THE BUSINESS OF STOPPING AIDS:

A CASE STUDY OF A NON-GOVERNMENTAL ORGANIZATION IN SOUTH INDIA

by

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A Thesis Submitted to the

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To Rob Annandale, for his constant support and encouragement.

Abstract

Non-governmental organizations (NGOs) have the potential to make a great impact on marginalized communities. In order for NGOs to realize that potential, the context within which their activities are carried out must be better understood. Fisher (1997) has suggested categorizing NGOs based on their positions relative to the discourse of the fields in which they work. Seidel (1993) has identified two groups of discourses within the field of HIV/AIDS: the medical discourse, focusing on medical aspects of the disease, and the rights and empowerment discourse, focused on the underlying social, economic, and political contexts of infection.

One of the NGOs involved in AIDS control in India is Tabiyat (a pseudonym), which has been providing AIDS education, prevention, and care since 1993. The purpose of this project is to understand the challenges experienced by Tabiyat in running its programs. The organizational aspects of Tabiyat include its Advisory Group, its parent organization (Sehyogi – also a pseudonym), its staff, and funders. Sehyogi, the Advisory Group, and staff, articulate a common discourse and work together to achieve program effectiveness. Different funders articulate a variety of discourses, and in some instances, discursive tension has a constraining impact on the potential for Tabiyat to achieve its objectives.

Tabiyat has seven programs of activity: Education, Sex Worker Protection, Women's Reproductive Health, Ward (Community)-Based, Healthy Highways, Care, and

Networking. Many of Tabiyat's activities fall within the dominant discursive environment, but there are some that are in opposition to it. With its focus on HIV transmission and condom use, the Education Program fits within the medical discourse. In contrast, the Women's Reproductive Health Program includes activities which fit into the medical discourse, such as STD management, as well as activities which fit into the less dominant rights and empowerment discourse, such as advocating for women's health as a human right.

It is difficult to categorize Tabiyat as working either within or against the dominant discourse. The fluidity of discourse means that the dominant voice from issue to issue is likely to be different. Further, Tabiyat's activities which work against the dominant discourse fall into already-existing discourses which are becoming more dominant.

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Chapter 1: Introduction

Need for Study

HIV is a growing problem in India. The government of India has a National Aids Control Organization (NACO), which governs nationally based AIDS control projects with the support of organizations such as the World Health Organization and UNAIDS. In 1999, NACO initiated the second phase of the National AIDS Control Program (NACP-II), which sought to decentralize AIDS control projects through the creation of individual state-level AIDS Control Societies. The Canadian International Development Agency (CIDA) and the University of Manitoba are directly involved in India's NACP-II in two states.

CIDA provides financial support to the University of Manitoba to work with NACO and the two states' local AIDS control societies to develop effective AIDS prevention activities. Part of the University of Manitoba's role in India is to help the State AIDS Control Societies identify organizations, including non-governmental organizations (NGOs), to participate in the development and implementation of state-level AIDS control programs. In order to identify NGOs with which to work, the CIDA-funded project must gain a better understanding of NGO challenges and processes.

Understanding NGOs

One of the difficulties in understanding NGOs is the wide variety within the NGO community. The activities in which various NGOs are engaged, as well as the

situations in which they work, are so diverse, that the label "NGO" explains almost nothing about the organizations it describes (Fisher, 1997). Even within the India-specific context, the wide variety among NGOs makes categorizing them problematic. Not only do their environments vary, but the organizational makeup of individual NGOs is likely to be different from one to the next, even within the same region. NGOs have the potential to make a great impact, both on communities in developing countries and marginalized communities at home. However, in order for NGOs to fully realize that potential, the context within which NGO activities are carried out must be better understood. Case studies of NGOs will illuminate the processes of these often-complex organizations, which will further illuminate what processes lead to effective NGO work.

William Fisher (1997) has suggested that categorizations "based on function, organizational structure, and relationship to a locality or to a state . . . are a poor basis either for forming development policies or for guiding the pursuit of social justice" (pp. 448-9). Fisher instead suggests categorizing NGOs based on their positions relative to the discourse of the fields in which they work.

One of the NGOs involved in AIDS control in South India is Tabiyat,* a component of the Sehyogi NGO based in one of the larger cities. Tabiyat has been delivering care, aid, and counselling to people with HIV and AIDS, as well as setting up STD clinics and providing AIDS education, since 1993. A better understanding of the

organizational context of Tabiyat, and the processes involved in its activities, will help the overall project to better understand NGOs as a whole.

Study Purpose and Objectives

The broad purpose of the project is to understand the challenges experienced by an Indian NGO in running its programs in the field of HIV/AIDS care and prevention. More specific objectives are as follows:

1. To understand how the components of Tabiyat, including its ideology, organizational resources, and staff, impact its programs;
2. To understand how the relationships between Tabiyat and other organizations with which it works, including the state government, the business community, religious organizations, funders, other NGOs, and the communities it serves, impact Tabiyat's programs;
3. To understand Tabiyat's programs in terms of the discourse within which they are conducted;
4. To understand how Tabiyat's challenges are affected by its position in terms of the discourse within which it works.

The next chapter will discuss the origins of NGOs, as well as India's unique history of volunteerism and activism. The term "discourse" will be defined, and Fisher's theory of categorizing NGOs based on their position with regard to discourse will be discussed in detail. The various discourses around which Indian AIDS NGOs must

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* To maintain confidentiality, all names of organizations and individuals have been changed.

work will also be discussed. Chapter 3 contains a detailed account of the methods used to collect and analyze data on Tabiyat, followed by a chapter reviewing India's current AIDS situation and the government's response thus far. The following two chapters will present the results from the data collected on Tabiyat, and the final chapter is a discussion of those results, with particular emphasis on Fisher's theory of categorizing NGOs based on discourse.

Chapter 2: Literature Review/Theoretical Framework

Introduction

This chapter will trace the origins of "development" and NGOs, with specific reference to India's unique NGO situation and the historical traditions which led to it. Following that will be an introduction of William Fisher's theory of using discourse, and NGOs' positions with regard to it, as a way of understanding NGOs. The chapter will end with a discussion of the discourse of development and AIDS specifically, both on a general level and within the unique context of India, including some examples of Indian NGOs.

The Development Industry and NGOs

The development industry emerged after the Second World War. Development, in the context of the industry named for it, is difficult to define (Hancock, 1989). It is often used interchangeably with "progress" (another difficult word to define), and was originally associated with scientific, technological, and industrial advancement (Shakow & Irwin, 2000). More recently, however, it has also been used to refer to economic growth, measured by the gross domestic product (GDP) of a country (Millen et al., 2000). It is evident that the word "development", used excessively by everyone involved in the industry, has no universally accepted meaning; its definition varies depending on who is using it:

> Common sense seems to suggest that development – *progress* – is a relatively simple, straightforward idea. When things "develop," they grow stronger and get better. Yet the notion of development now

> dominant in economics and public policy has a variety of hotly contested meanings and implications. "Development" is at once a metaphor (with echoes of Hegel's philosophy of history and Darwin's theory of evolution), an inventory of particular government strategies, an idealized model for human culture and society, and a highly political reflection of power distribution worldwide. (Shakow & Irwin, 2000; pp. 48-49, emphasis in the original)

The post-World War II era gave rise to the creation of several important international institutions immediately following the end of the war: the International Monetary Fund (IMF), the International Bank for Reconstruction and Development (better known as the World Bank), the General Agreement on Tariffs and Trade (GATT), a precursor to the World Trade Organization (WTO), and the United Nations (UN). The International Bank for Reconstruction and Development was established to help rebuild the economies of countries such as France, Germany, and Japan after the war, but by 1948, they were providing "development loans" to countries identified as "underdeveloped" (Gershman & Irwin, 2000; p. 19). This was the beginning of the development industry. Although institutions such as the World Bank and the UN are arguably its backbone, the industry includes almost any flow of capital from the wealthy nations of the world to the poor nations of the world (Hancock, 1989). Thus, the development industry is broad, and includes governmental agencies such as the Canadian International Development Agency (CIDA) and the United States Agency for International Development (USAID), private funding agencies such as the Ford

Foundation and the Gates Foundation, as well as private corporations such as Halliburton and Union Carbide. Obviously, each of these organizations will have a different definition of development, but they all believe, rightly or wrongly, that their development initiatives are improving the lives of people in "developing" countries.

Development projects in "underdeveloped" countries are meant to raise the standard of living for their citizens. Unfortunately, these projects are sometimes detrimental to the very poorest. An example of this in India is hydroelectric dam development. Dam construction leads to an increase in availability of electricity and drinking water for India's population, as well as flood control during the monsoon season. However, opponents to dam development believe that too many of India's poor suffer because of them. Perhaps the most notorious of India's dam projects are those along the Narmada River, which flows through the states of Madhya Pradesh, Maharashtra, and Gujarat. Dam construction began in 1974, and continues today (Singh et al., 1999). One of the largest and most contentious of the dam projects on the Narmada is the Sardar Sarovar project in Gujarat, which began in 1987 despite a lack of environmental assessment and the fact that an estimated 70,000 rural poor would be displaced as a result of the dam (Hancock, 1989). Locals along the Narmada Valley who voice their protest against dam construction risk arrest or even murder (Baviskar, 1997). Smaller dams, such as the Hirakud dam in Orissa and the Bargi dam in Madhya Pradesh, also result in the displacement of hundreds of thousands of rural poor, as well as an increase in public health concerns such as malaria outbreaks (Banerjee, 1997; Singh et al., 1999).

It is within the climate of ineffective and potentially harmful development projects from the World Bank and large development corporations, both private and government-run (Hancock, 1989), that NGOs began expanding rapidly in the mid 1980s as an alternative to the traditional development industry. Non-governmental organizations (NGOs) were defined by the United Nations in 1968 as "either consultative bodies related to [their Economic and Social Council] ECOSOC or to the official governing bodies for other UN organizations and bodies."(Gordenker & Weiss, 1997) NGOs trace their roots back to the end of the First World War, and participated as both advisors and observers at the meeting of the allied countries after World War II that led to the formation of the United Nations (Iriye, 1999). Today, they are an important and growing part of the development industry.

Local, community-based NGOs are perceived to have many advantages over local governments and Western governments involved in development. They have smaller, less costly administrations, and therefore a faster response time to crises and emergencies (Mercer & Liskin, 1991). They are also seen to be more innovative and flexible than governments (Streeten, 1997). They are often more trusted by marginalized communities, and also understand those communities better (Silimperi, 1995). They tend to work with and strengthen local institutions, and their staff members are enthusiastic and committed (Streeten, 1997). Perhaps most importantly, they have the potential to empower and advocate for the poor, the communities most vulnerable to traditional development projects (Bebbington, 1997). The World Bank,

recognizing the potential advantage of NGOs working in the health care sector, urged developing countries to deliver health services through NGOs in its report *Investing in Health* (Smith-Nonini, 2000).

The reality of NGOs, however, is much more complex. There is a "sense that traditional ideas of development alternatives have not fared well" (Bebbington, 1997; p. 119). NGOs do not always reach the poorest community members, they often involve top-down processes and established methods, and they commonly collaborate closely with governments (Streeten, 1997). Many NGOs working today act as private contractors for industrialized governments dispensing aid money, or perform civil service duties for developing countries (Economist, 2000), blurring the line between government and non-government. Partnerships between NGOs and governments often amount to little more than NGOs delivering health services the government deems necessary; even in cases where NGOs ostensibly have a role in program planning, NGO suggestions which with the government disagrees are likely to be ignored (Smith-Nonini, 2000). Considering that NGOs are defined by their name as an alternative to government, close government ties may render the name "non-governmental organization" meaningless. Moreover, the activities in which various NGOs are engaged, as well as the situations in which they work, are so diverse, that the label "NGO" explains almost nothing about the thousands of organizations it describes (Fisher, 1997). There are so many variables impacting NGO project outcomes (including the NGOs themselves) that it is almost impossible to determine the causes of NGO successes and failures (Fernando, 1997).

NGOs have been criticized for focusing too much on short-term projects, rather than long-term projects (Streeten, 1997). Part of the problem is that if an NGO's source of funding is unreliable or insecure, it becomes difficult to plan long-term projects (Hudock, 1999). However, community empowerment is a long and difficult process, with no immediately obvious results (Streeten, 1997; Zaidi, 1999). Thus, NGOs whose funders require progress reports at short intervals will have a hard time carrying out participatory and community empowerment projects. There is also evidence that participatory projects, when not carefully planned and monitored, run the risk of involving only the community's elites, who may hijack the project and use it for their benefit (Streeten, 1997).

Small NGOs are encouraged to "scale up" to make a more significant impact on their communities (Uvin, 1995). However, such growth may create a dependency on funders or international NGOs. Funds which are tied to specific activities prevent NGOs from responding quickly and flexibly to changing community needs (Hudock, 1999). NGOs may be forced to abandon their ideologies if they clash with those of funding agencies (Fisher, 1997). The more funding an NGO has, the more time it must devote to administrative work, such as writing proposals, project reports, and financial reports, taking away from potential field time (Hudock, 1999). Partnerships between local and international NGOs run the risk of developing an unequal power relationship wherein international NGOs, as the donors, choose which local NGOs to partner with based on their ideologies, and often make the bulk of the decisions about

how the project work is carried out (Stirrat & Henkel, 1997). There are also internal challenges involved with scaling up. Organizational expansion not only changes the focus and impact of NGOs; it can change their structure and makeup, leading them to be more hierarchical (Edwards & Hulme, 1992). Altruistic work and organizational survival are not always compatible; sometimes, organizational survival means putting the needs of the organization ahead of the needs of potential beneficiaries (Hudock, 1999).

It is difficult (if not impossible) for most small, local NGOs to influence the broadest power structures such as the World Bank and IMF; their influence on government is also smaller than that of these large institutions (Edwards & Hulme, 1992). NGOs whose philosophies are at odds with those of the dominant voices in the development industry find it hard to work within their frameworks (Bebbington, 1997). NGOs whose philosophies clash with the local government are also put at a disadvantage, as "government [normally] controls the wider frameworks within which . . . organizations have to operate." (Edwards & Hulme, 1992; p. 16)

The NGO community and the environments in which NGOs must work are diverse and complex. Indian NGOs work in a context that includes not only the government of India and larger power structures, but also important traditions unique to India and its history. A discussion of some of these traditions follows.

Indian Context

There are a number of factors specific to NGOs working in India. One of these is the fact that the government is more involved in poverty-alleviation initiatives, including AIDS prevention, than many other countries. Another is India's history of activism and volunteerism among the local population. To a great extent, NGOs in India grew out of these two traditions. In order to understand the specific context of NGOs working in India, it is important to understand the important traditions from which they emerged.

The Activist Tradition

There is a long tradition of activism and politicism in India, going back to the time of British rule. In the early 19th century, when American Christian missionaries began work in India, they found Indians to be quite hostile to the idea of conversion to Christianity (Gordon, 1997). The East India Company met with similar hostility when expanding their economic colonization of India to political and educational colonization. In 1857, unhappy soldiers, peasants and landlords rose up against British soldiers after they offended Indian cultural sensitivities by smearing Indian soldiers' ammunition with animal fat (Kulke & Rothermunde, 1998). This "mutiny" extended to nearly all of Northern India, brought down the East India Company, and nearly brought down British rule (Kulke & Rothermunde, 1998). Activism and protest continued throughout the period of British rule, including protest against British censorship of Indian press in 1878, violence and terrorism in response to a failed 1905

attempt to partition Bengal, and Mahatma Gandhi's campaign of non-cooperation and civil disobedience in the early 20th century. A massacre of Indian protestors by the British military in Panjab in 1918 served only to fuel Indian protest, as well as Gandhi's radicalism; in 1920 he called on Indians to boycott all things British: materials, education, justice, titles, and elections (Kulke & Rothermunde, 1998). In the 1930s, he organized a boycott of the British salt tax. Indian activism during this time was not restricted to the followers of Gandhi; violent protests such as the murder of British police in Chauri Chaura in 1921 and the destruction and vandalism of the 1942 "August Revolution" were also part of the Indian resistance to British rule (Kulke & Rothermunde, 1998).

Indian resistance to British rule was evident in medical and public health campaigns in the 19th century as well. According to David Arnold (1993), the Indian public resented attempts to force Western public health practices upon them. The introduction of smallpox vaccination by the British in the 19th century, and the aggressive vaccination campaigns, were viewed as an attempt to destroy a sacred part of Indian culture. Before the arrival of the British, the Indian custom to protect people from smallpox was variolation, a religious ceremony which focused on a ritual invocation of Sitala, the goddess of smallpox (Arnold, 1993). Vaccination was equated with foreign rule, and was thus feared and mistrusted.

According to Arnold (1993), many of the British public health campaigns in colonial India were perceived by Indians as attacks on their culture. Public bathing and

consumption of sacred water in Hindu rituals were major causes of the spread of cholera in mid-19th century India. When a religious fair in Hardwar was broken up in 1892, Indians saw the act as one of religious intolerance, not public health (Arnold, 1993). According to Arnold, British medicine in India was most successful when they worked in conjunction with Indian elites, who claimed to speak for the masses. In Arnold's view, these elites often had only the interests of the upper classes in mind; their cooperation still gave the programs the necessary legitimacy among the Indian population (Arnold, 1993).

Indian activism has not waned in the late 20th century; Indians continue to speak out against the government and private corporations involved in projects they believe to be detrimental to India. In 1994, locals in Goa protested the creation of a DuPont factory because its contract included an exemption clause to protect the company from any responsibility in the event of a chemical accident (Holtz, 2000). In 1995, Karnataka farmers stole pesticide-resistant seeds from the Cargill Corporation, and threatened to destroy KFC restaurants in Bangalore because of the fast food chain's negative effect on small farmers (Holtz, 2000). Clearly, the tradition of activism and protest in India is still strong.

Volunteerism and NGOs

Volunteerism, like activism and protest, has a long tradition in India. Informal voluntary activities were an important part of religious life in pre-British India

(Mukhopadhyay, 1995). British rule in the 19th century led to a weakening of many traditional religious customs, and organized voluntary activities emerged. Many of the volunteers, such as Gandhi and Annie Besant, were working in reaction against the activities of Christian missionaries and other foreign organizations whose motives were suspect (Fernando & Heston, 1997; Mukhopadhyay, 1995). A great number of these volunteers formed groups and associations in the 19th century; the British government often viewed these organizations as potential threats to their power in India (Fernando & Heston, 1997). It is these organizations, with their roots in both volunteerism and activism, that were the early precursors to NGOs.

After independence, the Indian government attempted to involve NGOs in their health, social, and development projects, both government-designed and NGO-designed (Garain, 1994). However, many NGOs had grown out of a tradition of activism and suspicion, and these characteristics had carried over into NGO-government collaboration post-independence. In the mid-20th century, the majority of NGOs receiving funding were large, bureaucratic organizations (Garain, 1994). Common projects carried out by these organizations included flood relief, primary health care, education, well-digging, and rural development (Tandon, 1989). In the 1960s and 1970s, with the gap between rich and poor growing, NGOs from the activism tradition began to increase. Fearing protests on the scale of those from pre-independence, the government of India passed legislation limiting the ability of NGOs to obtain foreign funds in 1976 (Garain, 1994; Tandon, 1989). Despite repressive

legislation, many NGOs in India continue to engage in activist-style social justice projects.

In addition to differences in the historical tradition from which they emerge, Indian NGOs may differ in many other ways, including region, environment, and organizational structure. The variety among NGOs in India makes categorizing them a desirable goal. It is hoped that NGO categorizations will facilitate a better understanding of NGO processes. Fisher (1997) has suggested that categorizing NGOs based on traditional distinctions such as organizational structure is not useful in terms of facilitating or improving development work. Instead, Fisher categorizes NGOs based on the development discourse to which they ascribe.

