Bodies of Knowledge:
The Contested Construction of Technologies and Information of the HIV/AIDS Epidemics in Calcutta and New York City

by
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Abstract

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Adviser: Dr. Barbara Katz Rothman

My dissertation considers how knowledge about HIV/AIDS is produced and received, with respect to the effects that information has on individual bodies and on whole communities, or populations that end up organizing as communities. I have produced a comparative social history of community based organizing around HIV/AIDS knowledge in New York in the mid-to-late 90's as compared to similar organizing in Calcutta in the late 90's to 2002. Specifically, I report and compare how immigrants (many of them queer or workers in the sex industry) did such organizing in New York and sex workers (many of them immigrants or queer) did in Calcutta. Critical to my study is the matter of how we commonly come to see risky behaviors as conflated with dangerous people. This question becomes all the more interesting as more money is channeled into international work on AIDS prevention and treatment (by organizations such as the World Bank, major non-profit sources like the Global Fund for AIDS, and by private funders like the Bill and Melissa Gates foundation). Over the past two decades, social movements to contest the stigma and

social control that have many times accompanied these public health campaigns have also increased in vigor and in visibility. So how has the social construction of knowledge about HIV/AIDS served: (1) in many cases, as a vehicle for social control targeted at the bodies that serve – symbolically and/or materially – as 'dangerous' vectors for disease; and also (2) as a vehicle for certain politically disenfranchised groups to galvanize themselves into effective movements claiming access to information, to health-care, and to representation?

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Chapter 1: Approaching this Dissertation

Framing the Problem

My dissertation considers how knowledge about HIV/AIDS is produced and received, with respect to the effects that information has on individual bodies and on whole communities, or populations that end up organizing as communities. Some of the groups I studied did only retrospectively identify with each other as the risks and stakes they shared in the HIV/AIDS epidemic became clear. I have produced a comparative social history of community based organizing around HIV/AIDS knowledge in New York in the mid-to-late 90's as compared to similar organizing in Calcutta in the late 90's to 2002.

Specifically, I report and compare how immigrants (many of them queer or workers in the sex industry) did such organizing in New York and sex workers (many of them immigrants or queer) did in Calcutta. These groups found themselves, first, connected to each other by the stigma and social obstacles they faced, which were exacerbated by the association of these groups with the 'sources' of the AIDS epidemic. Critical to my study is the matter of how we commonly come to see risky

behaviors as conflated with dangerous people. This question becomes all the more interesting as more money is channeled into international work on AIDS prevention and treatment (by organizations such as the World Bank, major non-profit sources like the Global Fund for AIDS, and by private funders like the Bill and Melissa Gates foundation). Over the past two decades, social movements to contest the stigma and social control that have many times accompanied these public health campaigns have also increased in vigor and in visibility. So how has the social construction of knowledge about HIV/AIDS served: (1) in many cases, as a vehicle for social control targeted at the bodies that serve – symbolically and/or materially – as 'dangerous' vectors for disease; and also (2) as a vehicle for certain politically disenfranchised groups to galvanize themselves into effective movements claiming access to information, to health-care, and to representation?

In Calcutta, although the work there started in diverse quarters – from queer organizations to infectious disease clinics to, really, the home-based initiatives of concerned citizens suddenly working together – it coalesced around the organizing by sex workers, most notably in the Sonagachi red light district. The Sonagachi sex workers have organized on a modified labor model, and they have received a great deal of

attention from the international media and from transnational bodies like the United Nations/World Bank AIDS program. In New York, the community-based organizations (CBO's) I looked at were mostly agencies serving immigrant populations that began as tiny grassroots *ad hoc* groups and grew, in two cases, into high profile, well-funded, self-described corporate-style establishments. I worked for one of these groups for five years, during which time the nature of the organization changed radically, leading to a series of rifts and protests that have, in turn, yielded another grassroots group. These cycles of formation (initiation of a group or program Æ complaints and conflict Æ rift or separation Æ formation of a new wing) are common in this sort of local organizing, and many of the people I knew as an AIDS worker and whom I interviewed as a social researcher affiliated themselves with a series of groups over a period of years. In these cases, people's personal, political, and professional networks overlap significantly.

So why compare the two cities? I will explain the comparison in greater detail as I go along in the dissertation, but to begin with, there is my political stance that more international research very much needs to be done, especially where health and medicine are concerned; and HIV/AIDS, of course, became a global pandemic so early and so visibly. I

was also struck by the similarities between the municipal policies of New York and Calcutta and by their symbolic juxtaposition at the intersection of the first world and the third. The one city, in the mid-90's, was aggressively capitalist in bent, and the other had a communist government, at least nominally (CP-West Bengal). And yet, both city administrations instituted very similar schemes of getting rid of the homeless, suddenly cracking down on the underground sex industries that had long been tolerated (and which contributed to the economic flow of the cities), and initiating all sorts of bizarre rules intended to improve 'quality of life' and the city's morality.

For example, the Calcutta police decided at one point to get rid of the horrible image of hand-drawn rickshaws in Calcutta. Indeed, these rickshaw-*wallahs* are probably the poorest working people in the city, but the police simply began arresting them and confiscating their vehicles, separating them from their best available means to a livelihood in the name of eliminating the squalor associated with such work. This, I thought, was quite similar to Giuliani's criminalization of homelessness through cracking down on behaviors like public urination, building squatting, and panhandling. In the New York crackdown on the 'squeegee men' who contributed to the image of the city as full of mayhem but also provided a

'service' for a 'fee' and a minimal income for themselves, parallel rationales were at work[1]. In denouncing poverty, the city administration blamed those who were poor rather than the mean political economy that demanded broad poverty as a balance to high affluence.

Given this, the issue of AIDS became a real flashpoint and symbolic topic amidst these processes throughout the 1990's. There was also a great deal of interaction and cooperation between organizers in the two cities, with activists sharing strategies over e-mail and supporting each other's campaigns through fundraising or by holding 'sister' events. And as well, the dual city study reveals many aspects of the profoundly urban nature of HIV/AIDS as an epidemiological, a cultural, and a political phenomenon. So, there are some crucial intersections in the two stories that off-set their differences and provide nuanced and more generalizable insight into the urban politics of managing the HIV/AIDS epidemic.

A final point on the comparison concerns the categories into which those who write about the pandemic frequently break it down: into seemingly discrete epidemics apparently determined by geography and strain of HIV (type 1 or type 2). These epidemics are actually distinguished

[1] I am indebted to the input of my writing group in working out the details of this comparison and, in particular, to Penny Lewis for raising the example of the New York squeegee men.

by populations defined largely by where people live (locations often vaguely described as 'Africa' or 'the inner city') and what behaviors they engage in; but, these characteristics, in turn, are determined more by race and level of poverty than by other factors. Cindy Patton, in her books *Inventing AIDS* and *Fatal Advice,* describes in detail how the media, in the late 80's and very early 90's, distinguished amongst the [gay, urban, white] AIDS (explicitly unqualified) epidemic, the 'heterosexual AIDS' epidemic [in North America and Europe], and 'African AIDS.' Paul Farmer, a decade later, described in *Infections and Inequalities* the persistence of these categories and the strange position Haiti holds amidst them. To the limited sense that we can speak of an African epidemic, we must see that it is also usually, but not always, an heterosexual one, often but not uniformly urban. The 'African' epidemic, too, is concentrated in certain countries of the southern part of the continent and amongst the poorer people in those countries, but Africa remains in much North American conversation as a single, monolithic place (by implication when not explicitly stated so).

Haiti is not an African country and is in the northern hemisphere, but it is largely populated by Black people, has an impoverished economy and a warm and tropical climate, so journalists and scientists

alike have linked it to the African AIDS epidemic. Farmer relates how, throughout the 1980's, researchers posed semi-fantastic theories about how voodoo rituals and cultural practices of drinking raw blood had carried HIV from the African continent to Haiti when, in actuality, it was a relatively simple epidemiological exercise that ultimately showed the infection more likely traveled to Port au Prince *via* tourists from the US or Europe. Strangely and subtly but not so surprisingly, the epidemic that strikes so many urban African Americans (gay and straight) in the US is sometimes connected more soundly to African AIDS than to any US category of transmission. Meantime, Asians in the US are slowly being subsumed into the white ethnic grouping and still often left out of HIV transmission studies entirely, slipping back into invisibility and a position of assisting the dominant class just as Asian American political movements that energetically questioned assimilation and the model minority myth were coming to fruition. In both cases, the racist reasoning behind such collapsing is painfully clear.

Inserting Asia into the comparison somewhat upsets the dichotomy that exists between an US/Canadian/European epidemic and an African one. From our US view on Asia, we tend not to see the similarities and connections between its countries and cultures and those

of Africa. Particularly, parts of Asia seem like more accessible tourist spots, less dramatically poor, less symbolically 'other' than what we think of as Africa. Unlike the Haitian case, the unproven assumption has always been that HIV traveled to Asia through the sex tourism of affluent whites, erupting there from red light centers in Bangkok, Goa, or Bali. Ironically, much of such tourism is actually conducted by white Australians, from the southern hemisphere and the fuzzy edge of Asia; and, the trade and labor routes between African and Asian countries have long carried infections, income, politics, musical styles, etc. back and forth.

In avidly denying that the Calcutta AIDS epidemic was a local problem, the municipal government initially only sought to blame European tourists, both overlooking the similarity to the sub-Saharan epidemic and perhaps feeling more comfortable with a connection to a less severe and whiter one. A 1996 *New York Times* feature on AIDS in India, however, led the trend of referring to the country's epidemic as 'the next epicenter' or 'the next Africa.' (Burns 1996, see also Monaghan, 2004) Somewhere between this lumping together of all third world people, including those who are poor and of color in wealthier countries, and the aggressive positioning of Africa as unitary and separate from all else, I attempt a more subtle comparison between two cities that share large

immigrant populations, a great deal of human traffic in and out of their borders, and histories of highly organized poor and working classes.

My Research and Methodological Approaches

My research is fundamentally qualitative. I used a combination of methods to collect and comprehend my source material. The backbone of the research is a social history I constructed from archived material recording and describing the development of organizations, the organizing work done by informally gathered activists, various educational campaigns or workshops, and the obstacles encountered along the way. These archives were the institutional ones kept by certain groups and the personal ones that some interviewees gave me access to; I also accessed the archives at AIDS libraries in New York and Philadelphia. I fleshed out this history by using face-to-face and telephone interviews and participant observation to draw a personal map of AIDS organizing in these cities. This research is supplemented by my reflections on the problems and patterns I encountered in my own AIDS work in New York. While I did not draw any specific events or references from that work experience for analysis here, I did use my experience to inform my

understanding of the material I read and my conversations with informants.

My interviews were collected through a sort of modified snowball sample of people involved in organizing around HIV/AIDS or providing care for those with HIV in Calcutta and New York. My entrée into this network began with people I worked with through the AIDS education and advocacy I did with one group in New York for five years, doing Bengali-English interpretation for clients and outreach prevention education in Asian immigrant communities as well as developing educational materials and coordinating education programs. During this time, I also did some fundraising for AIDS groups in India and, through that conduit, 'met some people who knew some people.' These HIV/AIDS organizing circuits in both cities are relatively small, and my sample allowed a good cross-section of them. I also worked as a liaison with other groups in New York and with HIV/AIDS, sexual health, and queer organizations in Calcutta. I did my participant observation at the meetings of organizing groups in New York and Calcutta, and I conducted interviews with organizers from Calcutta over telephone and in New York when they were traveling here or, in two cases, because they had resettled here. Finally, to round all the information out and situate it

within the vein of common conversation, I conducted content analyses of a broad review of the media reportage on the global pandemic, attending to major newspapers and to the reports and newsletters made public by groups such as the World Bank, the World Health Organization, and the Centers for Disease Control.

In most cases, I did not tape record interviews to protect informant confidentiality and also did not keep records of names or any specific identifying demographic data. Rather, I identified interviewees by the city in which each worked, the years s/he worked, and the type(s) of work s/he did, and assigned each interview a pseudonym later. I believe not only that these extra measures helped me to provide the confidentiality I promised but also that explaining them during my interviews helped reassure my informants that they could speak frankly and openly with me. While I certainly think that every researcher must view her informants with some measure of healthy skepticism, it is also important to give them every possible reason to speak candidly, especially with such a politically charged topic as the HIV/AIDS epidemic and the high competition that exists for funding and credibility for AIDS workers. In taking this methodological perspective, I am echoing Rose Weitz and Victor Ayala in the sociological studies they did of the lives of

people with AIDS in the late 80's and early 90's. In my approach to my informants and the networks of people I studied, I owe a great deal to Patricia Clough's book *The End(s) of Ethnography: From Realism to Social Criticism* (1992) and to extensive conversations I had with Hester Eisenstein and Barbara Katz Rothman about conducting participant observation within social movements.

This research focuses on the years between 1994 and 2002. In 1994, the emergence of combination antiretroviral (ARV) therapy was still a couple years away – although only a few élite clinicians and researchers knew we might be that close and no one knew what the true implications of such treatment might be. ARV therapy eventually changed HIV-disease from a fatal to a chronic ailment for those who can afford the treatment and who react well to it, and it created a greater divide between the epidemic that afflicts wealthier countries and that which afflicts poorer ones. In 1994, too, the Calcutta government was still vehemently denying that there was any serious AIDS problem in the city at all, blaming foreigners for any cases that became impossible to ignore. Within a few years, the city's epidemic grew beyond denial and the public health information posted and distributed by citizens' groups made the reality of the disease clear as Calcuttans daily passed billboards, read

leaflets, and heard public service announcements on television. The US immigration laws restricting those with HIV had not yet passed into disastrous effect. After they changed in 1996-1997, deportation (now euphemistically termed 'removal') loomed as a possibility for any immigrant – legal or not – with HIV. Services available for positive immigrants all but disappeared, and it became increasingly difficult to motivate or provide for non-US citizens to test their serostatus. The immigrant service agency for which I worked was audited around this time and barred from employing or providing housing or food subsidies to anyone without full documentation. The face of HIV/AIDS care, advocacy, and knowledge-making changed with these events in Calcutta and New York.

In 2002, I completed the bulk of my interviews as immigration laws in the US further tightened, the debate about whether antiretroviral patents should or could be honored in poor countries continued on, and the epidemics in Calcutta and New York both deepened. It is now evident that rates of transmission in both cities are on the rise, and there are new fears that antiretroviral therapy might become decreasingly effective over the coming decade. Given this picture, I offer an historical and comparative account of some successful community-based

organizing around the epidemic in these two cities. This is organizing that yielded real and beneficial results for the people in these communities and which made current knowledge about how to prevent HIV infection, and how to treat those with infection, more sensitive and useful. Although the HIV/AIDS epidemic has become too much a matter of course in most media and seems to have lost its edge of urgency for many people, it has grown to what I consider terrifying proportions. Prevention work has advanced little since the late 1980's and has had a negligible effect in most communities, so it seems opportune to consider the strategies and circumstances of two local movements that have been fairly successful and to consider how to work beyond the limits that have defined these movements.

To contextualize these two local movements – and the interplay between them – I first offer two case studies of global controversies concerning the management of the HIV/AIDS pandemic that have drawn in activists, clinicians, policy makers, and corporations, from several countries spanning several continents. The first is the debate concerning the validity of patents on antiretroviral drugs and treatments for opportunistic infections associated with HIV-disease, and the second concerns the question of whether male circumcision should be promoted

as a preventative measure against HIV transmission in those parts of the global south that have high rates of infection and little established practice of circumcising infant boys. I offer a review of the major events surrounding these cases and a consideration of the various political positions at play. Both cases provide international issue-focused examples of the same sorts of power negotiation and processes of mobilization, collaboration, and group formation and dissolution that we see in the rest of the dissertation. Chapter 4 considers the role of national, community, and bodily boundaries and of the military model in the epidemiology of AIDS and in the history of urban public health responses to infectious disease. This is followed by a chapter offering a feminist and symbolic interactionist understanding of communication strategies and obstacles amongst AIDS activists and service providers in Calcutta and New York and collaborating between the two cities. Finally, I offer a chapter on the everyday lives of those most affected by, and most involved in working to ameliorate, the HIV/AIDS epidemic in these cities: How did the conditions and circumstances of their lives change with the epidemic? How exactly did they work together, forming coalitions to produce services and political influence for themselves?

Most importantly, my interest in writing this dissertation – like my earlier interest in doing advocacy and education work around HIV/AIDS – is to contribute to the vast efforts that many people are making to slow the spread of the disease and make treatment more broadly available and more effective in the long term. Because of this, while my dissertation has been years in the producing, I feel a real sense of anxiety about whether this information can be useful. Cindy Patton, Simon Watney, and Paula Treichler produced beautiful, critical, cultural analyses of the epidemic as it unfolded through the 80's and early 90's, which have been very influential for me. I believe that these books have, in some crucial respects, been more insightful and relevant than the policy papers, statistical analyses, and directives produced at the same time, but I aim to produce something in-between[2]. I give here critique and opinion and

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[2] At my dissertation defense, Patricia Clough asked about the essential matter of what the space between the practical and the theoretical might be, let alone what can fill it, because the binary I set up here assumes that the theoretical and practical (cultural studies *vs.* social services, perhaps) are different for each other. I am grateful for this push to consider this issue more profoundly and to state it more clearly. I wish to clarify that, although studies about HIV/AIDS have continuously established and reaffirmed this binary, it is an artificial distinction. There are not actually two sides to the struggle to reign in the harmful effects of this epidemic, and simplistic slogans like, "Stop AIDS," really are just political maneuvers that bely the complex thinking and relationships behind them. A member of the CUNY/NCRW seminar "Human Security: A Gendered Approach," which I have mentioned elsewhere in this document, once suggested that perhaps some of the seminar participants were activists who wanted to actually change the world while other were academics who wanted to understand it. Needless to say, because the seminar comprised a roomful of politically engaged intellectual feminists, many of us took deep offence. My years as a graduate student have not been a series of back-and-forth gestures between thinking (the studying, reading, and writing) and

sociological framing, but I also hope to give a simple record that might serve as a resource and a sort of reference for those trying to (re)produce such movements at every new turn that this epidemic makes. It is a sensitive and intelligent *practical* approach that can have best effect.

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doing (the teaching, the social work, the marching and picketing). Rather, thinking and doing always happen together. This might be Marxist praxis or anarchist critical resistance or some other kind of politics. In writing that I want this thesis to occupy a space between the purely theoretical and the purely practical, I mean only that I want it to point to the presence of each in the other and to act against all the artificial binaries, the futile defending of which has sadly slowed our reactions to this growing pandemic.

A note on my use of the name "Calcutta" as opposed to "Kolkata"

In 2001, the Indian and West Bengali governments officially changed the spelling and pronunciation of "Calcutta" to "Kolkata" to symbolically throw off the city's colonial heritage as the world symbolically entered "the new millennium." It was an important move with strong meaning for most everyone with a tie to the city. The British, in establishing the city as their colonial headquarters, had named it Calcutta (meaning the place of Kali) because the area, then a collection of inter-dependent villages and estates, was known for its affinity for the goddess Kali. And, indeed, Bengalees do always pronounce the city name *KOL*kata while other South Asians tend to say *CAL*cutta and people outside the subcontinent most often pronounce the name cal*CUT*ta. Each pronunciation speaks volumes about the background of the speaker and her/his relationship to the city. The way I myself pronounce the city's name shifts with the contexts and languages in which I am speaking. The cause of denouncing a colonial regime that was brutal and total in its control of the city and Bengalees is one for which I feel great sympathy.

For this dissertation, though, I stay with the old spelling of Calcutta for a few different reasons. First, while the symbolic refusal of the city's colonial past is both important and admirable, this political motive – like most others – was far from pure. This anti-imperialist moment in India's government was also a moment of religious nationalism that called on a corruption of the Hindu and Buddhist philosophy, which I hold dear for its holistic and compassionate approach to the world, to justify murder and oppression of religious and ethnic minorities, most notably Muslims and Christian missionaries, in India. The spirit of anti-imperialism, too, was compromised by the greed that was leading to a prioritization of military, high finance, and corporate interests above the basic needs of the bulk of India's citizenry. Through the mid-1990's, India was joining the World Trade Organization and building a World Trade Center on recently drained swamp land in the north of Calcutta; supporters of the "Hindu" nationalist Shiv Sena murdered journalists – irrespective of religion – who opposed their rule in the state of Maharashtra; massive hydroelectric dam projects were moving forward along the Narmada river, destined to displace millions of villagers with no other means to dignified existence; and the names of Indian cities from Bombay (now Mumbai) to Madras

(now Chennai) to Calcutta (Kolkata) were changing to symbolically denounce imperialism.

As the now-classic feminist example goes, it is easier for those of us with a relatively great deal of privilege to talk about the violence endured by a poor woman beaten by her husband than the violence she endures when she must walk several miles to collect the day's water or watch her baby sicken and die from malnutrition. We who are relatively quite wealthy are not so easily freed from complicity in these latter examples of daily violence arising from forced scarcity as in the first. So, it seems false to speak of a throwing off of colonial histories when the people in this study have very much continued to suffer from imperialism: if no longer from outright British colonialism, then from the callous greed of their own lawmakers and the harsh cruelty of the Bretton-Woods model of development and the deepening inequities of globalization.

And finally, I wonder if it can ever be wise to disavow history – whether colonial or not – especially as I write this social history myself. Salman Rushdie has written plaintively of his longing for the old Bombay of the mid 20th century, where syncretism and disorder were celebrated more than bemoaned, and I spoke to several Calcuttans in their 60's and 70's who spoke of that city's golden age in similar terms – of a vibrant arts

and political scene and very ethnically mixed neighborhoods. Even if these memories are clouded and colored by nostalgia and sentimentality, they speak to ideals about complex communities that I would like to bring to this dissertation and, to do this, I will write about Calcutta and New York, with all their history and all their problems and all their richness – conflicted and cooperative – of culture, community, and society.

Chapter 2: Patents, People, and Power

In this case study of the debate about patents on, and international access to, antiretroviral drugs for HIV-disease therapy, I want to show how the activism and politics at the heart of this issue are closely tied to the movements mobilizing against other patents that prevent poor people from accessing resources basic to their lives. This type of AIDS activism – where the most robustly transnational stakes are those placed by local activists who interact and cooperate with other local activists in other countries – signals the more recent phase of work done, since the advent of combination antiretroviral therapy in 1997. This is the sort of case that connected sex workers mobilizing for better legal services in Calcutta with immigrants and other queers of color defending their community resources against Giuliani's "quality of life" campaign. The common issues of access and representation were clear for these two groups of people representing all those with HIV who would not be benefiting from the antiretrovirals even as the emergence of these drugs changed the nature of HIV-disease as we commonly think of it.

Particularly, this case highlights the tension between seemingly transnational corporate interests that are actually interwoven with the investments of first-world governments and the needs of poor communities and less politically influential nations. Like the political scientist Leo Panitch (1996) and many others have said, globalization is actually strengthening some states over and against others while seeming to slide behind the veil of transnational finance and markets and regulation. What, then, are the various interests placed, in terms of treating HIV/AIDS on a truly global scale? And what position does India, in particular, hold in this situation?

It is important to situate this question in the context of the history of activism around food and drug related patents over the last two decades. This has been very visible in India with regard to the neem tree[3], basmati rice, and drinking water rights, and throughout other Asian and Latin American countries with respect to other crops and, everywhere, local rights to naturally occurring potable water. We must also

[3] The case of the neem tree patent is somewhat less known than those of basmati rice and the continuing water rights issues throughout South Asia and poor communities everywhere. The leaves of the neem tree have been used by Indians for food and as an ayurvedic healing agent for at least hundreds of years, and throughout the 20th century, Indian companies have also used neem as an element in herbal soaps, toothpastes, etc. Dupont Corporation tried, in 1999 and 2000 to take out a patent on neem that would both prevent Indian companies from using neem in their products and prevent independent farmers from selling their stock to local markets. On ethical grounds, this patent was later diluted in Europe to allow for local uses to continue.

foreground the huge role that social inequity plays in the way the HIV/AIDS epidemic manifests. This might seem obvious, but the circumstances of the epidemic vary so broadly across geographical and class-based zones that the crucial factor of socioeconomic position is too often overlooked. Anthropologist Patricia Antoniello recently told an anecdote about a talk she had given at a conference on HIV/AIDS, in which she referred to AIDS as a fatal disease[4]. A doctor in the audience took issue with this characterization, countering that the disease is now *chronic* instead of *fatal*. To call HIV-disease[5] chronic, of course, assumes that everyone who is infected has access to combination antiretroviral therapy for the course of her/his life or for the decades it might take for an especially easy and tractable infection to be "cured," that s/he reacts well to the therapy, and that there is no eventual tapering off of the recuperative effects of the drugs. Most importantly, such an understanding of HIV-disease walks a fine line between the trap of grossly

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[4] She told this anecdote at a session we co-facilitated of the seminar, "Finding Human Security, Facing Global Capital: A Gendered Critique," jointly organized by the CUNY Graduate Center's Research Center for the Study of Women's in Society, the National Council for Research on Women, and UNIFEM.

[5] "HIV-disease" refers to the symptoms of illness associated with HIV infection. This is to be distinguished from the infection itself, which may not automatically produce symptoms, and from AIDS, which is more rigidly defined by the Centers for Disease Control as the concurrent presentation of three or more opportunistic infections from their list of those diseases associated with AIDS. "AIDS" is used to refer to this defined state of illness as well as to the epidemic as it is commonly culturally and politically understood.

inadequate distribution and implementation of drug therapy on the one side and that of the frightening prospect of broad-scale resistance to the anti-HIV medicines on the other.

The antiretrovirals discussed here were developed as a multi-pronged AIDS treatment through the 1990's that can inhibit the ability of the retrovirus[6] HIV to replicate itself, thus preventing the escalation of the infection into the full-blown disease. They are administered in combinations commonly called 'the cocktail' that dramatically extend the life-spans of most people with HIV (although I will refer to this treatment as ARV, antiretroviral, therapy because this term is more precise and more neutral than 'the cocktail'). The development of most of these drugs was largely funded by public monies, notably through the National Institutes for Health in the US (see CDC booklet *Emerging Infectious*

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[6] A retrovirus is a virus that uses RNA as a template to replicate itself within a "host" cell. HIV uses cells of the immune system to do this, spreading itself through an infected body as the process of copying itself also undermines the immune system, making someone with HIV-disease vulnerable to a host of opportunistic infections. Various types of antiretroviral drugs interrupt different phases of this replication process and, so, a *combination* of these drugs, along with others to prevent or combat opportunistic infections comprises what is often called the "AIDS cocktail." Many AIDS workers take exception to the term because the therapy is meant to target HIV before AIDS symptoms become prevalent and because it implies that one combination works for everyone. In an ideal situation, the combination any individual receives is tailored to her/his own medical history and daily circumstances. In its implementation, though, many people receive one of a few different standardized combinations of three antiretroviral drugs which, together, are know as Highly Active Antiretroviral Therapy (HAART).

