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WE ALL HAVE AIDS: CIRCULATIONS OF RISK, RACE AND STATISTICS IN
HIV/AIDS PREVENTION

by

THURKA SANGARAMOORTHY

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

MEDICAL ANTHROPOLOGY

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

AND

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Thurka Sangaramoorthy

For my parents, Nala and Kathirethamby Sangaramoorthy, for demonstrating through practice the true meanings of sacrifice and hard work, and for teaching me how to embrace difference and diversity both in myself and in others.

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When I was writing the dissertation, like many others, I often felt it to be a lonely and isolating practice. At the time, I failed to realize that it was a communal process all along. It is only now, at this end stage, do I realize that there were many people and institutions helping me along from the beginning. I wish to convey enormous gratitude to many people who have played an important role in the formulation and completion of this journey.

In 2006, a few months after I had gotten back from fieldwork, I received the terrible news that Gay Becker, one of my committee members and cherished mentor, had passed away rather suddenly. While discussing the tragedy with my dissertation chair, Philippe Bourgois, I learned that he would be leaving for the University of Pennsylvania. I was stunned and feared that I would not finish the dissertation. There were many individuals at the University of California, San Francisco (UCSF) and Berkeley that came to my aid and helped me produce a body of work of which I am really proud.

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I would also like to thank everyone at the Institute of Health and Aging at UCSF for their support. They have truly been my adoptive family for the past several years. Sharon Kaufman worked tirelessly to save Gay Becker's wonderful grants, and helped insure that my funding would continue. I am so grateful to Yewobdar Beyene and Edwina Newsom for allowing me to stay the course with my funding and with providing much needed support that allowed me to finish in a timely manner.

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In addition, I am gratefully indebted to Philippe Bourgois for all of his help as a former dissertation committee chair and current committee member. His astute recognition of the problems of ethnographic research has invariably taught me to become a better scholar and more importantly, a critically engaged person in the world. Furthermore, he has steadfastly reminded me of the importance of voicing my own reservations and struggles with bringing

seemingly disparate theoretical strands of scholarship together. Without his support, I would not have been as confident in asserting the benefits of dialog between studies in biopolitics, science and technology studies, and critical medical anthropology.

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ABSTRACT

This dissertation is an ethnographic and epidemiological investigation of HIV/AIDS treatment and prevention. This research focuses on South Florida, and explores how global health and policy frameworks of HIV/AIDS affect the health and well being of transnational immigrants such as Haitians. It traces the circulation of knowledge about HIV/AIDS prevention from sites of surveillance and regulation to various clinics and hospitals to the social worlds of Haitian immigrants. Interviews with HIV/AIDS experts and public officials, as well as Haitian clients, demonstrate that global technicalities of disease prevention are inherently linked to individual practices and local politics of difference.

Specifically, this project explores how the politics of difference permeates HIV/AIDS prevention in the United States. As discussions of the biological basis of race continue to gain traction in light of recent demographic changes and advances in genetic research, this research documents how medical, epidemiological, and social constructions of HIV/AIDS risk fuse notions of pathology with racial and cultural differences. It reveals that notions of individual responsibility in HIV/AIDS risk management often become inseparable from notions of racial, ethnic, and immigrant identities. It argues that HIV/AIDS surveillance practices help to reinforce categories of individual and collective difference, and sustain race and ethnicity as risk factors for HIV/AIDS. In addition, this project highlights the specific problems facing diverse immigrant and ethnic populations, and reveals that Haitians strategically identify with various institutions and diseases in order to access critical resources. Here, it illustrates that public understandings of health interventions are complex, and as a result, translations of HIV/AIDS prevention do not occur smoothly or as planned in Haitian communities. Finally, it argues for a re-envisioning of health disparities to emphasize their productive capacity in generating subjectivities, domestic and global policies, and scholarly research initiatives. This research posits that disparities in health, as realized in the socio-political and scientific realms in which they are engaged, are being made into everyday social instruments of action for securing funding, gaining political power, and obtaining forms of welfare benefits.

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ONE:

How do We All Come to Have HIV/AIDS?



1

As I was standing on the outdoor platform of the University of Miami’s metro-rail stop during a seemingly endless, blistering hot day, a large black, white, and red poster instantly caught my eye. It was a depiction of numerous celebrities, scientists, political leaders, and social activists standing and walking barefoot in several graduated rows on concrete blocks. The image of these people was entirely in black and white. It was the white and red lettering, however, that initially drew me to the poster. It read “WE ALL HAVE AIDS” in large print across the front row of the people pictured. “WE ALL HAVE AIDS” was in white, while “AIDS” was in bright bold red lettering with a much smaller print reading “IF ONE OF US DOES.” The lettering, in red, stood in stark comparison to the black and white images of the people depicted. It was the first time in my life I had seen such an explicit public advertisement for HIV/AIDS.²

I saw this print repeatedly for several months in early 2006 on subway trains and platforms in Miami. The poster, as it turned out, was part of a multimedia campaign heralded to be the largest public service announcement about HIV/AIDS ever launched in the United States. The initiative was spearheaded by the American Foundation for AIDS Research (amfAR), KnowAIDS, a multimedia campaign funded by the Henry J. Kaiser Family Foundation and Viacom, and fashion designer Kenneth Cole, the current chairman of amfAR. The “WE ALL HAVE AIDS” campaign, as it is called, was initiated to raise awareness of the damaging effects of stigma in the prevention and eradication of HIV/AIDS. In describing the mission of the campaign, amfAR (2005) declares, “It is a powerful display of the unity and solidarity we all share with the 40 million men, women, and children living with HIV/AIDS around the world.”

By calling attention to unified responsibility and global response to HIV/AIDS, the “WE ALL HAVE AIDS” campaign serves as a powerful trope for recent transformations in politics, economics, biology, medicine, and technology. Indeed, the expansive growth of biotechnology, global economic markets, and evidence-based medicine has propelled many debates surrounding the impact of such developments on the relations between society and science.³ Various scholars have tended to conceive of these changes as epochal, citing this period as the “the biotech century” (Rifkin 1999) and the “the century of the gene” (Fox Keller 2000). Some have sounded warning sirens about the unrestrained proliferation of such technologies and knowledge and their subsequent modes of exploitation and profiteering (Rifkin 1999). Others have focused not on the beneficial and detrimental effects of such changes, but on how these modifications, both broad and minute, have come to be conceptualized, rationalized, and distributed (Rabinow 1999; Rose 1999, 2007; Lock et al.

2000; Dumit 2003; Franklin and Lock 2003; Clarke et al. 2003; Thompson 2005). Nikolas Rose, for instance, posits that these broader shifts indicate not only new transformations of individual and collective identities, but also changes in the conceptualization of life itself (Rose 1999; 2007). In the field of medicine, this has meant a gradual move toward a focus on health and well-being rather than illness and disease, where the maintenance of optimal health constitutes an individual and collective responsibility (Clarke et al. 2003; Rose and Novas 2004; Rose 2007). The increasing attention put forth on responsibility parallels the proliferating rationalities of risk, which are no longer contained in the confines of the hospital or asylums, but exist and flourish in minutiae of everyday life. It is in this way that we all become implicated as carriers of risk, and always already occupy a nebulous space between illness and health (Clarke et al. 2003). It is in these multiple ways that we all come to have HIV/AIDS.

Scholars investigating these broad transformative processes also disclose, however, that these shifts are unstable and inconsistent, and operate in unequal and in discriminate ways by selectively targeting or excluding groups along the bases of race, gender, class, and other divisions. Much like the public health rhetoric of the uncontested nature of various disparities in health care and outcomes, such scholarship, rooted in the social sciences and science and technology studies (STS) also presumes the indisputable existence of such stratifications and their potential to generate, reproduce, and be co-constitutive of the broader changes occurring in the late twentieth century. This reasoning parallels David Harvey's (1990) paradox of post-modernity,⁴ and posits that there is a simultaneous existence of structural and social inequalities as well as a common responsibility in the prevention and management of individual risk. That is, we all have HIV/AIDS, but how we come to have,

experience, and manage HIV/AIDS is highly dependent on groupings of race, ethnicity, color, sexuality, gender, national origin, and other notions of difference.

My dissertation seeks to better understand this paradox through the discourse and practices of HIV/AIDS prevention and intervention efforts in Miami, Florida by focusing on the ways in which individual and collective difference and the universality of risk for disease and illness co-exist. By ethnographically investigating how such modalities and practices of risk, health disparities, and biomedicalization⁵ operate and travel at the level of situated experience, I surmise that the rationalities of risk in HIV/AIDS research and surveillance data are profoundly linked to representations of community, identity, culture, and difference among minority and transnational populations in the United States. Based on extensive ethnographic and epidemiological fieldwork in HIV/AIDS treatment and prevention programs in Miami-Dade County, this research demonstrates how HIV/AIDS comes to be disseminated, understood, appropriated, and contested by both service providers and the Haitian clients they serve. It highlights the specific risks and problems facing diverse immigrant and ethnic populations, and reveals how individuals come to identify with various institutions or diseases and negotiate critical resources.

More importantly, my dissertation shows that the notions of individual responsibility in HIV/AIDS risk management often become inseparable from notions of racial, ethnic and immigrant identity. Utilizing a framework that combines medical anthropology and STS, I examine how the health and well being of individuals and groups are affected by larger social formations, cultural norms, and local and global politics. By doing so, I demonstrate that HIV/AIDS prevention and intervention is a site of struggle not only between numerical representations and human agency, but also classification systems and governmental

rationalities, individual suffering and community politics, and scientific technologies and racial imaginaries. My emphasis on multiple forms of sociality and citizenship among Haitians in Miami is an important and interesting contribution to current frameworks of risk and racial and ethnic disparities in health because they point to the varied productive and dynamic implications of broader transformations in both subjectivities and governance of life itself. Such considerations also make compelling the need to reframe and rework several disciplinary and conceptual divides between medical anthropology, public health, and STS through close ethnographic accounts of individual and institutional stories of HIV/AIDS.

It is difficult to ascertain whether and in what particular ways emergent social forms by way of community politics are more entrenched in difference than those grounded in the idea of a social state. It is equally challenging to tease out the ways in which difference does or does not constitute a politics of exclusion, or if indeed a politics based on difference is one that is always already predicated on exclusionary rationalities and practices. In this project, I ask the following questions in order to better understand the relations between difference, risk, and governance. In what ways do Haitians clients and their health and social service providers negotiate concepts of “risk?” What meanings are produced through discourses that link risk with race, ethnicity, or culture? How do Haitian clients comply with, contest, and reconceptualize official discourse about them? In what ways do Haitians negotiate relations between biology and citizenship? These questions are increasingly important for research in HIV/AIDS in the United States because of the continued focus on specific personal behavioral risk factors and the use of epidemiology as the dominant trope for understanding risk in medical and clinical interventions. By attending to the ways in which official and non-official discourses about risk, health disparities, and biomedicalization operate at the

level of situated experience among Haitians and Haitian-Americans, this project moves toward reframing studies of suffering and structural violence, as well as locating future directions in the confluence of science and technology studies and medical anthropology.

Pieces of the Puzzle: Spatial Chronologies

New York, NY 2001

During my final year as a Master's student in public health, I was asked to serve as a graduate intern for a new offshoot of the Tri-County Community Health Advisory and Information Network (CHAIN). CHAIN is a prospective study, under the guidance of Columbia University and the New York City Mayor's Office HIV Health and Human Services Council, which provides a comprehensive assessment of the delivery of HIV/AIDS services and an analysis of unmet needs from the perspective of people living with HIV/AIDS in the five boroughs of New York City. In 2001, several researchers and policy makers agreed to expand the scope of CHAIN to the surrounding Tri-County regions of Westchester, Rockland, and Putnam counties in order to document the growing numbers of HIV-positive individuals in suburban areas through surveys. The surveys represent quantitative profiles of individual need for and encounters with health and social services as well as self-assessments of his or her current health status, with each participant being re-interviewed.

A senior colleague confided that the project was having a difficult time recruiting a significant number of Haitians and Haitian Americans through health and social service agencies, and even though Haitians were accessing such services, they almost always refused to participate in the research. The project directors felt that "stigma" was the main issue due

to Haitians' historical positioning as AIDS carriers at the beginning of the epidemic, and as a result, they were implementing a Likert-type scale to measure stigma in these new surveys. According to my practicum agreement, I was to aid the project in "understanding of substantive issues related to disclosure, stigma, and service needs among a suburban HIV-positive Haitian population." I researched the detrimental impact of the Centers for Disease Control's (CDC) labeling of Haitians as one of the four initial high-risk groups and felt confounded when health statistics in New York counted Haitians as African-Americans. Although disappointed to never work with Haitians specifically in the project due to programmatic changes, I left with lasting impressions of the limits of public health practices in framing complex relations between health statistics, disease categories, and racialized identities.

San Francisco Bay Area 2003

As part of required coursework, I conducted fieldwork for 12 months with Haitian community organizations located in the San Francisco Bay Area. My research explored the social, political, and cultural complexities within these organizations during a period of extreme political unrest in Haiti, a period in which Haiti celebrated its bicentennial and saw the violent removal of former President Jean Bertrand Aristide from office. Community leaders reasoned that the paucity of a "substantial" community in the Bay area resulted in a lack of interest and weight given to issues related to HIV/AIDS. Although some community organization members remarked about a few people "not doing so well," there was nothing else that they would divulge about HIV/AIDS and its relationship to Haitians living in the Bay area. Thus, my research did not involve direct framing of illness or disease, but it did

underline the importance of conceptualizing health from a broader perspective, not just as the absence of disease or universal access to health care, but as an ongoing struggle against political, economic, and institutional injustices.

Boston 2003

I found myself trying to calm my nerves in the middle of Haitian Kreyòl⁶ class. I was there to get language training, and felt strangely out of place with the rest of the students. During introductions, everyone (except for me) revealed that they were either working in Haiti or about to embark on trips to work for “humanitarian relief organizations.” It failed to occur to me that they were all missionaries until two married students spoke passionately about the ways in which their first trip to Haiti was life-altering, and how they felt it was their “call from God” to improve the lives of Haitians, which set off the rest of the class in comparing various mission work.

Later that week, I made phone calls to a list of health and social service organizations that worked with the very large Haitian population in the area, but was only able to make contact with one. Located adjacent to a church and in an area with a sizable Haitian population, it was housed in an unassuming white house without any signs or any indication that it was a clinic or an organization working with HIV/AIDS patients. Inside, the carpets were wearing away, and some of the moldings on the walls were slowly peeling off. In the small waiting room, there were some brochures about safe sex, contraceptive use instructions, and HIV/AIDS in English and in Kreyòl. I met with the directing physician who, when I told him that I was leaning toward the topic of stigma, seemed utterly unimpressed. He simply stated that they, those who had been working with Haitians and

HIV/AIDS, knew that “Stigma is a key factor. There are several stigma components such as race, class, immigrant status, language barrier, etc. that contribute to both intra and inter community stigma.” He told me Boston had the fourth largest population of Haitians in the United States, behind New York, Florida, and New Jersey, and there was a high impact of HIV/AIDS in the community. He explained that Haitian women and children were most at risk and that a majority of Haitian HIV/AIDS cases were documented as “risk not specified” for HIV/AIDS. Finally, he mentioned that his organization was trying to formulate national alliances with other Haitian agencies working with HIV/AIDS without much success. When I asked him the reasons for such difficulties, he said “It’s always about politics and money with Haitians; we don’t want to fight this together” without any further explanation.

Miami 2005

After a long day at Miami General Hospital, I was exhausted and dreading my long commute back home. Although I had a car, I was not used to driving and often found myself taking chances on Miami’s notoriously dysfunctional public transportation. Today, as was my luck, I got off the train only to find that I just had missed the bus. This meant that waiting for the bus for 30 minutes was the better option than standing around for the next train which would not come for another hour. Finally, the bus came and after I boarded, I found myself staring out the window aimlessly, reflecting on the extraordinary number of interviews that still needed to be done. There were only four or five people on the bus when I got on, and it was really quiet. In another five minutes, an older Black man and I were the only ones left. The driver, who was Hispanic and middle aged, suddenly pulled over near a Café Cubano and said that he would just be two minutes. He didn’t address the older

gentleman, who was standing directly in his view. In fact, he didn't even look at him. Instead he craned his head and twisted his body to look at me even though I was sitting back further, on the opposite side of his view. The older man had been standing by the door as if he were about to get off soon, and I felt bad that the bus driver decided to take a coffee break without letting him off first. But he didn't say anything to the driver or to me, not a word. He just sat down on the seat opposite mine, looked at his watch, pressed his lips together, and waited.

The bus driver emerged with a small styrofoam cup full of Cuban coffee and tiny little plastic accordion cups that looked like thimbles. He looked at me and asked if I wanted some coffee. I had never had Cuban coffee, so I walked up and he separated the thimble cups around the larger cup, poured a small quantity to fill up the thimble cup, and handed one to me. I offered the older man some to which he laughed and shook his head to say no. The coffee had a tan frothy top layer which was very sweet followed by dark strong coffee. I sipped it while the bus took off again. The old man walked to the front of the bus and said something to the bus driver in Spanish⁷ and got off at the next stop. As we were driving, two Black women got on consecutively at different stops. Both sat in the front. One of the women yelled out, "AIR CONDITIONER!" as a command. I was not sure if the driver didn't hear her or didn't want to respond. She kept shouting "BUS DRIVER" with increasing crescendo. After what seemed like forever, he responded with a confused but deliberate "Huh?" to which she responded fiercely, "It's hot in here, you gotta turn the air conditioner up!" He mumbled something to her which I couldn't hear, and she angrily replied "You trying to be funny?" She became upset yelling at the top of her voice saying "That's all you had to say. Shoot! You can't treat me like this! It's not those days anymore. Not no more!" The other

woman didn't say anything. When this lady didn't get a response from anyone on the bus, she again repeated angrily "It's not those days anymore! You can't be telling me to get off the damn bus!"

I witnessed such confrontations frequently while living and working in Miami for 15 months. These altercations were suggestive broader class, ethnic, and racial discord that somehow seemed to set Miami apart. Indeed, other scholars have remarked upon the unique assemblages related to race, ethnicity, immigration, geography, history, and gross inequalities in both health and in other socioeconomic and political realms have made Miami distinct from other cities in the United States. Miami has often been called amongst others the "City of the Future," the "American Riviera, and "Paradise Lost" (Allman 1987; Portes and Stepick 1993; Croucher 1997). Croucher states that "Miami is a new city—a city without a long, rich history, a city not comfortably situated within established social, economic, and political traditions of the United States, a city without a firm or deeply rooted identity" (1997: 2). Portes and Stepick further echo this sentiment in their declaration that "Miami is not a microcosm of the American city. It never was" (1993: xi). Miami, unlike other cities, was erected by wealthy entrepreneurs who hoped to attract residents and vacationers to its sunny climate and attractive coastline rather than by pure commercial or manufacturing interests (Allman 1987; Grenier and Stepick 1992; Portes and Stepick 1993). It slowly evolved from a tourist resort to an embattled complex city. Many have remarked that Miami's transformation in the twentieth century has been politically over-determined; that is, its geographic proximity and economic and political connections to Latin America and the Caribbean have made the city a logical entry point into United States, and its close ties with Cuba, Haiti, and various other South and Central American countries have given it a

major role foreign politics (Grenier and Stepick 1992; Portes and Stepick 1993; Croucher 1997; Stepick 1998; Stepick et al. 2003).

This change was first initiated by the Cuban Revolution as thousands of immigrants built a prosperous enclave in the early 1970s. Cubans immigrants clashed with the older, more-established Southern migrant, Jewish, and African-American communities due to their political conservatism, anti-communism, and relative isolation in building parallel but unconnected social and cultural institutions. Waves of new immigrants—Cubans from the Mariel boatlift, Haitian refugees escaping political and economic oppression, and Nicaraguan exiles fleeing the Sandanistas—have continued to fashion a turbulent ethnic kaleidoscope in Miami. Miami has the highest percentage of foreign-born residents of any area in the United States, and proportionally 50% more than Los Angeles and New York (Stepick et al. 2003). Most residents in Miami are recent arrivals from Latin America and the Caribbean, and the population growth rate is due more to immigration than to local birth rates, distinguishing Miami from other cosmopolitan regions of the United States (Stepick 1998). This has meant that political migrations have also produced novel economic phenomena such as the dramatic increase in substantial pools of labor and economic opportunities due to the growth of the Cuban and other ethnic enclaves—a case where politics and economics have co-evolved, turning Miami into a major trade hub (Portes and Stepick 1993). As a result of immigration patterns and national foreign policy, socio-racial phenomena acquire unique configurations in Miami, where a national ethnic minority, Cuban Americans, have forced a reverse acculturation, a “Latinization” of space and place, by substantially controlling the socioeconomic, symbolic, and political power (Portes and Stepick 1993; Marcelin 2005). This has led many communities to vie with each other for political and economic power,

which sometimes has resulted in violent strife including the Liberty City Riots in 1980, one of the worst racial confrontations in U.S. history,⁸ and two other major racial riots in 1982 and 1989,⁹ as well as numerous other confrontations such as the anti-bilingualism legislation in 1980¹⁰ and a three year economic boycott of Cuban owned businesses in 1990.¹¹

One major ethnic dichotomy that is continually constructed is that between Haitians and Cubans. Miami is home to the largest concentration of Haitians in the country (Bureau of the Census 2004). There is no exact figure as to how many Haitians are living in Miami: the U.S. Census in 2000 estimated the total to be around 95,669, but local agencies estimate the number to be around 200,000 and Laguerre (1998) estimates this to be close to 500,000. Laguerre (1984; 1998) has described Haitian immigration to the United States as occurring in waves paralleling major repressive periods in Haiti. The first wave began in the 1950s and 1960s and consisted mostly of Haitian professionals fleeing from the Duvalier government,¹² as well as a few skilled laborers from the middle and lower classes needed to fill the vacuum left in U.S. industries as a result of the Vietnam War. The most recent wave of Haitian immigrants, often called the “boat people,” has come from more rural areas and modest backgrounds, and has had to endure intense U.S. governmental detainment and deportation. Public opinion of recent immigrants as diseased and backward has increased discrimination and prejudice, and intense class differences among Haitians have contributed to more socioeconomic disparities (Stepick 1998). Stepick and colleagues (2003) have argued that Haitian economic integration to Miami has been different from other groups because of the unavailability of even unskilled jobs, leading to a fabrication of informal economies much like those fashioned by third-world rural migrants to cities. This has then led to a kind of segmentary cultural and political assimilation in which many Haitians are caught between

being subsumed into African-American inner city life and maintaining distinct social worlds (Laguerre 1998; Stepick 1992; Portes and Stepick 1993; Stepick 1998; Stepick et al. 2003). As a result, recent Haitian immigrants and their families reside mostly in the inner city of Miami-Dade County. Today, Little Haiti, Homestead and Florida City are areas heavily populated by recent Haitian immigrants and are among the most economically, politically, and socially marginalized communities in South Florida, while Kendall is an ethnically mixed middle class community, home to more than 60% of Haitian middle class families (Stepick 1998).

These frameworks position Miami as a key case study in reframing the debates not only on immigration, the dynamics of assimilation and acculturation, and nationhood, but also on acute differences and disparities. Formed through social interaction and embedded in various and shifting contexts of power, the divergent experiences of multiple communities in Miami elaborate fluid sets of transnational dynamics and local practices. The city itself becomes a physical space in which established theories of assimilation, acculturation, and ethnicity have been troubled, and social and political identities are being continually reconfigured. As such, Miami holds contemporary significance as a lens through which convergences of people, rationalities, goods, and places can be viewed.

Haitians, Miami and HIV/AIDS

Miami continues to emerge as a key participant in the national debates about HIV/AIDS prevention and intervention, and thus represents a place where relations between race, ethnicity, and HIV/AIDS continually evolve. Current HIV/AIDS research indicates that both new AIDS cases and HIV infections continue to rise exponentially among minorities

(Fleming et al. 1998; Fleming et al. 2000; Karon et al. 1996; Karon et al. 2001; Levenson 2004). HIV/AIDS has had a significant impact in both Florida and Miami. Florida has the third highest number of cumulative AIDS cases in the nation, while Miami ranks fourth in metropolitan areas reporting cumulative AIDS cases (Florida DOH 2003). Blacks account for almost half of these cases and 56% of all new cases (CDC 2002; KFF 2003). The annual case rate of HIV/AIDS for blacks in Florida (142.7 per 100,000) is twice that for blacks across the nation (77.4 per 100,000) (KFF 2003), and HIV/AIDS is the leading cause of death for black males and females living in Florida (Florida DOH 2003). HIV/AIDS rates for Haitians nationally, regionally, and city-wide are very scarce. In 2003, the Florida Department of Health (2003) estimated the state's annual case rate for Haitians to be at 28.3 per 100,000 compared to 184.4 per 100,000 nationally. Scholars have stressed that these estimates are gross undercounts due to patterns of housing, family networks, high mobility, distrust of government and health officials, immigration status, and other factors (Stepick and Stepick 1992; Marcelin and Marcelin 2001). In addition, Marcelin and Marcelin (2001) argue that county health officials have begun to estimate new HIV/AIDS cases only from 1999 onwards, and annual reports since then reveal that Haitians count for 11-12% of all new cases of HIV/AIDS, the highest for all groups subsumed under the "Black/African-American" category. A majority of these cases (80%) were found during mandatory blood tests for adjustment of immigration status, and not as a result of effective surveillance or voluntary testing (Marcelin and Marcelin 2001).

As a result of such increases particularly among African-Americans and Latinos, discourses around race and ethnicity are steadily brought to the forefront. Many scholars and practitioners argue that existing HIV/AIDS intervention programs fail to work in

communities of color because they are not culturally appropriate (Martin et al. 1995; Page and Marcelin 1999; Williams et al. 2000; Marcelin and Marcelin 2001; Marcelin et al. 2006). They also claim that grouping together different ethnic groups into single labels such as “Black” or “Hispanic” obscures specific risks that prevent the successful formulation of research and community-based preventive intervention strategies. They advocate for more nuanced tabulations of racial and ethnic categories to be standardized at a time when significant demographic changes, public debates and movements, and recent advances in genetic research have increasingly called into question biological distinctions between races.

These discourses are particularly salient for Haitians in Miami and for those who work with them. At the beginning of the HIV/AIDS pandemic, in the early 1980s, the CDC and many public health officials inferred that Haitians were at a high risk for HIV/AIDS, and in 1990, the FDA prohibited anyone of Haitian descent from donating blood. This positioning of an entire nationality has had adverse reverberations for Haitian emigrants worldwide, especially for those residing in the United States. Such classifications and labels, although later repealed, caused a tremendous amount of fear and discrimination towards the community, and instigated a plethora of anti-Haitian sentiments and practices such as housing evictions and job losses (Farmer 1992; Nachman 1993; Fairchild and Tynan 1994). Reports of HIV/AIDS in Haitians still reflect widespread prejudices about Haitians as unclean and disease ridden (Farmer and Kim 1991; Farmer 1992; Nachman 1993). As a result of these incidences, many Haitian and Haitian Americans, fearful of repercussions, self-identified as other Black immigrants or as African-Americans (Farmer 1992). This trend continues today among many Haitian youth and adults as a reaction to existing negative

stereotypes of Haitians (Laguerre 1984; Stepick 1992; Nachman 1993; Portes and Stepick 1993; Zephir 1996; Laguerre 1998; Stepick 1998; Stepick et al. 2003).

Furthermore, the calculus of blame served only to reinforce resistance and hostility toward public health educational and intervention programs by numerous Haitian communities (Farmer and Kim 1991). Many professionals, intellectuals, working class communities, religious groups, and leaders continue to evade any relationship to the epidemic; many face stigmatization from within their communities for their association (Farmer and Kim 1991). In addition, many HIV/AIDS prevention and educational programs are accountable not to Haitian communities, but to their sponsoring institutions—the same government agencies, such as the CDC, whose policies and decorum were deeply resented. These issues, along with homophobia, language barriers, notions of health and well being, political and economic marginalization, and immigration status heavily impact the way that information of HIV/AIDS is conceptualized, received, and adopted.

My project demonstrates that a thorough understanding of HIV/AIDS must be borne of multiple disciplinary convergences. Thus, it attends to the processes that stabilize particular imaginaries of HIV/AIDS, risk, and Haitians as facts and truths. Taking seriously Stacy Leigh Pigg's concept of the "social production of commensurability," this project seeks to answer "What are the practices through which actors forge, provisionally or lastingly, common measures, standards, and frames? How are perceived differences bridged or mediated? What are the consequences of the routinization of certain conceptual paths of connection? What links the social production of facts in one site to the acceptance of them in another? And what, in the context of an epidemic, might the consequences of these patterns of linkage be?" (2001:483). I argue that these inquiries are not just critical to those working

on HIV/AIDS issues outside of the United States, they are also fundamental to understanding HIV/AIDS prevention and awareness right here in the United States. Conceptions and practices surrounding HIV/AIDS prevention and intervention in the United States are currently undergoing multiple transformations as programs geared towards largely white gay and bi-sexual men and intravenous drug users are beginning to be translated, reformulated and appropriated for racial and ethnic minorities in the United States. These shifts provide an important analytic for the ways in which many marginalized and underserved groups come to negotiate various biomedical and public health rationalities and paradigms. Although Pigg's (2001) pivotal questions refer to the development of an analytic that explores the ways in which science moves out of the Western context, I illustrate that it is ever more crucial to pay attention to the practices and discourse of people on the so-called margins, especially in the "West," and to the ways in which they avoid, engage, challenge, and outright refuse these processes. More importantly, by outlining the complex movement of knowledge production and expertise among various constituents who work in the field of HIV/AIDS, including physicians, social workers, patient advocates, technicians, and Haitian consumers, and by focusing on the ways in which these individuals circulate ideas and technologies of HIV/AIDS and themselves across different fields, I provide an analysis of the ways that transnational biomedicine, technology, expertise, and policy travel and situate themselves outside biotechnical settings and into public life in out-of-the-way places situated in "Western" biomedical contexts. Here, I argue against the presumption that in the United States and other Western countries, where HIV/AIDS has had a long history, knowledge about HIV/AIDS and its prevention is established. As my research will show, there are many continuing controversies and struggles against various approaches to HIV/AIDS programs in

official and popular discourses. Paying close attention to such debates provides new ways of thinking about economically, politically, and socially marginalized populations in the United States and how they come to interpret, internalize, and refute health interventions and constructions of difference.

Anthropology of HIV/AIDS in the United States

If anthropologists wish to participate concretely and convincingly in stemming an epidemic that is exponentially growing in African American and Hispanic communities, I posit that there must be a serious effort to understand past and current directions in the anthropology of HIV/AIDS in the United States. This is fundamental if we are to overcome disciplinary, theoretical, and methodological boundaries which seem to increasingly obscure spaces of collaboration and convergence as well as seeing beyond socio-cultural and structural frameworks of group level risk for HIV/AIDS. This project is both informed by and conjectures relationships between two seemingly disparate theoretical and substantive scholarships pertaining to the United States: the anthropology of HIV/AIDS and the anthropology of migration and displacement. Although anthropology has consistently been alert to the intersections of disease and migration, particularly to discourses surrounding migrants as disease carriers, the multiple connections between the HIV/AIDS epidemic and migrants within the United States has been under-theorized. In reviewing early anthropological contributions to the study of HIV/AIDS, Parker (2001) argues that individual research projects and publications, rather than a formal or systematic research response as a discipline, formed the mainstay of initial anthropological responses to the epidemic. Anthropology and other disciplines¹³ were remarkably unsuccessful at distinguishing

themselves in their responses to the epidemic and, consequently, the tenets of HIV/AIDS research were conceptualized largely through a biomedical lens, with a focus on the individual, making the development and implementation of a social science research agenda that was equally substantial and effective more difficult (Parker 2001). This framework arguably reflected much of the initial anthropological work which, rather than dissecting the study of biomedical construction and contextualizing of HIV/AIDS, sought to provide social and cultural input into concepts of risk behavior defined solely in terms of sexuality and drug use.

Many anthropologists working on the front lines early in the epidemic were those focusing on medical anthropology and sexuality, and working in diverse fields of study and settings. As a result, some of the initial works spearheaded by anthropologists have been edited interdisciplinary volumes dedicated to HIV/AIDS research (Gorman 1986; Feldman and Johnson 1986). Papers in these collections as well as others during this decade focused mainly on contributions to epidemiology, collecting quantitative assessments of risk behaviors, including but not limited to types and frequencies of sexual interactions, sexual partners, drug use and needle sharing, transfusions, migration and travel to places with high frequencies of HIV/AIDS rates, and even religious behavior as in the case of Haitian voodoo (Darrow et al. 1986; Des Jarlais et al. 1986; Feldman 1986; Kotarba et al. 1986; Moore and Le Baron 1986; Coates et al. 1989; Day 1988; Abramson and Herdt 1990; Chitwood et al. 1990; Des Jarlais et al. 1990; Booth et al. 1991). During this period, anthropologists also contributed to research surrounding the symbolism and cultural constructions of HIV/AIDS (Bateson and Goldby 1988; Farmer and Kleinman 1988; Marshall and Bennett 1990). The principal goal of these early studies, thus, was to play a role in public health disease

prevention and intervention programs designed to minimize behaviors associated with increased risk for HIV infection (Parker 2001). Although many anthropologists began to advocate for cross-cultural understandings of such programs, many still adhered to the principle of behavioral change with an individual focus.

As increasing numbers of anthropologists became involved in both domestic and international HIV/AIDS research, as more information regarding disease etiology and transmission was offered, and as public health programs began to proliferate across diverse socio-cultural settings, questions regarding the foundational tenets of research principles and intervention and prevention strategies themselves began to arise (Marshall and Bennett 1990; Herdt et al. 1991; Parker et al. 1991; Parker 2001). Several themes of analysis were prominent during this time. One resonated with ongoing debates in anthropology regarding the paradigm of science itself (Gilman 1988; Patton 1990; Herdt and Lindenbaum 1992; Treichler 1992, 1999; Epstein 1996). For instance, Cindy Patton (1990), in her groundbreaking book, *Inventing AIDS*, critiques the ways in which social science scholars fail to question the ability of science to make and to disseminate truth claims. She states:

Even more rarely do we question the ability of science to *know*... Knowledge is perceived to arise from science and filter out in to the social and imaginary world. The knowledges of the epidemic [that come from the social and imaginary world] arise and compete (most visibly in the policy arena) but is the logic of *science* that anchors the power relations which determine *whose* knowledge counts as “real,” as “objective.” (Patton 1990: 53)

She argues further that science has become the foundation of HIV/AIDS knowledge, thwarting ethical and normative shifts precisely because knowledge itself is validated only in relation to the scientific models of human behavior which continue to medicalize bodies. Other scholars, similarly, analyzed the production and rationale of the categorization of “risk” and risk groups and behaviors without fully investigating the scientific production of

knowledge about risk. These debates, however, mainly raised questions regarding the differences between risk group and risk behavior, and the ways in which “subgroup” cultures had been created and validated in HIV/AIDS discourse (Glick-Schiller 1992; Herdt 1992). Scholars like Marshall and Bennett contended that anthropologists needed to focus on risk behaviors rather than risk groups because “all people are at relative risk as a result of particular behaviors—their own or others” (1990: 4). These viewpoints were supported increasingly by studies which illuminated the limitations of behavioral interventions that focused solely on education or individual psychology (Herdt et al. 1991; Parker 2001). As a result of research findings and larger disciplinary discussions, anthropologists had begun to champion prevention and intervention programs focusing on broader sociocultural, political, and structural forces that frame the concept of group-level risk rather than those based on individual psychological and behavioral models (Parker 2001).

The 1990s, on the other hand, marked a proliferation of anthropological contributions to HIV/AIDS research and discourse. Much of this work posed considerable challenges to biomedical, epidemiological, and psychological HIV/AIDS research paradigms. Parker (2001) discerns that there were two major anthropological approaches during this period: one focusing on the interpretation of cultural meanings as opposed to quantifiable behavioral data and the other concentrating on structural factors contributing to susceptibilities of HIV/AIDS. The directional change toward a more interpretive anthropology was mainly influenced by symbolic interactionism, the postmodern turn in anthropology, women’s studies, and (what was to become) queer studies¹⁴ (Herdt and Lindenbaum 1992; Levine 1992; ten Brummelhuis and Herdt 1995; Parker 2001). These interdisciplinary forces helped to formulate a growing trend of analyzing descriptions of behaviors concerned with local

categories of meaning as well as intra-cultural variations. This also spawned research with a focus on gender, race, and class. Queries regarding multiple identities in diverse cultural contexts, signification of HIV/AIDS within minority communities, and lack of community organizing and ownership around the epidemic became critical anthropological agendas (Worth 1990; Quimby 1992). Similarly, studies of women heavily disparaged earlier (and persisting) categories such as “sex partners” and “prostitutes” and sought to clarify the variations involved in the cultural ideals for heterosexual relations and gender roles (Worth 1990; Kane and Mason 1992; Sobo 1998; Triechler 1998).

At the same time that increasingly nuanced cultural interpretations of the epidemic were growing, research focusing on structural violence and HIV/AIDS was also on the rise. Such research, influenced by the growing disciplines of development studies, political economy, postcolonial studies, and ethnic studies, illustrated the ways in which macro level factors mediated socio-cultural dynamics at the local level (Quam 1990; Singer 1994; Farmer et al. 1996; Singer 1998). HIV/AIDS in already oppressed communities was seen to be not a single epidemic, but one that was a synergism of disease and social conditions. Analyses of the role of political economy and structural violence in drug use among the poor and disenfranchised, the formation of urban gay enclaves, and the subordinate position of women took center stage in the political economy of HIV/AIDS in the United States (Singer 1994; Singer 1998). These studies underscored the myriad of social processes that were responsible for higher rates of infection in gay and bisexual men, drug users, women, and babies in racial and ethnically minority communities.

Much of this work helped to expand the scope and effectiveness of prevention and intervention strategies. Approaches to increase social movements to challenge various kinds

of social inequality that produce and sustain the epidemic had begun to occur. In addition, HIV/AIDS intervention research had also looked toward theories of collective empowerment in order to examine issues related to power and subjugation, in which community and grassroots activists and educators are counted upon to provide transformative educational environments, and where participants have a chance to reflect on their own lives and situational contexts (Singer 1998; Parker 2001). This turn has offered and continues to offer the potential for generating appropriate change and growth from within communities and groups themselves. Focus on the political economy of HIV/AIDS and on a more interpretive anthropology has generated a move toward a better understanding of the interrelatedness of disease and social transformations not just in terms of risk reduction and disease prevention, but also in the formulation of health as social, political, and economic equality.