The Development Discourse

Deborah Lupton (1994) defines discourse as "a coherent way of describing and categorizing the social and physical worlds" through patterns of "words, figures of speech, concepts, values, and symbols" (p. 18). It is through discourse that "social reality comes into being . . . it is the articulation of knowledge and power, of the visible and the expressible" (Escobar, 1997; p. 85). Discourse provides "a means of 'making sense'" (Lupton, 1994; p. 18) of a given concept by articulating precisely how to make sense of it, by "constructing a certain field of knowledge" (Lupton, 1995; p. 13) around it. When a discourse is particularly dominant, "only certain things [can] be said and even imagined" within that particular context (Escobar, 1997; p. 85). Michel Foucault referred to this phenomenon as a "Regime of Truth":

> Each society has its regime of truth, its 'general politics' of truth: that is, the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true. (Foucault, 1984; p. 75)

In Foucault's view, discourse is an important aspect of power relations. Foucault (1978) sees power as a "multiplicity of force relations" (p. 92). These force relations can either support one another, creating a system of power, or contradict one another, isolating themselves from each other. Power, according to Foucault, comes from everywhere. Our traditional idea of power is in fact only the "terminal" form power takes. There are no absolutes in Foucault's power; forces are constantly shifting. Marginalized groups may be complicit in their marginalization, if their force is part of the system of power which keeps the group down in its terminal form. Discourse can produce and reinforce power, but it can also undermine and expose it. Silence as well can either work for or against power, depending on the situation (Foucault, 1978).

Paulo Freire's views on the dichotomy between the oppressors and oppressed of the world demonstrate how Foucault's regime of truth and power forces work in practice. According to Freire (1970), the oppressors (be they individuals, religious or social groups, governments, or countries) control the oppressed through power structures

built into the current regime of truth. The ability of the oppressors to continue holding their power over the oppressed depends on "how well people fit the world the oppressors have created, and how little they question it." (Freire, 1970; p. 57) For the oppressed to wield power (as Foucault understands it) of their own, they must first "develop their power to perceive critically the way they exist in the world . . . to see the world not as a static reality, but as a reality in process" (Freire, 1970; p. 64).

Fisher's perception of development discourse follows the ideas of, among others, Arturo Escobar. According to Escobar, the development discourse as it is today has its roots in the decade after the end of the Second World War. Prior to that, in the 1920s and 1930s, a common view of development (held by Mahatma Ghandi and others) was that of "a process rooted in the interpretation of each society's history and cultural tradition" (Escobar, 1997; p. 91). After the Second World War, the development discourse underwent a significant change:

> Development fostered a way of conceiving of social life as a technical problem, as a matter of rational decision and management to be entrusted to that group of people – the development professionals – whose specialized knowledge allegedly qualified them for the task . . . these professionals sought to devise mechanisms and procedures to make societies fit a pre-existing model that embodied the structures and functions of modernity. (Escobar, 1997; p. 91)

The development discourse fell victim to Edward Said's concept of Orientalism, which embodies the developed world's tendency to view all cultures different from its own as a generalized "other", with no variety among themselves (Said, 1978). The possibility that the "pre-existing models" to which developing countries were expected to conform might be inappropriate was rarely considered, and the advice of those who were not "development professionals" was rarely given any credit (Escobar, 1997).

Fisher (1997) draws a distinction between those who view "contemporary development processes as . . . basically positive and inevitable" and those who view "both the dominant development paradigm and the implementation of it fundamentally flawed" (p. 443). The former group tend to think of NGOs as part of a "progressive arm of an irresistible march toward liberal democracy that marks the end of history", while the latter tend to think of them as "a means to resist the imposition of Western values, knowledge, and development regimes" (p. 442).

According to Fisher, those who accept the dominant development discourse view NGOs as "apolitical tools that can be wielded to further a variety of slightly modified development goals" (Fisher, 1997; p. 444). Indeed, the very term "non-governmental organization" implies a distance from both government and politics. However, that connotation is misleading. It perpetuates the concept of NGOs as apolitical, separate from politics. Clearly, NGOs which struggle against the dominant development discourse can be seen as engaged in something of a political battle. However, the

NGOs which work within the dominant discourse are not apolitical – nothing, after all, is truly apolitical. By claiming to be so, they are surreptitiously contributing to maintaining the status quo (Agger, 1998).

In contrast, NGOs which struggle against the dominant discourse are much more openly political. Those who find the development industry problematic view NGOs as "vehicles for challenges to and transformations of relationships of power . . . engaged in a struggle for ideological autonomy from the state, political parties, and the development apparatus" (Fisher, 1997; p. 445). They may engage in activism against projects they see as detrimental to the people they serve, collaborating with other activist groups to lobby political forces for change. For example, Indian NGOs, along with Northern NGOs and environmentalists, have launched an international campaign to protest the Sardar Sarovar project on the Narmada River through political lobbying (Fisher, 1997). NGOs such as these have the potential to initiate, encourage, and support "an insurrection of subjugated knowledges" (Foucault, 1980; p. 81; cited in Fisher, 1997; p. 445).

According to Fisher, NGOs which battle against the dominant development discourse are decreasing in numbers, while the ones which fit into the current models of development are increasing (Fisher, 1997). This can in part be explained by what Fisher points to as the "danger posed to NGOs [by] the resilient ability of the development industry to absorb and transform ideas and institutions" (Fisher, 1997; p. 445). Thus, many NGOs that start off struggling against the dominant paradigms

change into NGOs that fit into those paradigms after enough time in the development industry:

> The heterogeneity of the NGO field makes it easy for political forces to establish or co-opt NGOs. One of the ways this occurs is through funding. (Fisher, 1997; p. 453)

Because the large funders (including the World Bank, the United Nations, foreign governments, and some private foreign donors) usually ascribe to the dominant development discourse, they are more likely to fund NGOs which fit into their pre-existing "models of governance or development" (Fisher, 1997; p. 455). Thus, the bulk of funds available for NGOs tends to go to those which fit these models.

Due in part to the tradition of activism discussed earlier, India's development discourse is more varied than in many other countries. The distrust and suspicion that many Indians have of government projects and international corporations is also evident in the public opinion of NGOs. Many view them as puppets of the government and the development industry, corrupted by foreign funds, and associate them with the Christian missionaries from the time of British rule (see, for example, Rahul, 1995; Swaminadhan, 1997). Some organizations in India, particularly those working against the dominant development discourse in activities such as community empowerment, shun the label "NGO", adopting terms like "social movement" instead, to avoid the stigma associated with NGOs (Fisher, 1997; Kulkarni, 1996).

However, many Indians recognize that although some NGOs work within the dominant development framework as Fisher understands it, many others work in opposition to it. There is a strong discourse within India's intellectual community of alternatives to development, including community empowerment and activism (see, for example, Ghosh, 1997; Ghosh & Dey, 1998; Jain, 1997; Jayal, 1997; Sen, 1996; Sengupta, 1999; Sheth, 1997). NGOs working within this alternative discourse are applauded and encouraged, and are seen as instrumental in helping poor and marginalized communities challenge the status quo (Garain, 1994; Jain, 1997; Sengupta, 1999). Indian NGOs, particularly those working in opposition to the dominant discourse, must be understood within the context of India's long traditions of activism and volunteerism. These traditions make it easier for NGOs to mobilize communities to fight for their rights. A strong discourse around alternatives to traditional development within the Indian intellectual community is also beneficial to Indian NGOs working against the dominant development discourse. So prominent is the discourse in opposition to traditional development ideas that the Times of India, the country's main English language paper, has run articles in the past criticizing the development industry (The Times of India, February 8, 2003).

Due in part to the tradition of activism in the country, there are a significant number of Indian NGOs working against the dominant voices around them. Seva Mandir in Udaipur is one of the oldest examples of India's activist NGOs. Established in the early 1970s, their aim was to empower the poor and provide a forum within which the

community could protest against social injustice and government corruption (Mehta, 1997). Today, they work to promote literacy, women's rights, public health, and community cooperation, as well as encouraging political empowerment and public activism. Shri Bhuvneshwar Mahila Ashram (BMA) in Uttar Pradesh promotes environmental sustainablity, and measures development not by how much money is made off of the land, but the quality of the lives of those living on it (Goldsmith, 1995). Urmul Trust, an agriculture and livestock NGO in Rajasthan, acts as a communications liason between the state government and its community (Mankodi, 1995). It lobbied the government extensively during a 1994 disease outbreak among sheep, alerting them to the problem and pressuring them to take action. Also in Rajasthan, Mazdoor Kisan Shakti Sangathan (MKSS) works to expose and eliminate government corruption and misappropriation of funds (Dey et al., 1995). Rural Communes in Maharashtra trains locals to work in grassroots projects within their communities, as well as working to create political awareness in communities and encouraging local traditions and culture (Garain, 1993). The Centre for Youth and Social Development (CYSD) in Orissa provides training in health, education, forestry, and agriculture, as well as training youth activists and engaging in policy research and advocacy (Uvin et al., 2000). Charka is a national network of Indian NGOs which try to influence major Indian newspapers to inform the public about the plight of the poor and oppressed by publishing stories they write (anon., 1995). Finally, Mencher (1999) lists several NGOs working against the development discourse. SEWA-Ahmedabad grew out of the labour union movement, and still functions in some ways as a labour union, in addition to providing other services such as microcredit. Pradan

serves as a liaison between the Indian government and the rural poor by informing communities about already-existing government programs, forcing the government to carry out these existing programs, and lobbying the government for new programs and policies to help the rural poor (Mencher, 1999).

Within the field of reproductive health, Indian activist NGOs have contributed to a shift in focus from population control to women's sexual health rights (Ramachandran, 1996). Activist NGOs are seen as important in maintaining this focus, as well as ensuring that the reality of reproductive health services reflect the rhetoric (Sen, 1996). This new reproductive health focus has made talking about sexuality and sexual issues much more acceptable in Indian society, which in turn has made HIV prevention projects much easier (Ramachandran, 1996). Within the specific category of HIV/AIDS prevention and care, activism-oriented NGOs are helping sex workers to organize and demand their rights.

There are also a number of examples of Indian NGOs working within the development discourse in the NGO literature. Ghose (1995) mentions the Young Mizo Association (YMA), the Women's Association (MHIP), and the Elders' Association (MUP), all working within the state of Mizoram. Although they are all successful, large-scale NGOs with branches throughout the state and established enough to have a certain level of political influence, they remain service-oriented and largely "represent the interests of the middle and upper classes." (Ghose, 1995; p. 21) Uvin et al. (2000) mention several NGOs which work within the dominant

development framework. The Association of Sarva Seva Farms (ASSEFA) in Tamil Nadu has programs in rural development, small business development, and housing; in addition, they work within government programs in primary health care and education. Myrada has projects in Tamil Nadu, Karnataka, and Andhra Pradesh, focusing on sanitation, economic development, and social infrastructure development; much of their work is in collaboration with state governments. Shri Bhubneshwari Mahila Ashram (SBMA) in Uttar Pradesh implements integrated development projects for PLAN international, as well as carrying out drinking water initiatives for the state government. Finally, URMUL Trust in Rajasthan implements programs in health, education, and microcredit in collaboration with the Rajasthani government (Uvin et al., 2000).

Thus far, we have discussed NGOs within the context of a general development discourse. However, the discourse around AIDS prevention are unique to the development industry, and quite different from the development discourse as discussed up until this point. For the purposes of the current study, the AIDS discourse needs specific comment.

The AIDS Discourse

The earliest AIDS discourse, and one that is still dominant today, is what Gil Seidel (1993) refers to as the medical discourse. The medical discourse focuses on the physical symptoms of AIDS, as well as the method of transmission of the virus. People with HIV/AIDS are viewed as either "core transmitters" or members of "risk

groups". HIV/AIDS is viewed purely from the short-term perspective, and prevention of transmission is advocated through the use of condoms (Seidel, 1993).

More recently, a group of discourses which Seidel refers to as the discourses of rights and empowerment have emerged, which shifts the focus of AIDS prevention from short-term behavioral aspects of transmission to the underlying social, economic, and political contexts of HIV infection. According to Seidel, these discourses were articulated by "dissenting voices seek[ing] to challenge and fracture the dominant medico-moral representations which constitute a source of power" (Seidel, 1993; p. 175).The rights and empowerment discourses include human rights, ethics, and activist discourses. The human rights discourse has its roots in the 1948 UN Universal Declaration of Human Rights. Within HIV/AIDS, this discourse is concerned primarily with the concept of health as a human right, as well as the rights of AIDS patients to respect and dignity. Similarly, the ethics discourse is concerned with beneficence, equity, and social justice (Seidel, 1993). Finally, Seidel describes the activist discourse in AIDS research as combining many elements of the human rights and ethics discourses, but from a grass-roots or political pressure group perspective, with local voices often being more prominent than those of the West (Seidel, 1993). Altman (1999) underscores the importance of "community control" within this discourse (p. 568).

Like the global AIDS discourse, India's particular AIDS discourse can similarly be categorized into two groups of discourses. The first discourse falls into Seidel's

medical discourse, as well as what he refers to as a medico-moral discourse. Like the medical discourse, it focuses on the physical symptoms of AIDS, "risk groups," and the transmission of the virus. Unlike the medical discourse, however, prevention is advocated through abstinence and monogamy instead of condom use (Seidel, 1990; Seidel, 1993). The dominant AIDS discourse of the government of India and NACO generally falls within the medical discourse, as their focus is primarily targeted interventions of high-risk groups and condom promotion (NACO, 1999). As these two groups are arguably the most powerful in India's fight against AIDS, it can be argued that the medical discourse is the most dominant Indian AIDS discourse.

Within India's medico-moral discourse, AIDS is often associated with sexual deviance, sin, shame, disgrace, fear, and karma (blaming victims for the sins of their previous lives). In a recent Times of India article, HIV spread was attributed to "sexual promiscuity" and "drug addiction" (The Times of India, November 24, 2002). These associations have led to stigmatization of people with AIDS, the justification being that these people deserve their serostatus (Bharat, 1999). Equally alarming, the medico-moral aspect of India's AIDS discourse leads to a false belief that monogamy protects sexually active people from AIDS (without taking into account the sexual activity of the partner), a belief that is promoted in Indian AIDS information pamphlets (Seghal & Singh, 1993).

The medico-moral discourse appears to be the dominant discourse of AIDS issues around the sex trade in India. Within the medico-moral discourse, sex workers are

either judged as sexually deviant and sinful (leading to police brutality and public scorn, among other problems) or as the victims of a sexually deviant and sinful client population, in need of rescue. Within this particular aspect of the Indian AIDS discourse, sex worker clients are depicted as drunks and thieves, while the women are depicted as victims and "slaves" (Sinha, 1999). It is this perception of sex workers as victims who need to be rescued that has led to the common goal in India of rehabilitating sex workers out of the industry.

The second AIDS discourse in India falls into Seidel's category of rights and empowerment discourses. Although this discourse appears to be less dominant in India than the medical and medico-moral discourses, it is still apparent. There have been a number of articles in The Times of India criticizing the stigma to which HIV-positive people are subjected (The Times of India, January 24, 2002; April 23, 2002; January 21, 2003). Additionally, there have been articles critical of the government's AIDS policies, including the continued illegality of homosexual activity and police violence against sex workers (The Times of India, July 27, 2002; February 16, 2003). The issue of care for people with AIDS, particularly with regard to availability of anti-retroviral drugs, is extremely prominent within this discourse (Positive Voice, 2001; Positive Dialogue, 2001). Indian pharmaceutical companies consider it "a point of prestige" that they offer anti-retrovirals at a lower price than anywhere else in the world (The Times of India, August 10, 2001). This discourse, in contrast to the medico-moral discourse, is more in line with the general AIDS discourse dominant in the industrialized world.

AIDS NGOs which work in opposition to the dominant discourse typically work by lobbying government to change laws which hinder AIDS prevention, such as anti-gay legislation and prostitution laws. Any discussion of AIDS NGOs struggling against dominant discourse must begin with AIDS Coalition To Unleash Power, or ACT-UP. They are the pioneers of activist AIDS NGOs. Established in New York in 1987, ACT-UP is dedicated to pressuring the American government to implement policy change through civil disobedience (ACT-UP NY). Their civil disobedience, always nonviolent, consists of such activities as infiltrating a Republican cocktail party and unveiling a banner reading "Lesbians for Bush" and buying out three sections of a baseball stadium and chanting anti-AIDS slogans during a baseball game (Gamson, 1989). ACT-UP's civil disobedience activities are usually very public, as when members snuck on to a New York evening news show during the first Gulf War, chanting "Fight AIDS, not Arabs" (Beyrer, 1998). Currently, one of ACT-UP's main initiatives is pressuring the U.S. federal government into funding needle exchange programs.

The American government is not the only target of ACT-UP; pharmaceutical companies that produce antiretroviral drugs are commonly demonstrated against for their prohibitive-cost pricing practices (Gamson, 1989). In protest of the slowness of the FDA in approving new drugs for AIDS treatment, members of ACT-UP hold protests in front of the offices of the FDA and chant the names of alternate drugs to AZT, as well as publicly sell foreign alternative treatments (Gamson, 1989).

ACT-UP has a number of affiliated organizations, such as the Youth Education Life Line, or YELL, founded in 1989, which offers AIDS education, and Housing Works, founded in 1990, which offers housing for AIDS patients, such as children whose parents are deceased (ACT-UP NY). ACT-UP now has chapters in 13 cities, including New York, San Francisco, Los Angeles, and several international chapters, including one in India (ACT-UP NY). Their international counterparts engage in the same nonviolent civil disobedience as the American chapters; at the Second International Conference for Non-Governmental Organizations Working on AIDS in Paris in 1990, ACT-UP France disrupted the closing ceremonies to protest the French government's slow response to the AIDS epidemic (Lucas, 1991). ACT-UP is not prominent in India.

Perhaps the most celebrated Indian AIDS NGO engaged in a struggle against the dominant discourse is the Sonagachi Project in Calcutta (Nag, 2001). Established in 1992, it works with women in a red-light district through peer sex workers, educating women about HIV and promoting condom use. The Durbar Mahila Samanwaya Committee (DMSC) grew out of the Sonagachi Project, and lobbies the Indian government for more humane treatment and working conditions for Calcutta sex workers. They held India's first national conference for sex workers in 1997, and formed the Usha Cooperative Society, a sex workers collective (Nag, 2001).

Many of the principles that groups such as ACT-UP and Sonagachi fought for in the past, when the medical discourse was the dominant voice, are now part of the dominant rights and empowerment discourse. Drug decriminalization, needle exchange programs, the elimination of laws outlawing homosexual activity, and increased rights for homosexuals and sex workers have all been incorporated into the dominant AIDS discourse. Although these battles are no longer as radical as they once were, the NGOs fighting them do not stop as long as there are still dominant voices in opposition to them.

Although ACT-UP and Sonagachi appear to fit into Fisher's category of NGOs struggling against dominant voices in AIDS prevention, it must be kept in mind that this categorization has been based on descriptions of these organizations from the literature. Up until now, there have been no published examples of efforts to apply Fisher's theory to a specific NGO through an ethnographic case study. The current study is an attempt to understand Tabiyat, an Indian AIDS NGO, in the context of the various discourses within which it must work. Having described these discourses in this chapter, the next chapter will describe the methods used to collect data on Tabiyat, followed by a chapter reviewing literature and data on India's response to the HIV epidemic. Following that will be chapters describing Tabiyat's organizational structure, staff, programs, activities, and their relationships with organizations around them, including the government of India, other NGOs, and funders.

Chapter 3: Methods

Design

A case study is an investigation of "a unit of human activity embedded in the real world." (Gillham, 2000) Case studies are designed to understand a "contemporary phenomenon within its real-life context." (Yin, 1989) Typically, the "case" of interest can only be understood within this context; often, it is so embedded in its context that it is difficult to determine where the case begins and ends (Gillham, 2000). Case study methodology uses a range of sources of evidence to understand the complexities of a single case (Stake, 1995). Because of the "real-world" complexities which are usually inherent in the case, no single source of evidence is sufficient. Multiplicity of sources is a defining characteristic of case study research (Gillham, 2000).

NGOs are particularly well-suited to case study methodology. In order to understand an NGO, one must understand its myriad associations with other organizations on multiple levels as well as in various (and varied) fields; it is important to recognize that a fundamental component of NGOs are their "fluid and changing local, regional, national and international processes and connections" (Fisher, 1997). Lisa Markowitz (2001) advocates using "a mix of assorted research techniques" (p. 43) to study NGOs. NGOs' affiliations with other organizations are becoming more complex and wide-ranging, and may be formal or informal (Fisher, 1997). Clearly, it is not possible to separate an NGO from its context. Further, the ever-increasing complexity of NGOs necessitates a methodology which uses several sources of evidence to capture

as much of this complexity as possible. A small but growing literature of case studies of NGOs already exists (Markowitz, 2001; Roberts, 2000; see also Fisher, 1997).