Diseases: A Public Health Response, 1998), but their production, distribution, and their patents have primarily been in the hands of large, western-based but transnational pharmaceutical conglomerates like GlaxoSmithKline, Pfizer, and Bristol-Meyers Squibb. So, AZT, for example – which is the earliest and still the major one of these drugs – was publicly developed in 1964, largely tested by the National Institutes for Health soon after that, but marketed by GlaxoWellcome, which was given exclusive rights to the drug, in 1987 for distribution to treat people infected with HIV.

The full controversy surrounding these patents got under way in 1997 and 1998 when Brazil and Thailand decided that the level of their national HIV/AIDS emergencies precluded them from honoring the patents of those companies that charged US$10,000-US$15,000 per person per year for treatment. Thailand began producing its own generic version of AZT while Brazil began locally producing 8 of the 12 then available drugs; both countries, at this point, were suffering from very high levels of HIV infection that were concentrated amongst the poorest and least resourced members of their citizenry. The expected death and illness rates would have gutted the national *infrastructures* and economies if these governments had not taken action. While activists in other parts of Asia and in sub-Saharan Africa bought medicine from Thailand to

distribute to their own AIDS patients, Brazil presented the world with an impressively solid position on their need for and rights to AIDS treatment, combining prevention education with the application of cheaply and locally manufactured antiretroviral cocktails to cut their national death rate from the disease in half.

In 1999, several pharmaceutical companies led by GlaxoSmithKline filed suit for international recognition of their antiretroviral patents, and the Clinton administration backed their suit at the time. The World Trade Organization's TRIPS (Trade Related Intellectual Property Rights) agreement, since 1995, had given drug companies 20 years of patent protection in all member states and required states to bring their own domestic policies in line with this, but a 2001 amendment recognized the urgency of the AIDS epidemic and declared that it would allow LDC's (less developed countries) to sidestep patents in cases of 'dire emergency.' This, then, is the problem because, although there is still nothing like adequate distribution and implementation of antiretroviral therapy, the circumstances in much of Thailand, in urban India, increasingly in Sri Lanka and Eastern Europe and, most intensely, in many of the countries of southern Africa are simply dire. For a country like India – very poor by first world standards and relatively powerful by third world

standards – membership in the WTO is a great boon to the affluent end of the national economy and to the nation's global political standing. But adherence to WTO policies like TRIPS can be disastrous because India does not have the infrastructure or state funds to compete with nations like the US or Britain.

The Indian pharmaceutical company Cipla (like several other, smaller, such companies in India and Pakistan), meantime, began producing its own generic versions of the antiretrovirals (along with many other drugs for various conditions ranging from malaria to impotence, which are under patent in the US or in Europe) and providing them to healthcare agencies in poor countries at costs of 1/3 to 1/10 of what the major conglomerates were charging. Cipla has been able to produce generic versions of these medicines because India does not recognize international "composition of matter" patents; so, as long as a manufacturer does not exactly duplicate the mode of synthesis, the end-product itself is fair game. The Thai state-run pharmaceutical manufacturer used a similar loophole, citing differing amounts of chemicals per tablet (though not necessarily per dosage), to justify their own generic antiretrovirals and treatments for certain opportunistic infections. Cipla's drugs go to South Africa, to Ghana, to Doctors without

Borders throughout Africa and the Caribbean, and to Thailand, as well as to clinics within India itself. Of course, we must acknowledge that Cipla is getting rich off their business at the same time; the company is certainly not an altruistic non-profit. Cipla and its president have also become points of pride in India, where Cipla workers are seen as *Indian* technicians and scientists and marketers underselling the western-based companies that rely on *imported* Indian technicians, scientists, and marketers.

The standard keeps shifting as the US government has backed drug company patents through a 'Fast-Track' bill introduced in 2002, which promised a stricter enforcement of pharmaceutical patents to ensure high quality and, again, with the Bush administration's Presidential Advisory Committee on HIV/AIDS (PACHA), which just decided in April 2004 that the $15 billion dollars that Bush largely withdrew from the Global Fund for AIDS to commit to fighting the epidemic i n 14 African and Caribbean countries over the next five years will not be used on generic medicines, citing their unverifiable quality as the reason.[7] The

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[7] It is noteworthy that the Clinton Foundation immediately responded that they would be using their money to buy and distribute the largest quantity of the best-priced drugs they could and that they did not believe that generic drugs were lower quality, despite the fact that Clinton himself set the precedent for the patent rights of pharmaceutical conglomerates when he was in office. In this election year, too, the Clinton Foundation went on to point out that Democratic

administration avers that these drugs must be tested regularly by the FDA or by a similar institution in one of the following first-world countries: Europe, Japan, Australia, Canada or New Zealand.[8] The major drug companies agree with this stricture, and questioning the quality of the available generic drugs has been a major facet for their defense of patents.[9] The truth is that the World Health Organization and World Bank have tested the drugs produced by Cipla and other manufacturers of generics and approved their use. The president of Cipla claimed in an

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candidate John Kerry is more interested in attacking AIDS aggressively than in backing big business.

[8] Somewhat ironically, some southern African leaders like Abner Mason, founder and executive director of AIDS Responsibility Project, have praised the PACHA decision, giving a not unreasonable justification for their praise: that they believe new pharmaceuticals should no longer be tested on poor people, as there is ample evidence that they long have been. But the Bush administration's complicated logic is constructed exactly to produce these sorts of connection while, in truth, it is doing little to alleviate the intensity of the AIDS problem in southern Africa. The fact that they withdrew pledges to equal most of the promised US$15 billion from the Global Fund for AIDS is a good example of this. The Global Fund provides financial backing and other resources for community-based and local initiatives that pass their broad and flexible review system while the Bush administration aims to distribute its US$15 billion in a top-down fashion, through an opaque conduit of connections, starting in 2005 if Bush is still in office, and reserving a third of that money exclusively for faith-based programs that promote abstinence rather than safer sex.

[9] After a talk I gave on this topic at New York University, a representative of GlaxoSmithKline, who had not been present at my talk or the question-and-answer session following it, approached me to ask aggressively if I had "ever considered" whether it was ethical to give poor people untested pharmaceuticals. Because I had given roughly a third of my talk to addressing this issue of testing, I was amazed at his question and amazed, too, at how closely it resembled – almost verbatim – the position put forth by a Dutch spokesperson for the same company who was featured in a film (Joost de Haas' *Patents and Patients,* 2003) I had also shown at the lecture.

interview for the film, *Patents and Patients* (de Haas, 2003), that the FDA has observed his laboratories and tested their product as well.

At the time of these first controversies, Cipla had until 2006 before the Indian government would be compelled by its membership in the WTO to honor international pharmaceutical patents and stop the production and distribution of generic versions. In 2003, the WTO made a humanitarian declaration extending that deadline to 2016. Regardless, trade- and aid- based pressure continues to be put on the governments of poor countries by the US and the law teams of these major pharmaceutical companies to stop the production and distribution of these drugs well before that time. Since 2001, certain pharmaceutical conglomerates have initiated programs to provide large amounts of their antiretrovirals to southern African nations at very significantly reduced rates, but even these programs are too limited although they are commendable efforts to address the now undeniable fact that the HIV/AIDS epidemic has reached proportions beyond former "alarmist" projections. They only scratch the surface of the need, reaching an overly bounded circle of people with HIV, and are not long-term enough to provide the therapy throughout peoples' lifetimes. Further, Pfizer and GlaxoSmithKline, which have both launched such programs, have an

ominous rhetoric: they are using their influence to provide for AIDS sufferers in the third world what their own governments cannot or will not do for them. Their ultimate message is that the best hope for long-term treatment for many of these people is not public or non-profit routes to medication but a greater reliance on the private sector, although that is pretty much what we have come to in terms of managing the epidemic. The question looming large seems to be how *global* the reach of that sector can be.

Now Cipla is the major one of several Indian pharmaceutical companies that have been producing and distributing antiretrovirals at a small fraction of the cost incurred in buying them through the major pharmaceutical companies. Most notably, Cipla developed and distributed one combination pill that provides three different medicines (thus, a full treatment regime) and makes them much easier to take because they are taken as one pill twice a day rather than three pills three times a day. The frequency of application has a significant effect on the results because the ability of a patient to follow the often very rigorous schedule of antiretroviral therapy is dependent on whether the treatment will be usedl and, most importantly, adhered to over the long term. If people with HIV take antiretr ovirals irregularly or only in the short

term, there is a strong possibility that they will develop a resistance to the drugs and, potentially, that they could pass this resistant strain of the virus on to others. Making the treatment relatively easy to take, then, is a major concern, and the difficulty of providing consistent treatment to the poorest sufferers with the least access to public health infrastructure is a major concern in the provision of HIV medicines to poor countries.

Patent-holding pharmaceutical conglomerates like GlaxoSmithKline maintain that it is ill-advised to make combination therapy available in poor countries until these countries develop sufficient infrastructure to facilitate the *consistent and long term* distribution and implementation of antiretroviral therapy. Public health infrastructure is certainly desperately needed in poor countries as well as in poorer areas of richer countries. For example, in the US, HIV, like poverty and incarceration, disproportionately presents in African American and Latino communities, and it is these same communities that have the least access to adequate healthcare, housing, and employment and insufficient routine and flexibility in daily schedules, hampering timely adherence to rigorous medicine schedules. Better infrastructure is needed in these communities not only to facilitate the implementation of ARV therapy but because poverty and racism are killing their members at alarming rates in

a number of ways – disease, starvation, and violence amongst them; it is the lack of infrastructure that makes them vulnerable to disease to begin with. This is the case in much of Africa and Asia as well, and the AIDS epidemic only serves to dramatically exacerbate an already existing problem.

It is absolutely true that infrastructural improvement is crucial because the misapplication of ARV therapy could indeed lead to new strains of drug resistant HIV as has happened with TB. To say that improved infrastructure must first be put in place before drugs are put in place, however, disregards that the epidemic is itself a threat to infrastructure and that the hope that comes with antiretroviral therapy is important to a social openness to testing and diagnosis. The Centers for Disease Control, in their Global AIDS Program, assert that infrastructural planning and development are required to ensure that ARV therapy is provided in poor countries in such a way that does not lead to drug resistance, but *it is also necessary* to simultaneously procure sufficient amounts of affordable drugs, *in the long term*, which is what the pharmaceutical giants' programs cannot offer.[10]

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[10] This is an impressively balanced statement from our central epidemiological institution, which is now barred by our current administration from even stating on its web-site that consistent condom usage is a good way to prevent HIV infection

Certainly, by infrastructure, the pharmaceutical companies and public policy makers first mean the institutional and structural mechanisms that will allow for regular testing, for regular visits to the clinic, for an individual to get the necessary drugs on schedule and to have the minimal latitude in her/his schedule to take those drugs at the right times. At the most basic level, sufficient infrastructure would come in the form of a broad base of properly trained doctors, nurses, pharmacists, and social workers who have the support to work either home-to-home or in a wide network of local clinics. Much of the care-work that would be carried by such a public health system is now done invisibly and informally by predominantly female family members, who must themselves also do the regular housework and work outside the home to supply a diminished household income. This burden is immense and is not sustainable as a public health strategy, particularly when these caregivers fall ill as well, as they very often do, with no one to, in turn, care for them.

The division has long been that wealthier countries can attend to treatment concerns while poorer countries must concentrate only on prevention. The 2001 WTO declaration that allowed that patents could be over-ridden, if there were a public health emergency and if

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because that contradicts the Bush administration's position against condoning gay sex or the use of birth control.

companies refused to negotiate their terms, also stipulated that the first priority of a debtor nation (presumably excluding the US) should be to prevent the spread of an epidemic – as if this were something people would not want of and for themselves, with or without the WTO declaration. The focus everywhere should, of course, be on prevention, but prevention efforts have been very limited in their effects, and the massive proportions of the global AIDS epidemic necessitate immediate response. Further, as Cindy Patton and Lori Garrett have documented (Garrett, 2000; Patton 1996), the efforts that go into maintaining and improving prevention campaigns have actually declined since 1989. Paul Farmer, the director of the Program in Infectious Disease and Social Change at Harvard Medical School and a real advocate for the world-wide improvement of public health systems, writes:

> So, why is treatment not central to AIDS policy in resource-poor settings? Because we're told it's "not sustainable." Why? It costs too much. And why is that? To answer this question, we'd need to look at the manufacture and sale of pharmaceuticals – an industry that, as noted, has consistently had amongst the largest margins of profit. [he quotes Marcia Angell] 'The pharmaceutical industry is extraordinarily

> privileged. It benefits from publicly funded research, government-granted patents, and large tax breaks, and it reaps lavish profits. For these reasons, and because it makes products of vital importance to the public health, it should be accountable not only to its shareholders, but also to society at large.' [Farmer goes on to say...] What then is not sustainable? It is not the cost of HIV treatment that is not sustainable; it's rather the opposition to treatment in high-burden areas that is not sustainable. It's not morally sustainable, it's not intellectually sustainable, it's not socially or epidemiologically sustainable. (Farmer 1998, xxvii, xxviii)

Farmer, like others, points to the unimaginable global burden that would accompany an unchecked epidemic.

So then how does this struggle over pharmaceutical patents for AIDS drugs interlock with other patent struggles going on in South Asia, especially in India and Pakistan? The flouting of intellectual property rights in this matter owes much to thinkers and activists like Vandana Shiva and to precedents like the resistance of Indian farmers to the introduction of bioengineered mustard and cotton seeds into their fields and to the patenting of basmati rice and the neem tree by the Texas Rice Tec corp.

and Dupont. Rather than AIDS activists in Asia and Africa taking their cues from their counterparts in the US, which was the case through much of the 80's and early 90's, this issue of rights to medicine has been positioned solidly in the vein of other, older fights to gain essential resources such as water rights, debt relief, and the grain grown by local farmers. The privatization of public resources does not necessarily lead to efficiency and fairness but can lead to hoarding and outlandish profits for some at the expense of extreme poverty for others.

Most recently, Monsanto[11] has been involved in an international legal struggle for the patent on a type of wheat derived from strains developed in northern India and Pakistan over the past century. This type of wheat yields the majority of flour used in South Asia to make *rotis*, the "daily bread" that is an absolute staple for people in much of South Asia (a *staple* to a degree that perhaps has no counterpart in the food life of the US). This practice of applying for profit-making patents on public products that are crucial to basic subsistence applies equally to food and public health. Vandana Shiva, who is the director of The Research Foundation for Science, Technology, and Natural Resources in India, and

[11] Monsanto has figured prominently in the history of these patent battles. For example, it had formerly introduced self-terminating seeds to Asian farmers, seeds that yielded large crops but could not be used for more than one season, thus requiring poor farmers to buy a new course of seeds each year, which constituted a great financial burden for them.

many others call this biopiracy: that is, stealing public resources for private gain.

In 1997, India successfully prevented the University of Mississippi from patenting the medicinal qualities of turmeric, which is also essential to the South Asian diet and to *Ayurveda* and other homeopathic or natural healing, on the basis of the patent being immoral. TRIPS has a tiny clause that disallows the enforcement of 'immoral' intellectual property rights. From plants, we move to medicine derived from plants. Indian pharmaceutical manufacturers, in addition to producing antiretrovirals, also produce drugs for the treatment of cancer, TB, and other chronic and acute diseases, and South Asian activists have closely linked these debates. A recent (2004) commentary in the Pakistani newspaper DAWN called the efforts to patent wheat "neobiocolonialism," and Shiva writes:

> Nothing less than an overhaul of western style IPR [Intellectual Property Rights] systems with their intrinsic weaknesses will stop the epidemic of Biopiracy. And if Biopiracy is not stopped, the every day survival of ordinary Indians will be threatened, as our indigenous knowledge and resources will be used to make patented commodities for global trade. Global corporate profits grow at the cost of the food rights, health

> rights and knowledge rights of one billion Indians, two thirds of whom are too poor to meet their needs through the global market place. (1999)

So, to return to my first point in this paper, I believe – like many others – that the matter of negotiating the pharmaceutical patents on antiretrovirals should not be considered within the scope of the minutiae of trade agreements and patent law. Instead, it should be debated within the scope of an ever-expanding global population that depends on ever-diminishing natural resources and the projected course of an epidemic that promises to grow much larger before we can effectively delimit it, and to be exacerbated by the concomitant epidemics of multi-drug resistant tuberculosis and malaria. Because the effects of an unchecked HIV/AIDS epidemic will increasingly reverberate across class and national lines over the coming two decades, it is shortsighted and dangerous to play linguistic or legal games with respect to treating the disease at this point. If infrastructure must be built up to apply the current treatments appropriately, that should be the first priority of every body – public or private – with the financial or political means to achieve this. And, if prevention is crucial for poor countries (and for rich ones), then we

must take a cue from community-based groups that are treating it as more than a formality and creating effective prevention and education campaigns.

Chapter 3: Male Circumcision and HIV Prevention:

The Culture and Political Economy of the AIDS Epidemic

This chapter critically examines the history of the public health debate surrounding whether male circumcision should be promoted, as a key part of an HIV prevention campaign, in those parts of the third world that currently have high transmission rates but no established practice of circumcising boys. The fulcrum of the argument is the uncertain science suggesting that circumcised men are significantly less likely to contract HIV than are men with intact foreskins. I contend that the issue is a heavily racially and culturally inflected one, which cannot be simply decided through the application of somewhat questionable clinical-scientific rationale and, further, which cannot replace the real need for social changes to slow the spread of HIV and to address the existing pandemic. The question of male circumcision as a public health measure is an old one that has always brought together the trajectories of race, gender, and cultural grouping. The case of the HIV/AIDS pandemic is no different, although it is a defining element of our current age and, as such,

highlights other flashpoint questions for 21st century "global society" even as it further complicates the varied meanings of circumcision.

This case study offers an example of another controversy that draws in the same lines of dissent, collaboration, and the negotiation of power as those that define the battle to determine AIDS knowledge most advantageously for members of politically marginalized groups. The issues raised in this debate, and the tactics employed by those argued for or against the promotion of male circumcision as a mode of HIV prevention, overlap with those relevant to local organizing in New York and Calcutta. The topic of male circumcision is particularly salient for health advocates and cultural activists in Calcutta because the ever-sharper economic polarity in that city and local tensions between a sizable Muslim population and the Hindu majority make physical markings of community both commonplace and highly contestable. A circumcised penis is very much an indicator of questionable citizenship in that context – possibly 'Western' and appealing or possibly a sign of a minority subject to persecution. It would be close to impossible, in such a context, to suggest that this matter needs to be considered in scientific isolation.

Many writers have detailed how the epidemic of HIV/AIDS exists in our social imagination as well as our physical worlds and signifies

variably as we use it to negotiate our understandings of communities, practices, and identities (Martin 1994, Patton 1996, Sontag 1989, Treichler 1999, and Watney 1994, for example). These two aspects of its social conception and physical manifestation are in interaction, and effectively managing the disease requires our attending to its multi-faceted social meanings. Male homosexuality and Black masculinity have been prominently reconceptualized in light of their different but overlapping associations with HIV risk and prevalence. There has long been a slippage between the risks correlated with certain physical behaviors or attributes (such as unprotected sexual intercourse and sharing needles for drug use or, simply, being Black) and the perceived threat posed by those who display those attributes to those who do not. In many cases, public health authorities have both tacitly and explicitly assumed that men limited by economic or racial marginalization are unable to learn to modify their behavior to reduce their HIV risks, therefore needing bodily barriers to be put in place. Some risk factors, thus, are essentially racially, economically, or culturally circumscribed. I consider, here, the now long-standing debate – through the popular and professional media – of the possibilities and problems posed by an international campaign to promote male

circumcision as a preventative measure against HIV infection, particularly amongst men in poor nations.

I did a review of articles published in professional medical and public health journals, in the popular press (newspapers, news magazines), in the newsletters and press releases of societies and organizations, and on line. I used the qualitative sociological and cultural studies methods of discourse and text analysis to apply a critical sociological framework to understand and contextualize this debate. My framework derives from the traditions laid by Erving Goffman, Michel Foucault, and Angela Y. Davis and works within the field of AIDS studies (Patton 1990, Watney1994, Treichler 1999, etc.). What I offer here comprises a review of that literature as well as my own informed conclusions as to the possible benefits, limitations, and harm that could arise from promoting male circumcision as a preventative measure against HIV transmission in poor countries.

The History of the Debate

At the tail end of the 1980's, medical anthropologist Priscilla Reining superimposed a map, depicting areas where male circumcision is routinely practiced throughout Africa, on a map depicting the spatial

distribution of HIV transmission rates on the continent. She found a surprising correlation, indicating a relationship between the practice of male circumcision (the surgical excision of the foreskin of the penis) and lowered rates of HIV infection. Other researchers had been conjecturing about the possibility of such a correlation, and her finding set off years of controversy and exploration into the subject.

In the summer of 2000, at the International Conference on AIDS held in Durban, South Africa, reports were made suggesting that the direct, causal link between male circumcision and a lowered risk of contracting HIV was a certainty, determined a virtual fact by numerous, randomized studies. Several authorities – such as Anthony Fauci of the US National Institute of Allergies and Infectious Diseases, who has long been a central figure in the management of the pandemic – called for a campaign to promote the use of circumcision amongst those communities, particularly, in southern Africa, in India, and in Thailand, that have rapidly escalating rates of HIV infection but do not have a widespread custom of circumcising boys. The issue, however, remains uncertain and controversial today. Studies have yielded conflicting data, and the complex ethical and material circumstances of the problem have prevented researchers from conducting very much experimental

inquiry, although a couple key studies have emerged in recent years, especially one conducted in Pune, India that showed circumcised men, indeed, less likely to contract HIV. Still, most of the existing conclusions have been drawn from observing those who come to clinics, seeking treatment for sexually transmitted diseases (STD's), and demographic correlation such as Reining's work, and even the findings of the Pune study have been heavily questioned by several experts in the field. Beyond questioning how repeatable the results of that study might be in another context, there is also the major question of whether such a link between circumcision and HIV risk might translate well to actual public health applications.

Critics of the proposal to promote circumcision as a preventative measure aver that the studies are inconclusive, do not adequately account for confounding factors such as communally-bounded sexual behavioral patterns, and discount the relevance of cultural and social factors in forming community attitudes – regarding the acceptability of male circumcision and regarding the sexual practices that shape rates of STD transmission. I argue that, indeed, the proponents of the campaign discussed here operate on the basis of two assumptions that I find both

troubling and risky, as an HIV/AIDS researcher and as a former HIV/AIDS community outreach worker.

First, there is a disavowal of the racialized, cultural, religious history of the practice of male circumcision. Except in the situation of North America in the late 20th century, boys have been circumcised, almost exclusively, on the basis of religious or cultural traditions – whether practiced by Jews, Muslims, or less populous tribal groups such as the nomadic herders of central Australia. As such, circumcision is a purification ritual; it is a rite onto a path towards a traditionally circumscribed manhood. In this capacity, the rite is accompanied by culturally bounded expectations of male behavior with respect to hygiene and sexuality. It is a practice conducted within a cultural context, as is the decision not to circumcise boys. Throughout history, and certainly throughout the twentieth century, circumcision has served not only as a marker of socially bounded manhood within a group but also as a marker of an individual who is decidedly out-of-group.

Even in the US, which, since recent decades, has the 2nd highest rate of circumcision in the global North (falling just behind Israel, where male circumcision has an explicitly religious rationale, and well ahead of any other nation), the popularization of male circumcision was justified

largely on the grounds of moral motivations couched in the language of clinical medicine (Van Howe 1999). The individual-health implications of the procedure were always shakily grounded and secondary to the social-health implications. A primary justification for circumcision, in US medical discourse, was the claim that, in reducing the natural lubrication of the penis' shaft, it would make masturbation more difficult for boys and, in reducing sensation of the penis, it would lower the male sex drive, thus undermining the urge to have extra-marital or pre-marital, or otherwise deviant, sex. Circumcising boys promised an effective means to controlling their sexual deviance. Of course, whether circumcision does reduce sensation is impossible (and, perhaps, irrelevant) to judge. Rather, popular authors of social standards have had to concede the point and turn away from the drive to control masturbation. In 1971, the American Academy of Pediatrics stated that there are no medical indications for circumcising boys.

Secondly, the promotion of so radical an intervention – one which requires a permanent and surgical alteration to the intimate physical person rather than behavioral changes – contains, within it, an underlying despair at the potential efficacy of educational programs. Education, as the most hopeful and likely of HIV-prevention campaigns,

flounders when public health workers conclude that men and women cannot be adequately counseled to make informed decisions regarding their own health. Those proposing the promotion of circumcision assert that existing safer sex education would remain in place and that informing the public about the possible benefits of male circumcision, itself, constitutes education. I do not doubt that this would be part of the proposed institution of the policy, but maintaining a steady and effective emphasis on HIV-prevention education work has been extremely difficult, both for lack of economic resources and for lack of dynamic and creative thought about how best to do the work. Prevention efforts have been extremely limited in their worldwide effects, although they have had great results in some populations, at some times. These limitation can in part be explained by the minimal funding, attention, and prioritization given to developing, testing, and adjusting prevention work for different groups of people at different phases of the pandemic. The few success stories – particularly amongst gay men in North America in the 80's and 90's and amongst sex workers in Eastern India and in Thailand – demonstrate what prevention can achieve in these cases where members of communities with deep knowledge of their own needs and

circumstantial challenges took on the work of stunting the epidemic amongst themselves.

When gay men in California were told in the 90's that circumcised men have a lower chance of contracting HIV than uncircumcised men, though, rates of infection briefly actually increased as men who had formerly effectively practiced safer sex suspended those habits, expecting that their risk factors were already sufficiently low (Russell 2000). We have also seen how the existence of the antiretroviral cocktail has made the epidemic amongst wealthier populations in US cities seem not so dire, not so important to avoid (see Signorile 2001 for a cogent, if heavily countered view on this matter; also see "letter to the editor", *New York Blade*, 2003, for a commonly expressed viewpoint[12]).

To truly educate populations about the potential health benefits of circumcision means also to inform them of the possible adverse effects (that is, to inform them of the studies that have produced counter-claims and of the studies that indicate no relationship whatsoever and, most especially, of the fact that circumcision is no guarantee against infection).

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[12] "Nothing in this 'study' ('Uncircumcised Men at Higher Risk for HIV, Oct. 17th) compels boys to submit to this exploitative, hateful surgery.... Prejudicial articles like this will backfire and actually encourage circumcised men to feel safe, without condoms, and to spread HIV and STD's to their partners." (John McCann, Manhattan, in a letter to the editor of *The New York Blade*, 28 November 2003)

It is also to educate about the very concept of *risk* such that it is clear that, even if it is shown conclusively that circumcision *can protect* men from contracting HIV, this does not mean that circumcision *will protect* against the contraction of HIV. If we conclude that the programs educating men to use barrier methods to protect themselves and their partners cannot work, how much greater a challenge is posed by the task of communicating complicated findings and abstract concepts – in speaking to communities about circumcision, its potential benefits, and its necessary limitations? Further, what might the differential effects of such a campaign be according to gender? Women are far more likely to contract HIV from a men in sexual encounters than *vice versa* and the logic that circumcision might keep men from contracting HIV from their wives and casual sexual partners and then transmitting the virus to their wives only runs in one direction. It is unlikely to have enough of an effect on rates of transmission in those communities that are most at risk (specifically, those who have sex with highly mobile men – soldiers, truck drivers, etc. – in southern Africa, the Caribbean, and South Asia.