Currently, although HIV/AIDS infection and prevalence rates have slowed or stabilized in a few areas such as the United States as a whole, in many countries in sub-Saharan Africa, they have grown rapidly. In 2000, nearly four million people were newly infected; in 2003, nearly five million new infections were estimated (UNAIDS 2004). There are some who argue that even with these monetary and technological developments, many countries seemed to have let their guard down in terms of HIV/AIDS (UNAIDS 2004). For instance, in some industrialized countries like the United States, widespread access to antiretrovirals as well as the transition of the concept of HIV/AIDS from an infectious disease to a chronic illness seems to promote the idea that HIV/AIDS has been defeated domestically and that it's become solely a "third world" problem.

With public and academic attention in the United States increasingly on issues of genomics, stem cell research, and obesity, and as HIV/AIDS entrenches itself more and more

in African-American and Hispanic communities, some claim that the national consciousness of the epidemic is on an overall decline (cf. Levinson 2004). Current anthropological research of HIV/AIDS focuses internationally on the social, economic and political consequences of the epidemic in countries with the greatest impact, and the productive and repressive role of governments and non-governmental structures (Schoepf 2001). With some notable exceptions, I feel that those concentrating on HIV/AIDS in the United States have not underscored these same considerations, but rather continue to focus on sexuality, drug use, people living with HIV/AIDS, prisons, and gender and race issues, following theoretical directions which treat culture as complex, variable, and resulting from a range of interconnected social and structural interactions. My work is informed deeply by more recent theoretical turns, approached by a handful of scholars working in HIV/AIDS in the United States, which explore issues related to knowledge, power, discourse, and practice (cf. Epstein 1996; Treichler 1999; Bourgois 2000; Parker and Aggleton 2003).

Again, I strongly contend that there is arguably a fair amount of stagnancy in research related to domestic HIV/AIDS which has not moved beyond the aforementioned work focused on cultural interpretations and the political economy HIV/AIDS. This is not to say that this type of scholarship is no longer important, because it is. However, I assert that those of us doing work in the United States on issues of HIV/AIDS can learn valuable lessons from scholarly work currently being conducted in international settings which provides nuanced interpretations of the movement and uptake of scientific knowledge and public health practices related to HIV/AIDS (cf. Farmer 1992; Setel 1999; Lyttleton 2000; Pigg 2001; Nguyen 2003, 2005; Biehl 2005; Fassin 2007; Hyde 2007). I argue that the interstitial spaces where convergences of scientific information, public health programs, transnational political

stakes, and popular imaginaries of race and ethnicity should not be seen to exist only “outside” of Western contexts. These types of highly mobile convergences, which continually produce, shift, and recreate concepts of race, ethnicity, risk, subjectivity, and identity occur in Miami and other places in the United States.

My work on HIV/AIDS prevention and intervention programs in Miami situates itself at precisely these nodes of intersection and provides better understandings of the ways in which knowledge of HIV/AIDS risk in the United States is still being developed, extended, and modified. For instance, as the CDC moves to implement more rigid standardization procedures for HIV/AIDS surveillance, instabilities of how to measure, operationalize, and interpret notions of HIV/AIDS risk are being rendered visible. In Miami, emergent technological tools such as the Program Evaluation and Monitoring System (PEMS), used for data entry and surveillance evaluation, and the Serological Testing Algorithm for Recent HIV Seroconversions (STARHS), a surveillance method used to temporally locate HIV/AIDS infections, are causing tremendous amounts of contention in the official representations of HIV/AIDS risk. As a result, health officials in Miami have come to question the viability of translating programmatic interventions at local levels and HIV/AIDS counselors have come to express uncertainty about their roles as mediators of risk. Such ruptures in expert rationalities often collide with Haitian clients’ conceptual rejection of the separation of internal and external risk. These developments, in turn, create multiple sites of tension in the ways in which official imaginaries of risk recreate and institutionalize social and structural inequalities in the field of HIV/AIDS prevention and intervention. Throughout this project, I show that even though certain knowledge about HIV/AIDS has become what Pigg calls “a template of accepted facts” (2001: 481), it is misleading to construct all

discourses of HIV/AIDS in the United States as “established,” for they are ripe with structural ambiguities and conceptual discontinuities.¹⁵

Contagious Others: (Im)Migrants in the United States and HIV/AIDS

Anthropological approaches presented in the preceding section have been arguably crucial to the expansion of discourses away from and beyond the search for the origin of HIV/AIDS. Early in the epidemic, when researchers were grappling with identifying a virus source and the specifics of disease progression, several cases of HIV/AIDS in African nationals living in the United States led scientists to predict that Africa was a potential source. Cindy Patton (1990) argued that these narratives allude that disease in Africa is a product of both nature and culture. She states, “Disease in Africa is considered natural, conjured out of the primordial nought or caught from animals imagined to live side by side with Africans” (Patton 1990: 82). Patton emphasized the iconic representation of HIV/AIDS as emblematic of Africa’s underdevelopment, “as if a lack of Western-style industrialization, rather than a virus, was the cause of AIDS in Africa” (1990: 82). In addition, when public health officials announced in 1982 that a few Haitians immigrants had contracted HIV/AIDS-related opportunistic infections and denied homosexual and drug activities, the press as well as noted researchers inferred that poverty and voodoo were somehow risk factors and that heterosexual transmission was a more “primitive” or “atavistic” stage of the development of HIV/AIDS (Gilman 1988: 102; Sebatier 1988; Farmer 1990). Anthropologists were among the first to denounce such rationales (cf. Gilman 1988; Farmer 1990; Farmer and Kim 1991; Nachman 1993).

These types of engagements prove to be especially important to the formulation of the dominant tendencies in the current study of migration and displacement in relation to HIV/AIDS. Migration and HIV/AIDS, on their own, are incredibly complex and pressing issues, and generate discourses that promulgate an “us” versus “them” dichotomy. Surprisingly, studies integrating migration and HIV/AIDS are incredibly scarce. The published literature over the last two and a half decades has been overwhelmingly epidemiological, with much focus directed toward migration as the way in which disease is spread and migrants as vectors of disease transmission (Quinn 1994; Haour-Knipe and Rector 1996). Others have been mainly oriented toward policy and legal issues related to containment (Kuntz 1990; Fairchild and Tynan 1994; Goodwin-Gill 1996). Many scholars of displacement, however, have been silent on issues that bridge migration and HIV/AIDS because of the fear of having their arguments misinterpreted and, worse, influence policies related to mass testing, deportation, and further stigmatization (Decosas et al. 1995). As a result, the relationship between migration and HIV/AIDS has been downplayed or almost entirely ignored.

Of the few studies that have examined the relationships between migration and HIV/AIDS, almost all have highlighted the uniqueness of this epidemic as compared to other infectious diseases. They argue that migration facilitates other infectious diseases only insofar as it results in a greater mixing of people and increases the possibilities of introduction of disease into a new territory or group (Carballo and Siem 1996; Haour-Knipe and Rector 1996; Caldwell et al. 1997). They also stress the importance of understanding that “migration” and “migrants” are blanket terms that incorporate a variety of people and movements including legal immigrants, short-term visitors, refugees, asylum seekers,

migrant workers, illegal migrants, military, and students, all of which require particular attention and analysis. The HIV/AIDS pandemic, however, illuminates more so than any other disease that migration is not only a key factor in the practices that facilitate transmission, but also a result of complex political, social, and economic issues.

Given the variety of points of analyses, the scholarship of migration and displacement is incredibly diverse. There is no overall encompassing theory of migration (Portes 1997). One such early perspective still utilized today by many policy studies of HIV/AIDS perceives migrants as reacting to “push factors” within their communities of origin and “pull factors” in host communities. The focus is on individual migrants, their respective communities, and the interrelationships between the two. For instance, much of the early and current policy and epidemiological work in HIV/AIDS in sub-Saharan Africa presuppose that HIV/AIDS diffused from areas of labor demand (i.e. urban areas) to areas of labor supply (i.e. rural districts) (Quinn 1994; Caldwell et al. 1997). In these analyses, host and home communities are seen as politically, socially, and spatially divergent, which in turn, obscures the fact that behavior found in urban centers often reflects those found in rural areas (Craael 1997; Dyson 2003). Another related perspective on migration is framed in terms of a world systems theory about unequal relations between “center” or “core” and “peripheral” countries, in which colonialism and development lead to the extraction of value from the periphery by the core, ultimately inducing resource depletion of the former. This conceptual framework greatly emphasizes notions of history and power. It also pays attention to national attempts of managing migrant flows and foreign capital as it relates to the social and political body of the nation. Migration, in such studies, becomes a wholly exploitative process through which certain areas and their inhabitants prosper while others languish.

As growing criticisms of the structural reductionism of “center” versus “periphery” theories surfaced, scholarship focusing on subjective experiences of those displaced and victimized came to the fore under the rubric of diaspora studies. Two of the most prolific writers of diaspora are Paul Gilroy (1987, 2001) and Stuart Hall (1997), British cultural studies scholars, who historically reconstruct the Atlantic as a site of interconnection and complex structures of oppression. Once conceptualized as a forced or sentimental displacement from the homeland, diaspora has attained new epistemological and political resonances (Brazier and Mannur 2003). Diasporic citizens experience multiple identities that are often expressed and experienced in hybridized forms rather than essentialized native identities (Clifford 1994; Laguerre 1998). The works of Farmer and Kim (1991) and Steven Nachman (1993) best illustrate interconnections between HIV/AIDS and diaspora, and in particular, the effects of HIV/AIDS risk group categorization on the Haitian diaspora in the United States.

Another major approach toward studying migration, transnationalism, turns its attention toward the complex partnerships and tensions between states, global capital, and migrating populations, a focus that was often lacking in diaspora studies and world systems theory.¹⁶ The notion of transnationalism is influenced by studies of globalization, and exemplifies expansive interconnections between people, places, ideas, and things. Scholars of transnationalism pay particular attention to the ways in which cultural flows, social imaginaries, and political-economic structures shape and influence the movement of people, ideas, and objects. Transnational communities are viewed, thus, as dense networks across political borders created by immigrants in the quest for economic advancement and social and political recognition. Although the notion of transnationality is utilized in a multitude of

different ways, many anthropologists denote it in terms of connection, flexibility, and multiplicity across borders intensified under late capitalism (Basch et al. 1992; Laguerre 1998; Ong 1999).

Literature on transnationalism also encompasses the recently emerging field of the anthropology of citizenship (Hann and Dunn 1996). Although citizenship is conventionally understood within the legal framework of modern democratic nation-states (Castles and Davidson 2000), analyses of transnationalism expand contexts of citizenship outside of the juridical sphere. They explore how, in addition to nation-states, various global institutions—transnational non-governmental organizations, international organizations, and multi-national corporations—today construct citizenship by employing various policies and practices; these policies and practices shape people’s behavior in everyday life in specific ways in relation to certain objectives (Laguerre 1998; Rose 1999; Ong 1999, 2003; cf. Foucault et al. 2000). The anthropology of citizenship also describes counter-strategies that enable individuals to evade interventions by authoritative institutions. This becomes possible by a neo-liberal ethos adopted by the states and social institutions in Euro-American countries since the 1980s. This neo-liberal ethos has enabled states and institutions to solve problems in the era of welfare policies through efficient management, and it compels them to adopt moral values and practices (Rose 1999; Strathern 2000). This ethical demand hinders the state and institutions from exploiting citizens as mere objects. Citizens are also motivated to protect themselves from potential violation by self management and acquiring knowledge; and this, in turn, enables citizens to negotiate with authorities and claim their rights (Petryna 2002; Rose and Novas 2004).

Thus far, projects in migration and HIV/AIDS have largely failed to build upon these tenets of transnationalism and citizenship.¹⁷ However, much of their data and conclusions suggest that a transnational framework would prove beneficial in developing effective policy and programs for migrant populations (cf. Ferreira-Pinto et al. 1996; Farmer and Kim 1991). Some working in HIV/AIDS prevention and intervention acknowledge that traditional programs advocating safe sex and clean needles will not and do not work for populations on the move, and have designed innovative alternatives that are themselves transnational with varied rates of success (Brussa 1996). Others declare the usefulness of integrating “what’s at stake” for members of the community—in this case, HIV/AIDS transmission and racism—instead of cognitive behavioral approaches which repeatedly have shown no relations between the degree of knowledge about HIV/AIDS and the adoption of preventive measures (Farmer and Kim 1991: 217). These same discussions are occurring in Miami, where a myriad of transnational communities are being heavily impacted by the HIV/AIDS epidemic. Many physicians, counselors, and activists working with Haitians often speak of the difficulties in translating dominant frameworks of HIV/AIDS prevention to their clients who often travel and have multiple partners living in both Haiti and the United States. Others point out that the structure of institutional health interventions is itself a massive barrier to Haitians in Miami. For example, Dr. Eloise, who works at a Haitian health clinic, told me:

First of all most of them come illiterate, they don’t read and then they are black. They also have FEAR of deportation. Most of them don’t have any legal status so they don’t have any papers. Here in the States we know everything is about filling out papers and providing a lot of information like social security numbers. So there are a lot of requirements to be part of health care that they don’t have or even if they do have, they don’t want to provide it because of fear of deportation.

It is by paying close attention such official and non-official discourses of HIV/AIDS and risk that I am able to integrate concepts of interconnection and circulation found in transnational

studies with the emergent forms of individual subjectivity and social identity found in the scholarship on citizenship. In so doing, my research holds the potential to highlight not only the role of institutional forces in mediating citizenship structured by racial and ethnic boundaries, but also the emergence and presence of novel identity formations and subjectivities.

Furthermore, in much of the recent literature on migration and HIV/AIDS, there seems to be a slow but pervasive move away from generalizing HIV/AIDS prevention and intervention efforts for migrant and minority populations, and more attention focused on developing programs that are more population and culture specific. Many institutions have adopted or are adopting “culturally sensitive” and “culturally competent” approaches which are designed with well-meaning intentions: to sensitize health providers to the special needs and vulnerabilities of different populations with the goal of providing accessible and appropriate care to all. However, the conceptual framework for these approaches often produces defined sets of values, principles, and behaviors which then translate “culture” into a blueprint (Hunt and Arar 2001). Cultural knowledge becomes a reified thing, to be acquired and institutionalized, to ensure patient cooperation, to facilitate diagnosis, and ultimately to buttress dominant biomedical paradigms. In order to counter such essentializations, many anthropologists have called upon health care workers to be more self-reflexive by examining their own situated contexts and beliefs, and to develop an approach to managing clinical problems based on negotiation between the two perspectives (Hunt and Arar 2001; Ong 2003). I argue that these critiques are modern derivatives of earlier perspectives on cross-cultural encounters in health care such as semantic network analysis

(Good and Good 1982), explanatory models (Kleinman 1980), and the anthropology of sickness (Young 1982).

So where does this leave us? Many agree that HIV/AIDS prevention providers and programs need to be open, flexible, appropriately cognizant of and responsive to a variety of issues including culture, and to be able to contemplate continuous compromises. But these changes are rarely implemented given institutional, time, and other pragmatic limitations of many HIV/AIDS clinical and public health settings as well as social, economic, political, and other practical restrictions faced by patients. As a result, it has become exceedingly easy to point fingers at the limitations of public health and biomedicine, and to offer solutions that do not transcend well beyond academia. I believe strongly that those of us working on domestic HIV/AIDS issues on the “outside,” in anthropology and in the social sciences, have not done much better than our colleagues working in public health and biomedicine.

In order to do better, anthropology must reconceptualize the field of HIV/AIDS in the United States in an era of transnational migration and citizenship. We must not only trace how certain knowledge about HIV/AIDS or identity comes to constitute notions of citizenship and culture, we also have to explore how such knowledge is circulated. Briggs states, “Disseminating racial and medical knowledge involves not just communicative circuits but their ideological constructions as well” (2005: 270). Using new directions situated at the nexus of medical anthropology and STS, my research examines the circuits through which particular kinds of discourses about HIV/AIDS, numbers, and subjectivity move and transform. Scholarship on transnationalism and citizenship is fundamental to this project, for it elucidates the ways in which the representations and rationalities of HIV/AIDS move, are taken up, and transformed by various institutions and people in Miami. In turn,

my research on HIV/AIDS prevention and transnational Haitian communities in Miami builds upon and contributes to scholarship that do not divorce local micro-politics of disease from broader logics of power and practice.

Race, Ethnicity, and HIV/AIDS

The concepts of race and ethnicity are profoundly polemical topics as they are entrenched in the daily lives of so many people, and their usage in the field of HIV/AIDS has come to constitute key debates surrounding risk and governance. Many historians of science and race theorists position the modern day understanding of race as beginning with naturalist Georges-Louis Leclerc in 1749 and his arbitrary classificatory system of categorizing people into different groups based on skin color, social attitudes, and political relations (Stocking 1968; Stephan 1982; Appiah 1992; Gilroy 2001; Lee et al. 2001; cf. Reardon 2005). Montagu (1964) points out that the emergence of the concept of race is rooted in biological differences materialized during Western exploration and colonialism, including the African slave trade, as an effective method utilized by Europeans to organize and manage populations. Others contend that it was American colonists' subjugation of Native Americans and African slaves that laid the groundwork for later biological constructions of race (Cooper and David 1986; Krieger 1987; Omi and Winant 1994; Smedley 1998). Omi and Winant (1994) further argue that as the age of discovery and conquest gave way to management of populations, nation-building, and Enlightenment ideals of the natural rights of man, it became necessary to rationalize the continued racially organized exploitation of others, which laid the foundation for scientific classification and ordering of races into immutable and natural categories and hierarchies. Naturalized distinctions were often

mobilized to substantiate health differences between various groups, such as rates of immunity or susceptibility to disease based on race, in order to buttress racist projects of labor and slave exploitation (Kreiger 1987; Anderson 1996).

Beginning in the late 19th century, the germ-theory of disease and other novel scientific discoveries led to a gradual shift away from ideas regarding innate resistance and vulnerability to disease and toward a view of individuals as receptacles and circulators of disease. As slave and colonized bodies became conceptualized as reservoirs of disease and as threats to civilized groups, new methods of disease prevention, such as surveillance and management of intimate spheres of daily life, were employed (Anderson 1996; Stoler 2002). In the United States, even after slavery was abolished, race and racial ideologies gained greater potency, as biophysical features of difference shifted from being markers of social status to being internalized as the basis of individual and group identities, making race the overriding symbol of human identity (Smedley 1998). Social Darwinism and natural selection began to gain momentum, as medical and social scientists sought to apply Darwin's model of evolution to human populations, portraying inferior races as primitive and intellectually stunted (Gould 1981; Smedley 1998). This period also marked a shift from the study of static races to one concerned with the study of natural variation in populations (Stephan 1982; Reardon 2005). The professionalization of certain disciplines, most notably anthropology, was closely related to such studies of operationalizing race (Harrison 1995).

Although resistance to various frameworks of race was always prevalent in one form or another, many scholars, including anthropologists, highlight the period between the World Wars as the beginning of the retreat of scientific racism (Barkan 1992). During this era, social scientists and anthropologists, including Boas, Montagu, Du Bois, Benedict, Mead,

and Livingstone, building on advances in human biology, physical anthropology, and population genetics, argued for the re-appropriation of science from racists (Barkan 1992), and for the divorcing of biophysical and morphological characteristics from language and culture¹⁸ (Harrison 1995). Many called for the adoption of a “no-race” position and the framing of intergroup difference by highlighting ethnicity-based associations (Montagu 1964; Harrison 1995). With the diminishing power of race as an analytic, over time, ethnicity, a concept seen as the more intellectually appropriate category, became a primary mode through which socio-cultural and inter-group boundaries came to be understood (Harrison 1998). Well into the 20th century, predisposition to disease through biological, environmental, and socioeconomic factors continued to be associated with race and ethnicity, and racialized bodies became increasingly pathologized, marking not only the further expansion of biomedicine and public health into daily life, but also the transformation of these two institutions into agents of governmental rationalities and social control (Foucault 1978; Shah 2001).

There have been a handful of critiques of this dominant narrative of the idea of race in science. Reardon (2005) for instance contends that not all scientists concurred on the “no-race” position. Others argue that there were ongoing constructions and strong usage of race in biological terms in both science and medicine despite many anti-racist movements in science (Cooper and David 1986; Miles 1989). Scientific and political developments and events, including the UNESCO statements on race, exemplify some of these inherent contradictions between the challenges made to the scientific basis for the inequality of races and the redefinition and reformulation of race along population genetics and new studies of

human variation and evolution. Many fundamental questions related to the construction of ordering schemas based on human differences, therefore, did not disappear.

Similarly, recent anthropological works have been vocal about the discipline's lack of involvement in public and political discourses surrounding race and ethnicity since World War II. Harrison (1998) and Shanklin (1998) argue that even though the dismantling of race's biological validity was groundbreaking and notable, sustained anthropological research on the social construction and folk concepts of race and ethnicity has been minimal and trite.¹⁹ Harrison contends that "anthropology's earlier antiracist project gave such priority to exposing the 'bad science' of racial thinking that the culturally resilient folk concept of race and its institutionalization in law and, it should be added and underscored, the economy were left unchallenged for a much too extended interim" (1998: 611). Frankenberg (1993) attributes this negligence to the persistent belief of many anthropologists that the revelation of truth and the elimination of ignorance automatically amended social injustices. Such silence also has been noted in the examination of anthropology's own legacies of complicity in colonialism, development, and other exploitative and exclusionist policies both domestically and internationally (Shanklin 1998; Starn 1986). Many anthropologists working on the study of race suggest that in order for disciplinary contributions to the alleviation of race and racism to occur, many more anthropologists need to pay attention to the political consequences of the discipline's "color blind stance" (Shanklin 1998: 673) and race-evasiveness (Frankenberg 1993). The caveat with such arguments, however, is that they undergird the notion that racial classifications are necessary to the documentation of disparities in health, labor, politics, and social life (Harrison 1998;

Shanklin 1998; Smedley 1998), and that the elimination of these categories would be a sign of a “more pernicious racialization” (Visweswaran 1998: 79).

Thus, although race and ethnicity currently encompass a multiplicity of meanings, and are a confluence of biological and social factors used to categorize humans, the usage and conflation of the two continues to be highly debated and problematic in the United States. Health research related to racial and ethnic disparities in health, especially in the field of HIV/AIDS prevention and intervention, is one area where these issues are particularly challenging. A great deal of HIV/AIDS intervention and prevention still focus on specific personal behavioral risk factors, and as a result, concentrate primarily on obtaining explanations for differentials in HIV/AIDS rates at the level of individual variation (Parker 2001). Research estimates that the epidemic is concentrated in and still increasing among Black men and women who account for over 50% of all new HIV/AIDS cases (Fleming et al. 1998; Fleming et al. 2000; Karon et al. 1996; Karon et al. 2001; CDC 2002; KFF 2003; Levenson 2004). A growing cascade of scholars and practitioners, however, have argued that the deeper subtext of such rising numbers illuminates that HIV/AIDS is taking root deeply in impoverished and marginalized communities, where underlying issues pertaining to the broader socio-political and economic factors serve as driving forces of the epidemic (Farmer 1992; Scheper-Hughes 1994; Singer 1994, 1998). Although these factors have been slowly incorporated into larger public health discourses, they have become, as a result of the rhetoric of health disparities, synonymous with race and ethnicity as risk factors for increased vulnerability to HIV/AIDS. Much of this is due to the nature of epidemiology itself, which serves as the dominant trope for understanding risk in medical and clinical interventions.

There are growing critiques waged against epidemiology that highlight its proclivity for reductionism, in which the individual serves as a prime unit of analysis, groups are rendered homogenous, and race and ethnicity are assumed to be individual characteristics instead of social relations of power (Cooper and David 1986; McMichael 1995; Krieger 1994). These criticisms will only continue to grow in light of new discoveries in genomic medicine as alarm grows over the potential neglect of social, structural, and environmental factors affecting the excess frequency of diseases amongst certain populations. In addition, as the mining of genetics differences in disease among racial and ethnic group encroaches on even HIV/AIDS, a disease largely seen as part of behavioral (and not genetic) medicine, HIV/AIDS practitioners and researchers will have to reconceptualize ways of confronting the concept of race and ethnicity as risk factors for HIV/AIDS. For instance, Stephens and colleagues (1998) have concluded that about 25% of whites (Northern Europeans in particular) are heterozygous for a CCR5 (a receptor used by HIV to enter cells) variant, which is protective against HIV infection and progression and is virtually absent in other groups, insinuating racial and ethnic differences in protection against HIV/AIDS (Burchard et al. 2003). Although much is still unknown at this time, this research is sure to effect notions of HIV/AIDS susceptibility, transmissibility, and responses to infection, particularly along ethnic and racial lines.

Race and ethnicity are indeed central topics in the debates surrounding HIV/AIDS prevention and intervention programs. Much research has revealed the ineffective impact of existing disease intervention and prevention programs, originally designed for white homosexual and bisexual men and intravenous drug users, within African-American and Hispanic communities (Singer 1994, 1998; Sobo 1995; Levenson 2004). These findings

have prompted many health advocates, social scientists, and practitioners to argue for the development of new programs that address unequal, inadequate, or inaccessible services, educational and employment vacuums, structural underdevelopment and dependency, racism, sexism, and homophobia along with HIV/AIDS prevention. In Miami, the criticisms also extend to current modes of classification by race and ethnicity (i.e. “Black/ African-American” or “Hispanic”) because their failure to address specific risks of diverse groups subsumed under these generic categories (Martin et al. 1995; Page and Marcelin 1999; Williams et al. 2000; Marcelin and Marcelin 2001). My project traces the continual contradiction between the discourses which advocate for increasingly precise categories of difference based on race and ethnicity and those which move away from conceptualizing race and ethnicity in simplistic, mono-dimensional ways. In doing so, it demonstrates the multiple ways in which the concept of racial and ethnic health disparities have traversed into the realm of commonsensical reality, as facts which no longer need to be explained or deliberated.

Risk in Context

The problematic of the renewed interest of race in the age of genomics has reignited national debates on race, and in the field of HIV/AIDS, these debates are powerful nodes through which notions of risk and personhood become realized. Various scholars have called attention to emerging encroachments of the confluences of biomedicine, technology, and genetics into everyday life and the drastic reworking of common concepts of bodies, identities, governance, and ethics (Rabinow 1999; Rose 1999, 2007; Lock et al. 2000; Dumit 2003; Franklin and Lock 2003; Clarke et al. 2003; Thompson 2005). These changes have

been loosely labeled as “biomedicalization” (Clarke et al. 2003: 162) or “biomedicalism” (Thompson 2005: 249). A key component of biomedicalization is that new ways of thinking about others and ourselves have proliferated and group differences, broadly defined, become constitutive of and reproduced by the processes underlying these broader shifts. It is assumed that differences, in terms of race, ethnicity, gender, race, and class, are both essential components of and a result of these new transformative processes of biomedicalization. As a result, inequality, difference, the politics of exclusion, or however one wishes to define these sets of problems within a biomedicalization framework, have become taken-for-granted concepts.

Biomedicalization further enhances difference as a given reality by generating multiple interconnected sites in which rationalities of risk are elaborated. These permutations of risk, in turn, both materialize from and influence the various dimensions of hierarchy and inequality. Thus far, there have been three major theoretical trajectories through which risk has been understood: cultural symbolism, risk society, and governmentality (Lupton 1999). Although different in their approaches to conceptualizing risk, all three call attention to the broader shifts in biomedicalization: from the diagnosis and treatment of disease through clinical mediation to the emphasis on risk factor analyses and prevention. To better understand the ontological relations between risk and inequality in a time characterized by the proliferation of new forms of subjectification and governance, this project reframes the health disparities debates within the context of risk. In doing so, it argues that scholarship, which builds on Foucault’s concept of governmentality (1979) and biopower (1997) and elaborates on the notions of biosociality and biological citizenship, is a critical contribution to current approaches of risk and health disparities. Over the last two

decades, there has been an overwhelming agreement among academic scholars, researchers, public health practitioners, policy makers, and health advocates that health disparities are a growing cause of concern and an urgent social problem. However, there is little consensus on the scale, sources of, and resolutions for health disparities. The concept of disparities itself signifies differences (in health access, in health experiences, cultural, biological, etc.), and becomes understood by some scholars, particularly those who build on Foucault's notions of biopower and governmentality, as co-constitutive of broader changes in the politics of life and labor.

I argue, in this dissertation, that risk discourses are critical to frameworks surrounding health disparities, as risk becomes understood as a highly negative or undesirable outcome and as a technique to predict future occurrences of hazards in the present. I find that the conceptualization of risk is framed differently in the various approaches to health disparities: much of the epidemiological work on health disparities maps risks directly onto hazards while political economists of health and illness tend to view the ontological relations between risk and hazards as opposed. Much like those who build from Foucault's governmentality thesis, I view both risks and hazards as mutually constructed, and thus, find that the study of the ways in which risk and hazards come to fruition more useful in my work on HIV/AIDS than those which contemplate their existence or reality. Following Rose's (1999) concepts of the emergence of communities as sites of governance and the slow dissipation of the social, my study of risk also moves away from notions of social insurance as a means of distributing risk to those which focus on self-management of risk.

Ethnography on the Ground: Challenges of Conducting Clinical and non-Clinical Fieldwork

I conducted ethnographic research in Miami, FL for 15 months, in July 2004, and from July 2005 until August 2006, six weeks of which included intensive language training in Haitian Kreyòl. My data collection comes from the following arenas: 1) observations of social and health service agencies, 2) interviews with doctors and patients, and 3) epidemiological and surveillance data.

Although the value of methods of field and participant observation can often be taken for granted, they allow for detailed and documented observations of the complexity of the interactions and interrelations among people, objects, and places (Becker and Geer 1957; Geertz 1973; Fitzpatrick 1981; Leininger 1985; Kutsche 1998; Bailey 2000). My primary field sites were Miami General Hospital and Santè Ayisyen. Miami General Hospital is a non-profit, tertiary care hospital and the primary teaching facility for a local medical school. It is one of the full-service providers for the uninsured in South Florida, and a place where a majority of medically impoverished immigrant communities receive care, including Haitians and Haitian Americans. It is also a leading center for HIV/AIDS care and treatment, and thus, produces official discourses of HIV/AIDS through clinical research. Miami General Hospital²⁰ conducts weekly and bi-weekly educational classes on HIV/AIDS in English, Spanish, and Kreyòl for both patients and community members. In order to trace the how information about HIV/AIDS disseminates and becomes reinforced in a setting that encompasses both clinical and research agendas, I attended these meetings regularly, as well as other HIV/AIDS related special events and grand rounds. These clinical education classes allowed me to document the ways in which clinical experts were interpellating clients in relation to particular rationalities of HIV/AIDS risk (i.e. safe sex, antiretroviral adherence,

positive living) which converged on imaginaries of responsible citizenship. I was also able to witness the complex ways through which Haitian clients themselves produce alternative stories and internalize governmental discourses of HIV/AIDS, risk, and identity.

Santè Ayisyen is a non-profit community-based organization providing health and social services to the underserved Haitian population of South Florida. It provides a wide range of services including counseling, case management, food assistance, health education, HIV/AIDS prevention case management, street outreach, HIV/AIDS testing and counseling services, primary health care, research, training, and technical assistance to professionals in the fields of social sciences and medicine. I conducted participant observation several times weekly at Santè Ayisyen, sitting in on HIV/AIDS testing and counseling sessions as well as HIV/AIDS case management meetings, participating in bi-weekly street outreach programs, and attending several health fairs. These situations allowed me to document the ways in which knowledge about HIV/AIDS, risk, and citizenship circulates. In addition, because Santè Ayisyen is positioned as a key constituent in Haitian community politics and a vital provider of health and social services to underserved Haitians, conducting fieldwork there helped me to better understand politics surrounding the concepts of community and identity through individual and institutional discourses.

In addition to these two facilities, I conducted fieldwork at many other critical institutions. One included the Office of HIV/AIDS, one of the largest programs at the Miami-Dade County Department of Health. Their initiatives included HIV/AIDS prevention and education, patient care, AIDS Drug Assistance Program (ADAP), Health Education and Risk Reduction, Counseling and Testing Services, Surveillance and Senior HIV Intervention Project (SHIP). In addition, this agency conducts professional training for health care

workers, counseling and testing providers, and the community at large. Over the course of several months, I was able to conduct both informal and formal interviews with key staff members and attend major educational training seminars on HIV/AIDS. These trainings were important not only because many institutions and professionals with whom I worked required that I become knowledgeable and trained in HIV/AIDS issues in Florida and Miami-Dade County, but also because they gave me the opportunity to learn as both a participant and as an observer the ways in which health and social service providers were trained. My professional trainings were not limited to the Office of HIV/AIDS, as I also attended continuing education classes designed for health professional sponsored by the Health Start Coalition of Miami-Dade County.

Other fieldwork sites included several health and social service organizations located in Little Haiti. These agencies were critical not only in providing services, but also served as research and advocacy groups representing the Haitian community. I collaborated with providers from these agencies to gain a better understanding of their work and the community politics surrounding other Haitian community organizations. I also worked with providers from other larger agencies not located in Little Haiti and whose focus was not on the Haitian community per se in order to compare services and outreach in other communities, particularly for African Americans.

I also attended weekly meetings of the HIV/AIDS Planning Board for the county and its various committees and sub-committees, composed of health department administrators, community health workers, activists, and lay people, in order to understand the ways in which different constituents developed and disseminated information related to HIV/AIDS. As a result of my involvement with these different community coalitions and contacts from

primary field sites, I was able to participate and help plan community events related to HIV/AIDS, most of which centered on World AIDS Day 2006 and the National Black HIV/AIDS Awareness Day in February 2006.

I conducted approximately 53 in-depth, semi-structured interviews, lasting from 45 minutes to three hours, with 31 Haitians and Haitian American clients accessing health services or those who were HIV positive, and with 22 health and social service professionals working mainly with Haitian clients. Interviews with providers were done in English; interviews with clients were done in both Haitian Kreyòl and English, depending on the preference of the participant. All interviews in Haitian Kreyòl were conducted with the aid of a Kreyòl-speaking translator who helped to clarify more complex parts of the conversation. Almost all prospective informants for the study were recruited at various health and social service agencies, while several were recruited with the help of those already participating in the study. I chose two convenience samples of informants from these main research sites, because I was interested in examining the ways in which notions of risk, race, and HIV/AIDS were understood and acted upon by a sample of service providers and their Haitian clients. My two groups of informants do not include a statistical “representative” sample, but rather the social worlds (Clarke 1991; Strauss 1978) of those involved in the continual negotiation and transmission of these concepts.

Equal numbers of informants who were providers were interviewed from Miami General Hospital and Santè Ayisyen, including health educators, physicians, health educators, and social workers. At the Office of HIV/AIDS, seven key personnel were interviewed, including those who worked in prevention, health services, education, outreach, ADAP, and surveillance. Seven other health and social services professionals from

additional community based organizations with whom I interacted were also interviewed. Interviews with providers elicited data about relationships with Haitians clients identified as at high risk, especially perceptions of benefits and obstacles encountered. These interviews provided information regarding assessments of the current field of HIV/AIDS research and services, and in particular, the ways in which these programs accommodate immigrant and minority communities. In addition, I interviewed three providers multiple times and spent numerous days with them, paying attention to the institutions and individuals with whom they interacted.

A majority of informants who were clients were women (23), over 30 years of age (22), and not HIV-positive or did not disclose their HIV status (20). Sixteen of these informants were recruited from Miami General Hospital, while 8 were recruited from Santè Ayisyen, and 7 were connected to outside health care institutions. Interviews of Haitian clients elicited data about life experiences, conceptions of body and body processes, sex and sexualities, and health and illness. They documented themes related to understandings of HIV/AIDS and associated discourses surrounding risk and risk behavior, and questions related to identity, issues surrounding race relations, racism, and social, economic, and political barriers. I interviewed three informants multiple times, and often spent numerous days with them in a variety of settings such as health and social service institutions, homes, churches, stores, and other similar locales in order to better understand their daily lives in Miami.

In addition, I also collected written materials²¹ produced by the U.S. Census Bureau, the Centers for Disease Control, the Kaiser Family Foundation, Florida State Department of Health, Miami-Dade County Department of Health, University of Miami, and various local

community based organizations so that I could trace the various intersections between community affairs and politics, HIV/AIDS and other public health information, and governmental and public discourses about Haitians.

Overcoming Obstacles

Miami or Little Haiti in particular, proved to be a difficult place to conduct fieldwork due to the nature of my research. Because I was working with Haitian community organizations and their clients, considered by many to be “difficult” to penetrate, and because I was working on issues related to HIV/AIDS, which many considered a taboo or a stigmatized topic in the community, numerous obstacles in terms of accessing institutions and providers, and therefore, Haitian participants existed. Entry into field sites and potential informants depended greatly on a “gatekeeper” system, in which I was often denied entry unless I secured a well regarded individual able to verify and vouch for my presence and research. I was finally able to gain access to a number of key institutions in Little Haiti with the help of a key individual who was well connected to community organizations in Little Haiti. This individual also provided me with a university affiliation to the University of Miami (UM), and which gave me legitimacy as a “local scholar” or “UM student” in many of these field sites. Should the critical importance of being established as a “local” get lost on the reader, the following scenario should serve to buttress my claims. Meeting the executive director of a local advocacy agency in Little Haiti, I introduced myself as a student from the University of California San Francisco and Berkeley studying health practices of Haitians in Miami. She responded by stating that she didn’t understand why I was so far away from home, and why I wanted to work with them. Several days later, I returned with a letter from

my gatekeeper on official University of Miami letterhead. After seeing this letter and having talked to my gatekeeper over the phone, she exclaimed “Oh, you are from the University of Miami. Well....I didn’t know that. You should have said so in the first place. Welcome!” There is little doubt that UM is seen as a bastion of power, influence, wealth, and resources within the city of Miami, and in many ways, without this affiliation, I would not have gained entry as smoothly.

Not all of my sites of study involved a gatekeeper or demonstrating institutional affiliation. In these instances, I always negotiated entry into institutions through health educators and outreach workers, rather than high-level administrators or institutional bureaucrats because of their accessibility and direct contact with Haitian clients. Often, they were deeply interested in the problems of my research and voiced that these concerns mirrored their own. Many were very savvy about notions of “culture,” “risk,” and “community” and invited me readily to participate in activities and meetings that they organized for their Haitian clients. In all instances, I followed proper protocol measures in protecting confidential information.