Specifically, this project is a qualitative instrumental case study. An instrumental case study is one in which the research objective is to understand a general phenomenon by closely studying a single case (Stake, 1995). Qualitative case study methods have their origins in ethnography, a methodology derived from cultural anthropology, where it was traditionally used for studying culture in remote villages (Morse & Field, 1995). Ethnography is commonly used in epidemiology to study effects of culture on health and health care, but it is also used to study organizational culture (Morse & Field, 1995), as is the focus of the current study. Ethnographic methods have been shown to be effective in studying organizational culture in South India in the past (Thapan, 1986).

Ethnographic methods were first applied to a study of an organization in the late 1920s, what has come to be known as the "Hawthorne Study", the results of which were published in 1939 (Schwartzman, 1993). The Hawthorne plant was an industrial plant in Chicago. Western Electric, the company who owned the plant, initiated a study of worker satisfaction using a traditional, controlled-experiment style. However, worker productivity seemed unrelated to the experimental variables, and when productivity did rise, it stayed high once the variables were removed. The investigators began to consider the possibility that the experiment, by altering the social structure of the work environment, was in itself responsible for the increase in

productivity. As there appeared to be complexities impossible for the controlled-experiment method to capture, the investigators switched the nature of the study from a controlled experiment to an exploratory attempt to describe and understand the organizational environment in the plant, using interviews and observations. The Hawthorne study was followed by other ethnographic studies of organizations in the 1930s and 1940s, including shoe factories, restaurants, schools, and hospitals (Schwartzman, 1993). Since then, ethnographies have been conducted in virtually every organizational setting imaginable, from department stores to software companies to police stations (Markowitz, 2001; Schwartzman, 1993).

The Hawthorne study demonstrated that quantitative methods cannot be used within an organizational study until you have a good understanding of the organizational culture, and the best way to attain that understanding is with a qualitative case study, which is, in essence, what the Hawthorne Study was. Qualitative methods, unlike quantitative methods, do not have determination of causation as a central goal of research; instead, the central goals of qualitative research are description and understanding (Hahn, 1999), which are the goals of the current study. There are several other reasons that a qualitative case study methodology was the best choice for the current study. Qualitative methods are ideal for exploratory studies, where little is known about the subject of study (Morse & Field, 1995). They are also better suited for complex, multifacted situations, where part of the research goal is to understand informal realities from an "insider's" perspective (Gillham, 2000). Qualitative methods are better suited than quantitative methods to assess subjective variables in

an objective manner (Hahn, 1999). They are also better suited to the observation of variables which cannot be removed from the context in which they occur (Morse & Field, 1995), as well as variables over which the investigator has little or no control (Yin, 1989). Finally, qualitative case study methods are more appropriate when the process leading to a particular result is of as much interest as the result itself (Gillham, 2000).

Generalization in the statistical sense of the word is not possible in case study research. Rather, case studies rely on analytical generalization, in which "the investigator is striving to generalize a particular set of results to some broader theory." (Yin, 1989) In the case of the current study, the theory to which the results will be generalized is the one put forth by Fisher, discussed previously in Chapter 2. The application of the current results to Fisher's theory will be discussed in Chapter 7.

Participants

Tabiyat's main objective is to create AIDS awareness among vulnerable populations and high-risk groups (such as sex workers), but they also have programs designed to improve care and counselling for HIV infected people (Prinselaar, 1996). AIDS awareness is promoted through street plays, pamphlets, and education programs conducted in garment factories, youth hostels, and prisons. Tabiyat also promotes awareness among physicians and other health care workers, as well as families of HIV positive individuals, in order to reduce the stigma associated with HIV infection. Counselling services are available to those who have been rejected by their families,

and individuals with HIV are referred to physicians who are known to be sympathetic and nonjudgmental.

An examination of Tabiyat program was conducted in the past (Prinselaar, 1996), but did not use a multimethodological approach. Moreover, they focused on ground-level reactions to programs. There is a need for a broader understanding of processes and interactions at other levels, as well as an analysis of programs in relation to the AIDS discourse in India.

The specific objectives of the current study are as follows:

1. To understand how the components of Tabiyat, including its ideology, organizational resources, and staff, impact its programs;
2. To understand how the relationships between Tabiyat and other organizations with which it works, including the state government, the business community, religious organizations, funders, other NGOs, and the communities it serves, impact Tabiyat's programs;
3. To understand Tabiyat's programs in terms of the discourse within which they are conducted;
4. To understand how Tabiyat's challenges are affected by its position in terms of the discourse within which it works.

Data Collection

Data collection took place from November 2001 to January 2002. The methods followed those suggested by Stake (1995) and Gillham (2000). Both Drs. Blanchard and O'Neil were on-site for much of the investigation. Before data collection began, a meeting was held between Dr. O'Neil, Dr. Blanchard, Radha (the director of Tabiyat), and myself to discuss and establish the specific methods and parameters of the study. The aspects of Tabiyat to be studied, including identification of people to be interviewed, and events and activities to be observed, were determined in consultation with Radha and other Tabiyat staff. I negotiated with Tabiyat the details of access to employees as well as clients, access to any existing records, requirements for any additional resources to be provided to Tabiyat in return for "hosting" the study, confidentiality of data and sources, arrangement of draft reviewers, and ownership of data. A detailed description of the study was given to all employees of Tabiyat during a meeting, in Kannada, by Radha. Subsequent data collection followed ethnographic case study methods as described by Gillham:

- Document/record review (Weeks 2-6). This included letters, policy statements, minutes from meetings, evaluation reports, regulations, guidelines, as well as archived records. Document and record review provide a formal and historical framework for the case.
- Observation (Weeks 2-8). This consisted of observing the daily work of Tabiyat staff within their offices and recording observations.

- Participant observation (Weeks 3-8). This consisted of attending meetings, workshops, events and activities of Tabiyat and recording observations.
- Interviews (Weeks 5-8). This included conversations, open-ended interviews, and semi-structured interviews with several different key informants both in Tabiyat and in organizations and agencies who work with Tabiyat.

Interviews began with informal conversations with as many people as possible, followed with more structured interviews with a smaller group of key informants. Interviews and conversations were conducted in English; when this was not possible, questions were translated into Kannada with the help of informants who speak English and Kannada. Interactions between NGO staff and others (including clients) were observed, with the permission of everyone involved.

Markowitz (2001) has recommended focusing on specific NGO projects as a way to examine NGO processes and linkages. The current study thus examined each of Tabiyat's various projects in detail, tracing their origins and their development to their current implementation. In using Tabiyat's projects as the focus of the data collection, other issues emerged from the data analysis, the methodology of which will be discussed below.

Data Organization and Analysis

Data was organized as described in Scrimshaw and Hurtado's Rapid Assessment Procedures for Nutrition and Primary Health Care (1987), a procedure manual

designed to maximize the productivity of qualitative studies of short duration. Analysis began with organizational charts to show the interrelations between the various people – including staff, clients, and outsiders who came into contact with them – involved in the daily activities of the NGO. Time-ordered lists were used to understand the daily schedules of NGO workers. These organization techniques were used throughout the data collection period. Interviews were transcribed and analyzed on an ongoing basis during data collection. Also throughout the data collection phase of the project, preliminary clustering of related information was conducted in order to identify patterns in the data early on. Subsequent data collection was in part guided by this ongoing data analysis.

Following the data collection period, field notes were interpreted using methods described in Scrimshaw & Hurtado (1987). Data was primarily classified using taxonomic analysis. In the current study, taxonomic analysis consisted of classifying information into categories based on themes and patterns identified during data collection, as well as subsequent examination of the data. Formal taxonomic analysis was supplemented with direct interpretation of the data.

Validity and Reliability

Validity and Reliability was addressed using triangulation of both methods and sources. Triangulation of sources consists of collecting data from many different sources bearing on one issue, while triangulation of methods entails using multiple methods to study a single issue. Because it enables researchers to approach their

questions from a great number of perspectives, triangulation offers a deeper understanding of complex issues.

Ethical Considerations

All employees were given a description of the case study, and had the option of not participating. Consent forms were subsequently filled out by anyone taking part in the study. Notes from observations and interviews were taken in one notebook, kept in the possession of the investigator at all times. Notes from the notebook were transcribed into a computer file which was password-protected. The password was known only to me and the members of my committee. The original notebook and consent forms were stored in a locked filing cabinet, kept in a locked office.

Publications resulting from this study will not mention Tabiyat by name without the express written permission of Tabiyat and every effort will be made to publish results from this study in collaboration with Tabiyat core staff. Information has not been attributed to individuals in any direct way, and names have been changed in the interest of anonymity. People who came into contact with Tabiyat were told about the study, in the language of their choice. They were given the option not to be observed. Those who chose to be observed did not have any identifying information recorded for the purposes of the case study. Copies of the chapters on Tabiyat were sent to Radha and other senior employees of Tabiyat.

Limitations

The case study methodology has several limitations. Studies of NGOs in particular present unique methodological challenges (Markowitz, 2001). First, there is a risk of investigator bias influencing the findings (Yin, 1989). Case studies deal with subjective phenomena, and although qualitative methodology is designed to measure subjective variables in an objective manner, the very fact that the variables are subjective leaves case studies open to subjective interpretation that is biased by the investigator's personal beliefs and ideology, as well as what s/he hopes to find through the research (Stake, 1995). This challenge is particularly relevant to studies of NGOs, where the researchers are at risk of over-identifying with "their" NGO, and unconsciously ignoring negative information (Markowitz, 2001). Second, as already mentioned, statistical generalization is not normally possible in a case study. Although analytical generalization is desirable, even this is difficult, as each case will have aspects that are unique to that particular case (Gillham, 2000). Third, case studies are a potentially large investment of time and resources (Yin, 1989). This time investment is an issue not only during the data collection phase, but at all points in the research process, including the analysis phase, when it may take a considerable amount of time for findings to become apparent (Stake, 1995). Finally, there are countless ethical considerations, including privacy of all actors involved in the case (Stake, 1995). Particular attention to ethical issues is extremely important in case study research. Case studies of NGOs are especially sensitive to ethical issues, particularly when examining aspects such as funding sources and staff salaries

(Markowitz, 2001). The steps taken to address the ethical issues of the present study have already been discussed.

Along with these limitations found in the majority of case studies, there were many limitations particular to the current study. First, in an effort to compensate for the high time and resource cost of case study research, the time period over which this study was conducted was shorter than ideal. The period of time was sufficient for the purposes of the study, but more variables could have been examined, and more detailed information could have been gathered, if the data collection period had been six months, instead of two months.

Language ability was a great barrier to communication. Most of Tabiyat's employees spoke English as a second or third language. Although many conversations were conducted in English, many others, including during meetings, were conducted in Kannada. Even when employees were speaking English to one another, often their accents were so thick that not all of the words could be caught. When they spoke to me, they would speak clearly and slowly, but overheard conversations were often difficult to follow unobtrusively. Employees would often translate their Kannada conversations to me, but I had no way to determine the accuracy of their translations, and it would be easy for them to leave out anything they did not want me to know about.

Another limitation of the current study was Tabiyat's need to protect their clients. No interviews were permitted with any of Tabiyat's clients, particularly HIV-positive individuals or sex workers. Employees would sometimes provide vague, general information on clients during site visits, but detailed information was kept confidential. Thus, data concerning the clients of Tabiyat is not as rich and detailed as would be ideal. I was not allowed to sit in on many of the meetings at Tabiyat because the matters discussed were of a sensitive nature, and the staff wished to keep the information from these meetings confidential. I was permitted to attend general staff meetings, but meetings among the core staff members, as well as those among field staff, were not open to me.

A fourth limitation was the freedom to take notes in my field notebook. I was not permitted to openly write in my notebook during field visits. A good rapport with the community members with which they work is crucial to Tabiyat, particularly when they are trying to reach sex workers, who are understandably wary of groups who want to interfere with them. As a result, I could not write down information as it happened; rather, I used mnemonic devices to remember as much as possible, surreptitiously writing single words in my notebook to remind me of events later. When I returned home after field visits, I would immediately write up my notes on my laptop, using the mnemonic devices and the single words in my notebook to recall as much detail as possible. Although I was able to gather quite a bit of data using this method, much detail was inevitably lost.

Due to the need to travel extensively to carry out my fieldwork, I was limited as to how much equipment I could bring with me. I decided that a laptop computer was absolutely essential, but I was unable to also bring recording equipment. Thus, no interviews were tape-recorded. Instead, I again used single words written in my notebook to remind me of things the interviewees talked about, similar to the single word technique I used during field visits. Again, much of the richness and detail of the data from the interviews was lost without recording equipment.

Finally, receiving feedback from Radha and other Tabiyat staff became extremely difficult once I was no longer in India. Communication at that point was limited to email, which proved to be a complicated and inefficient way of corresponding with staff at Tabiyat. These emails were supplemented by in-person meetings between Radha and members of my committee still in India. Radha expressed during one of these meetings her dissatisfaction with Chapter 5, but did not give any specific feedback on the nature of the chapter's problems. Through collaboration with my committee, we speculated on where Radha's concerns may have been, and the chapter was revised. However, without specific feedback from Radha, it is impossible to know if her concerns were addressed. Thus, the material in Chapter 5 should be interpreted with some caution, as concerns over its accuracy remain.

Part of the first data collection method used, document review, included reading Indian and international literature on the AIDS situation in India and the

government's response to the epidemic. The following chapter is a summary of that data.

Chapter 4: India's Response to HIV/AIDS

Background

The first Indian to test positive to the HIV virus, a Chennai sex worker, was discovered in 1986 (Asthana, 1998; Jain, 2002). Since then, the disease has been progressing at an alarming rate. Estimated HIV prevalence among selected samples of Mumbai sex workers increased from 10 per 1,000 in 1986 to 350 per 1,000 in 1992 (Nag, 1994). Among samples of blood donors in Mumbai, estimated prevalence rose from 10.5 per 1,000 in 1991 to 22.9 per 1,000 one year later (Nag, 1994). Although Nag (1994) cautions that the validity of these numbers is questionable, it appears that there were dramatic increases in Mumbai's HIV prevalence in the first ten years of the epidemic. Between 1994 and 1997, the estimated HIV prevalence among adults in India more than doubled (Maniar, 2000). By 1996, all states in India, with the exception of Arunachal Pradesh, had officially reported HIV cases (Balk & Lahiri, 1997).

The government of India's response to the epidemic was immediate; in fact, the Indian Council of Medical Research initiated an AIDS surveillance program in 1985, a year before AIDS had been discovered in India (Balk & Lahiri, 1997). However, the government did not immediately address the issues of HIV prevention and care of AIDS patients. In the mid- to late-1980s, AIDS was still perceived as a Western disease among most Indians (Arnold, 1997).

Some of India's recent experiences with epidemics, such as syphilis, cholera, and smallpox, had occurred during the British Raj (Arnold, 1993). There is evidence that British responses to these diseases often focused on perceived "backwardness" of Indians and their medical traditions. "Modern" medical treatments would replace traditional, Hinduism-based treatments with no explanation to the local population, reportedly leading to suspicion, hostility, and resistance (Arnold, 1993). After British rule ended, Indian medicine underwent significant changes. The Bhore committee of 1946 set the standard for 20th century Indian medicine. According to the committee's report, health care was the responsibility of the state, and should be available to all Indian citizens, regardless of their ability to pay (Rao, 1998). The report called for an increase in primary health care services, as well as services for maternal and infant health (Arnold, 1996). It also called for an increase in health education, to increase the number of health care workers available (Arnold, 1996). Preventive health was emphasized through a call for compulsory innoculation against both smallpox and cholera, as well as the establishment of a Malaria Control Programme (Rao, 1998).

The Malaria Control Programme was initiated in 1953 through funding from WHO, USAID, and the Rockefeller Foundation, and relied on technical strategies such as DDT spraying to control the disease (Kamat, 2000). The programme was extremely successful, and was renamed the National Malaria Eradication Programme (NMEP) five years later, with an eradication goal of seven to nine years (Talib, 1996). However, the 1970s saw a dramatic increase in malaria incidence and mortality, due in part to DDT and chloroquine resistance, as well as dam projects, population

migration, and other peripheral factors (Kamat, 2000; Talib, 1996). The government modified its malaria program in 1977, focusing not on eradication, but the prevention of mortality and a decrease in incidence (Rao, 1998).

Smallpox eradication was a more successful Indian public health campaign than malaria control. The National Smallpox Eradication Programme (NSEP) was established in 1962; its main focus in the 1960s was vaccination, along with surveillance and outbreak containment (Singh et al., 1977). The NSEP succeeded in 1975, but only after important epidemiological breakthroughs (Rao, 1998). Indeed, both the NMEP and the NSEP depended primarily on technical 'magic bullet' style solutions to the diseases (Rao, 1998).

Nineteenth and 20th century experiences with epidemics each provided challenges to the government of India's response to AIDS. According to David Arnold (1997), with this new "Western" disease, the government was not interested in once again allowing the West to dictate its responses and priorities, as it had with cholera and syphillis in the 19th century (Arnold, 1997). However, it could not follow the 20th century models of smallpox and malaria, as there was no technological 'magic bullet' to rely on in the case of HIV/AIDS. Despite pressure from Western donors, India's AIDS policy in the 1980s was restricted to surveillance measures (Ramasubban, 1998).

However, those surveillance measures rapidly demonstrated that India was not, in fact, immune to the HIV epidemic, as had been assumed (Nag, 1994). In 1990, the

government of India and the World Health Organization initiated a short-term AIDS plan, with the Ministry of Health and Family Welfare taking over the responsibility of surveillance (Arnold, 1997; Balk & Lahiri, 1997). The plan covered only four states – Manipur, Maharashtra, Tamil Nadu, and West Bengal – plus Delhi (Balk & Lahiri, 1997). Two years later, the National AIDS Control Organization (NACO) was established (Balk & Lahiri, 1997; Jain, 2002; Ramasubban, 1998). The first of NACO's five-year plans to combat AIDS was initiated in 1992; its main focus was surveillance, in addition to limited targeted interventions in a few states (Jain, 2002; Ramasubban, 1998). NACO's AIDS prevention approach was primarily from a medical perspective during the first five-year plan (Jain, 2002).

HIV prevention in India is unique in that the government is heavily involved in the programs; thus much of the Western influence apparent in other developing countries is overridden by the beliefs and ideas of the Indian government. As a result, the politics of AIDS in India are situated more locally than in other countries, and the discourse is often more influenced by Indian values and knowledge than by Western values and knowledge. There is a great deal of contestation of Western values at the government level, in the form of resistance against funding requirements. Currently, there are two models of funding for HIV prevention and care in India: first, governments of Western countries giving funding to the government of India, and second, independent funding bodies giving money directly to NGOs, thus bypassing the government level.

Sexual Behaviour in India

In the 1980s, there was a widespread belief that the morality of Indian culture, with its conventions of early marriage and monogamy, as well as its taboos against premarital sex and homosexuality, would prevent AIDS from taking hold in India (Asthana, 1998; Ramasubban, 1998; Sinha, 1999). It was believed that infection would be restricted to high-risk groups, such as sex workers (Arnold, 1997; Jain, 2002). AIDS was associated with immorality, promiscuity, and sexual deviancy (Sinha, 1999). There was a strong tendency to blame HIV infection, and the risk thereof, on the victims' immorality (Jain, 2002; Ramasubban, 1998).

In reality, premarital and extramarital sex appear to be growing in prevalence in India. Attitudes toward extramarital sex appear to have undergone a certain amount of liberalization in the 1960s, as demonstrated by a survey of educated women in Delhi between 1958 and 1968 (Nag, 1994). The number of women who believed that extramarital sex among wives was justified in some circumstances rose from 11% to 31% in that time period. Additionally, the number of women who would expect their husbands to forgive them if they engaged in extramarital sex rose from 20% to 55% (Nag, 1994). An extensive study in three Maharashtra towns reported a range of extramarital sexual activity, from 7% to 11% (Savara & Sridhar, 1994). Surveys conducted in upmarket magazines in the early 1990s found that 56% of men and 44% of women had engaged in extramarital sex (Nag, 1994).