The Medical Surmise

Even before the AIDS epidemic became an observed reality, researchers had long suspected a connection between circumcision and the likelihood of contracting an STD. It seems likely that there is a link; but the problem is that there is little certainty whether the relationship is a direct or an inverse one, and the level of risk seems to vary from disease to disease and within populations. Those who argue that circumcised penises tend to be healthier claim that they are, quite simply, cleaner. The removal of the prepuce – or foreskin – opens up what, on an uncircumcised penis, is a warm and moist environment for the collection of residual secretions and the incubation of bacteria. Further, the inside lining of the prepuce contains quickly dividing cells – like those found on the cervix—which are particularly susceptible to infection or to aberrant growths. In combination with the aforementioned warm, moist environment, many say that this area under the prepuce constitutes a health liability. This area is also particularly susceptible to the formation of soft, open sores, resulting from STD's like syphilis or gonorrhea, which facilitate entry for other microbes like HIV. These two diseases are also important co-phenomena of HIV because people in a given population will typically visit sexual health clinics for treatment of these conditions

months or years before they begin to test positive for HIV they might have contracted simultaneously or soon following these infections. In San Francisco in 1998 and 1999, the disturbing news that HIV transmission rates were again on the rise after a period of reduced numbers was heralded, first, by a marked rise in the numbers of syphilis and gonorrhea cases. Whether these facilitated the later-perceived HIV cases, or whether they simply co-occurred, is not clear.

The assertions about the vulnerability of the foreskin are disputed by those who find that the existence of the prepuce actually guards against diseases. When boys are circumcised at a later age – such as at puberty rituals – the seam left by the surgery may remain exposed to rupture under friction, as during sexual intercourse. The surgery may also be a point of infection if it is not conducted under absolutely sterile conditions and if the circumcised penis does not adequately heal, as it sometimes does not for months or even years if the operation is performed after infancy. As well, the lubrication provided by the prepuce guards against minor lacerations, through which microbes can enter the body during intercourse. Some researchers have found that the lining of the foreskin is rich in a particular type of cell called Langerhans' cells, and herein lies another debate.

Whether the cells are present in any great concentration in the linings of human foreskins is, itself, uncertain. The cells function as part of the immune system – very effectively defending the body against most microbes; however, the external structure of Langerhans' cells provides a receptor site for the Human Immunodeficiency Virus. Those who have found a causal link between circumcision and lowered HIV rates consider these cells the key to the puzzle. If they are present in sufficient concentrations, and if they do function as receptors for HIV, this can explain why men with intact foreskins are more likely to contract HIV than those without (Short and Szabo 2000). The dispute continues because researchers and policy-makers continue to hesitate on what the relationship actually is and, more significantly, because it cannot be clear how the laboratory science would translate to its deployment as a public health strategy.

The Cultural Context

My question, in this paper, is not to decide whether circumcision can, in practical fact, prevent HIV infection or, conversely, facilitate it. It is, rather, the uncertainty of the matter that is pivotal in a situation of

extreme urgency, even if the now-chronic nature of the HIV pandemic sometimes makes the disease appear no longer so urgent. Some have drawn strong conclusions in favor of the theory while others have claimed to debunk it. However, too much of the argument against the theory has been located within the conversation of whether male circumcision is, ethically, a good practice or a bad one and, while this may well be a question of depth and lasting importance, it cannot be prioritized in the ongoing conversation of how best to assuage this intensifying pandemic that, contradictorily, has lost its air of urgency in many quarters. The combined factors of the chronic nature of the HIV epidemic, the coming-of-age of a whole generation of people who do not know the disease to be an aberration in the world, the emergence of combination antiretroviral therapy, and the entrenchment of highly conservative national administration and international welfare policies has led to a great rise in HIV transmission rates worldwide after what seemed to be a brief glimmer of false promise in the early 90's.

Several organized groups of people have organized against any promotion of male circumsision, but few have done this in the interest of questioning what might be profoundly unsound public health practice. Groups like NOCIRC (No Circumcision), which advocate against the

practice of circumcision, fervently promote the notion that all ritualistic genital surgery constitutes unnecessary barbarism and irreparably traumatizes the boys undergoing the procedure. David Gollaher, in his comprehensive history of circumcision, suggests that it is neither a necessary nor an innocuous tradition but is steeped in the politics of morality. The Jewish-American social review journal *Commentary* published a passionate response to Gollaher and activist/ policy-oriented groups like NOCIRC, decrying that circumcision is, again, under attack and associating this attack with the long and violent history of anti-Semitism. While I do not respond to any of the parties in this related dispute – and, certainly, do not intend this paper to take a stand as to whether circumcision is morally, socially, or personally harmful or beneficial – as I am addressing a related but different issue here, the urgency of these viewpoints indicates an important matter that the public health conversation has too glibly sidestepped. Circumcision is deeply rooted within, and enormously evocative along, cultural, communal, and social-psychological parameters. Its significance, in terms of symbolic masculinity and culturally circumscribed behavior, is the product of a long and racialized history manifested on the bodies, and in the identities, of individual men. 20+ years of planning broad-scale but unevenly effective

HIV-prevention education programs have clearly demonstrated to those of us working in HIV/AIDS research and social efforts that close attention must be paid to the shifting but distinct cultures and social forms of any given population if we are to influence them to alter their behavior or decisions.

Sabin Russell quotes Brian Williams, a researcher in South Africa, as saying that the promotion of circumcision promises a simple, cheap, and lifelong intervention. However, the very fact that it is a lifelong intervention – and, currently, an uncertain one – ensures that it can seem neither simple nor cheap for those expected to consider having the procedure done for themselves or their sons (Russell 2000). The public health discussion has nodded towards the resistance of people to accept and adopt the practice. Regardless, neither has it fully acknowledged the human and social investment in traditional prescriptions to circumcise or not, nor has it fully addressed the danger of promoting an invasive intervention that may have no effect at all or, worse, may possibly have a negative effect. We have ample evidence from the case of combination antiretroviral therapy and earlier suggestions about the relative safety of being circumcised that a faint promise of marginal security from the effects of HIV can lead to the abandoning of basic safeguards.

Given this, I am struck by why the possible link between circumcision and HIV prevention has generated so much excitement. My question, then, is what underlying concerns could be met by the adoption of circumcision as a public health measure that cannot be met by a renewed commitment to education: meaning greater funding, time, and attention to continuously improving and applying education efforts. Such a commitment, in fact, stands to be cheaper and more easily administered in the long run. Conversely, what exactly is it about the circumcision proposal that makes me and other many others so uneasy: what might its dangers be?

The Risks and the Presumptions

To begin with, I take issue with the level of intervention prioritized by the language of those advocating for widespread circumcision. Daniel Halperin and Robert Bailey, in their crucial 1999 paper published in the British medical journal *Lancet,* write the following:

> Perhaps because circumcision is usually imbedded in a complex web of deeply held cultural values and religious beliefs, many health professionals have been hesitant to

> integrate it with other HIV and STD prevention strategies. Yet these same health professionals have seldom hesitated to promote use of condoms or attempt other sweeping changes in sexual behaviour – practices that may be equally charged with deeply rooted cultural and religious meanings. (Halperin and Bailey 1999)

Here, Halperin and Bailey neglect to recognize the different levels of change required in promoting the use of prophylactic barriers as opposed to the practice of circumcision. They also implicitly suggest that the primary goal of public health workers is to "attempt sweeping changes in sexual behavior" while it seems evident that to do this, on must inform and enable people to decide for themselves whether and how they should alter their behavior and negotiate their risks. Given this objective, the "deeply rooted cultural and religious meanings" merely manifest an obstacle to AIDS-related public health work rather than representing the aspects of a social phenomenon that must be considered in programming intervention.

The circumcision advocates want men to have their foreskins removed and, yet, continue to use condoms. This is a pivotal matter

because if we do accept that circumcision reduces the risk of contracting HIV, as may well be the case, the projected measure of that risk reduction is still limited (according to the optimistic estimation of Roger Short of Melbourne University, as quoted in the Australian Associated Press [November 2003], circumcised men are between 2-8 times less likely to contract HIV, although this figure has been contested by others). It is a significant margin, but it is considerably less security than that afforded by regular use of condoms. Studies published in *Social Science in Medicine* in 1993 and 1997 showed that condoms prevent HIV transmission during vaginal sex 60-70% of the time when they are *usually* used and 90-95% of the time in couples who reported using them all the time. Of course, if men commonly and conscientiously used condoms, there would be little need for extensive studies into the effects of circumcision; while the latter matter is, as yet, an unclear one, it is certain that latex and polyurethane barriers, when consistently and properly used, prevent the transmission of HIV and remain perhaps the best promise of stemming the global rates of infection. An underlying assumption, in the excitement about the possible link between male circumcision and HIV prevention, is that men, in those countries with the highest rates of HIV infection, do not use – and cannot or will not use – condoms. But there are material factors, beyond

conscience and inclination, in the worldwide failure to fully impress condom usage.

Popular gay writers in the US like Andrew Sullivan have written in recent years that gay men are tired of wrapping themselves in latex and facing a future of infinite safer sex. They want to feel "freer" with their desire and so there is much media attention, of late, devoted to rising trends of barebacking (anal sex without a condom) and bug-chasing (a controversial phenomenon of HIV-negative gay men who want to contract the virus in order to give up the obligation for safer sex and to feel a sense of a "real" gay identity) (See Scarce, 1998, for a good review of these conversations). And whether these trends figure significantly in the rise of syphilis, gonorrhea, and HIV infections amongst gay men in US cities since 1999, this same period has also been the first in decades during which circumcisions performed on US baby boys has declined steadily. Gay men, especially those in cities, in the US have long been amongst those most immediately targeted for new plans of social control, pathologization, criminalization of certain populations in the name of the greater good and, yet, while the possible benefits of circumcision for preventing the seroconversion of US gay men has been circulated, they are not the intended subjects of this broader campaign to promote and

facilitate circumcision on the large scale. The great possibilities of safer sex were demonstrated in US cities in the late 80's and early 90's and rates of HIV infection declined. In addition to impressive political organizing power, the vast majority of urban gay men also simply had access to condoms – to free condoms distributed by public health programs and clinics; to reasonably priced condoms prominently displayed at drug stores, supermarkets, and sex stores; to condoms laid out at clubs, bars, and bath houses – and to the cool, shady spaces to store them. Not surprisingly, the urban gay men who did not experience a decline in infection rates were the poorest, with the least recourse to infrastructural aid. A misinterpretation of the findings of the longitudinal Young Men's Study[13] led to the false declaration that one-half of African-American men

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[13] The Young Men's Study was a large-scale, multi-city study of young men who have sex with men (MSM) and their HIV risk factors. The study was done in two phases, roughly divided into boys in their teens and early twenties and men in their twenties. It was not intended to focus on gay-identified men who have access to traditional gay organizations or sites; but, in practice, there was a significant bias towards sampling in sex work venues and in "gay quarters" of the cities surveyed. In our forthcoming paper "'People of Color,' Community Organizing, and HIV Risk: Critiquing the Young Men's Study in New York City," Salvador Vidal-Ortiz and I argue that the bias in sampling venues combined with an uneven racial sample (almost no Asians were sampled, for example, and a Black/white binary seemed strong in the study, which put African-Americans and Latinos roughly into one group and whites and Asians into another) and other methodological problems make the fact that the results of the study were reported in terms of racial group extremely problematic. The extensive, longitudinal nature of the YMS has made it an authoritative source in understanding the levels and types of risk MSM experience and the results were published in terms of the racial implications of the findings. In particular, the

are HIV-positive although most of them are not aware of it (see Benoit Denizet-Lewis' "Double Lives on the Down-Low", *New York Times Magazine*, 3 August 2003) and, in their case, circumcision has been promoted as a possibility because Black American men, it seems, have not been able to adopt safer sex successfully.

The problem of the HIV/AIDS pandemic coincides clearly with severe economic inequity and major lapses in the public health systems of countries, cities, and provinces that will not, in the US for example, or cannot, in Haiti for another example, address the epidemic on a social wellness model. This fact has been thoroughly researched and clearly written in highly accessible form by Paul Farmer (1999), Laurie Garrett (2000), Paula Treichler(1999), Simon Watney (1994), and many others. For safer sex campaigns in poor nations to have a measurable effect, they require a kind of attention and effort they have not been able to garner. Given this then, the promotion of circumcision will not happen alongside continued safer sex work; it will eclipse the possible effects of such work. If the assumption is that poor men or Black men cannot, will not use

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mass media picked up and propagated the rough findings of the phase I study done in New York and loosely generalized them to all MSM in the country. CDC (Centers for Disease Control and Prevention), 2001a. "HIV Incidence Among Young Men Who Have Sex With Men: Seven US Cities, 1994-2000." *Morbidity and Mortality Weekly Report (MMWR)*, 50, 21. pp. 440-444. June 1st.

condoms, lowering their risk factors will not further induce them to do so. What happens if the procedure said to lower risk factors actually does not do so? How would we measure the adverse effects of such an event?

This brings us to the circumstances of the sexual partners of the men at question here. One major long-standing argument for the health-benefits of circumcision is that it has been linked to a decreased chance of cervical, vaginal, and anal cancer in the partners of circumcised men. These are cancers often caused by exposure to human papillomavirus (HPV) (in the case of cervical cancer, it is almost always the case). In a paper published in the *New England Journal of Medicine* in April 2002 (Castellsagué et al), researchers found, through a control study of 3,790 women and their male sex partners, that there is a "moderate but non-significant" decrease in instances of cervical cancer for women whose husbands or boyfriends were circumcised. As with the projections about HIV, the findings in this case have always been hopeful but far from definite, and it is clear that circumcised men can and do still infect those with whom they have sex with HPV, which leads to cancer in many cases.

In discussing the health of the partners of the men at the center of this debate about circumcision and HIV risk, I do not mean only the wives and "future mothers" frequently invoked in this discourse but, as

well, the invisible girlfriends, sex workers and male partners that have been so conspicuously left out of this conversation. In particular, men who have sex with men and those men and women who do sex work have always occupied a strange and dangerous territory in public health discourse. Their health, wellness, families, and interests rarely receive adequate attention; but, they are often placed in the spotlight when considering "dangers" to more legitimate populations. Women's concerns in the HIV/AIDS epidemic, more generally, have historically received less attention from medical and public health authorities. At the 3rd International Conference on AIDS, in 1987, members of the International Women and AIDS Caucus protested that, "... women are largely invisible except in two roles: as vectors for transmission either perinatally or (putatively) through prostitution." (reprinted in Crimp, ed. 1991, 168) These two roles remain the most prominent for women in AIDS transmission discourse.

Public health talk, and especially that of the HIV epidemic, has long invoked images of the future generations – who are always already "innocent" – that are endangered by current epidemiological trends. Fixing the "future of the nation" (or the planet or the people) as the main reason for curtailing the spread of disease implies that the daily,

immediate suffering of people, today, is less important an issue than the larger-scale consequences for whole societies; and, in terms of ecological and economic disaster, one can make this argument. While some of the earlier work on the connection between male circumcision and HIV risk (Cameron *et al* 1989) drew data on men who visited commercial sex workers, the welfare of those sex workers was not highlighted. The concern, in focussing on the factor of the *prepuce*, was how to prevent transmission of the virus to men and, thereby, to their *wives* and, thus, to future generations, to children. There is an embedded and implicit hierarchy of which lives are savable – or worth saving – and which are not. A recent BBC special report on AIDS in Africa [this can be heard on-line at http://news.bbc.co.uk/hi/] highlighted a story of a two-year-old girl in South Africa who was infected with HIV after being raped. The story is, indeed, horrific, but it is also upsetting in what it represents as providing the "face" of African AIDS. The plight of AIDS orphans and street children is certainly both severe and intensifying, but to attend to the phenomenon, the focus must be on the daily behaviors and needs of the adult men, women, sex workers, drug users, mistresses, etc. who comprise the primary realm of infection. The persistent invocation, even at this late stage of the pandemic, of innocent children is disturbing.

Any possible sexual agency of sex workers and of wives is dismissed just as it is taken for granted that men provide a vector between sex workers – already likely infected – and wives – likely uninfected except through their husbands. The heterosexual identities and behaviors and heterosexist attitudes of the men visiting the sex workers are presumed, and the static nature of all these relationships is a given. If sex workers cannot be protected from HIV transmission, might we not, at least, attempt to protect the wives and future children of the men who visit the sex workers? The bleakness of this reasoning is what disturbs me.

It is clear that proponents of the circumcision proposal assert that circumcision could, potentially, prevent infections that are occurring now, regardless of existing education and condom distribution programs, and I do agree that this is an important point. It is not my intent to argue that we turn away from any avenue of prevention that might prove more efficacious than those we currently employ. Again, my concern is that the promotion of male circumcision as a barrier to HIV infection will lead to an erosion of other programs, to a greater diminishment of the social sense of urgency around the epidemic, and to a larger number of infections rather than fewer.

A deep and nuanced consideration of the questions of how to ethically and safely implement and manage a program to promote circumcision would require the same sorts of investigation and reflection that would improve and strengthen existing AIDS education. Public health programmers would need to consider, more deeply, what economic and relational factors prevent people from practicing safer sex. If education is aggressively pursued without effect, is it because its language is not accessible to those receiving education? Do educators present safer sex as only potentially reducing pleasure rather than enhancing it? Do high-risk populations have access to prophylactic barriers as well as the social latitude to acquire them without community disapproval? Feminists have long argued that economic disparity is intimately tied to gendered violence and to sexual intolerance (writers as diverse as Audre Lorde and Barbara Ehrenreich have argued to this effect). Can the current exclusions in the consideration of preventative interventions (men who have sex with men, sex workers, younger sexually active individuals, and wives capable of making sexual decision) be forefronted in determining the implications of a circumcision campaign?

While the above questions may seem obvious, they have not been adequately addressed and answered in the development of HIV

prevention programs. In addition, the critical questions of race and class have not yet entered the discussion aggressively or consistently enough. While the representatives of international public health organizations, like the World Health Organization and the World Bank's AIDS Initiative, are ethnically diverse and strive for cultural sensitivity, they continue to speak, too often, in clichés (like "cultural sensitivity") and to automatically grant primacy to the relative position of the wealthier and more internationally influential countries (specifically, the US) in the world and dismiss the concerns of smaller public health bodies in the global South. Those policies that may seem practical and common-sense to their inventors in Atlanta, Geneva, and London can be perceived by those expected to follow them, in Capetown, Bombay, or Bangkok, as flatly functionalist and racist.

Since the development of early AIDS education programs in the 80's, men of color – whether in Africa and Asia or Black men in the US – have been regularly portrayed as too sexual and inadequately cerebral to change their behavior, to use barrier prophylactics, or to assess their own risk for the disease. These stereotypes of men of color are hardly new ones and, certainly, not exclusive to HIV/AIDS discourse (although they continue to take new shape as in the reportage on the Black Down-Low

scene, which takes the very real public health predicament posed by men who have sex with men and do not use condoms or perceive themselves at risk for any infection, and portrays it as the highly sensationalized phenomenon of almost impossibly virile urban Black men engaging in shady behavior). Women of color have long been figured in the popular imagination as incapable of either asserting themselves sexually or of educating themselves and their partners about reproductive behaviors and outcomes. Because of this, reproductive planning amongst poor Black women in the US and amongst women in Africa, Latin America, and Asia has too often run the course of the insertion and implementation of devices (like Norplant and the IUD or the coerced use of Depo Provera) that have been deemed too unsafe for affluent white women (Roberts 1997). Ironically, it is the use of such devices – in *lieu* of barrier methods – that has, in addition to compromising their health and fertility, put many women at an increased risk for HIV infection, as well as other STD's.

This leaves me, and other critics, asking why the current discussion of whether to promote male circumcision limits itself to countries like South Africa, India, and Thailand. Italy has a very low rate of male circumcision, a very low rate of condom usage, and a rapidly rising rate of

HIV infection. Indeed, as recently as a hundred years ago, Italians in the US were still considered not-quite-white and public health dangers themselves; in much of New York City, Italian-Americans are still a legitimate "suspect class." Like Italy, Germany also has a steadily increasing rate of HIV infection and very low rates of circumcision and highly irregular condom-use. No one has yet proposed promoting circumcision in these, or other, European countries, although the fear of HIV has made itself present in their restricted immigration policies. There are also examples, throughout Scandinavia and in Japan, of coincidental low rates of male circumcision and HIV infection. Could the foreskins of men in impoverished countries be, somehow, differently susceptible than those of men in wealthy countries? Obviously, this is a rhetorical questions that begs no real response, especially as circumcision has been proposed for gay men in European countries but not for straight men. It does point, though, to a trend in public health. Poor men and men of color are seldom seen as the true counterparts of white and wealthy men, and men who have sex with men are frequently an exception to every rule. Even the language of "pandemic" and "epicenter" suggests that the real concern is not the welfare of those in southern Africa, in India, or in Thailand. Rather, the danger is in the possible advanced spread of HIV,

from these sites, to the global North. Without taking this argument too far, I mean to say that we must be wary of the subtle, not uncommon, suggestion that limiting the spread of HIV in Germany, then, is more effectively handled by circumcising men in Bangkok than in Berlin. In this vein, the popular science writers Richard Rhodes and Richard Preston (the authors of *Deadly Feasts* (1997), on Bovine Spongiform Encephalopathy and of *The Hot Zone* (1995), on Ebola, respectively) and even Randy Shilts' classic *And the Band Played On* (1987) all make reference to HIV crawling out of its hiding place in the shadows of Africa, becoming a problem when it emerges in North America. The massive spread of HIV in the global South is, indeed, a tragedy in itself; but, some of the institutional panic surrounding the projected possibility that the rapid spread will move on, even to those whom we can, ostensibly, educate to make good decisions for themselves.

It has taken us decades since the early years of discovering and understanding the epidemic, witnessing HIV spread much further and faster than initially expected and fashioning and refashioning harm reduction programs, to realize that minimizing and modifying risky behavior is more attainable a public health goal than the eradication of risky behavior. It would be ridiculous if we did not feel impelled to act as

quickly as possible, rapidly considering every new hope that presents itself. Certainly, health authorities have repeatedly been criticized for not moving quickly enough. Regardless, in considering circumcision as a viable intervention, it is fundamentally dangerous to let excitement over its possible prospects over-ride the possible consequences of its application. A more radical intervention does not promise more radically beneficial effects and, considering the ease with which communities once vigilant about the threat of HIV slide into non-concern as soon as they receive the promise of hope, might lead to a backslide. The immense energy which must go into developing a program to promote and provide low-cost circumcisions throughout southern Africa, India, and Thailand could be put towards assessing and redeveloping HIV-prevention education. A program to promote circumcision that is produced without this high level of investigation, reflection, and discussion must be prepared, at least, to be held accountable for its likely human consequences.

Chapter 4: Governing Infection; Securing Communities

> "From the point of view of death, disease has a land, a mappable territory, a subterranean, but secure place where its kinships and its consequences are formed; local values define its forms."
> Michel Foucault, *The Birth of the Clinic* (Pantheon, 1973, ch. 9)

My thinking about the importance of, the production of, and the uses (good and bad) of AIDS knowledge(s) is framed by the relationship between strategies of nationalism and the management of infectious disease epidemics more generally. At-risk individuals and communities respond to this relationship, to its nexus of assertions of power and the production of ideas, as well as to the infectious epidemic itself.

What I want to consider here is how infectious disease—epidemics, themselves, but more so, the *idea* of epidemic and the study and definition of it and its threat—can be used in state-building exercises. Plague existentially terrifies us even as it forms a crucial corner of the ecology in which we all participate; it has always occupied a

particularly important position in our social imaginations (and continues to do so). For example, HIV/AIDS, Ebola, and Mad Cow Disease[14] were major figures in the material and symbolic turn of the 21st century. The reporting of these diseases, the popular conversations surrounding them, played with all our common notions of near nations and far nations and valuable lives and expendable ones. They helped us define who is Us and who is Them. I argue what actually seems fairly obvious: that epidemiology is a state-supported exercise in the definition and redefinition of territorial boundaries even as it does the vital work of tracking and observing infection, purportedly to stop its spread. Sociologist Lisa Jean Moore defines epidemiology as the "statistical manipulation of risk," and this method is built on a military model for national defense purposes[15]. It is most aggressively and extensively practiced by state-backed organizations or by governments themselves, with the intention of delineating the outer limits, and tracking the movements of, an epidemic. Whenever and however possible,

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[14] more formally known as Bovine Spongiform Encephalopathy, transmissible to humans as Creutzfeldt-Jakob Disease

[15] Lisa Jean Moore offered this definition at a lecture she gave for the seminar "Finding Human Security, Facing Global Capital: A Gendered Critique," jointly organized by the CUNY Graduate Center's Research Center for the Study of Women's in Society, the National Council for Research on Women, and UNIFEM.

epidemiologists seek to make those disease limits conform to politically inscribed borders as closely as possible.

This is necessary for clarity, so we understand the movement of disease in the geo-political terms that structure the whole earth for us state citizens, but it also helps us know whose jurisdiction any particular outbreak falls into. Is this a CDC matter? County, state or federal? Does it belong to the US Army? Is it a US matter at all? The metaphors used to imagine and communicate epidemiology are frequently those of governance and of military defense, and they can address very personally intimate relations and behaviors. The metaphors of nation and foreignness, too, are reflected in the conceptual and administrative girding of the city. Epidemiology is an establishment of the modern city as it is formally practiced and generally understood and as it is derived from and linked to processes of militarization, industrialization, mercantilism, and nation building.

These were the bulwarks of the growing Western city throughout the 19th and early 20th centuries, as it emerged as a cornerstone of the new global society then being built out of the expansion of colonialism, exploration, and international finance. The immigration of economic or political refugees into American cities was viewed by native inhabitants

and authorities with suspicion as the immigrants seemed to pose a threat to the national body in terms of culture, social forms, violence, and disease. We saw this again in 2002-2003 when the constant threat of terrorism in New York and other major US cities was augmented by fear of SARS and 'the Asian flu.' An earlier instance of this was the quick reformulation of migration policies in many nations in response to the HIV/AIDS epidemic. This was not done directly after the emergence of HIV in North America but well into the 80's and in the US, even into the 90's, when it was already clear that HIV had spread beyond national boundaries and was spreading rapidly within them as well. The new HIV-related policies, however, mainly served to buttress preexisting biases against immigration, or against certain types of immigrants.

In tracking and plotting it, the disease or infectious agent can be figured as the enemy (variously described as brutal or stealthy or calculating or elusive); and, it travels along a number of fronts—the most immediate one, of course, constituting those bodies that the illness sickens and the lines of personal attachment and interaction in the communities affected by the disease. For people who become sick, and for the people who take care of them, these persons (their bodies and their selves) are the most important matter: to save them, to tend to them. For

epidemiologists, however, it is those populations that are not sickened that are most important. They represent the unvanquished territory: the ones who can still be saved and the critical population that must be defended. The fear people feel in the face of contagion, however, is essential to how epidemiologists understand and manage an epidemic, as they must manipulate and handle sickened bodies to define the outer edges of the contagion and to contain the epidemic within these limits. Infectious disease threats are necessarily always deeply interpellated with security issues and are played out with respect to nations and their borders. The virus is the enemy but it is also the weapon of the larger social threat behind it. This can be understood in multiple ways, as well, as certain members of the African American and gay communities hardest hit by the HIV epidemic in US cities have shown in their belief that AIDS is a government conspiracy meant to rid the nation of populations that the government does not value.