All of these measures did help me to gain entry, but I was only able to sustain this through negotiating expertise and free labor. One of the first providers that I met with, an HIV/AIDS educator and outreach worker, refused to work with me until I became certified by the local Bureau of HIV/AIDS. She wanted me to take certification class in basic HIV/AIDS knowledge and HIV/AIDS testing and counseling. When I told her about my training and prior experience with working with HIV/AIDS, she stood firm and reasoned that it was important for me to understand “local” problems in the field of HIV/AIDS. So I attended and completed trainings in HIV/AIDS in order to work with particular individuals

and institutions, and these certifications helped me to position myself as a student with expertise in clinical and non-clinical fieldwork. Although I never misrepresented myself as an anthropology student with training in public health, almost everyone either assumed or came to see me as a medical, nursing or social work student in training.

There were several additional problems of interviewing and recording informants. It often took long periods of time to obtain interviews with Haitian informants, some of whom I would lose contact with altogether because they either moved or their phone numbers were disconnected. Several informants also declined to be interviewed, often stating that their motivations were not “political.” Even though I tried to “depoliticize” my research and explain it as something that could potentially benefit them and other Haitians, it did not change their minds. Many informants did not want to be tape-recorded, including a couple of providers, and during these times, I took notes. I also never tape recorded informal conversations with anyone or any participant observation situations because many Haitian informants’ fear of having their identities disclosed. In addition, many informants or potential informants wanted or expected monetary compensation for interviews which I was not authorized to give. I often tried to get around this by providing car rides, translation help or food, but there were several times where my requests for interviews were denied because I could not offer them money. As one woman told me, “They’re giving out \$10 for interviews at [Florida International University] so if you are not going to pay me, I’d rather go there.” Although I was in disbelief the first time this occurred, I came to understand it as part of the culture of research in which informants have begun to expect, demand and receive certain levels of compensation for their valuable time and energy. My anthropological training has taught me that those who need to be compensated often will not provide “accurate” or

“truthful” narratives. However, I feel that at least in my fieldwork experiences, many informants, who have been oversaturated with requests to participate in research studies, expect compensation for what they feel is a valuable service being rendered. These are issues that must be included in future debates over anthropological and ethnographic methodologies.

Finally, once I gained entry and over time, I was integrated into HIV/AIDS testing and counseling sessions, HIV/AIDS educational classes, HIV/AIDS outreach, and the daily lives of my main informants quickly. Being a student, female, young, without family, speaking Kreyòl, and offering non-monetary aid all made me non-threatening and trustworthy to many of my participants, especially to older women who often readily played a motherly role. Many HIV-positive Haitians who attended the Kreyòl HIV/AIDS educational classes at the hospital also assumed that I was HIV-positive even though I was never asked my status or revealed it, and I am unsure how much this assumption helped continue my presence.

I was also called upon to work for the Office of HIV/AIDS as a consultant and petitioned to join the Board of the HIV/AIDS Partnership committee. Thus, overall, by negotiating expertise across multiple sites, embarking on additional training, and demonstrating contributory expertise, I was able to gain entry to and sustain multiple fields of study.

Organization and Summaries

In order to document circulations of discourse and practice of HIV/AIDS prevention and intervention programs, I use multiple ethnographic narratives. The dissertation itself is

divided into chapters that reflect these various shifts. Much like the wider movements of people and rationalities in the field of HIV/AIDS in Miami, the narratives within each chapter continually change and flow to mirror the ever expanding relations between various powerful and not so powerful constituents. As a result, there is necessary overlap as each chapter examines these complex entanglements between everyday practices and broader logics of power.

Chapter 2 entitled, “Treating the Numbers: Convergences of HIV/AIDS Surveillance and Risk Classifications,” focuses on various levels of surveillance that structure and are products of HIV/AIDS prevention programs in Miami. Through these analyses, this section explores the ways in which we come to know and govern ourselves through enumerative tabulations and categorizations of risk, race, and ethnicity. It also highlights, through ethnographic examples of clinical and non-clinical HIV/AIDS prevention settings, the circulations of what I call “numerical subjectivities,” the ways in which identity and subjectivity become entangled in numerical considerations and how certain diseases such as HIV/AIDS come to be identified with particular groups of people. By examining the deployment and interpretation of HIV/AIDS numerical data in Miami, Florida, this chapter demonstrates how specific identities and spaces of difference, through categories such as “heterosexual” and “high risk groups,” circulate, gain traction, and become meaningful for public health institutions and the people they seek to manage.

Chapter 3, entitled “Ethnography in Clinical Settings: Rhetoric of Prevention and Progress,” traces the interactions and interconnections between official expertise about HIV/AIDS prevention and public understandings and perceptions of science. This chapter illustrates the various ways in which notions of citizenship become constituted through the

discourses of expertise and governance in HIV/AIDS, and how they become entangled in the debates about relevant knowledge bases and questions over authority. Using the complex movements of circulating ideas and technologies among various constituents who are brought together in HIV/AIDS prevention, I document how clients become rendered as either responsible or non-biological citizens, as those who are able or unable to inculcate themselves to official discourses and practices of HIV/AIDS prevention. In so doing, I demonstrate the ways in which Haitians struggle to exist in-between and in-between both realms, positioning themselves as both productive citizens and impossible subjects across multiple sites in the field of HIV/AIDS.

Chapter 4, entitled “Normalizing Difference: Confronting Health Disparities and the Promise of Positive Living,” reframes more broadly the notions of biological citizenship and biosociality through the politics of difference in the field of HIV/AIDS prevention. Using the growing movement of “positive living,” I argue the official rhetoric of HIV/AIDS prevention and treatment merges individual responsibility with social responsibility through its construction and management of responsible, ethical, and enlightened biological citizens. Haitians in Miami, however, continuously work to simultaneously claim and reject such notions of biological citizenship and subjectivity, exposing the undercurrents of racial and ethnic difference embedded within contemporary projects of biological citizenship. This chapter also highlights the ways in which official rhetorics of racial and ethnic health disparities also serve to trouble current scholarship on biological citizenship and biosociality. By exploring how health disparities has become a taken-for-granted and commonsensical concept, I argue that inequalities and the risks associated with them can no longer be viewed as detrimental or favorable. Instead, they must be seen as productive representations of

broader transformations in the rationalities and practices of governance of life itself, where the programs, policies, and those implicated within health disparities must be understood through their productive actions, choices, and rationalities in the name of unequal burden of affliction and illness.

I conclude by outlining more broadly the reasons to reframe concepts of social suffering and vulnerability by providing ethnographic evidence of local strategies of resistance and resilience. In so doing, I also try to build upon scholarly work on structural violence. This chapter also asserts that medical anthropological research on HIV/AIDS in non-Western countries presuppose undifferentiated “Western” medical and public health paradigms which travel and impose prepackaged views on developing nations. Through reworking interconnections between science and technology studies and medical anthropology, this chapter demonstrates that it is equally important to attend to narratives emanating from the “West,” especially in medical contexts and from those who are marginalized. Finally, this chapter makes evident that transnational medical science, health policy, and expertise are continually repositioning themselves in scientific and public life situated right here in the “West.”

TWO

Treating the Numbers: Convergences of HIV/AIDS Surveillance and Risk

Classifications

It was another hot and unbearably humid day in Miami. I paced myself walking from the open parking garage to Jamie's office so as to not be covered in a layer of sweat before attending my first day of clinical classes. Jaime greeted me warmly with a kiss on the cheek. He was wearing his usual crisp, white, long sleeved shirt unbuttoned a couple of buttons and his belted dark jeans. I was relieved to walk into the building as the air conditioning enveloped me almost instantaneously; it was like jumping into a cold pool, startling and comforting at the same time. Jaime took me to the room where Dr. Cruz was going to speak. It was a cold sterile classroom with very bright overhead fluorescent lights and two dry erase boards that covered almost the full length of the front and side walls. There were about 25 plastic chairs with adjustable desk pieces that were facing the front of the room towards a large metal desk and some audiovisual equipment. The room also had a well worn but comfortable couch in the very back which seemed out of place with the rest of the bare furnishings.

Jaime and I were chatting for just a few minutes before a couple of African-American men walked in and exchanged greetings with Jaime. They were dressed in ill fitting clothes with mismatched colors. They sat down immediately on the couch and began to close their eyes. A wide variety of participants, a majority of whom were African-American, started to trickle in. There were about two individuals who were speaking to each other in Kreyòl and spoke to Jaime in French so I knew almost certainly that they were of Haitian origin. There

were about four or five clients who were conversing in Spanish with each other. Overall the room was filled with about 25 or so people, with equal numbers of men and women.

I sat next to a very skinny tall African-American man wearing black shorts and a black tank top; he had a shaved head and the pitch of his voice and laugh were very loud. Another woman sitting in front of me looked as if she was in bad shape. Her hair was messy, parted entirely to one side, making it seem as if that side carried the weight of her entire head. She had trouble keeping her head held up so that it constantly bent to one side like her hair. I could see a large red scar directly on the back of her neck. Another woman sat diagonally to me. She was a large woman wearing a teal and cream white flower dress with a matching cardigan. She seemed uncomfortable since she was moaning, huffing and puffing out loud with some regularity. She couldn't fit into the chair well and couldn't put the desk part down. She later proceeded to fall asleep during the presentation and snored loudly.

Another two women who walked in together; both seemed younger than the others, and were maybe in their late thirties or early forties. They wore matching yellow jackets and hospital badges, signifying their volunteer status. One woman had dark golden curly hair with fashionable sunglasses and tight jeans. The other woman had long dark braids and warmly greeted an older man in Kreyòl. They were discussing fervently a book titled "Natural Cures that They Don't Want You to Know About," which according to the women, was on "self-education" and the idea that "drug companies don't want to find a cure because they won't be able to sell their drugs." It generated a lot of interest from the rest of the group as the room grew noisy with their opinions on pharmaceutical companies and antiretroviral drugs.

In the middle of a heated discussion of the book, Dr. Cruz came in. His entrance was like something out of a movie, because it seemed to have the effect of viewing in slow motion. The almost immediate abrupt silence of the classroom was jarring but seemed somehow uncontrived. Time and motion slowed down, as it does when watching the dashing hero enter a scene for the first time. Dr. Cruz was very young and boyishly handsome, with a full head of shiny black hair and bangs that kept getting into his face. He was dressed neatly in a crisp white shirt, striped tie, and blue pleated pants. We all seemed to be watching in awe as he took off his white coat as soon as he came in. A look of pleasure came over his face as he recognized some of his patients in the room. He smiled and nodded to acknowledge them.

Suddenly, as if on cue, an African-American woman in the back, as soon as Dr. Cruz was introduced by Jaime, pronounced very loudly in a voice mixed with enthusiasm and pride “I am 400 CD4 count and 250 viral load, and I am the person that I am today because of this man.” She had a voice that carried weight which seemed misleading given that she was a tiny diminutive woman with extremely thin legs and arms. Her public declaration caught everyone off guard, even Dr. Cruz, whose face became slightly flushed as she continued to shower him with accolades. Perhaps to conceal his embarrassment, Dr. Cruz didn’t acknowledge her comments directly; instead he proceeded state “These venues are so wonderful in interacting with patients because as doctors, we only get 20 minutes with each of our patients and that includes filling out insurance forms and doing all these administrative things along with the clinical checkup.” He went onto speak about virology of HIV/AIDS, and answered questions regarding antiretroviral adherence and doctor-patient relationships. He ended the lecture by thanking everyone who attended and stated that he felt that he was also learning from them. Finally, he declared “You know, in medical school, our teachers

told us that ‘half of what we teach you will change in the next few years and the other half might not even be true’ so remember that medicine in a lot of ways is really a trial and error game.” This statement garnered a chorus of “uh-huh,” “yes,” and “that’s right” from the audience along with vigorous head nods of approval as if they were responding to a preacher after every verse of his church sermon. Everyone seemed to flock around him after the end of the lecture, perhaps to ask more questions or to speak with him about personal issues afflicting them.

I left the classroom reflecting on the woman’s comments at the beginning of Dr. Cruz’s talk. This was not the first time I had heard such a declaration of what I call “numerical subjectivity” in settings around HIV/AIDS in Miami. During a World AIDS Day celebration luncheon at Miami General Hospital, Jenisa Mann, an African-American guest speaker and hospital client, introduced herself by reciting a poem. In the poem, she described herself as someone who had a viral load of 178,000 and a CD4 count of 33 when she came to get care and treatment. She explained that she was very grateful for all the help and support that she has gotten and wanted to give back to the place that she had received so much from. Her poem was titled “Celebration” and was a narrative of her appreciation for a “second chance at life.” Like Jenisa, during county planning board meetings on HIV/AIDS, a white gentleman by the name of “Slim Jim” always introduced himself with his current CD4 count and viral load and referred to himself as a “PWA” (person with AIDS). He was the only one in attendance who identified himself in this manner, even though there were others at the meeting who were equally open about their HIV positive status.

But what struck me most about the woman in Dr. Cruz’s lecture, more so than Jenisa Mann and Slim Jim, was that I didn’t even know her name as she never divulged it to us.

She introduced herself to the class not by using her name or birthplace, but through a set of numbers. Her identity seemed deeply intertwined in these numbers that conveyed who she was as both a subject and object of numerical classification and scientific reasoning. She not only asserted her claims of subjectivity as represented by the disease that afflicted her, but she also communicated a story of triumph and achievement vis-à-vis her cellular statistics. At the same time, hematological and virological calculations signify her body as an object of statistical knowledge, utilized to gather individual and collective markers of disease transmission and progression. In a classroom full of people who interact in various ways, from skepticism to indifference, with medical personnel and with HIV/AIDS as a disease, her profound declaration had a disquieting affect on the class because her story, through numbers, personified an ideal patient and a responsible citizen.

Circulating Numbers

Public health discourses are almost always steeped in numbers. Numbers are instrumental in the conception and management of the health of populations through the practices of classification and categorization because they seem to make evident certain realities on the ground. Foucault (1979), in his seminal piece, “On Governmentality” argues that the notion of population came to be a central force, giving birth to the science of government only with the advent of demographic expansion, monetary abundance, and agricultural growth that occurred in the 18th Century. He positions statistics as a “major technical factor” in increasing the strength of the state’s through its role in managing the health and welfare of its population (Foucault 1979: 16-17). Statistics and other forms of knowledge used to gather and manage the health of populations have been associated with a multitude of modern state-building projects (Rabinow 1999). Fact sheets, statistical data

sets, and colorful graphs are fundamental to modern forms of government, and represent sites through which individuals, groups, and nations are rendered objects and subjects of scrutiny and enumeration.

Diseases, epidemics, and public health crises themselves are realized more concretely through the use and dissemination of numbers. However, it's not just the presence of numbers that defines, in many ways, public health discourses; rather, it is the burgeoning use of statistics itself that plays a fundamental role in how diseases and populations come to be known and acted upon. Raymond Williams brilliantly noted that statistical analyses were "devised in response to the impossibility of understanding contemporary society from experience" (1983: 170). Williams stated this in reference to the parallel emergence of the discipline of statistics and the new industrial London which was "unknowable" without statistical analyses. Goldman also has argued that early Victorian statisticians perceived statistics as a language whose rules provided "answers to the mysteries of the new society which had generated the language and which the language was describing" (1991: 434). As demonstrated in the opening vignette, statistics have indeed come to be more than social data or techniques used to uncover veiled implications of numbers; they are a language in themselves through which people like Jenisa Mann, Slim Jim, and the woman in Dr. Cruz's lecture come to know themselves and how we come to know them.

Like many scholars who have actively documented the pervasive power of statistical data in the overall management of nation-states and its citizens (Foucault 1977, 1979, 2003; Hacking 1982, 1986; Porter 1995; Bowker and Star 1999; Rose 1999; Briggs and Mantini-Briggs 2003), I also illustrate their continued and growing significance in the realm of HIV/AIDS prevention and intervention in Miami. In addition, I move away from analyses of

public health statistics that focus on deconstructing data, drawing attention to its shortcomings via faulty methodology or assumptions (Cooper and David 1986; McMichael 1995; Krieger 1994, 2000). This project is meant to be neither an exercise in deconstructing these statistics nor in determining their accuracy, as there are others better suited to take up that important task. Rather, I concentrate on the ways in which individuals and groups come to construct and understand themselves and society through statistical enumerations. For instance, how is it that we come to know ourselves through numbers? In what ways do identity and subjectivity become entangled in numerical considerations? Why have classifications by race, ethnicity, gender, age, and risk become commonplace and uncontested in health statistics? What work do such depictions of stark differences between categories of people perform? What is at stake for collectivities that come to identify with social and medical categories that emerge as a result of statistical enumerations?

In this chapter, I focus on various levels of HIV/AIDS surveillance and in so doing, illustrate the ways in which we come to know and govern ourselves through enumeration and resulting categorizations. I do this by tracing the circulation of statistics from CDC reports to local departments of health (DOH) trainings to individual interactions. However, I do not take this circulation to be self-evident or as a means through which meaning is simply transmitted (Lee and LiPuma 2002; Tsing 2004; Briggs 2005; Leshkovich 2007); rather I am interested in how and why certain numbers and categories travel and the ways in which particular forms of information and knowledge production about HIV/AIDS connect across difference. I argue that particular circulations, by their very movement, enable HIV/AIDS surveillance statistics and the resulting categories of risk to be what Bruno Latour (1987) calls “immutable mobiles,” materials meant to idyllically flow from one site to another

without change. In the field of HIV/AIDS, statistical enumerations are supposed to ideally flow “up,” from individuals to local testing sites to city and state-level DOH to the CDC and other national and global institutions, while knowledge about HIV/AIDS and resulting categories of risk is supposed to move “down” in the opposite direction. But, as I illustrate in this chapter, the contentious divides over existing HIV/AIDS risk transmission categories demonstrate that surveillance statistics and the multiple notions of risk it inculcates do not travel evenly or as they are intended.

In order to document these sites of friction, what Tsing calls the “the awkward, unequal, unstable, and creative qualities of interconnection across difference” (2005: 4), I take seriously Paula Treichler’s (1999) arguments that HIV/AIDS is as much about biomedicine and technology as it is about meanings, definitions, and attributions, and that HIV/AIDS has come to be linked to a series of preexisting worldviews, institutional discourses, material realities, and cultural phenomena. I’m also informed by Cindy Patton’s (1990) and Steven Epstein’s (1996) astute attention to the processes of democratization of knowledge around HIV/AIDS and the shifting relations between HIV/AIDS science and affected communities. However, I expand on their arguments by focusing on local and national discourses of HIV/AIDS surveillance and the ways in which they do more than just rearticulate established social divisions. I argue that such discourses are fundamental to the construction of new, complex, and unequal relationships between the science of HIV/AIDS prevention and intervention and certain categories of people. Both HIV/AIDS prevention programs and the people they seek to serve in Miami are implicitly and explicitly involved in the production, silencing, and distortion of numerical discourses around HIV/AIDS.

In this chapter, I demonstrate the work continually being done by numerical statements on HIV/AIDS, and in particular, the ways they shape the local politics of disease and community as well as the broader logics of power and public health practice. By examining the deployment and interpretation of HIV/AIDS numerical data in Miami, Florida, this chapter attends to how specific identities and spaces such as “heterosexual” and “high risk groups” come to hold significance for public health institutions and the people they seek to manage. Finally, I ethnographically illustrate the means through which identity and subjectivity become entangled in numerical considerations and concepts of risk, and contend that both HIV/AIDS experts and their clients are equally implicated in the production and circulation of certain kinds of knowledge about HIV/AIDS and notions of risk through enumeration.

The Science of HIV/AIDS Surveillance

HIV/AIDS surveillance and statistical data often appear flawless, impermeable, and sometimes daunting. For instance, compulsory trainings for those working in the field of HIV/AIDS in Dade County, Florida, usually starts with an introduction to worldwide, national, and local HIV/AIDS statistics, often in that order. In one such class, we were told that “there are 65 million infected worldwide, with 38 million people living with AIDS, and new infections happen at the rate of 9 per minute, 14,000 per day, and 5 million per year. Half of all new infections are amongst people ages 15-24 and 67% of all infections were in sub-Saharan Africa.” We were then instructed to view an HIV/AIDS map of the world, often color coded and numerated by continent. This map had listed “40,000 new infections” as occurring in the United States, with 10% occurring in Florida. Furthermore, we were told

that “of these, 25% of new HIV/AIDS infections were in people under 22 years of age, mainly 13-19 year olds, and half in women.” The instructor informed us that these statistics were rising because of “unprotected sex, peer pressure, and a lack of education.” She revealed that “HIV/AIDS is the number one cause of death in Florida in African Americans ages 25-44.” We then went onto discussing cumulative reported HIV cases and the fact that Florida has 11% of the HIV/AIDS cases in the United States.

These statistics are not new or unusual. In fact, many reports and publications pertaining to HIV/AIDS showcase these same kinds of numerical declarations at the worldwide, national or local levels. HIV/AIDS statistics are part and parcel of broader processes of HIV/AIDS surveillance and prevention, and as such, carry moral weight, represent various constituents, and inherently contain invisible mechanisms of categorization which act to configure the boundaries and existence of visible ones (cf. Bowker and Star 1999). Our aforementioned DOH trainer instructs us to read these HIV/AIDS statistics as indicative of the amount and the types of people who are infected as well as the speed at which these infections occur. However, these numbers represent far more than this; they allow us (and her) moral readings of people and places. By formulating a so-called portrait of the epidemic and by forecasting future trajectories of HIV/AIDS (cf. Porter 1995), these statistics have us infer that numbers are rising because certain kinds of people do not have adequate education, are having unprotected sex, and are conforming to peer-pressure. The numbers plotted on the map of the world convey spatial extension of the existence and movement of HIV/AIDS, with a kind of ground zero located in and radiating from “sub-Saharan Africa.” In addition, the comparison of global (65 million infected) and local statistics (40,000 new infections) works to reveal the pronounced gaps between the two and

further distances the U.S. epidemic from the non-U.S. epidemic. At the same time, however, these same numbers build connections between African-Americans in Florida and Africans in sub-Saharan Africa because both share undue burdens of death by HIV/AIDS.

This morass of numbers has the effect of telling a holistic story of both global and local HIV/AIDS. Such statistical discourses no longer need to outline, at least in this instance, the sources from which the numbers came or how they were produced. The only connection between the numbers is that they all relate to HIV/AIDS. For instance, the “40,000 new infections” in the United States may or may not represent the same “65 million infected” worldwide. Age, gender, and racial groupings of individuals also do not need to be exhibited the same way for global statistics as they are for national and local ones. What is emphasized, however, is that a majority of global HIV/AIDS cases are located in sub-Saharan Africa and that HIV/AIDS is the number one killer of African-Americans in Florida, implying an inherent relationship between certain groups of people and the disease. These statistics represent a project that constructs scales to simultaneously distance and connect imaginaries of global and local epidemics by compressing and inflating diverse forms of knowledge about HIV/AIDS collected from various sources and which represent different constituents.

In order to consider more thoroughly how such discourses of HIV/AIDS gain traction, I must first look at how and in what particular ways these statistics come to be produced and disseminated. The generation of HIV/AIDS statistics in the United States is complex, and occurs through multiple collaborations at various levels, from consumers to the CDC. However, the CDC’s claim that the collection of information about HIV/AIDS is necessary to the welfare of the public makes it seem as if it were an established process.

They declare that the garnering of these kinds of numbers is essential to disease prevention by stating:

Before we can stop the spread of disease, we need to know where infections are flaring up and who is being infected. Gathering this information in a systematic way is called surveillance—the primary way CDC tracks diseases. CDC’s HIV/AIDS surveillance system collects reports of cases of HIV and AIDS as they are diagnosed. (2006)

The CDC positions itself to be the primary gatherer of information about HIV/AIDS, but, in reality, they collect and process reports produced by multiple state and local health departments who obtain them from local clinics, hospitals, and labs. It is indubitably a complicated procedure that involves the coordination of various actors, organizations, and information technology systems. But as such systems of surveillance become more profoundly entrenched in the multiple sites of our daily lives (i.e. HIV testing through prenatal visits, routine physicals, etc.), they become more likely to be, as Bowker and Star state, “black boxed and thence made both invisible and potent” (1999: 325). The final products of CDC HIV/AIDS surveillance data, like those statistical portraits presented at the DOH training, erase the multiple and interconnecting social and material histories from which they sprung forth.

Therefore, it is crucial to conceptualize HIV/AIDS surveillance systems not as monolithic and static, but as those which have undergone numerous transmutations and which continue to evolve. HIV/AIDS surveillance has been conducted since HIV/AIDS was first identified (CDC 1999) to track the progression of opportunistic infections of unknown cause, and has continued to report nationwide cases of HIV/AIDS long after information regarding disease etiology and transmission became available. CDC (1999) concedes that the criteria utilized to report HIV/AIDS has changed progressively to reflect these new ways

of understanding the disease. For instance, the CDC revised HIV/AIDS reporting definitions in 1985, 1987, and 1993 in order to incorporate a more extensive range of what it labeled “AIDS indicator diseases and conditions” (CDC 2007) as well as HIV-antibody lab tests. As a result of these changes in surveillance parameters, more individuals came to be counted and HIV/AIDS classifications varied greatly. In 1987, a CDC Morbidity and Mortality Weekly Report (MMWR) detailed revisions to AIDS surveillance, stating:

The term ‘AIDS’ should refer only to conditions meeting the surveillance definition. This definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection in individual patients because there may be additional information that would lead to a more accurate diagnosis....The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice. (1987: 7S)

According to this passage, AIDS was solely a definition to be used for surveillance purposes in 1987. Clinicians were expected to demonstrate “good medical practice” and incorporate other information to determine whether AIDS was the most accurate diagnosis for an individual patient (CDC 1987: 7S). Even though clinical and epidemiological classification schemes of surveillance and diagnosis often appear to be continuous and integrated, this report indicates that the definition of AIDS was created to maintain consistency primarily for surveillance purposes rather than as a standard for clinical practice. Such gaps between epidemiological and clinical institutional practices showcase the sometimes incongruous classification methods used in clinical and epidemiological work (cf. Briggs and Mantini-Briggs 2003).²²

Current statistical reports of HIV/AIDS often make no mention of the kinds of criteria utilized to collect data. They appear well standardized and cohesive. Basic statistical reports usually include HIV/AIDS estimates and cases, as well as demographic categories of those

infected such as age, race/ethnicity, sex, transmission or risk category, and geographical location. The CDC also produces statistics to document what kinds of people are living with HIV/AIDS, along with their rates of survival and death after an HIV/AIDS diagnosis. In the latest surveillance report from 2005 (updated in June 2007), some of the “Highlights of Analysis” include HIV/AIDS cases overall, stratified by age, race/ethnicity, and sex. It states:

The estimated number of HIV/AIDS cases in the 33 states with confidential name-based HIV infection reporting decreased each year from 2001 through 2004 and then increased in 2005 (Table 1). In 2005, the estimated rate of HIV/AIDS cases in the 33 states was 19.8 per 100,000 population (Table 5b). **Age group:** From 2001 through 2005, the estimated number of HIV/AIDS cases decreased among children less than 13 years of age and in the following age groups: 13–14, 30–34, 35–39, 40–44, and 45–49 years. The estimated number of HIV/AIDS cases remained stable among persons 65 years and older and increased among persons aged 15–19, 20–24, 25–29, 50–54, 55–59, and 60–64 years. The largest number of HIV/AIDS cases occurred among persons aged 35–39 years and accounted for 16% of all HIV/AIDS cases diagnosed in 2005. **Race/ethnicity:** From 2001 through 2005, the estimated number of HIV/AIDS cases increased among whites, Asians/Pacific Islanders, and American Indians/Alaska Natives and decreased among blacks and Hispanics. Blacks accounted for 49% of all HIV/AIDS cases diagnosed in 2005. In 2005, rates of HIV/AIDS cases were 71.3 per 100,000 in the black population, 27.8 per 100,000 in the Hispanic population, 10.4 per 100,000 in the American Indian/Alaska Native population, 8.8 per 100,000 in the white population, and 7.4 per 100,000 in the Asian/ Pacific Islander population (Table 5b). • **Sex:** From 2001 through 2005, the estimated number of HIV/AIDS cases decreased approximately 1% among males and 19% among females. In 2005, males accounted for 73% of all HIV/AIDS cases among adults and adolescents. (2007: 6)

This kind of rendering of the U.S. epidemic parallels the same kind of work done by the statistics espoused by HIV/AIDS trainers in Miami.²³ Calculations shift from “rate of HIV/AIDS cases” to simply just “HIV/AIDS cases” to “percentages,” while notions of age group, race, ethnicity and sex are rendered calculable to even the most discrete categories (i.e. 13-14 [years of age]). These surveillance reports, rooted in social epidemiological thought and positivist methodologies, are devoted to establishing the chain of disease risk

causation from social environment, psychosocial influences, and biological pathways. Susan Leigh Star (1989) calls this a process of triangulation, where studies incorporate data from multiple domains to support a particular theory or hypothesis in order to reduce the accompanying uncertainty from the use of only one particular set of data. Janet Shim, echoing Star, states that triangulation has “several unintended yet important consequences: obscuring local uncertainties while emphasizing the ultimate ‘truth’ of a multifaceted model, and minimizing individual differences in favor of generalized, simplified findings” (2002: 138) Through triangulation, HIV/AIDS surveillance data translate structural and social inequalities into biomedical categories by first reducing broader forces and identities such as age, race, ethnicity, and gender into calculable variables, and then accepting as true that these discrete variables represent a “real” map estimate of the epidemic as a whole.

Furthermore, CDC surveillance reports are compiled from data spanning 33 states and 5 independent areas. Although all states have to report HIV/AIDS cases to the CDC, they have different methods of collecting and reporting this information. The CDC enables these kinds of temporally and metrically heterogeneous forms of data to appear standardized, having them emerge as seamlessly connected pieces of information when put together. But, as I will demonstrate in the next two sections, the practices through which state and local-level surveillance come to be standardized indicate messy and dense webs of circulation. Bowker and Star state that the process of building to a standardized code often includes the slippage between “the ideal standard and the contingencies of practice” and that the “practical use of standards frequently entail the use of ad hoc nonstandard categories” (1999: 15). They claim that this process involves the complicated negotiations between “builder(s) and inspector(s) which itself includes a history of relations between those people” (1999: 15).

I argue throughout the rest of the chapter, however, that the process of standardization-building in HIV/AIDS surveillance also involves the active and non-active participation of individuals and communities who are the objects of standardization themselves.

The Surveilling of Surveillance: Techno-politics of HIV/AIDS

A fundamental way in which the process of standardization is being implemented in Miami is through the technological changes mandated by the CDC to all publicly-funded HIV/AIDS surveillance programs. Program Evaluation and Monitoring System (PEMS) is one such technological change. PEMS is an internet browser-based program through which data entry and evaluation is conducted. The CDC purports that the PEMS system will allow for those funded through the CDC to collect information on various types of data including those at the agency, community planning, and programmatic levels. The second phase of PEMS was released in late 2005, and allowed health departments to collect client-level data for the CDC. According to the CDC, PEMS was designed to “ensure that CDC receives standardized, accurate, and thorough program data from health department and CBO grantees” (CDC 2006). Information such as agency information, program plan details, client demographics, referral outcomes, HIV test results, partner elicitation and notification, client use of services, behavioral outcomes, community planning, priority populations, and interventions are to be included. The CDC claims that this type of data collection will “help HIV prevention stakeholders examine program fidelity, monitor use of key program services and behavioral outcomes, and calculate and report the program performance indicators. PEMS will help CDC monitor, evaluate, and coordinate HIV prevention programs and support the rapid set-up of special studies and evaluation projects” (CDC 2006).

At the Miami DOH, however, PEMS was seen as another way that the changes in HIV/AIDS prevention at the national level did not reflect local realities. Joan Veracruz, a top official at the Miami DOH, explained her concerns and frustrations with the increasing level of restrictions placed on local DOHs by the CDC:

People's behaviors are hard to measure and the impact of our prevention efforts is therefore hard to measure. Another thing is that prevention is prescriptive. We get these things from the CDC saying "This is what you're going to do!" In the past, the educator had flexibility, they could have a say in the development of prevention programs. Now, it's more of a closed environment. The CDC has to come to Florida to do staff trainings now. The mentality now is that of quality assurance. Staff goes from being trainers to being facilitators. They guide discussions. This is one of the biggest challenges for them because one approach can't fit for everyone and we have to identify the perfect match.

So the process itself is the challenge. We have to adapt and tailor the ready-made programs to our target groups without taking too much away. We follow the DEBI system: Diffusion of Effective Behavioral Interventions. We didn't get training first, and we implemented it and then got training afterwards. There is even a new system by the CDC that's causing a lot of unhappiness and dissatisfaction. It is called the PEMS. It's a form of reporting that monitors the way we do education, outreach, and referrals. It requires that whenever we do education, outreach, or referrals, we have to do this system of reporting that asks a lot of information from clients. Well, the problem that the CDC doesn't understand is that often we do this in groups and these questions are very personal and ask a lot of sexual history and so forth. It really has to be done on a one-to-one basis and it isn't translated either.

I think we are missing the boat on behaviors. I think the problems are beyond behaviors. For instance, the priorities for the person might be different...the person beating me is also giving me food, clothes, a place to stay, and helps me take care of my children. She can't find a job or is making minimum wage, and unless we address these social issues that women and men like her face, we're not going to make a difference in Miami. The way that we do things now is that aggregate data points out the clients in need and the politicians want answers to see if behaviors are changing. This is the problem with public health. We don't have time or the money to really find out what is going on.

Ms. Veracruz's specific displeasure with the PEMS system was not isolated; it was a direct manifestation of ongoing changes at the national level which she felt did not translate to the populations in Miami. She felt strongly that these programs, in essence, are "interventions in

a box” that the CDC surmised could be just transplanted to any given group without taking the time with individuals and communities to adequately garner their needs and wants.

Although she indicates that there is a possibility of finding out the processes that are “really” going on, she postulates that they are indeed complicated and would need much time and effort to explore. Her discussion of the changing nature of the role of the educator or local interventionist, as exemplified in the next section, is worthy of note, especially because it seems as if PEMS itself is a tool with which the CDC monitors and scrutinizes local departments of health and their partnering organizations, along with the people they serve.

Are you a man, a woman, or both?: Lost in Translation

PEMS was not the only surveillance change being implemented in Miami. HIV/AIDS testing forms were also being restructured to aid in the standardization of HIV/AIDS surveillance. Dr. Ramon, a surveillance official and a colleague of Ms. Veracruz, informed me that these changes were necessary in order for the CDC to more effectively keep a “national database” in the face of diverse methods of data collection utilized by different states. She reasoned that this kind of statistical processing meant that it could be not only synthesized together as the same kinds of data, but also that diverse sets of data could be made comparable. When I inquired with another statistician working at the University of Miami (UM) as to how the process works, he just shrugged his shoulders, and suggested that I contact the CDC directly to find out. He declared that it was a “fragmented system” and that the process to “summarize data was difficult.” He continued by arguing that it is “really about getting people who are able to do the best job and to make sure that the methodology used is upheld by the validity of the conclusions. No data is perfect!” He emphasized that one should always consider the “competency” of the people collecting and

analyzing the data, because “sometimes emotional things interfere and people don’t do things objectively or sometimes data is used for political purposes easily.” He elaborated further, “Data isn’t always objective, and often people have an agenda to prove.” These two renderings of the circulation and processing of HIV/AIDS surveillance data indicate divergent but not contradictory views. The DOH official assumes that CDC data can and does represent a holistic picture of the epidemic even if it derives from different sets of data, while the researcher at UM portrays the system as “fragmented” and the resulting data as imperfect because of the individual actors involved. He argues that the “data isn’t always objective” because “people have an agenda to prove.” That is, if people with agendas were not involved, this data would be objective and would provide sound “conclusions” that directly represent the reality on the ground.

Both of these statisticians work with HIV/AIDS statistics in Florida. Florida is one of the 33 states that adhere to CDC’s recommendation of confidential name-based HIV/AIDS reporting. Since July 1997, every confirmed positive HIV/AIDS test has to be reported to the Florida Department of Health by laboratories and clinicians (Florida DOH 2003). The Florida DOH claims that “approximately 90% of all diagnosed HIV cases and AIDS cases are reported, which is the highest completeness rate of all diseases” (2005: 3). Likewise, at the Miami DOH, HIV/AIDS surveillance extends beyond the “reporting” of positive HIV cases and AIDS cases. Data is also gathered for all those who test for HIV. The state-run laboratory, through which all HIV antibody tests go, serves as a “safety net” and reports client information that goes unreported through doctors and clinics. The Miami DOH distinguishes between these two types of reporting as “active” surveillance (i.e. lab) and “passive” surveillance (i.e. physicians, clinics). Both kinds of surveillance may be

anonymous so that names or any other identifying information goes unreported to the state-wide database called HARS (HIV/AIDS REPORTING SYSTEM). At this level, any identifying information is removed and sent to the CDC by the Florida DOH. At a local DOH training, held in 2006, health workers were informed of a new surveillance system employed by the CDC called STARHS (Serological Testing Algorithm for Recent HIV Seroconversions). The new STARHS is meant to detect whether an individual was infected within the last year, and consists of both an additional test performed on the same blood specimen as well as additional questions on the testing questionnaire utilized to measure the approximate time of risk of exposure. STARHS has no known clinical utility because it is not accurate enough to provide results to individual clients but is considered useful at the population level to detect population-level incidence of HIV/AIDS.

