2010). As mentioned previously in section 2.4.1.2, a number of other barriers to PLHA and vulnerable community factors exist; some of these have been illustrated in the current study and will be discussed in the chapters that follow.

2.5 Summary

The genesis of civil society was discussed in this chapter, tracing the origins of civil society in the 17th century to the burgeoning of CSOs in recent years. A common feature of most definitions of civil society is that it is a sphere that is distinct from the state and the market, however it forms associations with both these entities. It comprises people who have common interests and who enter into voluntary associations. These commonalities were acknowledged in the current study and civil society was viewed as being composed of non-state, non-market entities. Some authors have also proposed the notion of manufactured civil society, wherein civil society associations are developed based on agendas propagated by the state and funding agencies. A rapid increase in civil society engagement in health and development sectors has been attributed to greater availability of knowledge about development issues, and the increased legitimacy of CSOs as providers of services that have better reach into marginalized communities than governments.

This chapter also covered the engagement of civil society in health, health policy making and the participation of PLHA in civil society. Civil society has been shown to improve the lives of poor and marginalized communities globally through service provision, capacity building and advocating for change in health policies. While there

is no question that civil society has significantly influenced the health of poor and marginalized populations, there exist numerous barriers to the growth and power of civil society. These include poor leadership, funding politics, donor dependency and poor mechanisms for monitoring and scaling up civil society interventions. This chapter also discussed the GIPA principle, which promotes the need for PLHA participation at all stages of policy and programmatic responses to the HIV epidemic. Literature indicates that PLHA participation remains largely confined to lower levels of organizations, and that few PLHA are involved in program and policy development.

CHAPTER 3: HIV/AIDS IN INDIA

3.1 Introduction

This chapter describes the epidemiology of HIV/AIDS in India and the national government's response to the epidemic. Particular attention is then devoted to HIV/AIDS in the state of Karnataka and the city of Bangalore where fieldwork and data collection were conducted. The chapter also briefly describes the work of the KSAPS, the state-level subsidiary of the NACO, which is responsible for the government's HIV/AIDS related activities in the state.

3.2 HIV/AIDS in India

The first case of HIV in India was diagnosed in 1986 in a FSW in Chennai, the capital city of the southern state of Tamil Nadu (Simoes et al 1987; Solomon & Ganesh 2002; Solomon, Chakraborty & Yepthomi 2004). As mentioned previously, the HIV epidemic in India is said to have a 'denominator problem'; the HIV prevalence is low, but the country's large population translates into a large number of PLHA (Doshi & Gandhi 2008). As a result, India has the third highest number of PLHA in the world (NACO 2013). Forty-nine per cent of PLHA in Asia live in India (UNAIDS 2012). Current estimates suggest that the adult HIV prevalence in India is approximately 0.27%, with nearly 2.1 million people living with HIV infection (NACO 2013). Children (aged below 15 years of age) account for 7% of PLHA while the vast majority of PLHA (86%) are in the most productive age group of 15-49 years (NACO 2013). The 'feminization' of the HIV epidemic is also clearly illustrated in India, with women constituting 39% of PLHA (NACO 2013).

Although there are millions of PLHA in India, the NACO recently reported a reduction in adult HIV prevalence and HIV incidence; the national adult HIV prevalence decreased from 0.41% in 2000 to 0.27% in 2011 (NACO 2013). The number of new HIV infections has declined, from an estimated 270,000 new infections in the year 2000 to 116,000 new infections in 2011 (NACO 2013). The NACO also reported a decline in AIDS-related deaths in the country between 2005 and 2011, with

approximately 148,000 people dying of AIDS-related causes in 2011 as opposed to 196,000 in 2005 (NACO 2013). It is believed that wider access to ART has played a significant role in the decline of AIDS deaths in the country (NACO 2013). The reported decline in HIV prevalence has however been contested by civil society members (this is elaborated upon in Chapter 5).

As mentioned previously, the HIV epidemic in India is heterogeneous in nature, with different modes of transmission prevalent in different regions of the country. Even within states there is wide variance in HIV prevalence and routes of exposure, between various districts (NACO 2006). NACO defines high-prevalence states and districts as having HIV prevalence of more than 1% among women visiting antenatal clinics (NACO 2008a; Steinbrook 2007). Pregnant women are presumed to have the same vulnerability to HIV as the general population (NACO 2008a) and prevalence among pregnant women is considered a proxy for incidence of HIV in the general population (NACO 2010b). The southern states of Andhra Pradesh, Tamil Nadu and Karnataka, Maharashtra in India's west, and Manipur and Nagaland in the northeast of the country together account for over two-thirds of HIV infections in India (NACO 2012a). Similarly, 195 districts in the country have been categorized as having high HIV prevalence (NACO 2010a).

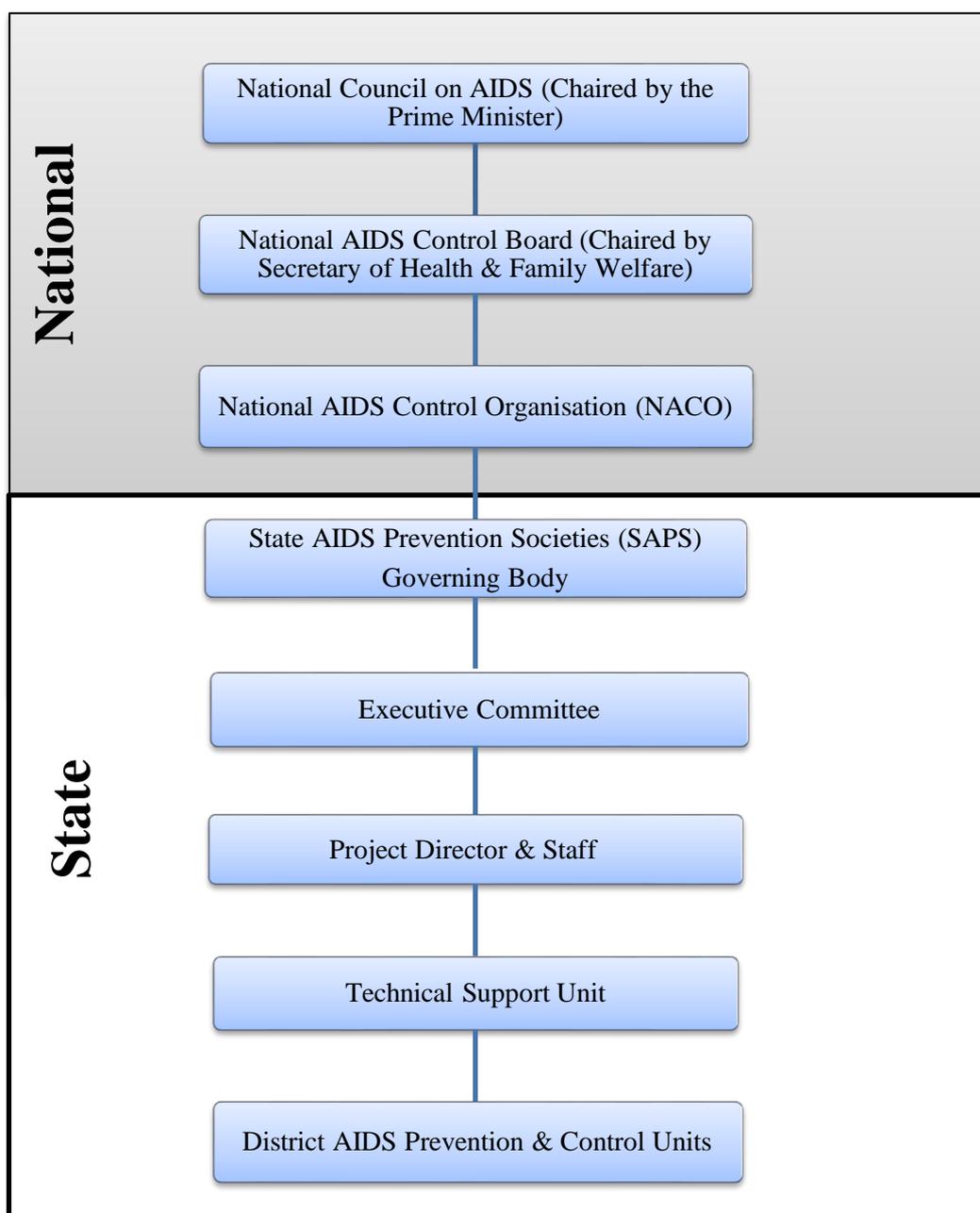
According to NACO, the primary routes of HIV transmission in India are unprotected heterosexual sex (including unprotected commercial sex with FSW), unprotected sex among MSM and injecting drug use (NACO 2012a). As previously mentioned, India's HIV epidemic is categorized as 'concentrated' epidemic (NACO 2013, p.10). A concentrated epidemic is defined as having HIV prevalence of more than 5% in sub-populations while remaining under 1% in the general population (UNAIDS 2011). HIV prevalence among so-called 'high-risk' or 'most at risk' groups, namely FSW, PWID and MSM, is higher than prevalence among the general population. HIV infection is believed to be transmitted from members of these high-risk groups to the general population through 'bridge' populations who constitute a significant proportion of the clients of FSW (NACO 2012a). The NACO has categorized migrants and truck drivers as these 'bridge' populations (NACO 2012a). The NACO used this model of HIV transmission to develop their targeted intervention approach to

reduce HIV prevalence, aimed at the high-risk and bridge populations. Estimated HIV prevalences for these high-risk communities in India are 7.3% in MSM, 9.2% in PWID and 5% in FSW (UNAIDS 2012). NACO has estimated HIV prevalence among male migrants at 2.35% and 1.62% among long distance truck drivers (NACO 2012a). During the conduct of the current study, many research participants critiqued what they perceived to be an excessive focus on the prevention of HIV among high-risk groups (these critiques are elaborated in Chapter 5).

3.3 Government Response to HIV

Initial reports of HIV in India were denied or received with skepticism by academics and politicians, who remained complacent (Ambati, Ambati & Rao 1997; Solomon & Ganesh 2002). In 1986, the government's initial response to HIV/AIDS included setting up an AIDS Task Force, which was jointly governed by the Indian Council of Medical Research and the National AIDS Committee formed by the Ministry of Health and Family Welfare. In 1990, a Medium Term Plan (MTP 1990-1992) was launched in four states, namely Tamil Nadu, Maharashtra, West Bengal and Manipur (NACO 2006). The MTP focused on Information Education and Communication campaigns, establishment of surveillance systems and ensuring the safety of the blood supply. The National AIDS Committee was subsequently renamed the NACO and subsidiaries – State AID Prevention Societies – were established in each Indian state (the NACO organogram is presented below in Figure 1). These state level Societies are autonomous, decentralized entities that implement the NACP, governed by a Governing Body (GB) headed by the State's Chief Minister and an EC headed by the State's Principal Secretary for the Ministry of Health and Family Welfare. Both these bodies have representatives from government departments, civil society and the private health sector. The NACO, in consultation with other government sectors and civil society groups, developed national HIV policies and programs, namely the NACP documents. Three NACPs had been implemented by 2013 (NACO 2013).

Figure 1: Organogram of the National AIDS Control Organization



Source: NACO 2006

3.3.1 NACP I – III (1992 – 2012)

The first phase of the National AIDS Control Program (NACP I) was initiated in 1992 and extended until 1999, with a budget of US\$84 million, primarily funded by the World Bank with technical support from the World Health Organization (NACO 2011). During this phase, a major focus of the NACO was the establishment of HIV

screening of the blood supply and treatment of sexually transmissible infections (STIs). An HIV sentinel surveillance system was also set up and professional (paid) blood donations were banned. In addition, NACP I led to the development of state level AIDS subsidiaries of the NACO.

In 1999, the second NACP was launched with World Bank support of US\$191 million (NACO 2011). During NACP II (1999-2005), the government's focus shifted from raising awareness about HIV/AIDS to changing the behaviours that cause vulnerability to the infection. As a result, targeted interventions were initiated through CSOs with a focus on high-risk groups and bridge populations (NACO 2011). Targeted interventions included Behaviour Change Communication, management of STIs, and condom promotion. In addition, school-based AIDS programs were developed to teach life skills to adolescents. Prevention of HIV through education designed to increase awareness of the infection was another major focus of this phase. Simultaneously, Voluntary Counselling and Testing (VCT) facilities were established and Prevention of Mother to Child Transmission (PMTCT) services were also initiated.

During the implementation of NACP II, policy initiatives included the formation of a National Council on AIDS, the development of the National Blood Policy and the provision of ART for PLHA (NACO 2006). The National Council on AIDS was formed, chaired by the Prime Minister and with membership from civil society, positive people's networks and private organizations (NACO 2006). HIV transmission through infected blood collected at blood banks was a significant concern during the early years of the epidemic. The National Blood Policy, developed in 2002, aimed to ensure easy access and adequate supply of safe and quality blood and blood products from voluntary and non-remunerated blood donors (NACO 2003). To do this, the policy established accreditation and external control mechanisms of blood banks and stricter screening of the blood supply for HIV and other blood-borne infections. Free ART was also initiated in selected hospitals throughout the country.

At the time of data collection for this study, the NACO was implementing NACP III (2007-2012). Since the first NACP, the NACO's focus has shifted from raising

awareness to changing behaviours, from a single, national response to decentralized, state and district-level responses and an increase in engagement with CSOs and PLHA networks (NACO 2006). The primary goal of NACP III was to halt and reverse the HIV epidemic in India between 2006 and 2012, by integrating prevention, treatment, and care and support. Specific objectives of the NACP III were to:

1. Prevent new infections in high-risk groups and general population
2. Increase the provision of treatment, care and support for PLHA
3. Strengthen the infrastructure, systems and human resources in prevention, treatment, and care and support programs at the district, state and national levels
4. Strengthen a nation-wide Strategic Information Management System (SIMS).

The GIPA principle, discussed in section 2.4.1, was incorporated into the NACO's work through the GIPA Policy during the third phase of the NACP. This policy called for PLHA participation in the country's HIV policy processes, building PLHA leadership and ensuring that the NACO, its subsidiaries and funding partners provided meaningful roles for PLHA (NACO 2010c).

3.3.2 Policy Position on Civil Society and PLHA Engagement in NACP III

CSOs were identified as integral to the country's response in the NACP III documents. PLHA and civil society participation were promoted as guiding principles for the implementation of NACP III (NACO 2006). The NACP III also promoted the development of PLHA networks and civil society forums in each district of the country. The state level subsidiary of the NACO was identified as being responsible for facilitating the development of civil society partnership forums at district and state levels. It was envisaged that these groups would have access to state and national HIV program implementation plans and reports and play a role in development of state and national policies (NACO 2006).

In addition, the development and strengthening of CBOs, where 'communities' were defined as members of NACO's high-risk groups, was promoted by the NACP III (NACO 2007c). NACO's 'Operational Guidelines for Targeted Interventions with

High Risk Groups' (NACO 2007c, p. 14) presents the following rationale for engaging CSOs and vulnerable communities in NACO's work:

1. When the community defines HIV prevention as part of their own agenda, *uptake of services and commodities is higher than when services are imposed upon them*
2. Community-led interventions leverage the existing organic bonding among community members so that individual high-risk group members *take interest in supporting their colleagues in accessing both information and services*
3. On many occasions, CBOs are found to be *most effective in scaling up HIV preventions programs*
4. Community-led initiatives allow members of the community to enable high risk groups to *play the role of a pressure group* as consumers maintain and reinforce quality of services, leading to sustained demand for high quality services
5. *Sustainability* of a program depends among other things on the level of ownership by the community.

Similar to the policy position on CSO engagement, the NACO's GIPA Policy (2010) highlights the role of PLHA in the fight against HIV/AIDS in the country. The GIPA Policy asserts the following:

1. PLHA will be *adequately involved in policy formulation and programs* related to HIV prevention, treatment, and care and support programs
2. PLHA participation will be *considered at the same level as professionals* in the design, adaptation and evaluation of HIV interventions
3. PLHA will *support the NACO, State AIDS Prevention Societies and all concerned partner agencies* for effective implementation of NACP III through linkages with available services, promoting ART adherence and providing psychosocial support at the grassroots level and *contribute to program and policy making processes by participating in NACO and state-level committees*
4. NACO, State AIDS Prevention Societies and concerned partner organizations will create an enabling environment for PLHA participation through the

development of workplace policies for PLHA, creation of funds for capacity building and empowerment of PLHA and the development of appropriate and meaningful roles for PLHA.

In addition, the NACP III guarantees to:

1. Facilitate the establishment of PLHA networks in most districts of all states by 2010
2. Develop and implement guidelines for direct involvement of PLHA in HIV prevention, treatment and care activities
3. Develop institutional structures within the NACO, State AIDS Prevention Societies and District AIDS Prevention & Control Units (DAPCU) for planning, implementation and monitoring of the GIPA Policy.

Despite this rhetoric, the extent to which civil society and PLHA engagement and partnerships has been fostered in the national HIV response has been questioned by many CSO participants of this study. This will be further explored in the following chapters.

3.4 Research Setting – Karnataka

This section introduces the study setting and provides a brief overview of the epidemiology of HIV/AIDS in Karnataka, and more specifically in Bangalore.

3.4.1 HIV in Karnataka

Karnataka is the 8th largest state in India in terms of area (Census of India 2001), with a population of more than 61 million people (Census of India 2011). Administratively, Karnataka is divided into 30 districts, which are further divided into 175 *talukas*. Bangalore, the capital city and study site, is home to approximately 10 million people (Census of India 2011) and comprises two districts – Bangalore Urban and Bangalore Rural (KSAPS 2010). Bangalore Urban is the largest district in Karnataka and approximately 16% of the state's population resides there (Census of India 2011). Bangalore Rural is one of the smallest districts in the state, with 1.6% of the state's

population residing there (Census of India 2011). The current study was conducted with CSOs working in both Bangalore Urban and Rural districts.

The first case of HIV in Karnataka was diagnosed in 1988 (KSAPS 2013). As previously mentioned, Karnataka has an estimated adult HIV prevalence of 0.63% (NACO 2012b) and 250,000 PLHA live in the state (NACO 2012a). HIV prevalence is concentrated among high-risk groups of FSW, MSM, and PWID. In 2009, estimated HIV prevalence in Karnataka was 17.6% among MSM (NACO 2009, p.6), 9.6% among FSW and 3.6% among PWID (NACO 2007a). Twenty six districts in the state are categorized as 'high priority' by the NACO (NACO 2008), defined as having more than 1% HIV prevalence among antenatal clinic attendees. Bangalore Urban is among these high priority districts.

3.4.2 HIV in Bangalore

The KSAPS estimates that approximately 118,000 FSW live in Karnataka, with approximately 45% living and working in rural areas of the state (KSAPS 2010). More than 21,000 FSW are estimated to be living in Bangalore Urban district and approximately 5,000 FSW in Bangalore Rural district. Karnataka has an estimated 25,000 MSM (KSAPS 2010); 58% are thought to reside in Bangalore Urban and 13% in Bangalore Rural (KSAPS 2010). Currently, there are no clear estimates of population size and HIV prevalence among PWID and transgender people in Karnataka or Bangalore.

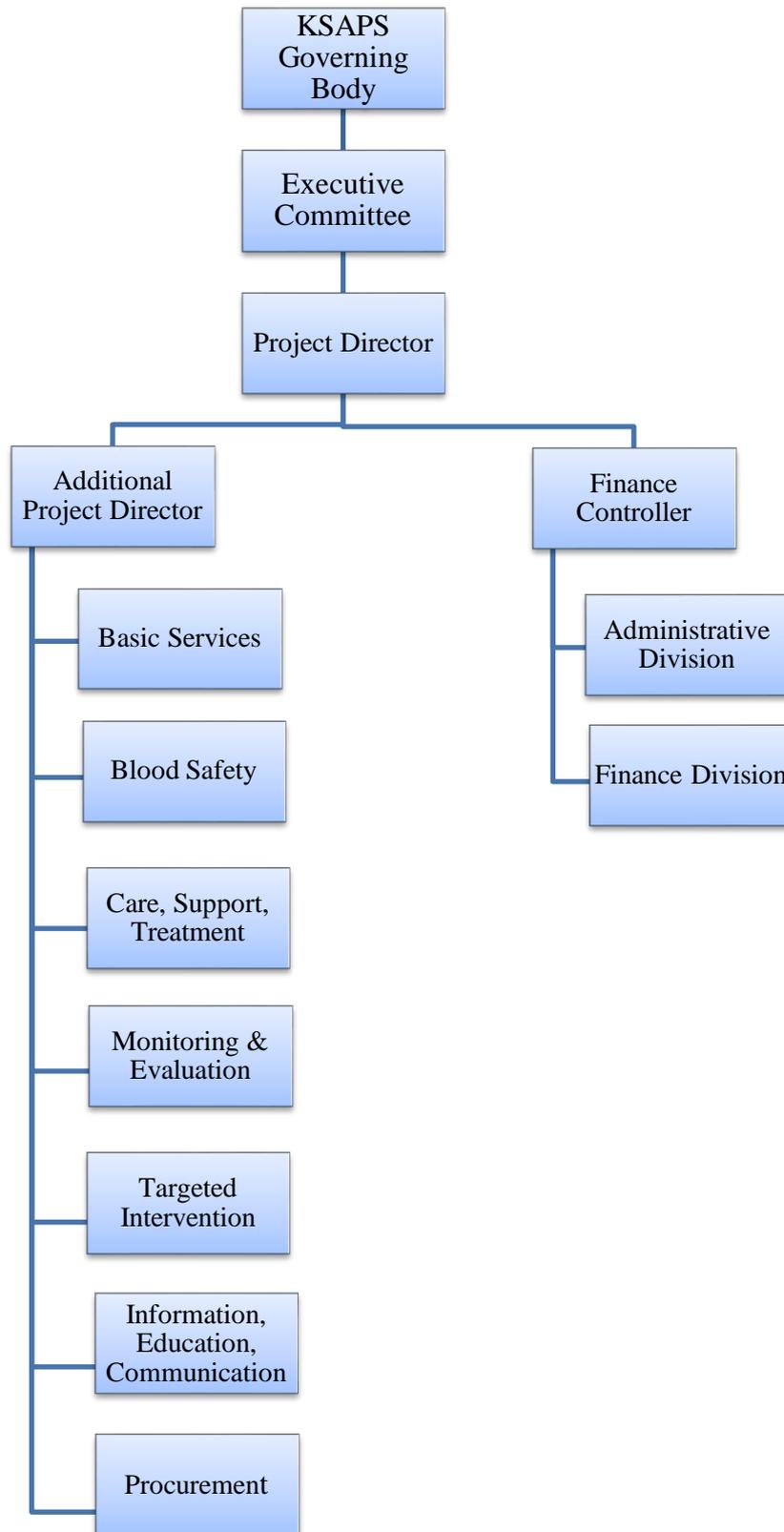
Prevalence of HIV infection among high risk groups in Bangalore Urban has been estimated as 10.14% in FSW and 16.4% among MSM (KSAPS 2010). No data are currently available on HIV prevalence among FSW and MSM in Bangalore Rural. It is likely that the populations of vulnerable communities and HIV prevalence within these communities are under-estimated due to difficulties in accessing members of the FSW, MSM and PWID communities. This lack of access may be caused by problems experienced commonly by vulnerable communities such as stigmatization, discrimination, shame and negative experiences with the government. Such factors have been documented in numerous settings worldwide (Brown 2003; Fleming et al 2000; Shawky et al 2009).

3.4.3 Karnataka State AIDS Prevention Society

The government body responsible for HIV/AIDS in Karnataka is the KSAPS, which has been operating in Bangalore since 1997 (KSAPS 2010). As mentioned previously, the KSAPS is governed by a Governing Body (GB) and an Executive Committee (EC) with representatives from government departments, senior staff of the KSAPS, members of civil society and the private health sector; the GB is headed by the Karnataka Chief Minister and the EC by the Principal Secretary for the Ministry of Health and Family Welfare. The GB has the most decision-making power in the KSAPS, but research participants asserted (see section 7.2) that the GB had ceded its administrative and financial powers to the EC since the GB met infrequently and its membership changed frequently. The Project Director of KSAPS holds the highest position in the KSAPS.

The KSAPS is involved in HIV prevention, treatment, care and support programs throughout Karnataka, mostly through funding partnerships with CSOs. Key responsibilities of the KSAPS include provision of public health and social sector services and planning, administration, monitoring and evaluation of HIV services at the state level. The KSAPS has its headquarters in Bangalore, and functions through the District AIDS Prevention & Control Units throughout Karnataka. The KSAPS organogram is presented in Figure 2 below, to illustrate its organizational structure and the responsibilities of the different divisions.

Figure 2: Organizational Structure of the KSAPS for NACP III



Source: KSAPS 2010

The Care, Support, Treatment and Targeted Intervention departments provide the links between the KSAPS and its funded CSOs. Members of these divisions, along with the EC members and senior management of the KSAPS, determine which CSOs to fund, monitor and evaluate CSO projects and have a direct bearing on the sustainability of the projects implemented by CSOs.

3.5 Summary

This chapter provided an overview of the HIV epidemic in India and in the research setting of Karnataka. It is estimated that nearly 2.1 million people are living with HIV/AIDS in India, which has a general population prevalence of 0.27%. India's HIV epidemic is concentrated within a few high-risk groups, namely FSW, MSM and PWID. The state of Karnataka, where this research was conducted has an adult HIV prevalence of 0.63% and is one of six states that account for over two-thirds of the country's HIV infections. Due to the concentrated nature of the country's HIV epidemic, the government has adopted a targeted intervention approach, with much focus on prevention of HIV among high-risk groups. The government body responsible for HIV/AIDS in the country is the NACO, which functions through state level subsidiaries. The KSAPS is responsible for government HIV programs in the state of Karnataka and a Governing Body and an Executive Committee govern the KSAPS.

CHAPTER 4: RESEARCH METHODOLOGY

4.1 Introduction

This chapter presents the methods used to address the research aims framed for this study. The chapter describes the actual process of research, including sampling and recruitment, data collection, data analysis, and ethical issues that arose during the conduct of the study. The use of self as an instrument in qualitative research as applied to this research is also discussed. Difficulties faced during fieldwork and the strengths and limitations of the study are explored.

4.2 Criteria for Site Selection

The research was conducted in Bangalore, Karnataka between 2009 and 2010. This research uses Karnataka as a case study and as an example of India's HIV policy processes and civil society engagement in HIV/AIDS. Karnataka was chosen as the research site due to its high general population HIV prevalence of 0.63% (NACO 2012b). Most CSOs engaged in HIV-related work in Karnataka have their headquarters in Bangalore; the number and diversity of these CSOs were crucial factors in influencing the selection of the study site. Most importantly, the KSAPS has its main office and key staff members in Bangalore. As mentioned earlier, Bangalore is home to the majority of FSW and MSM in the state. In addition, at the start of this study, I had lived in Bangalore for 13 years and had engaged with CSOs working on HIV/AIDS for nearly five years. Due to my previous engagement with CSOs working on HIV/AIDS and the relationships built through this work, I potentially had greater accessibility to these CSOs and their membership. Language competency in Kannada, the regional language of Karnataka, also influenced the selection of this study site.

4.3 Research Methods

This study was conducted using a qualitative approach. According to Denzin and Lincoln (2000, p.3), qualitative research is a "situated activity that locates the observer in the world. It consists of a set of interpretive practices that make the world visible." This thesis sought to gain an in-depth understanding of the nature of experiences of participation of civil society members, in particular those belonging to vulnerable

communities, in local HIV decision making processes. Exploring the context in which local HIV policies were made and the nature, dynamics and relationships within civil society and between CSO members and the government were critical to this study. Qualitative methods such as fieldwork, in-depth interviews and participant observation, were deemed the most appropriate approaches to gain detailed knowledge of the above-mentioned phenomena. In addition, it was imperative to use qualitative methods to ensure the voices of vulnerable communities were heard during the research process.

Specifically, both phases of this study were conducted using a grounded theory approach or ‘constant comparative methodology’ (Glaser & Strauss 1967). Grounded theory, which originates from the epistemological concept of symbolic interactionism, suggests that meaning is generated and negotiated through interactions with others in social processes (Blumer 1986; Jeon 2004). Grounded theory is a methodology that seeks to construct theory relating to important issues in people’s lives (Glaser 1978; Glaser & Strauss 1967; Strauss & Corbin 1998). This is done through a process of data collection that is described as inductive in nature (Morse 2001), in that the researcher has no preconceived notions to prove or disprove. Rather, issues of importance emerge through participant narratives. This methodology, well-suited to theorizing human understandings, is based on an iterative process characterized by a cyclical interplay between data collection and analysis (Glasser & Strauss 1967; Strauss 1987; Strauss & Corbin 1990). Using this approach, theory or interpretation of the data is initially generated based on early data and comparisons are subsequently made between this and incoming data (Strauss & Corbin 1994). In this way, both the analysis and the theory are ‘grounded’ in the qualitative data, and shaped and modified in accordance with emerging themes. The grounded theory methodology is commonly used to describe and explain social processes within specific contexts (Starks & Trinidad 2007), which this thesis attempts to do in the context of civil society and HIV/AIDS in Karnataka, India. The use of the grounded theory approach during data analysis is further discussed in section 4.3.5.

As mentioned previously, this research was conducted in two phases, with the results of Phase I directing the focus of Phase II. Phase I of the current study was conducted

over a two month period bridging July, August and September 2009. Data collection and fieldwork for Phase II were conducted over seven months between April and October 2010. Multiple data collection strategies were chosen for both these phases in order to increase understanding of the context and phenomena being studied (Duffy 1987; Goffman 1961). Using a grounded theory approach, these methods included fieldwork and informal discussions, participant observation, in-depth interviews and document reviews.

The following tables present a summary of the research methods utilized during Phase I and II of the current study:

Table 2: Phase I Research Methods

Research Objective/Question	Stakeholders	Sample/Selection	Research Methods Used
1.Understand the nature and constituents of civil society engaged in HIV/AIDS in Bangalore	<ol style="list-style-type: none"> 1. CSOs and PLHA networks <ol style="list-style-type: none"> a. Working on prevention b. Working on care, support, treatment c. Receiving government (KSAPS) funding d. Receiving private funding e. Working with vulnerable communities – MSM, FSW, PWID 	<p>Different levels of CSO staff – senior/middle management, peer/outreach workers</p> <p>Identified through preliminary fieldwork and snowball sampling</p>	<ol style="list-style-type: none"> 1. In-depth interviews 2. Fieldwork
2.Capture the realities and voices of PLHA and members of vulnerable communities in relation to their experiences of participation in civil society	<ol style="list-style-type: none"> 1. Networks of PLHA and vulnerable communities 	<p>Different level of network staff – Executive Board, managers, advocacy officers, outreach workers</p> <p>Identified through preliminary fieldwork, volunteer and snowball sampling</p>	<ol style="list-style-type: none"> 1. In-depth interviews 2. Fieldwork
3.Identify local HIV policy making agencies and mechanisms	<ol style="list-style-type: none"> 1. CSOs currently or previously engaged in HIV policy making processes 2.KSAPS staff engaged in policy processes 	<p>Purposive/snowball sampling</p>	<ol style="list-style-type: none"> 1. In-depth interviews

Table 3: Phase II Research Methods

Research Objective/Question	Stakeholders	Sample/Selection	Research Methods Used
<p>1. How do approaches, dynamics and collaborations within civil society influence the development of HIV policies?</p>	<p>2. CSOs and PLHA networks</p> <p>f. Working on prevention</p> <p>g. Working on care, support, treatment</p> <p>h. Receiving government (KSAPS) funding</p> <p>i. Receiving private funding</p> <p>j. Working with vulnerable communities – MSM, FSW, PWID</p>	<p>Different levels of CSO staff – senior/middle management, peer/outreach workers</p> <p>Volunteers, participants not employed by CSOs</p> <p>CSO members part of and outside BHAF</p> <p>In case of PWID, purposive sampling in NGOs working with PWID</p> <p>Identified through preliminary fieldwork, volunteers sought during BHAF meeting and snowball sampling</p>	<p>a. In-depth interviews</p> <p>b. Participant Observation of interactions between CSOs, vulnerable communities (meetings, events where CSOs, vulnerable communities collaborate)</p> <p>c. Document review</p>
<p>2. How do civil society and the KSAPS interact to negotiate and develop HIV policies and programs?</p>	<p>1. KSAPS and other government staff engaged in HIV-related work</p> <p>1. CSOs</p> <p>a. CSOs involved in advocacy and networks of PLHA</p> <p>b. Other prominent NGOs who closely interact with and/or receive funding from the KSAPS</p> <p>c. PLHA, members of vulnerable communities</p>	<p>Key officials involved in HIV policymaking and programs</p> <p>Purposive/Snowball Sampling</p> <p>Different levels of CSO staff – senior/middle management, peer/outreach workers</p> <p>Volunteers, participants not employed by CSOs</p> <p>CSO members part of and outside BHAF</p> <p>Identified through preliminary fieldwork, volunteer and snowball sampling</p>	<p>a. In-depth interviews</p> <p>b. Participant observation of interactions between CSOs and the KSAPS – public meetings, events</p>

4.3.1 Sampling and Recruitment

4.3.1.1 Phase I

Volunteer and purposive sampling techniques (Glasser & Strauss 1967) were utilized as the recruitment approach during Phase I of the study. Initially, I presented an outline of the research at the monthly meeting of the Bangalore HIV/AIDS Forum (BHAF), an informal network of CSOs working on HIV/AIDS in Bangalore. Participants at the meeting included staff of CSOs (senior, middle management, outreach workers and peer educators) and members of the FSW, MSM, transgender and PLHA communities. My contact details were given to the meeting participants and members interested in providing information, either through informal discussions or in-depth interviews, were requested to make contact. However, no potential participants volunteered, possibly due to my limited interaction with the community prior to seeking potential participants. As Phase I was an exploratory exercise and my time in Bangalore was limited, I had not spent much time with CSOs and community members prior to presenting my work at the BHAF meeting. This lack of familiarity and rapport may have contributed to the reluctance of potential participants to approach me and engage in discussions regarding my research. Former colleagues had warned me not to expect meeting participants to volunteer, as research and researchers were not well understood and research had a low priority in the lives of community members, as well as for CSO staff trying to deal with everyday struggles. From previous engagement with CSO members in Bangalore, I understood the perceptions of CSO staff that research was intrusive and that researchers often lacked an understanding of the community's contexts and issues due to limited interaction and absence of fieldwork in most study designs. As a novice researcher in 'the field', I was momentarily distressed at the lack of interest in my work from the CSO community in Bangalore, at least those present at the BHAF meeting. Maher (2002) noted that research is not very high on the priority lists of people who are disadvantaged and that people may be reluctant to allow their lived experiences to become research data. Similarly, Scott (1989 in Maher 2002) emphasized that silence is a classic form of resistance used by the powerless. I became aware of these phenomena soon after I commenced fieldwork.

To gain more insights into the communities and CSOs, and also to understand the community's apparent reluctance to participate in my research, I subsequently visited and held informal discussions with key CSOs working on HIV/AIDS and PLHA networks in Bangalore. This process helped to build rapport with and to understand CSOs' work and how CSO members interacted. With many CSOs this process meant getting reacquainted with key staff members, which was aided by my prior knowledge of key actors and relationships built during my years as a CSO member in Bangalore.

These informal discussions and immersion in the field aided the study in numerous ways. Firstly, this process helped me to become familiar with the field and the changes in CSOs/civil society members during my two-year absence. Also, repeated interactions with the community and hearing their stories helped me to better understand and appreciate the realities of CSO members, PLHA and vulnerable community members. Simultaneously, this process helped to make me more visible and therefore more familiar to community members. My presence in CSOs and introduction by CSO staff to community members gave me some legitimacy, an important factor in building relationships with community members. During visits to CSOs and PLHA networks, I once again requested volunteers for in-depth interviews; this process proved more fruitful, with multiple participants volunteering.

Purposive sampling was used during Phase I to recruit CSO members and policy makers. Purposive sampling permits the researcher to select information-rich participants so as to gain a deeper understanding of the phenomena being studied (Gifford 1996; Glasser & Strauss 1967; Patton 2002). Potential participants were directly approached in a non-coercive manner and invited to participate in the study; I explained the research goals and process, and invited them to participate in the study. As Phase I was exploratory, 'theoretical saturation', the point at which no new data emerges (Glasser & Strauss 1967), was not sought.

Eligibility criteria for research participants in Phase I and Phase II were identical. The criteria were that the participant must have been an active member of civil society engaged in HIV/AIDS in Bangalore, be aged 18 years or older and be able to provide written informed consent (in English or Kannada) for participation in in-depth

interviews. Civil society engaged in HIV-related work in Karnataka comprises a number of sub-groups including PLHA and key populations vulnerable to the infection including FSW, MSM, PWID and transgender people. It was deemed necessary to include all these key communities in this study to gain a holistic and in-depth understanding of civil society engagement in HIV-related work, in particular local HIV policy making

4.3.1.2 Phase II

A combination of sampling and recruitment techniques was utilized during Phase II of the study. I initially presented results of Phase I to the members of the BHAF during their monthly meeting and an outline of the proposed research. Potential participants were requested to indicate their interest in participating in the study. Unlike the previous Phase, during Phase II, this presentation was conducted after spending a month in the field building rapport and conducting informal discussions with CSO members and communities. This time spent on rapport building proved very useful, as community members and CSO staff became familiar with my presence in the field and generated discussion about my research. In addition, many CSO and community members remembered my initial data collection visit and were keen to understand the Phase I results. Following the BHAF meeting, three members of CSOs volunteered to participate in the study. In addition, others present at the meeting referred me to potential participants and circulated my study and contact details to community members. I also made brief presentations of my work and sought participants during two subsequent monthly meetings, at which time additional participants directly approached me.

As the study progressed, participants in both phases of the study were requested to suggest other potential participants, a method of snowball sampling (Biernacki & Waldorf 1981). Building rapport with the community and gaining their trust resulted in participants referring me to members of inaccessible communities, such as HIV-positive transgender women who solicit money from shopkeepers for their sustenance and MSM who were married to women. In Phase II, potential participants who belonged to a previously inaccessible community of HIV-positive transgender women who solicit money for their livelihood and who did not speak fluent Kannada or English came forward. Accessing this community was otherwise quite difficult as they

do not usually participate in networks of PLHA. Although these participants were able to provide written consent in Kannada, they were more comfortable being interviewed in Tamil (the language spoken in Tamil Nadu, a southern state neighboring Karnataka). I felt that these participants brought a unique perspective to the study and therefore broadened the eligibility criteria to include participants who spoke Tamil, a language I also speak.

In the later stages of the study, as themes started to emerge from the data, a purposive sampling approach was utilized to select participants who could provide rich, in-depth information on specific aspects of the research, such as the relationship between the government and civil society, the working of the KSAPS EC and the evolution of civil society on HIV/AIDS in Karnataka. This process continued until 48 participants had been recruited and theoretical saturation, at which point no new insights were obtained (Glaser & Strauss 1967), was achieved. Through purposive sampling, government officials and CSO members engaged in local HIV policy making were also approached to participate in the research. Only state-level representatives of the NACO, from the KSAPS were interviewed for this study and officials of the NACO were not approached for interviews. Interviewing NACO representatives at the national level was not feasible and was considered beyond the scope of this study which focused more specifically on state-level policy making processes. In addition, difficulties in gaining appointments of national representatives of the NACO and other practical difficulties made it unfeasible to interview national-level NACO representatives.

4.3.2 Participant Observation

Goffman (1989) stated that participant observation involves the researcher subjecting herself physically and emotionally to “the set of contingencies that play upon a set of individuals” (p.125) so that researchers can gain a better understanding of participants’ social, work and ethnic situations. Participant observation and immersion in the field enables the researcher to build trusting relationships with participants, enabling the exploration of sensitive issues and the concerns of participants. In my study, in addition to gaining a deeper understanding of participants’ lives, observation also provided opportunities to compare interview data about participants’ experiences via observed interactions between CSO members and with the KSAPS. During Phase II, I

conducted participant observation of key meetings in which different CSOs participated and also meetings between CSOs and the government. The rationale for these observations was to:

1. Identify key actors, contexts and processes involved in civil society and in HIV policy making, and to inform snowball sampling approach
2. Note the types and nature of critical interactions and conversations between participants (KSAPS – CSOs, different CSOs, communities within civil society).

Observations and contents of informal discussions with CSOs and community members were recorded as fieldnotes. Fieldnotes are detailed accounts of the researcher's experiences and observations (Emerson, Fretz & Shaw 1995) that include the researcher's personal feelings and impressions (Fielding 1993).

I observed five key meetings between community members and one high-level meeting between transgender people and top government officials. I also observed events held as part of the Global AIDS Week of Action in 2010, during which civil society members worldwide demanded urgency, accountability and more resources for the fight against HIV/AIDS (ActionAid 2013). In Bangalore, the Global AIDS Week of Action was commemorated through activities such as a human chain rally, street plays outside public hospitals that house ART centres and a candle-light vigil to spread awareness of HIV/AIDS and related issues. I also conducted observations at planning meetings for events and attended and participated in the actual events. Along with other CSO and community members, I held placards with messages about HIV/AIDS, marched through the streets, transported community members and gave out HIV information while street plays were staged. Through this participation, I shifted from being a participant observer to an 'observant participant' (Albert 1997; Brewer 2000; Moeran 2007), which allowed for greater access to information about the conduct and the dynamics between the parties involved in these events. During these events and during my visits to CSOs, I also observed the ways in which different CSOs and communities interacted and collaborated, including instances of apparent tension between civil society members, the ways in which these members reinforced each other, and

views expressed by these members. Informal interactions with CSO members provided me with background information on the work of these organizations, their core constituents, funding types and sources, and the geographical remit of their work. Observational fieldnotes were recorded by hand in notebooks. Prior to data analysis, key observations and incidents that were thought to be critical to support the in-depth interview data, were transcribed using standard word processing software.

4.3.3 In-depth Interviews

Semi-structured tape-recorded in-depth interviews (Silverman 2001; Taylor & Bogdan 1998) constituted the primary method of data collection. In total, 62 interviews were conducted as part of the study, and each ranged between sixty and ninety minutes in duration. In-depth interviews were conducted in both English and the local language, Kannada and recorded using a digital voice recorder. Interviews were conducted in a range of settings including CSO meeting rooms, but also sometimes in my car, outside offices and in stairwells. When interviews were conducted in open spaces within CSO offices, it was ensured that they were held after office hours so that no one could overhear the interview. Semi-structured interview guides (Appendices 2 and 3) were used to elicit information and direct the discussion during both phases of the research. During Phase I, interviews covered the following areas:

1. Evolution of civil society engagement in HIV/AIDS in India/Karnataka
2. Civil society and community stakeholders engaged in HIV/AIDS in Bangalore and Karnataka
3. Civil society initiatives to engage in HIV policy processes
4. Nature of participation of PLHA in civil society.

During Phase II, the guide explored the following key areas:

1. Collaborations between CSOs and the KSAPS to develop local HIV policies
2. Dynamics between CSOs and communities living with and vulnerable to HIV/AIDS
3. Nature and development of local HIV policies in Karnataka.