Authority, Identification, and Isolation

How do these ideas, then, apply to the epidemiology of AIDS, particularly in the context of dense cities, and the effects this epidemic has of highlighting certain populations of people as necessarily and

inevitably at elevated risk for HIV infection? In delimiting these populations, HIV/AIDS epidemiology exerts control over the bodies of these high-risk people to control the spread of the disease. Of course, these are often groups of people who are already marked by the authors of social norms for personal disciplining in order to better conform to dominant social standards such that new epidemiological priorities also serve as justification for medical authorities to exert control over their bodies.

Plague provides an instance of crisis that can not only justify but also call for intense repression of bodies. Quite obviously, contagion is usually first dealt with through mechanisms of quarantine and purification, once the source of contamination is identified. The massive epidemics of influenza and polio earlier in the twentieth century popularized Lysol and Clorox as ubiquitous household cleaning items—and thus critical to modern, domestic femininity[16] in the American middle classes—and used quarantine as almost the only uniformly enforceable technology of limiting infection in the population. Quarantine signs were a critical aspect of the culture of summer polio outbreaks earlier in this century

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[16] See Nancy Tomes' excellent book *The Gospel of Germs: Men, Women, and the Microbe in American Life* (Cambridge: Harvard University Press, 1998) for a more detailed description of this relationship.

even though the policy had no demonstrable effects at the time and we now know it was not a useful way of arresting the spread of the disease.

In New York, for example, there is the strong history of Hermann Biggs – a controversial and tremendously influential early architect of public health when he was chief of the city's division of bacteriology and disinfection from 1892 through the first 2 decades of the 20th century (somewhat ironically, he died of pneumonia in 1923). He used quarantine and aggressive, legally enforced methods of social control to famously and quite effectively fight diptheria, small pox, typhoid, and cholera and, with equal aggression if less effect, tuberculosis. Biggs had trained in Europe and figured himself as a politician as much as a physician, and he combined the older philosophy of sanitation and the newer one of preventing contagion through epidemiological tracking and monitoring and inoculation. In particular, Biggs targeted the uncertain and suspect disease associations of the incoming flood of immigrants around the turn of the century. It was Biggs who established the crowded and dirty urban sanatoria meant more to confine and isolate poor (and primarily immigrant or African American), tuberculous New Yorkers than cure them, and it was Biggs who confined 'Typhoid Mary' Mallon to live out her life on

North Brother Island in the East River. (Rothman 1994 and Walzer Leavitt 1996)

'Typhoid Mary's' story is well known. She was an Irish immigrant cook and asymptomatic carrier of the salmonella typhi bacillus. Over the course of her career, she was found to have infected 47 people with typhoid, 3 of whom succumbed to the disease. Under the authority of Dr. Hermann Biggs, the New York City Department of Health twice isolated Mary Mallon to a small cottage on North Brother Island in the East River. Her second confinement was for 23 years, until her death in 1938. In her history of Mary Mallon's case, Judith Walzer Leavitt offers an alternative and highly sympathetic reading of the sociopolitical significance of Typhoid Mary at the time. In it, she points to the intersection of the rise of microbial medicine, leading to a new understanding of infection and public health, and of the continuing conflicts in New York over the ongoing influx of Irish, Italian, and Eastern European Jewish, working class immigrants. These migrants were seen to threaten the stable social fabric by bringing with them strange customs, violence, and disease. Mallon, as a single woman who supported herself and sometimes lived with a male friend and lover to whom she was not married, particularly drew attention for the social threat she symbolically posed – not conforming to feminine

expectations or the current ethnic norm –as well as for the material threat she may have posed to the public health.

Biggs is perhaps best known for two comments he made about the need for – and implementation of – extreme and authoritarian efforts towards guarding the public's health. I quote both below:

> [In 1897, at the British Medical Association] The government of the United States is democratic, but the sanitary measures adopted are sometimes autocratic, and the functions performed by sanitary authorities paternal in character. We are prepared, when necessary, to introduce and enforce, and the people are ready to accept, measures which might seem radical and arbitrary, if they were not plainly designed for the public good, and evidently beneficent in their effects. Even among the most ignorant of our foreign-born population, few or no indications of resentment are exhibited to the exercise of arbitrary powers in sanitary matters. The public press will approve, the people will support, and the courts sustain, any intelligent procedures

> which are evidently directed to preservation of the public health. (quoted in Garrett 2000, 300) [and in Edinburgh at an international tuberculosis conference in 1910] The Board of Health in New York City has legislative, judicial, and executive powers. Its regulations on all matters pertaining to the public health are final.... I do not think that any sanitary authorities anywhere have had granted to them such extraordinary and even arbitrary powers... (Quoted in Walzer Leavitt 1996, 42)

Biggs' extraordinary powers extended to the use of the police force to track down and physically restrain those (at that time in New York, usually immigrants who were most vulnerable to infectious disease but did not necessarily trust the American medical system) who did not want to be inoculated while social welfare nurses injected them against their will. While the ethics of the Biggs health administration have only become more controversial with the passage of time, it is undeniable that his methods were impressively effective, even if ultimately limited in their influence. They elicit, however, mixed reviews from contemporary

commentators. Medical journalist Laurie Garrett (2000) and historian Roy Porter (1997) applaud his pioneering efforts towards establishing a public health infrastructure in the US, and Garrett laments the subsequent erosion of public health authority that led to stalemates in the face of AIDS and antibiotic-immune epidemics in the 80's. Medical historians Sheila Rothman (1994) and Judith Walzer Leavitt (1996), writing from the perspective of patients, view Biggs' philosophies with a more critical lens.

Walzer Leavitt writes, with reference to the biases against immigrant women that led Biggs' bureau to confine 'Typhoid Mary' and to Mallon's own suffering and insight into her case, "What Mary Mallon's story contributes to our efforts to create a more just health system [with respect to the contemporary outbreaks of TB and AIDS] is exemplary pitfalls to avoid and signposts for flagging important individual issues." Garrett describes Mallon as, "the belligerent and thoroughly uncooperative woman," much as Biggs had himself, 90 years prior. With reference to the early days of the AIDS epidemic, Walzer Leavitt writes, "Early experience with HIV infection indicates that American public health has not moved very far away from some of the social insensitivities evident in Mallon's day." She credits "the combination of local organizing and public efforts" with having the most effect towards slowing further

infection and helping those with AIDS, once the epidemic was already underway. Garrett writes that Biggs-style policies might have been exactly what was desperately needed at the beginning of New York's AIDS epidemic. (Walzer Leavitt 1996, 246-247; Garrett 2000, ch. 4, pt. II) And Rothman writes that Biggs' sanatoria Otisville and Riverside Hospital (located on North Brother Island) both fulfilled multiple functions, sometimes presenting as hospitals and other times as prisons or workhouses, sometimes professing to cure and assuage the sufferings of the poor and tubercular and other times only to confine and morally reeducate them. (Rothman 1994, 208-210)

Garrett, Rothman, and Walzer Leavitt are more in agreement with each other than not, though. They are all champions of an effective and broad-based public health system and critics of the bureaucrats and politicians who prevent such a system from establishing itself and having a lasting effect. They all write of New York City with admiration for its complexity, and they are very cognizant of the extreme extent to which social inequities and biases privilege some members of society (we can roughly describe this category as 'affluent') to live longer, healthier lives than others (and we can loosely describe this grouping as 'poor,'

although factors of race, gender, sexuality, citizenship, etc. greatly complicate this binary).

Walzer Leavitt insightfully considers the significance of Mary Mallon's case for understanding the management of HIV/AIDS in the first 15 years of its North American epidemic, especially with respect to three issues. "[The] identification and labeling of new categories of people who challenge the public's health; the question of isolation and its potential threat to personal liberty; and the attribution of blame and responsibility for the spread of disease." (Walzer Leavitt 1996, 233) Like her sympathetic reading of Mary Mallon's life, she offers an account on behalf of Gaetan Dugas, the Québécois flight attendant identified as 'patient zero' in the AIDS epidemic of the northern hemisphere and made infamous in Randy Shilts' *And the Band Played On*. It is almost impossible, in this late age of medical research, to expect the public to quickly assimilate information about absolutely new types of disease – especially slow-acting microbes like those that cause AIDS and Creutzfeldt-Jakob Disease. "To have expected Dugas, or any other early sufferer of AIDS, to understand immediately the ramifications of the disease that wracked his body or how his sexual behavior might be implicated and need to be changed was to ask too much." (Walzer Leavitt 1996, 235)

The overly narrow perspective of epidemiology, however, further specified by urgency and panic, was only keen to find *the origin* of the epidemic in the early 80's. And this served to hamper, rather than expedite, its understanding of the new epidemic. As Shilts himself writes (1987), the fact that babies in Harlem were presenting with AIDS was disbelieved for years because they did not fit the patient profile of adult, gay, white men even though their symptoms *exactly matched* the disease profile. And in the early 90's, sex workers in Calcutta greeted the news that they must begin using condoms in all sexual encounters with skepticism – a measure that, at the time, seemed guaranteed only to cost them clients and income and provide no safety against the invisible threat of a disease from which they felt quite distanced. Indeed, at that point, they were far more vulnerable to infection from clients than likely to infect clients, but it has always been easier to track infections in prostitutes than in the men who patronize them, thus marking sex workers as the evident sources of infection whether or not they are. As Simon Watney eloquently described this phenomenon in 1988:

> ... a 'knowledge' of AIDS has been uniformly constituted across the boundaries of formal and informal information, accurately duplicating the

> contours of other, previous 'knowledges' that speak confidently on behalf of the 'general public', viewed as a homogeneous entity organized into discrete family units over and above all the fissures and conflicts of both the social and the psychic. This 'truth' of AIDS also resolutely insists that the point of emergence of the virus should be identified as its *cause*. Epidemiology is thus replaced by a moral etiology.... This 'knowledge' is effortlessly stitched in the likeness of an already-famliar... picture of seemingly tireless 'national values' and the 'national past.' (Watney 1994, 48)

Moral Pathology, Classification, and Surveillance

The phenomenon of HIV/AIDS is further complicated because its modes of transmission are always already so easily associated with 'dirty' behaviors that involve the intimate exchange of bodily fluids (sexual intercourse; drug injection; blood transfusions; dentistry) and, still, the epidemic continues to spread almost unchecked despite the relative

logistical ease of putting up barriers to transmission. This creates a problem in the usual epidemiological modes of reason because, while many of us who have done AIDS education have repeatedly heard talk that "HIV is very hard to get" (meaning that we shouldn't worry so much about a virus that is difficult to transmit), its spread has not stayed within social, community, or state borders. The amount of intimate exchange amongst members of disparate populations must be much greater than traditional surveying or public health implements can readily address. The epidemiology of HIV/AIDS, then, turns to the classification and surveillance of groups of people who are deemed risky enough that their socially questionable intimate practices can, indeed, be made visible and legitimately monitored and governed. Discourse of safer sex and the dire consequences of not practicing it conceptually opened bedroom doors in the late 80's, particularly those of gay couples or young, 'promiscuous' people. Their practices could be obliquely conjectured and judged and, if they were to be infected with HIV, their behaviors and partners were laid open to their clinicians and visible to the seemingly less risky/ at-risk 'general public.'

In *Discipline and Punish* (1977), Foucault writes that the discipline of bodies, in rendering them docile, dissociates power from the physical

person, making it more usable, more capable but also making an individual less able to exert her/his own political will and potential. In discussing the shifts in techniques of social and bodily discipline throughout the 17th and 18th centuries, he writes, "If economic exploitation separated the force and the product of labor, let us say that disciplinary coercion establishes in the body the constricting link between an increased aptitude and an increased domination." (Rabinow [ed.], 182) It is this "constricting link" between the ability and the subjugation of the person that is fascinating to me. Particularly with relation to the development of knowledge and of policies of governance or treatment of HIV/AIDS, I am interested in the co-emergence of state-level institutions of monitoring and authority along with increasingly productive resistant organizations comprising those bodies perceived to be most at risk and most in need of close surveillance. Epidemiology, in making what is within the body (the infection or disease) knowable, visible, and traceable, makes the body itself – as an identifiable social unit, as the subject of surveillance – also visible and trackable. In writing about governance and security, both bodily and national, Foucault introduced the concept of biopower. He uses it to refer to those forms of power that are applied to people specifically because they are living, sentient, social beings. As

Colin Gordon put it in *The Foucault Effect*, biopower is "a politics concerned with subjects as members of a *population*, in which issues of individual sexual and reproductive conduct interconnect with issues of national policy and power." (Gordon in Burchell *et al* [eds.] 1991, 4-5) Biopower, then, refers to the exertion of state-level politics at the bodily level, and within the body, to the consolidation of the potential of a population to produce political effects.

The great popularity and influence of Antonio Negri and Michael Hardt's *Empire* and of *The Foucault Effect* collection have made 'biopower' an overused term in the last several years, but I insert it here because it exactly encapsulates the sorts of organizational force, effect, and potential that the groups I study in New York and Calcutta have experienced and deployed in their AIDS work. The sophisticated and profoundly resistant politics undergirding the explicit and implicit methods of these organizers – many of whom have not had access to much formal education or even learnt to read – point to the true organic potential of biopower, as Foucault explains it. I do not mean to imply that these groups do not struggle with their own internal hierarchies or conflicts. It is precisely because they do have these problems even as they manage to effectively challenge some of the most oppressive or neglectful of their

governments' policies that these groups in New York and Calcutta demand scholarly attention.

At the intersection of the military-style penal system and the militarized clinical epidemiological one, there are parallels and overlap between the management of the HIV/AIDS pandemic and the subjection of the reproductive systems of poor African-American women to criminal-legal controls. This is the production and implementation of biopower. For example, let us consider the series of cases through the 90's of pregnant women in South Carolina who were arrested and incarcerated when their prenatal blood tests showed positive for cocaine use. Dorothy Roberts has written of how, through the history of slavery and up to the present time, controlling the bodies of Black women has been the primary method of controlling and subjugating these women themselves – whether they were raped by slave owners and lynch mobs, 'bred' as slave mothers, or depicted as 'welfare queens' by conservative politicians of our own era. The authorities responsible for such policies as the forced implantation of poor, Black women with risky contraceptive devices like Norplant and the IUD have shadily claimed such actions are warranted by public health or social welfare. According to such reasoning, the state needs to do what is best for these women because it determines them

unable to do so for themselves and, in this inability, to constitute a threat for general society. And, insofar as poor Black women in the US present a symbolic threat to the state, incarceration has often been brought into play, not only as an end in itself but also as a means of reinforcing the reproductive control. Roberts, in describing the implementation of the policy, instituted in 1989 during the Reagan-Bush era's War on Drugs, demonstrates the slippage between medical authority and criminal detention.

> ... officials in Charleston, South Carolina, initiated a policy of arresting pregnant women whose prenatal tests revealed they were smoking crack.... Officers invaded maternity wards to haul away any patients in handcuffs and leg irons, hours after giving birth. One woman spent the final weeks of pregnancy detained in a dingy cell in the Charleston County Jail. When she went into labor, she was transported in chains to the hospital and remained shackled to the bed during the entire delivery. All but one of the four dozen women arrested for prenatal crimes in Charleston were Black. (Roberts1997, 170)

In this case, the Drug War and the prison system were used as justifications for, and as the means of, subduing Black American women. The monstrous charge being that, suffering from harsh structural and economic limitations, they had sought short-term escape from their difficulties rather than prioritizing the long-term health of their babies, for which they could find no infrastructural support and which might have been hard even to envision in their positions.

In very similar terms, I would like to consider part of a narrative of the relationship between sexual practices of "poor inner-city Black women" and their high risk for contracting HIV – in particular, two passages from E. J. Sobo's carefully written article, "Love, Jealousy, and Unsafe Sex among Inner-City Women" (from *The Political Economy of AIDS*, Singer [ed.] 1998). I use these passages because Sobo takes care to render her subjects in thoughtful detail and clearly means to benefit the population she describes. She works to explain and justify her language and conclusions. What I am trying to highlight, however, is the physical and emotional closeness of the practices and consequences she discusses, considering how very large and vague her category of subjects really is, except as it is thrown into relief in comparison with an idealized

and fairly monolithic 'general population,' and how elusive any conclusive categorization of these women and their behavior might be.

Sobo attempts to show that the women in her study *make the decision* to have condomless sex with their romantic partners based on their evaluation of the likely benefits resulting from this action, because they feel this nurtures relationships to which they are emotionally attached and on which they are often economically dependent. She makes the important argument that they do not simply fall into unprotected sex through ignorance. Although she offers comparisons between studies of white sexual behavior and Black [her chosen capitalization and my preferred style as well] sexual behavior in footnotes, her background section details only the sexual norms, preferences, and practices of poor Blacks, perhaps implicitly and reasonably assuming a relatively wealthy white reader for the expensive and highly academic volume in which her article appears. She writes about non-monogamy amongst her subjects:

> The high level of non-monogamous heterosexual intercourse recommended for and often achieved by [Black inner-city] men is traced to their lack of economic opportunity and their related dependence on favorable peer evaluations and tendency toward hyper-masculine compensatory behavior

> involving sexual conquests and over-misogyny. Women who depend on men for money can be forced by circumstance to ignore the infidelities of their male partners while engaging in "survival sex." Like men, some women have multiple partners, but most Blacks think this disrespectable. Multiple partnering among women has generally been analyzed primarily as a strategy by which resource bases are expanded. (Sobo in Singer [ed.] 98, 76-77)

What are some of the causes and effects of this sort of minute scrutiny of these people's lives: not only with whom they have sex but how and even why (the psychological motivations) and what emotional stakes they might place? They are designated a social problems group here by virtue of being subject to the vagaries of underemployment, racism, and increased structural susceptibility to health problems. As such, however, they are constantly monitored—by academics, social workers, policy-makers—by figures wielding scientific instruments and well-established institutions of knowledge-production who are hidden from scrutiny themselves. Poor Black men are so downtrodden by their circumstances in this rendering that what individual distinctions and emotional,

interrelational investments they might possess are dismissed or not even expected to exist. Poor Black women are wedged into a cramped position between functional survival and emotional suicide. As Paula Treichler, Susan Sontag, and others have written, AIDS has always served as an 'epidemic of signification' (Treichler 1999). In the US, male homosexuality and Black masculinity have very visibly been re-conceptualized in light of their different associations with HIV risk and prevalence, and the nature of the relationships that Black and/or gay men are able to have has been externally defined and closed off.

Social and structural explanations for the social problems of poverty, racism, and sexism are far preferable and keenly needed – from my own feminist, sociological perspective – over and against micro-level psychological ones. But writ too large, structuralism can be overdetermining, at the expense of humanizing those who suffer most from these social problems (as opposed to constituting social problems themselves). This is, I believe, a slim but critical point in understanding how surveillance and discipline are exerted together. The study of the minds, hearts, and sex practices of 'poor inner-city Blacks' is closely linked to their management in clinics and social welfare programs and, further, to the

resolution of how responsible this community might be for its own infection and how much access to aid and care should be available.

This is similar to the analyses that Walzer Leavitt, Cindy Patton, and others present of how many healthcare workers attempting to understand why AIDS was spreading so swiftly through gay men's communities in the early 80's depicted those men as unavoidably downtrodden by homophobia and self-loathing and driven to desperate and unhealthy acts. With the best of intentions towards preventing the further spread of the disease and protecting this population, these depictions served to further stigmatize gay men while it diverted attention from the real causes of transmission. Of course, and this is crucial in that it opens onto other horizons entirely, in my research, sex workers, the urban poor, undocumented immigrants, and other similarly stigmatized and highly politically marginalized groups have propelled and organized themselves as the complement to these processes of identifying, monitoring and disciplining.

Flexible and Strategic Responses

The Calcutta sex workers, in organizing themselves to prevent disease, augment workers' rights and supports, and garner or create

resources for themselves such as educational centers, legal counsel, and parenting help, worked with two models for mobilizing and improving the welfare of a community: labor unions and harm reduction. Let me address the latter first, which serves as a model for intervention with respect, both, to structural limitations and circumstances and to individual exceptions and self-determination. I do not mean to echo the postmodern financial ethic of ever-changing systems driven by the patterns of economic growth, unencumbered by the conditions of specific workforces or anything so inconveniently tied to human societies, but I would like to point to the *flexible* nature[17] of organizing done to reduce harm. Sex workers in Calcutta and immigrant AIDS workers in New York both used wide-ranging and highly flexible methods to address and serve the well-being needs of their communities and to make HIV prevention a real option for them.

Harm reduction refers to the concept of acting systematically to limit the damage that can result from risky practices – specifically the use of drugs or intoxicants, which has always been the focus of the harm reduction movement, but also other risky practices. Applications of the

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[17] Emily Martin's book *Flexible Bodies: The Role of Immunity in American Culture* offers an important and wonderfully complex perspective on the culture of AIDS in the 80's and 90's and its relationship to the newly emerging finance based, limitlessly flexible economy. (Boston: Beacon, 1994)

theory extend back at least to the early 1900's in England, when some clinics distributed free heroin to addicted workers in order to keep them functional and productive, but harm reduction has different and often distinct histories in different countries. Proponents of the approach assert that the central tenet of their work is simple pragmatism. When it is unlikely, undesirable (there are no suitable alternative paths to income, cessation of pain, etc.), or just too practically difficult to end damaging practices, it is important to explore other ways of reducing their harm while the practices themselves are continued.

The San Francisco Task Force on Prostitution submits that street-based prostitution is the most dangerous type of sex work that people do, frequently engaged in by those with the most vulnerability to poverty, violence, and disease. In these settings, sex work is indeed risky but hardly the primary problem at hand. Harm reduction for street hookers involves affording them legal latitude, health services, and the resources to protect themselves from violence as well as from STD's. Similarly, the Harm Reduction Coalition, in describing a workshop to train their outreach workers to advocate for street prostitutes, lists the following points of danger minimization: "personal hygiene, clothing and accessories, negotiating with customers, sexual services, on-the-job safety," as well as

sexual health and emotional trauma (from their web-sites, respectively, www.bayswan.org and www.harmreduction.org). The Community Front for the Prevention of AIDS in Sri Lanka does, in fact, emphasize that attending to personal appearance is an important way for a sex worker to augment her/his self esteem and self-assessment of personal and professional worth, to negotiate with clients for safer sex, and charge a higher fee. So they include clothing drives and appearance workshops in their STD prevention efforts. Both these groups, like the Calcutta SHIP (STD and HIV Intervention Project, sometimes referred to as the Sexual Health Intervention Project), maintain that someone who does not feel relatively secure in the immediate can have no motivation to prevent her/his infection with a slow virus. Similarly, Benjamin, one of the social workers I interviewed in New York told me he liked to take part of his allotment of travel money for escorting clients to clinic appointments and use it to take them to "nice restaurants, clean and bright ones" to eat after their appointments because he believed it made them feel better cared for as clients and patients. Feeling cared for, he said, helped them to persevere with unpleasant medical regimes and bureaucratic red tape and prioritize their futures.

The state-supported SHIP that began to train Sonagachi workers as peer educators in 1992 was founded on the principles that the basic problems in these women's lives had more to do with structural obstacles and interpersonal needs and disputes than with the morality of the work they did to feed themselves. The SHIP programmers assumed that the women of Sonagachi were degraded more by poverty and sexism than by their profession. Prior to this, most intervention programs for sex workers in India and elsewhere assumed that the sex work itself was unviable and that those involved were necessarily compromised citizens. They therefore focused on 'rehabilitation,' involving sex workers in religious classes and/or training them in alternative professions. Too often, however, these alternative professions were unstable cottage industries or else low-level service jobs that were as physically taxing as sex work – like constuction work or house-cleaning – and not nearly as lucrative. These programs, too, generally categorized those associated with them into two neat groups: programmers and participants. They failed to integrate the spectrum of risky behaviors on which most of us occupy a position somewhere.

So, harm reduction workers outreaching to heroin addicts need to acknowledge that they, themselves, might sometimes drink to the point

of embarrassment or develop dependencies on certain over-the-counter drugs and that the difference between a caffeine dependency and a cocaine addiction is one of degree as well as of quality. This is not meant to be a glib illustration minimizing the seriousness of drug addictions or alcoholism but, rather, to show that motivations and causes can be better understood when we attend to the similarities of related behaviors usually placed in different categories. When I did safer sex outreach with sex workers in Queens, the list of prompts for my brief interviews ranged from, "How long have you worked in this particular brothel?" to, "Have you ever offered a man any sexual service for paying your way into a club/restaurant/holiday?" to, "Do you sometimes feel pressured to have sex with your husband to receive money to do the shopping?" These are all exchanges of sex for money, but the scenarios and risks involved differ in each situation. The Calcutta SHIP took these sorts of questions and challenges into consideration when they initially designed their continuously developing program, and the Sonagachi workers anchored their labor union and self-advocacy group, the Durbar Mahila Samanwaya Committee (DMSC), in the space between such contradictions and overlaps. For them, working for better labor conditions

and nurturing their cultural wing and literacy education are as essential as condom distribution or providing clean needles for injection drug users.

When, in January 2004, the Gates Foundation selected the DMSC to be the model for a US$200 million HIV prevention program it is funding in six Indian states, not including West Bengal, only the union's public health work was recognized. This, in itself, is an extraordinary accomplishment, and there is great potential in the DMSC's integration into a program to begin such initiatives amongst other groups of sex workers who have not yet effectively organized themselves. The public health work this group does, though, is an aspect of their efforts to improve their own *working conditions* and, as such, reflects the DMSC's response to their occupational hazards. The DMSC took advantage of a structure and resources the SHIP offered them because of the HIV/AIDS epidemic and, while reducing HIV transmission rates amongst their constituency, mobilized to advocate for themselves in terms of a broad base of issues.

Calcutta has a long history of socialist mobilization and highly structured workers' movements. The city and state governments are communist – at least in name – but frequently authoritarian and capricious in their policies, such as when the city government forcibly

collectivized dairy production in the mid 90's. The government took away the animals (and independent means to income) of dairymen, requiring them to participate in one of a small number of dairy farms and distribution centers on the city outskirts, forsaking the sometimes multi-generational relationships many of these men had with regular client families. The reduced income and increased travel for Calcuttan dairymen comprised a real hardship for them, and the quality and availability of milk has been notoriously suspect ever since. The city routinely holds *bandhs* – which are general strikes, sometimes called for particular districts or industries and often meant to include all workers and business owners throughout Calcutta) – some of which are organized by the government. Others are organized to protest the government's decisions. The mood and purpose of a *bandh* can vary; they can be treated as holidays or irritating inconveniences or can give rise to violence. Their frequency, however, speaks to the prevalence of traditional labor organizing tactics in the city.