During the course of my fieldwork, new HIV/AIDS testing questionnaires reflecting STARHS surveillance questions were beginning to be utilized. On first glance, the questionnaire seems to have only an added column for predicting the time of infection, specifically asking clients if any risk factors or sexual relations with those considered at high risk were during the “last 3 months.” But on closer inspection, it seems as though the “risk exposure/behaviors” section from the old intake form has been completely transformed. In the older questionnaire, a client was asked if they have had sex with a male or female and the counselor was to mark either yes, no or unknown on the form. In the new format, the counselor asks whether the client has ever or in the last three months had sex with a male, female, or a transgendered person. There is thus the addition of a new “sex” category and the removal of the unknown category. This theme of eliminating other “unknown” categories continues throughout the form. For instance, a whole new range of questions have been

added to the new questionnaire asking whether, in the past three months, one has been incarcerated (answer choices: yes/no), has been a sex worker (answer choices: yes/no/refused), or had a recent sexually transmitted disease that is not HIV (answer choices: yes, self-report/yes, lab confirmed/no/don't know). The most noticeable changes, however, are found among the questions relating to risk exposure through sexual relations. The older forms ask the client if they have had sexual relations with a) injecting drug user, b) man who has sex with men, c) hemophiliac/blood recipient and d) someone with HIV/AIDS, risk not specified. The new forms, on the other hand, ask a series of ten questions both about the individual client's "risky" behavior while having sexual relations as well as that of their partner. Clients are asked if they have had sexual relations:

- a. in exchange: sex for drugs/money/other items
- b. while high on drugs
- c. with person who is an IDU
- d. with person who is HIV positive
- e. with person of unknown HIV status
- f. with person who exchanges sex for drugs/money/other items
- g. with person who is a known MSM (female only)
- h. with anonymous partner
- i. with person who has transfusions/transplant recipient
- j. no additional risk or partner information available

In addition, the person administering the questionnaire also has to ask whether any of these situations occurred during the last three months or ever at all. These questions are different from the previous form because they aim to elicit more specific information about behavior deemed "risky" such as drug use, anonymous and multiple-partner sex, and same-sex partners. Although these questions are more explicit and detailed, they still categorize "risky" behavior within the existing parameters of "high-risk" behaviors leading to HIV/AIDS infection including drug use, men having sex with men, and blood transfusion.

At Santè Ayisyen, a small Haitian clinic where I conducted fieldwork, these questionnaires began to be utilized in March 2006. Jerome, the main HIV/AIDS counselor, was a little annoyed about using them for the first time, mainly because they contained additional questions and he felt that he was already overworked and underpaid to have to translate even more questions on the spot without training. When I commented that I was excited to see him translate the new form, he managed a weak smile and rolled his eyes, retorting “M gen pa choix!” (I don’t have a choice!). During that day, the first client to come in and get tested was a tiny older woman who remained quiet throughout the testing session. Jerome explained the process of taking the test and about the confidentiality of the information. As he was filling out the top portion of the new form, the woman asked in Kreyòl “If one were to get SIDA,²⁴ what would happen?” Jerome looked up in surprise and said that they would go over all of it. He then went over the different tests and information about how HIV/AIDS was transmitted, along with the processes that he was mandated to follow if a client tested positive. The client nodded her head quietly throughout all of it, sometimes staring off into space. He then began to ask the questions on the new form. After obtaining information about her previous testing history, he asked whether she was male, female or both and she said “Comment?” (Come again?). She giggled nervously and looked at me as if I could offer an explanation as a woman. But Jerome didn’t crack a smile; instead, he remarked dryly that “There are people who change from one sex to another.” She responded simply by saying “female.”

He moved onto the questions about risk transmission. He often looked confused as to what to mark and the session took him a long time to complete mostly because he was translating as he was going along as there were no instructions or training as to how to

administer the questionnaire in Kreyòl. He asked if she slept “with men, women, or both,” and she answered “man and woman,” meaning that the nature of her sexual relationships is between a man and a woman. Jerome, however, looked up suddenly and uttered “What? You sleep with men and women?” The woman looked confused, then giggled nervously for a few seconds and said “No. No. What? I sleep with men only! What kind of question is this?” Jerome ignored her by silently marking the answer. Jerome then interpreted the question “Are you a sex worker?” as “Are you someone who has sex for money or other things?” The woman responded by saying again, “What? Uh-uh” indicating that the answer was no and then giggled. She then answered the other questions without any further comments or giggles.

The new questionnaire, in the context of this Haitian clinic, exemplified the complex translations (literal and otherwise) that are often negotiated between counselors and clients. Jerome was forced to translate, without any training, the questions to accommodate not only another language, but also different ways of understanding sexuality, gender, and risk. The client seemed confused and at times, outraged, about questions related to “transgendered” individuals and same-sex partners; more importantly, she was unable to have her questions answered adequately or in a manner that made her any more comfortable in the situation.

Hazardous Terrains: Frameworks of Risk

These changes to the testing questionnaire come on the heel of sharp criticisms directed at the way in which the CDC collects data with regards to “risk factors.” Since the beginning of the pandemic, the CDC has been tracking modes of exposure to HIV/AIDS, linking them to both behaviors and groups deemed “high-risk.” Even though an individual can be exposed to multiple risks for HIV/AIDS, surveillance records allow for only a single

categorization.²⁵ The CDC has employed a hierarchy of these risk factors since 1986, based on “the probability of transmission per act as well as the prevalence of infection among persons engaging in these behaviors” (McDavid and McKenna 2006: 287). Male-to-male sexual contact is at the top of the hierarchy (MSM), followed by injection drug use (IDU), MSM and IDU, heterosexual contact with an individual with HIV/AIDS or at high-risk for HIV/AIDS, and other. Thus, if a person is noted by a HIV/AIDS counselor as an intravenous drug user who has heterosexual sex with someone who has HIV/AIDS, the person will be classified as having an IDU risk category. Many scholars and advocates have called for the removal or the reformulation of such a hierarchy in order to understand the increasing impact of the epidemic amongst women and minority populations who often are captured in either the heterosexual or other categories (Hader et al. 2001; Espinoza et al. 2007; Mokotoff et al. 2007; National Women and AIDS Collective 2006). Because risk factor information is utilized in the distribution of federal, state, and local funds for HIV/AIDS prevention, advocates argue that much needed prevention and intervention efforts in these communities are lacking or even non-existent (McDavid and McKenna 2006).

As these debates demonstrate, the concept of risk is a highly prolific but contested categorization in the field of HIV/AIDS. Scholars in the social sciences have come to understand the concept of risk in biomedicine and other fields through three dominant frameworks (Lupton 1999b). The first is a cultural symbolic approach, originated by Mary Douglas (1966, 1968, Douglas and Wildavsky 1982), in which risk is viewed as a trope of blame and those at risk deemed dangerous. In this functional model, notions of risk are circulated through cultural mediums, and are seen as shared values which serve to uphold existing social structures. A second approach to the study of risk is informed by the concept

of “risk society,” most notably elaborated by Beck (1992) and Giddens (1999). Central to their analyses is the notion that in late modernity, a fundamental aspect of society is its self-reflexivity and its criticisms of the processes of modernity, which are no longer seen to produce goods but rather the dangers which make us feel vulnerable. Government, science, and industry, the core institutions integral to the functioning of late modernity, are understood to produce and propagate these notions of danger and risk. The importance of risk becomes fundamental to a self-reflective society. In addition, these theorists argue that there is a movement toward individualization in late modernity in which the production and management of risk become realized as a human responsibility rather than as a consequence of chance or destiny. The final perspective on risk builds from Foucault’s (1979) notion of governmentality, in which risk is one of the myriad of governmental strategies of disciplinary power utilized to monitor and administer populations and individuals. Risk, in this view, also gets deployed at the level of individual technologies of the self where the onus is on the self-management of risk and the increasing privatization of risk (Lupton 1999).

Although all three frameworks are important to understanding the concept of risk, many scholars have used the third perspective to frame recent shifts in the ways that we have come to conceive of health and illness. Adele Clarke and colleagues (2003) posit these transformations as those that have gone from focusing on the definition, diagnosis, categorization, and treatment of illness and disease to those which concentrate on risks and the commodification of life itself. Likewise, some scholars have argued that these larger movements are related to the proliferation of expert knowledge and normalizing techniques and practices. Deborah Lupton, for instance, attests that “Risk is understood as one of the heterogeneous governmental strategies of disciplinary power by which populations and

individuals are monitored and managed so as to best meet the goals of democratic humanism...to be designated as 'at risk,' therefore, is to be positioned within a network of factors drawn from the observation of others" (1999: 5). The implication here is that risk is ultimately controllable, as long as expert knowledge and self-governance are able to appropriately manage it.

Others scholars have argued that these transformations in governance are being created and sustained not just from the so-called experts but also from lay individuals (Clarke et al. 2003; Thompson 2005). Thompson, for instance, describes individuals and couples utilizing artificial reproductive technologies as people who, at certain times, actively seek out commodification and objectification of their bodies "both to have access to treatment and also to be biologically essentialized to individual, race, or nation in contesting or creating kinship" (2005: 275). Clarke and colleagues state that "The focus is no longer on illness, disability, and disease as matters of fate, but on health as a matter of ongoing moral self-transformation...Terms such as 'health maintenance,' 'health promotion,' and 'healthy living' highlight the mandate for work and attention toward attaining and maintaining health" (2003: 172). Individuals increasingly not only become, but want to be held accountable for their bodies, health, and well-being. Health becomes something to continually strive for, and the maintenance of optimal health constitutes an individual responsibility.

In the field of HIV/AIDS prevention and intervention, I also find that the third perspective, concentrating on the configurations of governmental strategies, most salient for understanding official and everyday conceptualizations of risk and numbers. Although I agree with these scholars in the conception of such relatively recent transformations of both subjectivities and governance of life itself, I also find that these broad analyses do not

translate neatly at the level of situated experience for many Haitians living in Miami. Certainly, in HIV/AIDS research and surveillance, the concept of risk has moved away from notions of social insurance as a means of distributing risk to that which focuses on the self-management of risk. However, in Miami, these formulations exist alongside and sometimes in contention with new (and old) articulations of targeted surveillance and testing based exclusively on behavior and categories race and gender which seem firmly rooted in biomedical discourses and practices.

Therefore, I contend that conceptualizing risk in HIV/AIDS prevention as a boundary object (Star and Griesemer 1989; Bowker and Star 1999; Shim 2002) is a useful way to add to these broader discussions of risk. Bowker and Star argue:

Boundary objects are those objects that both inhabit several communities of practice and satisfy the informational requirements of each of them. Boundary objects are thus both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites...The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting communities. (1999: 297)

As I will show in the rest of the chapter, the notion of risk is durable enough to circulate between public health institutions such as the CDC, experts such as researchers, clinicians, and HIV/AIDS counselors, and patient consumers. But it is also ambiguous enough to be the object of diverse, and at times, conflicting meanings. The notion of risk in HIV/AIDS prevention is diffusely and weakly structured in common use, but achieves more robust configurations in specific sites such as DOH risk literature, HIV/AIDS counselor trainings, and daily conversations of Haitian clients. Notions and significances of “risk” are multiple in HIV/AIDS prevention and intervention and mean different things to different constituents involved, but risk, as a boundary object, has the ability to orchestrate itself across this difference without requiring considerable conceptual or methodological agreement.

The Birth of a Risk Category: Operationalizing Risk in HIV/AIDS Prevention

Because boundary objects are loosely structured and, therefore, unpredictable and even contradictory, risk as a site of analysis provides a concrete way to study friction between enumeration and the categories they produce (cf. Tsing 2004). A fundamental component of the debate over HIV/AIDS risk is the changes taking place among transmission categories the CDC currently labels as “high risk heterosexual contact” and “no identified risk (NIR).” As stated previously, due to the changes to the 1993 case surveillance methods²⁶ and definition²⁷ of HIV/AIDS, there had been not only a sharp increase in the incidence and prevalence rates of HIV/AIDS, but also a marked rise in numbers of these two categories (Hammett et al. 1997; Haverkos and Chung 2001). A majority of cases in the NIR category are either reassigned to existing risk categories or remain without a risk category after health department surveillance follow-ups, while others are reclassified using a standard reporting delay adjustment weight²⁸ “according to the distribution appropriate for the sex and race/ethnicity of the case” (Green 1998: 146). A number of critics argue that these statistical adjustments utilized to reallocate NIR cases are faulty because they presume that the distribution of NIRs do not change over time and those NIR cases that are reclassified are representative of all NIR cases (McDavid and McKenna 2006). A surveillance official for Miami DOH corroborated this story. He told me that a few years ago, the rates for the NIR category were very high, so much so that he got enough money to hire two full time people to reclassify these cases by going back in the records to “figure out” the transmission mode, either through statistical recalibrations or through medical and testing records, resulting in lower numbers for the category.

These issues are pertinent to the ways in which HIV positive Haitians in Miami are documented in HIV surveillance reports because most Haitians fall under either the NIR or “high risk heterosexual contact” categories. According to the Florida DOH, with the NIR cases redistributed:

The major mode of transmission for cumulative adult HIV/AIDS cases in Haitians was through heterosexual contact (78%) while men who have sex with men accounted for 17% and injecting drug users 4%. Other risks, such as transfusions, hemophilia and mother with HIV+ status, accounted for 1% of the cases reported in Haitians” (Florida DOH 2006).

The redistribution of NIR cases like those for Haitians in both state and national surveillance reports have resulted in very similar outcomes: an inflation of numbers under the “high risk heterosexual” category. Over the past few years, the subject of the heterosexual risk category has elicited a number of debates over the ways in which the categorization itself obscures the rising rates of infection among women and minority populations (Zierler and Krieger 1997; Smith and Payne 1998; Treichler 1999; Dworkin 2005; NWAD 2007). In 1989, the CDC stated that 4% of all HIV/AIDS cases were attributable to heterosexual transmission and since 1986, the number of people who were reported to have sexual partners “at risk” outnumbered those who were born in countries with large heterosexual HIV transmission rates, meaning that the cases of heterosexual transmission from those infected in the United States were on the rise (CDC 1989: 423). In 1994, just a few years later, the CDC noted that cases attributed to heterosexual transmission had jumped to 9%, over a twofold increase (CDC 1994a; CDC 1994b). This report came at the heels of the changes made in 1993 to HIV/AIDS surveillance definitions and reporting, which included the addition of three new opportunistic infections including cervical cancer and tuberculosis and paralleled the rise in numbers of those identified as Black, Hispanic, and women.

Although the CDC had reported on heterosexual transmissions from the beginning of the epidemic, HIV/AIDS reports on heterosexual transmission, along with the increases in minority populations and females noticeably proliferated after 1993. Other researchers also warned of the “emerging heterosexual AIDS epidemic” (Klevens et al. 1998: 80) and the impending “epidemiological shift” (Hader et al. 2001: 1187) when analyzing surveillance data after 1993, often without serious reflections of the ways in which the 1993 CDC HIV/AIDS surveillance changes produced significant statistical increases in these groups that were always affected heavily but now began to be visible through the numbers. In fact, there has been a call for a separate “heterosexual” risk category altogether so that these cases do not get masked under the NIR category and then presumably get reclassified to existing risk categories (Smith and Payne 1998; NWAD 2007). There have been additional discussions surrounding the limits of the current surveillance system in indicating the numbers and rates of those infected through heterosexual transmission. Proponents, who assert that the surveillance system is flawed, argue that the presumed “heterosexual” transmission only captures those who are able to identify if their partner is considered as at risk by surveillance standards. That is, only those able to indicate that their sexual partner(s) is either MSM or IDU are presumed to be infected through heterosexual transmission (Smith and Payne 1998; NWAD 2007). Due to these limits, some scholars argue that the addition of an official “heterosexual” category will only recreate singular conceptions of risk rather than a better understanding of how individuals and groups are left vulnerable through a variety of economical, political, and social positions (Zierler and Krieger 1997; Dworkin 2005).

Despite these growing criticisms, the CDC and numerous public health researchers continue to present the rising rates of NIRs as a problem of “poor risk factor ascertainment”

and are currently working toward improving these methods through “scientifically designed projects” (McDavid and McKenna 2006: 289-91). The quantification of heterosexual transmission (and HIV transmission in general) is emblematic of what Mary Poovey (1999) calls a modern fact, where knowledge about transmission consists simultaneously of a numerical description treated as an objective representation of reality as well as the theoretical claims of what is counted and of how to understand the material reality of transmission. In the case of increasing NIRs, stark deviations from the numerical accuracy of HIV/AIDS surveillance and transmission determination seem to signify that the problem lies with the collection, analysis, and presentation of data. Epistemological ambiguities presented by the NIR category and heterosexual transmission are construed as debates over clinical and epidemiological methodology. That is, the CDC continues to conceive of the rising numbers of those who do not fit neatly within existing risk categories as a result of insufficient or inadequate data collection and disclosure, and seek to resolve these issues through more efficient surveillance and data redistribution rather than re-conceptualizing the methods through which surveillance takes place and the resulting categories that it produces. In this way, focusing attention on methods (i.e. how to count and classify) shifts the onus from concentrating on broader questions of the uncertainties of knowledge production (i.e. why count and classify) and in the process, enables different sets of data to be coordinated without insurmountable barriers (Star 1989; Star and Griesemer 1989; Shim 2002).

In Florida and subsequently in Miami, growing numbers of NIRs are indeed considered a “problem” (Florida DOH 2005a, 2006). At the end of 2005, Florida DOH reported that the state had higher percentages of heterosexual and NIR cases and lower MSM and IDU cases as compared to the United States as a whole (Florida DOH 2005a, 2006).

Much like the national surveillance data, there is a strong push at the state level to redistribute NIRs. In Florida, this consists of alerting providers to better ascertain risk, assigning NIR coordinators to follow up with NIR cases, and statistically redistributing NIR cases to existing risk categories (Florida DOH 2006). Ultimately, reducing NIR percentages is considered a mark of “success” (Florida DOH 2006).

A high percentage of NIRs in Florida consists of those who were born in Haiti, and Florida is one of the few states that documents HIV/AIDS surveillance amongst its foreign-born population. In HIV/AIDS surveillance forms utilized in Florida, Haitians are recorded as “Haitians” only if they were born in Haiti; otherwise, they are recorded as “Black/African-American.” When I questioned a surveillance manager about this particular way of counting Haitians, it took about 10 minutes for her to acknowledge that only those born in Haiti were being counted as Haitians in official reports. In addition, when I asked why heterosexual transmission (at 36%) is presented as “the major mode of transmission,” when NIR cases accounted for 52% in a 2003 report (Florida DOH 2003), she stated that I was being too “picky” and that the “major” mode was meant to indicate a “known” transmission mode. In other words, heterosexual transmission was the higher mode of transmission since NIR was not known. To officially report NIR as the most frequent mode of transmission in Florida would have meant an admittance of both epistemological and epidemiological uncertainties.

At the end of an intense hour-long conversation, this surveillance manager’s voice became highly elevated and she ended our conversation curtly by saying:

I talk to many people, even the media, and I am really worried about the way that people use numbers without understanding them, and twist numbers to fit their purposes. I worry about this a lot and am concerned because I take so much time and effort to explain how data is gathered and they just take it and used it in an inappropriate way.

The rise in her tone of voice and her response seemed to indicate that she was highly defensive in answering my questions concerning how certain people were being counted. Even though most of her answers about the ways in which data were presented in reports, specifically about Haitians, reflected the need to manipulate both the collection and presentation of high case rates deliberately, her refusals to clarify the ambiguities of such processes highlight the enormous stakes involved in keeping these statistics decontextualized from the multiple conditions which give rise to them (Bowker and Star 1999; Briggs and Mantini-Briggs 2003). To acknowledge that such counts of Haitians are an irregularity or that presentations of heterosexual transmission as the major mode of HIV/AIDS transmission are deviations would have been, as Briggs and Mantini-Briggs state, “an invitation to reproduce the conditions that rendered these numbers problematic” (2003: 267). Instead, it takes much less effort to translate my questions as misunderstandings of statistics and the surveillance method itself.

Counting Haitians and the elevated positioning of heterosexual transmission are growing topics of contention in Miami. Although those born in Haiti represent the highest percentage of foreign-born Blacks living with HIV/AIDS and the second highest percentage of the overall Black population living with HIV/AIDS in Florida (Florida DOH 2005b), there is currently no active HIV/AIDS prevention or intervention program that specifically focuses on the Haitian population in Florida. Many providers and DOH officials are caught between being acutely aware of the multiple needs among Haitians living in Florida and the ambiguous nature of the ways in which Haitians are positioned within surveillance data. For instance, a prevention official declared, “Our surveillance reports are our first big Bible. It

gives us locations to go to; it gives us a good heads up.” Ms. Veracruz, the DOH official explained:

There are priority groups which are determined by our surveillance department and then the strategic planning committee votes on groups. It’s actually a complicated process where we have all these sheets and we have to check off certain groups based on the evidence. I then take these groups and ensure that what is written gets carried out, and I assign staff to these target groups.

She listed the current groups in order of priority for the county as 1) Hispanic MSM, 2) Hispanic heterosexual women, 3) Black heterosexual men and women, and 4) IDUs regardless of race. She also explained that there were currently seven community-based organizations receiving federal funds from the county. Out of these seven organizations, none focused on heterosexuals in particular, whereas three focused on MSM. Additionally, even though two of the organizations were specifically targeting Hispanic MSM (a third targeted HIV positive MSM), surveillance reports estimate that 1 in 12 Black MSM are HIV positive while 1 in 18 Hispanic MSM are HIV positive (Florida DOH 2006b). When I asked her about the high numbers of Haitians living with HIV/AIDS and the lack of programs for them, to my surprise, she agreed with me. But, she placed the blame on the lack of state and county funding which did not enable her to divert money to more groups based on categories of race, ethnicity, and behavior. She stated:

I think in terms of surveillance data, we need to be more targeted. They classify them as Whites, Blacks or Hispanics but there are many groups under these categories that we don’t know if they are being affected. Zip codes are another way that we determined who is at need. It’s not about race but the social environment. We need to further pinpoint high risk groups like Haitians or African Americans. We try to implement programs in specific target areas for target groups in areas in need. We still need more of course. Right now, we have 2 programs for Hispanics, 3 for MSM, 2 counseling and testing but we don’t have anything targeting Haitians.

Again, for her as well as other health officials, solutions do not lie in the mistranslations between needy communities as determined by local surveillance statistics and those

determined by committees with allegiances to various community constituents. Rather, solutions can only come from further expansion of surveillance methods.

On the other hand, many providers, administrators, and officials working with Haitians, especially those within Haitian community organizations, were producing discourses of discontent about the lack of money and development of programs. Dr. Charles, one of the directors of the Haitian community organization where I conducted fieldwork, told me that they, like other organizations catering to Haitians, had to eliminate HIV/AIDS prevention and support programs due to a lack of both public and private funding. He spoke further about the dire situations that he and other leaders faced:

Dr. Charles: What happens sometimes is the resources are not distributed the way that they should. Politics has something to do with it. Politics definitely has something to do with it. Resources based on surveillance data.... I don't know about that. You see a lot of resources for example in South Beach. Yes, the surveillance data shows that there is a high rate there but what happens also is that the people from South Beach, most of them are white, gay people who are educated people that put pressure on the system. Yes, you do have resources located, resources applied to African American communities, and that's much much better than it was twenty years ago or fifteen years ago. But I don't see that in the Haitian community. I DON'T REALLY SEE that improvement in terms of services and things like that in the Haitian community per se.

TS: Why do you think that is?

Dr. Charles: I don't know. I don't know. Maybe politics, maybe because there is not that many people who advocate for the Haitian community. There are more Haitians even in healthcare but I still am not satisfied with the level of health resources placed in the Haitian community. That makes accessibility more difficult. You don't have a center in this area, so they're supposed to have to travel to get the services. And they don't have cars. And the system, the public transportation system is horrible. So these are the main issues.

Dr. Charles and many others often had to negotiate between using surveillance statistics to point out the enormous need for HIV/AIDS resources in the Haitian community and highlighting the ineffective impact of those same statistics in garnering them financial and

programmatic benefits. In these types of discourses, official conceptions of surveillance data as “Bible,” as text reflecting reality, was nothing more than politics in action, reflective of broader undercurrents of social and economic injustices existing in Miami. In fact, even though Dr. Charles’ organization was one that was highly regarded amongst HIV/AIDS activists and academics, a few months after I left Miami in August 2006, their medical clinic closed and their HIV/AIDS social services system was shut down due to a lack of funding and political fallout.²⁹ Similarly, another pivotal community based organization which offered services to Haitians was in a state of crisis after its building suffered irreparable damage from Hurricane Rita, and had to scramble to relocate and re-establish itself without much financial or logistical support. These instances are common, and reflect the widely unstable and precarious realities of both individual Haitians and organizations catering to Haitians in Miami.

Do You Love Yourself More than He Loves You?: Risk and Subjectivity

Statistical enumerations and categories of risk circulate not only between actors such as public health agencies, federal and state level departments of health, scientific and medical communities, activist groups, and community based associations, they also emerge in everyday conversations among individual clients who interface with the HIV/AIDS system in Miami. These clients are consistently inundated not only with numbers which relay HIV/AIDS rates of prevalence and incidence, but also those which represent the state of their health or risk of infection. They, like many consumers of health care, are encouraged and expected to have a working understanding of key numbers and risk classifications so that they are able to achieve a kind of “literacy” when it comes to managing their own health and

well being. In many ways, statistical data are used “as the necessary foundation for other knowledge” (Treichler 1999: 110), and they underpin ways of understanding self and other in the discourses and practices surrounding HIV/AIDS in Miami. This section observes the multiple and overlapping ways in which numbers and statistics produce and manage categories of personal and group level risk.

How are we to consider the associations between standardized classifications such as “risk groups” in HIV/AIDS research and the ways in which people categorize themselves, such as the woman declaring her CD4 and T-cell counts in the opening vignette? Ian Hacking maintains that an interesting and unexpected aspect of enumeration is the way it subversively creates and maintains classificatory labels. He states, “Enumeration demands kinds of things or people to count. Counting is hungry for categories. Many of the categories we now use to describe people are byproducts of the needs of enumeration” (Hacking 1982: 280). Furthermore, he argues that the process of “making up people” is doubly linked to control and is of recent derivation as these categories of people and things shifted from the bureaucratic realm of largely undisclosed information to the domain of public knowledge (Hacking 1986: 226). However, the mere labeling of people does not entirely create or condition the social reality of individuals and collectivities because it is only one constituent piece of the constitution of the subject (Hacking 1986). Similarly, Bowker and Star assert that “In the process of making people and categories converge, there can be tremendous torque of individual biographies” (1999: 224-25). I illustrate in this section that it is not solely governmental and other experts who forge a “reality” of risk that then becomes adopted by lay individuals. There are myriad of ways that people are made

through classifications of risk, and as new categories of HIV/AIDS risk come into being, new possibilities for action are also being constituted.

As demonstrated throughout this chapter, overlapping terms such as risk, at risk, risk factor, risk behaviors, and risk groups are often undefined, undifferentiated, and unquestioned in official discourses of HIV/AIDS. For instance, in a recent CDC report on national estimates of risk, the concept of risk is perceived as self-evident (Anderson et al. 2006). In a discussion of the methodologies utilized in the measurement of risk, the authors state:

The risk categories used in this report are based on known HIV transmission routes and epidemiologic studies. The behaviors used here to define increased risk are based on the HIV/AIDS Reporting System (HARS), which defines a route of transmission for each case of HIV and AIDS. HARS defines transmission in terms of broad categories (male-to-male sexual contact, injection drug use, heterosexual contact) and not specific acts; the HARS procedure has been followed in this report. (Anderson et al. 2006: 4)

These claims exemplify the ways in which the concept of risk and its derivatives are utilized in discourses surrounding HIV/AIDS. First, without a clear definition of the concept of risk, the authors assume that risk, like transmission, can be categorized. Second, they state that behaviors used to define risk are “based on” presumed transmission categories assessed by HARS and previous studies of HIV/AIDS. But the underlying presumption is that the concept of risk comes to stand in for behaviors which increase an individual’s chances of contracting HIV/AIDS (i.e. “male-to male sexual contact, injection drug use, heterosexual contact). Thus, even though the assumption is that heterosexual contact is a behavior practiced by many and is only considered a risk for exposure to HIV/AIDS in certain circumstances such as having multiple concurrent sex partners, the behavior itself becomes indistinguishable from risk. The notion of risk is highly ambiguous: it is a group of

behaviors that contribute to increased exposure to HIV/AIDS, stands in for the behaviors themselves, or could be conceptualized as something else entirely.

There is also a high level of uncertainty as to whether it is individuals or their behavior that is surmised as risk. In the methodology section of the same report, the authors continue to explain the ways in which risk is measured:

In 2003, 45 percent of new cases of HIV and AIDS reported to CDC were to men who had sex with men (MSM), 19 percent to injecting drug users, and 34 percent were accounted for by heterosexual contact. Based on this, injecting drug use and male-to-male sex in the previous year have been used to define respondents as being at increased HIV risk. (Anderson et al 2006: 2)

Reportable cases to the CDC are categorized as clusters of individuals, grouped together on the basis of what they do or what they have done at one point in their lives. The authors take a category composed of a group of people that have been labeled as “MSM,” extract the sole behavioral factor (male-to-male sexual contact) that is used to construct, and therefore, define its existence in the first place, and use it to classify those in the study as being “at increased HIV risk.” Again, grouping individuals based on one characteristic behavior and moving fluidly between groups of people and behaviors in defining risk makes more evident the indefinite nature of how risk is conceptualized and utilized.

This kind of flexible quality that risk embodies in official reports becomes obscured in local settings, where the notion of risk becomes a dynamic and forceful means through which HIV/AIDS experts construct clients and clients interpellate themselves to HIV/AIDS prevention goals. In DOH trainings for HIV/AIDS counselors in Miami-Dade county, for instance, the goal of prevention counseling is outlined as “to support individuals in making behavior changes that will reduce their risk of acquiring or transmitting HIV” (Bureau of HIV/AIDS 2005: pp II-A-21). The standards that are taught to counselors are those

established by the CDC, and include “Counseling Model of Behavior Change” which is used to illustrate the ways in which counselors should personalize behavior change for their clients. This model is rooted in the premise that “ownership of undesirable behavior” must occur before behavior change can be initiated. Thus, counselors are taught that in order to “influence” a client to “change their behavior,” they must induce their clients to “personalize the risk.” Although the concept of risk is not explicitly defined once in the more than 300 pages that make up the manual, there are instructions as to how to get clients to personalize his/her individual risks. They state:

A person who has multiple sex partners may not be aware that he/she is at risk of infection because of the common view that primarily homosexual men and injection drug users get HIV. Some who are at risk may even deny that risk. They may not believe information they hear regarding their risk or may ignore it. (Bureau of HIV/AIDS 2005: IIA, Page 23)

Risk, in these instances, is treated as existing within and outside the individual. It exists internally within an individual, alluding to an inherent state of vulnerability. It is also present out in the world, suggestive of individual exposure to an external danger or hazard. Thus, not only can one be at risk, that is, in a state where one is exposed to heightened probability of a hazard, but one can also possess risk herself. Risk exists as an inherent part of the individual and as something external to him or her. In order to be effective, counselors are told to persuade clients to personalize their risk by helping them take “ownership” of their risks. They are asked to transform clients’ conceptualizations from viewing risk as external to the self and outside the purview of one’s own actions to recognizing risk as part of the self and under “self-control.” HIV/AIDS counselors are taught to play a crucial role as experts in the mediation of risk, intervening at the level of the individual client and transforming perceptions of external risk into internal risk. Jerome from Santè Ayisyen, for example,

asked one of clients, Lourdes, to take the free condoms that he usually offers at the end of a HIV/AIDS testing session. Lourdes, like many other Haitian clients, politely refused.

Jerome was persistent, and began to ask questions about her contraceptive usage:

Jerome: Well how do you protect yourself from pregnancy?

Lourdes: I've been married for 11 years with my husband. He lives in the Bahamas and visits me monthly here.

Jerome: Well, do you know if he's being faithful?

Lourdes: He has another woman there in the Bahamas. I'm OK with the situation.

Jerome: Do you love yourself more than he loves you?

Lourdes: Yes.

Jerome: You have to take care of yourself. It's important to talk to your husband about protection especially if he is sleeping with this other woman.

Lourdes was still hesitant, as she kept rubbing her thighs with her palms for a minute or two, but she eventually seemed to warm up to the idea, taking not only the male condoms offered, but also asking for female condoms that Jerome had stashed away in his desk drawers.

Jerome, in his role as counselor, seemingly altered Lourdes' perception of her risk for HIV/AIDS in this interaction, at least enough to take the condoms offered (male) and not offered (female). By asking her "Do you love yourself more than he loves you?" Jerome is able to impress upon her that the onus of risk exists as part of her sense of self, rather than as an embodiment of her husband's other relationship, and therefore, the notion that only she is able to intervene on her behalf.

Some People are More at Risk than Others: Interconnections of Race and Culture

As demonstrated in the previous sections, risk is both fluid and situationally grounded in HIV/AIDS prevention. These dual characteristics of risk serve to naturalize their associations with race and ethnicity. In the same aforementioned 2006 report, the CDC advances implicit but self-evidentiary relations between risk, race, and ethnicity. The

authors' discuss distinctive factors such as gender, race and ethnicity and education levels, labeled as "demographic" in this report, and then summarize findings according to standardized racial and ethnic groups by stating:

Overall measures of HIV risk vary greatly by race and ethnic group. Among Hispanics, 14.8 percent reported HIV risk behavior or STD treatment in the past year. The percentage at behavioral risk of HIV among non-Hispanic white persons was 9.7 percent and among non-Hispanic black persons, 20.4 percent. This is consistent with findings that Hispanic and non-Hispanic black persons have higher rates of HIV and AIDS cases in disease surveillance data. (Anderson et al 2006: 6)

They indicate that measures of HIV/AIDS risk vary by pre-determined indicators such as race and ethnicity. They also state that because this is a survey based on self-reporting, that among those who self-identified as Hispanic, "14.8 percent reported HIV risk behavior or STD treatment." On the other hand, those who self-identified as non-Hispanic white and as non-Hispanic black are considered 9.7 and 20.4 (respectively) percentages "at behavioral risk of HIV." The concepts of *reporting* HIV/AIDS risk behavior and *being at* behavioral risk of HIV/AIDS are not necessarily the same, even though they are presumed to be interchangeable in this case. The difference here is that the former indicates that a certain percentage of Hispanics are giving self-accounts of behavior considered risky, while particular percentages of blacks and whites are assumed to be inherently in a state of behavioral risk for HIV/AIDS. The discursive move from "reporting risk behavior" to "at behavioral risk," although done without much reflection, foregrounds the fundamental analysis of the report: that some groups of people "have" higher rates of behavioral risk and, therefore, HIV/AIDS cases. Even though behavioral risk for each racial and ethnic group is calculated as a percentage of each group individually while rates of HIV/AIDS cases are calculated as between all those who have HIV/AIDS regardless of their racial and ethnic classification, behavioral risk is represented as directly proportional to HIV/AIDS rates and

the relationship between behavioral risk and HIV/AIDS rates becomes naturalized.³⁰ As relations between risk, race, and ethnicity come to be interconnected in these official reports, elevated rates of behavioral risk and rising HIV/AIDS cases become implicitly associated with particular racial and ethnic groups.

These kinds of connections between behavioral risk and high risk groups serve to disseminate ideological constructions of racial and medical knowledge in the field of HIV/AIDS prevention. So when Karrie, a veteran instructor who works on many HIV/AIDS prevention projects in the African-American community and identified herself to me as “a Black woman who wants to give back to her community,” declared to her class that “It’s just the way it is. Maybe it’s due to some predisposition that we have or due to social isolation and discrimination” when discussing why African-Americans are affected so much more than other groups, no one questioned her remarks and some even nodded in agreement. For Karrie, and for us in the audience, the relations between risk, race, and ethnicity have lost what Bowker and Star call their “anthropological strangeness” (1999: 299). In describing how naturalized objects maintain their relations of power, Bowker and Star state, “The more naturalized an object becomes, the more unquestioning the relationship of the community to it; the more invisible the contingent and historical circumstances of its birth, the more it sinks into the community’s routinely forgotten memory” (1999: 299). The relationship between risk, race, and ethnicity has not only taken root in popular imaginaries, it is also grounded in official narratives of HIV/AIDS. For instance, the CDC (2007), in its most recent fact sheet about African Americans and HIV/AIDS, states:

Race and ethnicity, by themselves, are not risk factors for HIV infection...Blacks are also more likely to face challenges associated with risk factors for HIV infection, including the following...sexual risk factors, substance abuse, lack of awareness of

HIV serostatus, sexually transmitted disease, homophobia and concealment of homosexual behavior, and socioeconomic issues. (2007:3)

The official stance, therefore, is that race and ethnicity are not related to HIV/AIDS per se but serve as proxies for HIV/AIDS risk, when combined with factors often attributed to cultural logic such as substance abuse and homophobia. This positioning gives rise to uncontested discussions of racial demographics of HIV/AIDS which indicate disproportionate numbers of African-Americans affected by the disease.

Such linkages become more firmly rooted through the production and validation of expertise in HIV/AIDS. Everyday discourses of HIV/AIDS institutional experts exemplify how such forms of logic operate and circulate in Miami. Almost every single person that I had contact with during fieldwork, both providers and clients, when asked if there were certain groups which were more or less likely to be susceptible, vulnerable or at risk for HIV/AIDS, asserted that everyone was at risk. A DOH official, for instance, told me “I think pretty much anyone. I don’t think that it just targets the unfortunate. HIV/AIDS is about individual behaviors and so really, anyone can get it.” Later in the conversation, she stated:

Lifestyle has a lot to do with it. I don’t think it has anything to do with being African-American. But with Haitians, you don’t really find that they have HIV because of drugs. It just has to do with getting it sexually and having sex. African-Americans I feel get it because of risk behaviors as far as drugs and alcohol, that’s what I think. I don’t think that African-American numbers are high because they’re just promiscuous. I think it’s mainly because of drugs, alcohol. Plus Haitians don’t get it because of drugs. I’m not saying that they’re exempt from drugs, but they don’t generally...I mean all these clients that come here, they become positive, they’re like housewives and stuff, you know, and their men are having a lot of sex with different women, you know...so.

She was not alone in her vacillation between the assertion that race and ethnicity does not equate to risk for HIV/AIDS and the linkages made between race, ethnicity, and behaviors

considered as increasing risk for HIV/AIDS. Another high level administrator confided that race and ethnicity were definitely not associated with risk of HIV/AIDS, but then stated:

I think that saying something like certain races are more at risk like that is purely political. I think in terms of African-Americans, the main thing is drugs. This is a huge drug center. There is what is called “drug holes” where drug use and drug deals are very prevalent. This is a big factor. They need to satisfy the great desire of addiction and drugs, and so they are willing to do whatever because they need to have the drugs. I think that discrimination is also part of it. I mean whites are having the same risk factors such as poverty and drug use but these are the issues that come up only for blacks.