Questions were asked in a conversational style and probes were used to elicit detailed responses. Liamputtong and Ezzy (2007) highlighted that a good interview is like a good conversation, where one person talks while the other listens, responds and encourages. Similarly, as I gained more experience, I started noting down key areas of information that I needed to seek from each participant and guided the direction of the conversation rather than following a question and answer style of interviewing. This approach resulted in participants discussing many topics beyond those outlined in the interview guide. For example, while not part of the interview guide, most PLHA participants spoke at length about their experiences of first being diagnosed with HIV, divulging this to their family members and the resulting emotional trauma. Transgender and MSM participants spoke at length about revealing their gender and sexual orientation to their families and the subsequent ostracization they faced. At times, these accounts made me uncomfortable although I had heard similar personal accounts from other PLHA in the past. Nevertheless, these narratives proved valuable in humanizing participants, as well as allowing me to appreciate their individual stories of living with HIV.

The demographic characteristics of the Phase I participants are presented in Table 2. Phase I of the current study was conducted over a two month period bridging July, August and September 2009. During this period, 14 in-depth interviews were conducted with CSO members who did not belong to a vulnerable community (n=5), PLHA (n=6), MSM (n=1), FSW (n=1), a transgender person (n=1) and KSAPS staff (n=1) and informal discussions were held with several key CSOs working on HIV/AIDS in Bangalore. No PWID were interviewed.

Eleven key CSOs that worked in prevention, treatment, and care and support, including networks of PLHA were represented in the first phase of the study. Organizations that received individual, government and international donor funding were represented. Although attempts were made to recruit more participants from the government and vulnerable communities, my limited time in the field did not allow for this. Emerging themes from Phase I were used to direct the study and develop research questions for Phase II. On completion of the Phase I analysis and after gaining HREC approval for Phase II, I returned to Bangalore to collect data.

Table 4: Phase I Demographic Characteristics

	CSO Staff (n=10)	FSW (n=1)	MSM (n=1)	PWID (n=0)	Transgender Persons (n=1)	KSAPS Staff (n=1)
HIV Status						
Positive	4	1				1
Negative	6		1		1	
Gender						
Male	4		1			1
Female	6	1				
Transgender					1	
Mean Age in years (range)	41 (26-55)	33	24		40	37
Education						
< 12 years	3	1	1		1	
>12 years	7					1
Type of Organization						
CSO	6				1	
Network	4	1	1			
Government						1
Employment Level in CSO						
Senior	5				1	
Middle	4					1
Community	1	1	1			
Years Active in HIV/AIDS Sector						
1-5	4	1	1			
5-10	4				1	1
>10	2					

The demographic characteristics of the Phase II participants are presented in Table 3. Data collection and fieldwork for Phase II were conducted over seven months between April and October 2010. During this time, 48 in-depth interviews were conducted with government officials (n=6), FSW (n=4), MSM (n=4), PWID (n=3), transgender people (n=6) and CSO members including PLHA employed at CSOs (n=25). In total, 15 PLHA were interviewed during Phase II. Twenty five CSOs, including networks of PLHA that work on HIV prevention, treatment, care and support, and advocacy and research were represented in Phase II of the study. CSOs that received individual, government and international donor funding were also represented in Phase II. Participants represented community, middle and senior management levels of CSOs. The lack of PWID representation was a critical limitation of Phase I. It was ensured that PWID participated in Phase II of the study and in-depth interviews were

conducted with three PWID and informal discussions were conducted with a group of eight PWID.

Table 5: Phase II Demographic Characteristics

	CSO Staff (n=25)	FSW (n=4)	MSM (n=4)	PWID (n=3)	Transgender Persons (n=6)	KSAPS Staff (n=6)
HIV Status						
Positive	6	3	1		4	1
Negative	19	1	3	3	1	6
Gender						
Male	15		4	3		3
Female	10	4				4
Transgender					5	
Mean Age in years (range)	42 (22-58)	36 (33-41)	36 (29-50)	30 (29-31)	32 (20-45)	42 (34-55)
Education						
< 10 years	6	4	2	2	6	
>11 years	19	0	2	1		6
Type of Organization						
CSO	17		1	3		
Network	8	4	3		6	
Government						6
Employment Level in CSO						
Senior	13	1	1			3
Middle	8		1		2	3
Community	4	3	2	3	1	
Years Active in HIV/AIDS Sector						
1-5	9	2	1	3	3	5
6-10	9	2	2			1
>10	7		1			

4.3.4 Document Review

Document analysis involves the study of public and private documents such as the minutes of meetings, newspapers, personal journals, diaries, and letters. It can also include quantitative data in the form of archival records (Tharenou, Donohue & Cooper 2007). Document research depends on the availability, accessibility and authenticity of the intended study documents (Bowling 2002). For this study, I reviewed both published and unpublished government and CSO policies and Annual Action Plans (AAP), most of which were available in the public domain. All reviewed documents were written in English.

Some documents were not reviewed as systematically as I would have liked due to lack of access. For example, I was denied permission to see the minutes of meetings of the KSAPS EC, the primary HIV policy making body in Karnataka. The minutes of these meetings were not made available to anyone outside of the EC, however, one of the research participants (an EC member) allowed me to review the minutes of 25 meetings for the period 2001-2010. I was not allowed to make copies of these documents nor take them outside the holder's office, but took brief notes on the discussions that took place, the decisions of the EC and the individuals involved in these discussions and decision-making processes. I then coded these notes and linked the information with interview data stored in NVivo software. These documents were used to identify key actors in local policy processes, issues discussed during key meetings and the progress and follow-up of program decisions (this is discussed further in Chapter 7). In addition, I reviewed the proposed budgets and expenditure statements of the NACO and the KSAPS. These documents were used to support interview and observational data.

4.3.5 Data Analysis

Data analysis for both phases of the study was conducted using a grounded theory approach (Glaser & Strauss 1967). This process, also known as the constant comparative method (Glaser & Strauss 1967) is an iterative approach to data analysis, involving a constant interplay between data collection and analysis. Using this approach, theory is generated from initial analysis and comparisons are made between this and new incoming data (Strauss & Corbin 1994). The researcher analyses data by constant comparison, initially of data with data, then progressing to comparisons between their interpretations translated into codes and categories and incoming data. The constant comparison of analysis to the data grounds the researcher's final theories in the participants' experiences (Mills, Bonner & Francis 2006). This process is suited to theorizing human understanding and facilitates the development of theory that is 'grounded' in qualitative data and modified based on emerging themes (Glaser & Strauss 1967; Strauss 1987; Strauss & Corbin 1990). This grounded theory approach informed data collection and analysis.

The final data set for Phase I consisted of 14 in-depth interview transcripts and approximately 50 pages of handwritten fieldnotes. The data for Phase II consisted of 48 in-depth interview transcripts and approximately 200 handwritten pages of fieldnotes. Interviews conducted in English were transcribed verbatim using standard word processing software. Interviews conducted in Kannada were translated and transcribed simultaneously in English. In addition, relevant sections of the fieldnotes were typed in standard word processing software. Data analysis was conducted in a reflexive and iterative manner throughout the research process. I attempted to finish transcription as soon as possible after interviews were conducted, noting emerging themes and areas for further exploration, in order to guide the process of purposive sampling. During re-reading of the transcripts and fieldnotes, summary sheets noting emerging themes and concepts were made for each transcript during the Phase II analysis. This process also helped to identify gaps in the collected data and topics for further exploration, which were then fed back into the revised interview guide. According to Padgett (1998), this is a process of going back and forth, between problem identification, data collection, analysis and writing up.

NVivo is a software package that facilitates the management of qualitative data by allowing researchers to store, code and retrieve data and therefore assists in identifying themes (Bryman 2001). Individual transcripts and typed fieldnotes were coded using NVivo 8 (Phase I) and NVivo 9 (Phase II) software and emerging themes were noted. Thematic analysis helps to identify themes emerging from the transcripts of participant interviews (Braun & Clarke 2006; Liamputtong 2009; Markovic 2006; Minichiello, Aroni & Hays 2008). Data analysis involved the three key processes of description, classification and connection (Gifford 1998). Axial and open coding, commonly used analytical methods for the grounded theory approach (Starks & Trinidad 2007), were utilized to classify data which were then analysed to determine any relationships between or within categories and for any contrasts (Rice & Ezzy 1999). First, transcripts and fieldnotes were read and re-read to identify emerging categories. Initially, open coding was done as transcripts were compared and classified into categories. Many sections of participant narratives were assigned to more than one code and category. Later, axial coding (Bazeley 2007; Strauss 1987; Strauss & Corbin 1998; Minichiello, Aroni & Hays 2008) was conducted to determine any relationships

and regularities between and within categories, thereby recoding and reassigning categories and participant narratives. Initially emerging categories revolved around antagonism between civil society members and the government and the nature of PLHA participation in civil society. As analysis progressed, themes associated with power, trust, leadership and accountability, community relationships and policy contexts emerged and recurred throughout the data analysis. These themes form the basis of the three analytical chapters of this thesis. Direct quotations from participants are extensively utilized in these chapters to enable the reader to assess the relationship between the data and the analysis and to give voice to the research participants.

An inductive approach (Morse 2001) to data analysis was utilized, wherein limited pre-determined structures and analytical frameworks were set out at the beginning of the research. Rather, utilizing a thematic content analysis method, the collected data was used to develop a structure to the analysis. No single conceptual framework was utilized for analysis as the study attempted to seek information regarding a number of areas related to civil society participation from diverse stakeholders and to avoid limiting the scope of the analysis. Instead, a number of analytical frameworks have been utilized in the results chapters to organize, clarify, explain and interpret the data. In addition, these analytical frameworks and theories assisted in adding value to my interpretations of the collected data. These analytical frameworks have also been used to support my data analysis and situate my data within the broader theoretical and practical literature.

4.4 Ethics in Research

This section discusses the ways in which the conditions of the UNSW ethics approval were met and also ethical issues that arose during fieldwork.

4.4.1 HREC Approval

Ethical approval for both phases of the study was obtained from the Human Research Ethics Committee (HREC) of the University of New South Wales (UNSW) (Approval 09123 for Phase I and 10067 for Phase II). Potential participants were provided with written and verbal information on the purpose of the research and the ways in which the resulting data would be utilized. Participants were also given information about

the informed consent process should they wish to revoke their consent and on the complaints redressal mechanisms, both locally in Bangalore and through the UNSW HREC. It was also explained to each research participant that the interviews would be digitally recorded and stored using pseudonyms in order to protect their confidentiality. These pseudonyms are used to identify participant narratives in this thesis.

All participants provided written informed consent for conducting interviews (in either English or Kannada). In accordance with HREC guidelines, all interviews were conducted in private or, when this was not possible, interviews were conducted during times when they could not be overheard. All interview participants living with HIV/AIDS (including those belonging to FSW, MSM, PWID and transgender communities) were reimbursed Rs.150 (approximately AUD\$5) for their time and any inconvenience or loss of income resulting from their participation in the study. Reimbursement to this group was provided also to acknowledge and show respect to their knowledge and experiences. In cases where participants had to travel to the interview venue, travel costs were also reimbursed in accordance with the HREC approval.

4.4.2 Ethical Issues Arising During Research

During fieldwork, I realized that conducting ethical research with vulnerable communities required more than compliance with the conditions of approval specified by the HREC. Formal guidelines like those delineated by the UNSW HREC and the Australian National Health and Medical Research Council (NHMRC) provide only limited practical assistance for dealing with the ethical dilemmas that commonly arise when conducting research with poor and marginalized communities (Ho 2006; Maher 2002). Before entering the field, researchers also need to carefully consider potential ethical and emotional (Vanderstaay 2005), as well as legal challenges (Maher 1997, 2002). Below, I consider some of the ethical issues that arose during my fieldwork.

Participants from PLHA and vulnerable communities often shared sensitive personal information with me, especially in relation to experiences in CSOs and dealing with government officials. Some CSO participants described experiences of participating in

government meetings and also provided examples of corruption and collusion within government agencies. These data posed a potential risk to participants if their confidentiality was not protected. Therefore, protecting the confidentiality of my participants and their narratives was my primary concern in the field and in reporting study results. However, the importance of confidentiality was less apparent for some, especially government officials, who constantly enquired about which CSOs I had visited, where I was accessing my participants and to which other government officials I had spoken. In one instance, members of a government-funded CSO wanted permission letters from the government for me to meet their community members. I felt that the government knowing which CSOs I was visiting could potentially jeopardize the identities of the participants affiliated with these organizations. However, this CSO's need to 'be safe' in case the government questioned their involvement in my study overrode the need to protect the confidentiality of any potential participants accessed through their organization. A similar disregard for confidentiality was displayed by the government official who was responsible for providing this permission letter. When I explained to this person the need for a permission letter, without identifying which CSO requested it, the government official suggested: "*Why don't we decide which organizations you will visit together?*" (Fieldnote, 23/09/2010). When I politely declined and informed this person that I needed to protect my participants' confidentiality, they suggested that I decide on my own and let them know which CSOs I would be visiting, so that they could provide separate permission letters to each of those organizations. As I attempted to explain to them that I was bound by ethical protocols and an obligation to my participants to protect their confidentiality, this person's demeanor changed; previously enthusiastic, this person suddenly lacked the time to discuss the matter further. In order to protect my participants' confidentiality and also appease the KSAPS official and the concerned CSO, I requested the KSAPS to provide me with a blanket permission letter which authorized me to visit any of the KSAPS-funded CSO projects. The KSAPS official relented and acceded to this request. Prior to such experiences, my understanding of protecting confidentiality was restricted to storing interview transcripts using pseudonyms in password-protected computers. As the example above demonstrates, protecting participants' confidentiality in the field is not so simple.

Perhaps the biggest ethical challenge that I faced during fieldwork was in accessing PWID. One CSO providing HIV services to PWID refused to allow me to meet their community members without the abovementioned permission letter. I felt that the permission of the government was seen to be more important than the willingness of community members to meet me. In other instances, members of one CSO requested that I gain permission from their organization's directors (in line with their organizational culture) before they could agree to participate. I chose not to interview these individuals, since seeking their superiors' permission would breach their confidentiality. However, in relation to accessing the PWID community, the idea that PWID would be 'allowed' to meet a researcher only if the government permitted it, appeared condescending and implied that this particular constituency's right to speech and freedom to participate in research was dependent on the government. Not once did any of these CSO members ask about any potential harms that participating in my study would pose for their PWID clients. On the contrary, I got the impression that such factors were of little consequence, as long as they had the government's permission in writing. By being involved in this process of seeking government permission to speak to PWID, I felt that I would be validating the perception that PWID did not have a voice and consequently felt very conflicted. However, I also needed to follow the rules of this particular CSO in order to gain access to a previously inaccessible community. As a researcher, the need for valuable data and filling the gap in information about the perspectives of PWID guided my decision to follow this CSO's protocol of seeking the government's permission prior to meeting the community with which they engaged.

Another issue I faced was not knowing whether I was giving enough back to my participants for the time and expertise they shared. In addition to reimbursement of members of vulnerable communities living with HIV/AIDS and PLHA from the general community for their time and travel, I tried to help community members and CSOs in as many ways as possible. Most often this was through giving participants a lift to their homes or wherever else they were headed. I also helped with referrals to health and NGO services and other unrelated services such as printers and designers, depending on the needs expressed by individual participants. My fervent note-taking

during CSO networking meetings resulted in me often being ‘volunteered’ as the official scribe for these meetings, especially when none of the other meeting participants volunteered to minute the proceedings. While these small services assuaged my need to do something to assist my participants, I felt that my assistance was meager in comparison to the needs of some participants.

While I had doubts about whether I could repay my debt to participants, I felt simultaneously that some participants expected too much from me, not individually, but from the study findings. Some PLHA participants explained to others that my work could potentially greatly influence the NACO and the KSAPS and that I would take all my findings to NACO and the KSAPS and demand action. In order not to raise unrealistic expectations, I had to explain to these participants that while I aimed to share my findings with many groups, I had little control over the outcome of the research and that the study may not have the impact they expected.

Remuneration of participants from the PLHA and other vulnerable communities also posed an interesting challenge, with a few CSO members advocating that I reimburse the CSOs these participants worked for rather than individual participants. They argued that such a contribution would aid in the sustainability of the CSO and in turn, perhaps assist more PLHA than only the individual participant. While I saw the logic in this argument, I did not agree and chose to reimburse individual participants to acknowledge and respect the time that each had taken to contribute to my study. For me, their willingness to participate in the research and to spend time with me took precedence over organizational sustainability. Participants’ approaches to reimbursement varied; only four participants asked how much they would be reimbursed prior to conduct of the interviews. Some participants took the money silently and with gratitude and others refused to take it noting that “*How can I take money from you? You are doing such a good thing*” (Fieldnote, 30/06/2010). I had to insist on reimbursing these particular individuals for their participation.

While not an ethical dilemma, I was also particularly challenged by my interviews with three transgender women, two of whom were HIV-positive, who begged on the streets for their sustenance. Historically in India, most transgender people engage in

either sex work or begging to survive (Nanda 1986, p.35). This is due to lack of education and the limited employment opportunities available to this community (discussed further in Chapters 5 and 6). Though I had met many sex-working transgender people previously, I had not met transgenders who begged for money on the streets, as they rarely participate in civil society. These women stated that they chose to ask for money on the streets rather than engage in sex work. These participants elaborated on their experiences of begging for survival, describing continual harassment and arrest by the police, and being taken to the ‘beggars colony’ (a rehabilitation center) and bribing the guards to be released. They also explained the extent of human rights violations they faced in the rehabilitation centers. The ease with which these participants spoke about their traumatic experiences was both fascinating and disturbing. Prior to meeting these transgender women, I had not confronted experiences of such dire poverty among my participants. These transgender women earned Rs.200 – Rs.250 (approximately AUD\$6) daily and spoke of times when they had very limited food and not enough money for health care. They were happy to receive reimbursements for their time and noted that I was reimbursing them nearly their entire day’s expected earnings for one hour of their time. Their experiences of extreme poverty and human rights violations challenged my thoughts on poverty, survival and the lived experiences of this highly marginalized community.

4.5 Self as Instrument

Grbich (2004) argued that qualitative research must be reflexive, meaning the researcher should constantly “take stock of their actions and their role in the research process” (Mason 1996, p.6). In qualitative research, it is imperative to provide information on the researcher who is the key “research instrument” (Gifford 1996; Patton 2002) and accept that the researcher is part of the research setting, context and culture they are trying to understand (Liamputtong & Ezzy 2007). Reflexivity is the process whereby researchers place themselves under scrutiny and acknowledge ethical and other dilemmas that may arise during the research process (McGraw, Zvonkovic & Walker 2000). Maher (2002) stated that fieldwork is a social process that provides opportunities to learn about others as well as ourselves. In this section, I elaborate on the reflexive process that I engaged in during the study and the lens through which I observed life, as well as this research.

My education and previous work experiences with PLHA across India shaped this research. I began this study as a 27-year-old novice researcher with prior training in social work and public health. At the commencement of the study, I had been engaged in HIV-related work in India for four years; one year as a student social worker and three years as a consultant to the National HIV/AIDS Unit of an international funding organization. As a student social worker, I spent one year working in a care home for HIV-positive women and children. During this time, I witnessed extensive physical and emotional suffering and the stigma and discrimination faced by this group, and occasionally was part of a group that would go to the morgue to collect the bodies of PLHA who had died. I also witnessed beautiful and energetic children wasting away due to the non-availability of paediatric ART. I held their hands during their last days and listened quietly while they asked me to do something about their pain. The lives and stories of the PLHA I worked with left a lasting impression and motivated me to do something. It was their lives that shaped my subsequent interest and career in HIV/AIDS. Later, as a professional, I continued to work with PLHA, mostly women and children, and (to a lesser extent) with FSW and MSM. I was involved in building the capacity of PLHA and national and local advocacy campaigns to protect their rights. This study topic arose from the constant questions that I asked myself during these campaigns. PLHA and CSO members put in so much effort, yet year after year it felt as if they were demanding the same services and the same rights; often I wondered what influence, if any, they were having on HIV policies and programs in the country. The question of the extent to which they were influencing the government, combined with my previous engagement with CSOs and PLHA in Bangalore, helped to define my choice of thesis topic. I viewed conducting research on the influence of PLHA and CSOs on policy making as having potential future benefits for PLHA and other vulnerable communities. Simultaneously, this process contributed to my aspiration to do something for PLHA.

Evered and Louis (1981) introduced the terms *inquiry from the inside* and *inquiry from the outside*. They characterized inquiry from inside by the “experiential involvement of the researcher” wherein the researcher learns by becoming an actor in the field (p.385). In contrast, inquiry from the outside was characterized by the “detachment of

the researcher”, in that the researcher learns by taking the role of an onlooker (Evered & Louis 1981, p.385). Having previously worked with CSOs and PLHA in Bangalore meant that in some respects I was an insider; this status provided me with many advantages, including sharing a language, cultural and traditional beliefs and of course, an understanding of the contexts in which HIV thrives in Bangalore/Karnataka. Due to these previous experiences and shared beliefs, I had the advantage of gaining an *emic* perspective (Headland, Pike & Harris 1990). This insider status made it easier to build rapport and gain the trust of research participants. However, for other reasons, I was also an outsider. I had returned to Bangalore as an independent researcher, a neutral observer and intending to assume a less activist role. I had also been living in Australia for two years prior to my return to Bangalore for this study, which led many in the field to introduce me to others as “Sowbhagya from Australia”. During my two-year absence from ‘the field’, many new players entered the HIV/AIDS field in Bangalore and Karnataka and I was a stranger to them. In these respects, I was interpreting the CSO/PLHA culture from the outside, through an *etic* perspective (Headland, Pike & Harris 1990). Abu-Lughod (1991, p.137) used the term “halfie” to define a person whose national or cultural identity is mixed by virtue of migration, overseas education or parentage. Being a linguistic and cultural “halfie”, I was able to communicate effectively and conduct interviews with participants in both English and Kannada and had the cultural understanding to relate to the experiences shared by participants, which again helped to gain an *emic* perspective. However, as I did not experience the illness and marginalization of my participants, I was able to maintain sufficient distance between their experiences and mine (Abu-Lughod 1991), thus also giving me an *etic* perspective.

A potential threat to my insider status was the power differential between the participants and me due to my education and socioeconomic status. I was conducting a postgraduate study, while many of my participants did not have a high school education. Initially I had not considered this difference in education levels to be of consequence; however, after I entered the field, I realized that the some of the terms I was using (for example, policy and policy making process) did not make sense to some participants. Consequently, I had to revise and simplify my questions in order to speak in terms that made sense to these participants.

Studying abroad also suggested a life of privilege, which made some participants question why I was interested in their stories. For some participants, my living in Australia equated with having access to significant financial resources. In one instance, during a monthly meeting of the BHAF, the discussion revolved around appointing a full-time HIV-positive staff member to coordinate the BHAF's activities. Many CSO members said that they did not have the funds to support this staff member. I was shocked when Tina and Indira, both women living with HIV/AIDS whom I had known for nearly five years, turned to me and said "*Why don't you fund this position? You live in Australia and you must earn a lot*" (Fieldnote, 18/06/2010). In relative terms I was much more privileged than the community members, but that I was a full time student with a nominal income was not relevant to them. The mere fact that I could afford to live and study in Australia made me (in their eyes) financially capable of funding this staff position. While some participants considered me to be from a more privileged socioeconomic background, for the most part, participants expressed surprise and happiness at my interest in their lives and my desire to produce research that captured their voices.

My life choices also set me apart from many of my participants. Female participants in particular considered me to be younger and therefore inexperienced at "knowing the problems women face". Many female community members enquired about my family and whether I had children. Not having a child yet was sometimes viewed as a trade-off for being well educated and currently undertaking a PhD. For some, not having a child despite being married for almost five years was contrary to what is expected of a woman in Indian society. As a result, I received much advice from female participants about the need to have children while I was "still young" and that children were more important than a PhD. While this type of advice may have been proffered due to the time I spent with participants and the rapport built between us, it is also customary in Indian culture for women to ask other women about their marital status and children and to give advice. During the first such instance, I felt awkward at being provided such intimate advice and was reluctant to divulge information about myself. However, further consideration led me to understand that I was also encroaching on their privacy. I wanted to know their experiences and feelings but was feeling awkward about

revealing some of mine. I realized that I was asking participants to disclose intimate details about their lives, but was reluctant to reciprocate when questions were asked about my life. Consequently, I became more relaxed about telling people about my own life story when asked and began to respond to advice on childbearing in a much more light-hearted way. Self-disclosure is important in conducting sensitive research with vulnerable groups (Bergen 1993; Kaufman 1994; Wenger 2002) and being open with participants about the researcher's own life experiences can facilitate rapport and trust among the participants (Reinharz & Chase 2002; Vance 1995). Self-disclosure and understanding the need for reciprocity in sharing information greatly assisted in building rapport and trust with my research participants.

4.6 Strengths and Limitations

The establishment of trusting relationships with the research participants was a significant strength of this research. Building trust and rapport is imperative for conducting research with vulnerable communities (Booth 1999; Reinharz & Chase 2002; Russell 1990). Seymour (2001) argued that a researcher's ability to establish rapport and build trusting relationships with participants is critical to research success. As mentioned earlier, the process of conducting fieldwork and building rapport allowed me ready access to PLHA and members of vulnerable communities. Familiarity with CSOs and community members and the mutual trust and respect developed during fieldwork were fundamental to gaining access to community members and also to enhancing the depth of narratives provided by participants. Gaining participants' trust meant that they were willing to share sensitive information regarding their experiences of bullying, corruption and power struggles within CSOs and PLHA networks and to provide details about their lived experiences with HIV/AIDS. The depth of the narratives participants presented significantly improved my understanding of the dynamics between communities and CSOs and the relationships between CSOs and the KSAPS.

Another strength of my study was its rigour, which was enhanced by the use of multiple data collection methods and data sources. Fieldwork involving methodological triangulation (Goffman 1961; Patton 2002) through participant observation, informal discussions, review of key documents and in-depth interviews

aided greatly in engaging participants and exploring their experiences. The combination of data obtained through documents, participant observation and in-depth interviews allowed data to be cross-validated. In addition, the research utilized data source triangulation (Goffman 1961) to ensure rigour, using multiple information sources such as CSO members, PLHA, FSW, MSM, PWID and transgender people. Recruitment of members of diverse communities through snowball sampling (Bernard 1988; Biernacki & Waldorf 1981) in Phase II also facilitated the identification of gaps in the data and issues to be followed up or clarified.

Accurate translation and back translation of transcripts by a bilingual English-Kannada speaker familiar with the HIV epidemic in Bangalore and Karnataka also enhanced the rigour of this study. Since I do not read or write Kannada, it was not possible to transcribe it directly. Instead, I simultaneously translated and transcribed Kannada interviews in English. This process was both difficult and time consuming and at times it was difficult to capture the exact meanings of participants using English terms. Transcripts and recordings of six randomly selected Kannada interviews (two from Phase I and four from Phase II) were given to a bilingual English-Kannada speaking former colleague to check their accuracy. This process helped to ensure that the meanings and interpretations of participants were captured adequately during translation. In addition, the data presented in this thesis are in narrative form and direct quotations from participants are used to illustrate the correlation between the data and my conclusions and the validity of my interpretations (Bruner 1986; Hyden 1997). The use of direct quotations also serves the purpose of providing a glimpse of the community's realities and experiences, particularly for readers who have limited knowledge about HIV/AIDS, the diversity of the vulnerable communities affected by the HIV epidemic and civil society engagement in HIV/AIDS in Bangalore and in India.

Phase I participants were provided with plain language summaries of the Phase I data in order to fulfill my ethical responsibility to share findings with participants and their communities. This process proved useful in ensuring rigour as the majority of participants communicated their understanding and perspectives on the findings. This process ensured that emerging themes of Phase I were grounded in the realities of

participants. Plain language summaries of the results of both phases of my research will be sent to all participants upon completion of the thesis.

I faced several difficulties during the data collection process. Fieldwork was time-consuming and at times physically and emotionally draining. Transcribing and translating interviews while simultaneously conducting fieldwork was also mentally exhausting. Some participants became emotional during interviews, but it was always a controlled emotional response. During these times, I stopped the interview until the participants felt comfortable resuming the interview. However, some participants requested that I not stop the interview and wanted their accounts and emotions to be recorded. The ease with which PLHA spoke of their imminent deaths both challenged and surprised me. Often I acquired sensitive information during my interviews and listened to multiple accounts of death, dying and violence. Some participants described highly traumatic experiences without expressing any emotions. I was disturbed with these accounts because they illustrated how these participants had come to terms with the trauma in their lives. Despite having developed an ability to detach my emotions from my work through previous engagement with PLHA, this exposure to illness, death, poverty and gross human rights violations took an emotional toll. I discussed these feelings with my supervisor and also a close friend who was conducting research with PWID in another Indian state, which allowed me to better channel my emotions.

Setting up appointments for interviews was often frustrating, particularly with government employees. Gaining access to organizations and individuals who are in power can be a major challenge for policy researchers (Exworthy 2008). I spent a lot of time making phone calls in order to set up interview times. Sometimes CSO members would arrive late for interviews, but for the most part they were apologetic about making me wait. With government officials, however, it was a completely different experience. I spent hours in government offices, waiting for participants to find the time for interviews despite having made and confirmed appointment times. Many hours of fieldwork were spent outside these officials' offices waiting to be called, sometimes only to find that the participants were not in the building or even in the state.

I arrived for my 3pm meeting with Arun, only to find his seat empty. His assistant informed me that he was on tour and had not come back. I informed her that he had confirmed the appointment through SMS the previous afternoon and she responded that in that case, he was likely to come in. I sent him a message informing him that I was in the building. After waiting 35 minutes, I decided to use my waiting time more efficiently and decided to move up one floor to chase up a letter I needed to visit some government-funded CSOs ... 5pm and I'm still waiting for Arun ... 5:15pm and I finally receive an SMS from Arun stating that he was travelling to a rural district in Karnataka and could not meet me anytime soon. It would've been good to inform me!! (Fieldnote, 25/09/2010).

My constant presence in government offices made me a familiar face, particularly to the support staff. Kind office assistants often offered me tea, and sometimes cake from birthday celebrations and frequently reassured me that the official I was waiting for would call me in soon. I was touched by these gestures, particularly since I often felt invisible in these offices. Initially, I viewed the innumerable hours spent waiting in government offices as lost opportunities for meeting other participants or participating in CSO events. While this was frustrating and made me angry, as time passed, I began to relax and to acknowledge that this process was typical of the Indian bureaucracy. I resolved to play their game in order to gain my data. In the government setting, I was at times also palmed off to a “subordinate”, who “could provide all the necessary information”, despite having previously met these government officials, discussed my work with them and explained why their personal accounts on the topic were crucial. While I attempted to provide explanations about why it was critical for me to interview particular government officials, some high-ranking officials stated that they just did not have the time to participate in an in-depth interview. In these instances, I provided information regarding my study and its objectives to the “subordinate” and discussed their work informally but did not conduct in-depth interviews. Some of these “subordinates” were helpful and took time to explain programs and programmatic issues; others clearly viewed me as a disruption to their work and asked me to come

back later. I soon realized that research was not a major priority for some government officials.

In contrast to many government officials, community members willingly gave their time and expertise and for the most part, arrived punctually and valued my work and time. Several participants also mentioned that no-one had asked them about their lives and experiences in such detail prior to my interviews and clearly appreciated that I had chosen to spend years studying their communities. As a result, these participants were happy to share their time and experiences with me.

As well as many strengths, this study has limitations. In Phase I, due to its formative nature and time constraint, I was only able to interview one participant each from the FSW, MSM and transgender communities and the KSAPS. Another limitation of Phase I was the sample's lack of KSAPS officials involved in local HIV policy processes. Despite vigorously seeking appointments, I was unable to meet key KSAPS policy makers during Phase I. A further limitation of the Phase I study was the absence of any representation from the PWID community, a group at high risk of HIV infection in both India and Karnataka.

During Phase II, I was able to interview participants from the MSM, FSW and transgender communities until data saturation was reached. I was also able to interview three PWID and to conduct informal discussions with a group of eight. The process of accessing PWID was time-consuming (as mentioned in section 4.4.2) and I had to convince many people that it was necessary. However, in spite of many attempts, I was unable to interview any female PWID. According to participants, female PWID faced more stigma than their male counterparts and also were less likely to access NSPs. Also, as mentioned earlier, purposive sampling was used to select information-rich interview participants but a few government officials clearly stated that they did not have the time to speak with me and opportunities to obtain rich data were foregone. While I tried to fill these gaps in information through interviews with other government staff, these attempts were not always successful.

Data collection was conducted until data saturation was achieved, a key aim of theoretical sampling (Corbin & Strauss 1990; Strauss 1970). It was determined that theoretical saturation was reached when no new data was emerging during interviews. Even though most data were saturated, there were still gaps in the information sought on local HIV policy processes in Karnataka during Phase II. Past and present CSO members of the KSAPS EC had been interviewed but questions remained unanswered regarding the true nature of the policy making process, the steps involved in policy decision-making and the extent to which different stakeholders participated in policy making. In addition, lack of information on the work of the EC and the secrecy that surrounded local HIV policy making – which extended to EC members being told by government officials not to discuss EC decisions with anyone else (as documented in the meeting minutes) – contributed to this gap in my data. This secrecy is illustrative of a policy process that is neither open nor transparent, and is discussed further in Chapter 7.

CHAPTER 5: SETTING THE CONTEXT

5.1 Introduction

This chapter presents the results of Phase I of the study. First, data regarding the CSOs engaged in HIV/AIDS work at the time of conduct of the study are presented. Next, the nature of the dynamics within civil society are discussed to provide a sense of the communities and CSOs engaged with during the course of this research and the ways in which they interacted and formed relationships. The chapter also explores the nature of the relationship between CSOs and the KSAPS. The nature and levels of PLHA participation in civil society are also illustrated. Finally, the chapter documents how these results informed the development of the Phase II study.

5.2 CSOs Engaged in HIV-Related Activities in Bangalore

While exact numbers were not available, research participants estimated that there were nearly 50 separate CSOs (including networks of PLHA and vulnerable communities) engaged in HIV/AIDS in Bangalore in 2009/2010. The numbers varied over time due to CSOs initiating or ceasing work based on funding. Most CSOs that engaged in HIV-related activities had their headquarters in Bangalore and worked in Bangalore as well as in other districts of Karnataka.

According to CSO members, civil society engagement in HIV/AIDS in Karnataka was initiated in the early 1990s after the impact of the HIV epidemic became irrefutable. Internationally, the first response to the HIV epidemic was from PLHA, their families and civil society, who organized themselves to tackle the epidemic (UNAIDS 2006). Similarly in Karnataka, research participants stated that CSOs became involved in HIV/AIDS through the needs and concerns expressed by affected communities. CSOs working on HIV/AIDS in Bangalore were diverse in terms of their size, areas of engagement, funding and the core constituents with whom they engaged. These CSOs ranged from international organizations to small networks of PLHA. The CSOs engaged in HIV/AIDS, their funding sources and the type of activities they engaged in are listed in Appendix 1.

The CSOs engaged in HIV-related activities in Bangalore differentiated their activities along the lines of prevention, treatment, care and support, advocacy and research activities. The majority of CSOs in Bangalore worked on HIV prevention while a minority worked on treatment, and care and support. Government-funded CSOs largely carried out prevention activities based on the targeted intervention approach and consequently focused on vulnerable communities of FSW, MSM, PWID and transgender people. Prevention activities ranged from raising awareness about HIV/AIDS, condom promotion with FSW, MSM and transgender people, prevention of parent to child transmission of HIV, health education campaigns and provision of clean needles and syringes for PWID. CSOs engaged in the treatment, and care and support of PLHA provided these services through care homes in and around Bangalore. Unlike most prevention-focused CSOs, those that focused on treatment and care and support engaged with PLHA from all vulnerable communities and the general population.

In addition to CSOs, networks of PLHA and vulnerable communities contributed to civil society engagement in HIV/AIDS in Karnataka. These networks were community-based, not-for-profit organizations that mostly employed community members and promoted the rights of PLHA and other vulnerable communities. At the time of fieldwork (2009 – 2010), there were at least 10 separate PLHA networks in the city of Bangalore, while each of the remaining districts in the state had at least one functioning PLHA network (Karnataka Network of Positive People 2012). The PLHA networks in Bangalore were mostly affiliated with larger CSOs while the majority of the other district-level networks were subsidiaries of the state-level Karnataka Network of Positive People (KNP+, a subsidiary of the Indian Network of People living with HIV/AIDS). All PLHA networks in Bangalore provided supplementary nutrition to their members and assisted PLHA with accessing employment and education. The PLHA networks also provided individual and group counselling and awareness programs on living with HIV/AIDS and the rights and entitlements of PLHA. A few of the networks also assisted in the development of small businesses (such as catering and tailoring) for PLHA. Support networks for vulnerable communities such as FSW and MSM were fewer in number but provided similar services to their members. There were no separate networks for transgender people affected by HIV/AIDS at the

time of the research; instead, transgender people were included in support networks for FSW and MSM.

Many CSOs in Bangalore collaborated to conduct advocacy activities through the BHAF, a network of organizations working on HIV/AIDS related issues, which advocated for the rights of PLHA and other vulnerable groups. Similarly, the Indian People's Alliance to Combat HIV/AIDS (IPACHA) was represented in Bangalore. These CSO networks attempted to bring together different CSOs to work towards the unifying cause of preventing HIV transmission and improving the lives of PLHA regardless of their funding sources and types of activities.

The majority of CSOs in Bangalore received government funding through the KSAPS and private funding through national and international donor agencies. At the time of fieldwork, the major donor agencies that funded HIV-related activities in Karnataka included the Tata Trust, the Bill and Melinda Gates Foundation (BMGF), Christian Aid, the Elizabeth Glaser Pediatric AIDS Foundation and the International HIV/AIDS Alliance. In addition, bilateral and multilateral funding agencies such as the Canadian International Development Agency (CIDA), USAID, the Department for International Development (DFID), the World Bank, UNICEF, the United Nations Development Program (UNDP) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM/Global Fund) also funded CSOs in Karnataka. The Global Fund funds were channeled to Karnataka through the NACO and its subsidiary, the KSAPS.

In addition to the KSAPS, most international donor funds were brought into the state through the Karnataka Health Promotion Trust (KHPT). The KHPT was set up as a partnership between the KSAPS and the University of Manitoba in 2003 to support and implement initiatives on HIV/AIDS and reproductive health (KHPT 2013). At the time of fieldwork, the KHPT received the majority of its funds from the Gates Foundation through its Avahan Project (BMGF 2010), USAID and the Global Fund through NACO and the KSAPS. The KHPT focuses on research and prevention activities, and acts as both a direct implementing agency for HIV programs and a funding agency to other CSOs to implement KHPT programs. The KHPT works in all 30 districts of Karnataka (KHPT 2013), giving it a geographical reach equal to that of

the KSAPS. At the time of conduct of this study, the KHPT acted as the lead agency for the Link Workers Scheme in 23 districts through funding from USAID and NACO-Global Fund (KSAPS 2010). The Link Worker Scheme is a NACO-promoted community outreach program that aims to provide access to HIV-related information and services to high-risk groups in rural areas (NACO 2009). For the NACO-Global Fund program, the KSAPS disbursed funds to the KHPT, which then disbursed these funds to the CSOs that implemented the programs at the grassroots level. The KHPT provided technical and managerial support for these implementing agencies (NACO 2010e). In addition, the KHPT implemented the KSAPS' targeted intervention programs in 14 districts of Karnataka while the KSAPS implemented these programs in only 12 districts (KSAPS 2010). As a result, the KHPT programs reached more vulnerable community members than KSAPS-funded CSOs did (KSAPS 2010). A prime focus of the KHPT is surveillance and research, and it mapped FSW and other vulnerable communities for the KSAPS and provided technical support to the KSAPS through its sister organization, the India Health Action Trust. The KHPT does not provide any funding to the KSAPS. The KHPT had emerged as a powerful CSO in the state, and many participants felt that it had a strong influence on the KSAPS' decision-making processes (discussed further in Chapter 7).

This study was conducted with participants from CSOs that engaged in prevention, treatment, care and support and research and advocacy-related work. Participants also represented CSOs that received government and international donor funding.

5.3 Us vs. Them: Dynamics within Civil Society

This section describes the dynamics between communities living with and vulnerable to HIV/AIDS and the relationships between CSOs working on HIV/AIDS in Bangalore to highlight the local context in which they operate.

5.3.1 Women Living with HIV/AIDS

In India, women's vulnerability to HIV/AIDS is heightened by their low level of education and patriarchal norms which place them in subservient positions (Mawar et al 2005), with little control over their bodies and few negotiation skills to protect themselves from HIV (Norr, Tlou & Norr 1993; Mawar 1995; Gangakhedkar et al

1997). Women constitute approximately 39% of PLHA in India, which includes FSW and women from the general population (NACO 2010b). A significant sense of segregation was noted between groups of women living with HIV/AIDS. A deep sense of having different identities and belonging to different communities existed among women living with HIV/AIDS who were not FSW.

[S]ex workers] are also women, but it's their behavior that is different. If you are with me and if I am a sex worker, I am also a woman, but I will always start looking for customers. But you [being a non-sex-working woman] will not do this. All of us are women and human beings, but we should control our behavior. If we travel by train to Delhi [or other districts of Karnataka for HIV-related work], we go together with them. Sex workers and transgenders will also be there in the train but they will not be quiet. They will be doing their work. It is not that we should not take them with us, but each one of us has formed a group. It is best that we work with the groups where we belong (Tina, 30-year-old female, peer counsellor at a PLHA network).

The language used by Tina, particularly that FSW and transgender women “will not be quiet”, is itself stigmatizing of these communities. Such feelings are likely linked to the stigma and discrimination against FSW in Indian society, which perceives women engaged in sex work as having low moral standards (Dandona et al 2006). Cornish (2006) found that traditional marriage and motherhood were key criteria for Indian women to be respected and that transacting sex denied respect to FSW. Kralik, Koch and Eastwood (2003) argued that the 'self' reflects 'being a person' whereas 'identity' is shaped by social interaction. Although non-sex-working HIV-positive women were stigmatized by the larger community for being HIV-positive, they prized their identities as wives and mothers, roles that are traditionally prescribed and respected in India. A common perception that monogamous women who contract HIV from their husbands are “blameless victims” while FSW are seen as promiscuous and “most blame able” (Mawar et al 2005, p.478) compounds the stigma against HIV-positive FSW. Ogden & Nyblade (2005, p.21) highlight that HIV-related stigma is used as a mechanism to deepen the boundaries of a “moral community”, which differentiates between ‘us’ who are “normal and righteous” and ‘them’ who are “deviant and fallen”.

Tina's example illustrates such a creation of boundaries, based on concepts of morality and traditions, between sex-working and non-sex-working women living with HIV/AIDS.

Tina recommended that PLHA work in groups in which they 'belong', distinguishing the collective identities of HIV-positive FSW and other women living with HIV/AIDS. Collective identity is a sense of commonalities, a "we-ness" (Chowdhury 2006, p.336), a shared definition that a group derives based on members' common interests, experiences and solidarity (Taylor & Whittier 1992). Tina stated that the similarities between women living with HIV/AIDS and FSW end with both being human beings and women. In this case, HIV-positive FSW 'doing their work', and their need to transact sex in order to sustain themselves, sets FSW apart from other women living with HIV/AIDS. It may be possible that some element of this "otherness" attached to FSW is caused by the fact that there is more funding available for FSW than PLHA. Some PLHA felt neglected by the NACO, in terms of lower funding and numbers of services for treatment, and care and support when compared with prevention efforts for high-risk groups (discussed further in section 5.5.1). This feeling of neglect by the government may also play a role in women living with HIV/AIDS wanting to have a separate identity from HIV-positive FSW. The development of a collective identity of being HIV-positive is hindered by the distinct sense of otherness attributed to FSW by women not engaged in sex work. This can potentially impact collective action by civil society members. Tina further elaborated on the segregation of HIV-positive FSW from PLHA:

In [my organization], we take [HIV] positive members. Now for sex workers, they have their own unions and groups. Transgenders have their own groups. So why should we get everyone else involved and work with them? If they want their own groups, they will be able to discuss their own issues and work them out. So we don't ask them to come for our meetings (Tina, 30-year-old female, peer counsellor at a PLHA network).