Sex workers in other parts of the world have organized, including strippers in San Francisco and prostitutes in some hotels in Bangkok, but the Sonagachi union arose from the SHIP preventative health program when sex workers made an explicit link between their susceptibility to

STD's (and to blame for the broadening HIV/AIDS epidemic) and their subjugation as workers. Interestingly, anti-HIV initiatives amongst immigrants in New York materialized, in two cases, when restaurant workers and taxi drivers who were mobilizing for better pay and job security also found that rates of HIV and other STD transmission amongst their constituencies were higher than average. This issue was complicated when becoming sick inhibited their ability to work and compromised their legal stability as working immigrants in the US. In both cities, however, migration status, working conditions, and health risks converged and prompted broad-based social and political work. And Wendy Chapkis argues in *Live Sex Acts: Women Performing Erotic Labor* (1997) that sex work can be liberatory and empowering for a woman who feels oppressed by the many and contradictory sexual proscriptions determined by gender norms, so that workers organizing themselves only stand to gain in terms of pleasure and wellbeing in their lives. While I am not in full agreement with the idea that sex work is primarily about pleasure and self-expression, I do believe it is undeniable that organizing for better representation and material conditions can only lead to increased opportunities for pleasure and health.

Community Strength and Individual Dignity

Illness is disruptive to families, to communities, to the lives of individuals, but it is also constitutive of new social groupings and experiential trajectories. Coping with disease, making sense of it creates new social realms and requirements, new social identities and relationships. These are tremendously productive and powerful processes. Indeed, community identification and alliances have more to do with interpersonal attachment and shared stakes and risks than with the redlining policies of epidemiological or housing authority agencies.

In her book *Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are* (republished as *The Book of Life* by Beacon Press in 2001), Barbara Katz Rothman gives a detailed, sensible, and loving argument for why racial categories and their genetic underpinnings cannot define relations amongst members of different racial groups. That part – and the shifting definition of the groups themselves – is produced socially, culturally, and personally. So she describes the difference between the relatively dispassionate, morally outraged response she can have as an academic critiquing the profoundly harmful nonsense of the book *The Bell Curve* and the very personal anguish of realizing that her daughter Victoria – who is Black – will

inevitably be judged by those hateful and irrational standards. Writers like Herrnstein and Murray (the authors of *The Bell Curve*), J. Philippe Rushton, and Dinesh D'Souza work hard to make race and racism seem natural, scientific, dispassionate, and right: therefore, no issue to contest at all. But, as Katz Rothman reminds us: "Race remains both a meaningless category, and one of the most meaning-laden categories we have for people. The biologists and geneticists may be more than ready to let go of race as a category of analysis – but the rest of us cannot afford to, not as long as racism exists." (Katz Rothman 1998, 85)

Every year, in my "Social History of the South Asian Diaspora" course, we read an excerpt from D'Souza in which he defends what he believes is the truth of the model minority myth, that the financial successes of Asian immigrants provide proof that it the cultural or genetic inferiority of Blacks undergirding Black poverty rather than institutional racism. An,d every year, my students – a majority of whom are always South Asian Americans themselves – respond with hot anger. They are angry at his offensive arguments, but they are also angry that, by ethnic and racial association, they are drawn into his category, angry at the realization that others (read: white Americans; Black Americans) make assumptions that my students agree with D'Souza and the model minority

myth. We highly educated Asians are able, up to a point, to assume that everyone around us views us as unique, idiosyncratic individuals who are made up of our own experiences and opinions and are not just members of a broadly and externally categorized group. While the many and varied ethnic and racial groupings of the Indian subcontinent are very clear in our social lives from an early age, we can imagine that American race is not for us; American race is overwhelmingly determined by the rough binary of Black and white while Asian Americans occupy an in-between space (and, as Katz Rothman reminds us, the racial *problem* is usually designated to comprise just the Black half of the binary)[18]. Early realizations that this is not actually the case are difficult to face, upsetting in their ability to challenge how we identify ourselves and relate to others.

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[18] For example The New York segment of the Young Men's Study, which examined the HIV risk factors of young men who have sex with men, conducted its research with four broadly defined racial categories: Black, Latino, Asian, and White. It reported its results, however, in terms of Black and White risk differences. The researchers chose to do this even though their findings were actually very complex, showing that Black men were more likely to practice safer sex but also more likely to contract HIV, suggesting a structural explanation for the discrepancy, and explained their findings with psychological justifications. The very diverse findings for the too-loosely defined Latino category were subsumed under t he category of "Black and Latino" in the report, although this report left off the Latino results. And the Asian section of the New York research comprised an N of only 3; but, because none of these men tested positive for HIV, the final report stated that Asian men in New York had an HIV infection rate of 0 and, therefore, were largely ignored like the Latino subjects.

Wealthy and economically mobile, white, gay and bisexual men encountered a similar shock as the North American AIDS epidemic was born in the early 80's, as they realized that the post-Stonewall advances that money and political lobbying had achieved were actually fragile. They could be threatened by the moral panic that accompanied an unsettling new disease in an era when new microbes were supposed to be impossible. Relatedly, I discuss elsewhere in this dissertation how some Indian gay men's groups used the understanding of AIDS as a gay disease to earn themselves funding and respectability. They were able to do this even though HIV transmission moves predominantly heterosexually in India, and even though the work they did with their funding was focused more on community building than AIDS awareness. These communities were tinted, however, by an epidemic that is known more for its cultural associations than for its actual courses of movement. Community based work around the HIV/AIDS epidemic has had everything to do with interpersonal affiliation and common ground in terms of shared risk for infection, and shared risk for blame for the disease. Migrant sex workers "brought it into India;" bisexual men "brought it into the home" (as if only heteronormative families live in actual homes); and "Haitians brought it into the US." As Cindy Patton writes repeatedly throughout her book

Inventing AIDS (1990), clinicians have too often shown that they are more interested in monitoring these populations at high risk for HIV infection than in helping them.

For example, in New York, when HIV/AIDS was still called GRID (Gay Related Immune Deficiency) very early in the epidemic, the shaky common understanding was that only men who had sex with men were at risk for the syndrome. This led to the association that, perhaps, their sexual practices were particularly depraved. Anal sex and multiple sexual partners were pointed to as intrinsic to homosexuality and, moreover, as perverse and unhygienic[19]. Or, perhaps, there was some inherent flaw that made them susceptible to HIV so that, along with neurosis and the tendency to pedophilia, GRID became another example of the pathological nature of homosexuality. Men who had sex with men (MSM) were posited as innately aggressive and irresponsible in their sexual patterns, and even gay writer Randy Shilts popularized this notion even as he rightly lambasted politicians whose homophobia kept them from attending to the growing epidemic. Conservative commentators like

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[19] Interestingly, I have attended quite a few discussion of the HIV epidemic in India where the perverse proclivities of sex workers are cited as a cause for their increased vulnerability to STD's, rather than the number of partners required by their work or the fact that prostitutes, unless they organize to advocate for themselves, are often not in a position to make demands of their clients, such as the use of condoms.

Jesse Helms theorized that this behavior might be fundamentally linked to the 'unnaturalness' (a thoroughly unsociological notion, of course) of homosexuality and the perils of masculinity unbalanced by its heterosexual position *vis a vis* femininity in the proper, domestic circle. While the mid 80's saw calls for compassion for the 'innocent' victims of AIDS, we found that practices and identities such as anal sex, promiscuity, female desire, injection drug use, closeted bisexuality, and simply being Black or poor largely precluded rights to social compassion.

Black men in the US have been characterized much as gay white men were then (and, to some extent, still are), regardless of their sexual orientations. Media accounts and even many progressive social scientific analyses such as E. J. Sobo's, represent Black men as abnormally (with the norm defined by straight, professional middle class, white men) sexually aggressive and neither willing to be, nor intellectually capable of being sexually responsible. Instead, they are heavily invested in a machismo that hinders communication and education, whether this investment is explained biologically, as Rushton does, or structurally, as Sobo does[20]. There is an explicit or implicit assumption in such analyses

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[20] I do not want, by this juxtaposition, to suggest that Sobo and Rushton are working from similar political positions or towards similar political ends. There is simply no comparison. While I wish to point to the methodological difficulties and pitfalls of research and reportage like Sobo's, such work is necessary to

that men of color are too strongly driven by their sexual appetites, and too seldom governed by moral and intellectual considerations, to learn to use condoms regularly or otherwise modify their behavior, thus necessitating physical modifications like circumcision. Their risk factors, thus, are 'naturally' racially circumscribed.

Recent conversation about the Black 'down-low' (DL) sub-culture[21] has brought both sets of presumptions together in a particularly treacherous way, as the institutional framing of DL men as self-loathing, closeted, and cloaked in secrecy provides a relief map against which out gay [white] men and heterosexual [monogamously partnered] Black men are seen as relatively accessible, informed, and successfully managing risk. It is the darkness of the DL man's body—his dark skin, his shady behavior, and the secrecy surrounding his desires—that codes him as a deeper source of infection now, remote from both the mainstream gay

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understanding and managing this epidemic. I censure writing like Rushton's outright and absolutely and hesitate to call him or his colleagues scholars at all.

[21] See Benoit Denizet-Lewis' "Double Lives on the Down Low" (2003), a very widely read *New York Times Magazine* feature that described the lives and HIV risk of Black American men who identify as straight and maintain primary romantic relationships with women but also have sex – usually unprotected in this telling – with other Down-Low men. While the issue Denizet-Lewis points to is an important one, and outreaching to heterosexually identified MSM has been a crucial aspect of HIV prevention work over the past 2 decades, this article pres ented the 'Down-Low scene' in sensationalized and inaccurate terms, drawing broadly on social fears about the threats presented by Black men more generally.

imperative to come out with pride and partner responsibly and the straight masculine clichés to assume responsibility for directing sexual relationships like a 'real man.' Further, the discourse about DL culture hearkens back to the early highlighting of closeted bisexual men as a prime conduit of infection. Not only is it the DL/bisexual man's own posited self-hatred, dishonesty, and perverse appetite that put him at high risk for HIV, it is the danger his behavior poses to his legitimate partner (not to himself or other shady partners) that makes his sexual practices a public concern. Oddly enough, in the global South, and in Calcutta, it is female sex workers—rather than the men who employ their services or male sex workers—who are viewed in this light: somehow, physically, essentially different from other women and in the public health focus primarily because they are sources of, or conduits for, HIV.

In *Flexible Bodies*, anthropologist Emily Martin considers the sociopolitical significance of markers of risk for HIV and other immune disorders.

> Is the immune system at the heart of a new incarnation of social Darwinism that allows people of different 'quality' to be distinguished from each other?... These days, we are often warned that an apocalypse of disease is

> coming soon, in which all of us will be tested but only some of us will survive. Oddly enough, most of these warnings do not involve AIDS. The writer Richard Goldstein points out that, until very recently, mass media coverage of AIDS positioned the general reader or viewer as a *witness* to HIV, but a witness who is safely immune to it.... [More recently the] position of 'the public' has moved from safe witness to participant in impending disaster. (Martin 1994, 229, emphasis mine)

She goes on to cite what *Hot Zone* author Richard Preston describes as the unicellular, not-alive and not-dead Ebola virus' *strategy* for its infective success. "As lethal viruses go, HIV is by no means nature's preeminent display of power." (Preston quoted in Martin 94, 230) HIV, after all, needs a fluid exchange and high concentrations of itself in the infected person's body. Again, as we have all heard, "HIV is very hard to get." Ebola virus, on the other hand, is more immediately gruesome and simply gross. It liquefies the bodies of those it infects, transmitting to anyone who touches that liquefied mass, perhaps when burying bodies. As any of us who have watched the horrible and untimely decline of

those with AIDS knows, though, HIV is gruesome in its 'methods' (if a virus can rationally be said to have a method any more than it has a strategy) as well, and it shares with Ebola its cultural roots in the dark continent of Africa and the dark sites of the dark practices of those on the margins of society.

The cultural rhetoric of HIV infection has formed and reformed communities of those most affected by this rhetoric as much as the material fallout of the epidemic has. In the rest of this dissertation, I tell the stories of some groups of people in two cities who responded to their forced categorization and marginalization by mobilizing themselves for better representation, better care, to self-determine their needs and affiliations, and to keep themselves alive.

As Alice Walker has told us, the secret to possessing joy is to resist. In that spirit, I do not intend to imply that the organizing work done by these communities is, by any means, flawless or straightforward or entirely egalitarian. It does offer us, however, the strongest model I have yet seen for responding to this epidemic that has grown beyond the proportions that we imagined 20 years ago, sparking social panic even at that point. HIV/AIDS continues to cause the horrible deaths of many, many people each year (I refrain from citing how many 10's of millions are infected

worldwide at this point because such numbers are difficult to grasp conceptually) and, yet, has somehow become an everyday matter that no longer seems urgent or horrifying. Facing such a disease, accompanied as it is by the epidemics of tuberculosis and malaria that also continue to grow, I find it remarkable that groups of people as systematically disenfrachised as those I discuss in this dissertation are can manage to envision and implement such far-seeing theories of power circulation, knowledge production, and community building.

Chapter 5: Gender, Communication, and Working in the Epidemic

In this chapter, I present gender-based and symbolic interactionist understandings of how communication and identification have figured as crucial processes in what and how organizers know about HIV/AIDS and about their own risk or infection statuses. Here, I consider how my informants became involved in AIDS work, how they moved into or formed the organizations they worked with, and how they communicated with others across this knowledge-producing web.

Gender as a Limit and as a Strategy

While my work builds on the fields of urban sociology, medical sociology, community studies, and the sociology of knowledge, its fulcrum is a gendered and feminist analytic framework. Let me organize this framework into a few major themes to put together the varied points of gendered inquiry in my research.

(1) In this project, motherhood is a *strategic* identity around which sex workers organized themselves. It serves, too, as a motif for promoting professionalism and legitimating one's work, especially for funding

and for drawing connections with other groups of women from very different backgrounds. My best example of this strategic use of motherhood is the high-profile and highly effective work of the Sonagachi sexual health project, under the *Durbar Mahilar Samanyaya Committee* (DMSC) – the sex workers' union whose title translates to "Committee of Women Working Cooperatively". They have lobbied to increase educational and healthcare resources available to them as *mothers* when such resources were hard to come by as *sex workers* or as *women*, and they have built their well-received international image, as a community, as *mothers* and *professionals* whose profession happens to be sex work, which – in this case – actually lends credibility to them as experts in sexual health and communication.

(2) Secondly, there are the connections amongst masculinity, sex, community, and risk. Masculinity is most visible in my research as it pertains to MSM (men who have sex with men) in NYC but also with respect to the male clients of female sex workers in Calcutta. There are carefully organized male sex workers' groups in India, but the Calcutta scene has, until recently, been dominated by the women of Sonagachi; and, while I spoke with some queer male organizers in

Calcutta, these people still focused the bulk of their safer sex and HIV prevention work primarily at women and children.

(3) In New York, masculinity seems to undergird much of the discussion about escalating HIV transmission rates and about various prevention campaigns. My colleague Salvador Vidal-Ortiz and I have critiqued the Young Men's Study (YMS), which was a multi-city longitudinal study on the HIV risks of young MSM (2001). The results of the study were published in terms of broad racial categories that were very misleading, but the now widely cited "fact" that 1/3 of all African-American men have HIV and do not know it comes from the NYC section of the YMS. There has recently been a great deal of media discussion of the Down-Low phenomenon, where Black men who have sex with men "on the down-low" are acquiring HIV and passing it to their wives and girlfriends (see the Denizet-Lewis reference in the previous chapter). It is an issue of importance, but it has been reported in highly sensationalized terms belying the intricate and intersecting negotiations of race, sexuality, and community for many minority men. This was an important finding in my research: many of the South Asian HIV+ MSM I spoke with in New York City defined their sexual activity with other men as social bonding that mediated their

sense of isolation in the US, simultaneously compromising and accentuating their senses of themselves as masculine and, relatedly, powerful subjects.

(4) AIDS organizing in the US has always been focused on gay men and a force of organizing gay men. Safer sex narratives often spoke of the need to eroticize care and social bonding in gay, male circles; and, the sex workers in Calcutta have picked up this same discourse of eroticizing care, of emphasizing social communication even when the sexual act occurs between partners who might wish to remain unnamed and somewhat veiled to each other. The sex workers, as the more visible ones in these interactions, often present themselves as the experienced educators of their clients. Such strategies have moved in both directions, from the US to India in this case and in the opposite direction in others.

(5) Related to this is the traditionally feminine caring work[22] which has been a strong aspect of the largely masculine field of AIDS activism in the US *vs.* the traditionally masculine political lobbying of the

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[22] As I have mentioned elsewhere in this dissertation, the burden of caring for those with AIDS fall primarily on the shoulders of women, across class and national boundaries. The traditional feminine role of caregiver is exploited in situations where men control family income or where they are infected first, often sickening before their wives and girlfriends. AIDS widows who become ill themselves are often left without caregivers or else have to depend on other family members or state-run facilities for all assistance.

hyper-feminized sex workers in Calcutta. The Sonagachi neighborhood has been a red-light district for at least a couple hundred years, not long after the advent of the British to Calcutta. It has long been a tradition that the artisans who craft the statues of the goddess *Shakti* (her name literally means 'female or feminine power' or, more generally, strength itself) for the *Kali puja* festival in the fall first take a fistful of dirt from Sonagachi to mix with the clay they use, thus imbuing the clay with the symbolic force of the district and its major profession. Swapna Gayen, secretary of the DMSC, wrote a letter in 2002 explaining that the DMSC would no longer allow this practice to continue. The women of Sonagachi did not want to be symbolically honored from a distance once a year while they continued being insulted, their civil rights daily flouted. Insisting that the sex workers be seen as contemporary laborers with material concerns is a strong and complicated stance. Gender is a matter of visibility.

Again, I focus on the work done by those employed in underground economies towards affecting and reformulating knowledge about HIV – as a disease, as an epidemic, and as a social and political

phenomenon – that has direct and indirect implications for the welfare of these individuals and communities. Further, I am examining the *communication* amongst agents in what I call the knowledge producing web of the epidemic in Calcutta and New York. In Calcutta, these are mostly women sex workers who are often but not always migrants or immigrants. In New York, I consider immigrants, mostly men, many of whom are working illegally either because they are not documented to be working in the US or because they are working "off the books," often in restaurant kitchens. Most of the HIV+ men I spoke with in New York are MSM (men who have sex with men). These two groups overlap not only because of their members in common but because of their common legal liminality, their shared status as sexual minorities, by their organizing into effective urban communities, and by their compromised citizenship at the national and local levels.

Drawing from the framing work of Michel Foucault, from the traditions of grounded theory and comparative and historical social science, from feminist scholars like Barbara Katz Rothman and Emily Martin, and from the tradition of critical symbolic interaction, I engage a sliver of the large subject of HIV/AIDS discourse in this chapter. Primarily, this research presents the verbal and face-to-face interactions, as they

are reported to me by my informants, amongst people from various social positions within these cities. Later in this chapter, I will turn the focus to the processes of medical interpretation and negotiation of different roles and positions within social service agencies. For now, my emphasis is on: (1) how immigrant MSM in New York present their joint negotiations of national identity, masculinity, and social affiliation; and (2) the ways the sex workers in Sonagachi present themselves as professional women and as mothers in order to legitimize themselves as holders and users of powerful knowledge about themselves, their families, their work, and their health.

The rate of HIV infection in India is rapidly escalating, with the National AIDS Control Organisation (NACO) reporting over 4 million cases at the end of 2003 and expecting this number could rise exponentially in the coming decade. The spread of HIV in India has always been primarily heterosexual, with injection drug use as a secondary conduit of infection, and homosexual sex a far less frequent vehicle. Activism around AIDS has been present in India's cities since the early 90's, although much of this, early on, did more to legitimize and fund gay men's groups through associations between homosexuality and AIDS taken from the US and Europe, than it did to establish AIDS organizations in their own right. One

prominent Bombay-based gay men's group, for example, received a significant amount of funding assistance from US groups but used little of this money to do AIDS work in India, especially not amongst those at highest risk in Bombay – girls and young women in their teens and early twenties. This demonstrated both the strong link between AIDS activism and gay men's organizing and the connection between organizing in India and the US. The advocacy and visibility work done by this Bombay group were no doubt very important, promoting the well-being and sexual health of its constituency, but its efforts were neither strictly nor explicitly meant to be 'AIDS work.'

The social and political marginality of gay men, however, is something many of my informants – whatever their sexual identity – sympathized with. One Bangladeshi man with HIV told me that, although he had contracted the disease through having sex with a man, he did not consider that behavior or himself to be gay. Mr. Ali did, however, identify with gay men, albeit through his work as an "off the books" dishwasher in the kitchen of a large restaurant in midtown. Although he was a legal immigrant and on a visa through his cousin, his work and his HIV status compromised that legality, and he felt constant anxiety – unlike many

other people I spoke with in similar situations – that he would be arrested or deported.

> I am not a gay. Those men, I knew even in Bangladesh, more like women really, but I did get it from a man – not a gay, just a friend of mine.... [I asked him how he distinguished between himself and a man who is gay] I know some at the restaurant, and you can tell, even if they are hiding it, they are worried at the time that they are hiding what they are. That's how I feel now too. I am so afraid that the police will come and see that I have this disease, that I don't have a green card, that I take my money home in my pocket (as opposed to a paycheck) and I think all the time that I have so much to hide.

Working and Communicating: Risk and Credibility

The organizing work in New York is a somewhat older story stemming from when the city was first in the spotlight as a 'hotbed' of HIV infection (although both cities remain cited as 'epicenters' of infection in the pandemic), and Bellevue Hospital long had the largest number of in-patients with HIV of any hospital worldwide (Shilts 1987, 363). In New York,

the gay liberation movement of the 70's and 80's was closely tied to AIDS organizing. Gay Men's Health Crisis (GMHC), now the largest AIDS service, advocacy, and education agency of its kind in the world, coalesced, as Randy Shilts' version of the story goes in *As the Band Played On*, from a tight network of gay men who knew each other socially and vacationed together on Fire Island, New York. Again, this type of flexible and organic political mobilization – blending social, professional, and political circles and occupying multiple roles with respect to the epidemic (bereaved lover, political agitator, and peer educator, for example) – has been characteristic of AIDS organizing. Gay groups did, like the ones in Bombay, become stronger through their negotiation of the AIDS epidemic.

Gender and sexuality have defined the trajectory and 'culture' of the American HIV/AIDS epidemic in other ways as well. It has, in New York and elsewhere, settled into populations of poor women – particularly, poor women of color – with a speed that is alarming. HIV transmission rates are increasing amongst women globally at higher rates now than amongst men (see the continuously updating information at http://womenandaids.unaids.org/ for current statistics). As is the case worldwide, poverty and the limited means to acquire income or other

resources force women into decisions and actions that put them at elevated risk for HIV and other STD's.[23]

In his book *Impure Science: AIDS, Activism, and the Politics of Knowledge*, Steven Epstein writes about the importance of credibility in AIDS organizing through the early 1990's. Epstein writes about the first marked and highly vocal high-risk group: white gay men in US cities in the 80's, "[it] mattered that these communities included... men with a degree of political clout and fund-raising capacity unusual for an oppressed group.... It was crucial that gay communities... had cultivated a disposition for appropriating knowledge and culture." (Epstein 1996, 12) I found that the struggle to be seen as credible holders of AIDS knowledge was a major theme in the interviews I did. This, of course, played out differently for, say, the South Asian American professionals I spoke with, who successfully organized in New York for the distribution of sexual health educational materials in accurate and easily understood Urdu and Bengali, than it did for the undocumented HIV+ Urdu and Bengali speaking MSM who were simply trying to establish working relationships

[23] It is interesting and disturbing that, while representatives at the UN, of the World Health Organization, and Doctors Without Borders frequently call for increased attention to the specific and growing needs of women and children in the HIV/AIDS epidemic, conservative commentators like Carey Roberts continue to criticze this stance as unfairly biased against men, "gender-bigoted," and a sign of why the Bush administration should have primacy over international bodies like the UN to determine world health policies.

with their doctors. I give here one example of how one man I spoke with negotiated for greater credibility.

One of my most articulate informants was Parvez, who believes he contracted HIV through his occasional sex work. He talked to me about how he, as a younger gay man, identified with his mostly Asian, older, straight-identified clientele. He said he understood that they felt they needed to hide themselves, that they had lost their identities in migrating to the US and New York and felt ashamed to hire a gay man to have sex that, in their home countries, might perhaps have been casually and quietly achieved through close networks of friends while circumventing labels or judgements for their behavior. Parvez said he actually identified with his clients and that something he really liked about their dates was that they afforded him the opportunity to speak Urdu intimately, which was personally very important to him. Between when he was diagnosed and our interview, Parvez had worked at HIV education and street outreach through a community-based AIDS organization that he had been referred to by his social worker. And he used his knowledge from this work in very interesting ways to make sense of his diagnosis.

> At first, of course, I was so angry and so scared. Like, how could this happen to me? And now where do I go, no? And

> I thought, fuck those men who won't use condoms, no? Just because they're ashamed of what they are, and now I'm ashamed too. But, now I understand denial. Because I want to deny this. And now I understand that men don't use condoms so that what they're doing doesn't have to be sex. We talked about this during my training, about MSM and internalized homophobia and HIV risk. And then I thought, maybe I was lonely and homophobic too. [I asked if he still does sex work.] [He laughs...] of course, of course, but now I understand. I say to them, you don't have to be gay, but I am, so we use a condom.

Parvez is conscious of how he negotiated his own ethnic identity and sense of not belonging in New York through his encounters with his clients, and so he is sensitive to how they negotiated what they understood as ethnically circumscribed masculine behavior in those encounters as well. I was impressed, throughout our interview, by how he wove back and forth between citing theories and examples from his AIDS education training or outreach work and offering an understanding of the complex production of identities and association that went on in the sex work he did. This

seemed important to him in making sense of his HIV diagnosis, and his outreach work clearly helped him come to terms with his seroconversion. I spoke with many people who, like Parvez, came into HIV/AIDS activism or volunteer work after they, themselves, were diagnosed. Steve Epstein writes that a distinguishing characteristic of the AIDS epidemic has been "the large-scale conversion of disease 'victims' into activist-experts", and several of the interviewees in my larger sample who worked in underground economies reformulated themselves as 'professionals' in every sense as they transformed into "activist-experts." Parvez, for example, expressed frustration at a new doctor he had seen recently who he said treated him, "like [he] was just any patient, not like [he] was a professional who knew about the treatment."

Conversely, however, the Sonagachi sex workers – and other groups who have organized like they have – used more conventional notions of a profession and a line of work to mobilize themselves on something quite like a traditional labor union model. These efforts were aided by the fact that the bulk of those organizing in the early years of this movement were women, many of whom were also mothers, and they called on familiar motifs and grievances to cement the grounds for their claims for aid and legitimacy. They also used the sophisticated tactic of

understanding health risks in broad, structural terms, more in the line of harm-reduction, and have been determined in holding the government accountable for the sex workers' health risks.

Dr. Smarajit Jana, the founder of the Sonagachi project, who has also initiated similar programs elsewhere in West Bengal and in Dhaka until they are handed over to their own communities, outlined some principles of the Sonagachi project.