Even though many providers and administrative officials said that everyone was at equal risk of contracting HIV/AIDS, they often equated this risk with particular lifestyle choices most often associated with culture. Briggs and Mantini-Briggs (2003) argue that such kinds of cultural reasonings serve as key apparatuses in connecting concepts of race and disease. In their discussion of the cholera epidemic in the Delta Amacuro region of Venezuela, they assert that changes brought about by globalization have both jeopardized the legitimacy of governmental institutions as well as given them novel ways of managing their populations (Briggs and Mantini-Briggs 2003). Nikolas Rose (1999), in tracing the ongoing dissolution of the “social” configurations of governmental strategies, has argued similarly that the notion of the “social” was born in the 20th Century, changing the aims, objectives, and spaces of governmental interventions. The State became a guarantor of social progress for all and the maintainer of the well being of the population, fulfilling its responsibilities by striving to reduce the risks brought upon by unbridled economic activity to individuals and families by inciting all citizens to work toward this goal mutually through their own action (Rose 1999). He contends that today, however, this territory of the social government is being redesigned by means of “detotalization” of society (Rose 1999: 135). Concepts of multiculturalism, pluralism, and the rights and values of different communities underscore these changes as

individuals are becoming increasingly understood through their fidelity to particular types of community standards, rationalities, and commitments. These communities of identity are characterized by race, ethnicity, locale, lifestyle, sexuality, and moral and religious allegiances in which the individual is connected with a network of like-minded others. Issues become problematized through characteristics of communities, their cultures, and abnormalities. Thus, equating drug use and having multiple sex partners with HIV/AIDS risk while simultaneously placing them in the realm of culture serves to naturalize social and structural inequalities. This has the effects that Briggs and Mantini-Briggs describe:

When the concept of culture is used to characterize racialized populations, its capacity to essentialize, exoticize, totalize, and dehistoricize is powerfully unleashed, reducing complex social phenomena to timeless sets of premodern traits that purport to provide a self-evident and exhaustive interpretation applicable to all “bearers.” Because cultural and overtly racial discourses are both capable of achieving these effects, even invocations of culture that are anti-racist can racialize populations effectively, and they wield their power without enabling target populations to make the sorts of appeals to liberal sentiment that would be prompted by overt public attributions of biological or intellectual inferiority. (2003: 313-14)

It is in this way that culture as risk continues to be powerful and self-sustaining conceptualization in the field of HIV/AIDS prevention in Miami. It allows for new ways of acting upon targeted individuals and groups that obscures ideological constructions of race and ethnicity on which they are based.

However, as I will demonstrate briefly in the rest of this chapter and more thoroughly in the next, Haitian clients produce powerful alternative discourses that divorce risk from cultural and biological rationalities. These discourses go hand in hand with the aforementioned sites of contention that have arisen as a result of the quantification of Haitians as a demographic group and their subsequent placements into transmission risk categories. Almost all Haitian clients are staunch supporters of the notion that risk for

HIV/AIDS is universal. For many clients, risk is not only universal but also a perpetual state of being, so that one is already always in a state of risk. Many felt that exposure to HIV/AIDS was primarily through sexual relations, and they reasoned that because almost all human beings practice sex, everyone was at risk. For these clients, the concept of risk is intimately linked to representations of moral, self-efficacious individuals, and contingent on individual choice. In addition, there were no distinctions between personal and group level risk; therefore, the concepts of internal and external risk could not be divorced. For example, Lissette, a young woman who brought her mother into the clinic for a preventive visit told me that the risk for young people like her was in personal values such as “making money fast” and “low self-esteem.” She reasoned:

Like people who don't want to work, they don't respect their bodies. They want fast money. Instead of working for money, they want it easy. But other people have more respect for themselves, their bodies, and they have only one woman. They won't catch AIDS. But people right now, they're looking at how to have a good world. For that, they think they need to have a good car, to have good things and so they are going to choose to sex because they don't want to work sometimes. But me, if everybody works, it would be not easy to catch.

For Lissette, risk exists as a danger that is both internal and external to the self. “Working” is a notion that insinuates actual labor, but also a frame of mind. Lissette uses the concept of working honestly to imply not using one's body to get material or social benefits and to represent a self-respecting and a responsible individual. According to Lissette, risk flourishes in the practices of not working hard and in the bodies of those who want to have a rich fast lifestyle without working hard (i.e. those who “don't respect their bodies”).

Similarly Rita, an HIV-positive woman who counsels other HIV-positive adults at the local hospital, was adamant that everyone was at equal risk for contracting HIV/AIDS but stated that “Everybody is at risk, everybody, but the level is not the same.” She elaborated:

Sometimes, I have to go by what [hospital administrators] want me to do but outside of the hospital, where I am talking to Haitian people, not only for HIV positive Haitian people on how to take care of themselves, I tell them my motto which is “Do not resist what is.” What is, it is your life, whether you are poor, you are poor, whether you are short, you are short. What can you do about it? Now, if you do know something to do about it, don’t sit on it, do it but if there is no way out...I’m a short tiny woman, OK? I’m a five something, and if I have a dream that I want to be six foot 5 tall, that’s now resisting what is. I don’t have a million dollars, if I am dreaming about the day that I have a million dollars, I’m lying to myself, and I’m resisting what is. If you say you’re fat, do something about it. If you say you’re too skinny, do something about it. So I feel that we humans will resist so much about who we are and we don’t do nothing. We blame our spouse, our friends, the government, the place, this, that, and we don’t really go to the right cause of it. We are trying our best to address symptoms and we leave the cause behind. How are you going to address symptoms? *Symptoms are having a cause that produces symptoms*. If we want to adjust the symptoms, go to the cause. So I think that’s what I always tell them, be honest to your own self. See what causes that. Go directly to the cause and resolve the cause, then you will have no symptoms. (emphasis hers)

Rita also alludes to the inseparability of internal and external risk, as well as individual and group-level risk. For her, the level of risk is not dependent on factors relating to age, gender, or race; rather risk is reliant on whether an individual is able to address what she calls “causes” of unhappiness, desire, and necessity. These causes exist both internal to the person, perhaps rooted in notions of self-worth and self-awareness, and external to the person as substantive and social goods.

Although these discourses do not seem explicitly misaligned with official underpinnings of compelling clients to be the mediators of their own risk, they give way to divergent conceptualizations of self-management of risk. As I will discuss in the next two chapters, managing risk, for many Haitians, translates into practices and performances that are not restricted to traditional HIV/AIDS prevention imperatives (i.e. safe sex, clean needles, living positively). Those who are HIV-positive also do not necessarily interpellate themselves to their condition in the same ways that the woman in the opening vignette does in declaring her identity through her CD4 and T-cell counts. Instead, those like Rita, who

straddles roles as an HIV-positive Haitian woman and as an institutional HIV/AIDS expert, approach their HIV/AIDS status not through enumeration, risk, and embodied performance, but as representations of everyday realities. Rita declared her view of being HIV-positive this way:

I read book that said HIV cause AIDS; I read books that say HIV doesn't cause AIDS; I read everything that contradict each other...I search, I get with the doctors, I go with alternative way, change my diet, exercise, read all the positive books that I can find. I did think about it but I don't think about it no more. It's the last thing that's on my mind to think.

Like Rita, Sissie is an HIV-positive woman who attends the clinical classes in Kreyòl regularly. She is a woman of petite stature with short straight hair, piercing large eyes, and a big wide mouth which showed all her pearly white teeth when she smiled. She dressed impeccably—clean pressed clothes that were always colorful and always put together in matching outfits, as if she took them right off the mannequins displayed on store windows. She always matched head to toe, with purses, stylish shoes and sandals, and jewelry. Her posture and attitude in class was also something that distinguished her. She was always staring at someone else when another person was talking, smirking to herself when something was said, or sucking her teeth and rolling her eyes. She often interrupted others when they spoke or would softly start saying something in the middle of someone else's speech. Sissie reflected on being HIV-positive and her ways of managing her disease:

Then when they do the test, they say the result is positive. I wasn't mad about it because I knew I was with somebody but I didn't know the person was sick. We went to take a blood test, I didn't know he had it or anything. He told me he was going to take me to the doctor so I came. So when I come here, [the nurse] take care of me, then I have a doctor here. The doctor really is taking care of me and the doctor tells me "I don't see that you need medication yet. What did you do? What did you do? What did you do?" And I say I drank my herbs, tea, and I drank my tea every morning. I drank my herbs every morning and I don't do anything anymore and they always tell me that I don't need medication yet. I don't have any problems. That's not a reason for me not to come to see my doctor. I always come and check with my

doctor in my appointment. I come to the hospital, I am in all the groups, I go to all the groups and I learn...you know...that's my experience there. I don't have any problems with that. I am not thinking about I'm sick; I don't have any problems for being sick at all.

Both women's interpretations of a HIV-positive status are rooted in having multiple choices in the care of the self. There are many clients, like the woman in the opening vignette, who fervently interpellate themselves to HIV/AIDS prevention rationale. They position themselves as active ethical citizens who are instrumental in formulating and transforming their own health destinies. But there are just as many, like the Haitian clients with whom I worked, who conceptualize risk as co-constitutive of everyday practices and human relationships and adamantly refuse individual or expert control and management of risk. Furthermore, Haitian clients are acutely aware of notions of risk and individual responsibility. As I will show in the next chapter, Haitians are continually negotiating multiple official and non-official discourses of HIV/AIDS risk and numerical subjectivity, all while the system circulates notions of their unsuitability as both numerical data and as responsible citizens.

THREE

Ethnography in Clinical Settings: Rhetoric of Prevention and Progress

It was December 20, 2005. I dropped by the HIV/AIDS education class at Miami General Hospital. This was a class being conducted in English (instead of Spanish or Haitian Kreyòl), and although a majority of attendees were African-American, there were a few clients present who were of Hispanic or Haitian decent. Ricardo, the education coordinator, was there with Steve, whom he introduced as an “AIDS advocate” and as “today’s speaker.” Steve was a young, tall, good looking man with a shaved head. The class slowly started to fill up and Steve directed people to move their chairs into a more semi-circle format because he wanted them to be “talking to each other and not talking to him.” He asked whether there were issues that clients wanted to discuss. Some hands slowly went up. One man indicated that he wanted to discuss side effects of medications, especially the hallucinogenic dreams that he’d been having while taking Sustiva. Steve began writing these questions down on the black board behind him. Another participant yelled out that he wanted to discuss dementia, while someone mentioned toxomoplasis, and an older man simply said “diarrhea.” Steve asked him if he wanted to talk about anything specific about diarrhea or just about diarrhea, and the man who I knew to have language difficulties as a result of a stroke muttered “diarrhea” amidst some muted giggles from other participants. Finally, a woman revealed that she was on new combination of medications resulting in mood swings, and wanted to talk about “how sometimes you are up and other times you just get down.”

Steve proclaimed loudly that he wanted to “empower” the participants by imparting information about “how HIV worked in the body.” He said that his goal was to “self-educate.” He began his discussion by drawing a small circle with one squiggly line in the

middle, symbolizing the HIV virus, and then drew another larger circle enclosing a tiny circle with two squiggly strands, representing the CD4 cell. He informed us that “the life cycle of HIV represented how it is made.”

In response to the drawings, a client raised his hand to ask “How long does a HIV virus live? What is the life span of the virus?” Steve looked a little caught off guard as he didn’t immediately respond and then slowly began to say “You know I’m not a doctor but ...” when as if on signal, a social worker who was in the audience, spoke up saying “It exists for 48 hours but the replication is so fast that there are always more than there are dying.” Steve, not to be outdone, pronounced “That’s what I thought but I wasn’t sure.”

Steve continued on. He uttered “What are cells that are most affected by the HIV virus?” A man in the front of the class answered “CD4 cell” and with a huge grin, Steve handed out some candy to him as a prize for the right answer. Next, he asked the group “What is the role of the CD4 cell?” People yelled out “fights the virus” and “to protect us.” Steve added, “Just remember to think of it as a general in the army that controls how it is going to fight infections.” Several people received handful of candy for their answers. Continuing with his lecture, Steve declared “Viruses are not intelligent organisms because they need a host to live and they exist in a half alive, half dead state.” He then asked “Why is that only CD4 cells that are affected by the HIV cells?” A woman replied that it was because they had the same “configuration.” Steve nodded his head up and down in excitement, rewarding her with candy and cried “Yes, these receptors match for the CD4 cells and the HIV virus and it is like a lock and key mechanism!”

He then proceeded to draw and to describe the HIV life cycle. He explained that the first mode was the attachment of the HIV virus to the cell. He posed a question about the

name of the entry fusion drug that stops the receptor from attaching to the CD4 cell.

Someone from the back yelled out “T20” and “Fuzeon.” A very thin gentleman seated in the front inquired “If it stops the virus right there, why don’t they give it to all patients?” Steve again seemed surprised as he stood silent for several minutes before responding, “I really don’t want to get into it right now because I think it’s a conversation you should have with your health professional, but my opinion, and it’s only my opinion, but I think that they don’t have enough experience with it and traditionally, in research many drugs are tested together, but this has not been done with Fuzeon.”

Another question was raised by a woman who had been quiet all this time. She asked whether HIV/AIDS research had stopped because it seemed as if all of the antiretroviral drugs were “masking the disease instead of curing it.” Steve declared that he would “gear [his answer] more toward facts and not opinions because there have been many strides made in terms of the kinds of drugs coming into the market. HIV as a disease state is young and people now can take one pill a day if they can which is really staggering considering that 25 years ago when HIV became known, people had to take 20-30 pills a day so we have progressed.”

All of a sudden, Steve’s lecture turned highly technical, as he discussed transcriptases and other particular enzymes and complex drug combinations. This seemed to have the desired effect; no one seemed to be asking any questions. However, a heavy set man with wire-rimmed glasses raised his hand after a long pause to ask “I have a question about pharmaceuticals. Do they share information with each other? Because it seems to me like they should because they could produce better drugs.” Steve answered curtly, as if in an

agitated tone “I think that this is a political discussion and we can have it after class. But generally, when these companies are in the middle of research, they don’t share information.”

It was noon and it was time for the class to end. When Steve realized the time, he added “I can stay a little late if any of you want to discuss side effects.” A man who had asked about Sustiva piped up and said that he was experiencing constant nightmares while taking this drug. Steve declared “Well...many drugs affect the central nervous system and although there was a blood brain barrier, Sustiva was one of those drugs which crossed the barrier. You would really have to talk it over with your health provider but there are some things that you can do like not taking it with food or to take it a few hours before bedtime so that one could sleep through the side effects.” A woman inquired “Can you tell me about my high cholesterol? Is it because of my meds, the food, or my age?” Steve quietly stated, “There is really no simple answer.”

Ricardo, the education coordinator, as if on cue, indicated that time had run out. Steve quickly concluded with the same upbeat tone that he started with saying “Remember that you are the driver of your medical care, and everyone else like your case manager and your doctor are just passengers along for the ride. You need to be empowered! Knowledge is power!” The audience responded with deafening applause. As the class was disbanding, I saw him talking briefly with clients, but never heard him keeping his promise to talk to them “off line” about some of the “political” comments that they made.

The preceding description of a hospital HIV/AIDS educational class is one in which knowledge about HIV/AIDS circulates in unpredictable and contentious ways. Steve, Ricardo, and other so-called experts vie to inculcate clients with scientific discourses about virology, immunology, and pharmacology under the pretext of consumer empowerment and

advocacy. They do not directly intercede in clients' care of the self; rather they foster strategies for the regulation and management of health through individual awareness and conduct (cf. Foucault 1979; Shah 2001; Rose 2007). Clients who answer correctly are seen as successful in understanding medical explanations and technologies of HIV/AIDS and are subsequently rewarded with candy. Those who question the role of science and pharmaceutical companies in certain knowledge-making practices related to HIV/AIDS are dismissed and their comments are deemed "political."

In this chapter, I trace how such official discourse of HIV/AIDS position these two groups of clients as oppositional: as those who do and do not understand modern medical notions of health and illness, conduct themselves in hygienic and responsible ways, and depend on expert mediation for their medical problems. Briggs and Mantini-Briggs (2003) have labeled this dichotomous positioning as one between "sanitary citizens" and "unsanitary subjects." They argue that sanitary citizens are seen as "those who contribute to the body politic by internalizing scientific understandings of health, disciplining their bodies, and sanitizing their environments," while unsanitary subjects are viewed as those incapable of or refusing to participate in such contributions and therefore, a threat to the well being of sanitary citizens (Briggs and Mantini-Briggs 2003: 319-20). Similarly, Nikolas Rose contends more broadly that "biological presuppositions, explicitly or implicitly, have underlain many citizenship projects, shaped conceptions of what it means to be a citizen, and underpinned distinctions between actual, potential, troublesome, and impossible citizens" (2007: 132). I illustrate, however, that even though much official rhetoric in Miami renders them as difficult subjects or uncooperative citizens, Haitians strive to occupy a liminal state

of existence, one that straddles the realm of productive, responsible citizenship and unmanageable, apathetic subjectivity across multiple sites in the field of HIV/AIDS.

This chapter also demonstrates the multiple ways in which these notions of citizenship, biological and otherwise, are being generated and configured in the discourses surrounding expertise and governance in HIV/AIDS. Medical anthropology and the anthropology of science, in particular, have long explored various ways in which knowledge about bodies, medicine, and science are formulated, reframed, and stabilized, paying close attention to the diverse and sometimes incongruous ways people conceive health and illness. However, as anthropologists Stacy Leigh Pigg (2001) and Linda Hogle (2002) have pointed out, these models have often left us in a continuous binarism: either what is called indigenous, lay, or public knowledge is being repackaged as complementary or as an appendage to science or it is being marked as incommensurable to particular scientific reasoning.

Many feel that recent scholarship in science and technology studies (STS) may provide new ways of seeing beyond this binarism. Current scholarship has demonstrated that the concepts of expert and expertise are highly dynamic, and historically and situationally grounded in practice. Work of scholars like Steven Epstein (1996) and Brian Wynne (1996) show that public understanding and perceptions of science are indeed advanced and highly complex, and are continually being created and sustained not just by experts but also by consumers of health. Both fields of study have much to offer each other, as investigations of biomedical knowledge production and practices move beyond laboratories and clinics, and into classrooms, streets, homes, and other public and private venues. Throughout this chapter, I use these disciplinary convergences to highlight the complex movements of

circulating ideas and technologies among various constituents who work in the field of HIV/AIDS, and how they become entangled in the debates about relevant knowledge bases and questions over expertise and authority, as well as community and risk. Furthermore, I confront the implications of the positioning of the anthropologist as expert in clinical fieldwork by discussing the various ways in which this anthropologist had to negotiate expertise across multiple sites, embark on additional training, and demonstrate contributory expertise in order to gain entry to and sustain multiple fields of study.

Ethnography and Expertise in Clinical Settings

Linda Hogle states that “Shifts in the relationship of authority and expertise are indicative of a convergence of political, medical-scientific, and market phenomena, at broader societal levels—a convergence that is redefining the nature of governance, health and welfare, and self-care” (2002: 277). Never has this rung as true as in the discourses and practices surrounding HIV/AIDS in the United States, which have become increasingly complex and diffused. There is tremendous movement and dispersal of knowledge production which extend both beyond the clinic but also outside the realm of researchers and clinicians. As I will show throughout this chapter, in Miami, like many other places where HIV/AIDS holds much at stake for various constituents, it is not difficult to locate those who are commonly labeled and perceived as experts. In fact, the field of HIV/AIDS has netted a sharp proliferation of those claiming expertise. In one of the largest hospitals in Miami, as well as in several local clinics and community based organizations, those with whom I worked included physicians, nurses, social workers, outreach workers, educational

coordinators, counselors, patient advocates, data managers, technicians, pharmaceutical representatives, and consumers.

At one level, the production of these experts occurs institutionally, with local health departments and organizations mandating that anyone working in the field of HIV/AIDS, even as a volunteer, must take at least a basic introductory course given on-site, and attend continuing update classes offered in English, Spanish, and Kreyòl. These training programs in Miami serve to establish site-specific credibility for a multitude of actors who go through the program; they also help to maintain legitimacy for the production of biomedical knowledge about HIV/AIDS and ways to conduct prevention and counseling. Scholarship in STS has long been concerned with such modes of construction of credibility and legitimacy in knowledge claims (Latour 1987; Shapin 1995; Jasanoff et al. 1995; Epstein 1996).³¹ Susan Leigh Star and James Griesemer (1999), for instance, state that consensus building is a fundamental part of scientific enterprises and requires a tremendous amount of work done by multiple actors to reconcile different social worlds from which they operate. These professional trainings exemplify a site through which such consensus is produced. They are what Latour (1987) calls “obligatory passage points,” sites through which anyone wishing to participate in the field of HIV/AIDS prevention in Miami must pass through in order to reach this goal. These trainings are strictly enforced; although I had been trained in epidemiology and worked in HIV/AIDS research, several organizations and informants refused to work with me until I was certified through these training programs. The trainings are both substantive and methodological in nature, and serve to institutionalize knowledge about HIV/AIDS and those who are affected by it (cf. Epstein 1996; Star and Griesemer 1987).

These trainings were ongoing and frequent, and varied from four hours for the introductory course to three full days for the testing and counseling certification. Given the time frame allotted, the classes seemed as if on continual high speed, crammed with a mass of information. Even though the trainers were motivated and dedicated to imparting information, at the end of classes, participants, including me, expressed feelings of fatigue and mental saturation. The basic introductory course offered participants a crash course in basic immunology, HIV transmission, prevention measures, counseling and testing overviews, legal issues, opportunistic infections, treatment strategies, and recent HIV/AIDS statistics. The course objectives for the longer HIV/AIDS testing and counseling training sessions were “to provide participants with basic HIV/AIDS information, to enhance participants’ knowledge of HIV transmission and prevention, to give participants a synopsis of HIV prevention counseling, testing, and referral, to improve participants’ understanding of the impact of HIV in persons co- infected with other infectious diseases, and to assist participants in identifying their comfort levels in working with clients who have various backgrounds, behaviors, and beliefs.” All of this was done within a total of 27 hours, over three days. Through a combination of lectures, group discussion, and role play situations, participants were instructed on proper nonverbal and verbal communication skills and basic counseling skills. The specific emphasis in the introductory training was on groupings of people who were said to be at high risk for HIV/AIDS worldwide, nationally and locally, while in the counseling and testing training, relationships between individual counselors and clients were given prominence.

Trainers singled out HIV/AIDS as an unparalleled epidemic because of specific concerns relating to stigma for which issues of privacy and confidentiality must remain

paramount. But participants were also taught to downplay such unique characteristics of the epidemic with their clients by reminding them about how HIV/AIDS, like any other disease, could be controlled with medication, leading to a “normal life.” In addition, they were instructed to de-stigmatize HIV testing by encouraging people to take the test voluntarily. This dual positioning of HIV/AIDS, as both a unique phenomena and a standard epidemic, has also been noted by scholars who have studied historical relationships between disease and its social construction (cf. Rosenberg 1989, 1992; Lindenbaum 1998; 2001). Charles Rosenberg (1989, 1992), for example, argues that HIV/AIDS, like previous epidemics of cholera and yellow fever, makes visible the links between biological events and their moral management. At the same time, HIV/AIDS is unprecedented not only because of the biomedical and technological advances that have aided in the construction of knowledge about the epidemic, but also due to the “self-conscious, reflexive, and bureaucratically structured detachment with which we regard it” (Rosenberg 1989: 11). Counselors-in-training are indoctrinated in this kind of reflexivity; they are taught to observe clients observe themselves. In the classes which I attended, trainees were lectured on the importance of recognizing that “counseling has to be a kind of personalized prevention plan,” so that counselors can individually assess a client’s knowledge of HIV/AIDS and risk. Verbal and non-verbal communication was touted as the cornerstone of HIV/AIDS counseling sessions (Miami-Dade DOH 2006: II-A-page 4), and the training director repeatedly highlighted that he wanted participants to walk away from this class knowing how to “have a conversation with the client.”

However, even in the trainings, many class objectives went unmet as counselors-in-training would relay non-scripted, more personal opinions. For instance, in one role play

situation where participants practiced how to conduct counseling sessions, one woman who was in the role of counselor told a client that because he was now HIV-positive, he should no longer have sex. She was immediately chastised for imparting this advice not only by trainers, but also by fellow trainees. In another interactive session, participants were given a list of statements and asked to find other participants who would answer “yes” to the statements. When I answered affirmative to thinking that I may have had a sexually transmitted disease in my lifetime, an outreach worker and fellow trainee stared at me for a few seconds and said loudly enough for others to hear “WHAT! And you seem like such a good innocent girl but I guess you’re not!” Nearby participants either rolled their eyes or expressed shock at her admonishment of me. These instances of chastisement of counselors-in-training indicate that moral imaginaries are grounded in clear distinctions between desirable and unsuitable sexual behavior. They also strongly make visible the highly porous relationship between standardized behavioral norms, made routine through such professional trainings, and individual perceptions of acceptable sexual behavior.

Private conversations with providers reinforced some of these aforementioned issues. In their conceptualizations of HIV/AIDS, many providers vacillated between envisioning HIV/AIDS like any other disease and perceiving it as an unparalleled epidemic. A case manager said:

I look at it like any disease that you just have to control like diabetes, like someone’s high blood pressure like that... Like if you had a headache, wouldn’t you go take aspirin, to make it go away and get better? If you were a diabetic, wouldn’t you take insulin? If you had cancer, wouldn’t you get treatment? So think of it as the same way.

But at the same time, she emphasized the unique social relevance of the disease itself, that it was a “window of all those social issues like homelessness and poverty.” Providers also

utilized multiple frames to talk about the meaning of the epidemic (cf. Rosenberg 1989; Epstein 1996). A health department official reflected, “Honestly, I think that it’s a reflection of the time that we are living in now. I think that it’s like a plague that God put on us for the ways and behaviors of man.” Another administrator spoke about the serious doubts that he has about what HIV/AIDS is because he had met a scientist who had been involved in making the HIV/AIDS virus. He confided that although he knew that this was a popular conspiracy theory, he still had his doubts because he could not fathom that cutting-edge technological advances in science had yet to produce a cure. He declared:

They are making drugs in HIV research that work miracles and you can see patients turn around so quickly and they still can’t find a vaccine. You tell me that there isn’t something to it. Money has a lot to do with it. The pharmaceuticals and a lot of people are getting rich off of this. There is something going on.

Most of these providers, like the counselors-in-training, have convictions of a biomedical cure and are faithful to the scientific endeavor; but they also feel strongly that HIV/AIDS is a representation of individual morality, pharmaceutical greed, and governmental complicity (cf. Rosenberg 1989).

These multiple ways of framing HIV/AIDS permeate counseling and educational sessions with Haitian clients. Like in the opening vignette, presenters ranging from pharmaceutical representatives to physicians to community activists lectured and imparted opinions on a variety of topics such as side effects of drug combinations and the pleasures of sexual intimacy in educational classes, designed for those “infected and affected by HIV/AIDS,” at Miami General Hospital. For instance, one guest presenter, a former social worker and self-described Haitian activist, held a discussion on what she labeled the “the value” of abstinence and monogamy. After having given a long speech on the significance of having social support and openly discussing sexuality, she repeatedly made the class declare

in unison the phrase “Those with SIDA should not have sex or have protected sex only in a monogamous relationship” in order to instill as she claimed, the “importance” of abstinence and monogamy. When an older man became inspired by this chanting and exclaimed that he had not had sex in the eight years since he’s been HIV-positive, she led us in giving him a standing ovation. Much like the HIV/AIDS counselors mentioned above, this presenter transitioned effortlessly between established narratives of HIV/AIDS prevention of safer sex behaviors and her own views of abstinence and monogamy.

Counseling sessions, on the other hand, were brief and the intake form was often the mainstay of the interaction between the counselor and the client, and therefore, the entire counseling session. Frequently, the session seemed like a lecture, with the counselor imparting information about HIV/AIDS virology, transmission, and risk instead of exercising the skills that were taught in professional training sessions: utilizing questions or “polite imperatives” to provoke clients to explain their concerns. Although a few clients asked questions or raised concerns about the information being relayed or personal situations, a majority remained silent and only answered the questions asked from the intake form. Counselors often breached the Department of Health’s “Fundamentals of HIV Prevention Counseling” by imparting their own moral opinions on to clients. For instance in one counseling session between a Haitian counselor and a very young Haitian female client who was there to get her test result, the counselor kept questioning the validity of her commitment to using condoms. He became agitated as she kept refusing his offers of condoms. He asked her even more sternly if she was responsible for obtaining protection, and she replied that her partner “brought the protection.” The counselor then raised his voice as if to scold a child, “Well, what if he doesn’t come with condoms one time, what will you do?” She shrugged

her shoulders and said “Well, we are always careful.” He persisted, “You can’t rely on that. I am going to give you condoms.” When she again quietly refused, the counselor yelled “You’re 17 and you shouldn’t be having sex anyway. I know you don’t want them but I am going to send you home with some condoms.” She let out a loud sigh and reluctantly took them and put them into her book bag. The young woman’s assurances of “always being careful” and having sex using condoms does not deter the counselor from insisting that she take the condoms he offered. At the same time, the counselor’s invocations of self-empowerment only heightens her refusals until the very end, when the prescribed roles between counselor and client are ruptured through the revelation of his admonishment of her for engaging in sexual relations at a young age.

Similarly, another counselor, in order to demonstrate how “real-life” counseling sessions unfolded, administered an oral HIV/AIDS test on me. During the session, he proceeded to fill out the risk transmission section by rapidly asking questions relating to both my sexual behaviors and those of my sexual partners, with his pen sometimes already marking the “no” box before I even answered. In the middle of the session, he declared, “I knew you didn’t have too many things.” Although it was a practice session, I was tested for HIV/AIDS and felt highly uncomfortable discussing my sexual history, drug use, or answering any questions asked of me because of this counselor’s comments. Although many of the counseling sessions that I witnessed were conducted with much professionalism and empathy, they still made apparent the ambiguous and inadequate nature of concepts that form the mainstay of the doctrines of HIV/AIDS counseling and prevention such as “confidentiality” and “neutrality” when put into practice. Stacey Leigh Pigg (2001) states that contemporary models of HIV/AIDS education have erased the culturally specific

historical formation of the modern notion of sex, one that transferred “sex” from a personal and emotional realm of public discourse to one of scientific rationality. She posits that this transformation of medicalizing sexuality made it possible to discuss sex education and safe sex with clinical objectivity in HIV/AIDS programs. I would add here that these transformations also make viable the naturalization of particular social relations between HIV/AIDS counselor or educator and client, ones represented by notions of nonjudgmental engagement and neutral guidance. But as these mock and actual counseling sessions and educational classes show, such interactions are not possible because they are always already rooted in hierarchies of expertise, a form of what Charles Briggs calls communicability, the “dynamic process that is established between discursive practices—including their ideological construction—and social relations, particularly social inequality” (2005: 283).

The ways in which the notion of “risk” is disseminated to and by providers and their clients is crucial to the understanding of these issues. As discussed in the previous chapter, the notion of risk forms a core element of the principles of HIV/AIDS prevention and intervention, and as a result, in the production of expertise in this field. In trainings aimed at professionals, instructors discussed risk extensively, and in testing and counseling practice sessions, instructors reinforced the ultimate goal of the counselor: extracting information to assess individual and group level risk. However, instructors never defined the concept of risk itself specifically. They addressed the ways in which one can be exposed and expose others to HIV/AIDS, how certain actions make individuals more likely to transmit or to get HIV/AIDS, and how certain groupings of people are more likely to have HIV/AIDS, all under the rubric of risk. Conversations and lectures moved fluidly between notions of “risk

group(ing)s,” “risk/risky behavior,” and “at risk” without much differentiation, while the notion that “we all have AIDS” was a popular quote used to underscore universality of risk.

Over the years, there has been a strong push in HIV/AIDS prevention to decouple stigma from the disease, by bringing attention to notions of universal risk. And as a result of research findings of the limitations of behavioral interventions that concentrated solely on education or individual psychology and larger public discussions, HIV/AIDS prevention and intervention programs have increasingly focused on broader socio-cultural, political, and structural forces that frame the concept of group-level risk rather than those based on individual psychological and behavioral models (Herdt et al. 1991; Parker 2001). The development of “community-level” prevention programs has been a key component of these responses, especially in collectivities deemed as at “high risk” (CDC 2005). These groupings are a result of various epidemiological and surveillance considerations and underscore significantly the blurriness between the ways in which risk is utilized in HIV/AIDS prevention. For instance, certain collectivities center around common “behaviors” between them that put them “at risk” such as “MSM” (men who have sex with men), “IDU” (intravenous drug users), and more recently “heterosexuals;” others reflect racial and ethnic makeup, gender, and age. Regardless of the divisions, the point to be made here is that like many public health prevention programs, it is often “communities” instead of autonomous individuals that have become the targets of HIV/AIDS prevention and intervention programs and messages. Concurrently, the production of expertise in HIV/AIDS prevention is both borne of and generates complex notions of community and identity.

Indeed, in conversations and interviews, providers and providers-in-training espoused multiple readings of risk, community, and identity. Many reiterated that everyone is at risk,

but also insisted that certain groups of people were more at risk than others. When prodded on working with those who identify and are identified as Haitian, many providers expressed that “culture” or the “nature of the Haitian people” put Haitians at risk. A community health worker, for instance, indicated that it was important to pay attention to “culture” when working with Haitians because practices like voodoo didn’t really allow for adherence to new medical trends, describing this as a tension between “tradition and assimilation.” Similarly, a physician revealed that Haitian culture was rooted in the notions of machismo and interacting with medical systems only when sick, and that this placed them at high risk for HIV/AIDS. Almost everyone approached revoked that risk was a direct result of ethnic or racial groupings; rather they interpreted risk as being attributed to “social environments,” “predispositions,” “social isolation and discrimination,” or “cultural factors” such as “low education and beliefs that led to risky behavior.”

As I discussed in the previous chapter, such cultural reasonings of risk are rooted in ideological connections between race and disease. As recent transformations in politics, economics, biotechnology, and medicine continue to propel the retraction of the social welfare state, issues related to health and illness become increasingly mediated through complex and multiple reformulations of the notions of community and culture. Institutional HIV/AIDS experts in Miami, under the new idiom of culture, seek to conduct intervention at the level of community, and in turn, naturalize social and structural inequalities through the rubric of culture. In official trainings of HIV/AIDS workers and counselors, for instance, cultural and moral discourses related to sexuality and risk become decontextualized and then reformulated as official practices of HIV/AIDS prevention and counseling. As documented above, culture even serves to explain away the dearth of HIV/AIDS intervention and

prevention programs for Haitians (i.e. because they are difficult to reach, reluctant to discuss HIV/AIDS, etc.). However, I argue that although such cultural discourses seek to establish connections between the beliefs and practices of Haitians and the production of institutional expertise, experts themselves are caught in a bind. Counselors and providers dynamically negotiate their position as those who have enlisted in the official discourses of cultural reasoning and as those who are embedded in the very same kinds of moral and social norms that they seek to act on.

Beyond Binaries

Haitian clients and community organizations are not necessarily passive participants in or recipients of these discourses. They participate fully in the production and maintenance of conceptions of HIV/AIDS, risk, and health, as well as identity, community, and culture. Haitians in Miami have had a long history of being targeted by local and national HIV/AIDS prevention and research programs, and almost all of the clients with whom I interacted had in some way interfaced with HIV/AIDS educational training either through HIV counseling, street outreach, or in formal and informal classes in local organizations and clinical settings. Although providers with whom I worked warned me that it would be difficult to get informants to speak about HIV/AIDS, I encountered very few dilemmas when discussing these issues. All of the Haitian clients I met readily shared their thoughts and stories of HIV/AIDS.

Very few of these clients ever utilized the words “virus” and “chronic disease” in describing HIV/AIDS; the vast majority, instead, conceptualized HIV/AIDS in terms of how it spreads from person to person through sex or drugs, or how they would react to it if they

had it. Others questioned what was generally taught about HIV. For example, whether it was really transmitted through needles or sex, or whether vaccines were not being found because people were making too much money off of it. Some offered explanations that seemed to merge biomedical notions of HIV/AIDS and personal interpretations. For instance, a woman who regularly came to Santè Ayisyen told me, “I remember one time they tell you SIDA is a virus. Everybody has it in their blood but sometimes, it’s not developed and for some people, if you don’t do it, it doesn’t bother you. You don’t have nothing but when you do...if you do prostitution, you can develop more. If you are on drugs too.” She constructs SIDA as a virus, which is the information she has been given by medical staff at the clinic, but she interprets this virus to be endemic to the human body. If someone were to “do prostitution” or be “on drugs,” then this virus will develop into the disease; if “you don’t do it,” then it will not develop into symptoms or a disease. SIDA for her, like many other informants, was not just an object or an entity, but a confluence of something experienced, a way of being, and a consequence of certain behaviors and actions.

For others, HIV/AIDS was seen as a means of garnering resources otherwise not available as concepts of health and well being overlapped greatly. Caniela, a divorced mother of two who was suffering from thyroid complications, spends almost all of her monetary resources on medication and health care bills. She had been working but recently had to stop because of her health condition. She was so strapped for money that she had recently sent her children to live with their father because she could no longer afford to take care of them. When I went to her apartment to speak with her, she complained of being constantly tired, broke, and feeling a loss of control over her life. She spoke eloquently about her long battle with health problems, poverty, and lack of insurance. She stated:

I know people who have SIDA. Sometimes, maybe if God give me SIDA, I can say that it would be better for me. Yes! Because before, I don't have a house to stay, I don't HAVE NOTHING for my two kids because [the government] doesn't give me nothing. I say "if I have SIDA, they will give me house to stay, they will give me money, they give me that." I have a lady who is my husband's friend. Friends say "she have SIDA." Now, this woman has EVERYTHING! She has nutrition, she has money for a house, she has EVERY THING. She has money and they pay her light bill and they give her food stamps. They give her everything. I don't know but they say she has SIDA. That's why I say maybe if I have SIDA, they will give me everything too.

For Caniela, SIDA symbolizes a litany of resources, from affordable housing to money to food. She spoke of SIDA sometimes longingly, as if she wished she had it rather than thyroid disease. She often alluded that her physical and social suffering were somehow wasted through thyroid disease because it offered her no material reprieve, as SIDA did for her husband's friend. In addition, like her friends, she views her husband's friend as someone who has SIDA because she seemingly is in a better social and financial situation. Here, SIDA, rather than evoking notions of discrimination and stigma, is suggestive of luck, prosperity, and desire.