Underlying power relations between women living with HIV/AIDS and HIV-positive FSW are revealed by Tina's statement. French (1985) defined 'power-over' as the

ability of one group to constrain the choices available to others. In this instance, women living with HIV/AIDS exerted power over HIV-positive FSW and transgender people by constraining their choice of participation in some CSOs and PLHA networks. In doing so, these women limited the choices available to FSW to participate in civil society, and their ability to access resources and support from CSOs that did not work exclusively with FSW. Non-sex-working women living with HIV/AIDS, a community that was also stigmatized, were exerting power over HIV-positive FSW and simultaneously stigmatizing and discriminating against them.

While Tina stated that it was best if people work in groups to which they ‘belong’, Mita, an HIV-positive FSW clearly perceived this type of exclusivity as discrimination:

Now [the PLHA networks] have regular meetings, but if we go there, they do not include us. They are [HIV] positive, but since we are [HIV-positive] sex workers, sexual minorities, they won't include us. They sit separately, we sit separately, and if there is a discussion, they talk a lot and we don't get many chances to talk. We don't get a chance to open up about our feelings and experiences, so we feel bad. They are humans, we are also humans. They are also PLHA, we are also PLHA. But the only difference is that we are sex workers or sexuality minorities. In this situation, why are they discriminating against us? (Mita, 33-year-old female sex worker, member of FSW Union).

The ability of HIV-positive FSW to participate in civil society may be further limited by their need to transact sex during the times when civil society groups meet or conduct events. If, in addition, HIV-positive FSW are not given the chance to share their concerns, it is unlikely that their voices and needs will be prioritized within PLHA networks. The perception that HIV-positive FSW have their own networks and unions in which to share their concerns may contribute to a reluctance by other PLHA groups to collaborate with them. This example illustrates that pre-existing cultural perceptions and social inequalities are also exposed in PLHA groups.

These two accounts of non-collaboration between HIV-positive FSW and non-sex-working women indicate that PLHA had a significant sense of belonging within their own constituent groups. Roth and Nelson (1997) noted that individuals develop HIV-positive identities through their association with PLHA communities and CSOs that work with specific communities. In Bangalore, this sense of belonging led to a situation where each community was comfortable with a narrowly-defined membership and, as a result of identity politics, unwilling to allow close interaction with other communities. This also restricted people's membership into CSOs which may have had potential benefits for them.

5.3.2 Men Living with HIV/AIDS

Some heterosexual men living with HIV/AIDS identified a distinct segregation between the MSM community and PLHA networks. Contrary to the example of women living with HIV/AIDS and HIV-positive FSW, heterosexual men living with HIV/AIDS wanted to have more interaction with HIV-positive MSM and felt that this group did not integrate with PLHA groups.

If a person is MSM, they will go only to an MSM organization. Even if he is HIV positive, he will not come to [a PLHA network] ... There are many [HIV] positive MSM, but they have not become a member [of my PLHA network] ... I don't know the MSM's actual problems or issues. Like this, how can I advocate for them, how can I mobilize the funds for MSM or [do any other work for them]? (Shivana, 26-year-old male, PLHA network member).

Shivana, a HIV-positive heterosexual man felt that PLHA networks were ill-equipped to deal with MSM issues because of a lack of understanding of their concerns. According to Shivana, PLHA networks wanted to include MSM issues on their agendas, but identified that most MSM were unwilling to join them. One MSM participant interviewed in Phase I also noted a differentiation from the community of heterosexuals, whom he termed as 'non-community':

For us, the heterosexuals are non-community members. In [my organization], right from the director to assistants, everyone must be from our community. So

there is equality here. In other NGOs, there are a lot of non-community people working there, and there are fewer opportunities for people from our community. In those NGOs, the heterosexuals treat the MSM differently. There is less understanding of our issues there (Daniel, 24-year-old male, member of a sexuality minority CBO).

Bartos and McDonald (2000) suggested that MSM communities often do not perceive a separate HIV community. They argued that when faced with combined identities of being gay and HIV-positive, MSM opt to choose one community to align with, and the gay community takes precedence. Similarly, Troiden (1989, p. 62) noted that MSM might "immerse themselves completely in a homosexual subculture" to avoid a heterosexual setting that reminds them of their stigma. This appeared to be the case for many MSM in Bangalore who identified more with the MSM community than with PLHA, and were more comfortable working within CSOs that cater specifically to MSM.

The PLHA community in Bangalore was fractured along the lines of sexual orientation and traditional notions that HIV-positive sex-working women were unlike HIV-positive women who did not transact sex. Participant narratives on relationships between PLHA belonging to vulnerable populations and PLHA from the general population revealed a lack of collaboration between sex-working and non-sex-working women living with HIV/AIDS as well as between heterosexuals and MSM living with HIV/AIDS, based on perceptions of mutual exclusivity and identity politics.

5.3.3 Influence of Funding on the Relationships between CSOs

In addition to identity politics, the relationships between CSOs working on HIV/AIDS were influenced by the type of funding they received. There was a perception among participants that CSOs that received KSAPS funding were better placed to voice their concerns and the concerns of the communities with which they engaged:

Now, [the NGOs that] are funded by the government, the KSAPS ... they have a close bond with the government. Whereas we are not funded [by KSAPS], so we don't have [a close bond with them]. They have a lot of say in the

[government's] policies; they can suggest changes. We have no voice in that. In that way [CSOs] are differentiated ... So, what we do is now, since the government has not recognized [my network], we all have become members of [the state PLHA network] or the district networks. So that we [can] have a say in [PLHA issues] highlighted there and fight for our rights. This is how we are pushing [PLHA into the state-funded networks] (Pallavi, 61-year-old female, PLHA network manager).

This participant felt that the state-level PLHA network, a subsidiary of the larger Indian Network of People living with HIV/AIDS, which had a close working relationship with the NACO, had better opportunities to advocate with the KSAPS because it received government funding. This belief led members of other networks in Bangalore to “push” their members into the state and Bangalore district level networks in an attempt to gain a voice in advocacy forums with the KSAPS. However, the extent to which the state and district level networks have more opportunities to influence the KSAPS is unclear. During informal discussions, members of these state and district networks discussed their inability to influence the KSAPS and also cited examples of tokenistic involvement of its members in the work of the KSAPS. One participant felt that receiving government funding actually made CSOs more likely to ally with the government tacitly rather than raise the problems faced by CSOs and PLHA:

See you need small organizations to come together [to advocate with NACO/KSAPS], but there is nobody to take up a leadership here. And you don't have anyone wanting to voice anything ... You will have people saying [that] we will take a stand in the meeting, the very day [in the] afternoon, you'll find the same director of the organization, or the senior manager sitting outside KSAPS [asking] “Hello sir, hello sir, what about my funding sir?” (Rahul, 50-year-old male, manager of a CSO engaged in HIV prevention and care and support).

Some participants also mentioned that there was a lack of trust between KSAPS-funded CSOs and CSOs that received private funding. Some felt that members of

KSAPS-funded programs would not collaborate with other CSOs, particularly in relation to advocacy programs. This sense of ‘us and them’ appeared to influence the ways in which CSOs collaborated; some participants mentioned that this weakened the potential influence of civil society working in HIV in Bangalore by preventing a collaborative and unified approach to advocacy and lobbying with the government.

Actually, there are few NGOs that get funding from KSAPS ... You know it's so funny that they won't even come to the [Bangalore HIV/AIDS] Forum meeting because they are getting funding from KSAPS. Even if [KSAPS] is doing something wrong, you know, they won't go along with other NGOs who want to raise their voices against KSAPS (Anusha, 27-year-old female, CSO advocacy officer).

This participant described the restriction this lack of trust between KSAPS-funded and privately-funded CSOs placed on the participation of KSAPS-funded CSOs in the BHAF. During fieldwork, many civil society members noted that CSOs that received KSAPS funding were often secretive about the KSAPS directives. As the BHAF was a space for advocacy, there was a common perception among CSOs, as well as within the KSAPS, that it encouraged its members to protest against the KSAPS. This also contributed to the KSAPS-funded CSOs staying away from the BHAF and its activities.

This section covered the dynamics within the PLHA community, in particular the identity politics that exist between sex-working and non-sex-working women living with HIV/AIDS and between heterosexual and homosexual men living with HIV/AIDS. Lastly, the difficulties in collaboration between members of CSOs that received KSAPS funding and those that did not were discussed.

5.4 Relationships between CSOs and the KSAPS

An exploration of the relationships between CSOs and the government, in particular the KSAPS, is integral to understanding the ways in which local HIV policies are designed and implemented in Karnataka. It is not possible to understand the HIV policy making context and policy processes in Karnataka without first understanding

the nature, depth and the complexity of relationships that exist between the KSAPS officials, CSO members, PLHA and members of vulnerable communities. This section describes participants' experiences of engaging with the KSAPS and later discusses the reasons for CSOs' lack of trust of the KSAPS.

5.4.1 Civil Society's Experiences of Working with the KSAPS

This section explores the determinants of the relationships between CSOs and the KSAPS, based on CSOs experiences of engaging with the KSAPS, their fear of being de-funded by the KSAPS and through examples of leadership instability and corruption and collusion within the KSAPS.

5.4.1.1 Tokenistic Consultation with Civil Society

Tokenistic and selective consultation with civil society was cited by some participants as a major barrier to the meaningful participation of civil society in HIV policy making and programming, both at state and national levels. Civil society can augment HIV-related services provided by the government (Berkman et al 2005; Zuniga 2006). However, this is dependent on meaningful and active participation and partnership development between civil society and the government. According to participants, this was not occurring in Karnataka. One participant discussed this tokenistic participation, citing the example of a GIPA consultation organized by the KSAPS. The GIPA consultation was held in 2009 with PLHA members of district-level networks in Karnataka, ostensibly for the KSAPS to gain a better understanding of issues faced by PLHA in the state:

The GIPA consultation has been supported by the NGOs ... [when I asked about the consultation] ... [A key staff of KSAPS] said 'why you are bothered about GIPA consultation?' [I told her] Madam, it is our program, so we want a GIPA consultation ... [she said], 'it is our duty to report to NACO, not yours', that was her response. Then, we told [our head office], then from NACO itself, they received the order, then within 15 days, they rushed and conducted the GIPA consultation (Amba, 42-year-old female, PLHA network member).

This participant noted that KSAPS personnel ‘gave’ duties to PLHA networks, with little consultation about the proceedings and agenda of the GIPA consultation. The participant acknowledged that the Project Director of the KSAPS was present and open to listening to concerns of PLHA. However, according to participants, no action plan or program directives resulted from this consultation. Tokenistic engagement of PLHA, where their opinions are sought merely to comply with donor or government policy expectations, is a key barrier to the participation of PLHA (Paxton & Stephens 2007). Such instances of partial participation of PLHA and lack of follow-up or action contribute to CSO members’ anger and frustration with the KSAPS. Data revealed that while CSOs and community members were consulted, they remained on the margins of decision-making and agenda-setting processes.

5.4.1.2 Fear of Losing Funding

Many of the CSOs working on HIV/AIDS in Bangalore were partly or wholly funded by the KSAPS. As mentioned previously, the relationship between CSOs in Bangalore was influenced by their funding source. According to participants, CSOs that received KSAPS funding were reluctant to collaborate with other CSOs, particularly in relation to advocacy programs. Data suggested that this was a result of the fear of losing KSAPS funding. One participant raised the fear of being de-funded if they questioned the KSAPS programs:

Our problem is that if tomorrow we raise this issue with KSAPS and say what you guys do is rubbish, then we are going to get targeted. They will not release [our] next grants, they will create problems for us or they will send a finance team or do something, blacklist us. How do we protect ourselves? Ultimately, governments look at what is most convenient for them (Rahul, 50-year-old male, manager of a CSO engaged in HIV prevention and care and support).

This participant’s statement indicated that in addition to feelings of anger and frustration, CSOs relationships with the KSAPS were also characterized by fear, particularly for those CSOs receiving funds from the KSAPS. NACO acknowledges that CSOs are “genuine long-term partners in NACP” (NACO 2010d). The partnership between the NACO, its subsidiary the KSAPS and CSOs is an example of

a public-private partnership in the health sector, with these two entities (NACO and KSAPS) as the main stakeholders in the partnership. The extent to which this relationship is a true partnership is open to question. Raman and Bjorkman (2009) comment that a policy announcement by the government is not a sufficient reason for partnerships to be initiated with CSOs. Yet, according to participants, in the case of the KSAPS and its funding partners, a policy announcement was exactly the reason for the inception of a partnership. NACO announced that it would increase its partnerships with CSOs primarily because CSOs provided direct access to community members.

A public-private partnership has five core principles: relative equality between partners, mutual benefit to the stakeholders, autonomy, accountability, and mutual commitment to agreed objectives (Raman & Bjorkman 2009). Cadbury (1993, p.11) defined a partnership as “power shared equally with all partners”. Using these principles to analyze the KSAPS-CSO relationship, participants’ narratives show that there was little equality, autonomy, power-sharing or accountability between the KSAPS and its funding partners. Rahul’s comment also raises the important role that power plays in the relationships between CSOs and the KSAPS; partnerships were dominated by the more powerful partner, the KSAPS. The potential for conflicts among stakeholders in a public-private partnership is dependent on the relative power held by each stakeholder and the degree of dependency between stakeholders (Raman & Bjorkman 2009). In this scenario, CSOs that were funding partners of the KSAPS were highly dependent on the KSAPS for their financial resources and sustained existence. Many of these CSOs were not large enough or did not have the capacity to sustain themselves without KSAPS funding. Stakeholder power is manifested by the KSAPS in the form of control of funding resources as well as ability to impose regulatory restrictions. The fear of having their grants delayed or being de-funded if they voiced their concerns was common among participants from KSAPS-funded CSOs. This fear may influence CSOs’ ability to participate in negotiations and policy making processes with the KSAPS; this in turn increases the potential for community realities to be ignored during these processes and the adoptions of a top-down approach to policy making (discussed further in Chapter 7). In addition, even if CSOs participate in decision-making processes, perceptions of potential threats from the

KSAPS may lead them to cooperate without questioning the government's interests and agendas, allowing policy and program processes to be dominated by the government.

5.4.2 Frustration and Mistrust of the KSAPS

The relationships between civil society and the KSAPS were characterized by frustration and a deep mistrust of the KSAPS and its staff by CSO members. These feelings were mainly caused by leadership instability, the lack of understanding of HIV-related issues by the KSAPS staff and accounts of corruption and collusion at the KSAPS.

5.4.2.1 Leadership Instability at the KSAPS

Perceptions of a lack of appropriate and constant leadership at the KSAPS contributed to substantial frustrations among CSO members. Most participants discussed frequent changes in leadership, particularly in relation to the role of the Project Director, leading to discontinuity of collaborative activities with CSOs and difficulties in establishing relationships between civil society and the KSAPS. The frequent changes of Project Directors were also noted by the Ministry of Health and Family Welfare in 2007, when the then Union Minister for Health criticized the KSAPS for its poor functioning and attributed this to frequent changes in leadership, including three Project Directors during 2006 (*The Hindu* 2007). Lack of leadership continuity may also be the reason for the constant underutilization of funds available for KSAPS, according to one participant:

Karnataka has always had the history of utilization of only 30% of the funds and they send back 70% of the money. The [Project Director] has changed, there is no leadership here. Every 6 months there has been a Project Director here (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

'Leadership gaps' occur each time there is a change in leadership when time and resources are wasted while a new person is appointed and starts their work (Szekeres, Coates & Ehrhardt 2008). KSAPS budget expenditure statements for the years prior to the data collection period revealed significant underutilization of allocated funds.

However, the amount of money unutilized was not as high as Aditi mentions above. In 2007-2008, 16% of the funds allocated to the KSAPS were not utilized and the figure was 47% in 2008-2009 (Ministry of Health and Family Welfare 2008, 2009).

The short tenure of the Project Directors of the KSAPS has also resulted in an inability to establish effective working relationships between CSOs and the KSAPS, as reported by most participants.

We are part of the [Bangalore] HIV/AIDS Forum. See whenever we plan for something, then we will go to the Project Director and submit our recommendations or our concerns. The Project Director will take it and say good, good, these are your concerns. They will appreciate us, but when we go for a follow-up after one or two months, that person will [have] changed (Amba, 42-year-old female, PLHA network member).

The lack of regular communication and failure to follow up by the KSAPS has led to frustrations within civil society. Although the NACO, CSO members and PLHA acknowledged the problems associated with frequent change in the KSAPS leadership, this continues to remain a problem to date. Since the completion of data collection (October 2011- August 2013), KSAPS has had four Project Directors (KSAPS 2013).

5.4.2.2 Lack of Understanding of HIV/AIDS by Appointees

One participant discussed the KSAPS staff's lack of adequate understanding of HIV-related issues. The KSAPS staff, especially those who hold higher positions, are appointed from the Indian Administrative Service which plays a major role in bureaucracy in the Indian government. The extent to which they are trained in relation to HIV/AIDS is unclear.

The new person who takes over has to know about HIV and by the time he thinks about doing something good, he is shifted to another place. We go [to the KSAPS] and speak everything, protest. We are spoiling our health and we are unable to do anything. We should not let these people get away with this (Anita, 30-year-old female, staff member of an international CSO).

According to participants, most Project Directors selected to head the KSAPS have no background in health or HIV-related issues. Project Directors and senior personnel are mandated to undergo HIV-orientation and induction training within three months of their appointment (NACO 2006). This training includes orientation to NACO's goals and objectives, project strategies, implementation and monitoring in addition to HIV-related topics such as magnitude of the epidemic, epidemiology and preventive approaches (NACO 2006). Participants asserted that the lack of experience on PLHA-specific issues resulted in the KSAPS staff applying their knowledge about other social constituent groups in India to PLHA.

I said "GIPA means what?"... [the KSAPS official said] "Greater involvement, yes I know, I am working in the community for the past 25 years, what do you [mean] to say? [That I] still have to learn?" Yes, I agreed. [The KSAPS official] is giving the example that she has worked with Self Help Groups, some government set-up, so that is her experience for the past 25 years. She has worked with beggars, so these are the examples she gives, in the rural areas ... with tribals, whereas coming to PLHA, we are a mix of all the communities, and all types of people (Amba, 42-year-old female, PLHA network member).

This perceived lack of knowledge and understanding about HIV/AIDS and the concerns of PLHA compounds CSO members' and PLHA's frustration towards the KSAPS.

5.4.2.3 Corruption and Collusion within KSAPS

One participant, who was among the first civil society members working on HIV/AIDS in Karnataka and who had a very close working relationship with the KSAPS, reported corruption and collusion within the KSAPS. This participant spoke of his personal experience during the early years of the HIV epidemic, stating that members of the local government directed the KSAPS to give funding to the relatives of local politicians who had little experience of HIV/AIDS and sometimes worked in completely unrelated sectors:

If you go into North Karnataka or rural areas, there is a bit of “you scratch my back and I’ll scratch your back”, because at one level, there is pressure on government or even civil society to go where the need is. But if there are no takers, see even the government when it does its evaluation may say “Ok, how many projects are there in let’s say Gulbarga?” This is one of the mandates. So what they say is see we have managed to set up ten projects. So even if somebody looks at it, they say “Ok, not bad, ten projects”. But if you actually go to Gulbarga and search out these projects, I’ll be surprised if you don’t have two tailoring institutes, one cattle shed, God knows whatever. And I’m not joking when I say cattle shed because that also has happened. We had a situation where funds were given to an entity which was said to be running a dairy but which was just a cattle shed. And they received 120,000 Rupees, so it’s all possible (Rahul, 50-year-old male, manager of a CSO engaged in HIV prevention and care and support).

In 2008, the World Bank reported that there was evidence of financial and procurement problems with India’s US\$193.7 million dollar NACP II (Aslam 2008). Funding for fraudulent NGOs was cited as a concern, prompting NACO to terminate 163 out of the 952 CSO contracts (Aslam 2008). Such incidents fuelled the anger and suspicion felt by CSOs, particularly those who believed they had been denied funding in favor of fraudulent or non-existent CSOs. Such instances of corruption reduce the credibility of CSOs working on HIV/AIDS and detract from their work, but can be addressed by better affiliation between CSOs and increased transparency on the part of NACO and the KSAPS.

At the start of the HIV epidemic in India, and with the advent of donor money, the number of CSOs working on HIV/AIDS mushroomed and many CSOs that did not work on issues connected with HIV/AIDS received funding. This has reduced in recent years due to closer monitoring of CSOs by World Bank/NACO, which have in recent years terminated contracts of corrupt and inefficient CSOs (Padma 2008). Calls for more transparency by CSOs have also contributed to this. Instances of corruption have contributed to key issues that characterize CSO-KSAPS relations – suspicion,

distrust, fear of being de-funded, concerns about funding and expenditure, poor management of HIV programs and leadership instability. As a result of these issues, most participants described their relationship with the KSAPS as antagonistic.

The relationships between the KSAPS and civil society were characterized by frustration, mistrust and at times, fear. This section illustrated this using civil society's experiences of engaging with the KSAPS. Participants highlighted examples of tokenistic consultation of civil society members, including PLHA and a fear of being de-funded if they questioned the KSAPS policies and functioning. In addition, this section covered the causes of frustration and mistrust on the KSAPS, in particular leadership instability, inadequate knowledge of HIV-related issues by KSAPS staff and instances of corruption and collusion within the KSAPS.

5.5 Civil Society Questions NACO Policies and Programs

In addition to the feelings of antagonism towards the KSAPS, most participants also noted hostility towards the NACO, the reasons for which are discussed in this section.

5.5.1 Feelings of Neglect by PLHA

Most PLHA participants and some CSO members voiced frustration at NACO's policies, particularly the targeted intervention approach, which directs most human and monetary resources to prevention activities for high-risk populations. Participants felt that this approach diverted resources and attention away from treatment and care and support programs for PLHA and acknowledged that this had been a cause of great concern and dissatisfaction for PLHA, who felt ignored by NACO.

According to [NACO], 0.36% of the population is infected. Then why should they invest so much money on [PLHA]? Anyway [PLHA] will die and it will not matter to them and it doesn't matter to the [general] population if [PLHA] die. It is not a major issue for the government ... Seventy five percent of money goes for prevention. Prevention is very focused on the targeted groups (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

Expenditure on prevention, treatment, and care and support at the time of the study

was guided by the NACP III for the years 2006-2011 (discussed previously in section 3.3.1). According to NACO (2006, p.7), “considering that more than 99 percent of the population in the country is free from infection, NACP-III places the highest priority on preventive efforts while, at the same time, seeks to integrate prevention with care, support and treatment”. NACO places highest priority on populations that are at highest risk of HIV namely FSW, PWID and MSM followed by bridge populations such as migrants, truck drivers and young men and women in the general community (NACO 2006). Aditi’s comment on the disparity between the resources expended on prevention and on treatment and care and support was consistent with NACO’s expenditure reports. For 2008-2009, NACO allocated a total of Rs.111.23 billion (US\$247 million) for the NACP III, of which 67.2% was spent on prevention activities among both high-risk groups and bridge groups and 17% for care and support of PLHA (NACO 2009). Though this expenditure was in line with the targeted intervention approach, CSO members and PLHA felt this did not reflect their needs. This raises questions about the appropriateness and relevance of HIV expenditure in India. The sentiments expressed by Aditi were also echoed by other participants:

The government’s focus is on the spread of the infection. But if I am positive and I die, it’s fine. If I live, that is also fine. This is the government’s vision. HIV should not spread. What about my life? If I die, they don’t care but I should not infect others, this is what government thinks (Roopa, 40-year-old male to female transgender, member of CBO for sexuality minorities).

This participant’s words reiterated a common perception among participants that the NACO’s main focus was on secondary prevention of HIV and that PLHA were only of interest in terms of preventing the spread of HIV/AIDS. PLHA can be critical to preventing secondary transmission of HIV (Green et al 2011; Ming et al 2012; Ssali et al 2012). Nevertheless, these authors also argued that understanding the social contexts of PLHA, including their access to ART, social networks, health and living conditions, is essential to effective secondary prevention. According to participants, few efforts were made by the government to understand the needs and realities of PLHA.

Some participants felt that children living with HIV/AIDS were most neglected by the NACO. This was reported to be a source of anger against the NACO and its HIV policies and services:

The government is not doing anything for positive children like hostels and boarding, and many children become dependent on their grandparents [when their parents die]. Nobody is there to take care of them. So the government is not taking any responsibility (Tina, 30-year-old female, peer counsellor at a PLHA network).

At the time of data collection, the number of children living with HIV/AIDS in India was unclear. In 2007, the NACO estimated that approximately 70,000 children were infected with HIV and that approximately 21,000 children become infected with the virus each year as a result of mother to child transmission (NACO 2007a). These figures were not updated during the data collection period. The major program for children living with HIV/AIDS is the National Pediatric HIV/AIDS Initiative, which aimed to provide ART to 40,000 children by 2012 (NACO 2009). At the time this study was conducted, the NACO did not fund programs to improve the psychosocial well-being of children living with HIV/AIDS.

Children's programs are few ... If one hundred children come to access services in the networks [of PLHA], only ten children are given importance, only ten children get funded [for education and nutrition] (Amba, 42-year-old female, PLHA network member).

This approach is also consistent with the targeted approach of NACO, which concentrates most of its attention and resources on the high-risk groups. Most participants agreed that funds for children living with HIV/AIDS were minimal, with only a few donor agencies, such as the Elisabeth Glaser Foundation and the Clinton Foundation, focusing on pediatric ART. In such a situation, CSOs who want to work with children living with HIV/AIDS have to choose either not to work with them or as Amba says above, limit programs to select children. Another participant, Benjamin, a 55-year-old member of a faith-based organization, stated that the lack of funding and

programs for children may be due to a genuine lack of understanding of the complexities involved in providing support for them. He explained that most CSOs feel ill-equipped to take on the responsibility of children living with HIV/AIDS, particularly as they enter adolescence. Therefore, perhaps limited programs for children were not only the result of a lack of targeted funding, but also a lack of capacity by CSOs to implement programs for them.

Maximum resources were available for the NACO's target populations in part due to the country's commitment to the Three Ones Framework, which promotes one national AIDS control authority (the NACO), one HIV/AIDS action framework, (the NACP) and one country-level monitoring and evaluation system (UNAIDS 2004). The single HIV/AIDS action framework dictates the country's priorities for resource allocation; the NACP prioritizes high-risk groups and funding partners are therefore mandated to engage with these communities. While the focus on target groups is valid and necessary as India's HIV epidemic is still concentrated within these groups, this narrow focus leads to many other vulnerable groups being neglected in HIV prevention, as reported by some participants:

We are always writing proposals. Really [there is a] dearth of money to work with general communities, who are [also] vulnerable ... So, if I have to work for fisher folk in some districts or tsunami affected areas, I can't ask the government of India for money. We will never get money; we will never get money from any of these larger agencies. The larger agencies will give money to work only with sex workers, PWID and MSM and everybody knows [this]. That is where the flexi money which comes from individuals comes to our benefit (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

The general population is given third priority in NACO's programs (NACO 2010b). Prevention activities for the general population include safe blood programs, mass media campaigns, Integrated Counseling and Testing Centres (ICTC) and Prevention of Parent to Child Transmission (PMTCT) services and condom distribution. Some participants felt that this approach overlooked the vulnerabilities of communities such as women in monogamous relationships, communities affected by disasters, children

and youth and people from economically and culturally disadvantaged communities. For example, Aditi mentioned fishing communities and tsunami-affected areas. Though data on HIV seroprevalence in fishing communities is sparse, particularly in South Asia (Allison & Sealy 2004), some fishing communities are at high risk of HIV infection. Factors influencing this increased risk include the high mobility of fisherfolk, time spent away from their homes, access to daily income and availability of commercial sex in fishing ports (Allison & Sealy 2004). Similarly, some communities in tsunami-affected areas may be at increased risk. Many tsunami-affected areas in Tamil Nadu and Andhra Pradesh had high HIV prevalence prior to the 2004 tsunami. The breakdown of health and social structures and deaths of health personnel following the tsunami in these communities greatly impacted HIV prevention and care (Mathai-Luke 2008). Participants felt that communities like these were overlooked by the government and private donors. Aditi also mentioned ‘flexi money’ that her CSO receives through individual donations which enables them to work with communities other than NACO’s target populations. However, this flexibility was not enjoyed by many CSOs in Bangalore, restricting the focus of CSO activities to the government’s target groups.

Some participants also questioned the ways in which prevention activities were carried out and the NACO’s focus on condom promotion despite recent advances in HIV treatment as prevention. The lack of a preventive vaccine in resource-poor settings has limited prevention options to date to behavior-related interventions (Green et al 2006; Lagakos & Gable 2008; Moore, Rosenthal & Mitchell 1996), including abstinence, faithfulness and consistent condom use (ABC approach). However, some participants questioned the efficiency and adequacy of the condom distribution approach, which focuses on the number of distributed condoms, often overlooking the contextual factors which may hinder condom use:

They say wear condom and [have] safe sex. For so many years the government is saying this. But what do we want? ‘Rowdies’ [thugs] torture us, we have all types of atrocities documented. But the government keeps giving [condom] messages and keeps talking only about condoms (Roopa, 40-year-old male to female transgender, member of CBO for sexuality minorities).

In 2010-2011, the NACO reported that 288 million free condoms were dispensed in India through social marketing strategies despite a target of 405 million free condoms (NACO 2012a). Evidence indicates that consistent, correct condom use provides 90% – 95% protection against HIV infection (Foss et al 2004; Laga & Piot 2012; Pinkerton & Abramson 1997; Stammers 2005). However, correct and consistent use is dependent on situational and contextual factors which determine sexual behaviors (Zwi & Cabral 1991). These include impoverishment, urbanization, lack of health resources (Zwi & Cabral 1991), limited HIV prevention programs, undermining policy environments, lack of human rights protection (Beyrer 2008, 2010), and history and culture (Donovan & Ross 2000). India has a culture of secrecy around sexual practices as a result of which condom use is not fully understood and adopted (Doshi & Gandhi 2008). Alcohol and drug use, education, and the absence of normal societal structures such as situations like military service and migration also influence sexual behaviors (Donovan & Ross 2000). Donovan and Ross (2000) argued that comprehensive HIV control interventions must be developed locally taking into account the abovementioned factors. Such an approach was lacking in India, according to participants. Participants felt that NACO's policies and programs neglected these larger contextual, social and individual determinants of sexual behaviors in favour of a focus on the number of condoms dispensed. In this case, Roopa also emphasized the disregard of the role violence played in consistent condom use.

5.5.2 Government Credibility Questioned

In addition to feelings of neglect, civil society's relationship with the NACO was characterized by a deep sense of distrust. According to participants, this distrust arose mainly from conflicting projections of the magnitude of the HIV epidemic in the country and the government's lack of transparency in relation to its expenditure on HIV/AIDS.

5.5.2.1 Civil Society Questions HIV Statistics

One participant voiced her concerns over ambiguous and changing NACO statistics indicating the status of the epidemic in India:

We feel definitely [that] there are more numbers [of PLHA] ... but the government comes back and tells the media and tells everyone that [HIV prevalence] is coming down ... so it's taking the importance [of the epidemic] away from the minds of people ... It's not that epidemic has gone away, the context in which the epidemic has thrived has not gone away (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

Skepticism about HIV surveillance and its projections in India has been ongoing for several years, mainly due to differences in HIV prevalence estimates published by the government and international organizations such as UNAIDS. This skepticism increased in 2007, when the NACO reduced its estimate of the number of PLHA in India from 5.2 million to 2.5 million (NACO 2008b; Zarocostas 2007). This revised estimate prompted the World Health Organization (WHO) and UNAIDS to decrease global estimates of PLHA from 40 million to 33.2 million; 50% of this difference was attributed to the reduction in prevalence of HIV in India (Zarocostas 2007). This reduction was largely hailed as a success of the NACP II and an indication that India's HIV epidemic was decreasing. However, the NACO later acknowledged that the difference in numbers was due to a new statistical methodology used in 2007, based on the National Family Health Survey (Srivastava 2007). Civil society members remain largely confused about the change in methodology, the reasons for this change and the source of the data upon which country estimates are based (Srivastava 2007). This confusion and uncertainty has contributed to civil society's distrust of the NACO.

5.5.2.2 Questions about Expenditure on HIV/AIDS

Participants raised questions regarding the lack of government accountability, particularly in terms of its expenditure on HIV/AIDS. One participant noted the ambiguity in the information in the public domain regarding the availability of funds for HIV/AIDS and the utilization of the NACO's annual budgets, stating that CSO members have no real knowledge of this information:

HIV funding from what we hear and what information is available in the public domain, when we look at the country scenario, there is a lot of money available ... But when you come to [the KSAPS], again there is very little information

available ... there is very little information available on what money goes on what issues in the districts to villages. So money just disappears and resources disappear as it comes down and down. Information disappears as it comes down (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

The failure to effectively communicate information on the NACO's expenditure, particularly at the state and local levels, was raised by many participants. At the time of fieldwork, information on HIV funding in Karnataka was available on the NACO website along with the audited expenditure statements for the period 2007-08 and 2008-09. However, as Aditi mentioned, the expenditure statements do not illustrate how much money had been utilized and for what purposes at the district levels. This lack of financial accountability at the district level was acknowledged as a shortcoming by NACO, which proposed in its NACP III Strategy Plan (NACO 2006) to set up District AIDS Prevention & Control Units, a primary duty of which was to monitor funds utilization at the district level. NACO envisaged a change in financial monitoring at the district level, to ensure that money does not 'just disappear'. However, the extent to which this monitoring is occurring and the details of budget utilization at district levels remains unknown. Aditi's statement not only reflects the lack of transparency by the NACO and the KSAPS, but also reflects the skepticism and distrust inherent in relationships between these government bodies and CSO members in Bangalore. CSOs have access to information about the availability of funds at the national level, but not the state/district level; they ought to have more access to the latter due to ongoing collaborative efforts and funding partnerships with the KSAPS.

Aditi also raised questions about distribution of resources, government program evaluation processes and whether HIV funding actually translated into better outcomes for PLHA:

It is not very clear what happens when [a funding agency] says we have given 100 million rupees to NACO. That goes many a times to the salaries of the people sitting in NACO, or setting up technical support facility for the State AIDS Prevention Society to function better. So, it's not clear at all as to how

[fund utilization] works. What is clear is that ART, ICTC and PPTCT centers are being initiated. But, how many people have looked closely at the quality of care, counseling that comes out of these centres? Is it matching with the huge HIV money [spent by NACO]? (Aditi, 46-year-old female, HIV/AIDS program manager for an NGO).

This raises important issues of resource distribution and utilization. From the information available in the public domain, effective utilization of NACO funds was difficult to determine. For example, in NACO's publication of its expenditure for the period of April 2009 to January 2010, salaries and infrastructure are listed under the strategic objective of capacity building (NACO 2010b). Capacity building was one of four main objectives of NACP III and is defined as "strengthening the infrastructure, systems and human resources in prevention, care, support and treatment programs at the district, state and national level" (NACO 2006, p.10). The expenditure statement indicated that out of US\$13.86 million spent on capacity building, approximately US \$6.61 million was spent on staff salaries and an additional US\$1 million was spent on vehicles, furniture, computers and meeting expenses; therefore more than half of the expenses (approximately US\$6.25 million) for capacity building was spent on salaries and infrastructure. It was, however, unclear from NACO's expenditure statement whether the salaries and vehicle expenses were spent solely under the capacity building objective or for all of NACO's programs. Salaries and infrastructure expenditure for prevention, treatment, care and support and strategic information management (NACP III's other three key objectives) were not mentioned in the statement. The distribution of salaries across cadres, states and districts was also unclear. In addition, NACO's expenditure report for 2009 indicated that of the approximately US\$52.3 million spent on care, treatment and support, US\$50,000 was spent on consultancy services while only US\$4,108 was spent on community care centers (NACO 2010b). Community care centers were developed to provide psychosocial support, ensuring drug adherence and provide home-based care to PLHA (NACO 2010b). It is puzzling to note that only US \$4,108 was spent on the 287 community care centers that were reported to be operating in India at the time this report was released (NACO 2010b). Such discrepancies support the concerns expressed by Aditi and other participants. Providing adequate and clear information to

the public would greatly enhance civil society's ability to understand NACO's fund utilization and aid in building trust.

Monitoring and evaluation of HIV programs and 'getting value for money' are also highlighted by Aditi's statement. The ways in which NACO evaluates its programs, the actors involved in monitoring and evaluation and the reporting of findings are not clearly outlined in NACO publications. Presenting evidence of the impact of HIV prevention, treatment, care and support and capacity building programs would increase NACO's credibility with CSO members. However, this information was limited and it was unclear whether government funding translated into better outcomes for PLHA and vulnerable communities. Establishing a strategic information system for monitoring and evaluation is one of four core objectives of NACP-III. The impact of HIV programs is presented mainly in terms of provision of services (for example, increase in number of ART centers, increase in number of targeted intervention programs, number of condoms distributed) and not in terms of the accessibility and quality of services. The experiences of PLHA and people vulnerable to HIV, with and for whom these programs are conducted, were not captured.

NACO's work was questioned mostly due to its inadequate provision of information, particularly regarding its expenditure and impact, in the public domain. Available expenditure statements were difficult to follow, with few opportunities for CSO members and members of the general public to question NACO. This has led to a strong sense of suspicion of the NACO by CSOs. Appropriate information on HIV-related expenditure and monitoring and evaluation (which was lacking), would greatly increase the transparency and accountability of NACO's programs. Transparency and accountability are core principles of good governance (Graham, Amos & Plumpré 2003). Cornwall, Lucas and Pasteur (2000) argued that there is a fundamental inseparability between accountability, transparency and trust. The absence of accountability and transparency in this situation contributes to CSOs' lack of trust in the NACO.

This section discussed the hostility felt by CSO members towards the NACO, its policies and programs. In particular, PLHA felt neglected by the NACO's focus on

prevention methods (especially condom promotion) with the high-risk groups. PLHA felt that this emphasis on prevention overshadowed the needs of PLHA and the contexts in which PLHA and other vulnerable community members lived. CSO members also questioned the NACO's credibility as the nation's leading HIV agency. Most CSO participants were skeptical of NACO's drastic reduction in HIV prevalence in 2007. In addition, many CSO participants raised the lack of transparency of NACO and KSAPS budgets and expenditure.

5.6 Nature of PLHA Participation in Civil Society

This section is concerned with PLHA participation in civil society. Barriers and factors facilitating PLHA participation are also explored. There was a consensus among participants in the current study that the participation of PLHA in CSOs was limited, the commitment to the GIPA principle was largely on paper rather than in practice and that there was a dearth of opportunities for PLHA to participate at decision-making and expert levels. Most participants were familiar with the GIPA principle and understood the underlying concept of involvement of PLHA at all stages of HIV programs and policy making. CSO and PLHA participants agreed that more PLHA need to participate in civil society and that CSOs need to encourage this participation.

5.6.1 Levels of Participation

Most PLHA participated in civil society through employment in CSOs as peer/advocacy/community outreach workers. Networks of PLHA employed the most HIV-positive people, in positions ranging from community workers to network presidents. From my observations and informal discussions with community members, it appeared that CSOs other than PLHA networks employed fewer PLHA than people who were not HIV-positive. None of the CSOs in Bangalore other than networks of PLHA were headed by HIV-positive people.

One participant questioned whether PLHA were aware of the reasons to participate in HIV-related events and meetings:

Sometimes we will see that some [PLHA] will only come when one network has

told them to come, they won't come when the other network tells them to come. They will say "I came because [this PLHA network] told me to come" and I feel this is not right. You should know why you have come, understand the issues. It doesn't happen like that here (Anusha, 27-year-old female, CSO advocacy officer).

The extent to which PLHA participated in civil society was largely defined and constructed by others, namely their employers and donor agencies funding the CSOs. Participation through protests and rallies against the government was a common point of involvement for PLHA irrespective of the vulnerable community to which they belonged.

As mentioned previously, there was recognition of the need for PLHA participation in the NACP III documents, and a few PLHA participated at decision-making levels. However, the extent to which their opinions were acknowledged was reported to be tokenistic. As one participant said:

Now, the government has their meetings, all these [positive network] representatives, in what they are taking active part? Why are they not talking about the issues of nutrition? They are just there for name's sake and kept there as a puppet. Their mouth is shut (Pallavi, 61-year-old female, PLHA network manager).

This perception of tokenistic participation of PLHA by government and some CSOs was echoed by other participants. During my discussion with a PLHA working for a large quasi-governmental organization, two other staff members came into the meeting room where the interview was being conducted. When I said that I was conducting an interview with this person, they seemed surprised and said "Interview? With you?" (Fieldnote, 07/08/2009). The disbelief on their faces was quite evident. This instance raised questions about the extent to which PLHA experiences and indeed their presence were valued in CSOs whose staff consist mostly of non-HIV-positive staff.

5.6.2 Barriers to Participation

The literature presented in section 2.4.1 illustrated barriers to the participation of PLHA in civil society. Many of these barriers were apparent in the current study. The most significant barrier to participation of PLHA in civil society reported by all participants was the fear of stigma and discrimination associated with the disclosure of their HIV-positive status. This finding is consistent with existing studies on the challenges to participation of PLHA in India by Paxton and Stephens (2007), Cornu and Dua (2003) and Chakrapani and Abraham (2010). While stigma translated into fear of social ostracization, losing employment opportunities and discrimination in health care settings, it also manifested as violence from the police and *gundas* (street thugs) in the transgender and FSW communities. Self-stigma and feelings of worthlessness and despair were also reported by some participants as hindering their participation in civil society. Some participants indicated that fear of losing family dignity also inhibited the participation of PLHA in civil society:

In my case, I have two daughters. I myself don't want to say openly that I am [HIV] positive, because if people come to know that their mother is positive, who will come and marry them? Would someone who is a college lecturer like it if people tell him that his mother in law is HIV positive? So people think about dignity and don't come forward to participate (Tina, 30-year-old female, peer counsellor at a PLHA network).

In addition to stigma and discrimination, the lack of leadership building within PLHA networks was also cited by some participants as a barrier to participation.

[A]nd only few PLHA, leaders are in all the programs. If I am a first line leader, I have to attend all the programs, all the trainings, I have to attend but second line leaders are not even getting the chance to attend the programs. This is also a barrier [for participation of PLHA in civil society] (Shivana, 26-year-old male, PLHA network member).

The PLHA community had a strong sense of who the 'first-line leaders' among PLHA were. They defined 'first-line leaders' as those PLHA who received most training and

participated in most events, media interviews and were most visible in civil society. Some PLHA discussed the over-participation of these first-line leaders, leading to a lack of significant capacity building and opportunities for other PLHA to participate in civil society. Beall (1997) argued that participatory health projects often result in those who are already powerful taking advantage of the opportunities offered by participation rather than communities uniting for collective benefits. Busca (2004) observed that the powerful may even obstruct the participation of the less powerful in order to maintain their dominance. Similarly, Bourdieu (1979, 1986) and Wakefield & Poland (2005) use the notion of group social capital to highlight that people in leadership positions can at times ensure that social capital and its benefits are concentrated on certain individuals thereby excluding group members with different norms and identities. This was reported to be a barrier to participation of PLHA, as some participants felt that opportunities to enhance their knowledge and skills were not generally available to PLHA other than the ‘first-line leaders’.