- Prostitution was accepted as a valid profession and no attempt was made at discouraging sex workers to practice prostitution or at rescuing or rehabilitating them. This reassured the other stakeholders in the sex trade that we outsiders were not going to disrupt their business.
- A thorough understanding of the sex trade, including the particularities of each red light area was developed to map the relation of power and conflicts in interests between different groups of stakeholders in the sex industry. Based on this understanding, specific strategies of manoeuvring were evolved and followed to win friends and neutralise enemies within the sex trade.
- Special activities were targeted at different sections of the controllers of the sex trade. These included madams, pimps, *babus* (or regular clients of sex workers), to orient them regarding risk of transmission of

STDs and HIV and also about the larger programme objectives to encourage them to work with us rather than pose obstacles for us. Professionalism and communication have been two key aspects of organizing the Sonagachi sex workers. Communication has been put forth as an important element of training these women as more competent professionals with greater agency and means to make good decisions for themselves. Indeed, peer educators represent the choice to insist on condom use as good business as well as important to personal well-being. They target literacy as an important cause and, so, numerous worker education centers have cropped up around and near the Sonagachi district. Peer education focuses on how to speak to clients and madames about sexual health, about violence, and about the need to use condoms. It also touches on the need for those in underground economies to have basic cognizance of the law, of the media, of the rules and requirements of the schools their children attend.

As I said earlier, the insistence of these women that they are mothers and professionals and *must have* support from the state to do this work well is savvy and productive. Swapna Gayen, to whom I referred earlier, recently published a letter saying that the Calcutta government, unless it radically changed policies regarding the criminalization of sex

work, would show its lack of concern whether the children of sex workers ate or starved or learned to read. This sort of deflection of blame that is usually placed on sex workers for being bad mothers to the state that is not supporting them as mothers is a radical move.

Some of these principles are based on those of harm reduction. As Ritesh, a former sexual health educator in Calcutta articulates them, the tenets of harm reduction as they informed the AIDS organizing in West Bengal focused on the importance of voice and communication. The most important aspect of organizing around HIV/AIDS, according to Ritesh, is to ensure that those populations most at risk of infection augment the ability to express what they need and what their limits and terms are for the help they must receive. He says this is what the government efforts and transnational organizations were not doing, and this is what local NGO's and public health groups must do, to understand wellness in broader community terms. They were understandably responding to an epidemiological (and political economic) crisis, but they did not attend to the fact that the people living in sectors they were red-lining as 'high risk' would continue to live in the circumstances that elevate their risk for many years to come. Identifying that there was risk was hardly a step, Ritesh

told me, towards understanding or controlling it. It was crucial that these people be able to speak to each other and for themselves.

Again, with a fair bit of success, this is exactly what the sex workers in the Sonagachi district have managed to do. Ritesh particularly lauded the efforts and insight of Dr. Smarajit Jana saying that, although Dr. Jana's understanding of the situation did not deviate so much from that of many other volunteers and organizers, that he was able to see so clearly despite his medical training and as someone with medical authority was crucial to changing the frame of public health work in Calcutta. He was as important in what he represented symbolically as in what he presented as the principles of outreaching to sex workers and other high-risk populations. Ultimately, both with Dr. Jana and because of Dr. Jana, Ritesh described the Sonagachi sex workers as "authors of their own health program."

The Person Doing the Job

Next, I address the question of how people working through formal social conduits – that is, in non-profit organizations or in collaborative relationships amongst doctors, nurses, and social workers whose clinics or hospitals sanction their group efforts – how these people

use knowledge about AIDS in complex ways, to control or to ascertain the relative power of different agents in communication. How do knowledge, power, and communication intersect in the planning of public health work around the epidemic or in non-governmental sites that provide care for those least resourced people with HIV?

Let me return to Epstein's point about credibility. The first organizers I interviewed for my research were South Asian professionals living in New York who began mobilizing to produce better sexual health materials for non-English-speaking immigrants in the city. They began this project after they had originally joined together to protest the Indian government's unviable policy of denying a local AIDS problem in the early 90's. These organizers had the clout and manner to be received and remembered in the offices of the Department of Health and Bellevue Hospital even if accomplishing their practical goals remained a more difficult task.

Their experience was very different from those of many other HIV/AIDS organizers in New York who had less commonly recognized credibility as knowledge processors and producers. I spoke with Fay, an HIV+ woman in New York who recently (2002) participated in a staged protest at the social work offices of the community based organization

that was advocating for her. The clients claimed the agency was not paying attention to their needs or treating them respectfully. These were all legal immigrants, but some of them work off the books, and all of them are in low-end jobs.

> You know, you just feel like they think you're nothing. Yes, you have seroconversion, yes, you have an ugly apartment, but you feel still. And this girl [her case worker] twenty years younger! I can be her mother, and she talks to me like I don't know if my head hurts or if I feel dizzy or when to take what pill. She treats me like my mind is gone, but I know more about this disease than her.

Fay had been involved in organizing for AIDS services to immigrants at the same time that the members of the South Asian organization that I just mentioned were. She was one of a large circle of workers, clients, and other people affiliated with this second group who rallied for subsidized access to treatment and the broader provision of services in multiple Asian languages, and Fay ultimately benefited very much from her use of ARV therapy.

To return to Epstein's terms of the activist-expert, Fay too became one, subsuming the identity of "disease victim" within this other, stronger one. She grants herself a stake in knowledge of the disease and her own body that she felt her case worker did not, and so she resented and suspected the care she received because of this. Fay expressed great anger to me, as well as a sense of betrayal and fear for her own condition, because she perceived herself as being neglected as a client and as having few other resources. Further, and crucially, she was angry at being discounted as someone with an important degree of HIV/AIDS knowledge who should have had more influence in the determination of her own care and options. This frustration of an ill person at a medical system, and the related public health system, that demands total authority and supremacy of knowledge is common to patients in many different situations – the elderly and cancer patients are examples of people who have organized for better and more respectful care. Fay's perspective, however, has a specific significance because it is situated within the activist history of people with AIDS or HIV who mobilize, negotiating issues of cultural stigma and bias that are brought closer to the surface by the visibility of the epidemic and structural points of

inequity that are exacerbated by the disease and its modes of transmission.

Benjamin, a younger, non HIV+ client advocate at this agency, who sided with the protesters, told me:

> You know, you just started to feel very culpable, very responsible, because you meet with your superiors and the board and tell them the clients are unhappy... and you get told, "Oh, you're so compassionate to worry about this, but it's just the way this system works. The people who are informed have to make the difficult decisions." I was told that I would learn, as I climbed the ladder in the field, that clients often take out their frustration on their disease at their case workers without realizing that you're just doing what's best for them....

Benjamin went on to say that he felt that many of the case workers and board members to whom he had taken client complaints felt indignant that they, themselves, were not being properly appreciated for caring for

people whose bad decisions and unhealthy habits had gotten them into these straits of being very ill without the necessary net of economic security. Benjamin felt that the root of his alliance with the clients rested on this very point, because he had also made some of the decisions and had some of the habits that his superiors felt compromised their sympathy for the clients.

Epstein presents that "credibility," as he uses the concept, is equally dependent on power and trust. He writes, "On one hand, credibility is both a stake and a weapon in the skirmishes between all those who are in competition to say what the world is like. On the other hand, credibility is the mechanism for forging durable relationships within which knowledge can reliably be exchanged." Credibility, its construction, and its differential deployment obviously constitute only one aspect of the significance of the quotes I offer here, and of the complex interactions of people with different positions in this struggle to claim and use knowledge of HIV/AIDS. It is a pivotal aspect, however, and in my research, I found that the notion of credibility appeared in most of my interviews as crucial to the various negotiations for service, information, and access to care.

The informants I have cited thus far mention their access to knowledge as determinative of the roles they are to play in negotiating the epidemic in New York. Beyond what they know themselves, whether they are seen as credible holders of information is important for how and whether they are heard by those with more power. This also influences the amount of power they judge themselves to have. Benjamin expressed a sense of guilt and responsibility in his role as mediator between the board of the agency and his clients. He was given – albeit also in a filtered manner – information that his clients wanted and felt entitled to and, yet, Benjamin was instructed not to reveal it 'for their own good.' Fay, as a client, was frustrated that the knowledge she had was not of the right sort to help her determine her own care and circumstances.

Another important feature of the power of knowledge in these client-provider cases is the differing significations of AIDS in different circles. Benjamin commented further on his unease with his superiors and their expectations of him.

> ... the thing is, too, that if you have, like, an MSW, then you have a bona-fide reason to be working in an AIDS organization. ...[but sometimes even then, or] otherwise, pretty much, you have AIDS or

> are at risk. That's who works with this stuff, people who care about it because they think they're going to get it, or their friends already seroconverted, or whatever. So my supervisor kept saying, get like a work outfit and wear it when you go to the hospital with your client so that people know you're working with her and not just her friend. But, I'm getting paid $10 an hour, so if I wasn't her friend, you know, and didn't always think that, if I'm in her position someday or something, I want somebody to be looking out for me, I wouldn't do this work.... [laughs] but I have, like, one pair of, you know, "adult" pants, and I wear them *in this office* so I get treated more seriously *here*.

Again, he expresses an identification with the clients, not the organization, as his motivation for working as an advocate; but, Benjamin also understands that he must straddle the varying perceptions that others have of him for different purposes. He wants the client to feel that he is an

equal who is aware of his own risk of seroconversion, but he wants his superiors to view him as someone who is "coming up the ranks" and deserving of professional treatment. He cited this need for professional relationships as important, also, because they will then give him information about his client's case that they do not release to her for fear of her noncompliance with their protocol or her doctor's prescriptions. To then pass on such information is to directly contradict what his superiors expect of him and his position, but he understands that he can be a better asset to his clients if his superiors have confidence in him as a worker and an ally.

Prashant, an organizer from Calcutta, told me that a delicate negotiation of the types of knowledge and experience he claimed for himself in different situations was necessary for him to be an effective liaison between groups. Prashant became involved in AIDS work in Calcutta through a series of connected steps. He came out as gay in the early 90's to an immediate family that was supportive but confused as to what this meant for his future. Prashant's larger family and college friends were not supportive, either of his being gay or of his decision to make an announcement about it.

He was finishing college at the time and planning to study journalism and, so, coordinated with another out gay friend to write articles for local newspapers, aiming for a target audience of those who identified, "You know, however, *khushie* [a literal translation from Bengali for gay or happy] or queer or just outside the straight norm." Through this self-identification as gay, and through interfacing with South Asian queer groups in North America, he became very interested in doing AIDS work. His news article partner was working in a clinic and aware that there was a deepening AIDS crisis in Calcutta that none of the hospitals was prepared to deal with and that the government was energetically denying. Although Prashant early realized that the epidemic in India was, if anything, a heterosexual one, he said to me, "Still, AIDS work is always about sex that wouldn't be visible if it weren't a problem so, then, you know, that seemed like a queer issue to me anyway." Many of the Indian organizers I spoke with expressed this to me, that the problematizing of sex and those having the problematic sex created alliances amongst populations that would not have been allied otherwise.

Prashant described to me how he used his degree and work as a journalist very self-consciously to begin conversations with doctors and nurses whom he tried to lure to planning sessions for an *ad hoc* prevention

campaign. At the same time, he used his own standing as someone whose social marginalization was determined by his sexual practices to gain credibility in the eyes of female sex workers whom he also tried to bring to these sessions. He described one such interaction.

> This woman had a million questions for me about whom I had sex with, what we did, where we went, who else knew about it, so on, and it was really making me uncomfortable, no? So, she was very perceptive... I mean, I think being perceptive is part of her job. And she said at one point, "Don't mind, *baba* [a casual term of endearment], it's just that all sorts of these people, health workers and what-not, ask me these questions, and I'm very happy to find someone I can ask them to. I want you to tell me things about sex I don't know, so I can know even more."

Prashant also found himself in difficult situations in planning sessions where doctors, on one hand, and sex workers, on the other, who were all speaking Bengali looked to him to 'translate' between them because they felt that they could not understand each other conceptually without

someone who both had a college education and an experience of illicit sex to mediate between them.

Lucy, a Chinese/English speaking medical interpreter who spoke with me also commented on the many levels of interpretation. Doing the literal translation was, first, a tiny aspect of communicating *meaning*, but there was so much more – in terms of the particular perspectives and limitations of each actor's position as well as attitudes towards the social significance of HIV/AIDS – that comprised her job interpreting between healthcare providers in New York and their non English-speaking and usually very poor patients. She felt that her work was even more demanding emotionally than mentally, all the more so because her various formal commitments to a highly specified understanding of confidentiality meant that she could not step out of her role as interpreter to do the more personal work that she often found was sorely needed, and sorely neglected.

She echoed Benjamin's discomfort with wanting to do the assigned job well and to be taken seriously even while feeling that the limits of the job, as prescribed by superiors, sometimes clashed with what she believed constituted compassionate behavior towards the client. Both Benjamin and Lucy told me that, as the agencies they worked for

changed and became more established and formal, their own roles there changed, moving from volunteer or activist to a professional status, requiring them to earn degrees and assume more accountability to the agency. They both felt profound personal confusion about these shifts.

Lucy and I had started working as interpreters at around the same time (1996) and were recruited in similar ways, although by different groups. We had both worked as AIDS educators and were called in by someone who knew us when an emergency case appeared – in both cases, an older man with full-blown AIDS who had collapsed, had been dropped at the hospital by himself, and was unable to speak with anyone on staff. We both had imperfect language skills and minimal interpretation experience, but we were given rush reviews of confidentiality policies and the associated paperwork and, after the initial meeting, were hired on a case-by-case basis. Lucy eventually earned an MSW and got formal training in medical interpretation, but she spoke to me of an early case.

> It's the four of us, the patient, me, the hospital social worker, and someone else from the agency.... And then they're saying to each other, "He's really bad, and he could die, and I wonder if he's gay," and then they turn to me and say, "Ask

him how old he is." And I'm thinking, oh my god, he looks like my uncle and, like, still stuck on how he could die, and I suddenly can't remember the polite way to ask about age, let alone if he's gay. But I really felt like it was important that I stay there and be totally flustered, you know? Better than for him to not have anybody there, so I was afraid to tell the social worker that I was having trouble. But, it's funny, they trust you to be in the situation because you've signed the confidentiality agreement and aren't supposed to have any kind of credentials except that you speak this language they don't, but in that situation – back then, or maybe now too – you end up being part social worker and part hand-holder. You can't absolutely be on their side if you feel like the patient needs something else. And you still hear the stuff they say that you have to pretend you didn't.

Confidentiality and *anonymity* are major terms for those working in the field of AIDS policy and services as they are for anyone in public health or social services and, so, some codes cross over easily amongst the various backgrounds that my informants had. These are issues of

importance for anyone working on the edges of legality. These terms and the slippery concepts they convey become anchors of credibility and authority in this field in a given city, and their formalization becomes crucial in these two cities where the pool of people working in HIV/AIDS services is relatively quite small, quite intimate with each other, and frequently privy to rich gossip. As Benjamin said, many people doing volunteer or direct social service work around the epidemic do so because they belong to high-risk groups themselves or associate closely with those who do. Of the informants I have cited thus far, all but one felt that s/he was 'of' the AIDS epidemic – through working illegally, through having the disease, through being gay, or through suffering with another chronic STD.

Let me, then, attend to my own roles, first as client advocate and prevention educator and, then, as a somewhat more removed social researcher; and, let me speak to the question of the responsibility of the researcher in a situation like this, where the stakes can be literally life and death. Having worked for several years as an HIV/AIDS educator and advocate, what did I do when my informants revealed the potentially unnecessary, and potentially significant risks in their daily lives? To what extent is it ethical to intervene – or not to intervene – with someone who is

an informant, having signed a form acknowledging an understanding of and consent to my research project, and not a caller on my information hotline or an attendee of my Saturday afternoon risk reduction workshop?

I left the agency where I had been working because I found it to be insufficiently supportive of its workers and clients and because I wanted to focus full-time on graduate school as I turned my focus to my dissertation, but also because I felt – like many people doing social work – completely emotionally exhausted. I remember riding the subway back from a clinic in Queens, after hearing that an HIV+ client, still too sick to leave the hospital, would soon be deported, and I thought that it was time to give up the social work and really become a full-time student. The issues at hand continued to be hugely important to me, and I think part of my motivation in studying HIV/AIDS organizing in Calcutta and New York was that it would be a continuation of my earlier work at a slightly safer emotional distance – which was necessitated by my interest in preserving confidentiality and some measure of impartiality as well as by the simple distance of academic analysis as opposed to the provision of personal care. I did find, however, that the emotional distance was only somewhat greater.

Like most AIDS researchers, I am invested in mitigating the impact of the epidemic, at the population level and at the personal level. While a service provider, I struggled to remember that the level of influence any of us can have on the lives of others is quite limited. As a sociological researcher, I constantly had to weigh my accountability to the informants who gave me their time. I do feel responsible, of course, to tell these stories and to articulate the importance of social networks in rallying against the AIDS epidemic and the social oppression that have been justified by it because these social networks provide the best model for more institutionally based public health work. I also felt compelled to get involved with my informants' work on certain occasions where my participation was needed and where I could. For example, I have been peripherally active with the movement of clients protesting that central agency that Fay was part of and, just now, am becoming more active with that group. Also, during a few organization meetings at which I was recognized as a sociologist doing participant observation, I was asked to and agreed to speak about my earlier experience developing outreach materials and organizing events. I tutored one informant who was studying for his English-proficiency exam to gain entry to a City University of New York community college.

Through the research for this dissertation and this chapter, I found that my own credibility as a holder and user of powerful knowledge was continuously called into play, or called into question. This was important in forming relationships of trust between my informants and me. I think this demonstrates the prevalence and wide-ranging importance of these social processes of acquiring, recognizing, and deploying knowledge of the HIV/AIDS epidemic to various purposes.

Chapter 6: Particular Worlds of Suffering:

Everyday Life and Building Coalitions in the Cities

In 1998, on a Greyhound bus to DC to attend a workshop on the new immigration policies with respect to HIV status, I sat next to a doctor-in-the-making, an intern from England who laughed when I told him I was studying medical sociology. He had been in New York "shopping up a storm," as he put it and yet managed to tell me, "We think your discipline's rather funny. You're quite irrelevant, you know." I bristled and answered, "Yes, you would think that, wouldn't you?" We apparently did not share views on the influence of capitalism on healthcare, and he clearly did not see what pertinence the social sciences could have for healthcare. I saw over the next day of workshops that most doctors do view not only sociologists, but most matters social, as irrelevant to their work. Attending to social concerns, to human welfare, often becomes the job of those people most deeply involved in preserving their *own* welfare, and understanding the processes and institutions that determine their daily lives alleviates the burden of responsibility placed on them for

foolishly squandering their own good health, opportunities for education and employment, and basic stability.[24]

In this chapter, I offer a social history that means to understand the "particular worlds of suffering"[25] of certain communities in Calcutta

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[24] An excellent reference on this perspective is the collection *Unhealthy Societies: The Afflictions of Inequality*. Ed. Wilkinson, Richard G. Routledge: New York, 1996.

[25] Paul Farmer's *Infections and Inequalities: The Modern Plagues* has been very influential for me in producing this dissertation. It presents a synthesis of Farmer's anthropological analysis of the political and cultural circumstances of the HIV/AIDS pandemic with his physician's practical experience of treating those with HIV or AIDS and, perhaps most engagingly, his activist's passionate appraisal of the seriousness of the situation. In his conclusion to the book, Farmer writes about the real need for a sociological vision to address the current crises of infectious disease. As he does throughout his book, and as we all do in trying to lace together the disparate bodies of our own influences and research into a cohesive document representative of our own ideas, Farmer intersperses all his thoughts with quotes from other writers. Let me, in turn, quote from his conclusion at length:

> McMichael [writes] "Modern epidemiology is oriented to explaining and quantifying the bobbing of corks on the surface waters, while largely disregarding the stronger undercurrents that determine where, on average, the cluster of corks ends up along the shoreline of risk." Some disciplines have trouble distinguishing rigor from rigor mortis.... "Anthropology and social history," argues Kleinman, in writing of international health, "offer a needed complement because they critique the deep-grained assumptions that need to be recast. Only through the concrete understanding of particular worlds of suffering and the way they are shaped by political economy and cultural change can we possibly come to terms with the complex human experiences that undermine health." It is patently unacceptable that we fail to see sociologically, for the events and processes and pathologies chronicled here, biological though they may be, are all of fundamentally social origin. They are biosocial.... As Bourdieu concludes in La Misere du Monde... "we cannot dismiss the effect [the sociological message] can have by allowing sufferers to discover the possible social causes of their suffering and, thus, to be relieved of blame." (Farmer 2001, 281)

and New York, at the level of daily life. These communities have been especially vulnerable to bodily transmitted disease, designated 'high-risk' for HIV infection and, thus, further stigmatized and controlled, as groups that already had very little power and very few choices in determining and sustaining their day-to-day lives even before the advent of AIDS. It is those everyday lives that I wish to focus on here, especially with respect to the mobilizing work these groups did. Michael Callen, speaking at the 1987 annual meeting of the American Public Health Association, called the daily life of living with AIDS, "the moment to moment management of uncertainty." He went on to describe his management of the uncertainty of his own disease, as a founding member of the People With AIDS Coalition.

> ... I'm a skeptic. If I believed everything I was told... then I'd probably be dead by now.... If I didn't arm myself with information, with diverse views, I would be unable to defend myself from the madness and gibberish that daily assault

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That he ends with a quote from Bourdieu is significant because Bourdieu understood how deeply interlocked is practical knowledge with theoretical understanding, such that it becomes meaningless to delineate the distinction between them. He also understood that social scholarship could attempt to ameliorate the world around us, to delimit suffering wherever possible.

those of us who have acquired immune deficiency syndrome.

(in Crimp, ed. 1991, 165-166)

Callen deftly managed not only uncertainty, but also AIDS knowledge and networks to stay alive[26].

This is also the social history of the impressive (though fragile and sometimes ephemeral) and unexpected cohesion these groups welded out of their social and political marginalization and even out of their vulnerability to this disease; again, I focus on the alliances forged on a day-to-day basis amongst individuals. I do not mean to suggest, as some others have[27], that the HIV/AIDS pandemic has actually been wonderful

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[26] He stayed alive, too, for 10 years after his diagnosis with HIV, and his political work and 1990 book Living with AIDS began to change the perspective that AIDS was an automatic and immediate death sentence long before the emergence of ARV therapy.

[27] See, for example, editorials written by Eric Rofes and Andrew Sullivan, both of whom declared that "AIDS is over" after combination ARV therapy became commonly available for North American gay men in the late 90's. Both authors have written that the AIDS epidemic served to consolidate gay men's divergent interests in the 80's and caused them to redefine their identity as a community. Although both men have long histories of scholarship and community organizing, I find that their perspective is tremendously limited and short-sighted. "Post-AIDS," as Rofes describes the era since ARV, there has emerged something like a gay male version of the more general, feminist sex wars. I would describe it (surely, not without contestation from other quarters) as positioning Rofes and Sullivan on one end – advocating for the discarding of cautions and protections in the celebration of a "sexual celebration of the gay lifestyle" – and writers (although diverse in their views) like Gabriel Rotello, Michelangelo Signorile, and Larry Kramer on the other end – who call for moderation and "responsible behavior" – and someone like Michael Scarce in-between, actively practicing

because it has led to a new, stronger gay men's movement and other sorts of beneficial political organizing. I do not think the advent of combination therapy has made the disease a non-issue and can not see that it is possible to say there is any positive aspect to the AIDS epidemic. Rather, it is the effective organizing work that many achieved *in the face of this crisis* that is my interest here: how was it done; why was it done; and what were its effects? Specifically, how, why, and how successfully have discrete individuals or small groups formed *coalitions* in Calcutta and New York to maximize their potential to make changes in the everyday lives of those who have HIV, those who are at greater risk for contracting it, and those who are seen as the greatest dangers in the epidemic? As I have already written, it is important now to take lessons from the past 25 years of trying and failing to manage the epidemic in order to revitalize efforts both to prevent spread of the virus and to treat, in the long term, those who have it now. Social mobilizing and community based efforts have offered us the best hopes of effectively addressing the AIDS problem.

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harm reduction. In the gay media, one routinely reads Rofes labeling Kramer a moralist and Kramer retorting that Rofes is a spoiled brat, but these personality battles veil the highly contested and important issues beneath.

Defending the City:

Daily Life for Dangerous and Endangered Citizens

The epidemic in Calcutta most likely extends back to the mid 80's or before but, until the end of the decade, researchers still believed that there were some national boundaries that HIV had not crossed, India's being one of them. By the early 90's AIDS cases were clearly present in Calcutta, and citywide reports of heroin use and extramarital sex were very much on the rise. There has been much attention, over the past decade, given to the 'new sexual mores' in India, whereby secondary school students have begun having sex, gay groups and gay bars have sprung up, cohabitation has become acceptable in certain circles of certain cities, and premarital sex has become less shocking (see, for example, the cover story of the August 1999 *National Geographic* [millennium supplement: Culture] featuring an image of a 'traditional' Indian woman in a sari seated next to her 'modern' fashion model daughter wearing a form-fitting vinyl catsuit). These reports usually link such 'changes' to India's liberalizing economy or to globalization, more generally, and the entry of cable television, Coca-cola, and MTV to the upper middle classes of the country.

I traveled to India 8 times between 1990 and 2002, with those trips spaced more or less evenly across that time, and so I keenly noticed differences in street scenes and in my family's homelife. In the summer of 2002 – when the US had issued a travel advisory warning its citizens away from South Asia following increased unrest between the now nuclear-armed India and Pakistan – riding along a highway in Goa, I was amazed at how different it seemed from the West Bengal I visited in the early 90's. The two states are on opposite sides of the subcontinent, with different demographics, and there was a decade's lapse between my points of comparison. Still, the two images I saw seemed to be of different countries and/or of different eras. The highway in Goa was strung with high priced car dealerships and road signs sponsored by Coca-cola, so that the speed limit postings and exit markers all urged you to drink Coke‰. In Calcutta in 1993, liberalization was already well under way, but my middle class relatives were just then signing onto waiting lists for telephone lines in their homes and buying mini-refrigerators for their kitchens, and I left behind Twix bars I had taken with me because my cousins coveted them like everything else American I had.

In 1995, the AIDS epidemic in India was already large and undeniable, although state governments continued to assert that it was

limited only to pockets of sex tourism and heroin use. Both sex tourism and the heroin trade have been popular in Goa for a long time, and the state's identification as an hedonistic vacation destination for Europeans and Israelis has been crucial to its economy in more recent years. In the summer of 2002, a time of year usually off-season anyway but not nearly as deserted as it was that year, there was hardly anyone visiting Goa. We were the only guests at the large, deluxe hotel where we stayed at a heavy discount, and the locals told us that they were feeling the economic strain sharply. My now adult cousin in Calcutta, riding me around the city (now constantly under construction due to World Bank infrastructural loans) on the back of his motorcycle a week later, told me he would rather I give him a gift of money to buy his girlfriend a present than give her some American good. After all, he explained, "You can get it all here now, and our candy bars are better than yours." A little amazed, I later watched *Buffy the Vampire Slayer* with him on one of the house's two cable-connected TV's.