It is within a larger framework of health and well being that conceptualizations of HIV/AIDS as a covetable resource need to be understood. Questions of health almost always elicited narratives of lack of insurance, money and other resources, as well as struggles with bureaucracy, poverty, and family. Many Haitian clients who frequented Miami General Hospital, Santè Ayisyen, and other small clinics spoke of not seeking health care early or often because of prohibitive costs, rude or unfair treatment, fear of seeing or being seen by other Haitians, and lack of time. One woman whom I met in the waiting room of a clinic told me:

When I come here, my pressure goes up, my sugar goes up. I don't really want to come here. Sometimes, when I come here I feel more sick with these people at the desk. They're very rude; they don't know how to talk to people. I don't know...it's

everywhere, believe me. It doesn't matter where you go. I have to buy four five medications and I don't even have money to go get it right now. My problem is with the people that work here. If you don't get the good service, people will not return. I came here at 10:15AM, and it's now noon. When you come here and spend five hours, it doesn't make sense.

Like her, many clients repeatedly mentioned how they either avoided going or were not able to go to clinics or hospitals simply because they could not afford to spend that much time away from work. These kinds of stories showcased the complex ways that clients navigated health care systems, often going from one institution to another to avoid accumulating enough bills to trigger a call from collection agencies, or avoiding certain clinics and hospitals because of a lack of money or dissatisfaction with rude personnel, or even bypassing medical institutions in Miami altogether to go to Haiti to get services and treatments.

Much like providers, client discourses of HIV/AIDS and health were also deeply rooted in formulations of concepts of risk and danger. Their stories revealed that they felt that sex was the primary and sometimes only way that people were able to get HIV/AIDS. Even though some alluded to the fact that people who use drugs and those who were promiscuous were more likely to get HIV/AIDS, almost all reasoned that because sex was the main way to get HIV/AIDS, anyone was vulnerable to getting it. Many Haitian women spoke of "taking precautions" but these didn't necessarily mean condoms or what is commonly advocated as safe or safer sex. For instance, Claudette, a woman whom I met when she brought her husband to get tested for HIV/AIDS told me "I'm not worried because I went to Haiti, and when I came back my daughter told me she saw [my husband] with someone and I told him I'm not going to have sex with you before you get tested. That's why I take him over there because I don't want to get nothing. I don't go in the street, I don't want

to go with no one, I just want to straight.” Claudette reasoned that the only way to keep “safe” or to ensure that she did not contract HIV/AIDS was to threaten her husband with abstinence until he proved via testing that he did not have HIV/AIDS. For her, safer sex equated to the assurance that her husband was not HIV/AIDS positive, validated only through testing; it did not mean rebuking the possible sexual indiscretions of her husband or using condoms if she was uncertain about her husband’s commitment to monogamy, as is currently taught to many clients by HIV/AIDS prevention programs.

These conceptualizations of risk and safeguard practices signal broader contrasts with established official norms of risk education and HIV/AIDS prevention. For instance, many clients frequently questioned or rebuked the epistemological foundations of HIV/AIDS risk reduction. They cited that one can never truly know about the actions or statuses of intimate partners, even husbands, hence the futility and even absurdity of official discourses of “being careful.” When I asked Florence, a young woman who brought her mother into the clinic, about how she and her friends viewed sex education and HIV/AIDS prevention programs in school, she wryly exclaimed:

What I am saying is that how can you be careful when you don’t know anybody. So it’s like you can have a husband and he can give it to you. You can have a wife and she can give it to you because you don’t know what she doing. My dad tells me all the time, “You don’t know anybody! Don’t talk to people!” And I asked him one day, “Daddy, do you really know everybody? You could never know anybody. You don’t even know me. I’m your daughter but you don’t know me. You’re my dad but I don’t know you. When you go to work, how do I know you go to work? How do I know if you’re not a criminal when you go outside? How do you know if I don’t go and prostitute myself? I don’t know you and you don’t know me. We don’t know anybody.

Florence’s comments problematize the epistemological basis of the official discourses of HIV/AIDS prevention and risk reduction—that one can ascertain and ultimately control one’s personal risk of HIV/AIDS. As noted earlier, HIV/AIDS prevention counseling is

rooted in the notion that clients are able to reduce risk of HIV/AIDS through recognizing their personal risk behavior and circumstances. This framing presumes the transparency of self-knowledge; that is, individuals can discover knowledge of risk merely through self-reflection because this knowledge is true, real, and therefore, waiting to be realized. Florence challenges this presupposition by asking “How can you know anybody?” Her question alludes to the opacity of knowledge and more importantly, challenges the very foundation of the rationalities of HIV/AIDS prevention and risk reduction by bringing into focus whether we indisputably know that we know. Florence contests these otherwise unquestioned assumptions of HIV/AIDS prevention, and in the process, renders visible the multiple and obscured forms of social organization, labor, and discourses that produce and veil such modes of knowledge making. Florence, like many of the Haitian clients described above, attempts to challenge the very ideas of knowledge production in HIV/AIDS prevention by reframing certain “facts” about HIV/AIDS, risk, community, and subjectivity as socially constructed and as highly dependent on the social relations of knowers themselves (cf. Shapin and Schaffer 1985).

Politics of Difference: Community of whom and what?

For many Haitians, life in Miami is embedded in conflicting and often contentious notions of community and identity. Miami represents and is experienced as a place in which these struggles are highlighted. Similar weather and proximity to Haiti, and an established route of migration brought many Haitians to Miami; for others, it was a second or third move from other areas of the country for similar reasons. Informants described life in Miami as “great” because Miami was seen as both a representation and realization of the American dream: that

with hard work and personal sacrifice, one would be able to not only live well, but prosper economically and socially. Life in Miami often elicited direct comparisons to life in Haiti, and rationalized to be “much better” in terms of economic opportunities, health benefits, political independence, and social diversity. Indeed, in comparison to Haiti, Miami seemed to offer opportunities in terms of jobs, even if strenuous and underpaying, education, and political freedom. For instance, Marie, the owner of a small dilapidated convenience store on the border of Liberty City and Little Haiti told me, “Yeah. My life in Miami is great because I got my little shop and I got five kids. All go to college. I can say nothing wrong because I try to live for myself, try to work hard, send my kids to school, then I can say nothing wrong with it.” Even though she was plagued with personal and financial difficulties, she praised Miami for giving her economic independence from both her husband and the State, so that she is able to live adequately and afford to send her children to college. For others, especially those who were HIV-positive, Miami was a place that was “lifesaving” given its free or affordable health services and its knowledgeable and competent health professionals. As Violette, an HIV/AIDS educational class regular, told me reflectively, “If I was in Haiti, I do believe that I would be dead by now.” Individuals, like Violette, felt that they were, in essence, “reborn” in Miami, having been given the opportunity to live again with medical and monetary support.

For many others, even those who echoed the praises of the city, harsh realities of segregation, marginalization, discrimination, and lack of economic viability leached into their descriptions of everyday life in Miami. Lack of affordable housing, poor public transportation, and low paying jobs were often the reasons given for seeing a bleak future in

Miami. Magda, a Miami resident for over 20 years, summed up her mixed feelings of the city in the following way:

Day to day to living is...all in all...I can say I do [and] I don't [love Miami] at the same time. I do for all the things I said before and also to me, the healthcare system is wonderful. I don't because the price of housing is high and the...if you drive, parking is another pain. You don't drive the transportation...the buses...is worse than paying. I hear people saying "pain in the neck" but I think this is pain on the whole body.

Magda, like many Haitians in Miami felt that the city gave them innumerable opportunities like healthcare that they appreciated having but the city itself was the cause of physical and social ills that they faced. Furthermore, several individuals felt that that daily life in Miami was "worse" than other places in which they have lived like Boston or New York City. A county administrator, for instance, described Miami as a lone city in which "the frontiers are real," where the boundaries between different ethnic groups are well defined and passionately maintained. For him, the broad ethnic segregation set Miami apart from other urban areas in which he had lived with a sizable Haitian population. To this extent, a few even expressed their desires to go back to Haiti but cited that they couldn't because of their responsibilities to family members here, a lack of money, and the severity of current political and economic situations in Haiti.

These views are supported by a recent wave of data. In June 2005, a Merrill Lynch report pegged Miami as having the greatest "bubble activity" in national real estate markets, with home prices increasing 85% since 2001 while per capita income increased by less than 3% (Stabley 2005). In addition, a 2005 report compiled by the Brookings Institution stated that the median household income for Haitians living in Miami-Dade county was \$27,284, well below the county rate of \$35,966, and that the poverty rates for Haitians in the county (30%) were almost double that of the county average (18%), with almost one-third of all

Haitian households qualifying as low income (earning below \$18,000). The report attributed these disparate rates to a largely younger population coming from an impoverished country, low educational achievement, low access to federal benefits, and a high percentage of income spent on basic housing costs (Sohmer 2005). Although these reports and the reflections of a few informants in Miami attested to the difficulty of sustaining a comfortable life in the city, discussions of life in Miami seemed beyond reproach. Instead, they yielded explicit symbolizations of a place in which countless possibilities and optimism occur for those fleeing poverty, death, and persecution.

The complex framework through which informants came to conceptualize Miami can be better understood through the distinctive body of literature that has developed around the notion of “community.” These studies tend to come from a variety of disciplines—sociology, anthropology, geography, and urban studies to name a few—and although abundant, they are not necessarily redundant or without depth. Brett Williams states that:

In popular and academic usage, the term ‘community’ seems almost hopelessly diluted. It is used everyday to describe entities at many scales and levels of meaning... Yet in the past, scholars have used the word to great effect. They have explored, reified, deconstructed, and debated “community” to work through such concepts as the “little” community, *communitas*, the organic community, and the imagined community... Thus, we can use community to explore categories of difference, transnational practices, political consciousness, cultural heritage, collective identity, or rallying around cultural symbols, believing that you belong to something bigger than you are... No matter what kind of community a community is, it is always a claim, a fiction, inscribed through symbols, ceremony, food, or a set of practices. It is almost always a site of disengagement and struggle as well as attachment and belonging, frequently serving as the target of political activity. (2002:346)

Increasingly, in the realm of public health, the concept of community is used widely and often without serious inquiry. In HIV/AIDS prevention in particular, community has become a core component of both the generation and dissemination of knowledge about HIV/AIDS

as well as in the production of expertise of affiliated participants. In this section, I will demonstrate the complexity and flexibility of the term in order to better understand the relationships between various constituents, practices, and objectives in HIV/AIDS prevention programs.

In Miami, notions of community were indeed plentiful: Haitian community, Little Haiti, target community, etc. Many Haitians in Miami expressed that a Haitian community did exist, but were unclear of whom or what this consisted. They spoke about how the community in Miami was a reflection of communities in Haiti, and that many felt bounded together by a common past of living in and leaving Haiti and of facing same problems of discrimination and marginalization in Miami. For those living in Little Haiti neighborhoods, there was a sense of familiarity, where one could freely walk and talk with friends and neighbors, sit out on the porch, listen to music, and talk loudly like one was able to do in Haiti.

Imaginations of Little Haiti, however, were not always idyllic. Little Haiti, to Haitians and non-Haitians alike, symbolized and made obvious serious fractures in the concepts of community. Little Haiti, according to both public and private perception, was a place of residence for recent Haitian immigrants or refugees, or economically disadvantaged Haitians. As these residents became more economically stable or affluent, they moved to other locales like the suburbs of Miramar and Kendall. These presumed geographical residential patterns based on economical divisions often intersected and fused with discourses of regional differences found back in Haiti that contributed to and sustained certain collectivities in Miami. Lara Pierre, a Haitian community activist explained that these notions of community rooted in notions of place, presented difficulties in Miami:

The most significant is where they came from in Haiti because it really informs in a lot of other things that they do here, either self-perception, who they choose to trust, who they associate with, and all of that and how vulnerable they become because of this sense of solidarity with the group from the same area so that somebody who's selling cars, will say you know you go to that person, you're kin folk almost because he's from your home town and he'll rip you off. And he'll do whatever and then, you don't want to go to the authorities because your mother and his mother back a long way. Your mother nursed, his mother nursed your brother or nursed you I mean they have all these like real STRONG linkages that you know when it comes to crime or violation of trust becomes really really hard to prosecute.

Thus, for Lara, practices of regional communitarianism bind individuals through affective memories of home. But these very same entanglements also serve to make individuals susceptible to physical and social harm. Lara also alludes to the notion that these linkages to Haiti shackle Haitians to codes of moral and legal conduct practiced in Haiti, leaving them unable to follow the social norms of their current situations.

Even with an overwhelming affirmative response of an existence of a Haitian community in Miami from informants, Lara and many others insisted on the prevalence of divisions and general lack of cohesiveness that set them apart from other ethnic communities in Miami. This notion of a divided community extends beyond simple political, economic, or skin color differences, expressed as social partitions found back in Haiti or something that is intrinsic to the Haitian people because of their history of conflict and struggle. The concept of a Haitian community in Miami was not only rooted in conflict and contestation, but borne of it. To many Haitians, the sense of an imagined community or nationalism (Anderson 1991; Creed 2004) failed to exist in Haiti, and further fails to resurrect itself in Miami. Trouillot (1990; 1995) attributes this to the Haitian Revolution, a feat in which Haitians led the only successful slave revolution in modern history and which still historically remains obscured and suppressed. The revolution created an independent modern state but not a nation, and thus, the development of a shared collectivity mainly

transpired from having a common language, religious practices, and cultural models, rather than sustained projects of nation building and citizenship (Trouillot 1990; Gros 2000). Such factors, along with long periods of internal political strife, foreign occupation, and forced economic and political isolation have given way to deep and complex societal divisions in Haiti (Trouillot 1990; Kumar 1998; Gros 2000).³²

Many Haitians in Miami expressed these notions of internal divisions rather mundanely, articulating that Haitians couldn't live together as a community. Richard, a regular at the hospital HIV/AIDS educational classes for Haitians, explained that these kinds of divisions were rooted in systematic divisions in Haiti, which are then transported here, and remains a pivotal impediment to the Haitian community achieving economic and political success in Miami. He stated:

Richard: Haitians are treated very well in Miami but the people who really look at Haitians the wrong way is the same Haitians, the same people. Haitian on Haitian.

TS: And why do you think that happens?

Richard: Lack of education, ambition.

TS: Do you think it will get better?

R: For me?

TS: For Haitians in general?

Richard: I believe it's because they don't have any understanding; they're going to be just like that.

TS: So even like kids and things like that, even when they grow up here?

Richard: They probably won't have the same thing.

TS: Do you think it's only Haitians, or do you think that other people have that too?

Richard: I don't believe the other nationalities are the same....The Cubans, if one person had a house, they always give a helping hand. That means if they have one place, one can just sleep here now and in a couple of hours, the other one come and get the bed and sleep so they help each other. They have one car today is for one. Some of them are sleeping; some of them are up. They really live together; Haitians are not like that. All the way that you could find a way to live with them, they don't want to understand that.

TS: Is it the same way in Haiti?

Richard: That's the same Haitian system. If you have a dollar in your hand, the person never give it to you. He sees nothing. My way is giving; I'm a giver but Haitians when you give them, it's like you owe them.

Here, Richard, like many others, positions himself as other, as someone who is a “giver,” who is not like “them,” not like other Haitians. When asked if the situation will change, Richard’s first thought is to ask whether it is pertaining to him, not for Haitians in general. In his description of why divisions exist amongst Haitians living in Miami, Richard revokes his own group affiliation in his denial of participating in behavior that is seen as representative of the Haitian community. This failure of unity for Richard and others is also self-imposed, as a response to widespread negative perceptions of Haitians in Miami. As illustrated throughout the chapters, official and non-official discourses of community are entrenched in conceptualizations of the “nature” of the Haitian people and of a “natural” Haitian identity. For many Haitians, this positioning placed them as “boat people,” uneducated and carriers of disease in popular and official imaginaries. Many strongly expressed this positioning as having been construed officially by immigration policies rooted in racial and ethnic prejudice, which then served to reinforce local resentment and envy between various ethnic groups in Miami. Henry Deveroux, a Haitian administrator, explained the positioning of Haitians in Miami as part of a larger discourse surrounding differential treatments for certain immigrants, particularly Cubans. He states:

In terms of being minorities, I think in terms of Haitians and Cubans, Cuban control the majority of the political and economic power in Miami and this breeds a lot of resentment for everyone else. They can also be more racist than whites too! I personally think that the situation in Cuba and Haiti is the same: the political instability, the threat of death. But the United States considers them different, and that is based on prejudice. It’s not as bad as it used to be, but it is still there. There is a lot of infighting also in groups, like between Jamaicans, African-Americans and Haitian because there is very little power to grab on to for these groups so they fight amongst themselves.

Henry contends that Haitians as a collectivity are not privy to certain political and economical resources allotted to other immigrant groups, which he cites is due to external

forces of racism and political and economic bias. He also declares that such predicaments are a result of internal problems within the community itself, such as lack of effective leadership and civic engagement which prevent broader movements of economic and political equality. Henry was not alone in his sentiments, as many informants evoked the notion that “Haitians can’t see the bigger picture,” as in voting as a unit to elect Haitian candidates. Jerome, an HIV/AIDS counselor, told me:

We are not a nation where we like to help each other which is sad. Even though the laws favors people coming from Cubans, but what you have to admire about them is that they do stick together. They help each other; they do everything. They are powerful politically because they are in certain political posts that they do get elected. They make sure that they are part of the mainstream America politically which is what we don’t do. It’s only recently that we are starting to do that and even then you would find people from the outside, like a Hispanic or a Caucasian, who would come in and try to pin them against each other. I can tell you that from the last election in North Miami. There was a Haitian running for mayor and a Caucasian, and the person elected was a Caucasian. This is hearsay because there was never an investigation done but there were a lot of talk that the Caucasian had Haitians doing his dirty work against the Haitian candidate which you will NEVER find in the Hispanic community.

Jerome, like Henry, ties together social relations in Haiti and in Miami as extensions of each other. In addition, like Henry, who states “If you have a dollar in your hand, the person never give it to you. He sees nothing,” Jerome maintains that politically, individual Haitians tend to compromise common goals of the group for personal gain. Lara Pierre declared that this type of behavior was due to “political baggage” from Haiti where “dirty politics” were the root cause of a failed political system, and she saw this as being resurrected in Miami. Gros describes these political conflicts in Haiti as of “kamikaze quality,” where “short term victories for a few and by any means necessary are pursued with zeal matched only by the certainty of defeat for Haiti as a country” (2000: 225). Lara echoes his sentiments by stating frankly, “[Haitians] don’t understand that having enough Haitian elected officials will give

power to everyone... and so it lowers the sum total of respect that people have for Haitians period because [people will start to think] these people you know, they're not like the Hispanics...they hate each other, they hate themselves." Lara's response indicates that the politics of blame and marginalization have come to constitute not only political-economic difficulties in Haiti and in Miami, but damaged subjectivities as well, as a lack of cohesiveness becomes symbolic of deep rooted self-hatred (cf. Gilman 1985, 1986; Fanon 1967).

In Miami, the lack of community civic engagement or mindedness was not only due to fears of repercussions such as deportation or even possible violence to family members in Haiti, but also because of perceptions that the community will not offer them anything in return. With the exception of a couple of activists, none of my informants expressed that they were involved in any community groups or activism. Many Haitian clients that I approached for interviews refused to participate, often citing that they weren't "political." Continual pleas and explanations of the research itself usually never succeeded in an agreement to participate. Later, during a conversation with Lara, a community activist, I learned from her that it was "natural" for these clients to think that speaking to me was "political." She explained that this situation was a broader dilemma for those working in social activism as well. She claimed:

We're always saying if you want to change the condition of your life, you really need to speak up, you really need to write your voices to be heard...NOT in protest... just you know an expression, a vision of an idea of this is what I want for my community. To them and all of that is political, and all of that brings repercussions [of a negative kind].

Lara indicates that speech or “being heard” in any manifestation is political for many Haitians, situating this sentiment in the long and complex history of Haiti where voicing personal sentiments was often silenced through severe retributions.

However Lara, like many others, felt that the political and economic positioning of Haitians in Miami has improved and is progressively getting better. She is part of a growing legion of Haitian activists promoting civic engagement amongst Haitian residents of Miami, by organizing protests, demonstrations, and voting drives, initiatives that were part and parcel of a larger push for self-advocacy and self-reliance in the realm of health, politics, and economics. These undertakings strongly parallel public health campaigns, such as HIV/AIDS prevention and intervention, that strive to make the individual responsible for his or her own health and well being, often obscuring broader historical and social frameworks. These activists have much in common with those who are not as hopeful for a brighter future, those who continually point to the stunted realization of political and economic gains for Haitians in Miami, and even those who emphasize that Haitians are a “naturally” un-political and a contentious community, drawing similarities to their naturalization as diseased, poor, and suffering. Both camps position Haitians as a collectivity invariably caught between a “natural” proclivity for non-participation and “cultural” baggage of strife and self-contempt. Community, for both activists and for Haitians themselves, is situated and lived through intricate managements of extrication, indifference, and fidelity. It involves a double bind of allegiance, belonging conditionally to a community to which many don’t wish to belong and claiming their loyalty to a community in Haiti that no longer stands, except for what it carries in term of miseries, poverty, and injustice. Finally, community is simultaneously lived as

vulnerability and resiliency—implying not necessarily powerlessness but surely unequal power.

Narratives of community—disease, suffering, responsible individuals

Narratives of community extend beyond political and economic participation, and into discourses of identity, personhood, and of the “nature” or “culture” of Haitians.

Although a majority of my fieldwork was done at public hospitals and clinics which attracted those with little or no insurance, rhetoric of Haitians and “Haitianess” offered insight into perceptions of not only poor and marginalized Haitians, but Haitians as a collectivity. Often these positionings lead to discourses of discrimination and prejudice. For instance, Junie, a HIV/AIDS counselor, discusses her own experiences:

Now for the Haitian people, we have the stigma that we are boat people, that we are people mostly coming from boats, and that we don't know how to read, how to write, that we don't know anything about hygiene. So when people encounter me and they say “Where are you from?” I used to take that and say “Where do you think I am from?” They will say every time, you are from the Bahamas, Jamaica, you're this, you're that. I say “What about try Haiti” and they say “no you can't be Haitian.” I respond “Why?” and they reply “Well, you don't look like them.” I say “Do they have a particular way that they look? Do all Blacks have a particular certain way?” and they will respond “No, but you don't speak the same way they do.” I finally say, “Yes, because I was fortunate enough to go to school and not only in Haiti because I went to college here. It will be the same for you because if you go to Haiti, you don't know how to speak Kreyòl. Or you learn to speak it well, you look like an American.” So we have a lot of stigma as the Haitian community that we have to try to get rid of, but it's difficult and living in Miami is even worse because you have the Hispanic community which is well established here and which I think that the laws favor than the Haitian community. So we have to work probably four times as hard as the Hispanic community while when they come here, it's well known and documented that when they do come by boats the way we do and they come from political hardship the way we do, economical hardship but the laws favor them... The worse thing is that [discrimination] is not only blatant but normal. It's just normal, that's the thing.

Junie speaks of confronting common perceptions of Haitians in Miami as looking and behaving unlike her. This leads her to observe through stories of identity politics that the notion of discrimination has been normalized and institutionalized. Many, like Junie, asserted that Haitians were especially targets of discrimination because they were perceived as African-Americans. Many Haitians adamantly discussed the need of Haitians to maintain a separate identity, although they indicated that working together with African-Americans to gain better footing in Miami politics and economical infrastructure was crucial. A Haitian physician, working at both Santè Ayisyen and Miami General Hospital passionately told me:

I don't think that Haitians want to be assimilated to any other culture. I don't think that they assimilate into the African-American culture. They're NOT African-American. They're not coming from the same parts of Africa. We don't have the same ancestors. We don't have the same customs. We don't have the same ANYTHING except the color of our skin in common and I think it's WRONG to ask a Haitian to say that he's or she is African American just based on the color of their skin. It's wrong!

Her comments reflect discourses of preserving and asserting a unique Haitian identity under the rubric of culture and ancestry, one that differentiated itself not only from African-Americans, but other black immigrants as well. However, such comments also circulated alongside and in conjunction with those that actively and inactively rejected a Haitian identity and collectivity.

These discourses of discrimination and identity intersected frequently with those surrounding access to healthcare, highlighting the intersections of health and personhood. There was an overwhelming tendency of both Haitian and non-Haitian providers to speak about the enormous lack of interest or access to healthcare in the Haitian community while simultaneously portraying the community as one which was "suffering." There was also a propensity to discuss these issues in terms of "nature" or "culture." For instance, Dr. Paul, a

prominent non-Haitian physician who heads one of the only Haitian clinics for HIV-positive Haitians in Miami-Dade, explained why he started the clinic. He stated:

One of the reasons that I started the Haitian clinic was that these people are very poorly treated and in fact once somebody said that it was impossible to treat...of course I can't mention names...somebody said that it was almost like practicing veterinary medicine. Such a terrible...I mean such a lousy remark. I was horrified to hear that and that day, I said I was going to start a clinic. I mean the reason that he said that was whatever you say they don't understand and whatever they say you don't understand.

The parallel to veterinary medicine, however, is not just about language barriers or mistranslations, but also rooted in racial imaginaries of primitivism, as if Haitians were somehow more “naturally” not suited for human medical interventions and technologies.

This became more apparent as our conversation continued, and Dr. Paul explained:

One thing is that the Haitian people are very subdued, like they are not very vocal so the result is like if they don't understand something, they may not say like “Look Doc, I don't understand.” Even if a Kreyòl speaking person explains it, they may just keep quiet. And they misunderstand instructions little bit more than others. Like when the pharmacies make mistakes, even if they know, they don't challenge the authorities very much. They are very subdued and they are very secretive. They don't want people to know. For example, I have some Haitian patients through the hospital, who when I say come to Haitian clinic, they say “No, I don't want to be mixed up with Haitians.” The Haitians, they don't want to mix with Haitians so that each other will know that they have HIV. And other thing is poverty. Most of them are unemployed. A fair amount are illegal and some of them don't know how to access services. So it's partly because the places that have services don't cater...they don't have Kreyòl speaking people and they are treated very badly. So those are the challenges that I have with Haitians.

Dr. Paul clearly indicates his disturbance of a colleague's relational stance between treating Haitians and treating non-human animals, but then categorizes his Haitian clients as beyond achieving total comprehension and compatibility in clinical encounters.

This positioning of Haitians as suffering and as incommensurable to modern medical interventions infiltrated an overwhelming majority of conversations with providers. For instance, a community health worker, in advising me about working with Haitians, warned

me that it was difficult to reach Haitians because of their “cultural” tendencies made them very “prideful” and reluctant to discuss certain topics like HIV/AIDS because of the reaction to ostracism and the prevailing notions in the United States about their uncleanness. Others warned me of obstacles often associated with the “culture” of the Haitian people which prevented them from reaching Haitians in HIV/AIDS prevention, including a lack of education and time, literacy, immigrant status, language barriers, and economic hardship. Furthermore, providers often perceived differential conceptualizations of HIV/AIDS or resistance to receiving healthcare as a direct result of a lack of education or from cultural beliefs. It is as if education is not necessarily the institutionalized kind, but rather “education” in terms of assimilation of ideas and concepts of biomedicine, and synonymously the shedding of traditional cultural beliefs. For instance, Dr. Bristol discussed his clients’ likelihood of not accessing the medical system properly due to factors related to cultural norms by stating:

And as far as access to healthcare, they don’t access healthcare that well because the Haitian culture is that they think that you go to doctor when you’re sick. If you are not sick, you shouldn’t go to the doctor. For them HIV is a big problem because here, they tell you “you have HIV” so then you have to go to the doctor. Now, they were feeling perfectly well before they started going to the doctor and when I give the medicine and they get sick because of the side effects, and they think it’s because of the medicine. So I mean that’s where the challenge is but we educate people and give them certain information about the pathogenesis of HIV and the transmission of the virus. We tell them that taking the medicine will make you feel sick because the virus is dying, so therefore it’s worth for them to take the medicine and the side effects will slowly go away. So once you convince them and they buy that and they take it, otherwise you lose them completely and it’s a big problem. They also have this thing about the voodoo you know. In fact I had a couple of patients who have said that “I don’t have to use a condom. I am cursed by an oungan but my wife is not. There’s no way that she’s going to get it because if I can protect her with my voodoo. Condoms are not necessary.” I mean he really believed it. So we had to send him for therapy later on and educate and educate and educate to convince him. In fact I had a Haitian doctor at that time and he was prepared to get an oungan to come and tell him that “I’m a voodoo doctor but I cannot cure HIV or protect you...”

Dr. Bristol equates lack of access to health care to cultural norms that do not favor preventive care. He fails to validate the assumption that antiretrovirals can cause negative physical and emotional side effects; instead he argues that it is Haitians who must be educated and even tricked into understanding medical explanations of HIV/AIDS. Belief in voodoo serves as the prime example of such incommensurabilities between modern medicine and traditional beliefs. Education in official discourses of HIV/AIDS stands in direct opposition to culture and the practices that it engenders. Dr. Bristol's comments represent the myriad examples in which providers attributed certain qualities and temperaments to "culture." But these discourses of characteristics and actions stemming cultural influences were often indistinguishable from those that derived from the "nature" of Haitians. Here, the notions of "nature" and "culture" intersect, approach, and overlap, resulting in identical meanings, essentializations, and explanatory power. Cultural reasonings of not only risk for HIV/AIDS, but also adherence to treatment and accessing health care in general are in the process of becoming naturalized as part of the official discourses of HIV/AIDS prevention.

In contrast, explanations most given by Haitian clients accessing the clinics and hospitals were that they often feared stigma and avoided dealing with rude treatment and unreasonable waiting times. A woman whom I met in a local clinic explained her frustrations with coming to get healthcare as this: "Four hours, sometimes you come at 11:00AM, you get hungry and weak because you waiting too long. When I come here I feel more sick." For this woman, feeling sick was a result of the interaction with health institutions. These stories of locating illness in direct relation to health care institutions and staff were abundant. Some complained that although they wanted to seek regular services, they could not afford to seek out necessary or preventive health services because it often

involved taking time off, often an entire day, from their hectic work schedules and jobs without paid sick leave. On rare occasions, many feared coming to the clinic or hospital because of being reported to immigration services. There were several times during my fieldwork where patient attendance was quite low, and many providers attributed this to fear of “immigration raids.” In early 2006, there was a prolonged scare in the aftermath of anti-illegal immigration discourses in the national media that lasted a couple of weeks where community organizations convened a meeting to address these issues. Here, they spoke of “strong rumors about the fact that INS trucks were picking up people” or that “you can get into trouble for associating with an illegal.” They stated that these stories weren’t completely preposterous because businesses, like the construction business, were suffering because many employed illegal immigrants. Many leaders were worried that people were not accessing health services and that the situation was becoming “dangerous” because sick individuals were potentially dying at home or women were delivering at home. These leaders were aggravated by government officials’ lack of transparency in this process, and were equally frustrated with their inability to reach Haitians who were not accessing services.

Similarly, stigma was reiterated frequently as a cause of keeping many from seeking HIV/AIDS testing and preventive services. Richard, an older Haitian gentleman who attended HIV/AIDS educational classes at Miami General regularly told me that he thought that many Haitians didn’t come to these classes because “stigma” prevented them from coming. Stigma for Richard signified fear of and judgment from having their condition revealed. Magda echoed Richard’s sentiments by saying, “If I tell another Haitian, they will tell others so I don’t tell anyone that I’m sick.” Thus, stigma was relational to disclosure of

personal information, and operated as a set of perceived obstacles that averted interactions with health care systems.

A few Haitian clients, particularly those working as patient advocates, reiterated their thoughts on why fellow Haitians were hesitant in attending HIV/AIDS prevention programs through the notion of what is often labeled as “HIV fatigue.” In HIV-positive adults, fatigue is a common symptom of either the disease or a side effect of HIV medications. However, both clients and providers discussed “HIV fatigue” as a saturation point that clients reached as a result of over-inundation of repetitive HIV/AIDS information, resulting in outright or indirect refusals to engage in HIV/AIDS prevention programs. For instance, a program administrator explained, “The community is become complacent about HIV, maybe they’ve become HIV fatigued. They don’t want to hear about it. To me, that can make someone...again if those folks are facing other separate problems, they may be less likely to hear the message of HIV.” For many providers like this administrator, the notion of “fatigue” was often associated with direct indifference and unconcern, sentiments that would inevitably lead to unsafe practices and an increase in HIV/AIDS within the community.

Many clients presented a differing view of “HIV fatigue,” contending that their needs for prevention programs, whether through educational class or counseling sessions, are drastically divergent from those currently being implemented. Through overt articulations and participatory conjectures, clients expressed that they desired a format that was less “educational” and more reminiscent of a “support-group.” They wanted classes that gave them information relating to their daily lives, on issues not only concerning their health or their illnesses, but also about immigration, poverty, housing, politics, transportation, depression, isolation, religion, family and re-socialization after an HIV-positive diagnosis.

Clients also stated that a lack of participation stemmed from inconvenient timing of classes and office hours, fear of being seen by other Haitians, and an aversion to discussing HIV/AIDS repeatedly. One woman emphatically explained, “Sometimes, I’m just too tired of talking about the same thing over and over again. It’s too overwhelming because you deal with the disease everyday and the last thing you want to do is talk about it more.” The notion of HIV fatigue for her was not due to complacency or to indifference; rather discussions of HIV/AIDS had become too consuming and too definitive of her daily life. Indeed, the HIV/AIDS prevention programs in Kreyòl were not well attended at many health care venues including those at Miami General, which hosted only 2-4 regular clients bi-weekly, as compared to the English and Spanish classes, each of which hosted 30-40 regular clients weekly. It was a similar situation in the health department training seminars in Kreyòl. The training manager for these seminars relayed that they “try” but have to consistently cancel these classes because not enough people attend or are interested in attending. These concerns indicate serious and complex misalignments between the ways in which experts much like Steve in the initial vignette propelled discourses of community, disease, and identity under the guise of prevention and how clients negotiate individual and collective participation and assembly in the name of science and public health.

In this chapter, I have demonstrated that notions of individual responsibility in prevention management and self-management of risk often become inseparable from notions of personhood and identity. Providers are constantly encouraging their Haitian clients, both positive and negative, to be the “drivers” of their medical care, to “be empowered,” and to see new “opportunities” being presented by being HIV-positive. But these ideal visions of patients are always already muted by constructions of a particular Haitian identity and

collectivity, as steeped in too much culture, too much ignorance, and too much hopelessness, and can only be transcended through education, equality, and modernization. Clients are fully implicated here as well. They continually orient themselves to various institutions or diseases, negotiate resources, and vie to live both inside and outside the system, all the while the system is generating data about the dangers of their particular group. Steven Epstein writes:

In the field of biomedicine, for example, certainly the patient who ‘does her homework’ and confronts her doctor with alternative perspectives about her own conditions is making a foray of sorts into the domain of lay participation. But when whole groups of patients suffering from the same disease establish new organizations, elaborate a collective sense of self, and then act in concert to challenge the medical conceptualizations of their condition and its treatment, then the intervention is potentially both more radical in character and more transformative in its consequences. (2003: 173)

As I have illustrated in this chapter and will more concretely in the next, this project is not an analytic of marginalized individuals’ attempts at altering science from “below.” But in the absence of collective participation due to complex economic, political, and social disenfranchisement and history, considerations of expertise and experts from the so-called margins demonstrate the acute difficulties of official and scholarly demarcations between individuals and collectivities, between community and identity, and between nature and culture. It is in these interstitial spaces, grounded by debates over governance and expertise, where there are many blurred sites of struggle and spaces of participation.

FOUR

Normalizing Difference: Confronting Health Disparities and the Promise of Positive Living

Jacques Chantal is a young man I met at Miami General Hospital. Even though he did not currently attend any of the HIV/AIDS classes or programs, Miriam, his social worker referred me to him, characterizing Jacques as an “ideal” person to answer questions about HIV/AIDS in the Haitian community because she considered him the embodiment of a “successful” client. The first time I met Jacques, he immediately identified himself as gay and as Haitian-American. He was young, in his late twenties, and had been HIV-positive for several years. When we sat down to speak in private, he told me a little more about his life and confided at the very end of the interview that he was currently in the country illegally. During the interview, he described his youth as one spent in cities along the East Coast of the United States, having immigrated as a young child from Haiti. He explained that he was deported back to Haiti as a result of minor drug charges when he was a teenager, and as a result, spent time living and working in Port-au-Prince. Although he knew that he was HIV-positive long before he was deported, he was not taking antiretrovirals until his health began to deteriorate in Haiti. He detailed his return to the United States through illegal means in order to have access to better medications and health care. Jacques spoke of his teenage years with fondness, not for “being stupid with drugs and sex” but for the kinds of freedom he associated with living without constant worry of deportation and having many friends with whom to interact. I spent a considerable amount of time with Jacques, and want to highlight here one such day in order to demonstrate broadly the ways in which Haitians in

Miami, like Jacques, negotiate the contours of citizenship and subjectivity vis à vis the biopolitics of difference in HIV/AIDS prevention programs.

First thing in the morning on July 14, 2006, I set out to pick up Jacques. I had agreed to accompany him for an appointment for affordable housing at Safe Haven, an organization that provided social and psychological services to the poor. I drove to the Saint Andrews residential center where he was currently living. It was a huge white building with a red roof, and took up about two city blocks. It was in a residential neighborhood bordering a major highway, and had a long high metal wire fence all around it like a penitentiary. Jacques told me that he didn't spend much time there except to sleep because he worked most of the time at his new job "off the books" as a waiter. He told me that he was feeling a little down because his phone kept getting stolen at the residence house and that last night was hard because he only got \$10 in tips. He said that he's been "waitering" for a long time, even back when he was in New York, and if he had his papers, he would "want to work in some of the fancy restaurants."

As we headed off to the appointment, he told me that his counselor had referred him to this organization and he described the independent housing situations that they offered with delight. Their brochure claimed that:

Safe Haven offers a continuum of residential settings ranging from highly supervised group homes to more independent satellite apartments. All residences are integrated into the community. The members are assisted with skills associated with daily living, i.e. education regarding self-care living skills, interpersonal communication, personal hygiene, grooming and tenant living skills. Staff give the residents the support and assistance necessary to help individuals become increasingly independent in community living. The goal is to provide safe, secure and affordable housing to the individuals served. All residents must be employed or participate fully in the program, and must attend mandatory weekly guidance counseling.