Another participant described the relationships between PLHA in the workplace, even within networks of PLHA, as a “typical boss and employee relationship”, where PLHA in lower positions followed the orders of those in higher positions. As a result of such situations, some PLHA found it difficult to voice their concerns in their work settings. This was also cited as a significant barrier to participation of PLHA, particularly for those employed in lower, community-level jobs. Fear of repercussions due to voicing their opinions, within networks of PLHA, was reported by one participant:

I am not secure, because [my current job] is my only livelihood in which I have to take care of myself and my family. OK, I cannot open my mouth, my voice, because this is the only daily earning that my family has. So while opening my mouth, I have to be very careful, tomorrow what will be there ... If I am raising my voice against an NGO, they will remove me from the job, next day, where will I go? Who will give me a job? (Amba, 42-year-old female, PLHA network member).

The concentration of training and visibility to the ‘first line leaders’ and a top-down approach, as mentioned by research participants, can serve to segregate PLHA

networks and reinforce relative positions within organizational hierarchies (Bourdieu 1979). The presence of dominant leaders within PLHA networks and the reluctance to build capacities of other network members ensures that “people who are known” (Bourdieu 1986, p. 24) speak on behalf of the whole group, thereby concentrating the power of these networks into the hands of these ‘first line leaders’ and also inducing a distance between those speaking and those being spoken for (Bourdieu 1979; Cohen 2001). This was cited as a critical barrier to PLHA participation in civil society.

Lack of adequate educational qualifications was discussed by some participants as another significant barrier to PLHA participation as employees of CSOs:

If we ask for a job, they ask us what our qualification is, what our experience is. We are not well educated. In such a scenario, how many people will be able to get good jobs? (Tina, 30-year-old female, peer counsellor at a PLHA network).

There was animosity within the PLHA community and those vulnerable to the infection towards people who were not HIV-positive being given better positions and receiving higher salaries within CSOs that offered none or few lower-paid positions to PLHA. Participants perceived that HIV-negative people received opportunities to participate and to speak for and make decisions on behalf of PLHA. As one participant put it, there are many “non-community people” working in CSOs.

The notion of credentialism (Collins et al 2007; Travers et al 2008) reported in section 2.4.1, wherein only PLHA who are well educated are seen as credible, was also highlighted in the current study. However, a recent increase in the employment of qualified professionals may also be part of the larger phenomenon of professionalization of CSOs in India. Kamat (2003) described this as a process whereby professionally trained staff constitute a significant portion of leadership in CSOs, due to a shift of organizational character. Kamat asserted that during the 1960s to 1980s, the leadership in community based NGOs was predominantly by middle-class leftists who were committed to social justice and understood the needs at grassroots level. Activists at that time, she argued, understood the need to ‘de-

professionalize' so as to build relationships with the poor (Kamat 2002; Kamat 2003; Miraftab 1997). However, Kamat noted a post-1980s shift to a managerial and functional approach to social change, which led to a greater extent of professionally trained staff playing more important roles in CSOs. This national level transition may also have contributed significantly to the employment of HIV-negative, highly trained and qualified personnel in CSOs. Increasing professionalization is also in part due to the need for accountability to donors that fund CSOs. To cope with donor demands, CSOs need expertise in proposal development, accounting and monitoring and evaluation procedures (Markowitz & Tice 2002). The need for professionals trained in these areas has become critical to funding sustainability. Staff members hired after the influx of donor funding were more likely to hold academic degrees and credentials while the participation of community members was often restricted to the grassroots level (Poster 1995; Safa 1995). This may have led to a decrease in the willingness to employ PLHA and members of vulnerable communities in decision-making positions. This phenomenon, however, was perceived as discriminatory to the PLHA community and was seen as further marginalizing the very communities that CSOs sought to help.

5.6.3 Factors Facilitating Participation

Though significant barriers to participation of PLHA in civil society were noted, participants also spoke about facilitators to participation. Participants noted that the most significant facilitator to the participation of PLHA who were previously not involved in civil society, was knowledge of their rights and entitlements. Provision of training and awareness programs by CSOs on the rights of PLHA, positive living and emotional well-being have had a considerable impact on the participation of PLHA in civil society.

They gave me information about rights, before that I had no such information. Then I thought why should it go to waste. I wanted to work, at least for my children. I was determined (Tina, 30-year-old female, peer counsellor at a PLHA network).

Courses on managing HIV infection, government benefits and welfare available for PLHA and their rights and entitlements were often followed by weekly or monthly

support group meetings, where PLHA were given an opportunity to discuss the problems they face. During these support group meetings PLHA shared their experiences of living with HIV/AIDS including stigma and discrimination and the problems they faced in everyday life once their HIV-positive status became known to others. Participants felt that these workshops built confidence, raised feelings of self-worth and gave them courage to initiate participation. In addition to the knowledge and skills imparted by these workshops, the presence and reassurance of others in similar situations provided a feeling of community and belonging, especially for newly diagnosed PLHA. Encouragement from members of CSOs and other PLHA was reported by PLHA as being pivotal to their decision to become involved in civil society. The process of joining the HIV/AIDS community is also a way of incorporating the HIV-positive identity into the lives of PLHA (Baumgartner 2007). Baumgartner argued that during the ‘immersion stage’ of developing an HIV-identity, PLHA join HIV/AIDS support groups and engage in learning and teaching others about HIV/AIDS. This process also allows them to feel more in control of their illness and their lives.

The will to survive was a cross-cutting motivator to PLHA participation in civil society. In the case of participants with children, survival was largely motivated by the need to secure a good education and future for their children. To live openly as a member of a sexual minority community was a strong motivator in the MSM and transgender communities:

Before joining [this organization], I had an ambition of living like a woman. If I have to live like a woman, I have to fight. Otherwise I have to sit in a corner, beg and eat. So that's why I joined [this organization] as an office assistant and now, I am the Director (Roopa, 40-year-old male to female transgender, member of CBO for sexuality minorities).

Roopa’s journey from working an office assistant in a CSO to being its Director speaks volumes about the resilience of PLHA and also of the ways in which CSOs have evolved. Such examples of personal growth and participation, however, were rare in Bangalore.

5.6.4 Absence of PWID in Civil Society

A surprising finding from Phase I was the absence of PWID in civil society activities. While PWID have been identified as a high-risk group for HIV transmission in Bangalore (NACO 2007a), people who identified as PWID were not visible in any CSO activities that I attended. There was also a lack of discourse around PWID and their vulnerability to HIV/AIDS in Bangalore. Most participants stated that they had never met a person who identified as a PWID in HIV-related civil society activities. These participants felt that PWID might have their own organizations and did not want to engage with other CSOs. However, it emerged that very few CSOs focused on HIV/AIDS engaged with PWID in Bangalore. Only one government-funded program for PWID existed at the time of conduct of this study. The lack of CSOs engaged with PWID in comparison with other vulnerable communities was clearly a barrier to PWID participation in civil society. This absence also speaks to the secrecy that surrounds injecting drug use in India. As in other parts of the world, possession and consumption of drugs in India can result in arrest, imprisonment and possible rehabilitation (UNODC 2010). The absence of PWID in civil society engaged in HIV/AIDS might also indicate that their vulnerability to HIV infection has not been adequately acknowledged by CSOs and the government. While I attempted to ensure representation of communities vulnerable to HIV/AIDS, particularly NACO's high-risk groups of FSW, MSM and PWID, I was not able to gain access to PWID to participate in the initial phase of the study.

This section discussed the nature of PLHA participation in civil society in Bangalore. Data revealed that most PLHA participated at the community level, rather than at decision-making levels. Significant barriers to their participation were reported, including stigma and discrimination and lack of skills and educational qualifications to adequately participate in CSOs. Participants also highlighted the factors that facilitated PLHA participation; these included knowledge about their rights and entitlements, belonging to a PLHA network, and the need to care for their children. The absence of PWID in civil society engaged in HIV-related activities was also an important finding of Phase I of the study.

5.7 Implications for Phase II of the Study

Phase I provided valuable contextual data as well as field and data collection experience. This contextual data laid the groundwork for Phase II of the study. On evaluation of the results of Phase I, it was determined that two emergent themes could influence local HIV policy making in Karnataka, namely the antagonistic relationships between CSOs and the KSAPS and the heterogeneity of civil society and the PLHA community in Bangalore. These two themes were selected for further exploration, with the final aim of understanding the ways in which civil society influences local HIV policies in Karnataka.

As mentioned, Phase I results broadly introduced the diversity of civil society engaged in HIV/AIDS in Bangalore and provided information on the types of relationships that existed within civil society. It illustrated the key stakeholders in HIV-related activities in Bangalore, which included a range of groups vulnerable to HIV, PLHA, CSOs that work on HIV prevention, treatment, care and support, advocacy and research and the KSAPS. In addition, civil society comprised CSO staff and members of the PLHA, FSW, MSM and transgender communities. The specific actors that comprise the ‘HIV community’ in Bangalore needed further exploration. Heller (1989) noted that both ‘locational’ definitions of community – based on geographical location – and ‘relational’ definitions of community – based on shared identities – can be used to describe a community as being homogeneous. The boundary of a community is drawn around members who are expected to be equals (Cornish & Ghosh 2007). For the scope of the Phase II study, the community of people living with and vulnerable to HIV/AIDS was viewed from a systemic perspective (Markova 2003), where a community is defined by interdependencies rather than likeness. The HIV community in Bangalore was not held together by living in the same locality, sharing the same identity nor by being equals. It was instead held together by an interdependent system in which each community and organization’s actions affected others by virtue of their participation in a joint activity (van Vlaenderen 2001). The boundaries of this community, types of partnerships and interdependencies that exist between CSOs and between communities living with and vulnerable to HIV/AIDS were further explored in Phase II.

The heterogeneous nature of civil society may act as both a benefit and a barrier to participation in HIV policy making. Diversity may be beneficial in times of protests, where the power of numbers as different groups unite becomes evident. This heterogeneity, however, can also be a barrier to civil society members reaching a consensus on raising community interests, particularly when CSOs align with funding mandates, as discussed earlier. Heterogeneity within civil society can also have implications for networking and collaborative processes at the community level. Despite their heterogeneity and complex dynamics in Karnataka, civil society groups sometimes united to interface with the government. Participants also noted varying levels of participation of PLHA in civil society, which may determine the extent to which affected communities can articulate their needs, both within civil society and to the KSAPS. These findings raised questions about whose agendas were propagated in civil society, different communities' ability to participate in civil society, accountability within civil society, power concentrations, interdependence of civil society groups and global and local forces that influence civil society's work. The implications of these complex dynamics on civil society's ability to influence local HIV policies were identified as a key focus of the next phase of the research.

The second key focus area of Phase II of the study revolved around the relationships between CSOs and the KSAPS. This relationship was characterized as fragile and hostile by Phase I participants as a result of frequent changes in leadership at the KSAPS, a lack of trust between civil society and the KSAPS, and tokenistic consultation of CSOs by the KSAPS. Evidence suggests that good relationships between civil society and government plays a crucial role in sensitive policy making on HIV/AIDS (Tantivess & Walt 2008) and that the involvement of local people leads to better-designed programs through egalitarian and democratic processes (Aasthana & Oostvogels 1996; Nelson & Wright 1995; World Bank 1997). Bernard, Kippax and Baxter (2008) discussed the importance of building and sustaining partnerships between government and non-government actors and responding to any partnership difficulties quickly to ensure the success of HIV responses. However, global research has also illustrated gaps between the rhetoric and reality of community participation; groups who wield the greatest power, including governments, local elites and development professionals, dominate the government-CSO partnerships (Shiffman

2002; Stern & Green 2005). Phase I data suggested that the KSAPS and a majority of the CSOs have a hostile relationship and often it was the more powerful KSAPS that dominated the HIV-related activities of CSOs in Karnataka. The nature of the partnerships between these two entities, particularly in relation to local HIV policy making demanded further exploration. Local HIV policy making is critical in a large, heterogeneous country like India, where national HIV policies cannot be applied across the board and effectively respond to the diverse nature of the HIV epidemic in different states/regions. Given this scenario, understanding the local HIV policy making process, and the ways in which civil society groups and the KSAPS interacted to negotiate and shape HIV policies, was crucial to the second phase of the research.

Phase II of this research explored the following research questions:

1. How do approaches, dynamics and collaborations within civil society influence the development of local HIV policies?
2. How do civil society and the Karnataka State AIDS Prevention Society interact and negotiate to develop local HIV policies?

CHAPTER 6: COMMUNITIES, VULNERABILITIES AND IDENTITIES

6.1 Introduction

This chapter describes the ‘HIV community’ in Bangalore and the contexts in which they live and interact. Participant narratives are presented to illustrate their individuality and identities as members of vulnerable communities. The social, economic and cultural circumstances that heighten these communities’ vulnerabilities to HIV infection are explored. It emerged that vulnerable communities encompassed several ‘micro-communities’. I use the term ‘micro-communities’ here to describe the smaller but distinct groups that share local identities, culture and at times, resources; together they make up the communities that are commonly referred to as ‘vulnerable’, ‘high-risk’ or ‘target’. These micro-communities and the ways in which their identities are constructed, maintained and changed, where necessary, are explored in this chapter. In addition, community collaboration is discussed using the themes of power, trust, development of community relationships, accountability and leadership of CSOs.

6.2 Vulnerability to HIV/AIDS

The popular discourse on HIV/AIDS in India revolves around routes of transmission of the infection and the communities that are at high risk of the infection. Information regarding these groups and prevention methods such as condom use is repeated frequently by government agencies and HIV awareness campaigns. However, the actual situations that make people vulnerable to HIV/AIDS are rarely discussed. Vulnerability is often contextual, and is dependent on social and cultural factors as well as political and economic developments (Allotey et al 2012). As Zwi and Cabral (1991) note, in relation to HIV/AIDS, high-risk situations and contexts are likely to be more important than high-risk groups and behaviours. This section briefly explores some of these risk situations and the vulnerabilities they pose for the HIV infection. The discussion of these situational factors here is brief as these are not the focus of this research; the purpose of this section is to highlight the existence of such factors that increase vulnerability to HIV infection.

6.2.1 Poverty

Participant narratives highlighted that poverty is one of the most significant vulnerabilities to HIV/AIDS in India. The Indian government acknowledges that approximately 37% of the country's population lives below the poverty line (Economy Watch 2010), although other estimates suggest that up to 77% of Indians live in poverty (Nanda 2010). The poor in India live with food insecurity, livelihood constraints and deep-set inequalities. Consequently, they are forced to migrate in search of work, live in crowded and unsafe conditions and seek occupations that heighten their vulnerability to HIV, such as sex work. All participants engaged in sex work cited poverty as the reason for their initiation.

It's been eight years since I started doing sex work. The reason was financial problems in my family ... My husband left me at my mother's house when I was pregnant. I worked in a garment factory the whole nine months. Then six months after the delivery, I went back to work. After the child was born, my [financial] problems increased, for the child's expenses, for all expenses, for my expenses, family's expenses, for food ... I felt very bad. I lived with my parents. They are not rich, they are poor people. Then I went to a friend's house. There, a lady came and I told her my story – that my husband beat me and drove me out of the house. That I was working but my salary was not enough. To that she said, don't cry for these things. People do this work, sex work. You can earn up to Rs.500-600 daily. Your problems can get solved. Think about it (Bharti, 41-year-old female sex worker, sex workers' collective staff member).

In addition to creating vulnerability to HIV infection, poverty also decreases the nutritional status of PLHA, and increases the severity of the symptoms associated with HIV. Inadequate facilities and insufficient free care in government hospitals force poor PLHA to seek expensive private health care. These costs lead the poor into debt and further penury (Reddy et al 2011). The lack of adequate health care also creates vulnerability to further ill-health. HIV and poverty therefore mutually reinforce one another in India.

6.2.2 Gendered Inequities

Patriarchy and adherence to strict traditional structures are the norm in India. Women are expected to bear children and do household chores, with little choice in their access to information and health care. Women's rights to self-determination, health, education and employment are often overlooked in the male-dominated Indian society (Doshi & Gandhi 2008). Evidence indicates that consistent, correct condom use provides 90% – 95% protection against HIV infection (Stammers 2005). However, gender inequalities hinder condom usage; removing these inequalities was assessed as the most effective method of preventing HIV transmission (Mann, Tarantola & Netter 1992; Mugweni, Pearson & Omar 2012; Parkhurst 2012). Women in India therefore have to fight both the HIV virus and the systemic and societal norms that make them vulnerable to the infection. As a result of gender inequality, an increasing proportion of Indian PLHA (currently 39%) are women (NACO 2011), illustrating the feminization of the HIV epidemic in India.

An increase in monogamous married women being infected with HIV has also been reported; their sole vulnerability to the infection is marriage (Newmann et al 2000). In spite of this, participants noted that women are increasingly being blamed for the spread of the HIV epidemic, by their own families, by society in general and also by government officials. One participant recalled a meeting in which a NACO representative openly blamed women for 'getting' the HIV infection:

[The NACO representative] said 'you ladies go somewhere and get HIV'. He specifically said ladies? Yes, he said "you women go here and there and come back with the HIV infection. And then you ask us for benefits?" (Winning, 39-year-old male, coordinator of an HIV alliance).

Another participant described how she was treated by her in-laws when they found out about her HIV status:

My husband died in 2003 and it was then that I got to know that I was also HIV positive. My in-laws told me that I spoiled their son's life and caused his death. They told me that I would die immediately. I used to think that I was in

my last stages and worried about my children. They made me stay in a tiny room where I had to spend all my time. I had to live in the conditions that they dictated. Even when my friends used to visit, my in-laws used to speak badly about me and insult my friends. They said they wouldn't give me or my children a single rupee of my husband's money (Anita, 30-year-old female, staff member of an international CSO).

Married women who live with HIV are discriminated against, and are more likely to receive insufficient or delayed medical care, according to participants. Many women who live with HIV/AIDS often provide treatment for their seropositive husbands and children, at the cost of their own health (Bharat & Aggleton 1999).

6.2.3 Culture and Exclusion

Most participants reported being excluded from families, employment opportunities and educational institutions based on their sexual orientation, their HIV status or their identity as a FSW. These exclusionary practices increased vulnerability to HIV infection, as illustrated by a transgender participant's story. Prathibha, a male to female transgender, explained the process by which she decided to get involved in sex work:

I did my electronics training, it was a three years course. I discontinued my course after six months ... because of the classroom environment, the friends, the lecturers. Their way of behaving towards me was not okay. Then, I took a strong decision that I have to discontinue my study, I should search for some other job. I jumped into Cubbon Park – it is one of the biggest cruising spots in Bangalore, where all the entire sexual minority community members come there to have sex, to pick up sex, to cruise, to chat, to fight, to have fun, to gather (Prathibha, 27-year-old transgender, human rights organization staff member).

Prathibha went on to add that while she was trying to earn a livelihood, she was completely unaware of the dangers of having unsafe sex:

When I was doing sex work [between] 2000 and 2004, I did not have any information. From 2000 to 2002, I was in here and there – home, Cubbon Park, home, Cubbon Park, my friend, Cubbon Park - I was that way. From 2002 December, I was completely involved in Cubbon Park in sex work, okay? I was involved and I did not know about condom, what is condom, and how to have safe sex (Prathibha, 27-year-old transgender, human rights organization staff member).

Prathibha's account highlights the interplay between poverty, marginalization and exclusion of transgender people that led to her increased vulnerability to HIV/AIDS. The social stigma attached to being transgender or homosexual forces many to avoid seeking information regarding safe sexual practices and other methods of preventing HIV infection. Consequently, there has been an increase in HIV infections among these communities in India. Prathibha gave up sex work in 2004 after being offered a paid position at a CSO working with sexual minorities. This position also gave Prathibha the information she needed about safe sexual practices and condom use. Luckily (as Prathibha herself put it), she received this information at a crucial time and she continues to be free from the HIV infection.

6.3 Vulnerable Communities in Bangalore

This section explores the different groups that constitute the vulnerable community and how they develop, maintain and occasionally change their identities. Through the development of local identities, these groups have become micro-communities, smaller groups that share an identity and culture. These micro-communities share resources, including services provided by CSOs; however, their members felt overlooked by the government and its HIV prevention programs which focus on the broader vulnerable communities of FSW, MSM and PWID.

6.3.1 Social Construction of Community Identities

The most interesting discourse on identity was shared by participants who belonged to the sexual minority community. Often during fieldwork, I heard the term sexual or 'sexuality' minority; an organization was described as 'working for sexual minorities' or a person was described as 'a sexual minority'. Most used this term to refer to MSM

and transgender people. I soon found that in the Indian context, using the term sexual minority oversimplifies the community and the identities of its members. As my interviews progressed, I was introduced to numerous local terms used to describe different micro-communities of sexual minorities. These included terms such as *hijra*, *kothi*, *panthi*, *jogappa* and *double decker*. Neither the literature nor my participants could provide information into the origins of these terms and how they were first coined. To understand the sexual minority community in Karnataka, it is imperative to understand the ways in which these micro-communities describe and identify themselves. Using participant narratives, I offer a brief description of these micro-communities. These identities were socially or self-constructed and differed from the high-risk or target groups identified by the government for its HIV programs.

Prathibha (introduced earlier), whose CSO works with sexual minorities explained the different terminologies used in Karnataka to describe these micro-communities and how their identities have been developed:

Sexual minority is a broad term which is used all over the nation. Sexual minorities include kothis. They are men having feminine character and do not want to be recognized like man or woman or transgender. Kothi is a separate identity (Prathibha, 27-year-old transgender, human rights organization staff member).

According to participants, *kothis* are men who are penetrated during sexual intercourse. Limited published literature exists about the *kothi* community. The *kothi* identity is fluid in nature and has been socially constructed (Cohen 2005; Boyce 2006, 2007). Participants explained that *kothis* can be of two types: the *pant-shirt kothis* who dress like men and the *sathla kothis* who cross-dress. According to participants, the *sathla kothis* mostly consider themselves to be women. During data collection, most of the MSM participants identified themselves as *kothis* and some suggested women's names when asked for a suitable pseudonym. *Kothis* identify as MSM but their gender expression is feminine. *Kothis* do not engage in sex with one another and they are attracted to masculine partners, whom they call *panthis* locally. The term *panthis* is used only by the *kothi* community to identify their sexual partners (Chakrapani,

Newman & Shunmugam 2008). Though members of the *kothi* community identify themselves as MSM, their sexual partners, the *panthis*, are generally assumed to be predominantly heterosexual (Chakrapani, Newman & Shunmugam 2008). Through their study of the *kothi* community in the state of Tamil Nadu (which borders Karnataka), Chakrapani, Newman and Shunmugam (2008) found that *kothis* are generally of low socioeconomic status and many of them engage in sex work for their sustenance. On the other hand, *panthis* may belong to higher socioeconomic strata and may either pay for sex with the *kothis* or be long-term partners. The power hierarchies and gender inequalities that exist in heterosexual relationships also exist in *kothi-panthi* relationships (Kesavan 2008). Participants noted that unlike *kothis*, *panthis* are often socially invisible and many are married men who secretly lead homosexual lives. *Panthis* potentially transmit HIV between the *kothis* and their own wives; however this epidemiological link has not been considered by the KSAPS nor by many CSOs working on HIV/AIDS, who homogenize *kothis* and *panthis* under the term MSM and were less likely to access these communities for HIV prevention activities. The *panthis* are also less accessible for HIV prevention and awareness activities than the *kothis* since they do not identify as MSM and often choose to remain hidden. No estimates of the HIV prevalence among these communities were available in Bangalore.

Prathibha next described the *double decker* identity:

And double decker, that's a person playing a double role in sexual acts. If a masculine person is there, he behaves like a feminine. If I am a double-decker person, I have some sort of feminine character, but I express this only at certain times, not at all times (Prathibha, 27-year-old transgender, human rights organization staff member).

The *double decker* identity is developed through the ways in which the community members engage in sexual acts. Men who engage in both penetrative and receptive anal sex are labelled *double deckers*. This label, similar to the label of *panthi*, was developed by the *kothi* community (Chakrapani, Newman & Shunmugam 2008).

Double deckers also fall within the larger group of MSM. Next, Prathibha introduced another micro-community within the MSM group:

We also have jogappas. We find them in North Karnataka. They are accepted by society because of tradition but not humanity (Prathibha, 27-year-old transgender, human rights organization staff member).

The micro-identities discussed previously were all defined by the community members' sexual acts. However, the *jogappa* identity is deeply rooted in Hinduism and Karnataka tradition. Limited written information exists on the *jogappas*. *Jogappas* are feminine, erotic men who are 'caught' by the Goddess Yellamma to act as her human agents (Bradford 1983). Yellamma, which translates as the 'mother of all', is a goddess whose deity is found in the Belgaum district in northern Karnataka, which is one of the largest pilgrimage sites in southern India. These feminine men are viewed by society as sacred women; they wear women's clothes (sarees) and adopt feminine ways (Ramberg 2009). According to Bradford (1983), most *jogappas* are homosexuals, but while 'modern' homosexuals are stigmatized, the *jogappas*' homosexuality is mostly culturally accepted due to its link to Hinduism. *Jogappas* are seen as being divine rather than homosexual. The transformation from men to sacred women also makes them transgender people, thus creating a very unique identity. Participants noted that this uniqueness makes it difficult to carry out HIV interventions with the *jogappas* as most government intervention programs do not adequately acknowledge their risk status. At the time of conducting this study, *jogappas* were not named as a high-risk community in the NACO's literature.

The MSM community in India, and in particular Bangalore, is distinct from its counterparts in other regions of the world. In addition to including groups such as the *kothis*, *panthis* and the *jogappas*, during fieldwork, I came across MSM who preferred to be feminine and identified as women. Some participants who identified as MSM requested that they be identified as female during the interviews and offered a female pseudonym. As in other parts of the world, others were covert MSM, who were married and led 'normal' lives. Sridhar, who heads a CSO focused entirely on these 'covert' MSM, described this community thus:

These covert MSM have their own jobs. They lead a simple life in the society, and are especially from the middle class. They are not from the high class or from the lower income group ... They are from the middle class group and they feel that they are secure. They are secure for the simple reason they have not exposed their sexuality. Majority of the MSM are married and see they have their family. They are not bothered about this issue of MSM. It's just their desire of ... sexual desire which they get fulfilled outside their family. And you know, for that they don't want their sexuality to be exposed to the society. They want respect in the society (Sridhar, 50-year-old homosexual male, MSM support group coordinator).

Within the MSM community, identities were also established based on interactions between community members and organizations such as the KSAPS. For example, Nandita describes below how the MSM community contains 'upper' and 'lower' classes of individuals:

Within the gay community, you have those who have knowledge – the upper class. When they are there, then those below at grassroots level, whether poor or our community, those who are struggling with being [HIV] positive, have problems doing sex work ... these people are not considered. Did anyone ask such people for suggestions? No. They asked NGO heads, CBO heads, those [homosexual] upper class people who work with NGOs, you had meetings and planned with them ... Upper class means those who know English, getting handsome salary, Indian Administrative Service officers, that kind (Nandita, 29-year-old homosexual male, sexual minority forum staff member).

Interestingly, during fieldwork it emerged that the MSM community used the term 'gay' to identify 'upper class' homosexuals. Most study participants described themselves as either MSM or a sexual minority. The Western term 'gay' was reserved for educated, wealthy homosexual men.

But gays don't say they are sexual minorities. They are well educated, rich, have high thinking capacity. They are on the internet, computer. High people, high tastes. But those who are below, poor, at grassroots level, poor sexual minorities – the gays don't know much about them because they don't meet them. They don't know what problems are at lower levels. They don't want to interact much with us (Omprakash, 30-year-old homosexual male, sexual minority forum staff member).

Identifying members of these micro-communities is often confusing for civil society members not familiar with each one's distinct identity. Sridhar explained that confusion and broad categorization of their identities has led many to move away from the larger MSM community and civil society:

There are a lot of men who identify as gay. There are a lot of men who identify as bisexuals. A lot of men identify themselves as hijras, kothis and a number of other things. But, they would not like to be called by any brand as gay, or even the MSM ... I have been working in this community from 1994. I have never felt that I am a gay or that I am a bisexual or I am a hijra, or a kothi or anything. I feel, very simple thing is 'I am a man'. I am a man, and I am attracted to men. But it is very unfortunate that community members, when they call him by some brand or name, he feels hurt, and he feels that 'this is not my space'. So that's the reason you know, lot of social spaces are getting destructive (Sridhar, 50-year-old homosexual male, MSM support group coordinator).

Homosexuality is viewed as deviant behaviour in India and was criminalized until 2009 (Lawyers Collective 2013a). Though homosexuality has been legally decriminalized, according to participants, this has had little impact on public perceptions. As a result, many MSM, particularly those who are married, continue to conceal their sexuality. Concealed homosexuality poses a significant threat to the control of the HIV epidemic. Verma & Collumbien (2004) highlighted that a significant proportion of MSM in India are married and engage in sex with both men and women. These covert MSM pose risks to both their male and female partners. At

the time of data collection, only one CSO engaged with concealed MSM in Bangalore and only its director knew of the identities of the CSO's members. Other 'outed' MSM often told me that they do not want to engage with the covert MSM because the latter group was not being honest about their identities. Accessing this micro-community for HIV-related interventions is likely to be difficult for the government and CSOs alike.

Another community that is deeply rooted in Indian tradition are the *hijras*. Prathibha explained briefly about the *hijra* community:

And we are having hijras, okay? [They] are having their own culture as I said – 700-800 years of history of its own ... [The hijras] are having seven gharanas. If you want to be a hijra, you have to pierce your nose and ears and be in one of those gharanas (Prathibha, 27-year-old transgender, human rights organization staff member).

Hijras are biologically male but live and dress as women; some are castrated (Aasthana & Oostvogels 2001; Khan 2001; Reddy 2005). The *hijra* community in India is divided into seven *gharanas* or houses. These houses have their own histories and rules by which its members are meant to abide. Each of these houses has a *guru* or a leader and each *guru* has followers, known as *chelas*. The relationship between the *guru* and *chela* is the most significant in the *hijra* community (Nanda 1985). When a person decides to join the *hijra* community, he is taken to visit the leaders of the seven houses and during the initiation, the *guru* gives him a female name (Thappa, Singh & Kaimal 2008). The *guru-chela* relationship is a lifelong bond of mutual reciprocity wherein the *guru* is obligated to help the *chela* and the *chela* in return is obligated to be loyal, obedient and care for the *guru* during her old age. According to the *hijra* participants, the *gurus* are the equivalent of the mother of a family and a *chela*, or follower is the equivalent of a daughter. The participants' identities as either a *guru* or *chela* or both dictate their position in their respective houses. One *hijra* participant, Neelambari, described how these identities are formed and the duties they involve:

Hijras will help us. Our [biological] parents won't help us. We will keep aside some money. Daily if we collect Rs.250, we spend 150 and save 100. We spend on clothes, make up things ... the money is just enough for all that. Now, I am earning and taking care of my guru. When I am old, I'll get a chela, I'll get a daughter. The hijra community will not get suppressed. It will keep flourishing. Now if I have a daughter, if she collects 200 rupees, we will eat together. When she is old, then a daughter will come to her. Do you understand? Then that daughter will help her [to live]. Now parents too, have four children, when all four grow up they earn and help the parents. So when we take care of [our daughters] when they are young, they will take care of us when we are old (Neelambari, 37-year-old transgender living with HIV).

In addition to the *guru-chela* relationship, *hijras* also form fictive kinship with each other. As Neelambari discussed above, 'taking a daughter' and 'becoming a grandmother' are common phrases used within this community. The *hijras* therefore have numerous identities within their own community. As a result of this kinship, *hijras* all over India are said to be connected to each other and there is a constant movement of individuals who visit their fictive kin in different parts of the country.

Studies suggest that a large proportion of *hijras* engage in sex work due to social stigma and employment discrimination, which limit their opportunities for income generation (Clements et al 1999; Nemoto et al 2006; Sausa, Keatley & Operario 2007). Although historically in India *hijras* have had a special status in society where they danced and gave blessings at births and certain festivals, current income generation opportunities for transgender women are limited to selling sex or begging (Hernandez et al 2006). Sex work for *hijras* adds to factors such as stigma and lack of education and employment opportunities that predispose them to HIV infection (Bocking, Robinson & Rosser 1998; Garber 1992; Melendez & Pinto 2007; Pisani et al 2004, Roy et al 2001; Westhoff, McDermott & Holcomb 1996). A meta-analysis of 25 studies on male to female transgender participants involving 6405 people in urban settings in 14 countries found a four-fold increased risk of HIV infection in transgender sex workers compared to biologically female sex workers (Operario, Soma & Underhill 2008). Lack of employment opportunities may force *hijra* women to

transact sex, and high levels of violence, particularly sexual violence, whether from pimps, street thugs or the police, may inhibit their use of condoms (Narrain & Bhan 2005). In addition, their health-seeking behaviors are often poor due to discrimination in health care settings (Deshmukh, Row Kavi & Anand 2004). The unique situation faced by the *hijra* requires tailored HIV prevention and testing programs, which can potentially reduce their risk of HIV infection as well as help to identify HIV-positive members of this community. Such an approach was lacking in NACO and KSAPS' approach to HIV interventions with the *hijra* community.

Some of the abovementioned micro-communities were constituents of more than one vulnerable community. For example, a *hijra* can be considered to be both a transgender person and a FSW if she engages in sex work. Similarly, a *jogappa* can be part of both the transgender and MSM communities. If members of any of the micro-communities contract HIV, these individuals would also be part of the PLHA community in Bangalore. Participants felt that these identities and diversities were not being recognized by the government and many CSOs. This, they feel, has implications for HIV interventions and also the extent to which these micro-communities are acknowledged by both civil society and the government.

6.3.2 Changing Identities

Most participants felt proud of their identity, which was based on either their HIV status or the vulnerable community to which they belonged. However, some participants discussed how community members at times had dual identities, one public and the other personal. Some community members were noted to be willing to change their identities if adequate incentives were provided. For example, one participant explained the process by which MSM started identifying themselves as male sex workers (MSW) in order to seek jobs from a CSO:

[Another MSM group] started providing job opportunities to the community members. And you know this led to lot of conflict in the community ... MSM is one community, but [the CSO] started giving jobs to MSWs. There were MSWs [in the community], but very few. Because of the job opportunity and the money they were getting, people switched over to this identification as male sex

workers (Sridhar, 50-year-old homosexual male, MSM support group coordinator).

As discussed in the previous chapter, some widows living with HIV/AIDS strongly disliked being associated with HIV-positive FSW. However, one participant described how she identified herself as a FSW prior to actually engaging in sex work in order to gain employment with a CSO:

[The doctor at the ART clinic] asked me about myself. I said I am a family girl, I had a problem and got infected. Now I want a job. They said to ask [an organization working with FSW]. I went and asked them and they said that those who go there are sex workers, so they will give opportunities only to sex workers. So there's no work for those who aren't sex workers. Not for me. Then the girls who saw me said 'Say she's a sex worker and take her on'. I didn't mind telling everyone that I was a sex worker [to get the job] (Anjali, 38-year-old HIV-positive FSW, sex workers' collective staff member).

The HIV epidemic in India, as well as government and CSO priorities, have changed over the years. Global acceptance of concepts of peer education to encourage behaviour change and the need for local ownership of HIV-related activities by community members influenced India's policies and programs. Following global trends and the policies of international funders, the NACP II (1999–2004) and NACP III (2006–2011) advocated for peer education, training and creating community leaders from the 'target' groups of FSW, MSM and PWID communities and for greater participation of their members (NACO 2012a). Consequently, a number of CSOs whose membership was limited to members of the high-risk groups were given the task of carrying out government HIV-related activities (BMGF 2010; NACO 2006). Peer education and the need for outreach workers from the affected communities created opportunities for jobs and welfare benefits for high-risk community members. Such developments caused some members to change their identities to seek these advantages. These accounts also illustrate the marginalization and desperation that

poor PLHA in Bangalore face, which causes them to reconstruct their identities as they juggle loyalties to different communities in an effort to gain rewards and benefits.

6.3.3 The ‘Empowered’ Identity

Some participants discussed developing an ‘empowered’ identity through participation in civil society. The process and outcomes of empowerment have been shown to improve life situations and interpersonal bonding, reconstruct group identities and enhance people’s participation in social movements, in an attempt to change unjust power relations (Bandura 1995, 1997; Collins 2000; Gutierrez 1995; Drury & Reicher 2009). Empowered individuals are able to redress and resolve issues of powerlessness and oppression (Molix & Bettencourt 2010). For most participants, an empowered identity was developed through their association with CSOs. Participants felt that belonging to a CSO and gaining information regarding medication and human rights led them to develop new identities as empowered and ‘responsibilized’ (Robins 2004, 2008) PLHA. Gaining confidence and a will to survive gave some participants a feeling of empowerment.

Initially, I was very upset about [contracting] HIV. When I came to [the community network], I realized that there are so many people like me, why shouldn't I also live happily? I got to know about living with ART. Like that I felt positive, I have HIV, but I too will live like everyone else. So I became courageous and came out into the world (Neelambari, 37-year-old transgender living with HIV).

Personal empowerment is a combination of personal efficacy and competence, a sense of control over life and the ability to participate to influence institutions and their decisions (Israel et al 1994). Labonte (1990) described the elements of personal empowerment as including improved self-esteem and cultural identity, the ability to reflect critically and solve problems, ability to make choices, increased access to resources, increased bargaining power and the ability to work with others. Most participants were supported by CSOs to become empowered PLHA:

Now initially I didn't know anything about HIV. I was only a widow with a small child. But when I started coming to [a district PLHA network], they provided training, training on rights, how we should speak, our language and our style of speaking. We were trained to speak before big people, how to behave before them. We didn't know this before. Now I feel empowered and can tell these people what the community wants (Devi, 29-year-old female living with HIV, PLHA network staff member).

Similarly, Prathibha mentioned her sense of achievement at learning English through her association with a human rights CSO:

So where I got job as a peer educator for 1800 rupees of salary, my English was not at all there. Only I was speaking Kannada, Kannada, Kannada ... After joining [the organization], the exposure that I got, the people who are coming [here] to know about the issues of sexuality minorities, many of them came from foreign countries, many of them other states. People who were speaking English, you know. I was having so much interest, the other people on the Board were speaking English. I was observing their pronunciation, observing their kind of flow of English and their sentences, their kind of presentation-doing, and interacting with people. So that observation, that made me to say, yes, I have to learn English. I should learn, I should learn. In that way, I took the determination and I began to speak with whatever English I knew. I started talking that way. Now I'm in the position where I do presentation in English, I do sessions in English on sex, gender sexuality. In that way, all of this I learnt by exposure. I'm very thankful for that (Prathibha, 27-year-old transgender, human rights organization staff member).

The use of English is an example of how funding agencies and their representatives disempower community members (Cornish et al 2012). Prathibha's ability to converse in English is a concrete example of overcoming disempowering processes to develop an empowered identity, through which she has built confidence in her communication skills. At the start of our interview, when I started speaking in Kannada, Prathibha self-assuredly said *"You don't have to bother with Kannada, I want to speak in*

English” (Fieldnote, 17/08/2010). The empowered identity, particularly among the disadvantaged, emerges from collective dialogue and raised consciousness as a result of collectivization, sharing discriminatory experiences and reflection of own social positions (Chen, Chen & Shaw 2007). Sharing concerns and developing bonds with other group members have been found to aid in the reconstruction of self and group identities, engender alternative worldviews and assist people to take charge of their own lives (Chen, Chen & Shaw 2004; Harding 1996; Hooks 1994).

This section concentrated on the micro-communities, the small groups that share a common identity and culture, that constitute the larger vulnerable communities of PLHA, FSW, MSM and transgender people in Karnataka. The ways in which their identities were constructed and sometimes changed were also discussed. In addition to their socially constructed identities, many participants also developed an empowered identity.

6.4 Community Collaboration

As discussed in the previous chapter, the intra- and inter-community dynamics of civil society engaged in HIV-related work in Karnataka was complex. In Bangalore, as in the rest of the country, PLHA and those vulnerable to the infection were encouraged to become active and to take charge of their own futures, a type of ‘biological citizenship’ (Petryna 2002; Rose 2007; Rose & Novas 2007) which provides rights and choices. Most became members of a network or union that provided benefits for PLHA, FSW or MSM. These networks often came together and collaborated to address the community’s issues and to demand their rights. From the outside, community members and CSOs appeared to collaborate with a common purpose – for protests against the government or a pharmaceutical company, or to organize events to highlight the plight of PLHA to the larger society. As fieldwork progressed, it emerged that the HIV community in Bangalore was not as cohesive as it first appeared. In this section, the ways in which vulnerable communities interacted and collaborated, with the ultimate goal of improving conditions for PLHA, are discussed. This is illustrated through an exploration of the power, trust and relationship dynamics that existed within and between the diverse constituents of civil society. This section also

describes the functioning of CSOs, in particular PLHA networks, through the themes of accountability and leadership.

6.4.1 Community Relationships

Most participants discussed the relationships between PLHA networks in Bangalore during interviews. For the most, part participants perceived that these networks sometimes came together for a specific event, but otherwise functioned fairly independently. Referral between CSOs was common, particularly to organizations that provided medical care and legal support to PLHA. Although PLHA groups, vulnerable communities and the CSOs representing them had the semblance of a united front, further exploration revealed that these groups were fragmented and in some cases had strained relationships.

Some participants, who had been part of the HIV sector for decades, highlighted that one of the key reasons for the lack of cohesion between CSOs was the way in which these networks were originally formed. One participant, Justice, recalled that in the initial days of the HIV epidemic, PLHA and members of other vulnerable communities were allowed to come together and form groups by their own will, to ‘organically’ collectivize themselves:

See, primarily, our belief is that communities have to evolve organically. They cannot be brought together and registered as an organization. And as you know, in some of the states with sex worker groups, that’s what has happened. And they have failed dismally. Our groups have really evolved – we took 5 years before they registered. We allowed them to collectivize and build solidarity before getting into an organization. So they’re very, very, very happy with how they have grown. Amazing strength that they have, it’s just amazing! (Justice, 58-year-old female, director of an HIV prevention CSO).

She noted that the PLHA networks in Bangalore and in the state of Karnataka have had very different types of genesis:

The positive networks, unfortunately, there were just too many players ... and different donor agencies. Different people all wanting to organize [the PLHA]. So I would select you and say you get a few people together and you register. And then somebody else will select somebody else. So I don't think they got a chance to, to really come together as people with a common cause. They came together with a common identity of being positive, but not about people who have a common experience of being positive. So wanting to be together for others was not adequately built in. So it's all about who wants to be the leader. Every movement, people have to look to themselves first, because they have been marginalized, deprived. So they will look to themselves first. But if there is a process which helps you to look from yourself inside out to, to others, then that is sustainable. But if it's not, if you just bring people together, once there is no money, it doesn't sustain (Justice, 58-year-old female, director of an HIV prevention CSO).

In Chapter 2, the idea of a manufactured civil society (Hodgson 2004) was introduced. This occurs when CSOs are developed based on government initiatives or funding mandates rather than evolving organically in response to community needs. Justice's statements indicated that some CSOs engaged in HIV/AIDS in Bangalore were manufactured rather than developing organically.