Although it does not appear to be as prevalent as extramarital sex, premarital sex is also evident to a certain extent in India. There have been estimates that approximately 10% of adolescent girls and 20-30% of adolescent boys engage in premarital sex (Jejeebhoy, 1996). Among the respondents of the above-mentioned magazine surveys, 30% of men and 23% of women reported having engaged in premarital sex (Nag, 1994). In the Maharashtra study, premarital sexual experience ranged from 14% among loom workers to 26% among white-collar workers and migrant workers (Savara & Sridhar, 1994). The West Bengal truck drivers survey found that only 2% had been virgins on their wedding night (Rao et al., 1994).

There is evidence that sexual behaviour in India is quite varied, not only among different regions, but also among different socioeconomic strata (Hawkes & Santhya, 2002). It should be kept in mind that the magazine surveys were targeted toward educated, middle-to-upper class, urban Indians, and therefore are not representative of India as a whole (Jejeebhoy, 1996; Nag, 1994). Magazine surveys also run a risk of selection bias (Jejeebhoy, 1996). However, the Maharashtra study and the West Bengal truck drivers survey suggest that premarital and extramarital sex are prevalent among other segments of Indian society as well. Although the numbers reported from the magazine surveys should be interpreted with some caution, what is clear is that premarital and extramarital sex in India are more common than had previously been assumed.

The current HIV prevalence in India is difficult to know. Most estimates are based on HIV prevalence at hospitals, antenatal clinics, and STD clinics. However, these estimates miss significant portions of Indian society who do not visit these institutions, such as poor women, who are unlikely to seek antenatal care (Ramasubban, 1998). STD clinics are avoided by many Indians for a number of reasons; this issue will be explored in more detail later in the chapter. Hospital data is also unreliable; the hospitals used for official government surveillance are accessed by 10-20% of the Indian population (Ramasubban, 1998).

At the end of 1997, UNAIDS estimated that 4.1 million people in India were infected with HIV (Chatterjee, 1999). A more recent estimate put the number of HIV-infected people at 3.7 million (Hawkes & Santhya, 2002). Other estimates of HIV prevalence in India are as high as 11.5 million, or 1.5% of the population (Maniar, 2000). The official estimated number of HIV-positive people in India is approximately 4 million (Chatterjee, 2003). Although overall prevalence appears to be still relatively low, due to its population size, India has more HIV infected persons than almost any other country (Maniar, 2000). HIV infection in India is concentrated in large urban centers where there are large numbers of female sex workers and male migrant workers. Recent surveillance in public hospitals in Mumbai found that 2-4% of pregnant women were HIV positive (Maniar, 2000). It has been estimated that prevalence among women attending antenatal clinics is over 1% in the states of Andhra Pradesh, Tamil Nadu, Maharashtra, Manipur, Mizoram, Nagaland, and Karnataka (Chatterjee, 2003).

The Sex Trade

Although India's sex trade was officially ignored until fairly recently, unofficially, it has been tacitly accepted for centuries. Courtesans were an important part of Indian life among the upper classes in the first few centuries AD, and devadasi is an institutionalized and culturally acceptable form of prostitution with a long and rich history (Nag, 1994; Sinha, 1999). The Suppression of Immoral Traffic in Women and Girls Act (SITA), instituted in 1956, assumed that prostitution was a "necessary evil" in light of men's "uncontrollable" sexuality (Nag, 1994; p. 521). There exists in India a double standard which requires women to be virgins when they marry and remain faithful to their husbands, but accepts that men need to have other sexual outlets than just their wives (Asthana, 1998; Sinha, 1999). Indian men are perceived as constantly preoccupied with sex, and it has been suggested that they commonly engage in extramarital sex when their wives are not available to them, such as during pregnancy and post-partum period, on religious days, or when they are working away from home (Asthana, 1998; Ramasubban, 1995).

This double standard has resulted in a significant demand for sex workers in India. It is estimated that there are currently one million sex workers in India, of whom 30% are underage (Sinha, 1999). Along with patriarchy, other determinants contribute to the sex trade in India. Rapid urbanization associated with economic development leads to an increase in migrant labor, as members (frequently the male heads) of poor

rural households migrate to urban centers for wage work (Savara, 1992; Ulin, 1992). This separation of families for long periods of time creates a demand for commercial sex work within urban centers. Furthermore, long-distance truck drivers, also separated from their families for extended periods, seek out commercial sex workers not only in urban centers, but also in rural villages along transportation routes (Heise & Elias, 1995). The West Bengal study, mentioned earlier, estimated that truck drivers who pay for sex visit 50 to 100 different sex workers in a given year (Rao et al., 1994).

Women who enter the commercial sex trade usually live in conditions of extreme poverty and marginalization (Asthana, 1998; Sedyaningsih-Mamahit & Gortmaker, 1999). Research on commercial sex workers in Mumbai has found that 90% had no education whatsoever, and less than 1% had ever voted in elections (Bhave et al., 1995). Gender inequality in access to education leads to a great number of unskilled female labour; lack of economic options for unskilled females leads many young rural women to migrate to urban centers to become commercial sex workers (Asthana, 1998; Evans & Lambert, 1997). The sex trade is more attractive to many women than their other economic options, such as factory work, as the money is better and the hours are shorter (Sedyaningsih-Mamahit & Gortmaker, 1999; Wawer et al., 1996). In addition to being impoverished, most commercial sex workers are highly stigmatized and socially isolated (Bhave et al., 1995; Sedyaningsih-Mamahit & Gortmaker, 1999).

Up until the emergence of HIV in India, the government policy on the sex trade was largely to pretend that it did not exist (Evans & Lambert, 1997). Sex workers were not the focus of NACO targeted AIDS interventions until 1993 (Asthana, 1998). Interventions specifically targeted at sex workers in India began in Tamil Nadu (Hawkes & Santhya, 2002). There is evidence that within Chennai, the sex industry is extremely diverse, with little sense of community among the women (Asthana & Oostvogels, 1996). Women's ability to negotiate condom use is connected with their economic position (Schoepf, 1998). It follows that commercial sex workers will not be in a favourable position to negotiate condom use. Empowerment strategies have been shown to be effective among sex workers in Calcutta, leading to the establishment of a sex workers' rights organization (Evans & Lambert, 1997).

Commercial sex work in India is fluid; it is estimated that less than one quarter of Indian sex workers are street-based (Asthana, 1998). Sheena Asthana (1998) suggests that the majority of sex workers in India sell sex surreptitiously, without the knowledge of friends and neighbours, and live in family households. These "family girls" tend not to consider themselves sex workers, and they make efforts to distance themselves from street- or brothel-based workers, who are more open about what they do (Asthana, 1998). An additional category of sex worker is Hijra, a third sex in India of castrated males who dress as women (Asthana & Oostvogels, 2001; Nag, 1994). Traditionally, hijras made a living by performing at special occasions such as weddings and childbirth, but are increasingly relying on sex work (Nag, 1994). There

are also a number of male sex workers in India; one study estimates that approximately 7,000 men in Chennai regularly visit male sex workers (Jain, 2002).

Men who visit hijras or male sex workers do not necessarily consider themselves homosexual or bisexual; most are either married with children or plan on marrying and having a family in the future (Asthana & Oostvogels, 2001). There is a widespread belief that AIDS is a disease of female sex workers and that it is not present in hijra and male sex worker communities; thus condom use is low. This belief, coupled with the fluidity of homosexual behaviour in India, is likely to accelerate spread of HIV into these populations and through them to the general population (Asthana & Oostvogels, 2001).

AIDS Awareness and Condom Use

Clearly, the variety and fluidity of sexual behaviour in India presents many opportunities for HIV transmission. Unfortunately, the level of AIDS knowledge of many Indians remains low. The previously-mentioned study of three towns in Maharashtra found that among married males, only 24% of white-collar workers and 15% of migrant workers believed that sex can cause sickness (Savara & Sridhar, 1994). The West Bengal truck drivers study found that 39% had never heard of AIDS (Rao et al., 1994). A study of women in rural Maharashtra found that fewer than 10% of illiterate women were aware that AIDS existed (Hirve & Sathe, 1999). Although 91% of college-educated women had heard of AIDS, fewer than 50% of them knew

that using condoms could prevent it; fewer than 20% of the illiterate women who had heard of AIDS knew to use condoms to protect themselves (Hirve & Sathe, 1999).

Encouragingly, there is evidence that AIDS awareness and knowledge is increasing in India. A 2001 India-wide survey found that 76% of those surveyed had heard of HIV/AIDS, with a similar number knowing about its transmission through sexual contact (NACO). Additionally, 73% knew that HIV could be transmitted through blood. Unfortunately, less than half (47%) of those surveyed knew that consistent condom use and monogamy with a faithful uninfected partner were the two main ways to prevent HIV infection (NACO). Awareness and knowledge levels remain low among women in rural areas; for example, only 6% of women in rural areas of the South Indian state where the current study was conducted had correct information about HIV (NACO).

There is evidence that Indians often have incorrect information about HIV/AIDS. Some of the incorrect beliefs about HIV include prevention through washing one's genitals with soap and water, protection from HIV through prayer to Hindu deities, and intercourse with a virgin to cure AIDS (Sinha, 1999). In one red light area of Calcutta, there was a widespread misconception that HIV could not be transmitted by oral sex; another common misconception was that having regular blood tests prevented HIV transmission (Bhattacharya & Senapati, 1994).

Reported condom use among Indians is unfortunately low. The above-mentioned study in Maharashtra towns found that less than half of blue-collar workers and migrant workers reported having ever used a condom (Savara & Sridhar, 1994). Another study in rural Maharashtra found that only 18% of married men and 4% of sexually active unmarried men reported any condom use at all (Mutatkar & Apte, 1999). The previously mentioned study of sex workers in Calcutta found that condoms were used for only 40% of the encounters (Bhattacharya & Senapati, 1994). The West Bengal study found that the majority of truck drivers never used condoms, and the ones who used them did so only occasionally (Rao et al., 1994). In the last five years, there has been evidence of an increase in condom use among truck drivers in India, as well as sex workers; however, condom use has decreased among male students (Hawkes & Santhya, 2002). The above-mentioned India wide 2001 survey found that 34% of males and 27% of females reported using condoms at every sexual encounter with a non-regular partner (NACO).

Stigma

In 1994, Tamil Nadu became the first Indian state to establish a state-based AIDS prevention organization, the Tamil Nadu Sate AIDS Control Society (TNSACS), with the help of NACO and foreign donors (Ramasubban, 1998). One of its first projects was a large media-driven awareness campaign. This campaign was controversial for what was perceived as a fear-based focus, and met with considerable public protest (Ramasubban, 1998). It has been suggested that constant exposure to fear-based HIV

information can lead to helplessness and fatalism among those already infected, as well as their further stigmatization, already a problem in India (Jain, 2002; Rawat, 1999). Indeed, Tamil Nadu's media campaign was followed by an increase in reports of violence against HIV-positive people in the state, quite likely a result of the campaign being too fear- and morality-driven (Ramasubban, 1998).

In India, there appears to be extreme social stigma attached to HIV positive individuals. Many hospitals will refuse admission to individuals known to be HIV-positive (Inderjit, 1992; Jain, 2002). HIV-positive patients have been turned away at medical clinics and dentists' offices as well, and they risk losing their jobs and their homes if their status is discovered (Maniar, 2000; Jain, 2002). Among those hospitals willing to admit HIV-positive patients, many staff wear masks and gloves whenever they are around them (Pandya, 1997). The bodies of deceased AIDS patients have been known to be wrapped in plastic bags, a practice that is not only insulting, but is beginning to be understood by the public to mean that the victim had AIDS, leading to further discrimination of the family (Rawat, 1999).

Part of the reason that AIDS is so stigmatizing in India is its association with promiscuity and sexual deviancy (Sinha, 1999). This stigma is not unique to AIDS; other sexually transmitted diseases (STDs) carry the same association. It has been suggested that few physicians in India specialize in STD treatment because of its low status as a specialization (Ramasubban, 1995). Further, there is evidence that people who visit STD clinics are associated with promiscuity and possible HIV infection,

leading to their stigmatization (Ramasubban, 1995). As a result, people suffering from sexual health problems are reluctant to visit STD clinics (Hawkes & Santhya, 2002). This is particularly true of women, who under India's patriarchal double standard, are not supposed to have problems such as STDs (Ramasubban, 1995). Both male and female STD patients are reluctant to discuss their sexual health problems with their spouses, and they are rarely advised by their clinicians to bring their spouses in to be tested (Hawkes & Santhya, 2002).

Fear of stigmatization is not the only deterrent to visiting STD clinics. Women tend to neglect their health needs in favour of taking care of other members of the family; they are also afraid of lost income by spending most of a day at the clinic (Thapan, 1997). The deterrents to visiting STD clinics are particularly complex among sex worker communities. Some may have no choice; in brothel-based sex work, the women are often forbidden to leave the brothel unattended (Bhave at al., 1995). They are also afraid of lost wages, not only by spending time at the clinic, but being told to abstain from sexual activity for a period of time (Evans & Lambert, 1997; Ramasubban, 1995). Sex workers tend to have low levels of health awareness, and view STD infection as an inevitable occupational hazard (Ramasubban, 1995). Financial security and the health of their children are both more important to sex workers than their own well being (Evans & Lambert, 1997).

People with HIV also experience stigma in their own neighbourhoods. They frequently experience harassment, and their family may suffer as well (Jain, 2002;

Rawat, 1999). As a result, many families keep members' HIV status a secret from their community (Sinha, 1999). However, this cuts the family off from potential wider support networks, at a time when their sick member is likely to be the main breadwinner, and care is left to members no longer in their prime (Bharat, 1995). In India, family ties are strong, and family is traditionally a primary source of support for people in need, especially during illness (Bharat & Aggleton, 1999). In spite of this, the AIDS stigma is so strong that some families reject their own HIV positive members. A recent study of household responses to AIDS in Mumbai found that infected individuals, particularly women, were rarely treated compassionately by their families (Bharat & Aggleton, 1999). Daughters and widows were often abandoned completely by their families. Even when HIV positive people lived with their families, the environment was often unsupportive, or even physically violent (Bharat & Aggleton, 1999).

Clearly, HIV prevention and care are important issues in India, not only for NACO and the various state-run AIDS control cells, but for the government as a whole. The fear and the morality focus of Tamil Nadu's awareness campaign, and the resulting increase in violence against HIV-positive people, has already been discussed. There are other prevention activities that can also inadvertently increase the AIDS stigma. Education efforts which focus exclusively on short-term intervention and stress individual responsibility may inadvertently imply that HIV positive persons "asked for" their fate, or that the AIDS epidemic should be "blamed" on "risk groups" such as commercial sex workers (De Bruyn, 1992). Furthermore, ineffective interventions

aimed at sex workers have the potential to worsen these women's situations. If the intervention makes them feel that they have little or no control over their lives, it may lead to anxiety and a sense of fatalism (Asthana & Oostvogels, 1996). Targeted interventions aimed at sex workers may increase their stigmatization, as well as discrimination against them (Asthana, 1998). Similarly, interventions which serve to further stigmatize sex workers by focusing on their role as "risk groups" and "vectors" may lead to denial by women who fear being further stigmatized (Schoepf, 1998). Sensitivity to, and understanding of, these women's situations are crucial if interventions are to help, rather than harm, the women at whom they are targeted. An effective and culturally sensitive intervention program should address both the short-term behavioral aspects and the long-term social and economic aspects of HIV transmission.

The Role of the Government

Although the earlier denial of India's HIV epidemic is essentially gone, and although it is becoming more and more apparent that sexual behaviour does not conform to traditional Indian stereotypes, there is still a reluctance among government officials to talk about sex, or to be seen as condoning immoral sexual practices by promoting condom use (Ramasubban, 1998). It has been suggested that progressive ideas within NACO tend to be hindered by the conservative majority, who do not want sexual discussions (Asthana, 1998). There are signs of this (as well as other aspects of Indian policy on HIV) changing, due to pressure from both Western donors and local NGOs

(Ramasubban, 1998). NACO's second phase, from 1999 to 2004, focuses on targeted interventions, but there is a recognition that more widespread interventions in addition to targeted programs are needed, as well as a recognition that AIDS is more than just a health issue (Jain, 2002; Rajan, 1995).

However, there are still problems with NACO's approach to HIV prevention. Program success is measured by the number of condoms distributed or number of STD cases treated, leading many NACO-funded organizations to rush their projects in order to show immediate results (Jain, 2002). There also appear to be organizational problems within NACO. Its substantial budget comes from the World Bank, along with funding from various international government bodies, including DFID, USAID, and CIDA (Jain, 2002). However, from 1992 to 1995, NACO only used 50% of its total allocated funding (Hawkes & Santhya, 2002). At the same time that NACO's budget is increasing, the government of India is cutting spending on health care, which some fear may lead to an increase in AIDS transmission through the re-use of disposable syringes and sloppy sterilization practices, particularly at small, non-urban hospitals (Qadeer, 1995). Health does not appear to be a high priority in India; in fact, India's annual health spending is approximately US$1 per capita (Hawkes & Santhya, 2002; Jain, 2002). There is evidence that India's elementary education system is as poor as its health care system, making it next to impossible to coordinate AIDS prevention and care efforts through them (Ramasubban, 1998). In some big cities, the poorest communities, particularly vulnerable to HIV, are "unrecognized" by the

government, and as such are not entitled to any services, facilities, or even legal rights (Sapir, 1996).

As early as 1995, NACO recognized AIDS as more than just a health issue, and attempted to involve governmental departments other than the Ministry of Health and Family Welfare in its prevention (Rajan, 1995). However, India's governmental departments are highly compartmentalized, a structure which discourages broad, integrated approaches to HIV prevention (Das Gupta & Chen, 1996). In some cases, governmental activities actually undermine NACO's programs, such as police harassment of sex workers (Asthana & Oostvogels, 1996). Better communication among India's governmental departments is crucial for HIV prevention programs to be optimal.

Now that we have a better understanding of the context of AIDS prevention in India, the next two chapters will focus on how Tabiyat conduct their AIDS prevention and care activities within that context.

Chapter 5

Results: Tabiyat's History and Organizational Structure

The following two chapters present the results from data collected on Tabiyat. This chapter traces Tabiyat's history and organizational structure, including its core beliefs and underlying philosophies, parent organization, Advisory Group, staff, and funders. The following chapter will discuss Tabiyat's programs and activities. As mentioned in Chapter 3, Radha was dissatisfied with an earlier version of this chapter. Thus, the material should be read with some caution.

History

This section provides a brief history of Tabiyat. It is based primarily on an interview with the director of Tabiyat, although information is also included from interviews with other Tabiyat staff, as well as an interview with the director of Sehyogi.

Sehyogi is a development non-profit organization which has been working in four districts of South India since 1986. Tabiyat (the word means "self-protection") was founded in 1993 to respond to the HIV/AIDS epidemic. At the time, Radha, the director of Tabiyat, was working as a research assistant at a local university which does HIV testing. She noticed that there were increasing numbers of people testing positive for HIV, but no services for them once they had that knowledge. The only HIV related - activity in the area at the time were some education talks at schools and industries. A mutual friend introduced her to the director of Sehyogi, who was also

concerned about HIV transmission in rural areas through blood transmission during childbirth. The two of them proceded to sell the idea of an HIV/AIDS initiative to the other Sehyogi sector heads, because in 1993, it was not seen as a major issue in the area. Only Sehyogi's director and Radha recognized it for the major probem it was.

At the time, there was no clear data on HIV/AIDS for the region, and there was also considerable public apprehension and misunderstanding. Originally, there were no plans for projects in urban areas, until, after some investigation, Radha and the director of Sehyogi realized that the need for interventions was greater in urban than rural areas. Thus, Tabiyat began with programs only in the urban center in which it is based. As Tabiyat has grown, their programs have spread; in 1994, work was started in a rural district, focusing on sex workers and truck drivers.

In Tabiyat's beginnings, Radha wanted to focus mostly on care and counselling for HIV-positive people. Counselling was started in three government STD clinics and one private lab. The private lab had difficulty keeping clients' confidentiality, though, so they stopped working with them almost right away. A colleague suggested to Radha that she start working with sex workers as well, but Radha was hesitant, as she had little previous experience in this area. After further discussion and receipt of a donation of a large supply of condoms, a sex worker program was initiated. This is how Tabiyat started: two core programs, counselling, and sex worker protection. They remain important programs in Tabiyat today.