Sex tourism and the heroin trade have been important to Calcutta's political economy as well, particularly as the local lower employment market became more unstable and the Indian economy liberalized over the past decade and a half, with the Bharatiya Janata

Party (BJP) in power in India and the unusually capitalism-sympathetic Marxist Community Party - West Bengal (CPM-WB) in quasi-permanent power in the state. Calcutta has been a city for 'foreigners' ever since it was established as the headquarters for the British presence in India. The sex work districts in the city were cemented at that time, both for the service of British officers and of Indian administrators who worked for the British. They were also vital through the post-Independence 50's and 60's, when the city had a lively nightclub scene, an active film industry and, as my parents and their siblings sometimes recall, clean streets and sophisticated coffeehouses to facilitate meetings for coffee, conversation, and on occasion, flirtation[28]. Economic recession came with the 70's, but the red light districts continued their business and dates moved from cafés to parks. From what I can draw from my formal interviews with informants and my informal conversations with Calcuttan friends and family, sexual behavior in the city (and in other South Asian cities) does not seem to have changed over the years nearly as much as its representation has. This representation does, indeed, have everything to do with globalization and nationalism, and the DMSC has targeted these political roots of the misrepresentation of their constituency amidst the AIDS fear that is still

[28] This café and nightclub culture is fictionally but specifically described in novels by Amitav Ghosh and Amit Chaudhuri as well as in some of Satyajit Ray's films.

relatively new to Calcutta (having taken root there perhaps almost 15 years later than in New York).

AIDS workers I spoke with described how the appearance of the AIDS epidemic in the city affected the discourse of sexual norms, acceptability, and deviance in Calcutta. Whereas certain sub-cultures and underground economies had always been commonly known, whispered about, and tolerated, city officials and health authorities began to term them unhealthy, dangerous, and foreign to the nation – in fact, they were understood to be *harmful* to the nation[29]. The DMSC, for example, has been labeled 'foreign,' both literally and metaphorically by the government, by NGO's, and by journalists alike. Almost every time I give a talk about the organizing work in Sonagachi, someone will ask me, "But aren't they all just trafficked minors from Nepal and Bangladesh?"

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[29] An interesting parallel to this situation is that of the annual Indian Independence Day Parade held in New York City, organized by the Federation of Indian Organization, an umbrella organization that also serves to guard the gates of which activities in the city can officially be termed "Indian." For several years, the FIO denied Sakhi for South Asian Women (a shelter and advocacy group for women who have suffered domestic violence) and SALGA (the South Asian Lesbian Gay Association) permission to march in the parade. The stated reason was that these groups were regional – South Asian – and not necessarily India, but officials made it clear that the real reason for their exclusion was that these groups were divisive (Sakhi) and unsavory (SALGA) and not appropriate for inclusion into the Indian American community in the city. After a few years of protest and appeals, Sakhi was allowed to march, although it took several more years or large-scale demonstrations, meetings, and lobbying before the FIO allowed SALGA to march in the parade as well.

And journalists writing off of governmental press releases routinely make blanket statements suggesting just this and asserting that the Indian AIDS epidemic stems almost entirely from these trafficked minors doing sex work in Calcutta. The solution they propose, however, is usually not aimed at improving conditions for the sex workers but at "cleaning them up," bodily and morally, trafficked minors and all. (for example, *The Weekly Telegraph*, 4 April 2001; *The Times of India*, 26 June 2004; even *Frontline* reporter Raney Aronson, whose work on Sonagachi is generally detailed and accurate, makes these statements.) In truth, the minors and sex workers of age from Nepal and Bangladesh are in the minority; the DMSC has initiated a special committee to prevent trafficking or the introduction of underage girls into the trade; and, the Indian women in their 20's, 30's, 40's, and 50's who make up the majority of sex workers in Calcutta are just as much at risk for HIV infection from their clients as they pose risks for their clients. This has been key to DMSC strategizing: to present themselves as mothers and citizens who deserve support.

Of course, very similar ideas and processes concerning foreignness (loosely defined) took hold in New York and other US cities. These are the reverses that temporarily stalled the gay rights movement and fortified the new Right and their 'family values.' Fear of AIDS also

fueled Giuliani's 'quality of life' campaign in New York. As Robert Lederman – self-described 'Artist, Activist, and Anarchist' – wrote in 1999,

> It's unlikely that Giuliani is a racist in the mold of the Klan or white supremacists. He doesn't hate minorities and the poor, they just don't have a place in the corporate fascist police state he's trying to create. Like an efficient CEO eliminating unwanted employees, poor and minority New Yorkers must be downsized in order to increase N.Y.C. Inc.'s profits.

Panic is wonderfully effective at hardening opinions and boundaries, and the AIDS epidemic has always been politically manipulated in terms of national borders and issues of security. Let us remember that, years before the unconscionable confinement of Afghani and other Muslim prisoners there with no access to representation, Guantanamo Bay was used to quarantine Haitians with HIV for well over a year, also without recourse to advocates on their behalf, when they tried to enter the US as political refugees after the ousting of Aristide in Haiti. Daily life shifted somewhat for everyone with the AIDS epidemic and political responses to it, but this was most fundamentally so for those who were at elevated risk for infection or those who, living at the edges of

social or political borders, were represented as being the greatest dangers in the epidemic.

Constituency Centered Initiatives, Harm Reduction, and Community Wellness in Calcutta

The Calcutta sex workers' collective, the DMSC, was formed by women who were brought together by the state sponsored STD and HIV Intervention Project (SHIP) in 1992. This project, tremendously infuential and implemented by Dr. Smarajit Jana, later came to be known as the Sonagachi Sexual Health Project. It was initiated by the National AIDS Control Organisation (NACO), through a grant for AIDS work from the World Bank. NACO deployed the All India Institute of Hygiene and Public Health to begin HIV/AIDS related prevention and care work amongst sex workers in Calcutta, where they assumed the AIDS epidemic was spreading from the brothels throughout the city. The Institute of Hygiene, in turn, delegated the work to a handful of national NGO's and several local community-based organizations who provided the labor, space, and detailed, logistic plans to proceed.

From the very beginning of this project, sex workers were recruited as peer educators and also as programmers and planners. The

SHIP also adopted a holistic approach to caring for them as well as preventing HIV transmission amongst them and with clients. Before the program was launched, the Institute of Hygiene had conducted a 3-month survey on the practices and needs of sex workers and, so, the program began with objectives of providing care and education as well as providing condoms and training sex workers to distribute those condoms to their colleagues and explain how to properly use them. Peer educators were paid sufficiently to reimburse them for the time they spent working with the SHIP so that this work would not be an additional burden to them in terms of time or money. This sort of attention to the lived daily experience of the sex workers is what made this program into a model for others. While many programs had included sex workers or IV drug users in their implementation, none had really put the constituency at the heart of the project.

As members of the DMSC recorded this early moment in their organizing work, "What is unique about the approach of SHIP is that it gave sex workers a central status within the programme right from the beginning. The leadership of SHIP tried to imbue a genuine spirit of partnership between the Project team and the community of sex workers." In 1994, the Socio Legal AIDS Training and Research Center

began doing legal literacy workshops with the workers, and the following year, the program was given over completely to their administration. As the literature and interviews from Dr. Jana, the early SHIP leadership, and the founding members of the DMSC state over and over, a central principle of the program was to help sex workers on their own terms, without asserting external expectations or moral judgements and without dismissing the emotional and material complexity of the women's lives. It was essential that the women of Sonagachi felt motivated, of themselves, and secure in attending to their health needs, their emotional needs, and insisting on safer sex. This was the only way to create the circumstances necessary for them to consistently practice safer sex, voluntarily undergo STD testing, and seek treatment for diseases.

Earlier this year, in 2004, Subrata Mukherjee, the mayor of Calcutta, offered to the DMSC that sex work could be legalized if prostitutes would consent to mandatory HIV testing to receive and maintain professional licenses. The DMSC vehemently refused this offer, averring that only they can effectively and rightfully regulate themselves and that mandatory testing would undermine the trust built between sex workers and local healthcare providers. An article recently published in the *Times of India* (26 June 2004) on the HIV/AIDS epidemic in the country

and the DMSC's refusal of mandatory HIV testing ignorantly stated that sex workers are "infested" and the absolute source of the spread of what the reporters rather loosely call the "AIDS virus." This attitude that sex workers must be 'purified,' at whatever cost to them, to ensure the health of the rest of the nation has been dominant in AIDS prevention rhetoric since the early 80's[30], despite the fact that HIV infection amongst most commercial sex workers is actually quite low.

The principles of the DMSC and the Calcutta SHIP closely parallel those behind the harm reduction movement begun in England in the 80's. Although harm reduction focuses on drug use – particularly IV drug use – rather than prostitution, the goals and concerns overlap with the work being done in Sonagachi. As the New York-based Harm Reduction Coalition explains their objectives on their web-site,

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[30] This logic is very similar to that promoting the circumcision of men in southern Africa and South Asia to slow HIV transmission rates. This logic assumes that sex workers are bound to become infected anyway and that they are the central point, the source of infection for the locality. In truth, according to the Prostitutes' Education Network, HIV rates amongst prostitutes, internationally, only indicate that they are one of several high risk groups and seldom the most afflicted of these groups. A large percentage of clients, too, participate in other high risk activities as well, such as IV drug use or unprotected sex with multiple partners other than the sex workers they patronize. Because the receptive partner in intercourse runs a far higher chance of contracting HIV or another STD than the insertive one, clients might well pose a greater risk to sex workers than *vice versa*.

> Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. Harm reduction strategies meet drug users "where they're at," addressing conditions of use along with the use itself.
>
> Because harm reduction demands that interventions and policies designed to serve drug users reflect specific individual and community needs, there is no universal definition of or formula for implementing harm reduction.

Harm reduction seeks to make dangerous practices less damaging because the approach acknowledges that it is not absolutely possible to eliminate those behaviors altogether nor to externally motivate people to change their practices in the long term on the basis of moral or legal arguments. Further, other dangerous circumstances in an individual's life (poverty, abuse, etc.) may make risky practices like drug use or sex work understandable or necessary. Neela, a Delhi-based social worker who organized with an *ad hoc* group of teachers and healthcare workers in Calcutta to promote a prevention campaign for street children

in the late 90's, told me of her difficulties advocating for the wisdom of harm reduction.

> Because, you know, I had been working in an adoption agency before and was living in Calcutta at that time, and [one of the other organizers] approached me and said, "Neela you know about abandoned children. Maybe you really understand street children." I right away took offence at her using the word "abandoned" because these are very, very poor children from destitute parents who end up with us. I have no right to say they've been sloughed off by anyone but those of us with too much food, you know? And how can I understand a street child? But then I came to see how naïve these people were. So we were talking about child prostitution, and I suggested we do health workshops with them, give them food at the workshops and teach them about condoms, and my god, everyone was so angry. They were all like, "So you think it's fine? For 10 and 11-year olds to be having sex?" And, of course I don't, but they weren't going to feed and educate these children or track their parents down and give them good jobs. I mean, maybe they

> wanted to, maybe we all wanted to, but we couldn't or wouldn't or whatever. So then, I thought we should teach the children about safe sex [sic], clean needles. We should do health clinics, we should maybe even support Mother Theresa. I mean, these are *thousands* of children, and these other people want to have morals about underage sex? If we can't make their lives good, I thought, maybe we can at least keep them alive but, *yaar*, sometimes philanthropy's really cruel. [I asked what they ended up doing.] They did some kind of soup-kitchen thing for a while, not a bad thing, and moved a few children into an orphanage or something. But they're not orphans; they're poor. I was glad to get back to Delhi.

For the group she was working with, "understanding street children" seemed to mean understanding their inner motivations, as if these were divorced from their external circumstances. Neela thought they seemed unable to grasp the lack of choices in the day-to-day lives of these children. She went on to say that what the children really needed was a better economy and a completely overhauled

educational and housing infrastructure but, in lieu of that, condoms and a daily meal seemed both feasible and terribly important. As Barbara Katz Rothman has said, what they needed was a much better world. Until that better world comes into being, they needed ways to make their daily lives less dangerous. This was the most important aspect of the Sonagachi organizing: that it did not maintain a narrow focus on the practice of sex work and its moral significations but, rather, surveyed the full lives of those involved in sex work, including the reasons for which they chose[31] to engage in prostitution and why they did or did not practice safer sex.

As Katz Rothman wrote in *Recreating Motherhood*, a woman's 'right to choose' if or how she will become a mother is circumscribed by the limitations of her environment and resources. When she is choosing to have an abortion or not, for example, she is often making a decision that seems like the only one possible in her situation, the only option that does not come with costs that she considers unbearable. Perhaps she simply

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[31] Referring to sex work as a choice is a highly controversial notion. While it is often the most lucrative, and sometimes the safest, occupation available to impoverished women and men, it is usually 'chosen' from a stunted array of few viable employment options. There is also a large range of risk and reimbursement for those doing sex work in different situations. As Svati Shah demonstrates in her research on women in Bombay who sometimes do construction labor and sometimes do sex work (presented in a talk at NYU, 2004), these women would rather do the construction work – although it is badly paid and extremely physically demanding – but it is sometimes simply unavailable or pays so badly that feeding the family, or oneself, necessitates turning tricks, with significant risk but with relatively good remuneration.

cannot afford to have a baby and also finish high school. Perhaps she simply cannot raise the $400 and find a ride to the reproductive clinic two counties over that provides abortions one morning a week. Perhaps that mother leaving a six-year old child at an orphanage in New Delhi, to whom she must feel an immeasurable attachment, cannot view that separation as an abandonment so much as a relinquishing of a child she cannot sustain and keep alive. "Choice may be a useful or even essential political tool and concept, but it has a way of flattening everything out, reducing everything to the same level, all individual choice." (Katz Rothman 2000, 181)

So offering condoms to a child prostitute and talking about how to ask a client to use them does not necessarily expand her/his horizons, and it might be tremendously inaccurate to say this child *chooses* to do sex work when the other option is starvation. However, if it is not possible to offer shelter and education and the time to grow up and plan a future, condom programming in such a case may well be the offer of some (albeit very limited) choice as opposed to none. The negotiation of social morality (or, in some cases like this, common decency), the calculation of subsistence, and reducing the immense daily danger that poor people

encounter is an exercise laden with traps and complications. The DMSC has not always negotiated such paths successfully or without trouble.

As I have already written, the connection between the AIDS epidemic and gay rights was somewhat forced in India in the 1990's where there was not a strong epidemiological link as there had been in the US, but it was also to be expected because of the character of the pandemic as a cultural phenomenon and because of the shared marginality of gay men and people with HIV. The inclusion of male sex workers – some of whom self-define as gay and/or as transgender while others self-define as very straight – in the DMSC has been complicated. As Nitai Giri, the only male sex worker featured in Shohini Ghosh' *Tales of the Night Fairies* documentary on the organizing work done in Calcutta said, "Look at the way I look. I have long hair, long nails - what other work would people accept me in." After a reluctant entrance into the sex trade, he also reluctantly joined the DMSC but is now very involved in the Komal Gandhar cultural wing where he dances and acts in the troupe's educational performances. His reluctance to join DMSC was not just due to the representation of the organization as a women's collective, however. He was also responding to expressions of homophobia and transphobia from members of the union.

Prashant recalled some of his interactions with the female sex worker peer educators as frustrating sessions of educating them about homosexuality while some of them tried to seduce him, "to cure [him]," so Ami, a transgender sex worker from the neighboring state of Orissa, told me that she found a great deal of ignorance and hostility about gender non-normativity beneath a rhetorical veneer of acceptance. She said that, although she was born a man, she identified very much as a woman, not as a *hijra*[32] and wanted to be treated like a peer by other sex workers. While many understood this and accepted her as one of them, Ami said that there was also a strong undercurrent of a vocal minority that thought she was "unnatural and wrong" and made her feel threatened. For a group like the DMSC that tries to represent the concerns of over 60,000 sex workers throughout a large and populous state, it is close to impossible to understand and gauge the full compass of lived realities and dangers and so it seems that even a local, self-regulating group is necessarily subject to power disputes and to other conflicts within it.

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[32] *Hijras* are a broadly recognized community of transgender persons in South Asia, who present a spectrum of identifications from male to female to something other altogether. They have very defined communities that are marginalized from 'general society' and sometimes do sex work, but they are also drawn into religious rituals in a very complex way. They have their own patron Hindu god/dess and temples devoted to her/him, and they are often called to weddings and naming ceremonies for babies to bless the event in return for payment. Not all transgender persons in South Asia identify as *hijras* because their community is so culturally specific and carefully circumscribed.

Immigration and Survival in New York

The United States Immigration Service runs the largest HIV-testing program in the world, with a policy of testing anyone applying for a visa of any length and theoretically (and often practically) denying entry or immigration to those who test positive. These policies were put in place in 1987 and strengthened in 1993. The 1992 International Conference on AIDS, scheduled for the US, was moved to Amsterdam in protest of these policies and because organizers feared that delegates with AIDS would not be allowed into the country. Bavaria more famously set an early precedent in the late 80's as the only Land in Germany to deny residence of longer than 3 months to any visitors who test positive. In Bavaria, as in Colombia, Canada, and a few other countries, administrators get around the logistic impracticality of testing every visitor with a policy of testing those who are "suspected of having HIV," leading to the unfair deployment of stereotypes as 'profiles.' Several countries require HIV tests only for those migrants who wish to study or work in the "host country." In the US, HIV testing is rarely used for short-term visitors, although those who willingly declare their positive status are subject to interrogation about the

nature of their visit and to surveillance while in the US. The HIV immigration ban is more commonly used to deny long-term residency to those who entered the country as non-immigrants, to regulate who receives public social services or welfare, and as the stated cause for removing undocumented immigrants.

The US HIV travel and immigration ban became codified in 1993, despite the fact that Clinton met with ACT-UP and UAA (United for AIDS Action) members as a new president, in 1992, and repeatedly made promises about working to strengthen the rights of those with HIV and AIDS. AIDS workers, in fact, campaigned strongly for Clinton's election, with slogans like "Vote as if Your Life Depended on It" (ACT-UP 1992 poster, viewable on-line at www.actupny.org). The ins and outs of HIV-related immigration policy have, in fact, gotten so complicated that the San Francisco AIDS Foundation has produced a lengthy and tremendously useful manual for service providers on how to guide clients through the rules (http://www.sfaf.org/policy/immigration/). They begin this document by cautioning advocates, "Never tell clients to go to the Immigration and Naturalization Service (INS) by themselves.... If noncitizens go to INS by themselves, INS may arrest them and remove them from the United States (formerly called "deporting them") before they have the chance to talk to

a lawyer." The manual repeats this advice throughout and, indeed, when I worked as a service provider, one potential client was channeled into the removal process directly from the hospital room in which he was recuperating from a collapse caused by full-blown AIDS, which had brought him to the ER. I was called in only to translate and explain to him that he would be sent back to Bangladesh and not allowed to return to the Bronx home he had lived in for several years.

In 1996, this immigration ban was broadened to have greater effects on the lives of those who had been living in the US – as documented or undocumented immigrants – in the long term. Formerly, anyone who had spent over 6 years in the US was eligible for certain forms of public services, and anyone living in the country for that period of time who could prove that s/he would undergo 'hardship' (vaguely defined) in returning to the country of origin was exempt from deportation. Further, there had been a humanitarian policy of not removing long-term immigrants with HIV, who had been infected in the US; after 1996, positive serostatus became a cause *for removal* more often than grounds for deferring or waiving deportation. From 1997 on, a major shift occurred wherein the deportation process sped up, leaving far less time between the initiation of removal procedures and deportation itself. Previously,

many immigration advocates had counted on the expected lag time to figure out ways to begin the legal immigration process or to at least prepare those facing deportation, emotionally and materially.

After September 11, 2001, the process sped up still more, leading to the 'Special Registration' of immigrants from 'suspect' or 'known terrorist' countries. These countries were mainly Islamic, and immigrants were encouraged to volunteer for registration as soon as possible. Many of these people, seeking to comply with the law, were detained and deported on the basis of minor infractions. Even those who got through the registration without such complications, however, endured the hardship of spending hours on queues in front of the federal building in downtown Manhattan, only to enter the building and spend up to 10 hours in waiting rooms awaiting either an uncomplicated registration or, possibly, interrogation and detention. It is no secret, however, that the immigration and naturalization process is fraught with fear and uncertainty for non-citizens even under the best of circumstances. Nebulous threats like the 'war on terror' or the anxiety surrounding the HIV/AIDS pandemic make the process even more treacherous and capricious, and AIDS

activism and immigration advocacy have always overlapped tremendously in terms of relevant issues and involved workers.[33]

Those immigrants who make up the working poor in New York – in service jobs, doing manual labor, or as undocumented employees – still formed a crucial segment of the city's economic and social structure post-1996 but, whereas they had formerly had some assistance for medical and other subsistence needs, they were now barred from those basic aids. Ironically, this increasingly came to mean that they could neither safely gain access to HIV testing nor to AIDS care, actually making those of them with HIV more liable to transmit the virus to others. As I quoted my informant Mr. Ali in another chapter, he felt, like many others in his position, a new shame and fear that only partly had to do with his serostatus directly. A great deal of his emotional response was due to the obstacles and stigma associated with HIV/AIDS. He said, "I think all the time that I have so much to hide," and elaborated as follows:

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[33] I am thankful to my colleague at the Asian/ Pacific/ American Studies Program at NYU, lawyer and instructor Liz Ou Yang, who organized a series of teach-ins and other *fora* on special registration and educated me about the process. Ms. Ou Yang has provided *pro bono* advocacy and advice to many immigrants from Islamic countries who have faced removal post-September 11th, and the work she does is a wonderful example of the sort of organic, visionary, and impactful grassroots efforts responding to the ever-tightening immigration policies in this city.

> I worry that everyone knows and, if they knew, that could only hurt me because... what can they do? They can't help me. Only I can help to keep myself alive, although of course, she [his case worker at the agency] helps me too. But all this anxiety: this isn't really living. I have no energy to ever protest about anything at work, at the clinic.... Sometimes I think that's the real thing, that they want us to be quiet and just work so everyone can think we're not here.

Being a person with AIDS meant for Mr. Ali that he could no longer be an independent adult in the way he had been. Even before becoming sick and being diagnosed, he faced difficulties. Although he had the relative luxury of living by himself, his tiny Lower Eastside apartment was frequently opened to cousins, nephews, and friends who needed places to stay. After he became ill, however, all these men became somewhat suspect as the need to determine whether he was sexually involved with any of them influenced his conversations with his case worker. I accompanied her to see him on a couple different occasions when he had a guest staying with him and, although his case worker did not speak the same language he did – only a similar one – I

watched as she tried repeatedly to push Mr. Ali to identify what exactly his relationship to the man staying with him was. Each time, the conversation escalated through confusion to a stalemate, with each party flustered at the end. These episodes did not improve understanding between the two but, rather, thwarted what was often a very helpful and always a much needed relationship. Mr. Ali confided to me that he wished he were strong enough to have all his case meetings at the agency office rather than at his home while his case worker told me that it was only during these visits that she felt she had a real sense of what his daily life was, however incomplete her perception might be.

Mr. Ali did not respond well to his medications, and he did not take any antiretrovirals beyond AZT. The medicines he received to battle opportunistic infections made him nauseous and seemed uneven in their efficacy. His case worker and doctor could not decide if this was primarily due to his noncompliance (he would stop taking the medicines when the nausea arose and then start taking them again when his symptoms reemerged) or if the regimen he was given just did not suit him well. His persistent infections, nausea, and dizzy spells, however, made it increasingly difficult for him to get around by himself and increasingly complicated his ability to hold a job. I accompanied him from his home

to a doctor's appointment one day. We spent over an hour taking two buses to travel a distance I knew I could have walked easily in less time. While we were waiting to transfer buses, he had a dizzy spell and had to sit down on the curb. Once we reached the hospital, it took us 15 minutes of waiting for elevators and walking down long, exhausting hallways to reach his clinic, where we waited for almost two-and-a-half hours for his appointment. During this time, he vomited once and, after I got him a sandwich to eat, he fell asleep for 30 minutes. The wait at the hospital pharmacy was also lengthy, and the entire visit, from home back to home, took well over six hours, after which Mr. Ali was completely exhausted from this routine, monthly visit for blood-work and prescription refills.

When he had company or attention, however, he seemed to rally. He used his limited English to encourage others he met during his long waits at the infectious disease clinic at the public Manhattan hospital where he received treatment, and he was an active member of the support group at the community based agency that advocated for him. He went out of his way to welcome new members and followed up with them and described himself to me as an 'AIDS worker' too. Like Parvez, Mr. Ali used what he saw as the professional responsibilities of the AIDS

field (unlike Parvez, he received far less instruction and never formally did AIDS education work himself) to mitigate his fear and loneliness. Fear and loneliness did seem like the major factors affecting his quality of life, and they clearly affected his health as well. Living alone might have been convenient when he was healthy and working, but as a man who was almost always ill and who seldom left his home, having visitors became very important to Mr. Ali.

Because of this, his case worker's questions about his relationships to the men who stayed with him ultimately became a real point of contention between them. She was held accountable by her agency for acting to ensure that Mr. Ali did not have sex with anyone without explaining his serostatus and what measures could be taken to prevent transmission. As such, she had to ask those questions. She was also the one who handled all the welfare paperwork to maintain the monthly payments that allowed Mr. Ali to remain in his own home and frantically scrambled to preserve what she could of these payments in 1997 and 1998. Another issue of conflict between them was that Mr. Ali was more likely to complain about the services he received than to be grateful for them. He found his once-a-week home care aid to be rude and felt frustrated that they could not communicate. He did not like the

hot food God's Love We Deliver brought to his apartment. He and his case worker emphatically agreed, though, that he was very fortunate to have a home to live in, which served as a stable base for him while the rest of his life seemed perpetually in flux. The provision of AIDS care as a part of public services was slow in coming in both New York and Calcutta and has been unevenly applied since it was put in place; housing is often woefully neglected.

> ...We would like to add our protest to yours as you stand before the post office and raise your voices against the lack of spending for AIDS research.... We just wanted to join our voice with yours, to reach out to our brothers and sisters on the outside who have the freedom to protest and get involved. We want you to know that we are with you in spirit. Please, do not stop raising your voices. Gay or straight, black or white, man or woman, we are all in this together and must unite. If we do this now, then maybe, God willing, we will walk away from this crisis, with our lives and our dignity.

Statement of Prisoners in the AIDS Ward on Rikers Island to those demonstrating at an ACT-UP action at the General Post Office in New York, 1987 (reproduced in Crimp 1991, 160-161)

Shelter for the Sick

Housing people with HIV or AIDS has always been a major issue in the management of the epidemic, because those who live in poverty are so much more likely to become infected and because AIDS can prevent an individual from continuing to work. In many cases, just the stigma of having HIV compromises employability. This, then, is another example of how this epidemic exacerbates preexisting and persistent problems of social inequity. Housing for the poor has always been contested and inadequate, but this problem only grew in cities through the 20th century, as did many other matters of basic subsistence. We have a more affluent, materially inflated notion of what constitutes the 'middle classes' now than before, but it is also increasingly difficult to justify or implement public assistance for those who are poorest. What public assistance is now provided is often due to alliances drawn amongst private service agencies, individual community organizers and demonstrators, and activist lawyers who use the court system to hold the government accountable to its own most humane policies.