As mentioned in the previous chapter, participation in civil society by PWID was virtually non-existent in Bangalore. Other vulnerable communities appeared to have no relationship with the PWID community. Participant narratives indicated that the lack of a relationship between the PWID, PLHA and other vulnerable communities stemmed from disinterest in understanding each others' concerns; this disinterest appeared to be common to both the PWID and other vulnerable communities. As a participant who injects drugs, Jamal explained:

IDUs don't participate much [in civil society] because from beginning, I didn't get involved in it. [Our] only motivation is taking drug, drug, drug. I never questioned: Why government is doing something? Every time I will see in the papers, news and all [about protest rallies against the government]. And also

we see, 'No taking drugs, no taking alcohol'. HIV also spreading very badly because of drugs injecting and all. I see many rallies and all, but I never participate (Jamal, 31-year-old male who injects drugs).

Campbell & Scott (2012, p.181) discussed the need for HIV projects to create “transformative social spaces” through which people can develop an understanding of how to improve their health. A PLHA network that forms organically at the community-level is likely to provide such a ‘safe place’, wherein PLHA can engage in dialogue and debate (Vaughan 2010). Such dialogue can enable PLHA to take ownership of and incorporate new information and ideas into their existing worldviews and practices. The development of such social spaces is essential for the mobilization of PLHA and the sustenance of PLHA networks. Participants, however, felt that such spaces were not created by the funding/planning agencies. Rather, PLHA networks were seen as mechanisms to demonstrate the number of PLHA present in a geographical area and to further state/donor agendas. Participants asserted that many networks were formed solely due to funding mandates and several networks became competitors for HIV funding. These networks are examples of manufactured civil society, which are more accountable to funders than the PLHA community. Consequently, relationship building within PLHA networks and between PLHA networks was given little attention.

During my time in the field, a few members of the BHAF decided to form a Task Force to enhance the relationships between CSOs, to begin a multi-sectoral collaboration across organizations, and to fight for the rights of PLHA. This was seen as a way of creating an empowered group of PLHA who were members of different CSOs, and an attempt to address the concerns of PLHA without demanding they be members of any particular PLHA network.

So the decision to start the Task Force, whose decision was it? It was the decision of all PLHA together. Meetings kept happening. PLHA were not getting what was due to them. So PLHA came together and took this decision. At least if we do this, will we get our benefits. Otherwise NGOs keep working, NGO heads keep talking ... so we came forward and said, we have these

problems, will we get solutions? Give us training and we will find a way. So we approached the Forum [to start a task force] (Indira, 31-year-old female living with HIV/AIDS, PLHA network staff member).

Empowerment and critical consciousness represent people's abilities to make decisions, achieve equity and enact change (Champeau & Shaw 2002; Minkler & Wallerstein 1999). Empowerment requires the development of what Paulo Friere (1970, 1973) termed 'conscientisation' or critical consciousness. The process of empowerment of PLHA in Bangalore had been taking place for many years. Perhaps with the Task Force, they were beginning to develop critical consciousness regarding the realities that shaped their lives and their ability to transform those realities (Friere 1970). Participants noted that initiatives such as the Task Force mentioned above were ways to finally take control of their situations, move away from the politics among PLHA, refocus on providing benefits for the larger community and meaningfully participate in civil society. Freire (1970) termed this 'critical transitivity', the achievement of conscientisation through the dynamic relationship between critical thought and actions. Campbell and Jovchelovitch (2000) argued that this level of consciousness is only achieved through a social process of learning through dialogue and participatory relationships. Through processes of constructing and consolidating relationships within the PLHA community, the BHAF Task Force members were reclaiming their right to participate in civil society.

6.4.2 Power

Power is an essential part of organizing communities; a community organization exists to facilitate change by influencing individuals and social systems (Alinsky 1969, 1972). In the previous chapter I discussed power using French's (1985) concept of power-over and power-to, particularly in exploring the dynamics between sex-working and non-sex-working women living with HIV/AIDS. In this section, I illustrate power relations within PLHA networks using Foucauldian theory.

Foucault (1979) defined three main expressions of power: exploitative (the power to control people's economic lives), dominance (the direct power to control people's choice) and hegemony (the power to control people's perceptions so that their actions

are controlled by dominance). All three of these manifestations of power were apparent in the PLHA networks in Bangalore. Participant narratives were laden with examples of power struggles between PLHA networks, between members of these networks and domination by leaders.

Rajni's story provides an excellent example of exploitative power. She spoke at length over two interviews about the circumstances that caused her to leave the district PLHA network. She became involved in trying to start a network for women and children living with HIV/AIDS. When the district PLHA network that she worked for came to know of this, they withheld her salary:

I was involved in starting a new network. I was also working for the district PLHA network. When the leaders there found out [about the new network], they didn't give me my salary for three months. They said, 'you have started a parallel network because you are working only with women in that network'. They didn't give money for my project for months and didn't even give the other staff their salaries. Finally, I resigned. I didn't want them to suffer because of me. Even after I submitted the resignation letter, the staff didn't get their salary for a long time (Rajni, 43-year-old female living with HIV, PLHA network staff member).

Rajni's experience became well known among PLHA and was recounted by several other PLHA research participants as an example of the power that network leaders exert over their staff. In this instance, reporting to the state-level PLHA network about withholding of staff salaries also yielded no results, according to participants. This resulted in an entire team of PLHA facing financial hardship. For fear of losing their jobs, most of these PLHA continued to work for the network's project; it was only after Rajni resigned that the rest of the team were paid their pending wages. Similar instances of exploitation of PLHA by network leaders were discussed by several participants.

In the abovementioned instance, the salaries of the staff of Rajni's project were withheld until she resigned from her position. Other participants explained that not

receiving their salaries on time every month was a usual practice in some PLHA networks. Here, participants described that exploitative power, or the power to control their economic lives, was exerted by PLHA leaders and sometimes funding organizations. Some participants felt that funding projects for a limited number of years was also a method of controlling their economic lives. Devi, a participant working on a government funded project in a local PLHA network, explained:

The [funder] gives projects for so many years and after that there is nothing – what do we do after the project is over? They don't give funding properly. Now I haven't gotten my salary for the last three months. The salary should come correctly once a month. The KSAPS says that PLHA should have a good quality of life but how do we do this without money? ... We are supposed to get our salaries from [the national PLHA network], but we usually get it every three or four months. Getting them to release funds and getting salary on times is always a problem (Devi, 29-year-old female living with HIV, PLHA network staff member).

Exploitative power is therefore exerted by PLHA leaders and funding agencies. This has significant impacts on the lives of PLHA who are dependent on their monthly salaries to maintain their families. Participants who discussed delays in getting their salaries highlighted the difficulties this caused in meeting their families' nutritional needs, paying for their children's education and the anxiety this caused in their day-to-day lives. In addition to exploitative power, an example of dominant power by PLHA network leaders was illustrated by some participants.

Often [the national PLHA network] sits taking absolute control and basically saying 'we call the shots and we run the show and you guys do whatever it is we ask you'. So the [state and district] networks again did not have their own real identity. Yes, they had a name, they represented either Delhi or Karnataka or whatever ... But [the national PLHA network] again, for whatever might be the reason, was always very choosy as to whom they will support, how they will support. If you're going to start something it should be under our blessing

(Rahul, 50-year-old male, manager of a CSO engaged in HIV prevention and care and support).

Participants reported that it was fairly common for individuals to form their own networks after a disagreement with the leader/staff of the network to which they previously belonged. Others, including Rajni, described how members of some district-level PLHA networks attempted to sabotage the formation of other networks in the same area. Shwetha described her experiences of attempting to initiate a network of HIV-positive women in a rural district of Karnataka. According to her, many women living with HIV/AIDS felt that their voices were unheard in the existing male-dominated PLHA networks and expressed a desire to have a network that focused on women and children. However, she and her supporters faced tremendous difficulties during their attempts to register their network. In an example of hegemonic power, the leaders of other PLHA networks spread false information about these women in order to alienate them from the larger PLHA community and also attempted to influence government officials.

'Why should you form a network'? they asked. We already have one, why form another one? It was a kind of fight between [that PLHA network] and us. So they began giving wrong information to people, saying 'don't go to them, they have come to form a network. If you go, you have to involve in their network, it's not a good network'. [They said that] we are taking bribes from the Ministry. That kind of misinformation [was given]. They created problems and the registration was kept pending (Shwetha, 34-year-old female living with HIV, PLHA network staff member).

The narratives above illustrate the many anecdotes of power struggles and dominance that were shared during fieldwork. The misuse of power posed a significant problem in the PLHA networks in Bangalore. These networks were developed to address the needs of PLHA, particularly those who are marginalized. Yet, those who had power within the networks often wielded it in ways that reproduced structures of domination and subordination within the group. The exertion of power in PLHA networks is significant as it is likely to influence the type and nature of HIV-related activities that

are initiated in Bangalore. The PLHA community in Bangalore are heterogeneous and fragmented, in part due to the number of PLHA networks that exist in Karnataka. Infighting for opportunities and power has led to factionalism.

6.4.3 Trust

Trust between communities and CSOs is crucial to collaborative community engagement in HIV/AIDS. Community collaborations are considered risky ventures (Butler & Gill 1995; Das & Teng 1998) and some level of trust is required to initiate and maintain them (Huxham & Vangen 2005; Webb 1991). Trust is also cited as one of the main components of social capital, which is necessary for social integration, economic efficiency and democratic stability (Coleman 1988; Putnam 1993, 1995; Fukuyama 1999). In chapter 5, the community members' mistrust of the government, in particular the KSAPS, was discussed. The Phase II data also revealed a mistrust of PLHA organizations and their leaders. Many participants noted that their experiences of unjust power relations, dominance and control by PLHA leaders led to a lack of trust of these members and the institutions they represented.

Zucker (1986) described three types of institutional trust: characteristic, process and institutions-based. Characteristic-based trust develops from social similarity and cultural congruence; process-based trust develops incrementally and is tied to past experiences and accumulation of knowledge. Institution-based trust, according to Zucker (1986) is impersonal, goes beyond interpersonal interactions and is tied to formal societal structures and institutions. Research participants' data illustrated that shared characteristics had not resulted in trusting relationships among PLHA, as suggested by characteristic-based trust. On the contrary, members of PLHA networks expressed that they no longer felt like these networks and their leaders shared their concerns or served to benefit the community. As one participant explained, there was a common perception that PLHA leaders were only interested in improving their own standards of living:

When I went on the Board [of a PLHA network], I wanted to change the system. I stood for election, won and got on the Board. And there I realized that in the governing body, the PLHA are all one kind – the worst kind. All of

them are money-minded. No one has service for the community as a priority ... they look to see what they can get, but not what to do for other PLHA (Indira, 31-year-old female living with HIV/AIDS, PLHA network staff member).

Similarly, past experiences and exchanges resulted in mistrust instead of building process-based trust. Many participants gave accounts of not trusting PLHA leaders to work for the larger community. Another participant spoke about the constant infighting within and between PLHA networks:

We should fight KSAPS or NACO, not amongst ourselves. We are all [HIV] positive people, we all have rights. And it's a democracy, everyone has the freedom to work for the community. But why can't we reduce this fighting among ourselves and work together? Now already a lot of fighting has happened (Shwetha, 34-year-old female living with HIV, PLHA network staff member).

Lewicki and Bunker (1995, p.153) described knowledge-based trust (KBT) as: "I trust you because I know enough about you to know what you will do, even if I cannot or will not try to control it". According to these authors, Knowledge-based Trust arises when a 'trustor' observes a certain pattern of behaviour in the 'trustee', through observation and experiences with them, and expects this to continue. While this theory explains the way in which trust is built over time, research participants' narratives indicate that a similar pattern of building mistrust has occurred within PLHA networks. Power struggles and dominance by PLHA leaders has led to the building of a deep-rooted mistrust of these leaders, as participants gained knowledge about their behaviours and actions. Unbalanced power relations within PLHA networks were a key cause of community members losing trust in these institutions. Consequently, past experiences led to the loss of institutions-based trust, as suggested by Zucker (1986). Lack of trust also negatively influenced the 'bonding' social capital within these PLHA networks. 'Bonding' social capital refers to trusting and cooperative relationships between members of a network who share an identity and see themselves as being similar, in this instance due to their HIV-positive status. One participant

explained that some PLHA leaders exerted their power over anyone who attempted to oppose their leadership by immediately removing them from the network:

If someone opposes [the leader's decisions], the next day, they are blamed for something. Some allegation is foisted on them to remove them from their job. That kind of thing has happened a lot. Whoever has raised their voice has been removed from the job without a valid reason (Gangadhar, 40-year-old male living with HIV, director of a PLHA network).

Trust is a critical factor in building social capital within PLHA networks; as mentioned in section 2.3.2, social capital is defined as the networks, norms and social trust that facilitate cooperation for mutual benefit (Putnam et al 1993). According to Bourdieu (1986), social capital comprises the resources linked to the possession of durable networks of acquaintance and recognition. However, in this instance, the lack of trust between members of PLHA networks lessens their social capital. Trust is a functional equivalent of power and control (Bachmann 2001; Das & Teng 1998). Trust, power and control are therefore key variables in community collaboration. Power and trust are also cyclical in nature; if exercised appropriately, power can enhance trust (Vangen & Huxham 2003). The development of trusting relationships can in turn increase the power felt by participants. However, my data revealed a cycle of mistrust among PLHA in Bangalore. Such a cycle will be difficult to reverse without better accountability and leadership within PLHA networks.

A positive local identity, sense of solidarity and equality with other community members and generalized norms of trust, reciprocity and support between community members are essential for community cohesion (Putnam 1993). Trust in other PLHA network members influenced their interconnectedness, information exchange and the strength of ties built over time (Green et al 2011). The development of social capital, through bounded, cohesive groups is important both for member well-being (Putnam 2000; Wilkinson 1996) and collective action (Wakefield & Poland). However, the lack of trust in other community members and PLHA networks constrained the level of engagement of PLHA in civil society and extent of community cohesion in Bangalore. This lack of cohesion combined with the mistrust of government officials discussed in

the previous chapter, presents a significant challenge for the participation of PLHA in civil society. Literature indicates that trust can be built through an accumulation of positive experiences over time (Mukherjee et al 2012; Sanstad et al 1999) and as parties repeatedly interact (Gulati 1995; Lewicki & Bunker 1997). In addition, Ring (1997) argued that if trust does not exist, it can emerge from formal and informal processes of transacting. There is a need to address trust issues within PLHA networks in Bangalore. Increasing transparency, opening channels of communication for all PLHA members and holding leaders accountable for their actions are possible ways of doing this.

6.4.4 Leadership in PLHA Networks

In this section, the quality of current PLHA leaders, as discussed by participants, is explored. PLHA network leadership styles varied from autocratic to limited democracy wherein leaders were elected for fixed terms. Participants noted difficulties in finding effective community leaders and also that many of the current leaders were more interested in self-preservation than working for the larger PLHA community. Some participants also noted that many PLHA leaders were unwilling to give up their positions and foster the development of other community leaders:

There is nobody to take the leadership [of our PLHA network] forward. Those who are there just continue to be there, those below don't come up. I'm telling you openly – there is no freedom [to build leadership]. If I am a leader, I should share information, only [then] can I develop a second-line leader. But we don't have that kind of opportunities [in our PLHA network] (Rajni, 43-year-old female living with HIV, PLHA network staff member).

Leadership of PLHA networks offered a route to social and economic advancement. Gaining a reputation as a community leader or HIV-positive speaker also provided opportunities for local and foreign travel. One participant who was a board member of a PLHA network explained:

Why won't PLHA give up their position? Because they are money-minded, they won't give up their authority. They think that when they get on the board,

they will get more money. They will become big people in the community and it will also help their families. So [board members] only think of what they will get out of it. They have to stop thinking like that though. We all have to think about what we can do for our people. That doesn't really happen. That is why networks keep breaking up (Indira, 31-year-old female living with HIV/AIDS, PLHA network staff member).

In Bangalore, leadership issues combined with power struggles in PLHA networks and the consequent lack of trust among community members posed significant barriers to community collaboration. Leadership within PLHA networks has played significant roles in national and international advocacy for rights of PLHA, ART provision and social equity in countries such as Thailand (Lyttleton, Beesey & Sitthikriengkrai 2007), Uganda and Brazil (Gauri & Liebermman 2004). PLHA engagement in HIV policy making was initiated in these countries well before it started in India. Closer attention to building leadership and trust among members of PLHA networks can create a better environment for collaboration and advocacy on HIV/AIDS.

6.4.5 Accountability

Accountability can be defined as a process by which a party justifies its actions and policies (Emanuel & Emanuel 1997) and is a key aspect of governance (Gostin & Mok 2009; Power 1997). Accountability, or the lack thereof, was a key theme to emerge from the Phase II data. Most PLHA participants felt that PLHA leaders were not held accountable for their actions and behaviour towards other community members. Many participants reported corruption within PLHA networks. One participant, Indira, recalled multiple instances of corruption and coercion by PLHA leaders. In one instance, two former presidents of a state PLHA network were believed to have acquired land using donor money. The money was apparently 'saved' from the funding they received by reducing staff salaries and project expenditure. These former leaders have now moved away from PLHA networks and are currently consultants for donor agencies.

Once I went to a [PLHA network] meeting, please keep this confidential ... The people there had acquired land! The [leaders] had saved money from their

funds and put it into something else. Some fraud happened and I'm sure it is still going on. I asked them, 'what are you doing? Can't you support some poor [PLHA] with that money?' They said it was the network's money and they know what to do with it. They bought five acres of land with it. Who is going to enjoy that in the end? After all the PLHA are dead? (Indira, 31-year-old female living with HIV/AIDS, PLHA network staff member).

Indira added that corruption in the abovementioned network continued although the leaders had changed. One PLHA who attempted to bring to light the corruption within this network was reported to have attempted a very public suicide as a last resort.

There was the case of suicide of a board member – she was threatened. It became a police case, and then it was covered up. They removed her from the [PLHA network's] Board. Without any authority, what could we do? She kept telling actively that money misappropriation was happening. She then gave a report on TV that she was threatened by Board members, and leaders of the network. Later, she came to the office and took lots of tablets and attempted suicide (Indira, 31-year-old female living with HIV/AIDS, PLHA network staff member).

Another participant added:

[PLHA] are not service-minded. They are money-minded people. They look only to survive. All of the networks have corrupt people. Wherever they can make money... that's what I meant when I said money-minded. By corruption, I mean giving less work in office to staff, giving less salary to them, then collecting that amount. Or creating a post with a new name and getting elected to that post and then drawing salary under that ... Then to hang on to that post, these people try and rig the next elections, they call the people they want for the election, then they have elections elsewhere than the head office. All of this is happening here (Gangadhar, 40-year-old male living with HIV, director of a PLHA network).

With the increase in development assistance funding for HIV/AIDS, corruption has become a growing concern. Recent examples include cases of fraud in grants from the Global Fund in Africa (Moatti & Moatti 2011). As previously mentioned, corruption among Indian NGOs engaged in HIV-related work has also been reported; in 2007, NACO shut down 176 government-funded NGOs after an internal review and a World Bank report found these NGOs to be inefficient and corrupt (Padma 2008). In the previous chapter, corruption within the KSAPS and its funded organizations was discussed. Phase II interview data suggested that corruption also occurred at the grassroots level. HIV-related corruption is embedded in widespread social and governmental corruption in India. Many of India's citizens accept this corruption tacitly as part of everyday life. In this manner, many PLHA also appeared to accept the corruption in PLHA networks, possibly a cultural response to corruption. However, this corruption poses a significant barrier to community collaboration and to the efficacy of HIV programs implemented by PLHA networks.

This section discussed the role of power and trust in building community relationships and collaborations. Significant power and trust issues in the community, in particular, within PLHA networks, were also revealed. Networks of PLHA provide powerful platforms from which PLHA can voice their concerns and advance their claims for greater involvement (Stephens 2004). A strong network also plays a critical role in advocacy, experience sharing and resource mobilization (Kamdar, Noor & Maseeh 2002; Kithinji, Ilinigumugabo & Chirchir 2002). However, in Bangalore, opportunities for these networks to organize into powerful agents of change were limited by poor leadership and lack of accountability. Addressing these concerns will provide opportunities for improving community collaboration through trust-building and sharing of power. In spite of these barriers, I observed that PLHA were starting to overcome these through processes of empowerment and conscientisation, as seen in the example of the BHAF Task Force.

6.5 Summary

This chapter described the HIV community in Bangalore and the contexts in which they lived and worked between 2009 and 2010. Poverty, gendered inequities and exclusionary practices contribute significantly to vulnerability to HIV/AIDS. These

everyday realities were often overlooked by the government whose main focus was on prevention of HIV through programs such as condom promotion.

The HIV community in Bangalore was found to be heterogeneous. Although broad terms such as sexual minority and MSM were commonly used, the constituents of these communities constructed their own identities at the grassroots level. These micro-identities were often not fully understood by other community members, the government and even CSOs engaged in HIV-related work. The plurality and diversity of the so-called vulnerable communities increases difficulties in identifying those most at risk and developing and delivering targeted programs.

The ways in which PLHA and other vulnerable communities in Bangalore interacted and collaborated were also explored in this chapter. While CSOs ostensibly united for common purposes, further exploration revealed that collaborations were often rife with power struggles, domination by some groups and individuals, and infighting. A cycle of power imbalances and control leading to mistrust was evident from participants' narratives. Power and trust issues were also closely linked to ineffective leadership and a lack of accountability and corruption within PLHA networks. These factors posed significant barriers to the collectivization and meaningful participation of PLHA in civil society.

CHAPTER 7: LOCAL HIV POLICY MAKING THROUGH THE EXECUTIVE COMMITTEE OF KSAPS

7.1 Introduction

This chapter explores local HIV policy making in Karnataka, through the exploration of the functions, members and decision-making processes of the Executive Committee (EC) of the KSAPS. As mentioned in Chapter 3, the KSAPS EC is the main body responsible for developing HIV policies in the state of Karnataka. The chapter first presents a rationale for the exploration of the EC as a means of understanding local HIV policy making. Then, the local HIV policy context, actors, content and processes are discussed, drawing on the narratives of participants, mostly those who were present or past members of the KSAPS EC at the time of data collection.

7.2 Rationale for Studying the Executive Committee

The NACO organogram in Chapter 3 (Figure 1) shows the link between the NACO and its state-level subsidiaries. As previously mentioned, the KSAPS is the NACO subsidiary in Karnataka, and is the “highest policy making structure regarding HIV/AIDS in Karnataka” (KSAPS 2013). The KSAPS is governed by two bodies, namely the Governing Body (GB) and the EC.

The GB of the KSAPS is headed by the Chief Minister of Karnataka, and at the time of the study had 22 members (KSAPS 2010). Key government departments (Health & Family Welfare, Education, Finance, Women & Child Development, Medical Education, Government Planning, Tourism, Youth Services) were represented on this body along with private health sector representatives from the Indian Red Cross Society and the Indian Medical Association. According to NACO guidelines, CSO and PLHA network representatives must be represented in the GB (NACO 2006). At the time of the study, only two civil society representatives were nominated to the GB by the KSAPS and PLHA were not present on the GB (Fieldnote 1/10/2010). In theory, the GB is responsible for approving the Annual Action Plan (AAP) of the KSAPS, its annual budget, conducting audits of the KSAPS and also for approving any new policy initiatives (NACO 2006). KSAPS officials, however, reported that as the

GB only meets twice a year, and due to the possibility of change in the government department representatives that attended these meetings, it delegated the abovementioned duties to the KSAPS EC (Fieldnote 1/10/2010). The NACO guidelines allow for the GB to delegate administrative and financial powers to the EC to improve financial and operational efficiency (NACO 2006). As a result, in Karnataka, the KSAPS EC acted as the primary local decision and policy making body, with the GB taking a more supervisory role. Administrative and financial powers for the KSAPS were conferred upon the EC and the Project Director of KSAPS by the Governing Body. According to the National AIDS Control Program III (NACO 2006), the EC in every state must:

1. Select and monitor NGOs to partner with the State AIDS Society (in this case, the KSAPS) to implement its programs. Quarterly reports of implementing partners are to be provided to the members of the EC
2. Have adequate representation of PLHA to ensure the greater involvement of PLHA
3. Be headed by the State's Principal Secretary for Health
4. Play an important role in NGO financial management by approving budgets of funding partners
5. Exercise powers in relation to approval of annual action plans/budgets, new policy initiatives and other administrative and financial processes.

The policy making role held by the EC led to it becoming a key 'case' for exploration during the second phase of the current study. A case is defined by Miles and Huberman (1994, p.25) as "a phenomenon of some sort occurring in a bounded context". Policy literature indicates that understanding the policy process requires the study of intergovernmental policy subsystems that are composed of bureaucrats, interest group leaders and specialists as the basic unit of study (Grindle & Thomas 1991; Sabatier 1991). The KSAPS EC constituted such a policy subsystem. A qualitative case study approach ensures that the context in which a phenomenon takes place is also studied (Mays & Pope 1995; Yin 2003). This approach was taken in the current study as the context in which the EC operated and made policy decisions was critical to understanding local HIV policy making. Interviews were conducted with

twelve present (in 2010) and past members of the EC, including those from CSOs. Available EC meeting minutes and AAPs were reviewed, however, as explained in Chapter 4, accessibility to these documents was limited.

7.3 Key Analytical Frameworks

Along with other theories, two key policy frameworks are utilized in this chapter to make sense of the collected data: the networks framework (Rhodes 1986; Rhodes & Marsh 1992) and the policy triangle framework (Walt & Gilson 1994). Rhodes (1986) developed definitions for five types of ‘policy networks’ ranging along a continuum from the highly integrated ‘policy community’ to the loosely integrated ‘issue networks’ (Hecl 1978). Rhodes (1990 in Rhodes & Marsh 1992, p.182) views policy making as based upon an “exchange relationship”, a “game in which central and local participants manoeuvre for advantage, deploying their constitutional-legal, organizational, financial, political and information resources to maximize influence over outcomes”. This relationship, according to Rhodes, occurs within a policy network. Rhodes (1986) distinguished the five types of policy networks based on their membership composition, the extent of interdependence between their members and the distribution of resources between members (Table 4).

Table 6: Rhodes Model of Policy Networks

Type of Network	Characteristics of Networks
Policy Community	Stability, highly restricted membership, vertical interdependence, limited horizontal articulation
Professional Network	Stability, highly restricted membership, vertical interdependence, limited horizontal articulation, serves interest of a profession
Intergovernmental Network	Limited membership, limited vertical interdependence, extensive horizontal articulation
Producer Network	Fluctuating membership, limited vertical interdependence, prominent role of economic interests
Issue Network	Unstable, large number of members, limited vertical interdependence

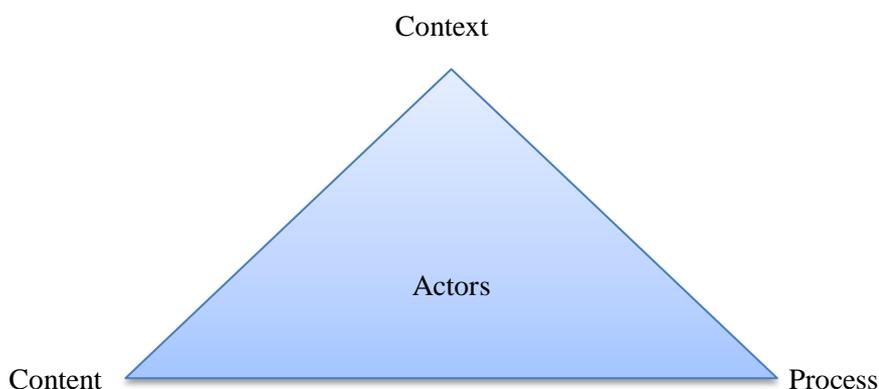
Source: Rhodes & Marsh 1992

Using collected data on the EC membership, it is suggested that while the EC can be viewed as a policy network, it does not conform to the definitions of any of the five types of policy networks suggested by Rhodes. Rather, the EC has attributes of

different types of networks and can be placed between the policy community and the issue network in Rhodes' model of policy networks, discussed further in section 7.5.5.

Policy networks are only a component of any discussion of the policy making process and outcomes (Rhodes & Marsh 1992). Other theories and frameworks exist that assist in differentiating policy issues. One such framework is the policy triangle framework (Walt & Gilson 1994), which was specifically designed to understand health policy making, particularly in developing countries. While Walt and Gilson acknowledged the importance of policy content, they developed a model for analysing health policy that incorporated the importance of the context, process and actors, as illustrated in Figure 3. These authors argued that policy processes and outcomes in developing countries often fail due to the lack of attention paid to the actors who influence the policy process and the context in which policies were developed (Walt & Gilson 1994). According to Walt and Gilson (1994), the policy actors, as individuals and as members of CSOs, are influenced by the contexts at both the macro-government and the micro-organizational levels in which they live and work. The context may also be influenced by social and cultural factors. The process of policy making is affected by the actors involved, their position in power structures and their own values. The policy content will reflect some or all of the earlier mentioned dimensions (Walt & Gilson 1994).

Figure 3: Policy Triangle Framework



Source: Walt & Gilson 1994

The following sections discuss the interplay between the policy context, actors, process and content. Much of the collected data revolved around the actors and the context. There are also unavoidable overlaps between the four elements of the policy triangle presented in the following sections.

7.4 Policy Context

Policy development is influenced by contextual factors (May 2003; Torgerson 1985) and can be viewed as a set of activities that take place within a specific historical and institutional context. The policy context includes the political, economic, social and cultural factors that affect policy (Buse, Mays & Walt 2005; Walt & Gilson 1994). Context can shape the policy process and provide an enabling environment for policy development; it can also pose significant obstacles to policy making. This section discusses the context in which the KSAPS EC functions through a brief discussion on the history of health policy making in India, the complex relationships between civil society and the KSAPS, and what participants identified as the most significant contextual factor that influenced the decisions made by the KSAPS and its EC, namely the nexus between the KSAPS and the Karnataka Health Promotion Trust (KHPT).

Most of the existing health programs in India are ‘vertical’ or top-down and were developed at the national level to address a single health issue. India utilizes a five-year planning process to determine national goals and priorities for centrally sponsored disease control programs. Despite the rhetoric of integrating these disease control programs and strengthening local decision-making, the five-year plans continue to reinforce a series of parallel health programs (Peters, Rao & Fryatt 2003). The NACP is considered the most visible vertical health program in India because of global attention and the substantial funding that it receives (John et al 2011). Health policy making in India, including on HIV/AIDS, has historically been largely *etatist* (Arts & Van Tatenhove 2004) and top-down in that traditional state institutions are the ultimate loci of authoritative power and determine the policy content and processes. In the case of HIV/AIDS, the NACO leads planning processes in consultation with state-level civil society representatives. This historical approach to government policy making is a key contextual factor that influences local HIV policy processes.

Other key contextual factors were discussed in Chapters 5 and 6. These include the relationships between the KSAPS and CSOs, which were characterized by hostility, anger, frustration and at times, fear. Data from this study also indicated that CSOs which received KSAPS funding and those that did not sometimes had poor relationships and were reluctant to collaborate. The diversity of CSOs and vulnerable communities engaged in HIV/AIDS in Bangalore and the dynamics between them also constitute the policy context.

Institutional context, in terms of the functioning of the KSAPS, is also significant to policy processes. As discussed previously, allegations of corruption and collusion of KSAPS staff was reported by many participants. Frequent changes of the KSAPS Project Directors and inadequate understanding of HIV-related issues by KSAPS staff were reported by many participants. In addition, the KSAPS had a history of under-utilization of the funds it received from NACO.

7.4.1 Nexus between KSAPS and KHPT

According to many participants, the KHPT (previously discussed in section 5.2) had a more powerful presence in the state than the KSAPS. The KHPT had a larger geographical reach and accessed more members of vulnerable communities than the KSAPS. The presence of a large, powerful organization which worked closely with the state-level subsidiary of the NACO and influenced its functioning was unique to Karnataka at the time this study was conducted, according to participants. In other states, the state-level subsidiary of the NACO had the most power to carry out HIV-related interventions and the most geographical reach through its funding partners. Most CSO research participants discussed their perceptions of the relationship between the KSAPS and the KHPT at length. Many of these participants felt that the KHPT had a 'stranglehold' on the KSAPS. However, research participants employed by the KSAPS and the KHPT felt differently and presented the KSAPS and KHPT as being equal implementing agencies in the state. Inconsistencies were found regarding the nature of the relationships between the KHPT and the KSAPS in the accounts of CSO members and the staff of the KHPT and the KSAPS. Narratives of participants belonging to CSOs, the KSAPS and the KHPT are presented below to highlight these

discrepancies and to give a sense of the relationship and the interdependencies between the KSAPS and the KHPT.

A participant who worked for the KHPT explained the genesis of the organization in Karnataka:

The University of Manitoba came to Karnataka under a bilateral project with CIDA and the national government around 2001 and we started working in [the states of] Karnataka and Rajasthan. In Karnataka – in both the states actually – one of the elements of the program was to build technical support of the State AIDS Prevention Society. So the project kind of mandated us to work with the [State AIDS Prevention Society] very closely, building their capacity while developing some demonstration projects in the rural areas and district-wide demonstration project which we have in North Karnataka. So by 2003 when Bill and Melinda Gates Foundation had identified Karnataka as one state that they should fund, the Health Minister then actually called up the KSAPS Project Director and said “we should secure this fund and we should do whatever needs to be done to secure this fund.” Bill and Melinda Gates Foundation came to Karnataka and saw our work under the CIDA project and was very happy to partner with the University of Manitoba. But University of Manitoba is an international organization or a university, so we thought it’s good to set up an Indian identity ... So we registered ourselves in 2003 with the trustees of KHPT being the University of Manitoba and KSAPS (Chitra, 38-year-old female, KHPT staff member).

According to the KSAPS, the KHPT supported its work and was its equal in regard to HIV/AIDS engagement in Karnataka:

We have another equal implementing partner – KHPT [which] basically is a separate trust promoted by the government itself just to get the [international] donor funds directly to the state. KSAPS being a state government agency, it has some constraints to route funds. For that, the state government only promoted KHPT. So we have actually in Karnataka two implementing

agencies for the state. Even though overall focal point as per the NACO is KSAPS, but equally there are two implementing [agencies]. We fund one [of their] programs. This is the only state [where] we have two implementing agencies ... Also, the KSAPS Project Director and Additional Project Director are the trustees of the KHPT (Sonali, 50-year-old female, KSAPS staff member).

However, CSO members unanimously disagreed with the statement that the KSAPS and the KHPT were equal implementing agencies. A CSO member described the relationship between the KSAPS and the KHPT as:

KHPT runs KSAPS. Let's be very blunt about it! (Thomas, 55-year-old male, doctor working with PLHA).

This sentiment was echoed by many other CSO members during interviews and informal discussions. Another participant commented:

It was more like a situation [between the KSAPS and the KHPT] of 'You scratch my back, I scratch yours'. It is as simple as that. It's very difficult to figure out where exactly one ends and the other begins (Rahul, 50-year-old male, manager of a CSO engaged in HIV prevention and care and support).

Most participants noted an inextricable nexus between the KSAPS and KHPT and many questioned the need for a second implementing agency in the state. One participant, Shankar, questioned the power the KHPT held over the KSAPS, which resulted in the KSAPS being sidelined in the state's HIV decision-making processes:

KHPT should be reporting to KSAPS. That should be the situation. And you know, there is a national program and a state program. Anybody else only should report to [the government] in some manner. I heard that the NACO leadership felt that KHPT is more efficient, and so they [allowed KHPT] to handle KSAPS. It is a very wrong decision. It's completely against the principles of democracy which the way it is practiced in our country. There

may be limitations [with the KSAPS], you know, but the purpose is to strengthen them, not to sideline them (Shankar, 42-year-old male, human rights CSO staff member).

Shankar raises another important factor in the relationship between the KSAPS and KHPT, that of capacity development and strengthening of the KSAPS. As mentioned previously, one of the key goals of the KHPT was to ‘build technical capacity of the KSAPS’. Many participants felt that instead of building the KSAPS’ capacity, the KHPT disempowered the KSAPS:

KSAPS got totally depleted of its strength and human resources and KHPT contributed to that. I would say that they took away many of the people who were in KSAPS into KHPT including the Project Director. And there were several who began to be funded by KHPT, so their allegiance changed, their thinking changed with the result that today, if KHPT were to pull out, the government structure itself has not been strengthened. If you consider 10 years [during] which University of Manitoba has been in this state, I don’t think they have strengthened any structure in the KSAPS, which [was their] primary proposal, mainly to strengthen government systems. Now what has happened is that support comes orchestrated from KHPT. There are no people in the government who have been capacitated. It’s more that ‘If you want the data, we will give you the data’. And because of that what has happened is that the KSAPS has not grown (Justice, 58-year-old female, director of an HIV prevention CSO).

Many participants also critiqued the agendas promoted by the KHPT. These participants felt that the KHPT’s main goal was to conduct research and publish findings rather than to improve the lives of the communities with which they engaged:

The [KHPT is] a different kind of organization – they have their own agendas, they have their own interests. They are a university-based organization. They have their publications to make and their allegiance is to their country [Canada]. Their primary concern is not to people, their concern is research

and publications. There are very professional, but it is not a development oriented [CSO] (Justice, 58-year-old female, director of an HIV prevention CSO).

When asked about the common perception amongst CSOs that the KHPT controls or has sidelined the KSAPS, Chitra (a KHPT employee) initially stated that such a situation did not exist and suggested a possible reason for such misconceptions on the part of CSO members:

I don't think any private trust can run a state. A state is a state, the kind of resources the state has, the kind of power that the state has, you can't run it. I think there was a little bit of confusion to start with because the [then] Project Director of KSAPS joined the KHPT as its Director. And the state couldn't find any suitable person to replace her [at the KSAPS]. So, basically what happened is that the most dynamic person from KSAPS joined KHPT and the government couldn't find any other dynamic or strong leader in KSAPS. So the roles kind of got a little bit merged, because she was from the government and the government knew her. And so they would sometimes ask her to do things for KSAPS. But the situation has changed since then (Chitra, 38-year-old female, KHPT staff member).

However, as the interview progressed, Chitra acknowledged that the KHPT did have an influence on the KSAPS:

We were one organization whose mandate was to build KSAPS' technical capacity. So there's no doubt that our work would influence KSAPS or KSAPS work would influence us. We've worked very, very closely, and our mandate more consultative, more cooperative and more to provide technical support to the KSAPS ... We built pilot projects to give a learning ground to the KSAPS. So I'm not surprised that [others think] KHPT's work would influence the KSAPS ... I think that it's natural for an organization which is working in such a scale [as KHPT], we work in most districts in Karnataka. So I think it is natural that we would influence and should influence the state's understanding

of targeted intervention and its [program] focus (Chitra, 38-year-old female, KHPT staff member).

While Chitra acknowledged that the KHPT does exert some level of influence over the KSAPS, another staff member of the KHPT stated the opposite, saying that the KHPT only provided data on HIV/AIDS in Karnataka to the KSAPS and did not influence the KSAPS in any way:

KHPT doesn't have influence over the KSAPS. The [current] Project Director [of the KSAPS] is good, listens to KHPT because there is good rapport but decides by his himself. He never decides on the basis of what KHPT is saying. KHPT only provides the KSAPS with data. There are lots of people who run the KSAPS and it's not easy for them to be influenced by the KHPT (Prasad, 37-year-old male, KHPT staff member).

During informal discussions with KSAPS and KHPT staff, it emerged that the KHPT also provided funding for three consultants who worked for the KSAPS. These consultants were in charge of scale-up of the KSAPS ART and Tuberculosis-HIV programs. Also, the Technical Support Unit (TSU) which conducts HIV surveillance and research for the KSAPS was run by a 'sister concern' of the KHPT, namely the India Health Action Trust. At the time of data collection, senior personnel of the KHPT managed the TSU. As mentioned previously in Chapter 5, the KSAPS also provided funding to the KHPT for the NACO-Global Fund Link Workers Program.

The narratives presented above and informal discussions conducted during fieldwork did not allow clarification of the exact nature of the relationship and interdependencies between the KSAPS and the KHPT and the extent to which the KHPT influenced the KSAPS. Participant narratives illustrated the interwoven nexus between the KSAPS and the KHPT, and there was a general perception that the KHPT dominated over and disempowered the KSAPS. However, KSAPS and KHPT staff downplayed these sentiments. Official documents also provided limited information regarding the nature of the relationships between KSAPS and KHPT. According to KHPT reports and its website (KHPT 2010, 2013), the KHPT works very closely with KSAPS to develop

Annual Action Plans (AAP), identify new areas for programming, expanding surveillance and ICTC coverage. The KHPT also represented Karnataka at NACO and national-level forums.

This section covered the policy context in which the KSAPS EC functions. In addition to the history of top-down health policy making approaches in the country, the hostile relationships between civil society and the KSAPS (discussed in previous chapters) were cited as contextual factors. The relationship between the KHPT on the KSAPS was also a key contextual factor that participants felt influenced KSAPS decision-making processes.

7.5 Policy Actors

The role played by actors in influencing policy processes has been widely discussed (Gilson & Raphaely 2008; Kingdon 1995; Rhodes & Marsh 1992; Richardson 2000; Sabatier 1991; Van Waarden 1992; Walt 1994; Walt & Gilson 1994). In this section, the policy actors that comprise the KSAPS EC, the ways in which these actors were selected, the leadership of the EC and the power relations between the EC members are discussed.

7.5.1 EC Membership

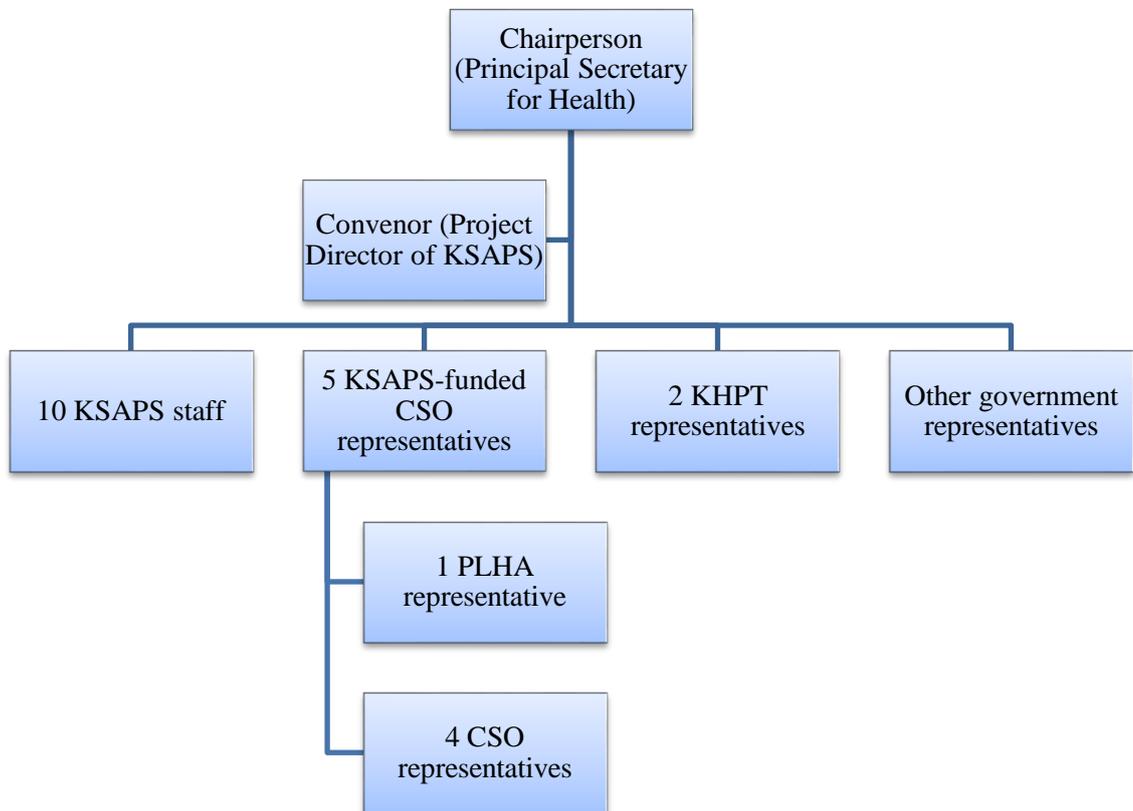
According to NACO, “for functional efficiency [the Executive Committee] should be a small and compact body with limited representation from key departments (finance being mandatory)” (2006, p.150). At the time of data collection, the EC consisted of 30 individuals who were representatives of government departments, senior staff of the KSAPS, and members of CSOs that received KSAPS funding. The EC was chaired by the Karnataka Principal Secretary to the Department of Health and Family Welfare. Sonali, a member of the KSAPS EC, described the membership as:

The Executive Committee Chairman is [the Karnataka] Health Secretary and Convener is the Project Director [of the KSAPS]. The Commissioner for Health, National Rural Health Mission Director, Women and Child Welfare representative and all the developmental department secretaries are also members. And one PLHA representing the state [PLHA] network is a member.