When the Sex Worker Protection Program started, staff had no knowledge of the sex trade, and no contacts to gain access to the sex workers. The program literally started with three crates of condoms. Radha and two other Tabiyat staff started by walking the streets, trying to find sex workers and talk to them about HIV. In the beginning, the sex workers were reluctant to trust the staff; Tabiyat staff were the first people who had ever approached these sex workers without wanting to use them, abuse them, or judge them, whose only agenda was to help them. It took some time and convincing to gain their trust. Tabiyat started recruiting sex workers to work with them as peers, helping to operate their sex worker program. Just as Tabiyat staff had to learn about and get used to street work, the peers in the early days had to learn about and get used to office work. They would often skip meetings or leave early because they were bored or wanted to get back to the streets. They had to learn professionalism, as well as how to take professional criticism. They also had to learn to put people's welfare ahead of "trying to get my friends jobs as peers".

In the early days, Tabiyat's philosophy on education was to work with unorganized groups. They felt that groups such as schools and unionized workers had enough supports and groups working for them. Tabiyat educated street youth, hotel boys, people who had no access to television, radio, or newspaper, people who were exploited and had no support to fall back on. A lot of work in the early days was done in garment factories, where female workers were often sexually exploited by their employers. These women, who lived in slum areas, started asking staff to come to

their neighbourhoods to do education sessions, which is how Tabiyat began working in slum communities.

After a brief absence for personal reasons Radha returned to the NGO and began to develop new services. A women's reproductive health program was started because the sex workers were sometimes uncomfortable accessing government STD clinics. Parvah, a 24-hour respite home for HIV-positive patients, was begun because sex workers and other HIV-positive people were dying of AIDS on the streets. Parvah was initially somewhat controversial; staff did not have any experience with residential care, they were unwilling to work at a 24-hour facility and be away from their families, and they feared the workload would be too high. However, there were people dying, and no place for them to go, so in 1997 Parvah was opened. A year after that, Tabiyat's physicians began to conduct clinical work with HIV and STD patients on Thursdays at a local clinic (previously the work had been carried out in the Tabiyat offices). Soon after that, a Home-Based Care program started, growing out of needs seen in Parvah.

Around that time, Tabiyat started getting pressure from Ayojan, a network of South Indian NGOs, to do more training and capacity-building with other NGOs. They were a little reluctant, feeling that their staff was already stretched with work, and they felt strongly about having field staff do the training so that they were well experienced in what they were teaching. However, they responded to the request from Ayojan and started focusing more on training and capacity-building. The training is challenging,

however; the NGOs they networked with were initially non-HIV NGOs. Thus, the empowerment techniques that were appropriate for their sectors were not necessarily appropriate for HIV work. Empowering women with micro-credit, for example, is easy for husbands to accept, because they benefit as well. Empowering women to use condoms with their husbands is a different matter entirely. Questions were asked such as how far an empowerment approach could be taken without the men becoming violent? Another problem was that some NGO leaders saw talking about sex as "unprofessional" and wanted to avoid it at all costs. Some NGOs, even after receiving training from Tabiyat, preferred to focus more on needle and blood transmission modes of HIV, and avoided discussions of sexual transmissions.

As of 2002, Tabiyat was moving more into research. A new grant enabled them to participate in a women's reproductive health research project, and workshops on building research skills were being held for staff. Additionally, Tabiyat was expanding their advocacy role. Efforts were being made to establish a sex workers collective in town, and Tabiyat was participating in a national initiative to prevent drug costs from rising in the future.

Missions and Core Beliefs

Since its inception, Tabiyat's missions have been the same:

1. Prevent, control, and contain the spread of HIV infection among a defined population
2. Provide counselling, care and support to those living with HIV and their families

Tabiyat has a number of core beliefs for each of its programs: prevention, counselling/care, and networking/training.

Prevention

- HIV/AIDS can be prevented.
- Every individual has the right to information on HIV/AIDS, leading to protection.
- HIV/AIDS is a problem of not only "high risk" groups, but the entire population.
- HIV/AIDS prevention is a development issue, so all development work needs to address it.
- HIV/AIDS prevention is a social justice issue, so all social movements need to include it.
- Preventing HIV/AIDS entails educating both men and women.
- HIV/AIDS prevention must address issues that lead to infection, such as poverty, power relations, gender inequality, and lack of livelihood options.
- The experience of working with people is more important to HIV/AIDS prevention than any HIV-specific expertise.
- STD treatment and access to condoms are key components in HIV/AIDS prevention; as such, all women and men have the a part right to them.
- People living with HIV/AIDS need to be of any prevention work.
- Community participation and ownership is critical to any HIV/AIDS intervention.

Counselling, Care and Support

- People living with HIV/AIDS have a right to good quality care that extends their life and relieves their symptoms.
- People living with HIV/AIDS have a right to dignity in life and death.
- All people living with HIV/AIDS have a right to counselling, care and support in the community where they live.
- Counselling, care and support in HIV/AIDS is a continuum.
- People living with HIV/AIDS and their families have a right to stay together.
- The families of people living with HIV/AIDS can be good caregivers if they are given information, training, and support.
- Counselling, care and support of people living with HIV/AIDS is a key component in prevention.

Networking and Training

- HIV/AIDS prevention and control cannot be achieved by any single group.
- Small interventions, however good, cannot halt the spread of HIV by themselves; scale of coverage is important.
- Government, NGOs, and communities must work together to stop HIV.
- Groups and associations of people living with HIV/AIDS must be part of all collaborations.
- No one model of prevention is adequate to intervene with India's diverse communities.
- Working in collaboration through networks and federations leads to broader coverage in prevention work.

- Many organizations working together are more effective than many organizations working separately.
- Communities have the right to choose culturally appropriate and effective intervention strategies.
- Communities have the capacity to understand and promote HIV prevention; therefore, information and skills related to preventive strategies must be transferred to community-based organizations and groups.

More detailed information on Tabiyat's programs and activities is included in the next chapter. The remainder of this chapter is devoted to Tabiyat's organizational structure. Sehyogi, Tabiyat's parent organization, has already been mentioned with regard to the origins of Tabiyat. We will now examine Sehyogi's role in the day-to-day functioning of Tabiyat.

Sehyogi

This section contains information on Sehyogi, Tabiyat's parent organization, and the nature of the relationship between Tabiyat and Sehyogi. The information in this section is based on an interview with the director of Sehyogi.

Sehyogi started in 1986 as an integrated rural development project. What Sehyogi staff found after some years was that the various activities within the project were somewhat limited in terms of achieving their full potential when they were all sharing the same director. The organization felt that growth could be more easily

accomplished if each sector of the program had its own director. This shift was based on the idea that a sector director would be able to demonstrate ownership of the program. Referred to as sector heads, they must possess three important abilities: the ability to provide conceptual direction, the ability to implement, review and modify those concepts, and the ability to equip team members with the skills to take those concepts forward. All of Sehyogi's sectors have evolved from the needs of its communities. There are currently six sectors within Sehyogi: urban development, rural/village development, the environment, information technology education, disabilities, and Tabiyat, the HIV/AIDS sector, of which Radha is the Sector Head.

The director's office of Sehyogi acts as a secretariat for its sectors. As far as Tabiyat's day-to-day business is concerned, this means that Radha is the Director and Sehyogi's Director provides her with administrative support. The Director looks after general administrative matters, but Radha makes all the programmatic decisions. The one exception is in the case of legal issues. As Sehyogi is the legal entity for Tabiyat, decisions of legal matters are made by Sehyogi's Director. Accordingly, if a staff member of Tabiyat breaks the law, the Director has the power to dismiss them. Tabiyat's funds flow through Sehyogi, and Sehyogi has funds that they can supply to their sectors in return for time or services. For example, Tabiyat provides HIV prevention training to one of Sehyogi's integrated rural development projects in return for funds. Additionally, Sehyogi has reserves, and can commit those reserve funds to its sectors to bridge shortfalls. However, these are for one-time situations only; Sehyogi does not supply funds continuously to its sectors.

Sehyogi encourages its sectors to take on their own names that are meaningful to them so that they have the option to become a separate group if they so wish. When that happens, Sehyogi's relationship with the sector becomes more of a network relationship. Sehyogi has a board of directors, which Tabiyat shares with Sehyogi's other sectors. The board can only provide Tabiyat with one-sixth of its attention. Radha (along with all the other Sector Heads) attends all board meetings, unless they are restricted for some reason. Along with the board meetings, Radha attends a monthly director's meeting and a bi-monthly Inter-Agency Cooperation (IAC) meeting. All of Tabiyat's core staff, plus a rotation of other Tabiyat staff, are invited to the IAC meetings as well, but normally not everyone invited attends. The director of Sehyogi is able to attend Tabiyat's core staff meetings regularly, but this rarely happens. If the core staff want him to attend a particular meeting, they will make a specific request.

For the most part, Sehyogi works within the same general philosophical approaches as Tabiyat. Sehyogi was instrumental in the development of Tabiyat's philosophies from the start, and still influences ongoing development. Radha indicated in my interview with her that she learned from Sehyogi at the very beginning to always remember to put people before programs. When asked about a Times of India article on AIDS in which the director of another prominent local AIDS prevention NGO was interviewed, a staff member commented that Tabiyat doesn't believe in all that publicity. She said that the director of Sehyogi doesn't believe in "beating your own

drum." She also pointed out that Tabiyat's focus is on reaching vulnerable populations, not the educated, the people who read The Times of India.

Tabiyat's role in Sehyogi also helps the parent organization to maintain their philosophies as well. The relationships between Tabiyat and other organizations will be discussed in further detail in the next chapter, which deals with Tabiyat's Networking and Training Program.

Advisory Group

Another organization which serves as a valuable resource to Tabiyat is its Advisory Group. Whereas Sehyogi assists Tabiyat in administrative and philosophical issues, the Advisory Group assists Tabiyat in technical issues. This section contains information on Tabiyat's Advisory Group, based on interviews with two Advisory Group members.

Tabiyat's Advisory Group is essentially a professional peer review group. It functions in both an ethics and a program review capacity. In contrast to a board, the Advisory Group is more technical than administrative. It used to be split up into care/counselling and education groups, but in 2000, they merged the two groups. The Advisory Group is made up of several faculty from a local university, a director of another NGO, a former project director of the local State AIDS Control Society (who

helps out with information on how to interface programs with the government health board), a retired professor with counselling skills, and a physician.

The Advisory Group meets twice a year to examine Tabiyat's half-yearly reports, assessing progress made, outcomes achieved, and new challenges coming up. They make suggestions for linkages within programs, possible new sources of financial and other resources, optimal use of current resources, and advise on how to liase with various governmental agencies. The Advisory Group tends to give more technical advice than ethical advice, in part because Tabiyat staff do not need a lot of help with ethical issues. Tabiyat, working on the ground level, sometimes loses sight of the broader issues; the Advisory Group is there to assist the organization to maintain a broader focus.

Tabiyat's Advisory Group sometimes expresses values that are not always consistent with the values and philosophy of the organization. However, these differences in perspective have not emerged as a problem due to the good working relationship which the Advisory Group has with Tabiyat. The Advisory Group helps Tabiyat maintain their philosophical position while providing a forum in which alternative perspectives can be openly discussed.

Now that Tabiyat's external organizational structure has been examined in some detail, we will turn to its internal organizational structure. In order to understand

Tabiyat's internal organization, we will examine in detail the roles of some of the key members of Tabiyat staff.

Staff

The following section describes the roles and responsibilities of some of the staff members of Tabiyat. It focuses primarily on the core staff, those in charge of programs, activities, and administration. Information from this section is primarily from interviews with the staff members, in addition to observation and participant observation.

The core staff consist of the director and five core staff members. Four of the core staff are in charge of coordinating specific programs: Education/Training, Care/Counselling, Women's Reproductive Health, and Sex Worker Protection/Healthy Highways. The fifth core staff member, the project officer, is in charge of the financial aspects of Tabiyat. The core staff meet once a week to discuss all of Tabiyat's programs. Although each program coordinator makes the decisions around his/her program in conjunction with the director and the project officer, all of the core staff have input into all the programs at these weekly core staff meetings.

The Project Officer has been at Tabiyat since 1994. She has a Masters in Social Work. Her job is to coordinate with the core team, taking care of all the financial aspects of Tabiyat. She started off as a counsellor, and had had six years of experience working as a counsellor at another NGO before starting at Tabiyat. In 1995, she became the

program coordinator for the counselling team. She meets weekly with the rest of the financial staff, and participates in a weekly core group meeting with the director and the rest of the core staff. She also attends the monthly general staff meetings.

The coordinator of the Sex Worker Protection and Healthy Highways programs is in charge of overseeing all aspects of the two programs. She began working at Tabiyat in 1998, as the co-coordinator of the healthy highways program. In 2001, she took over all of Healthy Highways, plus the Sex Worker Protection Program. She meets with the activity coordinators and paid peer sex workers on a weekly basis for updates and training. She also meets with the field educators in the Healthy Highways Program once a week, and meets monthly with the Healthy Highways peer sex workers for training and updates. She also attends the weekly core group meetings and the monthly general staff meetings when she has time. Because her work in the Healthy Highways Program necessitates extensive travel around the state, she is not always in town for the core group meetings and general staff meetings.

The coordinator for the Women's Reproductive Health Program is in charge of managing the program and guiding staff to ensure that services are delivered properly. She also does the bulk of the training, from one-on-one and group discussions to lectures. One of the field educators from the education program helps her out, as well as one of the doctors from the clinic. She does most of the decision-making for the program, although the rest of the program staff does have input. She is responsible for maintaining good relationships with the NGOs which refer patients to Tabiyat's

reproductive health clinic. She is a gynaecologist by training, and joined Tabiyat in 1996 as a part-time reproductive health consultant. She became a full-time staff member in her current position in early 2000. The Women's Reproductive Health staff meet every Wednesday to discuss problems, issues, or concerns that have come up over the previous week. They also meet every month, for a more in-depth discussion, which includes a review of the previous month's work, how many targets were met, why unmet targets were not met, and personal discussion of any problems that employees have with each other, to get them out in the open to avoid large interpersonal problems. The monthly meeting also includes plans for the upcoming month, establishing new targets, and budget planning. These monthly meetings usually last most of a day. Finally, she attends both the weekly core group meetings and the monthly general staff meetings.

The Education and Training coordinator coordinates both the Education and Awareness Program and the Networking and Training Program. He has been at Tabiyat since 1994, when they started the rural portion of the organization. He was the assistant project officer in the rural districts from 1994 until 1996, when he became the rural project officer. He has been in his current position for a year and a half now. He has a B.Sc. in physics, chemistry, and mathematics. Before Tabiyat, he was the senior organizer for a sanitation project. He meets once a week with the rest of the core staff, once a week with the education and awareness team, once a week with the ward-based team, and once a week with Ayojan.

The coordinator for the Care and Counselling Program has two jobs: she works directly in the field, as a counsellor, and she also coordinates all of the activities and programs in care and counselling. She has a Masters degree in Social Work. Tabiyat was her first job. She has worked at Tabiyat for six years, the first four as a counsellor, the following two as project coordinator. She has several compulsory meetings. She meets weekly with staff from each of the projects within the care and counselling program: Parvah, Prakriti (another respite home), the outpatient clinic, and the counsellors. She also meets on a weekly basis with the rest of the core staff, and attends the monthly general meeting among all of Tabiyat.

The director of Tabiyat oversees all activities and programs, in conjunction with the various coordinators. She is in charge of developing funding proposals, as well as networking with other NGOs and organizations. She meets weekly with the core staff, attends the weekly Ayojan meetings, and has three monthly meetings at Sehyogi: board meetings, director's meetings, and Inter-Agency Cooperation meetings. As well, she leads the monthly general staff meeting at Tabiyat. She is also available to attend any other staff meetings where her presence is requested.

Now that Tabiyat's core staff members have been described in detail, the remainder of this section will be a general discussion of the staff as a whole, including both core members as well as more peripheral staff.

Counsellors, who make up the majority of Tabiyat staff, are structured in specific ways. There are junior counsellors and senior counsellors. Whereas the senior counsellors usually have degrees in counselling, the junior counsellors often have 1½ month diplomas in counselling. However, on-the-job training and work experience are also important, as one of the junior counsellors has been working at Tabiyat for 4 years, while one of the senior counsellors has been at Tabiyat for 2 years. The senior counsellors usually came to Tabiyat with work experience; two of the junior counsellors were inexperienced, while one had a year and a half of work experience.

In total, there are eight counsellors at Tabiyat - two senior counsellors, three junior counsellors, two part-time counsellors (who have both been at Tabiyat on and off for six years), and the counselling coordinator. All of the counsellors work in all of the different activities within the counselling program - the outpatient clinic, two respite homes (Parvah and Prakriti), drop-in counselling, home care, and hospital outreach. They get a new duty roster each month which tells them where they are going. Counsellors have four salary grades. These grades are based on experience, attitude, and commitment. Counsellors move up grades as is appropriate.

Tabiyat's staff have similar characteristics as many people who choose to work at an NGO; that is, they are caring people who want to help others. When asked why she chose to work at an NGO, one staff member said because it is "good work". According to Radha, the two most important qualities that she looks for when hiring

new staff are an openness to learn and concern for people. She said that they were more concerned with having caring people than competent people on their staff.

Tabiyat Staff are willing to make many sacrifices in order to serve the communities in which they work. They sometimes give up job security, and work long, hard hours for relatively little pay. One core staff member told me that Tabiyat pays about the same as other NGOs and the government, but that the difference with government jobs is that the work is much easier, the hours are shorter, and there is more job security. She indicated that there is a conscious effort to keep all salaries at Tabiyat at Sehyogi salary levels. She admitted that "you can't raise families on this money". Another staff member told me during a field visit that Tabiyat staff need to have understanding families, because of the large amounts of work they have to do. I was told by another staff member that Tabiyat staff rarely attend plays or other evening activities, because their long hours mean that the evening is their only time to spend with family. The counselling coordinator is in charge of Parvah, Prakriti, and the Care and Counselling program. Prakriti is an overnight train ride away. She says she visits Prakriti twice a month, for two days at a time.

Tabiyat staff are also willing to give up benefits such as staff parties and holidays. According to one staff member, they usually have a staff party around New Years, but that year it was delayed because the staff decided to spend the money on the World AIDS Day activities, which weren't covered by any program. She also mentioned that Tabiyat staff rarely take holidays. According to her, the only time anyone takes a long

time off is when they get married, have a baby, or are extremely sick. Perhaps not surprisingly, it is difficult for Tabiyat to recruit staff who are qualified, caring, hard-working and willing to sacrifice job security and family time. One core staff member told me that counsellors and nurses are the hardest staff to recruit. Counsellors tend not to be interested in HIV work, preferring to work in an office setting. She said that many counsellors are not well prepared for HIV work. Another core staff member said that the reason that it was hard to recruit new counsellors was that many potential staff were not willing to work the long hours that Tabiyat staff regularly work. She mentioned particularly that it is difficult to find someone who is appropriate for the job of field trainer, because Tabiyat feels strongly about having the training done by someone who has a lot of field experience in development (at least 2-3 years). It is hard for them to find someone who has that kind of experience plus the right attitude and sensitivity to work in HIV/AIDS. Tabiyat's greatest resource is arguably its staff; they are sometimes hard to recruit, but they are invaluable to the work that Tabiyat does.

Tabiyat staff represent a successful aspect of Tabiyat's community empowerment initiatives. Some of the sex workers who volunteer as resource persons end up working as full-time staff. In fact, Tabiyat's clients are represented at every level of the staff hierarchy through either former sex workers or HIV-positive people. Radha, during my interview with her, said that she believes that Tabiyat's greatest strength is having sex workers and HIV-positive people at all levels of staff, not just a "token" here or there - there is representation all the way up to the core staff positions. This

way, they are reminded to keep the needs of the community foremost at all times. As a result of staff's commitment to the communities they serve, they feel that they have an excellent rapport with their clients, particularly with the sex worker community, a notoriously hard to reach population. During my field visit with the Sex Worker Protection Program staff, we would regularly run into sex workers who were familiar to the staff, and they would talk with them briefly. It was a very friendly exchange each time. The staff explained to me that they were volunteer peer sex workers, as well as sex workers who happened to be well known by Tabiyat staff. No one was fazed by my presence whatsoever.

Clearly, Tabiyat's staff members are among its greatest assets, and are a large part of what makes it a strong and successful organization. The strength that Tabiyat gains from its staff more than makes up for the difficulty they have in recruiting and keeping suitable staff. The final section of this chapter will describe issues related to funding the organization.