His counselor thought that he'd be "perfect" for this program. It was raining as we arrived, and there seemed to be about 20 people all milling about the front area and chain smoking. Few were talking; many were sitting silently still, staring into the air and not moving at all as if they were heavily medicated. Inside, there was a hallway leading to an expansive room where there were many rows of chairs and about 60-70 people packed to full capacity. Jacques surmised that this served as a soup kitchen on certain days because of the large crowd.

The woman with whom he had an appointment was tiny, short, and thin, with long black hair pulled back into a pony tail, and looked very young, like a teenager. Her small office smelled like vanilla, was incredibly tidy, and had dim lighting, akin to a spa. The woman listened patiently, nodded her head every once in a while, and then said that she would explain a little about their facilities, ask some questions, and give him the application. She explained that there was currently a waiting list, and that there were two parts of the application process, one being the application, the second being a health evaluation "which can be filled out by any physician."

She asked if Jacques received any public benefits and he responded "like what?" and she replied "like SSI or Medicaid." He told her that he was on Ryan White and she said that she wasn't "aware of that benefit." I added that it was called ADAP and that it provided him with free HIV/AIDS medications and health care. She told us that she understood but still had never heard of it as a public benefit. She then inquired about Jacques' work status, to which he replied that he was "doing something on the side." She emphasized that all residents were required to work or attend the programs fully because the housing costs were not fully covered as one still paid about \$300-350 a month out-of-pocket. Jacques' raised his

voice a pitch or two when he asked about the possibility of finding space in their homeless facility, but the woman explained that it was “for homeless clients or for people in emergency situations.” I asked her if it was easier to get off the waiting list if one was living in their homeless shelter rather than an outside facility like the Saint Andrews. She hesitated for a few seconds, and then said “Yes...it’s a little bit easier because we give priority to those in our facilities but we do include people from other places too.” She stated that he would have to fill out the application just to get on the waiting list.

She then implied that she would ask him a few questions and pulled out some forms. She began asking questions such as whether he had ever been treated for a mental health disorder, if he had been hospitalized for a mental health disorder, and if he was taking any medications for any disorders. He answered “No” to each question which must have surprised her as she kept saying “Oh, wow!” or “Huh?” after his responses. He explained that his current counselor from Saint Andrews was scheduling something for him which included a psychosocial evaluation. She finally stopped and pronounced that most of their services were for individuals who “experience severe and persistent psychiatric disabilities” or have “a severe history of psychiatric disorders like schizophrenia, bi-polar disorders, or major depression.” She said that most also have substance abuse problems as well. She put her pen down and looked directly at him and asked, “This is strange because most of the people that your counselor refers to me qualify but if you don’t have a history or are not diagnosed with anything, then we would have a problem with you qualifying.” In addition, she exclaimed:

You may also want to think about whether this is something that you want to do. I mean would you want to live in this kind of a facility? Some of our cases are pretty severe even in independent housing. I don’t know if you would want to live there if you even qualified under mild depression.

Jacques just nodded his head in disbelief and then quietly uttered if it was still possible to fill out the application because he didn't "mind living there." She asked him to talk to his counselor and to get the psychosocial evaluation done and to also think about whether he would again want to live there. We thanked her and left. As we were leaving, Jacques complained about his hunger, and asked if I had any free coupons for Subway sandwiches that were given out to those who attend clinical groups by pharmaceutical companies. I had an extra one and took him to get food. On the way we talked about the meeting and I asked him if he was fine with the kind of living situation that the woman described, which was so drastically different from the one he seemed excited about from reading the brochure. He said "I would still live there but her questions made me wonder if it was really independent living." He said that he would talk to his counselor to assess his options.

After lunch, we headed to visit his aunt, whom he described as a mambo and the owner of a Haitian botanica. She was leaving for Haiti the very next day and he explained that he wanted to give her some money to give to people that were taking care of his house in Haiti. He explained that his aunt was "suspicious of everybody and everything" and asked me politely not to take any notes while we were there. He quickly exclaimed, "I hate this stuff, this Haitian stuff. I mean I know she's involved with it but I really hate it."

The botanica was opposite a pharmacy, a little Haitian record store, and next to a car repair shop. The windows were completely covered in white sheets like curtains, and some statues were displayed outside the entrance. Inside, it was dark and every space was filled to the brim. On the shelves, there were wooden vessels, miniature chairs made of straw, plastic gallon jugs like the ones which hold paint in art classes, and plastic canisters like those which hold candy in mom and pop stores. Paintings of the Haitian countryside and various pieces

of clothing were hanging on the walls. A blue mat lined the floor, and looked comfortable enough for someone to take a nap or to serve as an examination table. Hundreds of dolls and candles lined the glass cabinets at the front of the store—some portrayed religious figures, while others depicted sexual reproductive organs or standard characters of men and women. There were also calabashes, voodoo flags, and cloth pieces of every possible color.

Suddenly, a middle-aged woman with a patterned head scarf and red painted nails introduced herself as Jacques' cousin and led us to the back of the store. She stared at me, and he quickly introduced me as a friend. I sat opposite him on a stool while he made himself comfortable on a folding chair facing his aunt. He opened his notebook and started taking out money from his wallet and writing. Jacques began telling his aunt about all the errands that he needed done. He mentioned names to whom money went—for instance, he wanted to give \$60 to a neighbor who took care of his house. His aunt, on the other hand, repeatedly asked him to write full names, addresses, and phone numbers. When Jacques couldn't think of the exact address or phone number, he described other people like family members who could help her track them down. He then handed over some cash for an identification card that he needed from Haiti. When he handed over about \$200 in total, Jacques exclaimed "Man, I have no more money because all of it went to Haiti!" He gave her additional money which he told me would go toward his bank savings account, currently under her care since he could not legally open a bank account. He explained, "I don't do nothing, don't go out, buy anything...I just do my thing, go to work, eat, sleep so all my money goes to saving up...I guess for a lawyer."

Soon thereafter, we left for his final appointment with a dermatologist at Miami General Hospital. On our drive there, Jacques confided that he was "scared" about being

undocumented. He asked if I would inquire with a lawyer friend about a few questions about his situation. He divulged that he was able to enter the United States through a governmental technical error and had procured a legal visa as a result. He was worried that if he got caught, the penalties would be severe. However, he thought that there may be chance of medical amnesty given his HIV-positive status.

We walked up to the hospital waiting room, where there were about 15-20 people. While we were waiting, police officers wheeled in two men, who looked to be prisoners as they were handcuffed to their wheel chairs. They were wearing hospital gowns and each had a small long black bag that he kept in his lap. One of men looked jittery and anxious, as he kept checking his hospital gown and adjusting it while keeping his hands well hidden beneath so that others couldn't notice the handcuffs. He would look up intermittently at the people in the waiting room and quickly glanced away when he did make eye contact.

Finally, Jacques was called in and as he reached the door, he stopped and asked if I wanted to come in. I went in. The attending physician was perky and had a slight accent. She inquired about Jacques' ability to speak English and after he replied "Yes" without an accent, she introduced herself to us and asked if I was his partner. Jacques laughed and indicated that I was a friend, she replied "Well, I'm going to ask you some medical questions and at any time you want her to step out let me know." She moved my chair away from the examination table, so that he could get undressed and be examined behind the curtain. He had explained previously that he had anal warts, and that they had disappeared after his previous physician "did the freezing thing." The attending asked him about his state of health, especially inquiring about his CD4 counts. Jacques repeated that he was feeling good and that he had been taking all his antiretrovirals on schedule. He added that he stopped

using the wart ointment on the advice of his physician because of an adverse reaction. She chided him in a friendly manner, explaining that he was supposed to stop using it only for a couple of days and then go back to treatment. She then inquired if he had ever seen a gastroenterologist. Jacques looked confused, asking “What is that?” She replied “It’s someone who checks your gastric organs because sometimes when you have these warts, the virus can spread and can go up your gastroenterol tract,” making a movement to signify her belly area. Jacques smiled as if to indicate that he understood and said that his doctor had indeed given him a referral but the nurse who was to schedule the appointment never told him anything. She encouraged him to make another appointment to make sure he had nothing “inside.”

When she was finished with the examination, we went to the HIV/AIDS clinic so that Jacques could inquire about his referral from the station nurses. When they asked him questions about names of physicians and reasons for the referral, Jacques stated that he did not know the information, saying “Oh, I forgot her name...she gave me a referral for what’s that thing where they put that thing and look inside you?” The nurses, in turn, just stared at him in a manner that indicated their displeasure, especially a Haitian nurse whom I recognized because she had lectured at a Kreyòl education class. However, they seemed patient and somehow managed to figure out that he needed a colonoscopy and a referral from a nurse who was absent. A nurse wrote down a name and phone number and asked him to call for the referral.

We went back to the car. As we sat in the car, Jacques made the phone call for the referral. The person must have asked for his hospital card number because he rifled through his wallet, screaming “Oh shit! They didn’t give me back the card, the red card.” He

explained that he couldn't do anything without this card and ran back to the hospital to find it. When he came back, we realized that it was already the evening. As I drove him back to the his residence center, he reiterated how much he was “terrified” about his legal quagmire, explaining that he was reluctant to hand over all of his savings to an immigration attorney who could very likely not do nothing in return. He expressed his thanks for my company, indicating that he “would have never gotten all this stuff done” by public transportation.

This day in the life of Jacques serves to highlight the complex webs of negotiation that many Haitians face daily in trying to secure economic and health benefits in Miami. Although Jacques may not experience the same types of obstacles as other Haitians in similar situations, as documented in previous chapters, such as illiteracy, facility with the English language, and economic demands on time, he too must endure institutional and social impediments in the face of legal and economic uncertainties. For instance, his undocumented status forces Jacques to traverse complex and sometimes hazardous situations with determination and resourcefulness. Such observations purport neither idealization nor particularization of Jacques' situation; they also do not aim to obscure his struggles with poverty and personal isolation. Instead, I argue that Jacques' day highlights the complex strategies that facilitate a broader framing the scholarship pertaining to biological citizenship and biosociality.

In this chapter, I illustrate these formulations through close ethnographic analyses of the multiple forms of the politics of difference in the field of HIV/AIDS prevention. First, through a discussion of the increasingly prevalent notion of “positive living,” I contend that the various processes, employed by health and social service officials and individuals like Jacques in the name of “personal responsibility” and “accountability,” serve to construct and

manage responsible, ethical, and enlightened biological citizens. Individual responsibility coexists, contradicts, and overlaps with social responsibility in the rhetoric surrounding HIV/AIDS, as exemplified by Miriam, the social worker's depiction of Jacques. Jacques is considered an "ideal" and a "successful" client not only because he takes his medication and is able to navigate through systems of health care without great difficulty, but also because he demonstrates characteristics such as self-sufficiency and self-management. Such attributes are the very foundation of the notion of "positive living," and they symbolize forms of empowerment vis à vis HIV/AIDS. As such, I argue that the "positive living" movement in HIV/AIDS prevention is fundamentally one of contemporary biological citizenship.

Second, I will demonstrate in this chapter that such notions of biological personhood and citizenship, as espoused by the concept of "positive living," are not always rendered viable or even sufficient for many Haitians in Miami, even Jacques, for whom such projects of citizenship embody contentious historical injustices and current practices always already steeped in inequality and discrimination. I argue that Haitians in Miami negotiate critical resources and strategically navigate through myriad of political, social and medical institutions by simultaneously claiming and rejecting citizenship projects of a biological kind. In so doing, they expose the racialized and nationalized forms embedded within contemporary projects of biological citizenship. By illustrating such examples that underscore the interconnections between the politics of difference and the management of individual and population health, I extend current scholarly debates of biosociality and biological citizenship.

Finally, this chapter highlights the ways in which the national rhetoric of racial and ethnic health also serves to trouble current scholarship on biological citizenship and

biosociality. By documenting the proliferation of racially and ethnically specific HIV/AIDS prevention programs in Miami, I argue that HIV/AIDS prevention and politics in Miami are structured through the concepts of racial and ethnic difference. Narratives of race and ethnicity here serve not only to undergird the health disparities debates, but also to make transparent local struggles to increase public support and awareness for racial and ethnic-specific health programs. Like the few scholars who critically attend to the complex features of health disparities, I also explore the various ways through which racial and ethnic disparities in health have come to be a commonsense reality. However, I offer broader analytical insights by attending to how such categories of racial, ethnic or cultural difference continue to be fundamental to notions of citizenship. I purport that the concepts of difference in health have become reinforced and normalized not just through institutional practices and policies, but also through scholarship that attends to social and structural inequalities and biological citizenship. As such, this chapter stimulates broader questions related to the ways in which differences situated along concepts of race, ethnicity, and culture come to be simultaneously reinforced and erased in distinct fields of study.

Chita Pa Bay (The More We Stay in Our Corner, The Less We Learn)

One day, in a Kreyòl based HIV/AIDS prevention education class at Miami General Hospital, Miss Jill, as we all called her, requested some advice from other class members about a situation that had been troubling her for the past couple of weeks. She explained that she received a letter which displayed the words “HIV/AIDS” on the envelope. She recounted that she felt “horrible” in getting such a letter at her home because those she lived with did not know that she was HIV positive. She felt outraged because she didn’t feel that it was

“right” for anyone to send such a letter to her home with “those words written on the outside for everyone to see.” Mona, a current hospital volunteer and newly minted patient educator, peered at Ms. Jill and all of us from over the top rims of her thick glasses. She took no sympathy and told Ms. Jill in a stern voice to “take responsibility” and to “call where the letter comes from.” Mona reminded her to forcefully demand to talk to someone in Kreyòl, and to insist on a translator if there wasn’t anyone available.

For each problem or question that a member of the class had, Mona had a Haitian proverb and related story to go with it. For Ms. Jill’s concern, she began by telling us of a Haitian proverb which she translated as “The more we stay in our corner, the less we learn.” Mona explained that it meant that “You should not wait too long to ask someone for something that you need.” She began her story by describing a woman who did not have enough money to feed her children so she decided to ask her neighbor for ten dollars:

This lady went to her neighbor and started describing her money problems, taking all day to sit and talk. While this woman was visiting with her neighbor, she witnessed many people entering her neighbor’s front door and ask for money. Her neighbor handed out cash to each and every one of these people that came. The end of the day approached, and the needy woman finally asked her neighbor for the ten dollars to feed her children. Her neighbor cried surprised and annoyed “What? That’s what you wanted all this time! Why didn’t you just ask me earlier? See that woman who just came by? I just gave her \$20 for the movies.”

Mona’s story garnered head nods, understanding moans, and sighs of agreement. Her insistence on asserting one’s right to privacy as well as her story detailing the importance of seeking out and obtaining needed resources stressed notions of self-responsibility and self-management in the face of living with HIV/AIDS. On the one hand, such clinical educational classes, public lectures, and private conversations, under the auspices of HIV/AIDS prevention and “positive living” programs, seek to produce individuals not only well versed in the self-management of risk and garnering resources, but also those who are

adept at changing the ways in which they come to conceptualize living with HIV/AIDS. On the other hand, such demonstrations instructing mainly Haitian, African American, and Hispanic clients in the art of “asking” or “demanding” material resources and social services serve to reinforce what legal scholar Dorothy Roberts (1997, 2002) contends as constructions of welfare recipients as immoral, dependent on state supervision, and incapable of governing themselves.

The concept of “positive living” is a growing movement that has become synonymous with HIV/AIDS in recent years. As those with HIV/AIDS live longer through antiretrovirals and better managed care, activists and providers seek to change people’s notions of living with the disease, rather than dying from it through public and private sessions aimed at empowerment and life-affirming attitudes. As one community-based organization in Florida put it, “The challenge is no longer HIV itself; instead, the challenge is how to take control of one’s own life, acknowledge the difficulties, face each day with renewed hope, and live with the reality that no one is alone in this battle” (OASIS 2007). Many positive living programs in the United States, like the North Carolina Council for Positive Living, focus on issues of personal and political empowerment through programs in activism and education. Others designed for global settings, like the United States Agency for International Development’s The Positive Living Project in Nigeria, emphasize economic development, extended health care, capacity building, and prevention. In clinical HIV/AIDS prevention education classes at Miami General Hospital, the notion of “positive living” is evoked repeatedly. For instance, immediately after Mona finished her story, Jaime, the lead health educator and a huge proponent of the concept, began to lecture on the importance of seeing things in a more “positive” way. Jaime, who is HIV-positive and has an HIV-positive

child, emphasized the importance of taking “the negativity of having a devastating disease and turn[ing] it into something positive.” He walked to the black board at the front of the class and wrote and underlined the words “positive” and “negative.” He then wrote “love” under positive and “fear” under the negative. He emphasized that “Humans have the power of choice and that they can choose which path to follow.” He continued by stating that “We can either choose the positive path or the negative path but when it often comes to disease, we choose the negative path of fear because of a lack of education and fear of discrimination and stigma.” Returning to his original dichotomy of “positive” and “negative” ways of thinking about disease, he asked what the notion of “disease” meant to people in the class. Class members responded by saying “deadly,” “unhealthy,” “virus,” and “depression.” Jaime nodded his head up and down rapidly as if these were the exact answers he wanted to hear. He explained that most people indeed do associate disease with “something negative,” and that the key was to “turn this way of thinking into positive things.” Mona pitched in and said “Yes, having a disease can give you a new beginning” by presenting you with an opportunity to “be healthy and to take care of yourself.” A client interrupted by asking “You mean like a crossroads or something?” This question elicited many nods from the class and Jaime continued by saying:

Yes, like a crossroads, where you can become more goal oriented by taking control of your life and yourself by taking your medications, going to the doctor and challenging yourself to keep on track. It can give people a lot of hope and can push people into being more responsible. You should present yourself at all times in a positive and powerful way.

“Positive living” programs have become integrated into HIV/AIDS prevention programs like this one at Miami General Hospital, and incorporate approaches of self-help by teaching that testing positive for HIV/AIDS equates to rebirth, second chances, and life crossroads. As

Jaime argues, a HIV-positive person should be thankful, gracious, and actively benevolent as a result of being a benefactor of such a transformative life course. This translates to becoming more self-aware and self-educated about the disease, its various attributes, and everyday life in general. For instance, an African-American woman in another class, conducted in English, declared:

In order to live for a long time, you have to educate yourself, be strong, talk your mind, and take care of yourself because only you can do this, and nobody else, not even your doctor. It took me a long time to make inner peace with myself and now I am thankful for the disease because I feel that I finally appreciate life and see it as a second chance. Don't just live but thrive! I used to come to these classes and go to support groups but now I don't go to talk about all the problems with my medications because I've gotten over it. I live with this thing called HIV. HIV doesn't live with me. HIV doesn't control me. HIV is not my biggest problem. You can't really just sit by and get down on the disease because you don't have time to do it. Look at me, I am normal, someone who stayed at home, did nothing but take care of my kids, went to church, did PTA, and am god-fearing. Now my friends are angry that someone like me is a victim of the disease. I am a victim, but I am not angry and I don't let that stop me from going on with my life and living it the best I can.

For this woman, positive living equates to a kind of personal uplifting based on education and advocacy that transforms her sense of self from someone who feels angry and victimized to someone whose life is mediated by positive living. She affirms that she has reached self-enlightenment, by making “inner peace” with herself and being “thankful” for the disease because she is “finally” able to “appreciate life” through her condition. In addition, she asserts her domination over her disease by invoking notions of choice and control, declaring that it is her who “lives” with HIV/AIDS. Like Jaime and Mona, this woman attests to the promissory nature of positive living, realized through new ways of relating to herself and others through somatic and biological meanings of HIV/AIDS.

The promise of positive living is not only individualizing, as demonstrated in previous examples, but also collectivizing. Positive living also means exercising greater

responsibility and honesty toward others, especially sexual partners. There is a strong sense that one has an uncontested responsibility to not spread the disease to others. For instance, a patient advocate explained to her clients:

I would never want to infect anyone else because I would never want the things that happened to me to happen to anyone else. Remember that day that you found out? I wouldn't want anyone else to have that feeling ever in their lives, even though now I feel blessed with all the things that were going on in my life.

Even though she now feels “blessed” by her situation, she expresses her unwillingness to have anyone else go through the transformative changes to reach that level of self-acceptance. The concept of positive living implies an inherent moral liability attached to intimate relationships, especially with those who are not HIV-positive.

This accountability does not end with sexual partners and acquaintances; in fact, it extends to others living with HIV/AIDS as well. For instance, a concept repeated often by both pharmaceutical representatives and by providers is that all clients attending clinical support groups and educational classes were lucky to receive antiretrovirals and other medications for free or for a modest fee. One nurse lectured a client who complained of the rising cost of medications by saying, “It’s a beautiful thing that you can get meds for free. Many people in the world who don’t have meds and they would do anything for this opportunity.” Like this advocate, many providers often reiterate the good fortune and luck of HIV-positive clients through obligatory terms. That is, they instruct clients on the importance of being faithfully adherent to antiretrovirals not only because these medications are life-saving and life-giving, but also because they are unavailable to many others around the world. To not be adherent to medications, therefore, implies that one is not taking responsibility for one’s own self and health, and at the same time, being disregardful to those who provide the opportunity for such drugs and to those who have no access to them.

Additionally, there was a strong push by providers to link this kind of responsibility to others with advocacy and activism in general. This was especially true for providers working with African-Americans and Haitians because these two groups were slotted to be the least involved in garnering resources and support for various HIV/AIDS issues. One extreme example of this was during a regular HIV/AIDS education class, when an African-American man named Chris commented that “society has blinders on over their eyes, mufflers over their ears, and a gag over their mouth,” in reference to how he was feeling about the public’s reluctance of aiding those living with HIV/AIDS. He exclaimed:

Whenever you turn on the TV, all you see is all those people with the “Stop Abortion” signs and they are protesting and what if we could have millions of people going to Washington for us. Nobody cares about AIDS.

Chris’s statements did not go over well with Ramon, a social worker. Ramon responded by asking Chris “How long have you had the disease?” Chris replied in an amused tone, half in disbelief and half in laughter, “I was diagnosed last year in May.” Ramon, as if he’d already known this answer, jumped in before Chris even finished, “And before then, what did you know about AIDS and what did you do about AIDS?” Chris, surprisingly calm as if he was ready for a debate, replied “I didn’t know nothing about the disease until I got it.” Ramon’s voice, at this point, became very loud and had a sharp cutting tone, and he was shouting feverishly at Chris and at the rest of us. He cried:

Well, I was going to do this later but I have to do it now. There were a lot of people who fought for what you have Chris. There are a lot of people who died for you. Many people went to Washington and tied themselves to flagpoles so that we could have the medication that we have today. What I think is the problem is that activism is not taken seriously right here in this room. When everything is gone is when you’ll start complaining. People like you are complacent and just don’t care about being advocates for budget cuts and for more services for AIDS patients. Remember how we and you guys said that we were going to write letters to politicians last Tuesday? Well, guess how many letters came out of that meeting? Nothing! Not one letter was

done so when you want to complain about how you don't have this or that or when this and that is getting cut, you have no one to blame but yourself!

Although there were a couple of women who were vocal about their support for Ramon by murmuring "tell em' Ramon!" the majority of the audience was left speechless by the tirade. The tension was somewhat undercut by a woman who talked of the difficulties of raising children who were HIV-positive and traveling to Washington DC to advocate for issues related to children who were HIV-positive. Following her lead, the patient educator steered the continuing conversation on to topics surrounding activism.

Ramon's episode was similar to other providers' lectures about the general lack of activism of African-Americans and Haitians. Providers and patient activists continually linked advocacy and activism with innate obligations of being HIV-positive—that if one were positive, one should get involved not only in making sure that services and support would be available for future generations, but also that resources would be maintained for those currently in need. Clients were told that in order to be "effective advocates," they had to be knowledgeable about information regarding HIV/AIDS, have unwavering focus to get results, and have strong rapport with others. In order to begin on the path to advocacy, clients were encouraged to have "respect" for themselves, others, and the cause. For instance, in his outburst, Ramon accuses both Chris and the rest of the class of complacency and indifference because they do not take activism "seriously." Using the communicability framework put forth by Briggs and Hallin (2007), whereby attention is drawn to the ways in which subjects and citizens are constituted through ideologies of discursive flows of knowledge and information, I argue that Ramon presupposes Chris's obligation to "act" as an active and responsible consumer who is able to use the forms of knowledge that he has received and processed to secure his social and medical benefits. Chris's inaction renders

him as a passive and negligent individual who is to blame for diminishing and potential loss of resources. His inaction, thus, makes difficult the linearity of knowledge-based hierarchies of communicability (Briggs 2005; Briggs and Hallin 2007). Ramon's construction of Chris and the rest of the class, made up of mostly African-Americans, Hispanics, and Haitians, as unethical and undeserving recipients of resources underscores their positioning as dependent and in need of governance (cf. Roberts 1997, 2002). It also highlights how the politics of difference, through race, class, and gender, structure access to what Steven Epstein calls the "lay expert identity" (1996: 293).

These notions of "positive living," of responsibility to self and others, did not always translate well or in the same ways to Haitian clients, activists, and providers. At times, "positive living" was (re)interpreted as a means to draw motivation and strength in the care of the self, regardless of association to HIV/AIDS. For instance, at a luncheon to celebrate World AIDS Day, a young woman, a spoken word artist from the University of Miami who introduced herself as a Haitian-American, applauded the "positiveness of people, especially those with HIV who have so much hope and praise and who provide inspiration for the rest of the world." Another young activist and health educator, a recent transplant from Haiti, encouraged "people to feel positive and to be strong, and being positive gives you license to live stronger than ever and to never give up." He reminded us in the audience that:

It is important to remember that being HIV positive means that one is not dead, but alive. When I am around HIV positive people, I feel so positive because of being around them always makes me feel so good because they are so positive in life.

Both of these speakers openly declared their HIV-negative status in their speeches, and conveyed that being "positive" about life was a model for everyone to adhere to, regardless of his or her HIV/AIDS status. It is as if the life lessons of "positive living" were those that

would help all Haitians struggle to beat the odds of living in Miami. That is, “positive living” provided a way to give those already marginalized economically, politically, and socially renewed hope for better livelihoods now and for the future.

In other instances, however, it was met with confusion and outright disregard by many clients, as well as Haitian providers. Using three of the most frequently discussed tenets of HIV/AIDS prevention, disclosure, adherence, and safe sex, I will demonstrate how Haitians in Miami are disrupting and challenging official discourses of “positive living.” First, disclosing to others was frequently touted by HIV/AIDS programs as something that “should” or “has” to be done when one is ready. In discussions with Haitian clients, there were many stories of rejection, abandonment, and violence by relatives and friends in the wake of disclosure of and HIV-positive status. Mona, the Haitian patient educator, counseled other Haitians who were HIV-positive to “think about disclosing carefully,” instructing them to conceptualize disclosure as a “choice” rather than something one has to do. She emphasized that the obligation of disclosure should only be to intimate partners, and that one should weigh the positive and negative consequences of disclosing (“sa bon oubyen sa pa bon” translates to “if it’s good or not good”) for anyone else, even family. During a HIV/AIDS intervention program for African-Americans where the discussion focused mainly on disclosure as representative of “taking control” and “not being ashamed” of one’s disease, Mona was the only Haitian present and she continually spoke against such reasoning. She recanted a personal situation as an example for the class:

For me, disclosing can’t be done in the same way to different people. This is because each person is different and sometimes it’s important to pay attention to certain people before you feel comfortable disclosing to them. I don’t have a problem disclosing but I could not disclose to my daughter for a long time. Just the other day, I was at church where very few people know about my status. There is a man at my church who is positive but he hasn’t told anyone. He was bringing over his girlfriend

to my house, and when my church friend, who did not know about me [being positive] but knew about him, found out about this and said to me “Oh, don’t let them drink out of your cup.” I knew then that I would not feel comfortable disclosing to this person.

Mona, like many other Haitian clients, perceives of disclosure as a complex series of strategic procedures. For her, each act of disclosure has to be thoroughly evaluated and is dependent on systematic assessments of people and situations. Mona counters the official rhetoric of disclosure in HIV/AIDS prevention, disclosing freely as a means of taking control or pride, by framing it as careless and foolhardy through a series of stories that serve to showcase the extensive reflection needed in each case of disclosure.

The conceptualization of disclosure as a personal choice among Haitian clients is fundamental to understanding the enormous lack of participation in HIV/AIDS intervention and prevention programs. It was rare to encounter a HIV-positive Haitian client who publically, even among other HIV-positive Haitians, declares her status openly. Even HIV positive Haitian providers who were adept at teaching HIV-positive clients about living without shame had difficulty in participating publically in HIV/AIDS issues. For instance, Thomas, a young Haitian-American social worker who was HIV-positive, explained that he would never participate in community caucuses or committees that decided on local policy issues even though he had been a lifelong activist for HIV/AIDS issues. When I expressed that I had been regularly attending these meetings and thought it would be beneficial to have someone like him advocating for issues relevant to other HIV-positive Haitians, he expressed his surprise to my comment by stating:

I would never go to those things because they assume that you are ready to proudly assert your HIV positive status. I could never ever stand up and tell people that I hardly knew that I am HIV positive. This isn’t because I am not an activist or committed to the issues because I’ve always been involved. It’s just that the assumption is outrageous, that you have to declare your status to be part of the

decision making process. I think that's what is wrong with these programs. It's dangerous because the people who you're going to be talking to aren't going to be ready to talk. I just don't think that's the RIGHT way to go. I think you need to meet people where they are instead of trying to DRAG them somewhere. You know we haven't done a good job at meeting people where they are, and you know, we need to create programs that are tailored to the population and the consciousness of the population instead of deciding this is how we want you to have it and then forcing it on you. It's not going to work.

Thomas' words express not only frustration with the current ways that intervention and prevention programs work, but also relay that it is the right of HIV-positive individuals to go about their daily lives and relationships as they see fit, as is contextually appropriate. Similar to Mona's insistence on evaluating each disclosure situation carefully, Thomas also maintains firmly that one should not follow prescribed formulas of what he calls "consciousness" or ways of being.

In addition to questions over disclosure, Haitian clients and providers also translate the official discourses of adherence differently. In HIV/AIDS prevention trainings and classes, adherence is symbolic of individual self-reliance and self-sufficiency, of "know[ing] your disease and how to fight it." Adherence to antiretrovirals equates to not only taking medications consistently, but also knowing at all times which medications to take, when to take them, each medication's effects, and how to communicate with providers confidently by being knowledgeable about one's body and tolerance levels. A Haitian nurse that lectured Haitian clients on the importance of adherence told them:

Adherence means patience, patience to understand and to let the medication take its time in effectively working for you, and patience with yourself in trying out and accepting medication and the disease. Adherence also means communication with your provider. This is crucial to adherence. You have to be open and direct with them, not only in listening to directions and advice but also give back, trust yourself in knowing your body and report any inconsistencies back to the doctor. Adherence also means to write notes ("ekri notes") which means that you have to keep records of your physical well being and to also be alert to yourself. You have to be careful and to pay attention and most of all, trust yourself more. There should be someone at the

pharmacy or doctor's office who should explain these things to you in Kreyòl and if there is not, make sure to have someone or to go to someone that could translate for you.

Adherence, as presented by this nurse, was simply not about ingesting antiretrovirals regularly. It represented transformations of self needed to accept medications, diseases, and one's lot in life. Adherence stood for patience, assertiveness, open and direct communication, record keeping, self-trust, and self-awareness. Adherence becomes a way of knowing and communicating about the suffering body and of survival of individual Haitians and Haitians as a collectivity.

Finally, safe sex and sex after a HIV-positive diagnosis is an important standard within the paradigm of "positive living." Having safe sex, that is, using condoms and other protection is fervently advocated in many intervention and prevention programs. Those who are HIV-positive are often told that having sex is "normal" and a "good thing" but only with protection. Many providers and educators encouraged and promoted sex after a HIV-positive diagnosis. One educator, for instance, during a class titled "Sex for Positives," declared "You have to [have sex] physically because the need is biological because your body has to release the fluids; otherwise it's bad for you." Many Haitian providers, however, rarely upheld these formulations of having sex. They repeatedly advocated the values of abstinence, monogamy, and fidelity. Mona, the patient educator, took pride in claiming that many Haitian practiced abstinence after receiving a HIV-positive diagnosis. When I asked if this was true of those in the Kreyòl class, almost every person shook their head to indicate "yes." When I asked for explanations, Renèe volunteered first and pronounced, "I have a husband but everybody sleeps in their own bed. I have no interest. As soon as you get virus, you shouldn't have sex." Helen expressed that she had similar sentiments after finding out

that she was HIV-positive, explaining “I get a disgusting feeling when I think about sex. My husband gave it to me and I feel bad with life when I found out for a long time. But now I’ve given my life to God.” Richard revealed “I know I’m sick. I don’t like to transmit to others.” Janvier told us that she didn’t want to tell anyone and kept silent, and Justine echoed these sentiments by saying, “I wouldn’t want to give it to someone else. I believe that my viral load is undetectable but I believe that if I had sex, the virus might flare up.” Jacques told us that he was abstinent for three years because he felt that his viral load would flare up if he had sex, but now, because of what he learned in class about using condoms, he feels less lonely and depressed. The only one who outright divulged that she was having sex was Irene, who revealed that she and her boyfriend were “sexing a lot” but because of his increasing demands to have sex without a condom even with her full disclosure of her status, she ended the relationship. For these individuals, the absence of intimacy was an accepted and expected result of their HIV-positive status due to fears of worsening their physical conditions and transmitting the disease to others, and because HIV/AIDS itself was a painful reminder of sex. Many like Helen felt that their HIV-positive status enabled them to give more of their time and energy to God and other religious endeavors like church groups and pilgrimages. Although HIV/AIDS is touted by providers as “not a moral issue,” full disclosure of a HIV-positive status with sexual partners has become the gold standard of ethics, and for many Haitian clients, the absence of sexual intimacy represents the bypassing of disclosure altogether. Furthermore, the choice of abstinence serves to publically and personally negate and even reject the practices through which infection occurred.

Claiming and Rejecting Disease: Rethinking Biological Citizenship and Biosociality

Notions of individual responsibility and self-management that define the “positive living” movement as espoused by HIV/AIDS providers and advocates and the kind of personal resilience and resourcefulness which represents many Haitian clients in Miami approach the idea of biological citizenship (Petryna 2002; Rose and Novas 2004). Rose and Novas (2004) argue that although biological considerations have long shaped many aspects of citizenship, a novel form of biological citizenship is materializing in the wake of expanding biotechnological and genomic innovations. This new type of biological citizenship represents emerging forms of subjectivities, ethics, and politics. They state:

As aspects of life once placed on the side of fate become subjects of deliberation and decision, a new space of hope and fear is being established around genetic and somatic individuality. In the nations of the West – Europe, Australia and the United States, this is not taking the form of fatalism and passivity, and nor are we seeing a revival of genetic or biological determinism. Whilst in the residual social states in the post-Soviet era, biological citizenship may focus on the demand for financial support from state authorities, in the West novel practices of biological choice are taking place within a ‘regime of the self’ as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice. (Rose and Novas 2004: 458)

The concept of biological citizenship as such is useful in understanding the complex links between HIV/AIDS and its impact on many Haitians in Miami. More importantly, the associations themselves require the troubling and broadening of the concept of biological citizenship. First, for many Haitians in Miami, HIV/AIDS represents economic, political, and social resources otherwise unavailable or unobtainable.³³ For instance, Irene, who is HIV-positive with a young HIV-positive daughter, explained her daily struggle to make ends meet in the context of a discussion regarding community problems:

I have something to say! Money is the problem. I got a \$1000 a month from the social worker but it’s not enough at all for all the things I got to pay for like my bills, housing, cleaning supplies, food, clothing for my daughter. My social worker told me that I got HIV not AIDS so I can’t get more benefits. I am very angry about it. Isn’t it

discrimination that people with AIDS get more than me and the people with just HIV? Don't I suffer the same? Don't I take the same medication? Don't I struggle the same with the disease? It would be beneficial if they could give some kind of certificate to buy supplies or groceries in addition to the money. My rent is a little less than \$300, my water bill is \$50, and my electricity is \$115. We can't live on this!

Irene's outrage of the differential resources made available to those categorized as HIV-positive and those deemed as having AIDS mirrored the resentment and bewilderment expressed by those who were burdened with afflictions other than HIV/AIDS about the unfair distribution of resources for those with HIV/AIDS. For these individuals, notions of health and well being are almost always embedded within broader narratives of poverty, political and social disenfranchisement, and destruction of traditional family ties, as well as the complex ways of negotiating resources and support. Here, as Rose and Novas (2004) argue, life attains tremendous potential value and becomes the basis of claims for economic rewards through such practices.

Compensation was not limited to monetary or health benefits from the government, but also included social and political clout. For instance, Mona was one of my closest informants and often served as an invaluable intermediary between me and other clients at Miami General Hospital and beyond. She was often hailed by providers and patients as a "model" for positive living. She had come to Miami General close to death over a decade ago, finding out that she had full blown HIV/AIDS, and in a matter of several years, she had been hired as a clinical patient advocate and educator. Mona leveraged her status at the hospital in numerous ways, often negotiating for myriad of resources for both herself and other Haitian clients. For instance, during a weekly educational class, a pharmaceutical representative walked right into the room while Jaime, the patient educator, was in the middle of a lecture on preventing HIV/AIDS. This was a common occurrence at Miami

General since much of the funding for HIV/AIDS intervention and prevention programs came from pharmaceutical companies. Jaime stopped his lecture and greeted the representative warmly as she pulled out some pamphlets. The representative introduced herself and began by saying:

Kaletra is very easy for patients to take and they take a round pill twice a day. Individuals that start on Kaletra as their first treatment can take it for 4 years as a single dose therapy. In our 7-year data, it was found out that if a patient takes Kaletra as their first regimen, the majority of them have undetectable viral loads. It's been also shown that their CD4 count has gone up tremendously for patients who take Kaletra as their first regimen.

She then pulled out an informational sheet, along with an invitation to a public lecture on "Understanding HIV Resistance" sponsored by Abbott Laboratories at a famous Cuban steakhouse. Jaime sang the praises of the quality of the restaurant and the featured speaker. Mona suddenly offered her services as a liaison, guaranteeing that she would be able to get many Haitians to attend the lecture. She indicated, however, that "transportation was the problem" and if Abbott labs could get a van for them, it would not be problematic. The representative replied that her company could not offer transportation but maybe they could get Medicaid or some other venue to supply it. Mona quickly asked "How many people do you need?" and the representative stated hesitatingly, "What do you mean? The restaurant can accommodate 100 people" expressing her confusion. This is when Jaime stepped in, explaining, "No, no. She can get people to come" and the representative nodded her head as if she understood and stated:

Wow! That's great! Maybe you can get some people and help translate at the dinner. They have a great salad bar and then they also come to your table and hand-carve meat for you.