GMHC (Gay Men's Health Crisis) fought Mayor Ed Koch on the need to provide beds and housing for those dying from AIDS, and the Giuliani regime made the matter worse with the broad-scale privatization

of city hospitals and his much-publicized battles with public housing agencies, including Housing Works, which strives to find permanent housing for people with HIV or AIDS. In 1997, the Department of AIDS Services and Income Support (DASIS, built out of the former DAS, Department of AIDS Services) was codified by the New York City Council, and common law 49 was put into place. This code mandated that DASIS has a responsibility to provide housing for homeless HIV+ people on the same day that they request it; DASIS is also bound to tell clients about the procedure of filing a complaint about services they received (or did not receive) from the agency, if they need to do so. In 1998, Mayor Giuliani appointed Jason Turner head of the Human Resources Administration (HRA), which oversees public housing and other welfare services in the city, and his appointment ushered in an era of mismanagement or hoarding of HRA funds, of neglect of basic HRA policies, and of the consistent employment of 'terror,' 'security,' or 'budget' concerns to justify these transgressions.

As John Caminiti, a former DASIS director, is quoted as saying in a report on the department created by the Brooklyn-based NGO *Make the Road by Walking,*

> At times it was clear that the only time our (DASIS) clients were deemed important by HRA officials was when they died and could be added to their figure of closed Public Assistance cases. Client services is not their concern. Lowering the Public Assistance roles and getting people back to work is. (CAHRA Report, December 2000, section 9)

Craig Willse, a former housing activist and tenant organizer, was involved in a series of actions for Housing Works in October of 2000, protesting the failure of HRA to provide the emergency housing they are bound by law to arrange for homeless people with HIV. He was, at the same time, working for a legal group advocating for the rights of those living in SRO (single room occupancy) residential hotels, but this legal group saw his activist work against HRA as problematic, not wanting SRO's to be given over to the public sector entirely. This sort of constant struggle between the public and private sectors for housing that is, by almost any standards, quite substandard at this point, indicates the level of artificial scarcity in the housing market in New York. SRO's are almost always run-down, often dangerous, lack kitchens and, sometimes, lack clean and functioning bathrooms. They are usually rented and paid for by the week

or month, adding to the instability of those with the smallest and most unreliable incomes. Still, they are often the best option for long-term housing for those who are poor but who still have some source of regular income, although for those who are ill, their extreme lack of facilities poses a great challenge to the daily needs of survival.

Craig described the conflicts in organizing first the 'DASIS watch' – where volunteers positioned themselves at the DASIS offices to try to find housing for those who were turned away by the agency's own employees – and then the action to draw public attention to what was happening. These were conflicts that specifically arose between clusters of people working at different levels of the group, with different amounts of power and legal protection. There was tension between the practical goals of social work and the more radical goals of activism, but this tension was resolved by the common commitment to the work of housing people with HIV, work which was currently being sorely neglected. Craig spoke optimistically about this tension, saying that activists and social workers crossed over in their goals and efforts and learned from each other's work.

DASIS Watch was organized by the New York City AIDS Housing Network (NYCAHN), a coalition of staff members at a number of private

HIV/AIDS agencies across the city. Each volunteer took a shift once a week to observe the treatment of DASIS clients during the day and then stay as long as necessary – often until 10:00 or 11:00 at night – to be sure every client was given an assignment for the night and that s/he was able to find the address and check in. Not only did these volunteers end up doing much of the work that DASIS staff were supposed to, they also watched for problems in the assignments that were given out. For example, that September, several clients reported being sent to a building that turned out to be a bank (Lobbia, 2000); so, DASIS Watchers phoned ahead to verify addresses before sending people out on the often long journeys to those sites. They also intervened to arrange for long-term assignments wherever possible, to avoid DASIS clients needing to return to the office each morning to await a room assignment for each night.

NYCAHN also worked with the Coalition for an Accountable and respectful HRA (CAHRA), which did similar sorts of monitoring for the welfare and public assistance system in the city more broadly. While these networks were tremendously effective at higher level politics and with flashpoint cases like the crisis at DASIS in the summer and fall of 2000, there were frequent complaints from members that the representatives of

these groups tended to be mostly white, highly educated people in their 20's who transitioned in and out of the field. Meantime, some of my informants, who commended specific actions of these organizations but hesitated to applaud the coalitions more broadly, said that the needs and participation of historically marginalized community-based organizations like the Harlem Coalition of Mercy remained underrepresented.

There was also conflict between the political expectations of the organizations involved in orchestrating the watch and the action – the lawyers and administrators who did the logistical and publicity orchestration – and those people who would actually be arrested at the demonstration. These people were generally younger (though sometimes significantly older), often poorer, and usually had more legal vulnerability and less status and power than the lawyers and administrators. As Craig explained, these activist-arrestees were not fully prepared for what to expect, and the emotional impact of being violently arrested was not appropriately considered beforehand.

The activists entered the DASIS headquarters on Water street, sat down in the lobby, blocking the entrance, and chained themselves to each other and to building fixtures. They started calling for the office to

be held accountable to its responsibilities towards HIV+ clients while supporters chanted and leafletted outside the building, and they waited to be arrested. When the police arrived, officers used bolt cutters to break the chains, handcuffed protestors, and physically carried them out one by one. While these tactics have become more visible and expected as the anti-globalization movement has grown and encompassed demonstrators from the US (activists in many other countries have long used such methods), up until the events in Seattle in 1999, they were mostly seen in the US in civil rights, anti-war, anti-nuclear, and AIDS actions – political movements known for their high level of passion and performance and for coalescing around acute, not chronic, problems.

Watching a video of himself being carried out of the building, handcuffed and still chanting at the top of his voice, Craig commented that he looked like "a crazy AIDS activist." And this is how they were treated after their arrests. They were detained for 36 hours before being charged, 12 hours beyond what was then allowable (although, since 2001, the 24-hour limit is no longer in place). And they spent almost a year in the courts, threatened with lengthy jail time throughout that year, before their cases were settled with community service.

Craig also explained how the court system became especially thorny for those activists who had outstanding legal records for what he carefully called "survival crimes," meaning those arrestable offences that one commits in order to survive: like sleeping on the subway; occasional sex work; stealing food; squatting buildings; etc. Craig was particularly careful not to differentiate too broadly amongst political crimes, survival crimes, and other criminal offences because they do, after all, exist on a continuum, and one of the Giuliani administration's attacks on poverty (which manifested more as an attack on the poor) was to criminalize those actions people without resources must take to subsist on a day-to-day basis. Although their actions did result in a change in attitude at the DASIS offices and a recommitment to housing poor people with HIV, they also led to a months-long ordeal for the activists involved and to a greater breach in trust between agencies like HRA and Housing Works and independent AIDS housing advocates.

The Grassroots and the Industry: Non-governmental AIDS Work

Writing a decade earlier, about an epidemic that was both profoundly different from and just the same as the one it had evolved into by 2000, Cindy Patton describes the tension between grassroots AIDS

groups and AIDS service organizations (ASO's) that developed through the mid-to-late 80's.

> The [People Living With AIDS (PLWA)] movement was initially a self-help movement which ran parallel to the emergent ASO's, but it quickly grew into a coalition of local groups which were dissatisfied with the increasing bureaucratization of the AIDS service organizations, despite the obvious affinities between the two movements.... Where once there was an easy slippage between helping oneself and helping one's community, the other-oriented model of the ASO's forced gay PLWA's into a 'patient' role which they had always hitherto rejected.... Staff/'patient' roles eased adjustment to the reality that the members and staff of these organizations were themselves being diagnosed with AIDS and testing HIV antibody positive. (Patton 1990, 10)

This relates back to Benjamin's comments in the "Gender, Communication, and Working in the Epidemic" chapter. He spoke of his difficulties negotiating the multiple positions he held in his agency: as an advocate for his client who was sympathetic to her needs and concerns; as a representative for the agency and its administration; as a self-perceived member of the population at high risk for HIV infection; and as a social worker in the making, who was using his education and work

experience to move ahead in this profession. Especially because AIDS service organizations splintered and reformulated themselves with such regularity, and because the division between the grassroots and the service industry became more blurry throughout the 90's, many of my informants reported feeling conflicted amongst the multiple positions they held with respect to AIDS work and to HIV risk. Parvez reflected this as he moved from client to part-time staff member, and another informant named Jay from the same agency told me his role and loyalties as an interpreter became confused when he himself seroconverted.

Welfare reform and immigration reform in the US and the pledge of US$191 million in loans from the World Bank to India for AIDS work made substantial changes in the day-to-day lives of poor people with HIV or at high risk for infection through the late 1990's. Organizing and coalitional work around the epidemic, begun in New York in 1981 and in Calcutta in 1992, also changed considerably as the number of groups serving different constituencies or causes grew along with their budgets.

Patton goes on to say,

> ... the groups based in gay community traditions [formed] the basis of what was to become an AIDS service *industry* which now stands in an institutionalized relationship to the medical

> industry and government.... Its structural similarity to other non-profit health organizations made it difficult for the AIDS service industry to work with smaller groups working with [multi-service] approaches. (Patton 1990,.12, emphasis in original)

Soon after the end of the 80's, however, the structure of AIDS service agencies in New York changed. Groups serving communities of color – like the interdenominationally based Harlem Coalition of Mercy and the private New York Asian AIDS Alliance – split off from other community-based multi-service agencies to focus on the needs presented by the epidemic. In addition to direct policy, education, and advocacy work, these groups also served as community liaisons to AIDS service organizations that had traditionally served mostly white PLWA's: ASO's that provided housing, home-delivered hot meals, discounted medicines, and legal clinics to people with HIV and AIDS. In this way, through the 90's, the AIDS service industry and the community-based multi-service organizations that Patton describes as at odds with each other through the beginning of the epidemic were pushed into a more cooperative and overlapping relationship with each other, although turf battles and conflicts of interest continued.

She writes that AIDS service organizations were "more familiar" and "more accountable" to private funders and government agencies (Patton 1990, 12), but this was also complicated by the emergence of ASO's that represented immigrant populations and communities of color. New York Asian AIDS Alliance (NYAAA) developed when an informal collection of Asian American social workers took time away from their full-time jobs to provide AIDS representation to a broad Asian/ Asian American population in the city, a group that was consistently overlooked in AIDS studies and outreach campaigns throughout the early 90's. As Will Liu, one of the early members, told me, city surveys in the early 90's reported that there were no AIDS cases at all amongst Asians even though each of these early members routinely came across Asians suffering from the disease in their daily work. In fact Will said that, at the time, there was a high rate of infection amongst older Chinese first-generation immigrant men who used morphine intravenously, but many of these men were never even officially counted as AIDS cases because they did not fit the current, expected profile of an AIDS patient. They were, however, unofficially treated for the familiar combinations of opportunistic infections. NYAAA (usually pronounced Nyah) eventually became an organization in its own right, although it originally only had the

resources to support one rented cubicle in another agency's office and one paid worker. The other members continued to volunteer, and the organization continued to grow, initially rooting itself in some radical principles of providing service to any immigrant with HIV – whether Asian or not, whether documented or not – who needed help, offering advocacy, food and housing, education and condoms, and even an under-the-table job if possible. NYAAA also started putting out their own printed AIDS awareness materials, translated into a growing number of Asian languages, and conducted their own surveys to counter what the government had overlooked in theirs.

Soon after the organization established itself, though, an influx of funding and the worsening condition of their director, himself sick with AIDS, necessitated a change in management. With the new director and his staff came a new set of principles of administration. The organization set itself an explicit goal of developing into a corporate-style agency, with significant funding (ideal amounts were now set in multiples of 100,000 or even 1,000,000 rather than the hundreds and thousands of the previous years) and broad recognition from the Asian/Asian American communities in New York and from the AIDS service industry more

generally. Indeed, they managed these goals quite well in the following six years, but with costs that some long-time workers deemed far too dear.

For one thing, the new administration effected clearer distinctions between supervisors and workers and between workers and clients. It was no longer possible to provide unofficial employment for undocumented clients, and it also became riskier for any workers – part-time or full-time – to have any undocumented 'second jobs.' This meant that it became more difficult, for example, to hire sex workers as part-time community educators, and this sort of flexibility had formerly been key to the highly effective prevention work NYAAA was able to do. It was also one way of fulfilling the radical principle of providing safe and non-exploitative employment opportunities to those who most needed them, but this principle shifted itself as undocumented workers and immigrants were moved away from the center of the agency in the interest of greater credibility with other organizations and governmental institutions.

The desired corporate model also meant that hours were changed to better fit the standard corporate work day. The late starting hours that the office had always maintained (10:30 a.m.) meant that many of the staff members could do late night outreach at clubs and bath houses, and also that it conformed to the schedules that many of

the very young staff preferred. The day now began an hour earlier, and supervisors grew stricter about lateness. As well, seniority had always been determined by years at the agency and overall experience, but it was now determined by level of education, which gave some of the longest-term staff members new superiors who were fresh to the field and had little to no work experience. Some of these staff members found the experience humiliating, and others remarked that the flexibility and independence formerly afforded had compensated for what had never been adequate pay in return for jobs that usually required well over 40 hours of work a week to complete. Two final changes included a prohibition against 'inappropriate' language in the office and the restriction of vacation days to 10 a year. Almost all staff members were immigrants, and almost all now taught, counseled, or facilitated workshops about sexual behavior for a living. The restriction on vacation days greatly complicated plans to travel internationally in order to visit friends or family, and the new surveillance of language made staff members feel censored and patronized.

Gallows humor and a casually bawdy atmosphere had also served as coping mechanisms, alleviating the emotional stress that

workers often felt from the circumstances of the field. As Benjamin had said to me in his interview,

> I mean, I know everyone in the office *cares*. If you didn't care, why would you do this work? Because, like, everyday you come in, you kinda take the risk of going home feeling devastated or burdened. The work takes a toll.

As I discussed in an earlier chapter, social work has a high 'burn-out factor,' with social workers exhausted from the emotional demands, physical requirements, and great amount of bureaucratic finesse needed for everyday tasks. Benjamin and Jay both described to me that an afternoon of travelling on buses and subways to reach a client home or clinic, the difficulty of seeing to that client's needs, often standing in line at bureaucratic offices and filing seemingly endless amounts of dull paperwork ruined the chance of having a relaxing or otherwise productive evening afterwards. They both talked about their efforts to create "havens" for themselves at home and at work to recover from the 'field'. With the changes detailed above, many workers felt that NYAAA no longer provided sufficient comfort for staff nor enough protection for clients and that it had made a full transition from grassroots organization to an agency of the AIDS service industry.

Similar conflicts arose in Calcutta organization that, like NYAAA, had grown from *ad hoc* collectives to influential institutions and, in so doing, had greatly changed their approaches and ideals. There was also conflict amongst workers with different backgrounds, as Prashant phrased it, "from different planets and eras," and with varying amounts of power to be heard. Neela described to me the points of friction that arose in meetings of the collective seeking to help street children.

> Always, you know, always it was the same... because there were quite a lot of us, all professionals of some type. And there was a hierarchy but, then, something like a reverse hierarchy too. The doctors and the one lawyer had the most prestige, and they would try to run the meeting and talk down to us. But then we social workers and nurses and lower clinical types [laughs] would argue and say, "No, you don't have the experience with people. These are just abstract ideas for you!" But these doctors, they were the activists and philanthropists at their clinics and nursing homes [a smaller, private hospital]. They were shocked to hear anyone say they didn't have enough experience. And, honestly, I don't

know. The thing was, kind of, none of us had enough experience.

But others reported similar kinds of discord, as Prashant also described in the "Gender, Communication, and Working in the Epidemic" chapter, when he was called on to act as a cultural translator between organizers from different professional backgrounds who spoke the same languages. In this regard, too, the Calcutta SHIP initiative and the West Bengal Sexual Health Project were very successful at persevering through the conflicts and distrust to persuade doctors, lawyers, social workers, nurses, volunteer 'housewives' not employed outside the home, and sex workers to cooperate and respect each other's particular areas of expertise. This did not happen immediately or automatically, however, and the DMSC, more recently, has encountered trouble within its constituency as some members have expressed dissatisfaction that literate, English-speaking, older workers – who represent a relatively privileged minority in the red light districts – have so fully become the representatives of the cooperative. These representatives argue that their language skills are needed to communicate with a broader spectrum of supporters and allies and that group decisions are still made collectively (DMSC list-serve archives, 2003). However, such disagreements show that

coalitional politics are always extremely dynamic: constantly in the process of formation, dissolution, and reformation.

HIV/AIDS and Survival Post-1996

Between 1996 and 1997, NYAAA and several other large community-based organizations in New York changed their structure, antiretroviral combination therapy became available to a first set of people living with AIDS[34] in the global north, immigration and welfare laws changed in New York, and the AIDS epidemic became a matter of common knowledge and discussion in Calcutta, due in great part to the efforts of the West Bengal and Sonagachi sexual health projects. As a result of these changes, the way we think of, speak of, and address the HIV/AIDS epidemic shifted as well. For those who are ill in this epidemic, the need for extensive public services continues but, increasingly, those services are not provided in a truly public sense but by private organizations that receive grants – sometimes from the government and often from private funders. In India and Calcutta, for example, monies provided by the World Bank and by the Gates Foundation have been

[34] These people, however, were no longer referred to as 'people living with AIDS' after the emergence of the 'cocktail' but, rather, understood in terms of their HIV infection.

invaluable in subsidizing the programs implemented by groups such as The Calcutta Nework of Positive People (CNP+), Development Management Consultants (a corporate philanthropic organization that provides goods and services requested by children with AIDS), Sanlaap (which provides a shelter for HIV+ women), and even the West Bengal State AIDS Prevention and Control Society. These various groups, only the last one based squarely in the realm of the public, along with several others like the DMSC from what is now a robust AIDS service infrastructure in Calcutta. AIDS historians (Crimp, Shilts and Watney, for example) have documented how integral coalitions of private and informal groups have been to creating a real AIDS service network in New York, since the formation of GMHC in 1981. These coalitions (of 'strange bedfellows,' in many cases) have attempted to address the needs of the epidemic as public time and money have turned, in both cities, towards finance and corporate interests and as both administrations launched their campaigns against the poor.

As Gregg Bordowitz said at a much-publicized action on Wall Street in 1987,

> As a 23 year old faggot, I get no affirmation from my culture. I see issues that affect my life – the issues raised by AIDS –

> being considered in ways that will probably end my life. For this reason, I think that if there is to be a movement that will shift the discussion of AIDS away from the moralizing, punitive attitude that has characterized this country's policy, it will be built out of an emergent popular culture, one that affirms the lives of those affected. It will be a counterculture that will grow out of a broad-based mobilization to end the global epidemic.... There are already moves to contain this growing activism.... The first targets of repression are, as always, the most disenfranchised. Thus, New York City's health commissioner Stephen Joseph has recently called for consideration of "mandatory AIDS testing [sic] for prostitutes and sex and drug offenders, as well as a heavy crackdown on all forms of prostitution." (in Crimp 1991, 183)

Bordowitz went on to speak movingly and optimistically about the possibilities of building on the AIDS coalition that was then growing in New York and San Francisco. He expected that the heavy involvement of immigrants in the US coalition meant that an international one was also being born, although it did not seem as urgent at the time. In an interview for the ACT-UP oral history project in 2002 (available at the ACT-UP

archives on-line at www.actuporalhistory.org), Bordowitz described the Testing the Limits coalition he was part of to oppose calls for mandatory testing. "We organized it like a Soviet-style collective. It was a consensus-driven collective. It was a collective of lesbians, gays, and straights formed to document emerging activism among government inaction around AIDS." In retrospect, Prashant told me that, having read this interview later and then gone back to learn more about the Testing the Limits movement of the late 80's and early 90's, he thought it might have served as a sort of unconscious model for the projects in Calcutta. "Like I didn't know about it and didn't know anyone else who did, but it still set the stage for what we tried to do there... I can't explain it exactly." He felt that the real overlap of circumstances, of needs inn the two situations created a sort of common consciouness, across time, space, and language division. However obscure his idea might be, Prashant was speaking of the bond he felt with others who had begun organizing out of a sense of emergency.

Bordowitz also described in this interview how, as bisexual man who had been living with a bisexual woman and eschewing categorical identifications, he made an explicit, political decision to identify as a gay man in 1987, in order to join the movement that was fighting the AIDS

epidemic at the time. The Queer Nation movement emerged soon after, encompassing those who were not necessarily gay but were certainly not straight either and who came together in feeling threatened, both by AIDS and by the governmental response to AIDS.

Although the international HIV/AIDS oriented alliances formed over the past 25 years have not managed to "end the epidemic," to "Stop AIDS!" they have had more effect in improving the lives of people with the disease than more governmental efforts. It was activists jointly planning across national borders and community barriers that really brought the issue of patents on antiretroviral medicines to the fore, supporting Brazil in its flouting of those patents. It has also been the cooperation of these activists that has advanced their strategies and helped them to educate each other about migration, treatment, gender, class, and racial implications of the pandemic, such that affluent gay men in the US have sometimes become very involved in the lives of poor, straight female sex workers in India, and *vice versa*. Bordowitz was speaking of his fear of contracting HIV, developing AIDS, and dying of it. The epidemic had begun to define the lives of men who had sex with men and, to some degree, still does, as it does for other groups as well. But Bordowitz did not die of AIDS and governmental neglect as he had

feared; his daily life – like Michael Callen's, like Parvez', like many others – was buoyed by the strength and attention of the international HIV/AIDS movement that they constructed with others who shared sensibilities and vulnerabilities with them. The strength of these alliances is that they simultaneously broadened categories of marginalization and collapsed barriers to sympathy and cooperation – even if very unevenly and imperfectly so – thus creating new spaces and options for people who had felt increasingly closed off and pushed out by this new epidemic and the conservative trends it had originally buttressed and exacerbated.

Concluding this Dissertation

When I began researching this dissertation four-and-a-half years ago, I was just beginning to consider staying in the academy after graduation instead of returning immediately to the field of social work, as had been my prior plan. It turned out that year of doing prevention and advocacy work would be especially difficult, utterly exhausting me and souring me on some of the principles of the agency for which I then worked. At the same time, throughout that year, I was presented with ever more examples of academics as real public servants, as able to truly affect the state of public health and social welfare in Calcutta and New York. That sense has stayed with me strongly through the researching, conceptualizing, reconceptualizing, and eventual writing of this thesis, and I sincerely hope that this end product seems practical as well as idealistic, current and relevant as well as historical.

I struggled with the ethical consideration of how best to protect my informants while maintaining a critical stance towards their words, and this was complicated by the fact that some of them were people I knew

professionally or personally, and some had been referred to me by my professional and personal contacts. I also feel a deep sympathy for the work these people have involved themselves in and, like Benjamin and others, a sense of identity with some groups designated at high risk for infection so that I share some of the personal investments most AIDS workers place in their collaborative efforts.

I am, however, uneasy about the circuits of interpersonal or personality politics that seem to almost inevitably develop amongst grassroots organizers. With a very few exceptions, I did not speak with the most visible spokespeople in New York and Calcutta (although I read many of their press releases, reports, and editorials), focusing instead on participants in demonstrations as opposed to their organizers and on lower level staff members rather than supervisors. While I believe the story told from this vantage point is important and underrepresented, I would like my future research on this topic to juxtapose these perspectives with those of the more visible organizers because it is their rhetoric that shapes the most public image of these networks.

While conducting my research, I would sometimes bump into an acquaintance who wanted to know whom I had been interviewing or what so-and-so said about some particular group. My inability to answer

these questions cast a certain measure of suspicion on me, and I noted with some distress how my position as researcher and my preoccupation with the dissertation process necessarily led to my displacement from a closer circle of organizers, activists, and advocates in New York over the past four years, to its suspect edges. I view this with some sadness and wonder if I could have approached and guarded my interviews in some way that would have allowed me to stay closer to the social heart of this scene, but tend to think not. The writer Wayne Koestenbaum calls gossip the "highest epistemology"[35] and, indeed, participating in gossip is an important way to communicate and position oneself, to gain trust and to display authority of knowledge in such informal but highly organized circles. In designing my interview methods, I drew from Barbara Katz Rothman's and Hester Eisenstein's strongly participatory observation of the midwifery movement and the Australian 'femocrat' phenomenon. Although they might disagree with this, I found that insider/outsider status is guarded with more vigilance and volatility in these 'AIDS communities.' Of course, this is reasonable because these communities are so often under surveillance or control anyway, and my separation from these

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[35] This comes to me through personal communication with his student, my colleague Jeffrey Bussolini.

circles has to do with my holding myself socially away from them as well as with the ways I communicated my research.

There is a great deal more for me to do with this project. I have more interview data that demands attention, and I would very much like to continue conducting interviews, perhaps giving more thought now to how my informants perceive me as well as how I perceive them. And I would like to move towards closing the gap that has developed between my own history as a community worker and what I hope is my future as an academic. Ideally, this document will develop into a resource for other organizers and activists and will serve as an honest record of the efforts and achievements of these groups in these two cities.

So let me end with a few words about these two cities, for which I feel great affection and attachment. Like many kids from the 'burbs, I aspired to move to The City and felt like a tremendous success in effecting that physical and psychological shift. Within my first months here, I savored Jane Jacobs' *The Death and Life of Great American Cities* like it was candy and, upon moving into Alphabet City two years later, devoured Neil Smith's *The New Urban Frontier* – appropriately, largely in Tompkins Square, occasionally glancing at the gentrifying shadow of Christadora House. Such is the myth and cliché of my relationship to New

York. Calcutta is even more mythologized for me – built for me as an idea from a young age just as much by movie images but also by the nostalgia of my parents and by distorted photographic still-like memories from my childhood visits there. Things change. Christadora House is now a site for fundraisers to prevent the even further gentrification of this very changed neighborhood, and Calcutta is cleaner, greener, and more full of sparkling concrete overpasses with each visit there. My family's houses have been remodeled, and I often lose my way around those old, now new, streets.

The municipal administration of each city has grown ever more conservative, and yet the people seem to be as defiant as ever. Calcuttans are known for their overblown politeness, but I have seldom encountered that on the city's streets or public transportation. In New York, I constantly discover spontaneous graciousness where I expect rudeness. And *vice versa*. Both cities are enormously complex, similar, and different. What I have told here is only one angle of one segment of the stories to be told from this epidemic, but that is the point I most want to make in this dissertation. Vitality requires diversity and, while HIV/AIDS might have thrown barriers around some communities, the human response to this pandemic has opened other possibilities: of identity, of

experience, and of expectation. Despite my usual pessimism (a characteristic quite at home in both cities) and my sometimes overwhelming anxiety over the many unintended flaws in this document, I would like to end with an openness about what might come next, and about what social mobilizing (and social research) can achieve.

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