Funding

Information from this section is from Tabiyat's operating budget, plus interviews with the project officer and the director.

As of late 2001, Tabiyat was receiving funding from five different donors. Although the amounts which each donor contributed varied greatly, no single funder accounted for more than 40% of Tabiyat's total budget. Three of the donors are Indian agencies;

the other two are Western. One of the largest funders is an American donor agency which has been funding Tabiyat since its inception. In the beginning, they provided close to 75% of the total budget, but that proportion has gone down to closer to 40%. As of 2001, they were planning to fund Tabiyat for two more years, and then withdraw most of their funding. At that point (2003), they will have been funding them for ten years, and their policy is to allow other organizations to have financial opportunities after that amount of time. As of 2002, Tabiyat had a new international funder. They were starting a large gender and reproductive health research project, and Tabiyat was responsible for the program side of it. This funding was being earmarked for the Women's Reproductive Health project and a new gender project.

The funding process is similar for all of Tabiyat's funders: after some initial consultation with the funder, the Director takes on the responsibility for developing a proposal in consultation with the appropriate project coordinator. The amount of time between submitting a proposal and obtaining funding varies among the different donors. While some agencies take three months, others can take up to a year. Once the funding is in place, all of the donors require reports. The number of reports required per year by each agency varies from one to five. The total number of reports required for all agencies in 2001 was 12. Most grants given to Tabiyat are for a period from three to five years. Each grant is for a specific program or project within a program. For example, within the Counselling Program, the Parvah and Prakriti programs each have their own grant, while counsellor salaries are paid from a third donor. The Sex Workers Protection Program, in contrast, is funded entirely by the same donor.

Tabiyat has had problems with some of its past and present funders. One of the biggest problems is paperwork. Tabiyat used to be funded by an agency that insisted on monthly reports, and refused to release the following month's money until the report from the previous month came in. It was difficult to conduct programs properly without knowing each month when the next installment of money was going to arrive. Another problem Tabiyat has experienced with funders is a lack of understanding or communication between the funding director and the funder's liason person who deals with Tabiyat, in turn affecting understanding between Tabiyat and the funding director. Frequent changes in the funding process was another problem, as was funders wanting actions and results more quickly than is realistic.

Probably the most distressing problem experienced by Tabiyat has been the amount of control that some funders require over the way that their funds are spent. Core staff recognize that Tabiyat runs a risk of being co-opted by their funders if they are not careful about whom they are funded by. According to one core staff member, they turned down a large grant because the money would have required staff spend 80% of their time on paperwork, and only 20% of their time in the field. The core staff feared that accepting the money and the conditions of huge amounts of paperwork "would have changed us as an organization." On occasion, Tabiyat must turn down funding because the funders want too much control over how the money is spent. A core staff member told me that a problem they commonly have with funders is a lack of flexibility in the way that the money must be used. She said that they have had this

kind of problem with two recent funders. One of them they stopped soliciting funds from as a result of the conditions tied to the money. Finding new sources of funding does not appear to be a concern for Tabiyat. The feeling is that there is no shortage of funding agencies available, and as a result of Tabiyat's good reputation, they are confident of being approved for funding once they have found a donor and submitted a proposal.

Part of the reason Tabiyat finds it so hard to work with funders who want a say in how programs are run is that the philosophies of the official donor agencies are often in conflict with those of Tabiyat, to the point that they may undermine Tabiyat's goals. While the goal of Tabiyat's Sex Worker Protection Program is to empower sex workers, the funders of the program are sometimes primarily interested in the numbers of condoms distributed and STD cases diagnosed. This discrepancy can lead to conflict with both the funder and other NGOs being funded by them. One core staff member told me during her interview that she believes one funding organization's money leads to commercialism. Another NGO funded by the same organization gives monetary incentives to sex workers visiting their STD clinic. Tabiyat staff believe that they may offer these incentives to increase the number of STD cases they report back to the funders.

Tabiyat's conviction about not having funders dictate how money is spent applies to all funders, even those who seem to express the same values as Tabiyat. One of their

funders has a set of "non-negotiable" principles. Although these principles are in line philosophically with Tabiyat's core beliefs, a core staff member told me that they would not work with them if they were their main funder because of these limitations. As they are a small funder, Tabiyat chooses to work within the non-negotiables.

Securing funding for specific programs can be difficult, particularly if the philosophy of the program does not fit within those of the funders. For example, Tabiyat has found that funding the respite homes is a challenge. One funder sent a representative to Tabiyat and criticized the AIDS respite homes, questioning the value of spending money on care for people who are going to die soon anyways. This was a case of a vast discrepancy between Tabiyat's philosophy and the funder's philosophy. In their experience with funders, Tabiyat has found that most funders prioritize prevention programs over care and counselling programs, which is in conflict with Tabiyat's philosophies of giving prevention and care equal priority. It is also in conflict with Tabiyat's philosophy of providing services where they are needed most, as the core staff perceive a dearth of hospital and palliative care programs for HIV-positive people in the area.

Another reason for the difficulty of finding funds for respite homes, as well as rural work and community-based work, is the current emphasis on cost-effectiveness. The representative who criticized Tabiyat's respite homes wants to do a cost-effectiveness assessment of the program. One core staff member complained to me that funders are primarily concerned with financial accountability, and that they overemphasize its

importance. Although the AIDS epidemic is now generalized in India, funders generally continue to focus on targeted interventions according to Tabiyat core staff. According to one core staff member, the World Bank emphasizes targeted interventions because they are more cost-effective than generalized interventions, and the Indian government wants the extensive funding that the World Bank allows them access to.

Finally, one of the largest problems with funders is the lack of understanding that implementing community empowerment and ownership can take a very long time to progress. Tabiyat is finding this to be a particular concern within its community-based program. The community within which they are working needs a great deal of time to get to the point where they are the ones who own the program. At the moment, the community expects Tabiyat to deliver services, and it is difficult for staff to convince them to become actively involved, especially to the point where the program is community-owned. Similar problems have been encountered with Tabiyat's sex worker collectivization initiative. According to core staff, the sex workers initially feared that they would lose their invisibility if they became collective, and they seemed to feel that their safety would be compromised if their invisibility was threatened. After some explaining about collectives, they became less nervous about the process. Progress is extremely slow, but it is a pace with which the sex workers are comfortable. Funders tend to expect results much more quickly than it takes with projects that directly involve the community. In Tabiyat's experience, funders are not understanding of the fact that community-involvement projects may take years to

achieve substantive results, and therefore impose unrealistic and unattainable timelines. Although this expectation by funders is not directly related to a clash in philosophies, differences in expectations about timing of results is another example of the challenges that Tabiyat faces in working with funders.

Summary

The various organizational aspects of Tabiyat, including its Advisory Group, Sehyogi, its staff, and funders, impact them as an organization, including the effective implementation of their programs and activities. Some of these organizational components, such as Sehyogi, the Advisory Group, and staff, work within the same discourse as Tabiyat, and impact them positively. Sehyogi, the organization from which Tabiyat originated, has been particularly influential in the development of Tabiyat's philosophies, as well as helping them maintain their priorities. Collaborative relationships such as these are undoubtedly what contributes to the growing strength of the philosophical values within which Tabiyat and these other organizations work.

Arguably, Tabiyat's staff have been the strongest and most positive influence on them as an organization. They are extremely dedicated to their work, and are willing to make sacrifices in order to conduct it. They are committed to the communities in which they work, and always ensure that their needs are their priority. As a result, they appear to have strong relationships with their clients. The staff of the Sex Worker Protection Program in particular seem to have an excellent rapport with the sex

worker community. During my field visit with them, I was continuously struck by how open and friendly the sex workers were with staff. I thought that my presence would lead to suspicion, but no one reacted negatively to me. I concluded that their level of trust of the staff must be high enough that because the staff accepted me, the sex workers gave me the benefit of the doubt. Tabiyat staff's rapport with the sex worker community may be a result of their success in keeping the needs and interests of their clients their top priority, instead of the priorities of the voices from the medico-moral AIDS discourse in India.

Other organizational components of Tabiyat, such as funders, may be part of a discourse against which they are working. There is a risk to Tabiyat of such groups impacting their daily activities. Whereas Tabiyat learned from Sehyogi to put people before programs, and other NGOs may be interested in programs before people, funders are often interested in financial accountability before people or programs. Funding agencies that focus primarily on targeted interventions, condom promotion, and STD diagnosis, all more cost-effective activities than community development and empowerment initiatives, are part of the medical AIDS discourse. Tabiyat likely finds it difficult to secure funding from such organizations for their activities which fit into the rights and empowerment AIDS discourse. Beyond the fact that an emphasis on cost-effectiveness and financial accountability result in the prioritization of activities within the medical discourse, such an emphasis suggests that there may be a new AIDS discourse emerging. This could be called an "economic discourse", in which there is a strong focus on demonstrating the economic advantage of AIDS

prevention and care activities. Indeed, there is already a great deal of emphasis on economic development through health improvement in impoverished countries within the international health literature (Jha et al., 2004; World Health Organization, 2001).

The next chapter will examine in detail the day-to-day running of programs and activities, with specific reference to the various discourses within which they must work.

Chapter 6

Results: Tabiyat's Programs

Now that we have a clearer understanding of the organizational components of Tabiyat, we will turn to an examination of their programs. This chapter presents information on Tabiyat's programs and activities over a two-year period, from January 2000 to January 2002. It is based primarily on advisory group reports and interviews with Tabiyat staff, but also includes information gathered through participant observation and direct observation for the later portion of the two-year period. A discussion of these activities follows.

It should be noted that, since the data collection period, Tabiyat's programs have undergone significant reorganization. Most notably, two of the programs listed here (the Education and Awareness Program and the Ward-Based Program) have been incorporated into a Rural Community-Based Program which did not exist at the time of data collection. These changes will be described in more detail in the individual sections for each program.

Education and Awareness Program

The education and awareness program includes HIV/STD education sessions and condom distribution in prisons, construction sites, and other job sites with migrant workers, as well as monthly street plays and puppet shows within different communities.

In 2000, a garment factory education program was handed over to another NGO as part of an overall plan to free up scarce resources for new initiatives. There were plans to phase out the prison education program through peer prisoner education and training, letting the peers take over the program altogether. However, the prisoner turnover was a concern. In 2001, another NGO working in the same prison began paying the peer prisoners working with them, leading Tabiyat's peers to demand payment as well. This, coupled with a relocation of the prison to an hour outside of town, led Tabiyat to drop the program and use the resources elsewhere in 2002.

When Tabiyat first started conducting awareness workshops for construction workers, the site supervisors, engineers, and others higher up were not interested in becoming involved, and told Tabiyat that they could only conduct their sessions off-site, at lunch hours. In response, staff had discussions with these higher-ups, explaining the AIDS situation, explaining how keeping their workers from contracting AIDS would result in them being more productive and working for the companies longer, and explaining how the message would be more effectively conveyed if there was a feeling that the workers' superiors were backing it up. After several such discussions, relations improved, and now, a good rapport exists between Tabiyat and the site engineers and contractors, who help by halting work during the education sessions, providing Tabiyat with financial compensation, making the sessions mandatory, and providing information about other sites at which to conduct sessions.

Condom distribution among construction workers is difficult due to the mobility of the population, but staff have been able to find volunteer construction workers to distribute condoms among their coworkers on a regular basis. Vendors near the construction sites are also stocked with free condoms for distribution. In 2002, Tabiyat had plans to involve contractors, engineers, and other secondary stakeholders in their program in order to scale up, increase coverage, and initiate community participation and ownership. The first part of this new plan was to conduct a situational analysis of the local construction industry.

AIDS Melas are conducted on a monthly basis. Melas are mini-"festivals" in which several educational street plays are performed. Tabiyat has 12 different scripts for HIV-themed street plays, depending on the target population (women, prisoners, construction workers, street children, rural, urban). Data from the Sex Worker Protection Program on where there are concentrated sex worker populations is used to decide where to hold AIDS Melas. Referrals to Tabiyat's clinical and counselling services are conducted at Melas as well. Along with the Melas, popular HIV education tools are audiocassettes and individual street plays. Audiocassettes have been an extremely successful intervention technique; the cassettes and songs are extremely popular. In early 2000, another NGO got Tabiyat involved with a group of fifteen street children. Staff began training the children to do weekly street plays, and encouraged other street youth from the local community to get involved in the activities. Later in 2000, Tabiyat gave the contact NGO training on conducting plays themselves, so that the program could be continued by them.

Along with a more community-based focus, Tabiyat is planning on providing large-scale information on male sexual health. The use of photographs in STD education sessions has produced good results, and will be incorporated into more male sexual health programs. There is a recognition that mass coverage programs will need to be combined with sustainable STD clinic services, and there are plans to implement an STD referral tracking system, as well as impact measure tools such as focus groups with the target population and behaviour surveillance surveys. As of 2003, it appeared that most of the Education and Awareness Program activities were being integrated into large-scale community-based programs in both urban and rural areas. These programs will be discussed with the Ward-Based Program, below. Male sexual health issues have been integrated into the Women's Reproductive Health Program, also discussed below.

With its focus on education about HIV transmission, STD symptoms, and condom use, the Education and Awareness Program largely works within the dominant medical discourse in India. Because of the great number of other NGOs working within this framework, Tabiyat is able to transfer projects from this program to other organizations, allowing them to focus on other areas which are within the less dominant rights and empowerment discourse. One of the most challenging of these areas is sex worker advocacy and collectivization. This and other activities related to the sex trade will be discussed now, as we examine the Sex Worker Protection Program.

Sex Worker Protection Program

The Sex Worker Protection Program started in 1994. The main focus of this program is to educate and empower sex workers in the city, be they street-based, brothel-based, *hammam* (public bath)-based, or home-based. Condom promotion and referral to Tabiyat's reproductive health services are also part of the program. Many of the program's activities are carried out by a system of peer sex workers, both volunteer and paid, who make contact with local vendors, hotel staff, brothel madams, and other sex workers in the field.

In late 2000, the street sex worker program received new funding. The funder's targets for number of sex workers reached, based on brothel-based sex work, were unrealistically high (60 per peer) for street-based sex work, where a "street stretch" or "area stretch" will contain anywhere from five to twenty sex workers. Peers were placed in areas with concentrated populations of sex workers in order to maximize their reach, resulting in the identification of previously unknown brothels and sex workers with which to work. However, by early 2001, Tabiyat had found that having paid peer educators for each stretch was impractical. The peer sex worker system was restructured and strengthened. Tabiyat now has peer "outreach educators" with a system of voluntary peers to support them. Activity coordinators from Tabiyat are responsible for the recruitment, training, field supervision and support of the outreach educators and voluntary peers, including organization of group meetings and problem

solving in the field. Since the restructuring, the peer base has been strengthened considerably. Tabiyat wants to continue to strengthen the new peer structure; one plan to achieve this is to maintain regular and systematic peer contact, as well as refresher peer training. Weekly support meetings, as well as systematic training sessions on communication skills, problem solving, legal rights, and care and support of HIV-positive people, were initiated in early 2001.

Informal peer education among the sex worker population, as well as peers educating men, has been occurring among the peer sex workers with which Tabiyat works. Education on condom use has led sex workers who previously refused condoms to now ask for them. In early 2001, a weekly STD clinic was set up for sex workers. It is difficult, however, for all sex workers to come that one day during clinic hours; a proposed solution is to systematically refer sex workers to doctors who currently treat sex workers. Tabiyat will train these doctors in working with sex workers and HIV-positive people, as well as provide follow-up support. Networking has also occurred with two suburban doctors. They take clients referred to them by Tabiyat staff, display posters for another local clinic where Tabiyat has clinical and counselling services, and distribute condoms and pamphlets supplied by Tabiyat. The weekly clinic will continue to operate as a secondary facility.

A program for part-time and occasional sex workers was initiated in early 2000, but then stopped due to lack of adequate staff. It is hoped that with peer recruitment it can be started again. Tabiyat used to have a program for night sex workers, alerted to the

night trade by bus drivers in the area. Night sex workers are generally young (in their teens) and choose to work at night to avoid harassment from older sex workers. Police harassment forced them to give the program up. If peers want to work at night, they do so on a volunteer basis, and Tabiyat is not responsible for police trouble. Four of the program's twelve peers volunteer their time for night work. If there are any hassles with police, the peers take care of it themselves, with bribes or "free services". Tabiyat also has a protection program for transgenders in *hammams*, public steam baths where commercial sex, particularly with transgenders, often takes place. Staff have an excellent rapport with the *hammam* community. There is an interest in strengthening the *hammam* program; an initial step in early 2001 was to explore the possibility of peer recruitment among the transgenders. The brothel-based sex-worker program is being strengthened slowly, thanks to the restructuring of 2001. Staff are reconnecting with relocated brothels, as well as locating new ones. A long-term goal is the enumeration of the city's brothel-based sex workers.

Tabiyat has representation at a national forum supported by UNDP, which examines issues such as police violence, child care, and forced child prostitution. In late 2000, a sensitization session was conducted with the Women Lawyers Association. Since the session, the Women Lawyers Association has requested a full-scale workshop and offered to conduct a session on Sex Work and the Law for Tabiyat staff. Sensitization workshops with other women's organizations are being planned for the future. Around the same time, Tabiyat trained staff from another NGO in sex worker protection, and connected them with some of their contacts. In early 2001, program

staff participated in an exchange with a Bangladeshi NGO and Sonagachi project, Kolkata. While the Bangladeshi NGO sent their truck driver program staff to visit Tabiyat, Tabiyat sent their staff to study program issues and sex worker movement issues. Staff learned about scaling up, capacity-building, system monitoring, and sex worker collectives. Everyone involved felt that the exchange was very useful and rewarding.

The city's sex workers are a difficult group to work with. Particularly in the early days of the Sex Worker Protection Program, they were reluctant to trust Tabiyat staff; as was discussed in the previous chapter, Tabiyat staff were the first people who had ever approached the local sex worker community with only the agenda to help them, without insisting on rehabilitation. It took time to gain their trust.

Other conflicts within the Sex Worker Protection Program are more specifically about the sex trade discourse, and how different groups view sex workers. Tabiyat's priority when working among sex workers is empowerment, rather than rehabilitation, which is the priority of the police in the area, as well as many other organizations working within the medico-moral discourse. For example, permission was sought from the local State Home to educate sex workers on remand, but the State Home insisted on a commitment of rehabilitation, so Tabiyat dropped the matter. Further, the medico-moral discourse may lead to a dehumanizing of sex workers, in that they are not viewed as equals to women not involved in the sex trade. Networking that Tabiyat has done on violence against women has not been beneficial to sex workers, because the

other organizations are reluctant to view sex workers as part of "women in general", and want the sex worker issues to be secondary to those of other women.

The largest challenge faced by Tabiyat is the police, primarily due to their often brutal harassment of local sex workers. Sex workers face routine violence (sometimes extreme) on all sides, most frequently from police. The education and training staff at Tabiyat, in conjunction with Ayojan, are in charge of the police training in the city. Tabiyat's initial response to police violence was to hold sensitization workshops for police about HIV and the sex trade, as well as have discussions with staff at higher levels in the police department. However, these efforts had little impact on the way police treated sex workers. One staff member from the Sex Worker Protection Program reported that they used to go and talk to the police commissioner about police violence against sex workers, and every time they did, the violence would stop for a while, but then return. In large part, the challenges with the police in regard to sex worker interventions appear to be related to a difference in philosophy on the sex trade. While Tabiyat wants to protect and empower sex workers, the police want to rehabilitate them.

By emphasizing rehabilitation of sex workers, the police are participating in the dominant medico-moral discourse on sex workers in India. Further, the extent to which the police participate in this discourse is influenced by the specific neighbourhood within which they work. During my field visit with the Sex Worker Protection Program, I noticed that the police were worse in one area of town (a large

shopping district) than the others (primarily bus stations, train stations, and downtown markets). The staff informed me that the police are particularly brutal in this area, and they are not understanding of the fact that they are educating about HIV, the way they are in other areas. One of the staff told me that there is public pressure to eliminate sex work in this area, which leads to the higher levels of police brutality and harassment. It appears that the intensity of public discourse on the sex trade differs among neighbourhoods, and impacts the way the police treat sex workers in each area. Within the Sex Worker Protection Program, Tabiyat's activities involve discourse not only on the global, national, and state level, but also on a community level. Collective action in response to police brutality is in the works in conjunction with other NGOs.