And NGO representatives are there. [They] are the non-official members (Sonali, 50-year-old female, KSAPS staff member).

At the time of fieldwork, there were five ‘non-official’ KSAPS-funded CSO representatives on the EC (four members representing CSOs and one PLHA representing the state-level PLHA network). In the meeting minutes, this group was referred to as ‘special invitees’. The remaining 25 members belonged to the KSAPS, the KHPT and other government departments. Figure 4 below illustrates the policy participants of the KSAPS EC:

Figure 4: Members of the KSAPS Executive Committee



7.5.2 Selection of EC Members

The criteria for selection of the CSO representatives to the EC were not clear from participant interviews or the EC meeting reports. Participants were not aware of any constitution or terms of reference by which the EC members must abide. When specifically asked, members of the KSAPS were also unable to identify the reasons for

selection of the CSO representatives. Only the presence of a PLHA representative on the EC had a clear policy explanation; the NACP III requires all the states to have a PLHA present on their ECs (NACO 2006).

Some KSAPS staff noted that CSO representatives were selected on the basis of their being experts in their field or due to a long standing relationship with the KSAPS (Fieldnote 1/10/2010). Relevant expertise forms a basis for participation in the policy process (Colebatch 2002). Yet, the criteria for being deemed an expert in the field, the number of years a CSO needed to have partnered with the KSAPS to be eligible for selection as an EC member, or the process by which selection occurred were not apparent. In addition, most CSO EC members were unclear about why they were selected to be members of the EC. The only CSO EC member who was sure about the reasons he was chosen to join the EC, Thomas, described the selection process:

The first Project Director [of the KSAPS] did not have much experience with HIV/AIDS. So he called me to his chamber and I had to really orient him to what is HIV/AIDS. He then wanted me on the EC, because of my experience and knowledge. He wanted me to be an invited member. Since then I have been a permanent invitee to the KSAPS EC. I attend their meetings regularly where all administrative and program related issues are discussed. And they invite me to the meetings, and that's how I go, and advise them on matters related to the implementation of their programs (Thomas, 55-year-old male, doctor working with PLHA).

Another participant also discussed experience and knowledge of HIV-related issues as key selection criteria:

I was chosen about four or five years ago mainly because of my background in care, support and treatment area. I don't know what really are the rules [to select EC members]. It could be the EC proposes that they need a specific area [to be represented] and names are proposed. And then [those individuals] are there in the EC ... and anyway we are not really Executive Members. We are

special invitees. So it's really not a judicial thing or anything (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Lasker and Weiss (2003) describe two types of stakeholder partnerships: the 'lead agency' model and the 'community engagement' model. In the lead agency model, partnerships are developed for one partner organization to carry out a predetermined program. In this type of partnership, most of the thinking, planning and designing is done by the lead agency. The relationship between the KSAPS and the CSOs it funds reflects this type of stakeholder partnership, with the KSAPS as the lead agency. This partnership had implications for the functioning of the EC, as CSO members were selected and invited to participate in local HIV decision-making processes rather than demanding a space for participation. However the criteria for inviting CSO participants remained unclear. Lack of clear criteria for inclusion of actors in policy processes has also been found in maternal health policy processes in India (Green et al 2011). This is perhaps indicative of a systemic approach to engaging with non-state actors in health policy processes in the country.

These participants also discussed the turnover of CSO EC members. Thomas described the rotation of CSO representatives:

The other four members other than me have this continuous turnover of them, because there are many NGOs and they have to be given representation. I am a permanent invitee, a constant fixture because of the technical knowledge I bring but they have been continuously changing ... But one positive network's people are constantly [on the EC]. It's the other three NGOs that they keep changing ... And these NGOs are always those funded by the KSAPS (Thomas, 55-year-old male, doctor working with PLHA).

In 2003 (EC Meeting Minutes 18/08/2003, p.14), the EC decided that "in order to ensure fair representation of the NGOs at the decision-making level of KSAPS, it is necessary for other CSOs also to participate in meetings." To ensure this, one CSO representative was authorized to nominate representatives of two to three KSAPS-funded CSOs as 'special invitees' for EC meetings. It was also recommended that

these CSO representatives were rotated annually. However, from further reports, it was unclear how this rotation took place. Benjamin also elaborated on the rotation of CSO EC members and the ambiguity in relation to the selection of special invitees:

Thomas is also called because of his expertise and background. There was one doctor from [northern Karnataka]. He's not an NGO person, but he's been in health care and I don't know what was, must have been some reason why [he was selected]. Uh, there's another NGO [representative] that was there, Dr Surya. I think he was there for some time. Now I don't see him. So there must be some process ... I don't know what it is though (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Some participants noted that in addition to the ambiguous selection criteria, there had been instances in which CSO members were removed from the EC because of the concerns and critiques they voiced. This provided support for the observation that the selection of the EC members was arbitrary and largely determined by the preferences of the KSAPS staff:

We questioned some of [the decisions made by the EC]. And they said 'Isn't it time we had a rotation?' So the two of us [who voiced our concerns] were out and they had somebody else replace us. Mostly, they also find people who won't say anything (Justice, 58-year-old female, director of an HIV prevention CSO).

In changing CSO participants at will, the KSAPS EC ensured that the EC decision-making processes were dominated by the government (essentially the KSAPS), and only individuals who were likely to go along with the EC decisions unquestioningly were included in local HIV policy processes.

Participants also mentioned that at times, the KSAPS EC decided to invite individuals to become 'permanent invitees' to the EC, who would not face the constant rotation that other CSO EC members did. These participants used the example of Dr Jacob Blanche, a CSO member affiliated with the KHPT, to highlight this; this example was

also illustrated in the EC meeting minutes. During the 22nd EC meeting (EC Meeting Minutes 21/08/2001, p.20), it was stated that “After a detailed discussion, the Executive Committee decided to have Dr Jacob Blanche [the Coordinator of a Canadian project], as a permanent invitee to the EC meeting of the KSAPS”. However, the nature of the ‘detailed discussion’ was not documented nor why this individual, a newcomer to the HIV sector in Karnataka, was deemed important enough to be invited as a permanent invitee on the EC while other CSO members remained temporary special invitees who could be rotated at will. This example also adds to earlier examples of the influence of the KHPT on KSAPS decision-making, as the CSO member in question was closely affiliated to the KHPT.

7.5.3 Leadership of the EC

Leadership of the EC was consistently reported as having a significant influence on the EC decision-making processes. Most participants discussed the influence of the leaders of the EC, namely the KSAPS Project Director (the EC’s Convenor) and the Principal Secretary for Health (the EC Chairperson). These participants felt that the efficiency of the EC was substantially dependent on these leaders:

The efficiency of the Executive Committee will depend on the Project Director and how well the person has understood the program and the implications of HIV/AIDS control. So it’s not worked with the same efficiency [over the years]. It depends basically on the leader (Thomas, 55-year-old male, doctor working with PLHA).

CSO EC members noted that the willingness to include CSO EC members in decision-making processes varied with different Chairpersons:

If there’s a good Health Secretary as the Chairperson, he exercises his good powers. See I remember when Mr. Gopalakrishnan was the Principal Secretary, he used to fix the [EC] meeting every month and every issue used to be discussed threadbare. And invariably he will ask the opinion of representatives like us, from NGOs ... But [another Chairperson], he never gave opportunity for talking. He made quick decisions. So leadership of that

Committee matters a lot. [With some leaders], if you make some effort to stand up and put forth your ideas, you are just snubbed (Vikram, 55-year-old male, HIV-prevention NGO staff member).

Benjamin described how one particular Chairperson decided to develop a simpler banking process for the CSOs that enabled them to receive funds in an easier and quicker manner. Prior to this, accessing KSAPS funds entailed frequent visits to the KSAPS office for the disbursement of funds, according to participants:

There were arrears for I don't know, from the time that KSAPS was formed – and these were all things that were not settled. KSAPS would say that the NGO has not given us a [funds] utilization certificate. That's not really true. Many of them were given, but then, in the heap of files, it was lost. And once, Thomas actually made this as a big issue. He said 'I submitted it three times and still you say you do not have it. And it shows that you know [his organization] is still yet to give their accounts so that amount stands as an amount that is not reconciled. And that's huge, in millions [of rupees]. So the Chairperson said 'What kind of finance department are you? If you don't have capable people, you change them. He took a quick decision to change the KSAPS banking system. Now we don't have to make so many trips to the KSAPS to get our funds. But the thing is lot of other EC chairmen usually took the EC to be like a you know, [insignificant] body where you just present your things and everybody say Hi (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Leadership position critically affects the ability of other group members to participate in collaborative processes. A dominant leader has the positional power to significantly influence the groups' decision-making processes while a weak leader may leave other group members directionless (Huxham & Vangen 2000). In this example, Benjamin praises the actions of a strong and dominant Chairperson who made decisions based on the concerns of CSO members. However, in doing something beneficial for CSOs, the Chairperson also made decisions with little discussion with other EC members. Such

decision-making rendered the EC a rubber stamp committee rather than one which made decisions based on quality discussions.

Other participants highlighted the role of the KSAPS Project Director in the EC decision-making processes. Thomas discussed his issues with some KSAPS Project Directors who decided not to invite him for EC meetings:

I have no problems in approaching people [at the KSAPS] ... and many Project Directors have welcomed my opinions. Having said that, I must also say that there have been times and some Project Directors – I will not name specifics – where because I speak my mind out, I've been kept out. I don't get the notice for an Executive Committee meeting. For quite a long period during one phase, it did not happen. And I think some of the positive people and other CSOs raised this ... And then the whole thing was discussed and I started again getting called to KSAPS EC. So things like who sits on the EC, what is discussed is all based on the individual [leader] (Thomas, 55-year-old male, doctor working with PLHA).

Thomas' quotation indicates that the power to decide which EC members get invited to meetings largely rested with the KSAPS Project Director. The frequent change of Project Directors at the KSAPS was raised during the Phase I study and discussed in Chapter 5. The consequences of this have been many including leadership gaps or delays in organizational functioning that takes place while each new leader gets settled, as discussed in Section 5.4.2. In addition to leadership gaps, one participant noted that the frequent change of Project Directors resulted in judgemental attitudes, possibly due to little time spent on sensitization to PLHA:

In KSAPS, if you take, whether it is the top level [Project Director], there were about 4-5 project directors who changed in the last 4-5 years. So some of them, I don't want to mention the names, but the project directors themselves don't want to [engage with community members]. Suppose we have a media workshop, in every media workshop, we have a few of the sex workers and positive people coming and giving testimony in front of the media ... But some

of the project directors have said 'No, I don't want sex workers in my workshop'. So even among the program people ... some of us still nurture that feeling okay, [sex workers] are doing something wrong. That judgemental feeling is still there (Dev, 47-year-old male, research organization staff member).

High turnover of KSAPS Project Directors, according to participants, meant that these individuals were not sufficiently familiar with issues related to HIV/AIDS and concerns of PLHA. These attitudes were likely to influence the types of community concerns that the EC considered. In addition, the leadership style of both the Chairperson and the Project Directors tended to be authoritative rather than democratic, where consensus is forged (Goleman 2000) with EC members prior to making decisions.

Effective leadership is the 'heart and soul' of policy making according to Hudson (1997) who emphasized that it is imperative in a shared policy forum such as the EC. Chrislip and Larson (1994) opine that leaders in collaborative initiatives such as the EC, where participants come from different institutions and sectors, must focus on promoting and safeguarding the collaborative process. Collaborative leadership requires leaders to facilitate interaction between diverse participants and patiently deal with participant frustrations and needs. However, participant narratives regarding the leadership of the EC indicated that the majority of EC leaders lacked an understanding of participatory decision-making and made quick decisions following little or no discussion with other EC members.

7.5.4 Power Relations between Policy Actors

This section concentrates on the interactions and power relations between the policy actors introduced in previous sections, and how they influence local HIV policy making.

7.5.4.1 Power Exerted by the KHPT

The power exerted by the KHPT on the EC decision-making processes was highlighted by participants using the example of the development of the KSAPS AAP. According

to participants, the KSAPS AAP, which sets out its work in the entire state for the given year, is supposed to be discussed during the EC meetings and then approved by the EC. The approval of the AAP was a key function of the KSAPS EC and according to KSAPS staff, CSO EC members, PLHA in particular, are meant to play a role in ensuring that the AAP reflects the community's needs:

[The CSO members] will be part of the consultation process. Whatever we take to the Executive Committee, the basic document is Annual Action Plan. To prepare an Annual Action Plan itself, we would have already consulted NGOs and networks. Okay, they were already a part of it. Then one representative out of that – one from NGO, one from the network, there's an opportunity for them whether we're rightly projecting what has been told in the consultation. That is what they'll observe and that is initially. Then in the mid-course when they come, if something is not happening, something is getting delayed, and then also they'll bring it to the notice of EC. 'It has to be expedited, this is getting delayed.' Those kinds of things, they have a huge role (Sonali, 50-year-old female, KSAPS staff member).

This version of the process was contradicted by CSO EC members, who asserted that they had a limited role in the development and implementation of the KSAPS AAP:

But [earlier], you knew at least what was proposed [in the AAP]. You knew what went in finally. This year, nobody was even consulted, nobody. They didn't speak to anybody. They wrote their own Action Plan which was not shared with anybody. And there was a meeting [of KSAPS and the CSOs it funded] where I questioned how they could not share, because we are equal partners in the process of implementation [of the AAP]. They said then 'you can't do anything. We can give it to you now. But you can't do anything because it has been passed.' So the attitude was that you know 'Don't think you can change anything. We have the power' (Justice, 58-year-old female, director of an HIV prevention CSO).

Dahl (1961) discussed the notion of power as decision-making, wherein some groups exercise power over others by initiating or vetoing policy proposals and decisions. The exertion of power as decision-making was illustrated by participant narratives regarding the development and approval of the KSAPS AAP.

Other participants noted that the development and approval of the KSAPS AAP was conducted by the KHPT, either directly or indirectly through the TSU of the KSAPS (which as previously mentioned was managed by senior KHPT staff):

The KSAPS Annual Action Plan, it's made by KHPT. It's an open secret. The Plan is made by KHPT and is presented by KSAPS officials in the Executive Committee meeting for approval (Thomas, 55-year-old male, doctor working with PLHA).

The development of the AAP by the TSU was acknowledged by the KHPT staff:

KSAPS Annual action plan is written by TSU ... TSU is there to support KSAPS. Annual Action Plan is written by TSU and finally okayed by KSAPS. Before TSU was there, there was no AAP written by KSAPS. They didn't write annual action plans! And in fact, KSAPS was the worst [State AIDS Preventions Societies] in the country. Now it is one of the best in the country! (Prasad, 37-year-old male, KHPT staff member).

While this participant highlighted the KHPT's positive influence on the KSAPS, through direct or indirect influence on the KSAPS AAP, some KSAPS officials, who were also part of the EC, denied any role by the KHPT in the development of the AAP:

No, the KHPT doesn't in any way influence the Annual Action Plan's development ... not really (Richard, 55-year old staff of the KSAPS)

KHPT reports and website state that one of its key roles was to work closely with the KSAPS to develop KSAPS AAPs. Yet, KSAPS officials denied this and maintained that the KSAPS and its funded CSOs developed the AAP. Reluctance by KSAPS

officials to acknowledge KHPT's influence on its AAP indicates that the KSAPS was not willing to publicly acknowledge the KHPT's influence on its decision-making processes. Although some KSAPS officials downplayed the power held by the KHPT, most CSO felt that the KHPT dominated KSAPS policy making and programming:

I feel that KHPT, they play a major influencing role in KSAPS, I think so - in my view, and my view may be wrong. And KSAPS also [shows] lenience towards KHPT. It's like a Big Brother. KHPT again it's a government-promoted trust, you know. I feel so, the policy level, they deliberately make decisions ... and [the KSAPS] won't accommodate others [CSOs] if they have to make a decision. Most of the policy, any technical issue, [the KSAPS] looks up to KHPT (Ambresh, 44-year-old male, director of HIV care and support CSO).

In addition, some participants reported that the KHPT exerted power over the KSAPS by selecting the KSAPS consultants funded by the KHPT. As mentioned previously, the KHPT funded three consultant positions within the KSAPS for the purpose of scaling up the KSAPS ART and Tuberculosis-HIV programs. One CSO member discussed the selection of these consultants:

[If KSAPS] has a well-experienced consultant, KHPT will lose its space and hold on KSAPS. They want a puppet. They will always recommend hiring a retired person who does not have knowledge so that [the KSAPS] would be dependent on KHPT. I told you, although I have been an adviser for KSAPS, I've never been consulted or asked to sit on the committee that selects consultants. KHPT, KHPT. It's the Project Director and KHPT people who sit and do that decision-making (Thomas, 55-year-old male, doctor working with PLHA).

Participants reported that although the EC could have sought clarification on the ways in which these consultants were selected, it had not done so. According to

participants, these examples indicated that the EC was complacent about the influence of the KHPT on KSAPS functioning and decision making processes.

7.5.4.2 Power Exerted by the KSAPS

While the KHPT exerted power over the functioning and decision-making process of the KSAPS and its EC, the KSAPS members of the EC were in turn reported to exert considerable power over the CSO EC members. CSO participants who were members of the EC felt that there was a power imbalance within the EC by virtue of the EC being convened by the KSAPS Project Director. Most participants highlighted the inextricable link between the KSAPS and the work of the EC:

If KSAPS is, is very active, then EC is also quite active. If KSAPS is not really active, then EC also is not active. I mean, we [CSO members] can raise issues at the EC, but it's usually the KSAPS that sets the EC agendas. And there are a lot of KSAPS officials on the EC, which I don't think is a good mechanism (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Van Waarden (1992) identified the most important features of a policy network as: the number and type of societal actors involved in the network, the major function of the network and the balance of power between its members. In this instance, the number of government officials far outnumbered the CSO members in the EC (refer Figure 4) and raised questions regarding the balance of power between the EC members. In addition, all the CSO members of the EC represented organizations that received KSAPS funding. CSOs were concerned at the power exerted by the KSAPS and expressed the fear of being de-funded if they questioned the KSAPS. These factors also tipped the balance of power within the EC towards the KSAPS. The sudden 'rotation' of EC CSO members when they questioned the work of the KSAPS, discussed previously, is another example of the power exercised by the KSAPS members of the EC.

In contrast to Dahl (1961), Bachrach and Baratz (1962) described power as non-decision-making, where powerful groups set agendas or limit the scope of these

agendas to ensure that certain issues do not enter the policy arena. As mentioned previously, inviting the members of the EC and sending agendas prior to the meeting is the responsibility of the KSAPS staffers on the EC, who are in charge of facilitating the EC meetings. By not inviting the CSO members who were vocal about the needs of the community and who questioned the EC's authority, the KSAPS EC members exercised their power to control the types of discussions that took place during the EC meetings. Another participant, Justice, spoke of the ways in which the government members of the EC, in particular the Chairperson and the KSAPS officials, controlled the discussions of the EC by inhibiting open discussions during the EC meetings. In addition, if certain topics were discussed, they were omitted from the EC minutes:

The EC meetings became like – especially during a certain phase – absolutely no comments could be made. If you did, it would not be minuted. You would send correction to the minutes – it would not be recorded ... [Other] government officials don't really talk because there's hierarchy in the room, so [the NGO members' voices are not minuted] and KSAPS decides what is written down (Justice, 58-year-old female, director of an HIV prevention CSO).

These are examples of exerting power through non-decision-making (Bachrach & Baratz 1962), wherein the powerful KSAPS members of the EC set the agendas for the EC meetings and limited the scope of the discussions that take place during these meetings. However, Justice acknowledged that this type of power did not characterize the EC at all times. Her narrative indicated that previously, CSO members of the EC were able to voice their concerns, discuss and debate what the KSAPS put forth in the AAP. She noted that even if all their concerns weren't incorporated into the EC, there was a satisfaction that CSO members were heard and a process of discussion was followed. Shifts in power relations were also dependent on the type of leadership within the EC.

Structuralist approaches to power promote the idea of dominant groups and repressed interests within policy making structures (Barker 1996). In the case of the EC, the KHPT and the KSAPS constituted the dominant interests whose agendas were promoted and accepted and the CSO EC members represented the repressed interests,

who were unable to speak up about their concerns and needs. Laverack (2010) stated that the policy process can be utilized as a 'power tool' through which elite groups can exert control over people and decision-making enabling them to have greater access to policy making processes. The study results show that a similar situation exists with respect to local HIV policy making in Bangalore, wherein the KSAPS EC was used as a power tool by the KSAPS and the KHPT.

This section covered the power relationships between the policy actors involved in the KSAPS EC. Grindle and Thomas (1991) highlighted the role of 'policy elites', those who have official positions in the government and the responsibility for making, participating and implementing authoritative decisions, in the policy process. The members of the EC can be viewed as policy elites in the context of local HIV policy making in Karnataka. The interview data suggested that three levels of power existed within this group of policy elites. The KHPT and its members in the EC held the greatest power and were reported to significantly influence the KSAPS and its decision-making processes. The KSAPS members of the EC constituted the second level of power in the EC, and exerted power over the CSO members of the EC by deciding who were selected to become members of the EC and which topics were discussed during the EC meetings. These CSO EC members lacked the power to make decisions and, at times, the more powerful KSAPS members of the EC even restricted their ability to participate in EC discussions.

Lomas (1997) highlighted the misconception that policy decision-makers are homogeneous. The KSAPS EC was by no means a homogeneous entity and the power relationships between participants of the EC significantly influenced its decision-making processes. Interpersonal relations are the cement of a policy network (Marsh & Rhodes 1992; Wilk & Wright 1987), but interpersonal relations between the EC members were characterized by power imbalances and CSO EC members' inability to engage adequately in the EC proceedings. The construction and maintenance of relations between stakeholders, which Colebatch (2006) called the "diplomacy of public authority", is critical to policy work. However, data from the current study indicated that power differentials and the turnover of CSO EC members posed significant barriers to the development of stable relationships between the members of

the EC and the organizations they represented. The constant turnover of CSO EC members, the lack of criteria for selecting these members and the refusal to engage with CSO members who questioned the authority of the KSAPS also indicated that these actors were under-utilized and undervalued. The power relationships between the members of the EC and the presence of a non-state agency that greatly influenced KSAPS decision-making, namely the KHPT, posed significant obstacles to the participation of CSO EC members in local HIV decision-making processes.

7.5.5 EC as a Policy Network

A policy network is a model for the relationship between interests and the government (Marsh 1983; Schmitter & Lehmbruch 1979). Scholars have used the concept of policy networks to highlight the complex interrelationships between state and non-state actors; these relationships can be contentious (Friedman & Mottiar 2004) or collaborative (Rhodes 1988). Access to a policy network is limited to the privileged few (Rhodes & Marsh 1992), in this instance, the members of the EC. By virtue of the presence of members of government departments and CSOs, the EC can be defined as a policy network. The KSAPS EC, however, displays characteristics of different types of policy networks (refer Table 4). The 'policy community' refers to an integrated group with limited number of participants, levels of continuity, a degree of balance of power and in highly technical areas, the presence of specialists from government departments and academic institutions (Tantivess & Walt 2008). Sutton (1999) described the policy community as a tightly knit group of elites who have access to certain information and knowledge, and excludes those that do not have such access. The EC has a highly restricted membership, another attribute of a policy community. The selection of EC members by the KSAPS and the large number of government officials participating in the EC suggests that it is a policy community dominated by government interests (Rhodes & Marsh 1992).

The frequent change in CSO members of the EC led to unstable relationships between EC members and a lack of continuity in the interests of the CSO members. Such instability and lack of continuity are characteristics of an issue network (Hecl 1978; Rhodes 1986). It is suggested that the EC has the characteristics of an issue network and a policy community. The lack of understanding of the EC selection process may

be indicative of the lack of shared decision-making within the EC, another key characteristic of the issue network. The EC can therefore be viewed as an example of an intermediate case of policy network (Rhodes & Marsh 1992) which does not conform exactly to the list of characteristics delineated in the Rhodes Model.

7.6 Policy Process and Content

This section focuses on the local HIV policy content and processes through an examination of the topics discussed during the EC meetings, the types of community concerns that were raised and, where known, the outcomes of these discussions. As mentioned previously, data available on policy content and processes was limited.

According to the EC members, the EC is an autonomous body which has the ability to develop policies based on local needs and concerns. However, any policy decisions made by the EC have to also be approved at the national level by the NACO prior to implementation.

There is a way to make local policy. But then one has to get it cleared by the Executive Committee which then will forward this to NACO, and NACO does, does honour this sort of change based on evidence. But the policy has to go through the EC. The EC has to clear it (Thomas, 55-year-old male, doctor working with PLHA).

A review of the available minutes of the EC meetings indicated that the majority of EC discussions and decisions revolved around staff salaries, the budgets of the KSAPS and its partner NGOs, social marketing of condoms and NACO guidelines for program implementation. During the meetings in the early 2000s, much of the discussion revolved around the science and social impact of HIV/AIDS, perhaps due to the need to provide such knowledge to EC members who were not involved in HIV/health-related work. The quality and depth of reports varied greatly over time as different individuals recorded the meeting minutes. Some of the minutes provided detailed accounts of CSO members discussing their concerns regarding incorrect media messages (KSAPS 26/02/2002), the need for medications for opportunistic infections, and TB (KSAPS 11/10/2002) and the need for accountability of CSOs engaged in

funding partnerships with the KSAPS (KSAPS 2/2/2008). However, in many other reports, there was almost no mention of CSO members being involved in the EC discussions.

Meeting minutes also indicated minimal discussion of the concerns of the PLHA and vulnerable communities. The lack of adequate nutrition for many PLHA who take ART was a common concern among PLHA and CSO members. Another concern of PLHA who were on ART was the long waiting times at ART centres. Many PLHA travel from other cities and towns to get their stock of ART from the Bangalore centres. These PLHA often wait in line for hours to get their ART without taking any breaks for meals. CSO participants highlighted that the difficulties faced by PLHA in seeking ART were shared with the KSAPS, but little had been done to rectify the long waiting periods. At the time of data collection, CSOs were taking turns each month to provide food and water to PLHA who waited in line to access ART, but were uncertain about how long they could continue to provide supplementary nutrition to PLHA on ART with their limited funding. According to CSO EC members, this issue was discussed in the EC, however no decisions were taken.

Issues relating to HIV/AIDS field that is part of NACO program can definitely be discussed [in the EC]. In fact, we have discussed about providing bus passes to PLHA to access ART. We have discussed issues of providing nutritional support to PLHA ... A lot of discussion has taken place. And they were trying to say that 'let us try to see some resources for that'. And with regard to nutrition, they were trying to say that there is no provision in KSAPS funding for that. But let us try to see in, from you know, other resources (Vikram, 55-year-old male, HIV-prevention NGO staff member).

The meeting minutes indicated that many topics were discussed without leading to any concrete decisions or sustained discussions. For example, the EC discussed the nutrition issue mentioned above by Vikram during their 52nd meeting (07/03/2009), wherein the EC decided to request other government departments (such as the National Rural Health Mission) to supply supplementary nutrition to PLHA. However, this topic was not discussed in subsequent meetings in May and September 2009. When

asked about this in 2010, participants were unsure about how this topic had progressed and what decisions had been taken. The lack of follow-up of key issues raised in the EC, such as that of supplementary nutrition for PLHA on ART, poses a challenge for the development of local HIV policies that are sensitive and responsive to the community's needs.

Similarly, Vikram described the lack of follow-up of another discussion topic raised by CSOs, namely the grading process by which the KSAPS appraised the CSOs it funded and the subsequent termination of its partnership with some CSOs:

See, this grading happened I think, two or three years back. I don't remember the dates but it did happen. And some of the very good NGOs which pioneered the HIV movement in the state were rated low ... There was a team constituted by the KSAPS. NACO mandate is for monitoring and evaluation. It gives a structure to it but the specifics are not. Specifics are not laid down in the NACO guidelines. So these people, they did on their own. They evolved a system and they selected the members who will go and do the evaluation [across Karnataka]. They made these teams [with] had people whom [the KSAPS] wanted. They were given a brief that these NGOs had to be given top marks. And the ones that received top marks, I was also told, that these NGOs were very close to some of the politicians (Vikram, 55-year-old male, HIV-prevention NGO staff member).

Vikram raises two issues, that of a rigged evaluation by the KSAPS of the CSOs it funded and allegations of corruption within CSOs. CSOs raised these issues at the EC meeting, which was documented, albeit in a limited manner, in the EC meeting minutes (02/02/2008). This discussion took place in relation to the World Bank Report which led to the NACO terminating dozens of partnerships nationwide (discussed in Chapter 5). During the discussion, some CSO members raised concerns over the lack of evidence provided prior to making allegations regarding corruption in some CSOs. These participants demanded another, more transparent investigation. The Chairperson requested a second investigation by the Public Affairs Centre, a neutral agency which had no ties with the KSAPS or the CSOs it funded; however the Public

Affairs Centre, citing the lack of skills necessary for such an undertaking, turned down this proposal. This issue was not discussed in subsequent meetings and without further investigations, contracts of five CSOs that were deemed corrupt were terminated.

Some CSO EC members explained that at times the EC discussions ranged from “mundane” to “shocking” and that decisions were dominated by the government and often taken in an arbitrary manner. Justice indicated that during some meetings, the comments made by government officials “shocked” her:

Decisions are taken in a very arbitrary fashion. What are these decisions based on? Maybe funding. ‘Why should we lose the money?’ or this one is troubling, ‘Let’s just get rid of them.’ I’ll give you an example. There was a group of counsellors who had protested for some rise in pay or something. Granted, they didn’t have the quality, they were people who were recruited based on various payments they made at various points [as bribes to secure their position]. And there’s a whole culture of demand without really responsibility. All that was not right – the way they had gone about it was not right. Some arrears [balances in salaries to be paid to the counsellors] had not been given. The discussion in the EC was ‘Oh, just stop them for a while, you know. Just don’t release their payment for 3 months’. See, for me, this was not the right way for a senior Government official to talk. You know, you call them, you talk to them and you say ‘This [more salary] cannot be paid, because this is not our policy.’ That’s acceptable. But if you say ‘Let them come down on their knees. Just don’t release the pay’, and it’s spoken in a public meeting! And did anybody question the [government] official? No, and I didn’t either because I was just so shocked (Justice, 58-year-old female, director of an HIV prevention CSO).

In this quotation, Justice also raised contextual issues, namely the corruption involved in the appointment of government HIV counsellors and these counsellors then making demands for pay rises from the government without adequately fulfilling their jobs. HIV counsellors are appointed through KSAPS funding to the ART centres and Integrated Counselling and Testing Centres (ICTCs). Justice’s statement alludes to

counsellors who paid bribes to be appointed and who then demanded pay rises without actually fulfilling their roles as HIV counsellors. This she terms a culture of “demanding without responsibility”. Participant narratives suggested that at times counsellors who lacked knowledge and experience on HIV-related issues and the specific concerns of PLHA were appointed to some ICTCs. Many participants also reported discrimination at ART centres and ICTCs when they recalled their initial experiences of living with HIV/AIDS. Justice also raised an important point regarding the ways in which major issues were handled by the EC, in this instance the discussion revolved around withholding salaries. As discussed in Chapter 6, withholding salaries was reportedly a common way the KSAPS and CSOs exerted power. Some participants also mentioned corruption and a culture of collusion among staff of the KSAPS, particularly under one former Project Director (see Chapter 5). In 2013, this former KSAPS Project Director was sentenced to three years imprisonment for collusion and misappropriation of funds during her tenure as the KSAPS Project Director (Times of India 2013), raising questions about the efficiency of the EC in identifying and controlling such practices.

Colebatch (2006) identified three types of framing of policy: authoritative choice, structured interaction and social construction. In authoritative choice, which Dye (1972, p.2) noted is “anything a government chooses to do or not do”, policies are made when a government makes a choice. Other participants have an advisory role (Colebatch 2006). The policy process adopted by the KSAPS EC can largely be defined as authoritative choice, as the government interests dominated. Despite the apparent involvement of CSO members in the EC, its policy process cannot be defined as a structured interaction (Colebatch 2006), which requires organized participation by multiple actors who promote diverse agendas and interests.

Though most CSO EC members reported limited opportunities to participate in the EC decision-making processes, some participants felt that being on the EC enabled them to enter discussions with the KSAPS outside the EC processes:

So to let the policy maker, the executing body know that these are things that the people are going through. But as I started working, I realized that there is

nothing much you can do in that one hour's meeting. But that, that role can be used in, for example, I can go to KSAPS office and I can say, 'We have an issue. Please do something about it'. So beyond an executive meeting, board meeting, we can influence. And that's what I have been actually probably more actively involved in. So that role of being on the EC gives me an opportunity to influence the KSAPS. And then they respect you a little bit more than probably if I was just in charge of [my organization], you know, so that, that difference probably is the big change (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Benjamin also raises an important point regarding the amount of time spent on policy processes. Most participants felt that very little time was spent on quality discussions during the EC meetings and also that meetings were held too infrequently. However, as Benjamin noted, EC membership enabled the building of relationships and connections that could create opportunities to enter into discussions with the KSAPS.

Numerous studies have shown the importance of 'policy information', wherein participants spend adequate amount of time discussing topics such as the magnitude of the problem at hand, the importance of various factors affecting the problem, the effects of past policies and the probable consequences of their policy decisions (Derthick 1979; Greenberger et al 1983; Hecllo 1978; Nelson 1986; Sabatier 1991). Data from the current study indicated that such detailed discussions rarely took place within the EC and decisions were often made arbitrarily and without adequate discussion. Discussion topics were also not followed up adequately, according to participants.

The development of policies occurs in multiple stages termed the policy cycle (Colebatch 2002; Hatcher & Troyna 1994; May & Wildavsky 1978) or the 'stages heuristic' (Sabatier & Jenkins-Smith 1993). These stages include problem identification, agenda-setting, identification of solutions, formulation and evaluation of options, policy implementation and evaluation (Bardach 2000; Bridgman & Davis 2004; Colebatch 2002; Collins 2005; Dugdale 2008; Kingdon 1995; Lewis 2005). The decisions taken by the EC, however, did not appear to follow a clear, systematic

process. Instead, most issues were raised during the EC meeting and decisions were taken immediately. Often, as noted by some participants, decisions were taken by the EC without a clear understanding of how the problem was identified. In addition, the constant turnover of EC members and the resultant inability of any of the research participants to describe the policy process also made it difficult to determine the policy cycle adopted by the EC.

The lack of transparency in local HIV policy processes was also highlighted in this study. Repeated attempts to seek documents that would shed light on policy processes and content – such as terms of reference for EC members or local HIV policy documents – failed, as participants reported that they were not aware of the existence of such documents. In addition, CSO EC members spoke of a deliberate attempt by the KSAPS EC to keep their decision-making confidential. EC meeting minutes reflected that CSO members have been reprimanded for discussing the proceedings of the EC with other CSOs, and were told to ensure that the EC discussions are treated as an “internal matter” and that “no [EC] discussions be circulated” among other CSOs (EC Meeting Minutes 15/06/2001, p.19). Participant narratives suggested that although this discussion took place a decade prior to data collection, the understanding that EC discussions were an internal matter remained.

7.6.1 Limited Participation of PLHA

The limited participation of PLHA in civil society was discussed in Chapter 5. In this section, the limited participation of PLHA in the local HIV policy process is discussed. The participation of PLHA and communities vulnerable to HIV/AIDS in health and HIV policy making have been shown to lead to the development of policies that reflect community needs and realities (Stephens 2004; Tantivess & Walt 2008). Civil society and affected community engagement in policy processes facilitates open channels of communication, the incorporation of valuable community expertise into policy processes and can be beneficial for all stakeholders (Coulby 2001; Gellert 1996; Koh 2000; Weiss 1999). A number of examples of the positive influence of PLHA and vulnerable communities on national HIV policies are elaborated upon in Chapter 8. Despite these successes in other countries, this research indicated limited and

tokenistic participation of PLHA and vulnerable communities in local HIV policy making in Bangalore.

As mentioned earlier, only one PLHA on the EC represented the state-level PLHA network and there was no representation of vulnerable communities. The development of policies that are sensitive to the local community is greatly dependent on the extent of consultation with community groups. The participation of PLHA in HIV policy making is a critical component of ensuring that their needs and realities are reflected in policy responses (Ford et al 2009; Stephens 2004; Tantivess & Walt 2008). However, most PLHA participants felt that their community was not consulted or adequately represented in the KSAPS policy making processes:

[The KSAPS] doesn't include positive people in policy making. I think that is the main problem. HIV-positive people know what their problems are. Generally outsiders don't know what their problems are, they don't understand. If HIV-positive people are included in policy making, then the real facts, what is happening, comes out. They don't let us sit in on policy matters. [The KSAPS] gives us a project, we get people together and work. [We are] like workers. They mustn't do like that. We know what our problems are. Someone sitting somewhere else is writing and giving it to us – that's wrong I think. If they include us, that will be good (Devi, 29-year-old female living with HIV, PLHA network staff member).

The decision to include only one PLHA on the EC was also raised by some participants:

Like EC committee ... they have one positive representative. And how much power [that person] carries? Okay, among so many people? I wish there were sex workers, sexual minorities there. One positive person! So how much weightage is there? [That] one person, will be very different from other people. Others will be highly educated, others will be government officials and often a positive person, sex worker, they'll be less educated ... I don't know

how much one person can push (Shankar, 42-year-old male, human rights CSO staff member).

Here again, the GIPA principle appears to be superficially implemented by the representation of a single PLHA and through this person, a single PLHA network, on the EC. The reasons for not seeking participation of more PLHA in the EC and other KSAPS decision-making processes remained unclear. It appeared that PLHA representation was sought to fulfil a policy mandate by the NACO rather than to actively engage with the community. Tokenistic engagement of PLHA, wherein their opinions are sought only to comply with donor or government policy expectations, is a key barrier to their participation (Paxton & Stephens 2007).

Limited participation of PLHA in decision-making processes is not unique to Karnataka. While there is international recognition of the GIPA principle and the need for the involvement of PLHA in program and policy development, the operationalization of processes to consult and involve PLHA remains undefined and haphazard (Mallouris, Casswell & Bernard 2010). Studies have illustrated that participation of PLHA at decision-making levels has been very limited (Cornu 2003; Roy & Cain 2001). Existing research also demonstrates that PLHA continued to participate at the ‘target audience’, ‘contributors’ and ‘speaker’ levels of the UNAIDS pyramid (discussed previously in section 2.4.1) rather than at ‘expert’ and ‘decision-making’ levels (Chakrapani & Abraham 2010; Cornu 2003; Magaz & Hardee 2004). Data from the current study adds to these findings and suggests that PLHA in Bangalore remained at lower levels of the pyramid or remain as “workers”, as Devi put it. Valuable opportunities to incorporate insights and expertise based on the realities faced by PLHA were therefore lost during the local HIV policy making processes.

Some CSO members questioned the extent to which the PLHA consulted by the KSAPS represented the larger PLHA community’s interests:

See, on the face of it, they consult [PLHA]. I mean, in every decision, like the network is involved. But what I am saying is, it’s all mechanical. Like the real participation, like the GIPA, we call, you know; that is not there. We have a

GIPA conference, but... there is a GIPA representative in every district. For example, in KSAPS, after getting the job, he completely becomes a KSAPS man. He is no more a representative of the community. And there are some places where the GIPA Coordinator post itself is given to a non-positive (Shankar, 42-year-old male, human rights CSO staff member).

Shankar's quotation reflects a common feeling that some PLHA who were recruited into the KSAPS and other government bodies became co-opted. These PLHA were subsequently not viewed as belonging to the PLHA community once they were employed in the KSAPS, but rather were seen as 'puppets' of the KSAPS. During informal discussions with CSO members, particularly members of the EC, it was suggested that the KSAPS at times recruited PLHA who knew little about the GIPA principle and about HIV/AIDS in general. These PLHA were less likely to question the KSAPS and its practices. One participant specifically recalled witnessing KSAPS staff deciding to recruit a PLHA who had done worse than other PLHA applicants (in the written test and interview) for a KSAPS position (Fieldnote 18/08/2010). Such practices suggest that while the GIPA principle was seemingly promoted by the KSAPS through the recruitment of PLHA, the recruitment process was conducted in such a way as to ensure the selection of PLHA who were less likely to make their voices heard.

According to some participants, the under-representation of PLHA in the KSAPS decision-making processes has also led to a lack of understanding of the concerns and realities faced by PLHA. Benjamin, a member of the EC, described a situation in which the EC Chairperson made insensitive suggestions with respect to HIV prevention:

There was once this Secretary who came in and he was very funny. He made this proposal saying that we should actually be taking up some government land on large scale, build homes and keep all the HIV people there. We were shocked because imagine, at the EC meeting, the Secretary is talking about this!! Then I was sitting very close to [the PLHA member of the EC] and I said 'you should speak. You have to speak first, then we can actually join.' She

really spoke and she said ‘What you are saying is absolutely crazy!’ Then all of us actually joined in and we talked about the pros and cons and all that. He was talking about like the previous leprosy initiative. Imagine, living 100 years behind! (Benjamin, 55-year-old male, staff of CSO focused on HIV treatment, care and support).

Benjamin’s quotation highlights key barriers to the participation of PLHA in local HIV policy processes: difficulties faced by the PLHA representative in voicing their concerns during the EC meetings, inability to discuss transparently issues emerging in the EC, and a lack of understanding of HIV/AIDS by the Chairperson of the EC. As mentioned earlier in this section, the extent to which one PLHA in the EC can stand up for themselves and voice the community’s concerns was questionable. The power relations that existed between the EC members and the fact that CSO representatives were a minority within the EC may also have contributed to the inability of PLHA to speak up for the community. In this instance, the PLHA representative needed encouragement and support from other CSO members to question the proposal of the Chairperson, highlighting the importance of providing support, enabling environments and skills to PLHA to enable them to meaningfully participate in decision-making processes (Chakrapani & Abraham 2010; Paxton & Stephens 2007; Stephens 2004, Travers et al 2008). Benjamin also highlighted another barrier to the participation of PLHA in the policy process, namely the EC leaders’ knowledge of HIV/AIDS and related issues. Leadership of the KSAPS and the EC played a critical role in the development of local HIV policies that are sensitive to the community. A lack of knowledge on HIV/AIDS and a resultant lack of sensitivity towards PLHA can hinder these leaders’ engagement with PLHA in the EC and the extent to which the PLHA actively participate in EC decision-making processes.