Tabiyat's most recent Sex Worker Protection Program projects include efforts to initiate a sex workers' collective, similar to what has been discussed with regard to the Sonagachi project in a previous chapter. The collective is a slow process, in part because the sex workers wanted an immediate result from the formation of the collective. According to Tabiyat staff, they also originally feared that they would lose their invisibility if they became collective, and they seemed to feel that their safety would be compromised if their invisibility was threatened. Once staff explained to the sex workers that changes take time, the formation of the collective began. All efforts have been in collaboration with the women themselves, and the initiative has been proceeding at a pace dictated by them.

As of 2003, Tabiyat had scaled up its rural sex worker interventions. Program staff in rural areas were working collaboratively with staff from the Healthy Highways Program, discussed below. There have been no updates about the collectivization process. Tabiyat appear to be focusing less on the Sex Worker Protection Program and more on new community-based programs, discussed with the Ward-Based Program, below.

By advocating for sex workers' rights and encouraging the formation of a sex workers' collective, Tabiyat's Sex Worker Protection Program is working against the dominant medico-moral sex worker discourse in India. At the same time, program activities include condom promotion, HIV transmission education, and STD management, all part of the medical AIDS discourse, also dominant in India. Thus, it is impossible to categorize the Sex Worker Protection Program as working either within or against the dominant discourse in India. As will soon become clear, this problem is apparent in other Tabiyat programs, including the Women's Reproductive Health Program, which will be examined next.

Women's Reproductive Health Program

The Women's Reproductive Health Program has been in place since 1996. Its activities include reproductive health education among patients and service providers, capacity-building for medical and paramedical professionals, other NGOs, and others working in women's reproductive health, and clinical services. Clinical services

include a three times per week lab-based clinic, a once per week syndromically-managed (diagnoses are made based on symptoms) clinic, and mobile STD screening camps (also syndromically-managed). To broaden the reach of the Women's Reproductive Health Program, staff are working closely with the Education Program staff responsible for male sexual health. As of 2002, there was a new reproductive health program for adolescent girls, whose image as clean and disease-free is leading them to be sought out by older men. The adolescent health sessions educate girls primarily on basic reproductive health and how to recognize infections. There were also plans to begin women's reproductive health services in maternity homes.

In late 2000, Tabiyat conducted an orientation on women's reproductive health for two NGOs, as well as four physicians from these NGOs. The training was designed so that they could sustain their own ongoing reproductive health programs for women. Two other NGOs began providing reproductive health services after receiving prior training from program staff. As of 2001, more NGOs were showing interest in developing women's reproductive health programs with help from Tabiyat. Unfortunately, because longer field-level training is needed to impart a fuller understanding of STDs, many groups have difficulty making the time commitment to complete the field-level portion of training. One plan to combat this problem was to break education programs into a series of sessions. Another proposed change is to move from staff-led to peer-led education sessions; staff want to put together structured education to train peers for this purpose. There are also plans to update the

education content of the training programs, as well as the information in Tabiyat's reproductive and sexual health pamphlets.

In 2001, linkages among the various parts of the Women's Reproductive Health Program were strengthened in an effort to improve follow-up of the STD patients seen at screening camps. Linkages were also improved between the Women's Reproductive Health Program and other programs within Tabiyat, particularly the Counselling and Education Programs. The Women's Reproductive Health Program is promoted at the Education and Awareness activities, and the Care and Counselling Program is promoted at the Women's Reproductive Health activities. A voluntary testing and counselling service for HIV was initiated at the reproductive health clinic, in addition to clinical services for HIV positive women. Counsellors began to accompany reproductive health program staff at STD screening camps as well.

Tabiyat is actively involved in IPP-8 (Indian Population Project) centres in and around the city. The Indian Population Project was a government initiative to reduce the country's birth rate, funded by the World Health Organization and the government of India. Tabiyat conducts rotating STD screening camps at the centres for women in the area. Staff have also been conducting reproductive health training sessions with the physicians in the IPP-8 centres, and as of late 2000, nurse training had been initiated. In 2001, however, the government and WHO pulled their funding, and the IPP-8 program was halted. The centres remain open, and Tabiyat continues to provide STD screening camps within them on a rotating basis, but many of the support staff

left, including "link workers" whose job it was to visit women in their community and encourage them to attend the camps. As of early 2002, physicians at the IPP-8 centres had not been paid for six months.

As of 2001, there was a desire to shift the Women's Reproductive Health Program to a more community-based structure. Programs were concentrated in three slum areas of the city in order for work to be more focused. Tabiyat is networking with two NGOs already active in these areas. There were plans to have women who live in the slums work as peers in the areas, in order to improve follow-up to Tabiyat's clinical services.

As of 2003, Tabiyat had expanded its Women's Reproductive Health Program to include men's sexual health activities. Educational material specific to adolescent sexual health had been produced. In addition, a large-scale research project examining the long-term social and economic risk factors of HIV infection has been initiated.

The focus of all of Tabiyat's Women's Reproductive Health activities is the promotion of reproductive health as a basic right for all women. Tabiyat staff encourage sex workers to visit Well Woman Clinic as their right to good sexual health. I attended a meeting among Sex Worker Protection Program staff and peer sex workers. A core staff member had the peers engage in role-playing, including a scenario with a sex worker who has little interest in learning about HIV. The response role-played was to tell the sex worker that the peer is not simply interested in

educating her about HIV, but general sexual and reproductive health. The peer tells her about STDs and the importance of treating them. Similarly, during a field visit to a brothel, Tabiyat staff encouraged two sex workers to visit the Well Woman Clinic. The sex workers initially balked at the idea, but became more interested when the staff began talking about STDs and general sexual health. They agreed to let the staff take them to the Well Woman Clinic the next day.

Generally, the Women's Reproductive Health programs are promoted in terms of women's right to be healthy and the importance of attending to their health:

> Women Work Round The Clock to Care for Others – They should also care for their own health (front page of Tabiyat's reproductive health clinic pamphlet)

Tabiyat has had conflicts with another organization which, instead of working to educate women about their right to good health, promises them money in return for attendance at their reproductive health clinic. Tabiyat feels that such cash incentives make clinic attendance into a commercial transaction, whereas they are trying to promote STD treatment as a health right to which all women are entitled access; encouraging women to attend the clinics is thus part of an empowerment process, one that gets lost with the cash incentive.

As with the Sex Worker Protection Program, Tabiyat's Women's Reproductive Health Program includes activities which work within the dominant medical AIDS discourse, such as STD management, as well as activities which work within the

rights and empowerment discourse, such as advocating for women's health as a basic human right. In contrast, the following program to be discussed, the Ward-Based Program, fits more completely into the rights and empowerment AIDS discourse.

Ward-Based Program

The Ward-Based Program is a brand new initiative in Tabiyat. The goal is to take all of Tabiyat's strengths, and put them into one area. The concept of an urban community-based program is a brand new one in the area. Sehyogi runs some rural participatory programs, but an urban program completely owned by the community is something new. There are no models to follow. The Ward-Based Program focuses on one neighbourhood in the city. It is a multilingual, multireligious, multicultural neighbourhood, with a mix of rich and poor residents. There are not many AIDS NGOs working in this neighbourhood right now, and there is no other community-based work in the area. Because of the heterogeneity of the area, it has complex needs. It was chosen for its mix of all parts of urban society.

Originally, the plan had been to bring all of Tabiyat's programs together for the Ward-Based Program, but this proved impossible without staff focused exclusively on developing the project. Also, Tabiyat wants the program to be community-owned. By taking all of Tabiyat's programs and conducting them in one neighbourhood, they were simply offering services, not implementing a community-based program. The community was not involved in deciding what programs were offered, where they

were conducted, or how often – all of those decisions were being made by Tabiyat staff. For the community to truly own the program, community members have to be involved in all aspects of it. Tabiyat wants the community to see that AIDS is their problem, and that they should be doing something about it. There has also been an emphasis on community program ownership as a right of the community.

As of late 2000, mapping had been done, capturing vulnerable populations, opinion leaders, and resources available to the program. Local community leaders willing to help staff reach the community had also been identified. In 2001, mapping continued, while relationships with key people were being built. Discussions were held with 18 community-based organizations and 21 local leaders about creating meeting points where the community could talk about sex and sexuality. Baseline data on STD care facilities and condom use was collected. A survey was conducted to understand the community's current knowledge about and attitude towards HIV and AIDS. According to the survey, a majority in the community knew about AIDS and its sexual mode of transmission; more encouraging was the fact that a majority also viewed it as a social problem and were willing to do something about it themselves.

As of the beginning of 2002, there were no links between Tabiyat and the community. Community groups with whom Tabiyat wants to link up include youth groups, caste organizations, slum development organizations, welfare organizations, merchants associations, religious committees, and politicians. Politicians normally send representatives to group discussions; it is hard to make contact with the politicians

themselves. The big hospitals in the area are involved, but no other NGOs. There are 17 other NGOs working in the area, but all of their programs are service-based, and completely separate from Tabiyat's Ward-Based Program.

The only groups who were problematic about getting involved in the program were religious groups. To convince the religious leaders to participate, Tabiyat shows them HIV/AIDS statistics, trends showing the spread to the general population, and explains to them that there are no boundaries in HIV/AIDS, that it spreads to all religions, castes, and ages. It affects all people; thus HIV is everyone's problem. The priests were reluctant, but agreed to participate after a few discussions with Tabiyat. The mosque committee also took quite a bit of convincing through a number of discussions with Tabiyat, but they too have agreed to help out. The only holdout as of early 2002 was the temple committee. They have said that they will not hinder Tabiyat's activities in the community, but staff cannot come into the temples, and they cannot name the temple committee as a participant of the Ward-Based Program. Tabiyat is still working on convincing the temple committee to participate in the program.

Progress is slow in getting community involvement, participation, and ownership. More time is needed to get to the point where the people are the ones who own the program. The community expects Tabiyat to deliver services, and it is difficult to convince them to become actively involved, especially to the point where the program is community-owned. Local people, particularly members of religious groups and

slum dwellers, are reluctant to accept or talk to Tabiyat unless they approach them through their leaders, and the leaders are difficult to make contact with, generally having busy schedules. Thus reaching the community is a slow process.

Program staff used to meet every two days with different community leaders and organizations. This was stopped, because the program was getting ready to begin focus group discussions with various community members. As of early 2002, they were finding community groups to participate in the focus group discussions, and hoped to start the focus groups later in the year.

As of 2003, the Ward-Based Program appeared to have been scaled down. Tabiyat now appears to be focusing on new community-based activities in three rural areas. Many of the principles of the Ward-Based Program, such as demonstrating to community members that HIV is everyone's problem and encouraging community mobilization, appear to be integral to these new rural programs. Tabiyat appears to consider these new community-based initiatives as some of their most important programs.

Community ownership is being promoted in other Tabiyat programs as well; the sex workers' collective has already been mentioned, in addition to ongoing community ownership efforts in the Education and Training Programs. Ayojan has also been emphasizing the transfer of skills to the community both as a right of the community and as a swifter intervention process.

Similarly, Tabiyat listens to communities when deciding what programs to develop, as well as when and where to develop them. For example, when I was at Tabiyat, they had just opened a new AIDS clinic in a rural district. According to Tabiyat staff, the locals were extremely enthusiastic about the new clinic. The government had wanted to postpone the clinic opening by two weeks, but the locals pressured the government to open it right away. Women in another rural town were also requesting women's reproductive health services. One core staff member, during a meeting discussing the community response to and requests for their programs, said that the time is right for this kind of work - the people are asking them to provide it. By involving the community at the program development stage, Tabiyat is not only laying the groundwork for future community ownership; they are encouraging the community to exercise their right to stand up to the government and other powerful groups over unpopular decisions. It is hoped that, in the future, it will be the communities working against dominant discourse and exercising ideological autonomy, rather than Tabiyat.

Participatory projects are popular in most development and AIDS discourse. However, many participatory projects surreptitiously devalue local participation even while they purport to involve the community (Pigg, 1995). As mentioned in the previous chapter, Tabiyat has sex workers and HIV-positive individuals at all levels of its staff structure, including senior positions. Further, work in the Ward-Based Program was halted and re-started when Tabiyat realized that they were not carrying out a truly community-led program. It appears that Tabiyat's community

empowerment activities are truly part of the AIDS discourse of rights and empowerment.

Healthy Highways Program

The Healthy Highways Program focuses on educating highway-based rural sex workers and their clients about HIV prevention, as well as supplying condoms and sexual health services. Sex workers in rural areas are harder to reach than those in the city; this is true even more so for highway-based sex workers.

Highway-based STD clinics take place every Friday, and are well frequented. The program has received support from transport organizations and some local medical help in the form of weekly health camps; in return, Tabiyat conducts STD training sessions in various rural areas. Among the physicians attending the training sessions, a few often agree to conduct weekly clinics along the highways. *Dhaba* (truck stop) owners and transport managers have also given Tabiyat space in transport offices to conduct weekly clinics. Clinical support is being expanded to more areas. Program staff train peer sex workers in various areas to inform others about HIV and distribute condoms at *dhabas* along the highways. As of 2001, there were plans to expand to new and busier "halt points" by handing over the old ones to peer workers.

Whereas Tabiyat's education program staff and Ayojan assist with police training in the city, in rural areas, the Healthy Highways Program staff must take care of police

training themselves. In one rural district where Tabiyat is active, there is a high police interest in sensitization workshops. In early 2000, a successful workshop was conducted in another rural area. As of late 2000, police sensitization workshops had been conducted and enthusiatically received in three more areas.

In 2000, the Healthy Highways Program was in need of a counsellor and a senior organizer. Recruiting suitable staff was proving to be difficult. Requirements for the positions were quite extensive; they wanted university-educated candidates who were available to work in rural areas, who could speak Hindi plus at least one southern language. As of 2001, a counsellor had been hired, but there was still no senior organizer. Instead, two members of the program's nine field educators would take turns being acting supervisors each month. In the month, they would conduct supervisory work once a week, doing surprise visits on the various Healthy Highways projects.

Once a month, the nine field educators get together and conduct an AIDS Mela in a rural village. Unlike those in the Education and Awareness Program, the field educators in the Healthy Highways Program only work in that program, because of the prohibitive cost of constant travel to the city. The majority of the field educators work at various points along the major highways, with a small number working in transport offices, and a few more working with peers in various areas where brothel-based sex work takes place. The peers are the access points to the various brothels, and they also identify new brothels. There are plans to conduct a survey to identify

new sex worker areas, as well as to network with other NGOs working in the area. As of 2003, the Healthy Highways Program staff were collaborating with rural-based staff in the expanded Sex Worker Protection Program, discussed earlier.

With its focus on condom promotion, AIDS education, and STD clinical services, the Healthy Highways Program works within the medical AIDS discourse. Conflicts with funders and other organizations, and similar challenges, are notably absent from the Healthy Highways Program.

Counselling, Care and Support Program

The Counselling Program is one of Tabiyat's core programs. Activities include pre- and post-test counselling for patients getting an HIV test, counselling and case management for HIV-positive people and their families, group counselling, professional counsellor training, and sensitization sessions on HIV issues for community members. General counselling services are provided at government hospitals, obstetrical clinics, Tabiyat's reproductive health and outpatient clinics, and Parvah, Tabiyat's respite home for AIDS patients. Confidential information collected at counselling centres is used aggregately to describe trends and changes in HIV/STD infection and population profiles and needs, as well as to monitor and evaluate programs.

The number of patients seeking counselling was rising dramatically between 2000 and 2002. The recruitment of new counsellors was a constant challenge. In the last six months of 2001, there had been several new counsellors who had come and gone, dismissed either because their work was unsatisfactory, or because they took long leaves of absence without enough notice or explanation. Many new patients were coming long distances from outside the city. In response, Tabiyat began increasing clinical and counselling services in rural areas. In 2001, weekly counselling services at a large government hospital were increased to five days per week, and Prakriti, a respite home in a rural district, was opened, with backup clinical and counselling services available in several villages nearby.

Antiretroviral therapy was becoming more of an issue for Tabiyat in 2001. It had become more widely available, and counselling staff attended education sessions on it. There was an interest in supplying antiretrovirals to patients, but cost was a concern. Staff wanted to supply them to as many people as they could afford, but because most patients would need them for life, there was a concern that supplying too many patients would lead to running out of medicine too quickly. Staff were concerned about the ethics of supplying antiretrovirals for too short a period of time. In late 2000, an application was made to a local funder for a reimbursement of medication costs, both for antiretrovirals and medicine for opportunistic infections, but as of the beginning of 2002, there had been no response. In late 2001, Tabiyat began building capacity for advocacy work around antiretroviral therapy.

The care and counselling needs of those patients who can afford antiretroviral therapy have changed. Counsellors help them examine various aniretroviral possibilities before starting treatment. Counsellors also encounter patients who must deal with anger and disappointment, either because they cannot begin antiretroviral therapy, or because therapy must be discontinued due to medical or financial reasons.

Home care visits have been extremely successful. The home care team consists of one counsellor and one nurse, working once a week. Due to the sprawl of the city, they usually can only cover a maximum of three or four homes in a week. During a home visit, the patient and family members receive counselling, support, and information on HIV, as well as basic nursing care such as feeding, oral rehydration, changing bed position, pain management, and oral hygiene. They lead to greater sensitization of not only family members, but also neighbors and the larger community. Home care visits are difficult to make frequently, though, due to the distance staff must travel to each individual home. As of late 2001, there was only one home care team; there was great demand for a second one, but due to budget constraints, this was not possible.

Admissions at Parvah increased from 2000 to 2002. As of early 2000, there was a shortage of trained nurses and counsellors, a problem that was dealt with through volunteer recruitment later in the year. Overworked, the existing staff were experiencing high levels of stress. There was an increase in admissions of patients in the more advanced stages of AIDS, leading to both more complex care needs and more terminal cases. In late 2000, concerned about staff burnout, Tabiyat sent one

Parvah staff member to receive 10-day training on caring for terminally ill patients. The staff member passed the training along to the rest of the staff, and since then, staff have become more confident in handling terminally ill cases. To further deal with potential staff burnout, Tabiyat increased the support care staff, trained staff in palliative care, and set aside time for regular personal and professional sharing among staff, as well as work-related meetings.

Another problem related to the trend of patients coming to Parvah at later stages of AIDS was an increasing length of stay for most inpatients. This led to a decrease in admissions, resulting in more patients seeking admission than beds available. Many of these patients were referred to the home-based care program, but it too was working at close to capacity. Many patients were referred to other NGOs known to have respite centres. Tabiyat engaged in networking to find other respite centres for the patients they had to turn away. This led to the identification of two convents willing to take women and children. In 2001, all patients turned away by Parvah were either found beds in other respite homes or given home-based care. Networking with other organizations continues in order to find as many alternative sources of care as possible.

Many of the patients coming to Parvah at late stages of AIDS were coming from rural areas. Patients were putting off travelling until they were seriously ill. Tabiyat saw a need for a rural respite home for HIV-positive people, and their response was to open Prakriti, a new 10-bed inpatient facility in a rural district. Local doctors were trained

in the city and brought back to offer local clinical services. As there had been many requests for it, home care services were being planned in the area. There had been some difficulty in finding a nurse to start the inpatient program, and as of early 2002, Prakriti was only a few months old, and there was still a need to strengthen the staff and programs. Home care was a priority.

As of 2000, there was an interest in improving documentation within the care and counselling program. Documentation was done manually by the counsellors themselves. In 2001, the possibility of purchasing software for documentation was explored, but proved to be too costly, and instead, the manual system was strengthened and improved. Documentation was increased to daily, weekly, and monthly updates, and follow-up tracking methods were improved with anonymous index numbers for each patient.

Tabiyat has implemented an ongoing nurses' training program at government hospitals. In 2000, counsellors took part in a 5-day Advanced Counselling Skills Workshop, which led Tabiyat to provide stronger emotional and psychosocial support. Group counselling sessions in hospitals have been very successful. They have led to bonding and mutual support among patients, as well as advocacy for basic services in the ward. Government hospitals provide space for Tabiyat to conduct their individual and group counselling sessions, they refer patients to them, and they generally respond positively to requests and suggestions. Ongoing concerns with counselling clients include TB medication compliance, cross-infection, patients

skipping post-test counselling sessions, loss to follow-up, and getting HIV negative husbands to be supportive of HIV positive wives.