Another participant raised the importance of adequate representation of vulnerable communities within policy making processes. Devi stated that while the PLHA community was consulted to some extent in the EC through the single PLHA representative, other vulnerable communities were completely excluded from decision-making processes:

At least they notice us. But MSM and FSW they don't recognize even if they are present. See our population, generally in Bowring ART Centre, there are 10,000 people of which 8,000 are taking ART and 2,000 are non-ART cases. In them, MSMs and FSW are very less. Look at it that way, where will they focus, tell me? (Devi, 29-year-old female living with HIV, PLHA network staff member).

Devi's statement raises the question of how diverse community interests and voices were represented in the local HIV policy making process. The diversity of the HIV epidemic makes it difficult to represent the full range of experiences and needs of PLHA. However, the active and meaningful engagement of diverse groups of PLHA, particularly those from socially marginalized groups, is critical to the development of responsive policies and programs (Mallouris, Caswell & Bernard 2010). Data presented here suggest that diverse groups of PLHA were not adequately represented on the KSAPS EC.

The issue of PLHA and vulnerable community representation raises questions about the legitimacy, extent and the coverage of a 'representative voice' (Stephens 2004). The PLHA representative on the EC and other decision-making bodies may not convey the voice of their constituency adequately. In Chapters 5 and 6, the dynamics between PLHA in the general population and those who were members of vulnerable communities were discussed. Data suggested clear identity politics between sex-working and non-sex-working women living with HIV/AIDS and also between homosexual and heterosexual men living with HIV/AIDS. In a context where these complex dynamics exist, it is questionable whether the single PLHA on the EC would be able to represent the interests and concerns of the diverse communities affected by HIV/AIDS in Bangalore. Opening up representation to other vulnerable communities, along with increasing the number of PLHA, may ensure more effective representation of community interests in local HIV policy making. This is of particular significance as the main focus of the KSAPS is on HIV prevention and most of its resources are spent on the targeted HIV prevention approach that focuses on the FSW, MSM, PWID and transgender communities. At the time of data collection, it appeared that these targeted approaches were being developed and implemented with little input from the

very communities the KSAPS prevention programs ‘targeted’. Consultative processes developed and coordinated with key vulnerable populations are crucial to identifying appropriate means of involving a diverse range of PLHA in decision-making processes (UNAIDS 2013).

Better understanding of the policy process by CSO members and sustained policy discussions with the KSAPS are crucial to improve community participation in local HIV policy making. Participation is also significant from a democratic governance perspective. Increased participation of CSOs and community members in policy partnerships can be a means by which accountability, transparency and responsiveness, all features of democratic governance, are operationalized and reinforced (Brinkerhoff 1999). However, data presented in this chapter indicated that meaningful participation of civil society and PLHA in local HIV policy making processes was not taking place.

This section focused on the EC’s policy processes and content. Participant narratives indicated that most EC decisions revolved around KSAPS budgets and staffing and that community concerns were rarely discussed. In addition, the presence of only one PLHA in the EC and the absence of representatives from other vulnerable communities raises questions about the extent to which community concerns are recognized in the EC and taken account of in policy processes. Most civil society participants felt that KSAPS engagement with civil society and affected communities was largely tokenistic and top-down in nature; CSO representatives and the PLHA representatives felt disempowered by the KSAPS and KHPT and were at times fearful of raising community concerns and questions. Participant narratives illustrated that the KSAPS included CSO members and one PLHA in its Executive Committee to fulfil NACO mandates of community participation rather than to maximize the potential benefits of community involvement in resulting local HIV policies. As a result, the CSO and PLHA representatives in the EC remained under-utilized and undervalued.

7.7 Influencing the KSAPS Policy Agenda from the ‘Outside’

Many participants who were not part of the EC questioned whether the five CSO members of the EC adequately “represented” the needs and concerns of larger civil society and vulnerable communities. These CSOs were perceived to be different by

virtue of receiving KSAPS funding and being invited to become members of the EC. As discussed in Chapter 5, there was a general perception that KSAPS-funded CSOs had better opportunities to engage with government decision-making processes. KSAPS-funded CSOs were inextricably tied to the government due to their funding arrangements and were expected to implement NACO's policies and programs. Participant narratives presented here and in Chapter 5 indicate that the fear of being de-funded prevented KSAPS-funded CSOs to question or contest KSAPS policy and program processes. Power relations within the EC resulted in CSO EC members not being able to express themselves; instead, CSO representatives often went along with EC decisions. These characteristics governmentalized KSAPS-funded CSOs represented in the EC, whom many participants felt largely represented government interests rather than community needs. To ensure that the needs and interests of other CSOs and vulnerable communities were heard, other CSO members were simultaneously attempting to influence the KSAPS policy agenda from outside the EC. This section discusses data collected from CSO members and PLHA who were not part of the KSAPS EC about their perceived roles in influencing the KSAPS' policy agenda.

At the time of the study, CSO members were attempting to present their concerns to the KSAPS and the NACO through the Bangalore HIV/AIDS Forum (BHAF) (previously discussed in Chapters 5 and 6). The BHAF brought together CSOs engaged in HIV/AIDS in Bangalore to create a group entity that was more powerful than the individual CSOs. The BHAF attempted to raise the concerns of PLHA and vulnerable communities by organizing public hearings by PLHA, presenting charters of demands to the KSAPS and holding protest rallies to bring the issues of PLHA to the forefront (Fieldnote 03/06/2010). According to participants, the BHAF also 'gatecrashed' events held by the KSAPS, such as World AIDS Day events and the 2009 visit by the UNAIDS Executive Director Michael Sidibe to Bangalore, in order to bring attention to the needs of PLHA and vulnerable communities (Fieldnote 04/06/2010). During these events, the BHAF provided the dignitaries present with briefs on the problems faced by the PLHA community. Among the community concerns that the BHAF promoted was the need for more ART centres that provided paediatric ART, improvement of Bangalore's Integrated Counselling and Testing

Centres (ICTC), provision of supplementary nutrition for PLHA on ART, provision of welfare benefits such as the Below the Poverty Line (BPL) cards which would enable PLHA to access subsidized food and consumables, and the need for inclusion of PLHA in the KSAPS decision-making processes. Although CSO members were continuously engaged in bringing these community concerns to the attention of the KSAPS, participants were unsure of the extent to which they were influencing the KSAPS. The BHAF has the potential to become a significant pressure group that can influence the KSAPS from the outside and hold it accountable. However, as discussed in Chapters 5 and 6, relationships between CSOs and community members were influenced by power relations and concerns with trust, leadership and accountability. These pose barriers to the collaboration of CSOs within the BHAF and also the possibility of the BHAF becoming a pressure group.

Some participants noted that civil society had become fed up with fighting with the government and had largely, lost its drive to influence the KSAPS agenda – perhaps an example of participation fatigue, wherein attempting to gain voice and participate meaningfully has become tiresome. Civil society is part of the ‘epistemic community’ (Haas 1992; Palmer & Short 2000; Walt 1994), interest groups that can influence policy by lobbying for change and demanding accountability from the state. Participation fatigue on the part of CSO members may hinder their efforts to actively engage with policy making processes.

[I was on the EC] for some three or five years, I don't remember. There were different people, not just me. Different people had opportunity to be on different steering committees. There were lots of committees constituted. At least content of policies and all, it would come into the public domain. You could question it. You could say 'Why are you doing it this way? This is not right.' But it's been different now. And we also, I would say, at some point, most of us have got so fed up. We are not engaging enough as well. So we've been lately taking about it that we need to engage more. Because its, see, as we also, in organizations there are new people who come in, who take responsibility. So they attend different meetings, and then they are humiliated,

then treated very badly. So people don't want to really engage (Justice, 58-year-old female, director of an HIV prevention CSO).

In Chapter 5, the antagonistic relationships between civil society and the KSAPS were discussed. Data indicated that these relationships were characterized by feelings of neglect, frustration, anger, mistrust and suspicion by PLHA. The difficult relationships between CSO members and the KSAPS resulted in frustration among the CSO members some of whom chose to disengage from the KSAPS rather than continue to demand a platform to voice their concerns. Participation fatigue can be a reflection of the CSO members' cost-benefit analysis of their participation in policy making given the limited opportunities to influence policies (Dahl 1970; Kathlene & Martin 1991; Kweit & Kweit 1987). Dahl (1970) argued that participation is a rational choice. Individuals choose to participate in policy making taking into account the time involved, the importance of the issue being discussed, their competence regarding the issue and also the likelihood that their voices will be heard. When participation is limited or only facilitated for a few CSO members (as seen in the KSAPS EC), there is no real potential for CSO members to impact policy (Kweit & Kweit 1987). Participation fatigue and lack of interest on the part of CSOs to engage in policy processes may facilitate a top-down approach to policy making where government interests continue to dominate policy processes and agendas.

Another participant added that the onus of making the policy making process participatory lies with the government's policy makers:

You've been here. You know the situation here, [participatory policy making] will not happen here. People are not empowered. Unless the KSAPS goes to its partners, encourage them, create space, platform for them to participate in policy – it's not going to happen. Civil society doesn't understand the importance of policy, the whole process. They may understand there is need for policy [but] how it is done, how they can contribute, they may not be clear, they may not know. Unless [civil society] is encouraged, create space ... Policy makers, people in power need to make this a process (Ambresh, 44-year-old male, director of HIV care and support CSO).

Ambresh acknowledged the perception that CSO members often did not have an adequate understanding of the policy process. During the initial stages of data collection, it emerged that many CSO members, particularly PLHA and those who worked at the grassroots level had very little knowledge about policy and the possibility of influencing policy processes. To overcome this, both CSOs and the KSAPS policy makers need to empower CSO members, PLHA and members of vulnerable communities to enable them to participate meaningfully in policy processes. Creating a space for participation and the provision of support and encouragement to participate in policy making leads to improved participation of affected communities and as a result, policies that are sensitive to the community's needs (Wallerstein 2002, p. 76). Such initiatives had not taken place in Karnataka at the time of this study, and policy making remained the domain of the government. In this instance, a possible first step to create space for CSO participation would be for the existing CSO members of the EC to engage and discuss the EC's policy making processes with other CSOs and community members. However, the guarded approach to policy making adopted by the government officials in the EC prevents such interactions between CSO members. To ensure greater participation of CSO members and PLHA in local policy processes, there is a need to make these processes more transparent and participatory.

However, some participants (government officials) contended that civil society members did not try hard enough to be a consistent part of discussions with the KSAPS:

I feel if the non-governmental organizations, civil society are really serious about the issues they are raising, then they should not stop there only, at the raising level ... and making papers. They should not stop over there. If they are really concerned about the community, they should follow it up. 'Okay, I have raised the issue; I have made a paper on it.' Okay. Fine. Then, what is the logical end you have taken? Whether you have sat with the concerned agency, any department? They're only interested in raising issues and making papers, that's what I can bluntly tell (Sonali, 50-year-old female, KSAPS staff member).

While many CSO participants agreed that there were not enough opportunities to engage in local HIV policy making processes, participants who were part of the government felt that the opportunities provided to CSO members were not being adequately utilized. Sonali highlighted the need to go beyond raising issues with the KSAPS and to enter into sustained discussions. There was a perception that while CSO members raised their concerns and presented lists of demands to the KSAPS, they did not follow up on the ‘papers’ they submitted. It is important for the KSAPS to provide opportunities to CSO members to engage in policy making processes, but it is equally pivotal that CSO members actively demand a space for themselves in local HIV policy processes and engage in sustained discussions with the KSAPS.

7.8 Summary

This chapter discussed the KSAPS EC, the main state-level HIV policy making entity in Karnataka. This chapter began with an exploration of the policy context in Karnataka through a brief discussion of the history of vertical health programs and hostile relationships between civil society and the KSAPS. Another key contextual factor that influenced the EC was the KHPT’s significant influence on KSAPS functioning and decision making. The EC comprised a restrictive set of policy actors, namely KSAPS officials, KHPT staff, representatives of KSAPS-funded CSOs and other government departments. The selection criteria for EC members remained unclear despite my analysis of interview data and official documents. Leadership and power relations between the EC members were found to have a significant influence on the quality, length and depth of EC discussions. Data indicated that EC discussions largely focused on the KSAPS budgets rather than the needs and concerns of PLHA and vulnerable communities. Many decisions were made arbitrarily and with inadequate discussion.

The unequal power relations between government officials and CSO members of the KSAPS EC and the lack of transparency of policy making processes posed important barriers to participatory local HIV policy making. Many participants asserted that the CSOs represented in the EC were governmentalized and as a result, did not adequately represent the community’s needs and interests. In addition, the limited consultation of

PLHA, lack of representation of vulnerable communities such as FSW, MSM, PWID and transgender people hindered participatory policy processes. As a result of these concerns, some CSOs took part in protests and other events to gain the KSAPS' attention and attempt to influence its policy agenda. However, many participants also reported participation fatigue, developed as a result of frustration with the KSAPS.

CHAPTER 8: CONCLUSIONS

8.1 Introduction

This thesis describes an exploration of the influence of civil society on local HIV policy making in Karnataka, India, with a particular focus on the participation of PLHA in civil society and in local HIV policy processes. This chapter summarizes the key findings of the study, explores their implications, and places them in context. Directions for future research are also suggested.

8.2 Summary of Key Findings

This research explored the relationships between civil society and government and the ways in which the two entities interacted to shape local HIV policies in Bangalore. The study also sought to understand the ways in which local HIV policies were constructed in a multi-stakeholder environment comprising CSOs, people living with HIV/AIDS (PLHA), members of vulnerable communities and government agencies and officials. This qualitative study was structured into two phases, both drawing on data collected through participant observation, in-depth interviews, document reviews and fieldnotes. The findings of both phases of the study are synthesized here in relation to the specific research objectives (stated in section 1.3).

8.2.1 Nature and Constituents of Civil Society

One of the key objectives of this study was to understand the nature and constituents of civil society engaged in HIV/AIDS in Bangalore. The study found that civil society was heterogeneous in nature, consisting of numerous CSOs and sub-groups such as PLHA, female sex workers (FSW), men who have sex with men (MSM), people who inject drugs (PWID) and transgender people. While precise numbers were unclear, research participants estimated that there were nearly 50 separate CSOs (including networks of PLHA and vulnerable communities) engaged in HIV/AIDS in Bangalore at the time of data collection (2009/10). The number of CSOs varied with the availability of funds for HIV-related programs.

CSOs in Bangalore were involved in HIV prevention, treatment, care and support activities for PLHA and also in research and advocacy initiatives. The majority of CSOs engaged in HIV prevention activities with the government-identified high-risk groups of FSW, MSM and PWID. At the time of data collection, ten PLHA networks were functioning in Bangalore, in addition to networks for other vulnerable communities such as FSW, MSM and transgender people. These networks were community-based, not-for-profit organizations that promoted the needs and rights of PLHA and other vulnerable groups. CSOs in Bangalore collaborated to conduct advocacy activities and at the time of the research, several CSOs were involved in the Bangalore HIV/AIDS Forum (BHAF), a network of CSOs engaged in HIV/AIDS that advocated for the rights of PLHA and other vulnerable communities. Funding sources for CSOs engaged in HIV/AIDS varied. Most CSOs received a combination of funding from the government, through the Karnataka State AIDS Prevention Society (KSAPS), the state-level subsidiary of the National AIDS Control Organization (NACO) and national and international donor agencies. CSOs that received KSAPS funding were mandated to work with the government-identified 'high-risk' groups and implement the programs promoted by the National AIDS Control Program (NACP). Few CSOs received donor funding only.

In addition to the diversity of the CSOs involved in HIV/AIDS activities in Bangalore, results also indicated that the HIV community comprised distinct 'micro-communities' or sub-groups, particularly within the MSM and transgender communities. These included the *kothis*, *panthis*, *hijras*, *jogappas* and *double deckers*. Valuable insights were obtained into the ways in which these micro-communities constructed their identities and organized themselves, and into their risks of HIV/AIDS. The identities of the *kothis*, *panthis* and *double deckers* were constructed based on the nature of the sexual acts they engaged in; *kothis* are feminine MSM who engage in sexual intercourse with *panthis*, who are mostly heterosexual and masculine. *Double deckers* are MSM who engage in both receptive and insertive sex. The *jogappas*, however, have a culturally constructed identity rooted in Hinduism. In addition, as elsewhere within the MSM community, the presence of a significant number of hidden MSM was noted. The diversity of the sexuality minority community, their identities, risk of HIV/AIDS, and ability to access HIV prevention services were not being adequately

recognized nor understood by government, according to many participants. These participants questioned the manner in which all the abovementioned micro-communities were categorized as MSM by the NACO and its subsidiaries.

Findings illustrated that civil society in the HIV/AIDS field in Bangalore consisted of a fragmented set of actors enmeshed in complex relationships, identity politics and power relations. A clear sense of community and locally constructed identities existed among the different sub-groups that comprised civil society engaged in HIV/AIDS. Findings of the study also provided an understanding of the determinants of collaborations between vulnerable communities and CSOs in Bangalore. Relationships between CSOs were determined based on their funding sources; participants noted that CSOs that received KSAPS funding were reluctant to collaborate with other CSOs, particularly for advocacy initiatives. The themes of power, trust, leadership, accountability and identity also emerged from the data. Power imbalances existed within and between vulnerable communities, and between CSOs, which reportedly posed significant concerns particularly in PLHA networks. It was observed that power was expressed within PLHA networks through exploitation and control of people's economic well-being and domination of PLHA choices and perceptions. PLHA networks were noted to reproduce structures of subordination and domination seen in other CSOs and government offices. These power struggles resulted in a sense of mistrust between PLHA, even between those associated within the same PLHA network. Lack of trust was a major constraint to vulnerable community and CSO collaboration and social cohesion within civil society engaged in HIV/AIDS. A perceived lack of effective leadership within these organizations exacerbated mistrust within PLHA networks. Many leaders were perceived to be interested only in self-preservation; others were viewed as being unwilling to share their positions and the accompanying benefits with other PLHA. The lack of accountability of individuals holding leadership positions within PLHA networks was also identified as a cause of mistrust, with corruption reported by many participants. PLHA participants cited examples of PLHA network leaders enriching themselves through project funds and colluding to win elections. Increasing transparency, opening channels of communication and holding leaders accountable were identified as possible ways of addressing trust issues within PLHA networks.

8.2.2 Relationship between Civil Society and the Government

Another key objective of the study was to explore the relationships between civil society and the government, particularly the KSAPS and the ways in which the two entities interacted to shape local HIV policies. The relationship between civil society and the KSAPS/NACO was found to be characterized by antagonism, mistrust, frustration and at times, fear. The antecedents of this mistrust and antagonism were varied and rooted in the history of civil society's engagement with the KSAPS and the NACO.

A significant proportion of PLHA and community members felt neglected and unsatisfied with the NACO's approach to their concerns and realities. Most participants were disappointed with both the prevention and care programs developed and funded by the NACO. Many participants felt that the targeted intervention approach to HIV prevention was myopic and overlooked members of the general community, such as monogamous married women among whom HIV prevalence has increased. Participants felt that this approach also diverted money away from treatment and care and support activities for PLHA. Vulnerable community participants were critical of the government's promotion of prevention methods such as consistent condom use without understanding of the realities faced by high-risk communities of FSW, MSM, PWID and transgender people. These included physical and sexual violence, poverty and difficulties in accessing and negotiating condom use. The NACO's credibility was also questioned by participants, particularly in terms of the lack of accountability regarding NACO and KSAPS expenditure on HIV/AIDS activities. Very limited information on NACO and KSAPS budgets and expenditure was available in the public domain. Civil society was highly skeptical of NACO's surveillance programs, mainly due to the sudden and significant decrease in estimated HIV prevalence reported by the NACO in 2007.

Civil society members' relationships with the KSAPS were influenced by the abovementioned perceived lack of credibility of government programs and also experiences of engaging with KSAPS staff. Most participants identified the frequent changes of leadership and a lack of accountability by KSAPS staff as the main sources of frustration with the agency. Participants felt unable to establish a relationship with

KSAPS staff due to their constant turnover, particularly the Project Director of the KSAPS. In the decade prior to data collection (1999-2009), the KSAPS had fourteen Project Directors (KSAPS 2013). In addition, many participants were frustrated with the KSAPS staffers' lack of knowledge about HIV/AIDS and understanding of PLHA concerns. Allegations of corruption and collusion within the KSAPS also dominated participant narratives. Participants felt that when the KSAPS engaged with civil society for policy and program development, this engagement was largely tokenistic. CSO participants did not feel that they were active and valued participants in KSAPS decision-making processes. Study results also indicated that the KSAPS engaged most with members of CSOs that it funded; members of CSOs that did not receive state funding felt largely ignored.

8.2.3 Local HIV Policy Development

This research sought to identify local HIV policy making agencies and mechanisms and understand the ways in which local HIV policies were constructed in a multi-stakeholder environment consisting of the KSAPS, diverse CSOs, PLHA and members of vulnerable communities. The KSAPS is responsible for implementing the NACP in the state, primarily through funding partnerships with CSOs engaged in HIV prevention, treatment, and care and support. The Executive Committee (EC) of the KSAPS is the main local HIV policy making body in Karnataka. Results highlighted the confidential nature of local HIV policy processes, many aspects of which were opaque even to those operating within the EC. For example, the EC functioning and issues discussed during meetings were not available in the public domain. EC members were categorically told not to disclose EC discussions to others and CSO EC members were unaware of the existence of terms of reference or guidelines for EC processes. Most CSOs that were not funded by the KSAPS had little knowledge about the EC, its functions and policy making role in the state. The private nature of state-level HIV decision-making processes posed a significant constraint to data collection for this study.

Findings suggested that local HIV policy context was significantly influenced by the relationship between the KSAPS and the Karnataka Health Promotion Trust (KHPT). The KHPT is a CSO that received a significant amount of international donor funding,

had a greater geographical reach than the KSAPS in Karnataka, and whose organizational mandates included strengthening the capacity of the KSAPS. CSO members and the staff of the KSAPS and the KHPT provided conflicting accounts of the nature and interdependencies of the organizations' relationship, although most CSO members agreed that the KHPT significantly influenced KSAPS functioning, decision-making and staffing. The influence of the KHPT on the KSAPS was exerted in several ways, including through the KHPT funding KSAPS consultants and its staff governing the KSAPS Technical Support Unit (TSU). Some participants also raised the issue that the KSAPS Annual Action Plans (AAP) were written by the TSU, with influence from the KHPT. CSO participants felt that through this influence, the KHPT decreased the capacity of KSAPS to guide the HIV-related work in the state and disempowered the agency. Local HIV policy making in Karnataka therefore occurred in a unique context in which two powerful organizations, one governmental and the other largely externally funded, dominated the local HIV decision-making processes.

The policy actors involved in local HIV policy making included government officials, staff of the KSAPS and KHPT, and a limited number of civil society members representing their CSOs (all funded by the KSAPS). The EC was dominated by the Chairperson, the Principal Secretary for Health and the Project Director of the KSAPS, who convened the EC meetings. Only five of the 30 EC members represented CSOs and of these, only one was living with HIV/AIDS. CSO participants who were not part of the EC questioned the CSO EC members' ability to represent the larger community's needs. Other CSO participants perceived the CSO EC members to be governmentalized and largely following the NACO/KSAPS policies without question or contestation.

Data from the current study indicated that there existed significant barriers to the development of stable relationships between the members of the EC. The turnover of KSAPS staff and CSO EC members and the failure to invite key civil society representatives constrained the development of stable relationships within the EC. Power relations between EC members hindered the participation of CSO representatives in EC processes. According to participants, there existed three levels of power within the EC. The KHPT exerted the most influence over the KSAPS EC's

decision-making, and particularly over the development of the KSAPS AAP, which guides its HIV-related activities in the state. The second level of power was exerted by the KSAPS through the large number of KSAPS officials on the EC, the EC being convened by the Project Director of the KSAPS and the EC meeting agendas being developed by KSAPS staff. As a result of the power exerted by the KHPT and the KSAPS and the fear of being de-funded, CSO EC members reported being unable to voice their concerns and questions during EC meetings. This ensured that the KSAPS officials dominated local HIV policy processes.

EC discussions largely focused on the KSAPS budgets and staffing, and to a much lesser extent, the needs and concerns of PLHA and vulnerable communities. For the most part, policy decisions were taken to ratify NACO policies. Many participants reported that decision making by the EC seemed arbitrary, with inadequate discussion and infrequent discussion of community concerns. The lack of adequate representation of PLHA on the EC indicated that the Greater Involvement of People Living with HIV/AIDS (GIPA) principle was far from an implemented reality in Karnataka. The lack of representation from vulnerable communities such as FSW, MSM, PWID and transgender people in the EC also hindered the development of local HIV policies that reflected the realities of these communities. Data illustrated that it was difficult for CSO members on the ‘outside’ to influence the EC and its decision-making processes in Karnataka. Participants who were not part of the EC reported a participation fatigue due to difficulties faced during previous engagement with the KSAPS. This discouraged these CSOs from engaging with the KSAPS and attempting to gain voice in policy processes.

8.2.4 PLHA Participation in Civil Society

This study attempted to capture the realities and voices of PLHA and members of vulnerable communities in relation to their experiences of participation in civil society. PLHA participated in civil society through their employment in CSOs and PLHA networks or through participation in activities organized by these groups. While PLHA contributed to CSOs at various levels, ranging from peer worker to directors of PLHA networks, most PLHA participated at the grassroots rather than at decision-making levels. Spaces for PLHA participation were defined and constructed for PLHA

by others, namely their employers and donor agencies funding the CSOs. Participation through protests and rallies against the government was a common point of involvement for PLHA irrespective of the vulnerable community to which they belonged.

Study results revealed several barriers and facilitating factors to PLHA participation. The most significant was a fear of stigma and discrimination at various levels: family, society, educational and health care institutions. Unwillingness on the part of PLHA to disclose their HIV status publicly also posed a significant barrier to their participation in civil society. Another important barrier was the lack of educational skills among PLHA; many participants reported that CSOs were more likely to employ educated people with English proficiency to communicate with funders. Consequently, PLHA felt that CSOs were selecting ‘non-community’ people over community members who were living with HIV/AIDS. Factors that facilitated and motivated PLHA participation in civil society were also illustrated in the results. These included knowledge and training provided by CSOs and community members’ significant will to live with HIV/AIDS in a positive manner. Awareness about their rights and entitlements, positive living and communication skills were also identified as important motivators for PLHA participation. Having these skills reportedly increased the sense of self-worth and confidence of PLHA. Sharing their journeys with HIV/AIDS with other PLHA provided a sense of community and encouraged PLHA to engage in civil society.

In summary, this research found that local HIV policy processes in Bangalore occurred behind closed doors, was dominated by the government and failed to adequately acknowledge and engage the diversity of local community experiences, in particular that of PLHA. Policy participation was limited to a handful of governmentalized CSOs whose boundaries with the government were blurred. The failure of government to acknowledge local civil society’s heterogeneity and grassroots-level knowledge significantly contributed to hostile relationships with civil society. Policy processes were found to be arbitrary, inadequately coordinated and opaque to outsiders. Transparent, inclusive and participatory policy processes can lead to improved local HIV policies that cater to community needs and to better acceptance and uptake of

policies by CSOs, PLHA and other vulnerable community members.

8.3 Implications of Findings

This section discusses key findings in relation to the literature and their implications for policy and practice.

8.3.1 Changing Landscape of State-Civil Society Relations

India's civil society has been described as noisy, untidy, vibrant and creative (Chandhoke 2007). Nowhere is the ambiguity and diversity of civil society more visible than in India, with its many constituents, identity politics, power struggles and complex relationships with the government. In particular, the role played by state and non-state actors in public health through public-private partnerships is well illustrated in the Indian scenario.

As previously discussed in Chapter 2, modern civil society developed as a means to promote the idea of human rights and equality. Civil society grew due to the disenchantment with the state and often proved to be a space to exert the “power of the powerless” (Cohen & Arato 1994). As in many other parts of the world, civil society's appeal in India grew as a result of disenchantment with the government. Indian history is rife with examples of people's movements demanding their rights from federal and state governments. In the 1960s, the Naxalite movement initiated militant struggles against the power of the state. In the 1970s, numerous social movements arose to challenge the state's agendas; these included the farmer's, women's and the anti-caste movements. In the 1980s, the civil liberties and environmental movements became dominant. Health activists, including HIV/AIDS activists became vigorous members of Indian civil society in the 1990s. According to some experts (Kothari 1988; Nandy 1984, 1989), during these decades, civil society in India resided among the poor and marginalized. With the advent of the HIV/AIDS epidemic, however, the notion of civil society started to change. During this time, the landscape of state-civil society relationships in India also began to change, giving rise to a large number of CSOs that were non-governmental yet governmentalized.

With the establishment of the NACO, a considerable amount of funds from international agencies was pumped into India. India was viewed as the ‘next hotspot’ of the HIV crisis after Africa, and many bilateral and multilateral donors, including the World Bank, the Global Fund to fight AIDS, Tuberculosis and Malaria and the governments of the United States, the United Kingdom, Canada and Australia provided monetary resources to the NACO. Within the first few years after the NACO’s inception, its budget exceeded the budget for any of the country’s other disease programs (Mahajan 2008). In 2007, the NACO’s budget of nearly 2.5 billion US dollars (NACO 2008a) exceeded the entire remaining budget of the Ministry of Health and Family Welfare (Mahajan 2008). The substantial funds allocated to fighting HIV/AIDS were coupled with the requirement to partner with CSOs to implement the NACO’s programs at grassroots levels. This gave rise to a new breed of CSOs that aligned with the government, implemented its HIV programs and extended rather than contested the state’s authority. This was in stark contrast to the experiences of earlier generations of civil society members who fought against the government. The HIV/AIDS epidemic therefore fostered the growth of a set of CSOs that developed due to funding availability and whose boundaries and relationships with the state were blurred.

These blurred boundaries raise questions about the applicability of common definitions of civil society in the context of HIV/AIDS in India. A common feature of most definitions of civil society is that it is a sphere *distinct from the market and the state, yet it forms associations with both these entities* (Cohen & Arato 1994; Green 1993, 2000; Jareg & Kaseje 1998; Schechter 2000; Veneklasen 1994). This research was designed with this definition of civil society in mind; however, study results illustrated how difficult it is to distinguish aspects of civil society from either the state or the market, particularly for those CSOs that receive government or international donor funding. As research progressed, it became clear that the ways in which civil society was defined in the context of HIV/AIDS in India was fluid and that the boundaries between civil society and the state were constantly shifting as new actors entered the field. As mentioned in Chapters 5 and 7, many CSOs were professionalized or governmentalized and many sought international donor and government funding.

By seeking and accepting funding, many CSOs became inextricably linked to the government and it may be argued that the logic of one constitutes the other. In the context of HIV/AIDS in India, neither civil society nor the government are monolithic blocs; these entities fuel and are dependent on each other. Civil society and the state need each other for their survival. In Bangalore, these entities have developed a form of survival politics to ensure their sustenance in the HIV sector. The need to sustain projects through government funding makes CSOs dependent on the government. Similarly, the state's inability to carry out grassroots programs ensures a heavy reliance on CSOs. In recent years, due to social and health service provision becoming increasingly burdensome and expensive for the Indian government, states have begun to contract this out to the private and not-for-profit sectors. Consequently, the balance between the public and not-for-profit sector is changing as the not-for-profit sector grows more dependent on the government to sustain it; the government is also redefining its own relationships with CSOs and citizens (Smith & Lipsky 1993). Contracting services to CSOs appears to be a good collaboration of government and CSOs in addressing the country's health problems. Through this type of collaboration, many CSOs became bound by the government's mandates and adopted and implemented government HIV programs and policies. This research illustrates a number of problems resulting from this type of collaboration: hostile relationships between civil society and the government, power imbalances, lack of transparency and concerns regarding government and CSO accountability. These factors hinder meaningful collaboration between civil society and the government. This thesis also illustrates how policy spaces were constructed by the government and policy participation was limited to a few governmentalized CSOs. These CSOs seemingly had better opportunities to engage in local HIV policy processes. However, many of these CSOs were unable to raise community concerns and needs due to fears of being de-funded and power relations with the government. This dependency undermined any potential for CSO members to challenge government HIV policies. As a result, the government dominated local HIV policy processes, content and actors.

Similar findings about the fluid nature of the boundaries between civil society and the government in India have been reported by Sharma (2006) and Misra (2003, 2006). Sharma (2006), in her ethnography of a government supported CSO, argued that

distinctions between the state and non-state actors in India are not clear, as activities, funding and political agendas intersect to create a complex combination of power, agency and roles. Misra's (2003, 2006) work on the rise of the non-governmental sector in India in providing HIV/AIDS related services in India, also highlights the ambiguous role of the government in civil society initiatives. While previously civil society was a means for poor and marginalized communities to voice their interests, many CSOs engaged in HIV/AIDS have now become professionalized and the extent to which they can represent the community's needs and perspectives is questionable. Such CSOs have evolved from being mechanisms of social change through raising consciousness and making demands of the government (Kamat, 2002; Miraftab 1997) into organizations that further the state's authority.

The significant funding provided to CSOs for HIV-related activities and the need to comply with donor requirements raised questions about whether CSO accountability lies with the people or with funding agencies (Hulme & Edwards 1997). CSO accountability is multi-directional, with CSOs being accountable to their constituents, donors, the state and their own organizational values (Edwards & Hulme 1995; Tandon 1995). Recent literature on CSO accountability distinguishes between 'upward' and 'downward' accountability (Ebrahim 2003; Jacobs & Wilford 2010; Kilby 2006). Upward accountability is associated with relationships between CSOs and more powerful actors such as donor agencies and the state. Downward accountability describes the accountability of CSOs to the less powerful constituents and communities with whom they engage. Many authors argue that mechanisms used for upward accountability undermine downward accountability (Cosgrave 2006; Ebrahim 2003; Wallace 2007). For instance, a focus on meeting donor mandates and project plans can divert CSO staff's attention from changing community realities and interests (Wallace 2007). This research highlighted instances in which CSOs' need to meet donor mandates and develop project proposals led to professional, educated, English speaking 'non-community' members being employed and making decisions for PLHA and vulnerable community members. These community members questioned the ability of these professional individuals to understand community needs and capture these adequately in project proposals. Donor funding mandates have resulted in global professionalization and de-politicization of CSOs at the grassroots

level (Alvarez 1998; Kamat 2002; Miraftab 1997; Schilds 1998). PLHA also questioned the accountability of network leaders to the larger PLHA community. CSOs require systems that align incentives created by upward accountability with good practice in downward accountability (Edwards & Hulme 1995; Kilby 2006). Balancing upward and downward accountability therefore presents a considerable challenge for CSOs, particularly those that receive government and international donor funding.

In spite of the issues discussed above, this research also highlights the importance of both civil society and the government in reducing the impact of HIV/AIDS in India. Both civil society and the government are highly political and contested domains. Recognizing their interdependence can ensure maximal collaboration in the HIV sector. Devising ways for these two groups to engage more effectively to fight HIV/AIDS is key to future HIV policy making and program development. For the section of civil society that receives state funding, this could mean achieving a partnership with the government, with balanced power equations and transparency wherein both groups are accountable to the other. Brinkerhoff (1999) defines state-civil society partnerships as cross-sectoral interactions and combined efforts from both sets of actors with the purpose of achieving convergent objectives, while the respective roles and responsibilities of both entities remain distinct. This research, however, found considerable barriers to such state-civil society partnerships in the context of HIV/AIDS in Bangalore. Overcoming power, accountability, leadership and trust issues challenges the development of state-civil society partnerships.

In calling for more sustained and transparent collaborative action between civil society and the government, it must also be noted that civil society must continue to hold the government accountable for its responsibility to the citizens of the country. One potential method to do this is through community and civil society monitoring of government activities. Community and civil society monitoring of government health-related activities, in order to hold governments accountable, has been successfully conducted in relation to the implementation of the National Rural Health Mission in India (Garg & Laskar 2010) and in improving the health of poor communities in Peru (Frisancho 2008). In order to do this, CSOs employed a number

of strategies including representation in national program review meetings, critically reviewing program implementation processes, holding public hearings to bring attention to community concerns and developing strategic alliances with health care providers. This research however found limited examples of civil society holding the government accountable by CSOs that did not receive government funding attempted to hold the government accountable and bring about policy changes from the 'outside'. CSOs that do not receive state funding or those who are in an adversarial relationship (Tandon 2002) with the government are more likely to attempt to hold the government accountable. Civil society's ability to hold the government accountable is linked to citizenship and governance (Gupta 1997). Some authors such as Chatterjee (1997) and Beteille (1996) have represented civil society in India as being free from the concept of citizenship. Gupta (1997, p. 307) countered this argument by asserting that when civil society is separated from citizenship, the government is "let off the hook". According to Gupta, taking away the pressure on the government to be responsible for the country's people can lead to human rights violations by the government in a developing country like India.

Potts (2008) suggests a four-step process to ensure accountability by governments in relation to fulfilling the right to health of citizens. This includes (1) governments ensuring the incorporation and implementation of accountability processes into all health policy, (2) continuous monitoring by government and civil society to determine which processes work and which need to be changed, (3) procedures through which government is answerable to citizens and civil society (for example, judicial reviews, impact assessments) and (4) remedies to redress health and human rights violations, including restitution, compensation, rehabilitation and guarantees of non-repetition. This provides a potential framework for governments and civil society engagement, to ensure government accountability and also promote civil society participation in health policy making. Governance goes beyond the actions of the state and includes the role of citizens, both individually and in groups and the ways in which groups organize in society to make and implement decisions that affect them (Frishtak 1994; Turner & Hulme 1997). Democratic governance provides an enabling environment for socioeconomic growth by fostering shared, pluralist management and decision-making (Brinkerhoff 1998). Such an enabling environment provides space in which non-state

actors can operate both independently and in collaboration with the state (Salamon & Anheier 1997).

8.3.2 Considering Local Community Needs and Experiences in Policy Making

Chandhoke (2007) stated that the concept of civil society is at times generalized and oversimplified by both the government and civil society actors in India, and is readily provided as an answer to the “malaise of the contemporary world” (2007, p.609). Others such as De Waal (2003) question the appropriateness of placing much of the responsibility for HIV/AIDS interventions with civil society in developing countries like India. Initial global civil society engagement in HIV/AIDS came from the gay community in the United States, which consisted of relatively educated and confident individuals well placed to take a prominent role in the fight against HIV/AIDS. De Waal argued that their involvement led policy makers to assume that civil society engagement was an appropriate model for addressing HIV/AIDS worldwide. He questions whether this is an appropriate assumption in developing countries where civil society, in particular affected communities, are often poor, marginalized and lack financial, educational and political power. De Waal (2003) suggested that local contexts rather than global experiences need to be recognized as part of policy and program development in developing countries. In spite of questions raised regarding the emphasis on civil society to implement HIV/AIDS programs, this research indicated that civil society was a mainstay in the field of HIV/AIDS in India. Nevertheless, many research participants felt that the experiences and knowledge of CSOs, PLHA and other vulnerable communities and the local contexts in which they live and work had not been adequately considered in local HIV policies. This was due to a history of nationally developed health and HIV policies and also the limited participation of civil society members in HIV policy processes which, as mentioned previously, were largely government-led and directed, with the support of external resources.

This study illustrates that the state-level policy making body in Karnataka, namely the EC, largely ratified NACO policies with little attempts to fine-tune the national policy to fit the local situation. Peters, Rao & Fryatt (2003) note that over the years, Indian states struggled to maintain and administer secondary and tertiary health facilities on

their own and became increasingly dependent on the central government for financial assistance. As a result of states' reliance on the central government, the national government gained increasing financial and programmatic control over the states and this adversely affected the development of technical and organizational capacity (Peters, Rao & Fryatt 2003). In addition, this process led to the erosion of a sense of ownership and accountability for health outcomes at the state-level (Misra, Chatterjee & Rao 2002). Similarly, Dasgupta and Rani (2004) in their study of India's national health programs, found that the central government functioned in isolation and largely viewed state health subsidiaries as data-collecting agencies. They argued that the central government needed to work more closely with state governments as well as with the private sector and communities in order to improve health outcomes. Enabling states to develop policies and programs that best address local conditions and communities and to incorporate these into the national plan is critical to the development of policies that consider state and regional differences in the HIV epidemic. Two dimensions of the organization of states have a significant influence on their ability to make and implement policies: autonomy and capacity (Howlett & Ramesh 2003). This study has shown that while the state subsidiaries of the NACO are autonomous in theory, they largely implemented the NACO's policies without fine-tuning them to suit the state-specific contexts and communities. In doing so, the state agency had been reduced, in some senses, to an administrator of the central government's NACP.

Mahajan (2008) suggested that the failure to consider local realities started with the inception of the NACO and its policy processes. This author (Mahajan 2008) asserted that India's HIV policy arena is highly influenced by global 'foreknowledge' of the HIV epidemic. The author argued that this foreknowledge is highly generic, brings epidemiological models that travel across borders and prior social categories such as high-risk groups that are presumed to be the same across countries, and promotes pre-established public health interventions such as condom promotion which have been successful in other countries. This foreknowledge, the author argued, has homogenizing tendencies and tends to silence local experiences and history while international experiences are incorporated into India's AIDS policy making (Mahajan 2008). Similarly, Misra (2003, 2006) argued that the Indian state gained legitimacy by

‘constructing’ the HIV/AIDS crisis and then attempting to manage it by using international discourses of expertise on health and risks. It can be suggested that India’s HIV policies have been influenced more by international trends and agendas rather than local community experiences and needs. For example, participants of this study were critical of the targeted approach to HIV prevention and the focus on condom promotion without adequate understanding of the factors (such as violence and inability to negotiate condom use) that may hinder condom use. Many participants also questioned the grouping of all sexual minority communities under the MSM category, which overlooked their differences in terms of vulnerability to HIV infection and access to HIV prevention and care services. Similar to the findings of this study, Cohen (2005) questioned whether labelling MSM as a high-risk category made sense in the Indian context, where gender and sexual roles were different from what was perceived in the Western world. As India’s HIV epidemic remains concentrated within certain vulnerable communities, a targeted intervention approach is warranted. However, this research illustrates the need for a more holistic integrated approach to HIV prevention and care, which combines the targeted interventions with the socio-economic contexts in which vulnerable communities live. Globally, there has been a recent change from focus on biomedical and behavioural interventions to a more comprehensive and strategic programming that focuses on social and structural drivers of HIV/AIDS, also known as ‘combination prevention’ (Auerbach, Parkhurst & Caceres 2011; Coates et al 2008; Kurth et al 2011). As previously mentioned in section 2.4.2, combination HIV prevention combines behavioural, biomedical and structural HIV prevention strategies at individual, community and societal levels in an aim to address the needs of the populations that are most vulnerable to HIV infection (UNAIDS 2010). Addressing social and structural factors that increase vulnerability to HIV enables individuals to better protect themselves and others from acquiring the HIV infection (Auerbach, Parkhurst & Caceres 2011) and create and support AIDS-competent communities (Campbell 2009). An uptake of such a combination prevention that tailor interventions to the local epidemic and contexts would greatly enhance the efficiency and outcomes of India’s national AIDS programs and policies.

This study also highlighted that while NACO’s policy position on civil society engagement is optimistic, this optimism has not been translated into practice. In

section 3.3.2, I discussed the NACO's policy position on CSOs, in particular CBOs, and noted that active and meaningful engagement of CSOs in the national and local HIV policy processes remains inadequate. This could possibly be due to the limited understanding of local contexts and diversities within civil society and vulnerable communities by national-level policy makers. According to Cornish, Banerji and Shukla (2010) NACO makes several about vulnerable communities and civil society. One of these assumptions is that vulnerable communities are all uniform and community-led interventions would therefore lead to "organic bonding" and "ownership by the community" (NACO 2007c, p. 14). This position assumes that groups of FSW, MSM, PWID and transgender people across the country are likely to bond and share an interest in the health of their colleagues by virtue of their profession and identities. Using the example of sex-working and non-sex-working women and heterosexual and homosexual men living with HIV/AIDS, this research illustrated that these groups did not bond over their HIV status but rather had deep divisions and identity politics that hindered their collaboration. A number of studies have illustrated the diversity among FSW based on geographical regions, income levels, age and places where sex work was carried out (Chandrashekar et al 2006; Ramesh et al 2008; Sarkar et al 2006). This research highlighted the heterogeneity within the MSM and transgender communities, and the complex dynamics within vulnerable communities and the organizations they represented. Despite such findings, the NACO's policies homogenize all vulnerable communities and fail to take into account the diversity of these communities, especially between different regions and states. The dependence of CSOs on government funding for their sustenance decreases the likelihood that they will refute the government's abovementioned policy assumptions. To continue to receive funds, these CSOs are likely to describe themselves in ways that resonate with the language of the national HIV policy, repeating terms such as 'solidarity', 'ownership' and community 'bonding' rather than challenging these assumptions (Cornish, Banerji & Shukla 2010). Cornish, Banerji and Shukla (2010) suggested that deeper and wider consultation between civil society and the government, outside the context of project appraisal and evaluations, where civil society members are encouraged to raise the contradictions they experience between policy and practice will ensure that community diversities are addressed in HIV policies in India.

Civil society is a “realm of pluralism” (Rosenblum & Post 2002, p.3). Policy processes have failed to acknowledge the heterogeneity within civil society. As discussed in Chapter 2, many definitions of civil society describe it as being *composed of people who have common interests entering into voluntary associations* (Connor 1999; Deakin 2001; Green 1993, 2000; Raymond et al 2004; Schecter 2000; Veneklasen 1994; Walzer 1995). A key similarity among the definitions of civil society is that it is *constituted by individuals associating freely and building networks and other forms of social communication*. This research indicates that at times, people involved in civil society associations did not come together based on common interests. Instead many civil society groups developed based on the interests and agendas of funding agencies or the government, in a type of ‘manufactured’ civil society (Hodgson 2004). Veneklasen (1994) stated that civil society associations are bound by the values of trust, reciprocity, tolerance and inclusion, which are also critical components of social capital among CSOs. Building social capital, particularly in terms of improving trust, collaborative efforts and solidarity among CSOs engaged in HIV-related activities would significantly enhance their collective efforts while negotiating and engaging with the government. Health and developmental successes in other parts of India, for example in the state of Kerala, have been attributed to exceptionally high levels of social capital (Chathukulam & John 2007; Evans 1997; Heller 1997). The density of CSOs, social mobilization and solidarity among networks across the state has contributed to its impressive health and development indicators. The state also illustrates the benefits of a mutually reinforcing state and civil society, wherein the state built directly upon the health and educational resources already provided by CSOs. Pressures exerted by well-organized civil society groups have also led to more accountability of the government. Inherent social capital notions such as solidarity, trust and cooperation assisted these groups to collaborate for collective action and make demands from the government. Collaborative state-civil society initiatives such as the People’s Planning Campaign which aimed to strengthen local governments, improve transparency and accountability in governance, empower civil society groups and involve citizens in social, health and education services planning and implementation (Heller 2012; Nair 2012) illustrate the positive outcomes of state-civil society relations that are transparent and mutually supportive. Through the

People's Planning Campaign, CSOs that were engaged in diverse field such as health, development, education and women's empowerment collectively planned the state's welfare services; this example highlights the significance of trust, collaboration and networking in achieving greater civil society participation in policy and program planning and to improved health and developmental outcomes.

However, data presented in Chapter 6 indicated that many CSOs, including networks of vulnerable communities lacked these values and instead were characterized by power struggles, mistrust, ineffective leadership and lack of accountability. Civil society's diversity and pluralism in membership has created segments within itself that are not always collaborative and accepting. Many CSOs also compete for government and donor funding. Policy analyses suggest the need to consider the dynamic and complex inter-relationships between different civil society groups (Green et al 2011). These dynamics were overlooked by HIV policy processes in Bangalore, and policy makers assumed that civil society and vulnerable community members would share interests and therefore take ownership of community-level interventions. In addition, by limiting policy participation to CSOs that received government funding, policy makers made the assumption that these CSOs represented the needs and interests of larger civil society, which has been refuted by participants of this study.

This research also indicates that while the national HIV policy content has changed to include civil society engagement, the policy process largely remains top-down. This could arguably have been more necessary in addressing the initial anxiety around the HIV epidemic, when limited data was available and there was confusion amongst stakeholders in how to proceed with mitigating the impact of the epidemic. However, it is now nearly thirty years since the first case of HIV was discovered in India, and in these years, the role of CSOs in implementing government programs has been significant. CSOs and affected communities bring with them knowledge that contribute significantly to policy formulation and implementation. An understanding of civil society is critical for policy makers to adequately engage with its members, and as a result, ensure that HIV policies incorporate local experiences and needs. This research illustrated that the policy processes were accessible to only a few

governmentalized CSOs. In addition, local HIV policy processes were revealed to be confidential with little information available in the public domain. Developing mechanisms to engage in productive dialogues with non-state funded CSOs and others that may oppose the government is critical to ensuring that holistic HIV policies that consider differing experiences and opinions are developed. Processes for developing and implementing HIV policies need to be clear and appropriate to all policy actors, including CSO members at local and national levels. A policy approach that questions which civil society actors can provide the most useful knowledge and experience and involving these actors is critical to ensuring greater and meaningful participation of civil society in HIV policy processes. Similarly, developing mechanisms and guidelines to ensure that input is sought from all policy actors is necessary. For example, community-based monitoring provides opportunities to improve the participation of poor and marginalized communities, including PLHA and groups vulnerable to the infection, in health programming and evaluation. Based on these findings, this thesis suggests a more transparent, inclusive and participatory approach to local HIV policy development.

Althaus, Bridgman and Davis (2013) discussed the importance of policy ‘learning’ in the development of public policies. Policy learning entails recognising and incorporating changes in the environment, shifts in the needs of the community and lessons learnt through policy implementation and evaluation. Learning can also be achieved through policy feedback, which links the experience of service providers with the ideas of policy makers. Feedback loops and an appreciation for the policy environment, according to these authors, are critical to policy development and implementation to inform each other and to improve the policy process (Althaus, Bridgman & Davis 2013). Much has been learned about the nature of the epidemic, routes of transmission and vulnerable communities in the last three decades. Incorporating this learning into the policy process is critical to improving future HIV policies. While this thesis does not advocate a complete bottom-up approach to HIV policy making, a balance of national and scientific expertise with local insights and context-specific experience is suggested. The ‘top-down’ and ‘bottom-up’ approaches to policy making are not contradictory but complementary (Sabatier 1993). Finding the right balance between top-down and bottom-up community-owned, context-

specific processes are inherently a challenge, however both approaches are needed and there is an increasing need for both in HIV prevention and care (Laga & Piot 2012). Decentralized policy making has implications for eventual ownership of the resultant policy at grassroots levels (Green et al 2011), in this instance by CSOs. This suggests the need for opportunities for CSO and vulnerable community members to feed information about their specific needs into government policy processes. This process may lead to better uptake of HIV policies by civil society members.

Numerous studies provide evidence of civil society's role in ensuring that community needs are addressed in policy processes (Galvao 2002; Ford et al 2009; Leclerc-Madlala 2005; Oliviera-Cruz, Kowlaski & McPake 2004, Tantivess & Walt 2008). Civil society engagement in policy processes facilitates open channels of communication, the incorporation of valuable community expertise into policy processes and can be beneficial for all stakeholders (Coulby 2001; Gellert 1996; Koh 2000; Weiss 1999). Civil society played a key role in the development of the Brazilian HIV/AIDS program (Galvao 2002) wherein civil society members actively participated in policy formulation and evaluation. This was achieved through their presence on steering committees of the national HIV/AIDS programs and in other government forums (Oliviera-Cruz, Kowlaski & McPake 2004). Civil society also formed pressure groups to promote community concerns with the government (Galvao 2002). Oliviera-Cruz, Kowalski and McPake (2004) highlighted that the success of the Brazilian HIV/AIDS program was due to a united response by civil society and the government, through effective partnerships in which each sector complemented each other's expertise and resources. HIV policy making in Thailand provides a further example of the potential benefits of collaboration between civil society and the state. Tantivess and Walt (2008) identified the shift in policy making in Thailand as the government purposively acknowledged civil society groups in dialogue regarding key health issues and in the development of health policies. Similarly, Ford et al (2009) noted that civil society groups, in particular PLHA, have made a significant contribution to the provision of HIV treatment and care in Thailand. These authors concluded that the scale-up and sustainability of the country's ART program would not have been possible without the engagement of civil society. In Thailand, civil society groups came together to fight for a single cause and created a platform for joint action to

improve the lives of PLHA. The power of collective civil society action was also demonstrated by the South African Treatment Action Campaign (TAC), which, in collaboration with other civil society actors, dramatically influenced government policy in relation to ART provision. The strategies used by the TAC include ‘infiltrating’ internal spaces of the state and engaging with other civil society institutions. TAC’s voice was enhanced by community mobilization, galvanizing public support and skilled and dedicated leadership (Leclerc-Madlala 2005). These examples highlight the importance of civil society and government motivation to engage with each other to ensure the development of policies and programs that cater to the people most affected by HIV/AIDS.

8.3.3 Ensuring Greater and Meaningful Participation of PLHA

It has long been promoted that the beneficiaries of government policies and programs have a right to participate in their design, delivery and assessment. Successful engagement of communities in decision-making processes has been shown to result in policies and actions that are appropriate, acceptable and effective. This process can also influence individual well-being by improving people’s sense of control over their own lives and the decisions that affect them. As mentioned in Chapter 2, the GIPA principle propounded the right of PLHA to participate meaningfully in all aspects of HIV program and policy development. Numerous barriers to PLHA participation in civil society were illustrated in the study results. Participant narratives were filled with examples of tokenistic consultations. Using the study results, this section discusses the importance of policy formulation and implementation in relation to the greater and meaningful involvement of PLHA in program and policy development.

Many authors rightly assert that the development of policies that create an enabling environment for the greater and meaningful participation of PLHA in the development of programs and policies that affect them is critical (Paxton & Stephens 2007; Stephens 2004). Punitive government policies hinder the effective implementation of the GIPA principle (Maher, Coupland & Musson 2007). Eighty-five countries worldwide criminalize homosexuality (International Lesbian and Gay Association [ILGA] 2006) and at least 110 countries criminalize sex work (Global HIV Prevention Working Group 2010). Similarly, substitution therapy with methadone and

buprenorphine is allowed in only 52 and 32 countries respectively worldwide (Global HIV Prevention Working Group 2010). Criminalization of homosexuality, sex work and types of drug use cuts off the potential participation of constituent groups that are highly vulnerable to HIV and can play a pivotal role in HIV prevention. Legislation to decriminalize homosexuality, sex work and some types of drug use are crucial to achieving the GIPA principle. While India decriminalized homosexuality in 2009, participants highlighted that legislative action had done little to assuage discriminatory practices. Results indicated that participants belonging to the PLHA, FSW, MSM, transgender and PWID communities endured stigma at all levels of interaction, including within families, educational and health institutions and places of employment. Discrimination was also noted within the PLHA community, based on education levels and individuals' placements within CSOs. Punitive legislation combined with exclusionary societal and governmental practices have pushed many core groups of the response to HIV – such as homosexuals, PWID and sex workers – to the periphery of society, depriving them of their rights to participation and self-determination. Expecting participation of people from these marginalized communities is impossible without the development and adoption of enabling policies and anti-discrimination laws.

PLHA involvement in policy making ensures that policies are developed through an awareness of the impact of HIV/AIDS (Stephens 2004). This research indicated that participation of PLHA in local HIV policy making in Karnataka was minimal and far from meaningful. In addition, participants noted that concerns raised by the community were not always listened to, and certainly not 'heard', at the policy making level. The role of policies in implementing greater involvement of PLHA is twofold; PLHA must participate in policymaking (as the GIPA principle recommends), and simultaneously, policies and legislation to enable their participation need to be introduced. Colebatch (2006) identified three approaches to policy making: authoritative choice, structured interaction and social construction. HIV policy making is ideally a combination of these approaches wherein decision-makers play an active role (authoritative choice) and policies are made through collective and interactive processes involving the participation of key players that share a similar interest and mutual recognition (structured interaction) (Colebatch 2006). From a social

construction perspective, policies must also reflect the realities of PLHA and shared understandings which make collective action possible. Enabling policies and legislation are a necessary precondition to increase participation of PLHA in civil society. Stephens (2004) suggested two interlinked strategies to improve the involvement of PLHA in policy making: a social movement to influence national level policy making, as illustrated by the TAC in South Africa which changed South African access to ART (Treatment Action Campaign 2013) and a simultaneous institutionalization of PLHA participation through the appointment of PLHA to policy making bodies. Workplace policies to promote the employment of PLHA and anti-discrimination policies which give HIV-positive people opportunities to seek redress for discrimination can also foster greater and meaningful participation of PLHA in civil society.

This thesis highlights that in the context of PLHA participation, policy implementation is just as critical as policy development. My research illustrated significant divides between policy formulation and implementation in India. For example, the NACO's 2010 GIPA Policy asserts that "*PLHA are crucial to the HIV response. Involving them in national HIV responses is not just a question of moral responsibility. It is a highly effective way to improve national policies, strengthen HIV prevention and support scale up of treatment and care programmes*" (NACO 2010e, p. 2). India's GIPA Policy promotes the participation of PLHA in all aspects of HIV policy formulation and program implementation. However, this study has illustrated the gaps that exist in the implementation of this policy, particularly at the local decision-making level. This research and existing literature indicate that PLHA in India mostly participate at the community level, and very few PLHA are able to participate in HIV decision-making processes.

Implementing GIPA-related policies requires policy makers and CSO members to reduce barriers to PLHA participation and create enabling environments. The GIPA principle is rooted in the right to participate; all human rights are interrelated and interdependent (World Conference on Human Rights 1993, cited in Gruskin, Mills & Tarantola 2007). Improving the Indian government's commitment to protect the rights of PLHA and communities vulnerable to the HIV infection is a first step in reducing

barriers to greater and more meaningful PLHA participation. Stigma was repeatedly cited in this study, as well as in the literature, as the most significant barrier to PLHA participation. Reducing stigma is therefore crucial to improve participation of PLHA. Studies have demonstrated that stigma can be reduced through a variety of interventions including information provision, counselling, building coping skills (Brown, Trujillo & Macintyre 2001), community mobilization, protecting human rights and developing anti-discrimination legislation (Maluwa, Aggleton & Parker 2002; Parker & Aggleton 2003).

Lack of effective skills building to enable PLHA participation was identified as a significant barrier in this study and many previous studies on PLHA participation (Chakrapani & Abraham 2010; Cornu 2003; GNP+ 2008; Magaz & Hardee 2004; Paxton 2005; Paxton & Stephens 2007). Many participants felt that ‘non-community’ people with educational qualifications were recruited for high positions while PLHA were largely limited to community-level positions. Similarly, Kapilashrami and O’Brien (2012) asserted that mainstream development agencies have changed the nature of ‘expertise’ within PLHA networks in India, wherein grassroots workers who are the main link with the community often work as volunteers while employees with educational degrees and computer skills are sought to fill network positions. The limits on skill-building opportunities for PLHA are partly due to the fact that many CSOs and the government allocate most of their funds to HIV prevention or care service provision. Settings with resource constraints, limited spaces for activism, and poor political support for PLHA result in limited representation by PLHA (Kielmann & Cataldo 2010). While the Indian government receives a tremendous amount of funds to tackle the HIV epidemic (Mahajan 2008; NACO 2013), very little is spent on improving PLHA participation. Funding for PLHA participation is central to the application of the GIPA principle (Maxwell, Aggleton & Warwick 2008; GNP + 2008; Paxton & Stephens 2007). Government and CSO budgets for training of PLHA and small grants for development of GIPA programs in HIV prevention and care programs would contribute to building skills of PLHA to participate in civil society. Skill-building to enable greater and meaningful participation is critical and must start with increasing the availability of support mechanisms for disclosure, such as counseling, peer mentoring and information on the rights of PLHA.

As discussed in Chapter 6, appropriate leadership (or the lack thereof) had a significant influence on PLHA participation in civil society, policy processes and the collaborations between CSOs. Leadership building can ensure that PLHA have the confidence to engage in civil society. In addition to organizational and civil society leadership, political leadership is a necessity to improve PLHA participation. Political leadership and commitment to PLHA participation were key to the implementation of the GIPA Workplace Model in South Africa, which trained and appointed PLHA in organizations to initiate, review or enhance HIV workplace policies and programs (Simon-Meyer & Odallo 2002). Leadership and commitment also played a key role in the development of anti-discrimination legislation in Cambodia (Stephens 2004) and incorporation of the GIPA principle in the National AIDS Plans of Kenya (NEPHAK 2010) and Nigeria (NEPWHAN 2010). On the other hand, the lack of commitment to PLHA participation by governments in Cambodia, India and Indonesia led to inadequate policies to facilitate GIPA implementation (Paxton & Stephens 2007). In addition, this study found that lack of trust can be a considerable barrier to the engagement of PLHA. Building trust among PLHA and organization staff is fundamental to improving disclosure and participation. In addition, there must be continuous support to build the communication, negotiation and advocacy skills of PLHA to enable them to participate at every level of decision-making. As Roy and Cain (2001) comment, “It is far easier to train most PLHA for a particular skill than it is to help someone not living with HIV to understand the experiences of those infected”.

In India, attempts are being made to pass anti-discrimination policies such as the HIV/AIDS Bill to improve the quality of life of PLHA. This Bill, developed in consultation with PLHA and other vulnerable communities, CSO and government members, health service providers and trade unions, has provisions protecting the rights of PLHA, prohibiting discrimination based on HIV status and ensuring access to treatment (Lawyers Collective 2013b). The process of development of this Bill was initiated by the Lawyers Collective in 2003 and the Bill was submitted to the NACO in 2006 after gaining approval from PLHA and civil society members. However, to date,

this Bill has not been passed and is pending parliamentary approval. Such instances highlight the need for political commitment to HIV/AIDS.

Despite such barriers to civil society and PLHA participation, there are numerous examples of civil society, in particular vulnerable community, in which engagement has led to improved HIV program and policy outcomes. Particularly in India, an external evaluation of the Frontiers Prevention Project (which focused on HIV prevention among vulnerable communities) indicated that community-based prevention resulted in an increase in condom use and decrease in STIs among MSM and FSW (International HIV/AIDS Alliance 2006, 2014). This program was initiated and driven by vulnerable community representatives with NGO support and building their collective social capital was an integral component. Similarly, Avahan, one of world's largest HIV prevention programs, has a critical community mobilization component in their work across six states in India.

A recent study of Avahan's progress has indicated that meaningful participation of vulnerable communities such as MSM and FSW has led to collectivization and increased ownership of programs, which was associated with increased service coverage and quality, reduction in vulnerability, capacity building of these communities and improved program outcomes (Galavotti et al 2012). One of the most prominent examples of CSO influence on policy outcomes is that of the Treatment Action Campaign (TAC) in South Africa, which acted as a watchdog for the provision of treatment for PLHA and through constant advocacy and confrontation with the government, influenced the rollout of ART in South Africa (Friedman & Mottiar 2005). Today, South Africa has the largest number of people enrolled in ART worldwide (Jonsson & Jonsson 2012).

The examples discussed above highlight the significance of the participation of key affected communities in improving program and policy outcomes. However, such participation of PLHA and vulnerable community members in civil society can be both empowering and problematic, as illustrated by the current study. These individuals were encouraged to become active members of civil society and take responsibility for their own lives. Simultaneously, however, they struggled to meet basic needs in a

milieu of poverty and a lack of basic infrastructure. In arguing for greater and meaningful PLHA participation, it must be noted that skills mean little if health and livelihood resources such as ART, employment and housing are not in place. In stating that there is a need to reduce barriers to PLHA participation to ensure greater and meaningful participation of PLHA, this research also highlights the resilience of the PLHA community. This thesis acknowledges that PLHA participation was minimal in Bangalore and that spaces to participate were largely created for PLHA by CSO members and funding mandates. However, participant narratives indicated that some PLHA were attempting to maximize the opportunities presented to them to participate in civil society. Some PLHA were redefining participation using the opportunities provided to them and in doing so, they attempted to make their participation meaningful to their own lives. As discussed in Chapters 5 and 6, PLHA participants indicated that engaging in PLHA networks and working with other HIV-positive people was a meaningful and fulfilling experience. Others described ways in which PLHA tried to ‘push’ their way into bigger PLHA networks that were perceived to have an influence over the KSAPS decision-making processes. Some PLHA noted that they attempted to get elected onto the Executive Boards of different PLHA networks to try and influence decision-making. Another significant example of the ways in which PLHA tried to increase their opportunities to participate is through the development of the BHAF Task Force, previously mentioned in Chapter 6, through which PLHA attempted to enhance their knowledge and skills to negotiate with CSOs and the government and demand their rights are protected. It must be noted however that PLHA who were attempting to create spaces to meaningfully participate in civil society were those who had already had knowledge about their rights and the skills necessary to articulate their needs. This thesis asserts that generating definitions of meaningful PLHA involvement at local levels, through consultations with PLHA and simultaneously with discussions on reducing barriers to PLHA participation is critical. The question ‘meaningful to whom?’ must be constantly asked, at government and organizational levels. The participation of PLHA is best tailored to their local realities, culture and circumstances to ensure that participation is most meaningful to the people who are at the crux of the fight against HIV/AIDS.

Key Messages:

- Boundaries of state-civil society relationships become blurred with growth in national and international funding for health, in particular HIV/AIDS, giving rise to ‘governmentalized’ CSOs
- Changing landscape of state-civil society relationships emphasizes the need for government to ensure the incorporation and implementation of civil society participation and accountability processes in all aspects of HIV and health policy aspects (development, implementation and evaluation) and for civil society to demand this
- Developing partnerships between governments and CSOs that balance power, accountability and transparency in countries where government require CSOs to reach large populations, are essential
- Contextual understanding of local realities and concerns at all stages of health and HIV policy and program development, through participation of key affected communities is critical
- Participation of marginalized and stigmatized communities requires enabling environments, anti-discriminatory legislation and policies and capacity building (for policy makers, CSO representatives and affected community members)
- Political will, institutional mechanisms and budgetary provisions to ensure community participation is key
- Greater and meaningful participation is inextricably linked to human rights – governments and civil society have critical roles in ensuring that vulnerable communities’ rights are protected, including their rights to participate, self-determination, non-discrimination, to seek and receive health information and care, rights to express views freely
- Translating legal and policy commitments into specific measures of implementation an urgent need to improve civil society participation and also government accountability

8.4 Directions for Future Research

This study provided insights into the nature of civil society engaged in HIV/AIDS in Bangalore, the local HIV policy processes and the nature of PLHA participation in

civil society and in local HIV policy processes. However, questions remain that warrant further research.

A key area for future research is in relation to the changing nature of state–civil society relationships. Traditional definitions of state and civil society are changing, giving rise to groups and organizations that are hybrid in nature. Understanding the nature of governmentalized CSOs, their roles within larger civil society and their ability to act as links between the community and the government is necessary. Similarly, determining the roles of the government in India and elsewhere, in creating, maintaining and facilitating civil society is an area for future research. To some extent, Hodgson’s (2004) research on the ‘manufactured’ civil society sheds light on the work of government-funded CSOs. However, this research was restricted to the United Kingdom and did not assess the impacts of government funding on CSO agendas, actions and decision-making. The changing nature of civil society also gives rise to questions regarding CSO accountability to funding agencies, the state and the communities they work with. Assessing upward and downward accountability of these governmentalized CSOs and developing systems to manage both warrants further research. The influence of a powerful, internationally-funded organization on government decision-making processes was highlighted in this study using the example of the KHPT. Many CSO members felt sidelined by the affiliation between the KHPT and the KSAPS. Studies that examine the ways in which alliances that marginalize other CSOs are formed, and the resultant influence of these alliances on the government’s ability to engage with non-state actors, would be beneficial to understand how different civil society actors engage with governments.

This research draws attention to participatory policy processes and the ways in which the government engages marginalized communities. More in-depth studies on the role that marginalized communities play in these policy processes (using multiple qualitative methods including participant observation) is necessary to illustrate the ways in which these communities gain a voice in policy making. The question as to which methods of engagement of non-state actors, particularly those from marginalized communities, best ensure their participation in policy processes warrants further research. Further research into the differential access by diverse civil society

actors to both national and state policy processes is also suggested. Finally, more research into mechanisms to ensure the transparency of policy processes is necessary.

8.5 Final Remarks

The research described in this thesis explored the influence of civil society, in particular PLHA, on local HIV policy processes in Bangalore, India. The findings of the study contribute to existing knowledge on the nature and constituents of civil society, participatory policy making and PLHA participation in civil society. The thesis highlights the heterogeneity within civil society and the complex relationships between diverse civil society actors. My work also draws attention to the changing landscape of state-civil society relationships, particularly in developing countries like India where many CSOs are becoming inextricably linked to the government through funding agreements. These CSOs become governmentalized in many ways, raising questions about their accountability to the government and the communities with which they engage. The thesis also illustrated the difficulties marginalized groups face in participating and expressing themselves, particularly in policy processes. Although policies were developed in a multi-stakeholder environment, many of the stakeholders had no influence or voice in the policy processes. As a result of this, policies failed to adequately capture community needs and interests. This research also emphasized the need for more transparency in policy processes and the need for greater community representation in policy processes. The results of this study indicate that although PLHA participation was limited, PLHA strove to maximize the spaces constructed for them to participate in civil society, thereby attempting to make their participation meaningful to their own lives. These results can inform future health and HIV policy development and implementation processes in Karnataka and elsewhere to ensure that policies are developed in a participatory manner and adequately address the needs of local communities.

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APPENDIX 1: LIST OF CSOs ENGAGED IN HIV-RELATED ACTIVITIES IN BANGALORE

Civil Society Organization	Funding Sources			Types of Activities Engaged With			
	KSAPS	Private Funding	Membership fees	Prevention	Treatment	Care & Support	Advocacy/ Research
NGOs							
Society for People's Action for Development (SPAD)							
Population Services International							
Samraksha							
Asha Foundation							
Aneka							
Sangama							
Karnataka Health Promotion Trust							
Centre for Advocacy and Research							
Suraksha							
National Institute for Mental Health and							
Lawyers Collective							
SUPPORT							
Accept India							
Myrada							
ActionAid International HIV/AIDS Unit							
Snehadaan							
Freedom Foundation							
Infant Jesus Home							
Human Rights Law Network							
Swasti							
World Vision							
Association for Promotion of Social Action							
Community for Development and Learning							
Sthree Jagruthi							

Civil Society Organization	Funding Sources			Types of Activities Engaged With			
	KSAPS	Private Funding	Membership fees	Prevention	Treatment	Care & Support	Advocacy/ Research
Vulnerable Community Networks							
Karnataka Network of Positive People (KNP+)							
Arunodaya Network of Positive People							
Milana							
Samara							
Karnataka State Association for PLHA							
Sadhane							
Awaaz							
Karnataka Positive Women's Network							
Sankalpa							
Amruthamgamaya							
Jyothi Mahila Sangha							
Mangalamukhis							
Swathi Mahila Sangha							
Karnataka Sex Workers Union							
Vimukthi Mahila Sangha							
Gelaya							
Nithya Sumangali Sanghatane							
CSO Networks							
Indian People's Alliance to Combat HIV/AIDS							
Bangalore HIV/AIDS Forum							

APPENDIX 2: PHASE I INTERVIEW GUIDE

Section 1: Demographic Information

1. Age in years:
2. Gender:
3. Type of organization/Affected community:
4. PLHA – Yes/No
5. Date/Time of Interview:
6. Location:
7. Interviewer:
8. Others present:
9. Length of interview:

Section 2: Interview Questions

1: I would like to start by asking you about the evolution of civil society engagement in HIV/AIDS in India

Core Questions

1. Do you know when NGOs and other civil society groups first started working on HIV/AIDS in India/Karnataka? (Probes: How did this civil society engagement begin? Who were among the first groups to get actively involved?; ALSO ASK ABOUT WHEN THIS STARTED IN KARNATAKA?, RELATIONSHIP BETWEEN CIVIL SOCIETY AND GOVT)
2. What have been the motivations and/or hurdles to civil society engagement in HIV? (Probes: Are these still common today?, What steps have been taken to improve civil society engagement?)
3. Since when have PLHA been active in HIV work in India/Karnataka? (Probes: What do you think led to their involvement?)

Specific to PLHA

1. How long have you been part of the civil society movement in HIV? (Probes: What prompted you to participate?; How did you get involved?; How long after finding out your positive status did you start participating in HIV-related activities?)

2. The next set of questions are about current civil society initiatives to promote HIV policies and services

Core Questions

1. What are current civil society initiatives in HIV/AIDS in India/Karnataka? (Probes: Prevention vs. Care and support, Which groups are most active within civil society – exs: NGOs, religious organizations, media, advocacy groups? Are any affected communities more active in civil society? If yes, why do you think this is? What do you think are the differences between the situation in India as a country and the local situation in Karnataka?)
2. How effective do you think the current initiatives are? (Probes: Why do you think these initiatives are effective/not effective?; What could be done to make them more effective? Exs: Government ART, prevention services for target groups, condom promotion) ****NEED TO LINK THESE KINDS OF QUESTIONS TO SPECIFIC INITIATIVES SO THEY DON'T ANSWER IN GENERALITIES**
3. Any thoughts on why civil society is more active in some HIV-related areas and not in others? (Probes: What guides your organization to work in some areas/with certain communities and not with others? In Karnataka, which areas do you think get the most civil society engagement and which do not? What are the reasons for this? Differences between Bangalore Urban/Rural?) **** GET LOCAL DATA AS MUCH AS POSSIBLE**
4. What is the status of HIV funding in India/Karnataka/Bangalore? Do you feel the most affected communities/areas receive appropriate amounts of funding?

(Probes: Why/why not?; What can be done to change/improve?) ** THIS IS IMPORTANT, NEED TO GET MORE LOCAL INFORMATION

5. Which organizations do you currently receive funding from? (Probes: Impact of funding on groups engaged with, areas worked in)

3: Next I would like to discuss your perceptions of CSOs and their role and impact on HIV policies and services ** NEED TO EXPLAIN MEANING OF CSOs IF THEY ARE UNCLEAR ABOUT MEANING OF QUESTION

Specific to Policy-Makers/CSO Representatives

1. What are your perceptions of the role of civil society in influencing HIV services in India and locally in Karnataka/Bangalore? (Probes: What do you see as the role you/your organization plays?, Are your/your organization's/ civil society's efforts translating into changes in HIV services?, If so, how and what has the process been like?)
2. Has civil society influenced Government HIV policymaking in India/Karnataka so far? In what way? (Probes: What initiatives were undertaken to influence policies?)
3. What are the dynamics between civil society groups and the Government of India/NACO? (Probes: Have these dynamics changed as the epidemic progressed? How? What about dynamics with Karnataka State AIDS Prevention Society?)
4. In what ways do you think civil society has had an impact on reducing HIV prevalence in India?

4: Next I would like to ask you about the nature of participation of people living with HIV/AIDS in civil society

Specific to Policy-Makers/CSO Representatives

1. What are your perceptions of the involvement of PLHA in the response to HIV? (Probes: In what ways do you think they are affecting HIV prevention, care, awareness the country?)
2. How do civil society organizations actively involve PLHA? (Probes: Does your organization do this? How do or can PLHA participate in your organization?; How many currently participate?; At what levels do PLHA participate in your organization?)
3. What methods do you/your organization use to ensure participation of PLHA? How successful have these been?
4. Are you aware of the GIPA principle? (Probes: If yes, what is it? Is the principle being applied in India/Karnataka/your organization? If so, in what ways?)
5. What do you perceive as the priority issues for PLHA?

Specific to PLHA

1. What are the most important issues/concerns in your life at the moment? (Probes: Types of issues: health, access to treatment, financial issues, employment, What support do you have to address these concerns? Do you find the Government initiatives such as ART services, condom distribution, PMTCT, VCTC and community care centers helpful? How have civil society/NGOs helped you?)
2. What are your experiences of participation in civil society organizations? (Probes: In what specific ways do you currently or have you previously participated in civil society organizations?, Do you feel you are currently or have previously made a meaningful contribution to civil society?)
3. In what ways have you found your participation to be beneficial for your personally or your family? (Probes: How is it beneficial? Do you feel you give

more than you receive/benefit?; What could be done to improve participation of PLHA?)

4. What changes do you perceive in the HIV situation as a result of the involvement of PLHA? (Do you think there is enough participation of PLHA currently? At all levels? Do you think PLHA are in decision making positions?)
5. Are you aware of the GIPA principle? If so, what does it say? (Probes: How did you find out about the principle? How well do you think the principle is being implemented in India/Karnataka/your organization?)

5: Finally – and this is the last set of questions – I would like to ask you about enhancers/ barriers to CSO and PLHA participation in HIV/AIDS initiatives in India/Karnataka?

1. What kind of things could be done to help/encourage greater participation by PLHA in civil society?
2. What kind of barriers are there to improving/increasing PLHA participation in work of HIV-related NGOs, improving access to treatment for PLHA, decision making/policy-making levels? (Probes: Types of barriers : access to treatment, health concerns, financial constraints, others? How do you think these barriers can be reduced?)
3. What more do you feel needs to be done to help PLHA to actively and meaningfully participate in civil society? (Probes: Types of strategies, what type of participation is most meaningful?; If you wanted to get involved/more involved, what would you need to do this?)

Finally, is there anything else that you feel is important in gaining an understanding of the above issues, which has not been covered in this interview?

Thank you for your time and participation.

APPENDIX 3: PHASE II INTERVIEW GUIDE

PARTICIPANT OBSERVATION:

Participant observations will be carried out at meetings, public events where civil society groups interact with each other and with the KSAPS, in order to understand how these groups interact and negotiate policies, advocacy activities.

Broad rubric for observations –

1. Identify key actors, context, processes involved in HIV policymaking/civil society influencing policymaking
2. Note critical interactions and conversations between participants (KSAPS – CSOs, different CSOS, communities within civil society)
3. Highlight the history of the current setting/civil society engagement in HIV/AIDS/HIV policymaking

IN-DEPTH INTERVIEWS:

Section 1: Demographic Information

1. Age in years:
2. Gender:
3. Type of organization/Affected community:
4. PLHA – Yes/No
5. Date/Time of Interview:
6. Location:
7. Interviewer:
8. Others present:
9. Length of interview:

Section 2: Key Questions

1: Collaborations between civil society organizations and KSAPS to develop HIV policies

1. What is the role and position of the KSAPS in HIV policymaking?
2. What is the role and position of CSOs in HIV policymaking?

3. In what ways are PLHA influencing CSO agendas/HIV policymaking?
4. What is the nature of the relationship between CSOs and KSAPS officials?
Can you please share any examples which may help me to understand this better?
5. In what ways does this relationship influence HIV policymaking?
6. What methods are used by civil society members and KSAPS officials to engage the other in HIV policymaking?
7. What are your thoughts on local participatory HIV policymaking? Can you share one specific example where participatory policymaking has taken place?
If not, what are the reasons for lack of participatory HIV policymaking in Karnataka?
8. What are possible strategies to change/improve relationships between CSOs and KSAPS?

2: Dynamics between CSOs and communities living with and vulnerable to HIV/AIDS

1. Which communities participate most/least in HIV sector/policymaking? For what reasons?
2. Which CSOs are most active in civil society? In what forms do they participate?
3. What types of relationships exist between CSOs? Can you share one specific example that will help me understand the dynamics between different CSOs?
4. What have been your experiences of working with other CSOs/communities in order to bring concerns to the KSAPS's attention?
5. What types of decision making processes exist within civil society to determine which agendas/concerns are promoted in collaborative events/for policymaking?
6. What have been the experiences of PLHA of participating in civil society and interacting with other vulnerable communities?
7. What are possible strategies to change/improve relationships between CSOs within civil society?

3: Nature and Development of HIV/AIDS policies in India Karnataka

1. Who are the main stakeholders involved in HIV policymaking?
2. What type of local HIV policymaking processes exist currently? What existed previously?
3. What are your thoughts on participatory, community-based policymaking?
4. What critical shifts in HIV policies/policymaking have you observed in the past [since beginning of the epidemic, last 5 years]?
5. In what ways have HIV policies impacted CSO engagement/lives of PLHA?
6. What is the future of local HIV policymaking?

These questions were adapted for each stakeholder group and framed according to the context.

APPENDIX 4: PHASE I PLAIN LANGUAGE SUMMARY SENT FOR PARTICIPANTS' FEEDBACK

The Civil Society and HIV/AIDS in India study is a two-phase study of members of civil society organizations (CSOs) working on HIV/AIDS in India and, in particular, people living with HIV/AIDS (PLHA) who participate in civil society. The aims of Phase I of the study were:

1. Map the stakeholders – i.e. civil society organizations, Government bodies and other actors working on HIV in Karnataka, India
2. Identify potential field partners for Phase II of the research
3. Explore the attitudes of people living with HIV on their participation in CSOs

During the period of data collection (between July and September 2009), fourteen interviews were conducted (in both English and Kannada), of which six participants were living with HIV/AIDS, four of whom were members of various networks of PLHA in Bangalore. One participant each represented the communities of transgender, female sex worker and MSM. Out of these 14 participants, 6 were heads/high-level staff of organizations, 1 was a Government official, 4 were middle management staff and the remaining 3 were community-level workers. 11 major organizations that work in prevention, care and treatment, including networks of PLHA were represented in the study. All participants had a minimum of one year experience working in HIV/AIDS; the majority of participants had more than 5 years experience. Organizations that receive individual, Government and international funding were represented in the study. Interviews were transcribed word for word, translated and analyzed. These results will be used to develop research questions for the second phase of the study.

BRIEF SUMMARY OF FINDINGS

Phase I results reveal very valuable insights into the work of civil society in HIV/AIDS in Karnataka, and the extent to which civil society can influence Government policies and services. Key findings of Phase I include:

Participation of People Living with HIV/AIDS and Vulnerable Communities

- *Levels/Types of Participation:* Participants reported that there are not enough opportunities for PLHA to participate at decision making levels. It was noted that most PLHA participate as employees of NGOS, most often as peer/outreach workers and through participation in protests and rallies. Networks of positive people employ the most number of PLHA, in positions ranging from community workers to Executive Board members.
- *Barriers to Participation:* The fear of stigma and discrimination associated with an HIV-positive status was reported to be the most significant barrier. Stigma appears as fear of losing employment opportunities and discrimination in health care settings for PLHA and as violence from the police and *gundas* in the transgender, MSM and sex worker communities. Also, lack of leadership building within networks of PLHA, over-participation by “first-line” leaders was also cited by some participants. Incidents where PLHA are called to speak at events and rarely involved in planning and decision making has also been reported as a barrier.
- *Factors Increasing Participation:* The most important reason for PLHA participation is the knowledge of their rights and entitlements. Trainings and awareness programs by NGOs, specifically on rights of PLHA, positive living and emotional well-being, have had a considerable impact on the participation of all interviewed PLHA. In the case of participants with children, the will to survive in order to secure a good education and future for their children was found to motivate them to participate. The will to survive, by living openly as gay/transgender motivated members of these communities.
- *Participation is not same for all communities:* Within the PLHA groups, women, especially HIV-positive widows with children, were reported by some participants to be more active in HIV work than men, despite having less access to services and more difficult barriers to participation. Some participants discussed the MSM community to be most active in civil society, even though there are fewer in number and there are fewer organizations in

Bangalore working specifically on MSM issues. People who identify themselves as injecting drugs users are not very visibly active in civil society.

Complex Dynamics between Vulnerable Communities, CSOs

- *Community of PLHA is not a single, homogeneous entity:* Participants felt that groups of HIV-positive men, women, MSM, sex workers, transgenders have complex relationships between them, based on cultural and social beliefs (especially negativity against sex workers) and funds received for each community. Women living with HIV who participated in the study felt that female sex workers were unlike them in any manner. Most participants also discussed a distinct segregation between the MSM community and other vulnerable populations. Dynamics within vulnerable communities are also diverse – some participants mentioned people within the same community being divided based on their economic status and the type of job they have.
- *Dynamics within civil society:* Different communities within civil society, differences between CSOs and complex relationships between these groups have been reported by participants to lead to an inability to come together as one collective. Participants felt that this is caused by rivalry for acquiring funds, lack of interest in advocacy by organizations funded by the Government and differences in goals and capacities of CSOs. This may also affect civil society's ability to voice the communities concerns and influence HIV policymaking.

Relationship between Civil Society and the Government/KSAPS

- *Hostile Relationship with the Government:* All participants spoke about their relationship with the Karnataka State AIDS Prevention Society (KSAPS)/National AIDS Control Organization (NACO), which for most was one of hostility. Anger and frustration at the Government, specifically the KSAPS, its policies and employees were reported by most participants. Some participants discussed the difficulties faced in developing a funding partnership with the Government and the manner in which this funding restricts their work to the Government's target populations of sex workers, truck drivers, MSM and

people who inject drugs, mainly prevention work. The difficult relationship with KSAPS may have a significant impact on the extent to which civil society is able to negotiate their needs and influence policy-making and legislation at the state level.

- *Lack of appropriate leadership in KSAPS:* The frequent change of Project Director of KSAPS and the resultant inability to collaborate and communicate effectively with KSAPS was mentioned by most participants. Gaps in provision of VCTC and ART services were also noted by some.
- *Civil society's experience of working with the Government:* Discussed by most participants, this experience mostly was difficult and was reported not to have resulted in significant changes to the Government's programs and policies.

Funding Dynamics Influence Civil Society's Work

- *Funding influences civil society's work:* Most participants felt that the availability of HIV funds and the commands imposed by funding agencies greatly influences which communities are engaged with in HIV/AIDS programs; NACO's high risk groups are most engaged with; children are least engaged with by the Government as well as civil society, as reported by participants. Targeted intervention programs receive most funding while least amount of funding was reported to be available for human rights/advocacy activities.
- *Funding influences relationship between CSOs:* Participants noted that members of Government funded programs do not collaborate consistently with those who do not receive Government funding, especially for advocacy programs. Participants felt that as a result, there is a lack of trust on these organizations to voice the actual concerns of PLHA and CSOs, to the Government. This influences the ways in which CSOs collaborate with each other and some participants mentioned that this reduces the impact of the efforts of civil society working in HIV in Karnataka.