The services at Tabiyat's outpatient clinic were strengthened in late 2000 and 2001. A weekly STD consultant began working there in 2000, and in 2001, a dentist and ophthamologist began offering weekly services as well. Medical students visit the Clinic on a weekly basis, offering general practitioner services. A continued problem, however, is a lack of space in the clinic. Counsellors must share one cubicle, in which there is barely enough room for two people. There is funding in place to build a new site for the Clinic, but the processes involved in building it are bureaucratic and slow.

Linkages among other programs at Tabiyat were being strengthened in 2001. Referrals to the counselling program continued at education sessions and reproductive health clinics, and counsellors referred patients to Tabiyat's reproductive health services. Counselling sessions began at the reproductive health clinic, in return for reproductive health services for HIV positive women every Thursday at the outpatient clinic. Tabiyat was also engaging in networking to increase casework services such as food supplements, education sponsorships, medication, surgical interventions, job placement, and emergency support. There were ongoing attempts to involve other NGOs in care of HIV-positive people. Future plans for the Care and Counselling Program include building the program's infrastructure to cope with the complex and diverse needs of HIV-positive people who come seeking treatment at every stage of

infection. As of 2003, Tabiyat had provided program staff with extensive training in palliative care, and there were plans to continue providing this training.

In their Care and Counselling Program, Tabiyat is engaged in a fairly new struggle, growing primarily out of the issues of availability and affordability of anti-retroviral therapy. The World Trade Organization (WTO) has an intellectual property agreement which allows pharmaceutical companies a monopoly on drugs they patent for 20 years. As a result of this agreement, pharmaceutical companies are able to set prices for anti-retrovirals at any level they choose, usually much too high for the average HIV-positive Indian. Tabiyat is the local representative for the Affordable Medicines and Treatment Campaign (AMTC), an advocacy group fighting to get the Indian government to keep the cost of medicines down. India must change its patent laws by 2005 under a WTO agreement they signed, but according to an AMTC pamphlet, there are still a few loopholes that the government can exploit to keep drug costs low.

In my interview with Radha, she expressed a belief that Tabiyat would play a stronger advocacy role in the care sector in the near future, particularly with regard to rights for HIV-positive people and drug availability. In the beginning, there were no plans to engage in advocacy work in the Care and Counselling Program. They originally wanted to stay away from social justice issues, because Tabiyat staff did not feel sufficiently trained or experienced in the area. Any social justice concerns which were brought up by their clients would be referred to other organizations with more experience in dealing with such problems. However, Tabiyat's policy is to address

needs related to HIV that are not being met. The availability of anti-retroviral therapy for people with HIV is an important issue to Tabiyat, one that they felt was not being sufficiently addressed in the city. Radha wants to work with the government to ensure that care is available, as well as facilitate availability of care. As they did with pre/post-test counselling in their early years of operation, she sees Tabiyat as needing to convince the government that there is a need for care that is not being sufficiently met. As of 2003, Tabiyat was continuing to focus on advocacy, with a particular emphasis on discrimination issues.

In response to this perceived need for more advocacy around anti-retrovirals and care for people with AIDS, Tabiyat is building their capacity in advocacy and engaging in a struggle against the pharmaceutical industry. Their work in this capacity is reminiscent of ACT-UP's advocacy for affordable drugs. However, while ACT-UP's fight for affordable drugs began when the dominant voices in the debate were those of advocates of the pharmaceutical industry, there has recently been a shift in the general development discourse, such that the dominant voices of the debate are now the advocates of the HIV-positive population. Further, as mentioned earlier, the AIDS discourse in India contains a strong element of advocacy around anti-retrovirals. Tabiyat's involvement in the fight for availability of these drugs is thus an example of their participation in a strong India-specific AIDS discourse.

Networking and Training

Tabiyat networks with various members of the community in many different ways. We have already discussed the networking they do with physicians and other medical personnel in the Women's Reproductive Health Program and Care and Counselling Program, *dhaba* owners and transport managers in the Healthy Highways Program, as well as construction supervisors and engineers in the Education and Awareness Program. Tabiyat also networks with community-based organizations and other NGOs in almost every one of its programs. This section focuses on two programs devoted to training and networking with other organizations, followed by a brief discussion on Tabiyat's networking generally.

HASST

Ayojan, formed in 1998, links NGOs working in several sectors, including empowerment of tribal groups and low castes, gender equity, child rights, natural resource control, and HIV/AIDS. Tabiyat is the lead agency for Ayojan's HIV/AIDS Sector Support Team (HASST) in their state. Ayojan funds Tabiyat to train and build capacity for HIV/AIDS projects in non-AIDS NGOs. As of the end of 2001, training had been done with 10 NGOs, both Ayojan members and non-members. The most credible NGOs are chosen to train. Tabiyat takes its best practices, and transfers them to other NGOs, who integrate HIV/AIDS into their existing programs. These "best practices", originally awareness and education programs, are now moving into larger intervention programs. Tabiyat also coordinates with the HASST leader for another southern Indian state.

The idea of HASST is to build on the experience of NGOs working in other sectors by offering technical support and help in the planning and implementation of HIV/AIDS prevention and care initiatives. This technical support consists of an initial field visit for resource and needs assessment, help in planning the intervention, help with resource mobilization, and training. Tabiyat makes sure that during the planning phase, the larger HIV/AIDS issues such as confidentiality are kept in mind. They also make sure that the intervention is tailored to the population's needs and the NGO's strengths. Once the planning is complete and funding is in place, training consists of basic facts about HIV/AIDS. Other components of training depend on the characteristics of the NGO; the most common are HIV/AIDS and development, identification and management of STDs, sexuality, women's reproductive health, women's vulnerability, communication skills, street play preparation and training, and HIV/AIDS issues such as stigma, discrimination, confidentiality, and disclosure. Once training is complete, the interventions can begin, with NGOs responding to issues as they arise within the contexts of their own communities. There is a great emphasis on getting other NGOs to recognize HIV/AIDS as a development issue. From the beginning of 2000 to the end of 2001, eight NGOs committed to HIV/AIDS interventions; they all recognized it as a development issue and integrated their intervention work into their other sectors.

There have been problems in coordinating staff for the HASST program. In early 2000, there was a concern that trainers be experienced field workers, so the program

was restructured to ensure that trainers were all active in field projects. By the end of 2000, however, there was a concern that the training staff were all doubling up from other programs, and that the HASST program did not have any staff of its own. As of the beginning of 2002, doubling up was still a problem.

As of 2001, Tabiyat had been helping partner NGOs move from individual interventions to initiation of working through networks and federations in order to broaden the coverage of their prevention work. A greater emphasis was being placed on the transfer of skills to members of the community. Future plans included building a core HIV/AIDS training team within Sehyogi to take on the training of its various sectors, as well as development of monitoring and impact indicators jointly with HASST members.

Dehat

Dehat is an integrated village development initiative involved in 22 different villages. Like Tabiyat, Dehat is one of Sehyogi's sectors. There are ten projects within Dehat, one of which is Women's Reproductive Health and HIV/AIDS. The director of Tabiyat is part of the decision-making on this program, and Tabiyat provides direction, training, capacity building, and review (in exchange for funds), but has no part in program implementation.

Tabiyat's role in Dehat is to control the spread of HIV/AIDS in its project areas through a range of preventive and care interventions. This is done through awareness programs in each village, backed up with small group discussions and condom promotion. Staff work through women's microcredit self-help groups to reach women with information on HIV/AIDS and reproductive health. Community involvement in prevention work is encouraged through training of local NGOs, grassroots organizations and self-help groups. Tabiyat is seeking to improve access to care for HIV-positive people in Dehat's project areas.

As of 2001, rural clinical services were being expanded and strengthened in Dehat villages, particularly in those with which Tabiyat was already working. Community volunteers received training in street plays, developed a script on STD prevention, and held performances in their community, each followed by group discussions on sexual and reproductive health. There was an interest in finding new staff to lead the project on the ground in some of the more active villages, instead of those projects being managed from other locations.

The majority of Tabiyat's networks with other organizations have been positive. Although many of these positive relationships are in conjunction with Tabiyat's activities within the dominant medical AIDS discourse (such as physicians who treat STDs and *dhaba* owners distributing condoms), others are groups similarly working within a discourse of rights and empowerment, in areas such as community empowerment and advocacy. For example, one of Tabiyat's activities is a women's

reproductive health community-based project in three urban slums. There are two NGOs working in the areas that Tabiyat is networking with. One of them works in literacy, and the other works in children's advocacy.

One particularly successful collaboration with an NGO working against the medico-moral discourse was an exchange with another AIDS NGO in Bangladesh. Tabiyat sent their sex worker program team to visit the Bangladeshi NGO, and they sent their truck driver program team to visit Tabiyat. Tabiyat's sex worker team learned about scaling up, capacity-building, system monitoring, and sex worker collectives. According to one core staff member I spoke with, Tabiyat learned three important things from the exchange: one, they had become distanced from the sex worker community; two, they had not sufficiently addressed the problem of violence; and three, the Sex Worker Protection Program had become routine. This exchange helped Tabiyat reconnect with the sex worker community and avoid the "danger posed to NGOs [by] the resilient ability of the development industry to absorb and transform ideas and institutions." (Fisher, 1997; p. 445)

Although the exchange with the Bangladeshi NGO was a one-time collaboration, Tabiyat has ongoing relationships with other organizations working within the same philosophical approaches as them. One example is Tabiyat's networking relationship with Ayojan, who place a similar emphasis on the transfer of HIV prevention skills to the community both as a right of the community and as a swifter intervention process. Tabiyat's relationship with Sehyogi was discussed in the previous chapter.

Involvement in networks with groups working within the same discourse not only helps Tabiyat to maintain their philosophy, but also strengthens the discourse within which they work.

Summary

It should be kept in mind that many of Tabiyat's activities are in line with the medical discourse, arguably the most dominant AIDS discourse in India. They educate impoverished and vulnerable communities about HIV, its modes of transmission, and encourage condom use for sexual activity and early STD detection and treatment. These activities are viewed as important and necessary to AIDS prevention by almost everyone. However, Tabiyat goes beyond these standard HIV prevention practices in several activities. It is these activities that make Tabiyat an NGO "engaged in a struggle for ideological autonomy" (Fisher, 1997; p. 445).

By refusing to see sex workers as victims who need to be "saved", and encouraging them to come together as a community without feeling shame about their profession, the Sex Worker Protection Program is working against the medico-moral sex worker discourse in India. It should be noted, however, that by working against this discourse, they are in fact participating in another, less dominant discourse. The discourse of sex worker rights and empowerment is prevalent in Europe and North America, and the popularity of the Sonagachi project demonstrates that this discourse is growing more dominant in India as well. Tabiyat's participation in this discourse no doubt contributes to its growing dominance.

Further, Tabiyat's efforts to initiate a sex worker collective, also part of the rights and empowerment discourse, are in line with Paulo Freire's (1970) theories of educating the oppressed to question their position in society in relation to their oppressors. As such, Tabiyat's efforts around collectivization can be included in what Fisher (1997) refers to as "vehicles for challenges to and transformations of relationships of power" (p. 445).

Within the context of a country in which women's health is seen as last priority (Basu, 1995), Tabiyat's emphasis on women's right to reproductive health in its Women's Reproductive Health Program is an example of what Fisher refers to as "turn[ing] issues that directly engage the self, subjective experience, and daily life into crucial sites of political contestation." (p. 458) As with the sex worker empowerment initiative, this emphasis on women's health rights is an example of Tabiyat struggling against another India-specific discourse; in this case, the priority of women's well-being, it could be referred to as a patriarchal discourse, deeply rooted in India's history. Once again, it should be noted that Tabiyat, by working against this discourse, is participating in another – an Indian feminist discourse, centered around the improvement of the status and treatment of women in India.

Although Tabiyat are not always positioned against the dominant discourse in their programs and activities, they are always firm in their philosophy, regardless of what discourse it falls into. AIDS discourse, at least in India, appears to be extremely

complex, with opposing discourses often overlapping to a certain extent. The results of the current case study seem to suggest that categorizing NGOs on the basis of their discursive position, as Fisher has suggested, is not ideal for NGOs working in the field of AIDS prevention and care. The next chapter is a further discussion of Fisher's theory in light of the current findings on Tabiyat.

Chapter 7: Discussion

It is difficult to categorize Tabiyat as working either within or against the dominant discourse within which it must work. As has been demonstrated in previous chapters, they engage in activities which are within the dominant medical AIDS discourse in India, as well as activities which are within less dominant rights and empowerment discourse. The fact that Tabiyat works against the dominant discourse in some of their programs compounds many of the challenges that they face with external forces (for example, police, funders, and other NGOs) when the priorities of these groups are more in line with the dominant paradigm than those of Tabiyat. Finally, the current case study of Tabiyat underscores the limitations of using Fisher's theory to understand individual NGOs. Fisher focuses primarily on a general development discourse from the perspective of the West, whereas the dominant AIDS paradigm in India is more locally oriented, and not identical to the development discourse as discussed by Fisher. Further, the inherent fluidity of discourse means that the dominant voice from issue to issue is likely to be different, and NGOs are unlikely to fit cleanly into either of Fisher's categories.

Some of Tabiyat's activities are examples of Fisher's category of NGOs working against India's dominant AIDS and development discourse. They participate in advocacy work, particularly around care and treatment for people with AIDS. Empowerment is currently a popular buzzword within the dominant development discourse, including the AIDS discourse. However, the empowerment rhetoric often

does not translate into actual empowerment of marginalized communities (Fisher, 1997). Tabiyat's community empowerment and ownership initiatives are examples of efforts at a true empowerment process, in line with Freire's (1970) theories of empowering oppressed communities to recognize and question their oppression. In particular, their sex worker collective project is an example of helping a marginalized community stand up for itself. Within a dominant medico-moral discourse which believes sex workers should be either punished or rehabilitated, Tabiyat is constantly struggling to promote their view that sex workers should be respected and empowered.

Further, the inclusion in Tabiyat of sex workers and HIV-positive people at every level of the staff structure, including the core staff, is indicative of their close relationship with the community they serve. Clearly, their community involvement is more than a "rhetorical flourish" (Fisher, 1997; p. 455). The community has representation at all levels of decision-making, including those at the highest.

The challenges inherent in Tabiyat's work are affected by where those challenges are coming from, and the compatibility of the goals and priorities of the sources of the challenges with the goals and priorities of Tabiyat. More specifically, the less compatible the priorities, the larger the challenges. Tabiyat's relations with other organizations, including other NGOs, are affected in part by the compatibility of their philosophies with those of Tabiyat. Many of their negative experiences with other organizations can be attributed to the fact that these other organizations are working

within a discourse to which Tabiyat is in opposition. The police are an example of an organization with a vastly different philosophy on the sex trade. Whereas Tabiyat is working within the rights and empowerment discourse by attempting to give sex workers a sense of voice and community, the local police are working within the medico-moral discourse through rehabilitation efforts. The conflicting approaches lead to tensions and problems with the police in Tabiyat's Sex Worker Protection Program.

Another example of the challenges faced by Tabiyat working against the dominant discourse is their relationship with funders. Securing funding for projects such as the Ward-based program and the two respite homes is challenging, due to the emphasis on cost-effectiveness of many funding agencies. Tabiyat's relationships with other organizations are also affected by those organizations' discursive positions. For example, Tabiyat's Women's Reproductive Health Program experiences challenges with women's health organizations that do not focus on reproductive health as a woman's right. Their collaborations with organizations that work within many of the discourses within which Tabiyat works, such as Sehyogi, are more successful and rewarding.

In contrast, the Education and Awareness Program, which fits into the dominant medical discourse, experiences much fewer challenges than the Sex Worker Protection and Women's Reproductive Health Programs. Similarly, the Healthy Highways Program, which also works within the medical discourse, experiences

relatively few challenges compared with the programs working within alternative discourses.

As mentioned at the beginning of this chapter, Fisher's theory focuses on a general development discourse, as described by Escobar (1997) among others. This discourse, with its emphasis on a struggle against dominant ideas detrimental to local communities, is commonly represented in areas of development such as economics, agricultural development, and environmental sustainability. Within these areas of development, the dominant discourse is sometimes seen as having goals in direct opposition to the interests of the local community. One example of this is the Narmada River development, discussed in Chapter 2. While the goal of the government of India is to increase the country's supply of electricity, the goal of organizations opposed to dam construction is to protect those living along the river from flooding and displacement. The AIDS discourses, however, all have the same goal: to prevent the spread of AIDS. Further, activities within the less dominant discourses do not preclude activities within the more dominant discourses. Even ACT-UP and Sonagachi engage in activities within the medical AIDS discourse, such as condom promotion, along with their rights and empowerment initiatives. Thus, the competing AIDS discourses differ in subtler ways than those of agriculture and environment, with much more overlap between discourses, as well as organizations.

With this in mind, it is not surprising that Tabiyat works within the dominant discourse in many cases, from their condom promotion strategies and education

sessions to their advocacy work around antiretrovirals. Fisher's theory does not take into account the fact that discourses vary not only among countries, states, and neighbourhoods, but also among issues. There is evidence that certain issues, such as AIDS prevention among sex workers, are subject to competing discursive approaches. For example, it appears that the dominant discourse around sex worker prevention is the medico-moral discourse. The police seem to treat sex workers either as criminals, subjecting them to routine harassment and violence, or as victims, as is evident in their official goal of rehabilitation. The local State Home similarly seems to view sex workers as victims, as they will house only sex workers who commit to rehabilitation. The women's organizations with which Tabiyat attempted to network around the issue of violence against women appeared to discriminate against sex workers by treating violence against them as a secondary issue. However, the popularity of the Sonagachi project has led to a greater demand for sex worker interventions within the rights and empowerment discourse. When the discourses around HIV/AIDS in India are changing from issue to issue, it is difficult to categorize Tabiyat as either within or against the dominant discourse, particularly when there are several discourses competing for dominance around some issues, such as sex worker protection. Tabiyat's activities need to be understood as expressions of a variety of discursive approaches, and its effectiveness as an organization is in part a product of its capacity to manage the tensions implicit in these contrasting approaches.

Further, Tabiyat's activities which appear to be working against the dominant Indian discourse, such as sex worker empowerment, fall into already-existing discourses

which have the potential to become more dominant. According to Foucault (1978), discourse can produce and reinforce the existing power structures, but it can also undermine and expose them. Although AIDS education and condom promotion have long been part of the dominant medical AIDS discourse, the rights and empowerment discourse has grown from what Seidel (1993) referred to as an articulation of "dissident voices" (p. 175) to what may be seen as a discourse equally dominant as the medical discourse. As some of those "dissident voices" came from NGOs, including ACT-UP and activist NGOs in sub-Saharan Africa (Seidel, 1993), the growth of rights and empowerment discourses, which incorporate such activities as advocacy for sex workers, HIV-positive people, and antiretroviral availability, can be viewed as examples of what Markowitz (2001) refers to as NGOs' engagement in a "restructuring [of] the [development] system itself, from close to the bottom up." (p. 41). Fisher's theory does not take into account the inherently fluid and constantly shifting nature of discourse. NGOs working against the dominant discourse in some of their activities, such as ACT-UP globally, as well as Sonagachi and Tabiyat's already mentioned sex worker empowerment activities in India, are contributing to discourses which have the potential to grow in dominance. The growth of the rights and empowerment AIDS discourse provides evidence of such potential. Longitudinal study of the environment in which Southern Indian NGOs must work would help to determine if a similar discursive shift is indeed happening in India as well.

Within the context of the ICHAP project, the results of this study illuminate some of the challenges inherent in funding NGO projects. ICHAP must maintain an awareness

that they have their own discursive position, and if they only fund NGOs which work within that same discourse, they run the risk of excluding NGOs engaged in what Fisher refers to as "the rebellious process" (p. 459), a process with roots in India's long-standing activism tradition. Further, ICHAP is in the position to prevent "the resilient ability of the development industry to absorb and transform ideas and institutions" (Fisher, 1997; p. 445), and instead encourage alternative discourses to grow in strength, by funding activities working against the dominant discourse that go beyond the "rhetorical flourish."

To date, there have been no published examples of the application of Fisher's theory of discourse analysis to understand NGOs. Further such studies, particularly of NGOs working in different areas of development, would contribute to a better understanding of both NGOs and the discourses within which they must work, discourses that appear to be almost as varied and wide-ranging as the NGOs themselves.

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