Mona began translating the conversation to the rest of the class, eliciting excitement from them at the thought of free food. The pharmaceutical representative then proceeded to

whisper to Jaime that if Mona could get people to come, “We could figure out something for her” and Jaime, bursting with pride responded “Yes, she’s really good!” Indeed, I had seen Mona recruit others in the class for a number of different studies, groups and lectures, including my own research. Her influence and sway of other clients both in and out of clinical settings allotted her considerable ability to traverse multiple levels of administrative, political, and social activities.

These forms of biological citizenship, however, exist simultaneously with what Rose and Novas (2004) and Rabinow (1996) consider older considerations of citizenship, particularly those involving racial and sexual biopolitics. Rose and Novas state:

Inevitably, in discussing these issues, the spectre of racialized national politics, eugenics and racial hygiene is summoned from its sleep. Such biological understanding of human beings clearly related to notions of citizenship and projects of citizen building both at the level of the individual and of the nation state. Nonetheless, contemporary biological citizenship does not, in the main, take this racialized and nationalised form. The links of biology and human worth and human defects today differ significantly from those of the eugenic age. Different ideas about the role of biology in human worth are entailed in practices of selective abortion, pre-implantation genetic diagnosis and embryo selection. Different ideas about the biological responsibilities of the citizen are embodied in contemporary norms of health and practices of health education. Different citizenship practices can be seen in the increasing importance of corporeality to practices of identity, and in new technologies which intervene upon the body at levels ranging from the superficial (cosmetic surgery) to the molecular (gene therapy)...And while it is true that many states are once more regarding the specific hereditary stock of their population as a resource to be managed, these endeavours are not driven by a search for racial purity. Instead, they are grounded in the hope that certain specific characteristics of the genes of groups of their citizens may potentially provide a valuable resource for the generation of intellectual property rights, for biotechnological innovation and the creation of what we will term, following Catherine Waldby, *biovalue*. (2004: 440-41)

While it may be valid to claim that over time, differences have arisen in the ways in which the biological values of populations are managed and conceptualized, it is highly limiting to discount that a variety of forms of citizenship can be and are indeed present. As I have demonstrated in previous chapters and will illustrate in this chapter, for Haitians in Miami,

HIV/AIDS represents not only a pathway to garner much needed resources, but also a continuing legacy of unequal citizenship, power, and privilege based on the very notions of racial hygiene and biomedical and social primitivism.

In large part, due to existing biopolitical and public imaginaries of Haitians as natural carriers of disease,³⁴ many Haitians have and continue to come to understand and describe themselves away from biological conceptions. That is, many claim citizenship by the very process of detaching any biological attributes from their sense of self and community. This process of removal and separation happens in a number of ways. I have already discussed some of these concepts in the previous section, where Haitian clients continually reject interpellating themselves with the “positive living” movement. Another such mode of partitioning notions of biology away from the sense of self occurs through the re-imagination of HIV/AIDS as an outcome of multiple effects and as an everyday occurrence of suffering rather than an exceptional event. For instance, Michelle, an older woman who came to class infrequently, often positioned HIV/AIDS as an amalgamation of biomedical conditions and malicious spirit possession. Michelle often invoked these multiple notions of HIV/AIDS during and outside of class. In one Kreyòl clinical class, she argued:

I don't take disease from no man. A woman lives with my husband. She wanted to get even with me. She got jou jou (powder) and sent it to me. She told me to my face that I had to leave my husband or else someone was going to give me HIV virus.

Michelle uses notions of “disease” and “HIV virus” and incorporates them into a framework that reveals that jealous others and angry spirits as sources of affliction. These claims made other class participants uncomfortable as some averted their eyes from her, while others sucked their teeth or whispered to their neighbors. When Jaime, the non-Haitian educator asked her “Is it documented that you got it from no man?” Mona and some of the other

clients, fearful that Haitians as a collective would once again be marked as “ignorant” and “backward” through the rubric of cultural reasoning, forced the conversation onto other topics by responding “Do you really want to go there? We don’t want you to go there!” prompting Jaime to change the subject.

Others, like Renèe, depict HIV/AIDS as nothing out of the ordinary, as like any other disease, and as part of a broader notion of uncontrollable fate.³⁵ Renèe, a regular at the clinical classes, reiterates what I would hear often:

For me, HIV is like any other disease. God will eventually take us all, so what is the big deal? Don’t we Haitians all suffer in disease and in wellness? It doesn’t bother me, because I have a lot more things to worry about than this.

For Renèe, as for many Haitians, HIV/AIDS fails to be an extraordinary life event; rather it is an element of the cycle of life and death determined solely by “God.” HIV/AIDS also represents a fragment of a much larger condition of daily suffering of economic, political, and social marginalization. As Paul Farmer (1992) and Karen McCarthy Brown (1991) have documented, narratives of illness, disease, and suffering often implicate the role of human agency in bringing about affliction. Brown (1991) asserts:

“*Moun fèt pou mouri* [People are born to die],” Haitians are fond of saying, usually with a casual shrug of the shoulders. This proverb gives voice to both the pain of life in poverty-stricken Haiti and the stoic acceptance that, on one level at least, characterizes the Haitian attitude towards this life. *Mizè* (suffering, and, more precisely, the suffering of poverty) is an expected and recurrent condition...Because, for the great majority of Haitians, it is a given that life is filled with struggle and suffering, it is not inaccurate to say that problem-free periods are pervaded with an anxiety that anticipates crises just around the corner. (345)

The use of Brown’s (1991) analysis here is not to re-inscribe Haitians to a state of being incapable of understanding and utilizing biomedical models of disease or to reaffirm an “explanatory model” approach (Young 1982), where the dichotomy is drawn between “disease” as an organic, natural category and “illness” as the social and cultural construction

of disease of patients. In addition, it is not to say that Renèe, Michelle, and others are recasting simply the causes of HIV/AIDS and other misfortunes in terms of local sorcery or supernatural intervention from a need to impute agency. Instead, I argue that their stories serve to disassociate them from the solely biological characteristics of HIV/AIDS, as promoted by the official rhetoric of HIV/AIDS prevention. By reconfiguring HIV/AIDS through notions of the continuous susceptibility of suffering as well as through human and spiritual mediations, they constitute the biological simultaneously as manipulatable and as immutable destiny. I contend that these kinds of conceptualizations and actions act as a powerful trope against the promise of the “positive living” movement, and do not solely function within what Rose and Novas call “a political economy of hope” (2004: 452), a space in which the biological is no longer blind fate, but rather knowable and controllable, and where acquiescence and despair towards an uncertain future is condemned.

Another way that Haitians strive to disassociate biological configurations of subjectivity and citizenship is by not participating in HIV/AIDS prevention. As documented in the previous chapters, the concept of community is both complex and problematical amongst Haitians in Miami, as well as elsewhere. In the field of HIV/AIDS prevention and management in Miami, Haitians are a scarcity in clinical and non-clinical programs as compared to other ethnic groups. Such programs at Miami General, for example, host only 2-4 regular clients in bi-weekly Kreyòl classes, as compared to the English and Spanish classes, each of which hosted 30-40 regular clients weekly. Other clinics also expressed the futility in having classes in Kreyòl because of a lack of interest. Even the DOH has continually cancelled HIV/AIDS classes in Haitian Kreyòl for providers and volunteers because of a lack of participation.³⁶ I argue that these practices which shun collective

participation around HIV/AIDS and other diseases indicate not so much a fierce resistance to biomedical expertise and claims, but rather a way of divorcing citizenship projects from science, and therefore, biology in the face of complex historical, political, and economic conditions that render Haitians as unequal global citizens. In this way, notions of biosociality (Rabinow 1996; Rose and Novas 2004) as new forms of biomedical communities and activism, especially around the field of HIV/AIDS as documented Steven Epstein (1996), do not exist in the context of Haitians in Miami. Various modes of authoritative structures and policies have long conceptualized Haitians as biological citizens, through designations as AIDS carriers (Farmer and Kim 1991; Farmer 1992) and as those with tainted blood.³⁷ Unlike gay activists documented in Epstein's landmark work (1996), groupings shaped by the sense of a shared biological identity did not and continues not to take place among Haitians in the United States as a result of a confluence of factors. These include the biomedical, political, and social classifications which continue to cause a tremendous amount of fear and discrimination towards the community (Farmer 1992; Nachman 1993; Fairchild and Tynan 1994), the tendency to self-identify as other Black immigrants or as African Americans as a reaction to existing negative stereotypes of Haitians (Laguerre 1984; Stepick 1992; Nachman 1993; Portes and Stepick 1993; Zephir 1996; Laguerre 1998; Stepick 1998; Stepick et al. 2003), and resistance and suspicion toward public health educational and intervention programs (Farmer and Kim 1991).

Contemporary forms of biological citizenship as espoused by Rabinow (1996), Petryna (2002), and Rose and Novas (2004), therefore, are inadequate characterizations of many Haitians' relations to themselves, others, the nation-state, and various communities of transnational citizens. A conceptualization of biological citizenship must also take into

consideration that particular individuals and collectivities, much like Haitians in Miami who are always already implicated in citizenship projects that seek to classify them as inherently pathological, unclean, and disease ridden (Farmer and Kim 1991; Farmer 1992; Nachman 1993), want and strive to be citizens of a non-biological kind. Citizenship here may still take on biological considerations because of the use biological and scientific reasoning to take a stance against being associated with disease and illness. However, the main focus of individual and collective struggles for political, economic, and social rights are based on the decoupling of citizenship from biology and biology from citizenship.

Medicalizing Race, Racializing Medicine

Citizenship projects like the “positive living” movement in HIV/AIDS prevention programs, which integrate contemporary forms of governance through biological identities and collectives, are highly entangled in the politics of racial and ethnic difference. Given the continuing potency of the concept of race, it is not surprising that there has been much written about its development from classification schema to its usage as a biological reality in research and policy (Haller 1971; Gould 1981, 1994; Cooper and David 1986; Krieger 1987; Haraway 1989; Packard 1989; Barkan 1992; Harding 1993; Omi and Winant 1994; Harrison 1995; Gosset 1997; King 1997; Wailoo 1997; Williams 1997; Ernst and Harris 1999; Shah 2001; Anderson 2003; Reardon 2005). What is often attended to by those who study race and ethnicity is the ability of these concepts to be flexible and durable over multiple historical reconstructions demonstrating their use in fulfilling various social needs. Currently, race and ethnicity encompass a multiplicity of meanings and represent a confluence of biological and social factors used to categorize humans, but their usage and

conflation continues to be highly debated and problematic not only in scholarly spheres, but also in the daily practices of those involved in HIV/AIDS prevention. For instance, during a conversation with Dr. Anna Kerry, a physician researcher, she revealed that a majority of her patients were “Black, African-American” and “non-Hispanic.” When I asked whether these categories also included patients of Haitian descent, she was quick to point out with a resounding “No,” that it did not. She explained:

I make it a point to count Haitians differently because I feel like that they have different problems and issues that don't fall in line with those who are African American. This is based on my own professional opinion and experience.

Dr. Kerry's practices of counting Haitians separately are not unique in Miami, where in DOH forms and state-wide surveillance measures related to HIV/AIDS, Haitians are recorded as a separate racial and ethnic category.³⁸

Likewise, in much of health research today, ethnicity is mainly utilized to denote distinct groups based on nationality or culture, while race is used in reference to physical traits contributing to the development of hierarchies in the distribution of social resources (Wilkinson and King 1987). But as I will illustrate in this chapter, such distinctions between race and ethnicity are continually shifting as a variety of programs, policies, and people come to understand and interpret the notion of race just as socially and culturally constructed as the notion of ethnicity. Many scholars have raised contrasting views and questions about the inherent associations between these two terms and their scientific and social values (Duster 2003; Balibar and Wallerstein 1991; Gilroy 1987; Fullilove 1998). Some scholars connote the importance of investigating individual and group-level vulnerabilities to particular diseases (Comstock et al. 2004), while others claim that race and ethnicity have come to constitute biomedical categorizations where intra-group variations are obscured, inter-group

differences are inflated, and health inequalities attributed to social structural factors are veiled (Glick-Schiller 1992; Krieger 1994; Krieger and Fee 1994). These discourses are varied, complex, defy disciplinary boundaries, and not as diametrically opposed as they are often presented. For instance, many like Goodman (2000) and Krieger (2000) purport that although race and ethnicity should not be utilized for genetic or biological variations and that the attribution of ethnic and racial differences in disease to genetic differences exemplifies geneticization and scientific racialism, the tracking of the consequences of a racialized society must endure until all disparities based on race and ethnicity can be eliminated. Others similarly argue that the concepts of race and ethnicity are social constructs and, therefore, too rudimentary to be utilized in discourses surrounding health disparities; they call for explorations of the effects of racism, rather than race and ethnicity, as a causative model for health disparities (Kaufman and Cooper 2001). Yet others call for a race-neutral position of genotyping populations rather than utilizing self-identifications based on specific racial and ethnic categories (Wood 2001).

I contend that these works, although noteworthy in sounding alarms at the increasing biomedicalization of health disparities and in emphasizing multi-factorial models for risk, ultimately fail to question the role of scientific knowledge itself in the construction of the concepts of race and ethnicity as risk factors. In their arguments, there is inherent value placed on science, one that ultimately differentiates between “good” and “bad” science. These arguments seem to repeatedly equate “bad” science with reformulating old concepts of genetic and biological differences amongst races, and in so doing, fail to equally place a burden on how the paradigm of “good” science can also produce, propagate, and transform the discourse surrounding race and ethnicity. An analysis of situating knowledge, and the

ways in which this knowledge is attained and made significant in specific social and historical contexts is only extended to the science which fetishizes genetics and race as biology, so that science produced from underlying attitudes of racism and ethnocentrism is shown to fabricate direct causative links between race, genetics, and disease (Latour and Woolgar 1986). Furthermore, these arguments stress the importance of the continued usage of race and ethnicity in health research in order to document inequality and to measure success, invoking notions of progress, modernity, and nationalism, as well as correlating these outputs and values with an idealized, pure, and objective science, one which has the power to monitor the (racist and ethnocentric) ills of society.

In Miami, there is an overwhelming sense that in health research, tabulations of racial and ethnic-specific vulnerabilities to disease are fundamental to the success of public health prevention in HIV/AIDS. This sentiment exists not only among the health professionals that I have illustrated throughout these chapters, but also in published research which criticize current modes of classification by race and ethnicity (i.e. “Black/ African-American”) precisely because such broad categorizations mask the needs of diverse groups (i.e. Haitians) and their specific risks (Martin et al. 1995; Page and Marcelin 1999; Marcelin and Marcelin 2001). I argue that this is in line with much of the HIV/AIDS literature which demonstrates that the epidemic is taking root deeply in impoverished and marginalized communities, where underlying issues pertaining to the broader socio-political and economic factors serve as driving forces of the epidemic (Farmer 1992; Scheper-Hughes 1994; Singer 1994). But as I will show, such notable initiatives sometimes re-inscribe the validity and potency of the notions of racial and ethnic difference through various policies and practices.

Many in Miami, for instance, view HIV/AIDS prevention programs targeted specifically for certain racial and ethnic minorities as beneficial and a necessity. Dr. Jones, a prominent physician who runs a hospital clinic solely serving the HIV positive Haitian population in Miami declared:

I think that these programs are helping minorities and people of color because if not for these programs, they'd be in BIG trouble. So despite ALL the misgivings and the inadequacies, thank god that they are there because without them, they'd be GONE! So....thank god for all these things we have.

Dr. Jones attests that although he has “misgivings” about HIV/AIDS prevention programs specifically designed for “minorities” and “people of color,” he finds that these groups of people would be “in big trouble” or “gone” without such programs. The insinuation here is that these programs are literally keeping alive racial and ethnic minority populations. Dr. Jones’ assertion of the ability of such programs to represent matters of life and death exemplifies the ways in which both epidemics and the responses to them continue to be mediated through the discursive practices that ideologically construct notions of race and ethnicity (cf. Briggs 2005; Briggs and Hallin 2007).

This narrative of the life-saving benefits of minority-targeted HIV/AIDS programs is one that I heard often, even in free-running clinics that were continually struggling for funding and resources. For instance, at Santè Ayisyen, a local health clinic in the Little Haiti neighborhood, both the case manager and the HIV/AIDS counselor felt that intervention and education programs geared toward minority populations were working very well because they were seeing more people in the clinic than ever before. The case manager explained:

I think that it's good. Years ago, we used have to hunt to basically get 10 people test, now, you can see, since you've been here for the past couple of months, we're telling people to come back because so many people that's coming to get tested. People are coming on their own to get their results without even having to call them, trying to make contact or anything. So I think that the word is getting out that it's OK to get

tested, it's OK to know, it's fine, you have to know how to protect yourself. I think it's good because you see kids now are coming to get condoms. They're like "Hmmm...I'm not going in there if I'm not having a condom. I'm not having sex without a condom." So it's a positive thing.

This provider reasons that more people coming into clinics to get tested and to receive basic preventive health services signals the success of minority-targeted programs. She also confers that the information about the importance of getting tested for HIV/AIDS is reaching those for whom it is intended, and thereby constitutes a communicable map that demonstrates a hierarchical (and linear) flow of health information from biomedical experts to Haitian consumers (cf. Briggs 2005; Briggs and Hallin 2007).

In parallel fashion, other providers articulated that if these racial and ethnically-based programs were not working, statistics would "show" disproportionate rises in HIV/AIDS rates in certain groups, often internalizing the hegemony of statistical imaginaries. When I showed these informants some materials from the DOH that highlighted the disproportionate rates of HIV/AIDS in Miami-Dade and in Florida for minority populations, they did not fault the programs directly. Instead, they felt that this was a problem of "uptake," where those who were the targets of interventions failed to understand and follow changes in behavior.

An HIV/AIDS counselor, for example told me:

I don't think there is much I would have to change [about minority-targeted prevention programs]. I believe everything that has been designed works. Other than that, the gay and lesbian community, they are very knowledgeable about the disease and there is a big decrease in that community. It's only in the black community that the disease is increasing. So definitely something is going on there. Like I said, I don't believe that they don't get the information; the information is accessible! Now what they do with that information once they get it is a different thing. In fact, that's the study I would like to see...why is it that the information is available to everybody and everybody knows it because I know people who do outreach within the communities. Why is it still going up instead of the disease being the decline in the black communities?

Although he did not explicitly state why he thought the rates were increasing amongst African-Americans, his view is clear that the onus of dysfunction is not at the programmatic level. His statement “Now what they do with that information once they get it is a different thing” puts the burden of responsibility, and tacit blame, on the side of those being targeted by intervention programs. Others also echoed, explicitly and implicitly, this sentiment of locating the responsibility for increases in HIV/AIDS rates on communities or individuals themselves. Even Haitian clients with whom I discussed this issue told me that institutions were doing a good job of testing people and getting the information about prevention and intervention out; it was people themselves who “don’t do everything [that programs] educate them to do because they do whatever they want to do.” One of the most passionate and dedicated HIV/AIDS prevention educators that I met during fieldwork, Jaime, repeatedly warned me of what he termed “giving these people too much credit.” He was well versed in multiple approaches to conducting HIV/AIDS prevention education targeting Haitians, was very respected by all of his Haitian clients, and was openly HIV-positive himself. During our frequent conversations about my dissertation, he would listen empathetically, shaking his head frequently to demonstrate that he understood my arguments, only to turn around and lecture me gently:

Yes, I understand but it’s really about education. These people have almost no level of education. I mean I can see some of them who are learning and who are interested, but most of them....it’s nothing. They are just not listening....they are not getting it at all. We have to do something, try to really educate, get them to understand certain concepts about the disease.

Jaime, here, positions Haitians as what Briggs and Hallin term “biocommunicable outsiders,” those who “fail even to acquire the knowledge that would permit them to fashion themselves as biological citizens” (2007: 50-51). Dominant frameworks of public health prevention in

HIV/AIDS, through providers like Jaime, discursively deny Haitians neoliberal subjectivity—a chance to play the role of responsible consumers who actively manage their health and risk of disease (cf. Clarke et al. 2003; Briggs and Hallin 2007; Rose 2007).

Other providers also expressed these systematic modes of isolation of Haitian clients more reflexively. They spoke of the structural impediments built into HIV/AIDS prevention programs which made it nearly impossible for them, as providers, to translate and disseminate information to their clients effectively. Many felt that these obstacles found in HIV/AIDS prevention programs helped to widen the divergences between public health preventives and Haitians. For instance, a case manager Santé Ayisyen recounted how disconnected the programmatic rules and regulations of HIV/AIDS prevention are from the reality of her clients' situations. She states:

I went to a Ryan White training for case managers somewhere, and they told me that when a client comes in, have the client to give you a proof of their financial documents, go through their financial screening, and have them write a letter saying that they are the person supporting themselves. But my thing is half the people, more than half the people, 90% of the people that I deal with don't even know how to read and write. And they tell you that you cannot write the letter for them. You know, it's like when you're in a meeting, you are the only one that's dealing with the vast majority of minorities. I'm like this is bullshit. I write the letter for them and I tell them what the letter says, and I give it to them and now it's up to them to get it notarized. Because I'm here to help; I'm not here to make things worse. I cannot ask someone who just came from Haiti less than a year ago, who doesn't know how to read and write. Now what I do is try to help them if they want to English classes or something. I always offer that to them. A lot of them decline. Why? Because they can't go to school because they have to go to the farm or they have to do an odd job, they have to take care of the kids, or if their families send for them, they're taking care of the kids of the family, you know...they're being basically treated like slaves in the house and they're probably sleeping in a room somewhere. They don't have money to catch a bus; there's not enough bus passes...I only get six bus passes a month and I have to give it to the handicapped, the blind, the incoherent person you know. What can you do? It's like a lose-lose situation.

This case manager depicts the practices and assumptions of HIV/AIDS prevention that hold structural violence intact and prevent Haitian clients from accessing resources supposedly

available to them (cf. Bourgois 1995, 2000, 2003; Farmer 1992, 1996, 2001, 2004). She frames her own positionality as one fraught with tension of being betwixt and between, “helping” clients access services through unofficial improvisation while lamenting HIV/AIDS service protocols which fail to address the structural constraints of clients with language and literacy barriers. In turn, she simultaneously troubles and re-inscribes the logic of the linear communicable cartography of HIV/AIDS prevention (cf. Briggs and Hallin 2007) as well as the potency of race and ethnicity.

Even at the level of the DOH, there were parallel opinions about the constraints of minority-centered HIV/AIDS prevention programs. For instance, Geri Rodriguez, who works in HIV/AIDS prevention, recounted what she perceived as an ideal type, when local initiatives and community health providers had the flexibility of tailoring programs toward community needs:

When we were doing education and outreach back in the mid 1990s, one of our priority groups and areas was in Little Havana. The prevention wasn't successful and we were really having a hard time getting through or getting people enrolled. We did a community needs assessment and we had come up with 10 critical priorities of the community. These included gang violence, lack of work, immigration and health was number five. So what we did was we convened a town hall meeting and we got the chief of police to come in and talk about the gang violence, we got an immigration lawyer to come talk about immigration issues, and things like that. People really felt like we listened. They felt respected. We need to start listening again and at that point in time, it was working. That's what we need to do again, and we need to understand that behavior is a function of personal situation. The way that we do things now is that aggregate data points out the clients in need and the politicians want answers to see if behaviors are changing. This is the problem with public health; we don't have time or the money to really find out what is going on.

Geri's attitude reflects her dissatisfaction with the changes in public health prevention itself, which she believes follows formulaic and standardized methods governed by a combination of evidence-based science and larger political conventions. She expresses that there is a way to “really find out what is going on” amongst minority communities while arguing that

having more personal and sustained interactions with community members is a better way to adequately ascertain the needs that they themselves want. Her model depicts this community of individuals in Little Havana as active agents who are able demand certain kinds of resources through non-participation, and public health specialists as facilitators that aid the community in getting what they want. In this way, Geri, like the case manager at Santè Ayisyen above, implies that it is consumers who dictate the flow of knowledge of HIV/AIDS prevention through their “10 critical priorities,” while at the same time, denoting that such reformulations are necessary for the “enroll[ment]” of these clients to existing HIV/AIDS prevention paradigms.

These types of multiple framings were often employed by many health and social service providers in Miami who worked in HIV/AIDS prevention. Fred Dussy, for instance, works with rural migrant communities in Florida City and Homestead, areas in which a majority of the population is either classified as Hispanic or as Black/African-American. In speaking about the problems and advantages of race and ethnic-based prevention programs in HIV/AIDS prevention, he stated:

I don't like the way that prevention is done now, going and telling people about abstinence or giving them condoms. I think that intervention and prevention programs were working fine when we had to interact a lot with people. Like for me, for example, I like to put myself on their level, like I just dress like this, with a T-shirt and pants, and I talk to them like I would anybody else. This worked well for immigrants. They are not educated enough and that's what we need to do more of in immigrant communities. Yes, this is true for our population because it's a very rural community and it's better to go door to door, to go out there and understand what is going on instead of just expecting to pass out condoms and have them come in when they are infected. The whole CDC way of doing things is more political bullshit than anything else.

Fred perceives of himself as following a different mode of conducting prevention outreach than what is mandated by institutional authorities such as the CDC. He claims that by

placing himself on the “level” of his clients, that is, by occupying their communicable subject position, he can better “understand what is going on.” However, at the same time, he renders them as “not educated enough” and passive recipients of knowledge, underpinning ideological constructions of the social relations of power.

These examples, highlighting the implementation of racial and ethnic-specific programs in HIV/AIDS prevention, trace the ways in which knowledge about HIV/AIDS, race, ethnicity, and governmentality circulate and become stabilized and disrupted. The concepts of race and ethnicity are fundamentally entwined in the discourses and practices of HIV/AIDS prevention in the United States, and tend to take on a heightened presence in Miami because of its past and present turbulent and complex ethnic landscape, where diverse populations of those hailing from Latin America and the Caribbean along with African-Americans and Whites compete for various economic, political and social resources. Local HIV/AIDS prevention and treatment programs seek to construct ethical and responsible biological citizens by employing discursive processes which ideologically construct certain people as producers, transmitters, and receivers of knowledge about HIV/AIDS, race, and ethnicity (cf. Briggs 2005; Briggs and Hallin 2007). But these constructions of biological citizens are often mediated through racial and ethnic formulations of difference. Haitians and others who do not fit well into this communicable map or refuse to interpellate themselves to their prescribed subjectivities become positioned outside the realms of biosociality and biological citizenship through the pathologization of racial and ethnic imaginaries.

Unhealthy People: Framing Health Disparities

Discourses of race, ethnicity, and biological citizenship are fundamental to the understanding of health disparities. There has been an increasing push to link health and human rights, and the Universal Declaration of Human Rights, as adopted by the United Nations in 1948, proclaimed that the right to health is fundamental to individual and social existence and forms the basis for global citizenship ensured with other rights and freedoms (Mann et al. 1999; Farmer 2004). Implicit in this affirmation is that governments and individuals must both play a central role in ensuring that such goals are achieved. In the United States, these arguments have been translated through various approaches, the most far-reaching being the call to eliminate disparities in health care and outcomes. For instance, the “Healthy People 2010” report, published by the National Institutes of Health (NIH), represents nation-wide strategies for eliminating health disparities among different segments of the population, particularly those identified along racial and ethnic lines. This report delineates that disparities in health outcomes are a result of convergences of genetic variation, environmental factors, and specific health behaviors, all of which become formulated through racial and ethnic differences (Lee et al. 2001). Statistics used in the report are indeed staggering: death rates of African-Americans due to heart disease and all cancers are 30-40% higher than for whites, Hispanics are twice as likely to die from diabetes than non-Hispanic whites, and so on (USDHHS 2000). The clinical and social epidemiological research that produce these numbers focus on race and ethnicity as categories of natural distinction, which as a result, not only design the framework for improving health status, but also determine the measures of success needed to achieve such goals (Lee et al. 2001). In other words, the racial and ethnic taxonomies utilized drive both

the design and the results of studies investigating the biological basis of difference among groups, uncritical of any other factors or relationships. In addition, the notion that epidemiology can only highlight associations between variables and not causal inferences becomes lost in the production of epidemiological facts of health disparities along racial and ethnic lines. As Jonathan Kahn has shown in his discussion of BiDiI, the “race-specific” drug for heart failure, many of these “facts” behind health disparities no longer need proper citations or any citations at all, as they have “entered the commonsense realm of accepted reality” (2003: 475) and have become what Latour (1987) labels as black boxes. As I will show, health variations among populations, such as the differential rates of HIV/AIDS among racial and ethnic groups in Miami-Dade county, no longer need to be explained, for they have come to illustrate an authoritative truth about reality.

I agree with Kahn (2003) and others in their assessment that the health differences situated along racial and ethnic lines have been copiously documented but remain relatively under-theorized by social scientists and public health scholars. This is particularly pivotal in the realm of HIV/AIDS as it is a key component of the notion of health disparities. Research and policy interest in the concept of health disparities are difficult to date, but have existed for over a century in various forms. In fact, scholars such as Starfield (2006) date its history back to Engles’ “The Condition of the Working Class in England.” In the United States, however, race and ethnicity have become the cornerstones of these discussions even though there are myriad of elements that inform the discourses of health disparities (i.e. gender, socioeconomic status). Due to historical considerations of slavery and segregation, race has been long considered a factor in access to health care in the United States and has been the driving force of much research and activism (Gamble and Stone 2006).

Given the plethora of discourses surrounding health disparities, it is not all that surprising that there is no broad consensus on its definition. Health inequality can be broadly defined as the differences, variations, and disparities in health outcomes for individuals and groups, and Carter-Pokras and Baquet (2002) argue that there are at least eleven concepts of health disparities, each having different repercussions for research and policy. The World Health Organization (WHO) defines health inequalities as “composite measures of the variations in health status across individuals in a population” (Murray et al. 1999: 537), while the Institute for Medicine (2003) calls disparities in health care “racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention” and the CDC (2007) contends that disparities are unequal “burden of illness and death experienced by blacks or African Americans, Hispanics or Latinos, American Indians and Alaska Natives, and Native Hawaiian and Other Pacific Islanders, compared to the U.S. population as a whole... believed to be the result of the complex interaction among genetic variations, environmental factors, and specific health behaviors.” Furthermore, Gamble and Stone highlight distinctions between the terms “disparity” and “inequity:”

Disparity is a *descriptive* term that refers to differences between population groups in health status or access to medical care. It carries no moral loading and no connotation of right or wrong. Inequity is a *normative* term. Inherent in its meaning is a critique of differences as unfair, unjust, or morally wrong. The choice of terms is a matter of political strategy as well as meaning. (2006: 96)

While it may be true that using registers or specialized lexicons, and in this case, choosing one term over the other, may be a matter of political strategy and meaning, in the field of HIV/AIDS, both terms are used interchangeably and without distinction. For example, in official publications and speeches, the term “disparity” is used almost exclusively. I argue,

however, that these terms can no longer be distinguished as such. The term “disparity” has come to be intrinsically both descriptive and normative in meaning, and therefore, connotes naturally occurring phenomena that must be acted upon and managed in the name of morality, ethics, and human rights.

The valences of the concept of disparity extend far beyond research scholarship, and into policies, programs, and practices. The reduction of health disparities has become one of the NIH’s top priorities, and the agency has continually increased its budget to reflect this. In 2000, the NIH utilized 8% of its budget (about \$2 billion dollars) for health disparities initiatives, and in 2008, approximately 10% of its budget is allocated for such initiatives (about \$3 billion dollars) (NIH 2002, 2008; Waring 2007). With increased monetary resources being allotted to combating health disparities, new institutions have also increased significantly. Minority task forces have been established in Miami as a result of national directives to reduce disparities in health, and the CDC has also transformed its Office of Minority Health to the Office of Minority Health and Health Disparities in late 2005. The new office is said to expand on the goal of its predecessor, which was to “promote health and quality of life by preventing and controlling the disproportionate burden of disease, injury and disability among racial and ethnic minority populations.” The new office “has a broader focus on reducing health disparities experienced by populations defined by race/ethnicity, socio-economic status, geography, gender, age, disability status, and risk status related to sex and gender” (CDC 2007). This move from *promoting* “health and quality of life by preventing and controlling the disproportionate burden of disease...” to “*reducing* health disparities” (emphasis through italics mine) is important to consider because of the implicit assumption that the prevention and control of disparities in health are no longer possible or

feasible. Instead, by changing the goal to the reduction of the phenomenon of “health disparities,” the CDC alludes that national and local emphases have shifted to minimize processes that have come to be embedded intrinsically in society, and which now, can be only subject to moderation instead of elimination. The gradual removal of the realm of preventability from the concept of health disparities serves to indicate that the disproportionate burden of disease is no longer left to probability and therefore, that anticipatory action against this occurrence is no longer possible. As a result, the conditions of possibility for health disparities become increasingly non-existent; rather, health disparities itself becomes representative of naturally occurring phenomena. I argue that health disparities, in this sense, exist in the realm of the factual, where its existence is no longer debatable or questionable. As Latour (1986, 1987) argues, facts arise when there is no longer deliberation of something of which we have come to be convinced, and when the various processes central to such successful persuasion become obsolete. He compares facts to the cybernetician’s black box, which represents something whose structure and composition becomes taken for granted, leading to the concern and deliberation only of its input and output.

In fact, in 2007, the CDC issued a “heightened response” to current health disparities in HIV/AIDS, particularly to “reduce the toll of HIV/AIDS on blacks” (CDC 2007). As mentioned in previous chapters,³⁹ the CDC makes explicit the myriad of processes that serve as increased risk for HIV/AIDS, or as “input” in a Latourian (1987) sense. They state:

Race and ethnicity, by themselves, are not risk factors for HIV infection. However, because of a complex set of historical, structural, environmental, and cultural factors—including racism and discrimination, poverty, denial, stigma, homophobia, and limited access to health care—African Americans are more vulnerable to HIV infection. Racism, homophobia, incarceration, and stigma associated with being HIV

infected are all factors that make it hard to stop the HIV/AIDS epidemic in African American communities.

The “heightened response,” or the “output,” focuses on the expansion of biomedical prevention services, the increase of HIV/AIDS testing and treatment, the development of broader intervention programs, and the organization of community collaboration (cf. CDC 2007). There is no contemplation of the existence of health disparities in HIV/AIDS. Even the vast outpouring of numbers and statistics (as witnessed in the CDC 2007 report) used to bolster claims of the existence of health disparities do not need or require explanation or clarification. Furthermore, in this kind of rendering of health disparities, the idea of predisposition to disease through biological, environmental, and socioeconomic factors also becomes innately entangled with the concepts of race and ethnicity. Disparities in health, and in turn, difference situated along racial and ethnic lines, have come to be seen as endemic to society. As a result, notions of race and ethnicity come to be inherently characteristic of disparities in health, and serve to justify the construction and management of programmatic solutions based on race and ethnicity. Race, ethnicity, and health disparities become natural bedfellows; their linkages increasingly solidify and their authority expands through the very nature of the associations themselves.

A fundamental way in which the reification of the associations between race, ethnicity, and health disparities has entrenched itself in scientific and public imaginaries is through the scholarship on health disparities which has emerged over the past couple of decades. One such analytical framework is a series of studies, rooted in social epidemiological thought and positivist methodologies, devoted to establishing the chain of disease risk causation from social environment, psychosocial influences, and biological pathways. This approach biomedicalizes structural and social inequality by first reducing

broader forces and identities such as socioeconomics, race, ethnicity, and gender into calculable variables, and then accepting as true that these variables shape and operate through a range of pathways and are ultimately the “fundamental causes” of disparities in health status. These studies are varied and complex. Some focus on life-course approaches to explain health inequalities, tracing how hazardous exposures affect the body from before birth until death, and the ways in which risk accumulates or is refracted through critical periods of exposure (Smith 2003). Others highlight broader social determinants such as stress and various psychosocial factors to clarify the workings of health inequalities. One such example is the Epidemiological Catchment Area Study (ECA), the largest ever on psychiatric disorders, which concluded that low socioeconomic status strongly predicted higher risk for a varied number of psychiatric disorders (Williams and Collins 1995). A large and growing number discuss income inequality, social capital, and population health with regard to health inequality. For instance, Rogot and colleagues (1992), in analyzing data from the National Longitudinal Mortality Study, concluded that those with higher income and education have a lower risk of mortality than those with lower levels of income and education. Yet others argue that there are gradients in health outcomes, which are continuous across the socioeconomic spectrum, and therefore cannot be “due to absolute material standards” (Smith 2003: xxxiv). The Whitehall Study, by Marmot and colleagues (1987), perhaps the most revolutionary study of health disparities (or health variations according to the British), is a prime example of this. It revealed that British civil servants, who were considered neither the richest nor the poorest in society, had a social gradient in terms of health and disease—that is, the lower an individual was in the “social” hierarchy, the higher her risk of disease. Marmot et al. (1987) claimed that even when controlling for unhealthy

behaviors such as smoking, drinking, and sedentary lifestyle which could have been consequences of one's social hierarchy, the evidence pointed to more direct pathways to explain stratification and health. In other words, variables such as having little or no control in the workplace have effects on the body directly through the brain and on various hormones in the body, which then change one's physiology and biochemistry and increase one's risk for disease. Thus, the inequalities attributed to income or wealth or lifestyle factors are important but not sufficient to account entirely for risk assessment; the position of a person on the socioeconomic gradient exposes her to more environmental and occupational stressors and higher levels of stress, which then can have physiological and psychosocial effects, greatly elevating one's risk of disease.

Regardless of the approach, almost all of these studies condense, in one way or another, complex and interdependent relations contributing to stratification into quantifiable variables such as socioeconomic status (SES) or social capital. They also perform another critical move by mapping risks directly onto these variables (cf. Fox 1999). As the ontology of the variables is assumed to be actual and material, so is that of risk. The assumption is that the components (i.e. SES, race, ethnicity, income, etc.) underlying risk are universal, as are the mechanisms underlying intervention and treatment. This type of positioning of risk, as Fox argues, "establishes the potential for a formal process of scientific analyses of risk" (1999: 17). That is, the ways in which risks are measured as well as factors ascertained to contribute to risk in these approaches become normalized and universalized. Intervention, treatment, and prevention efforts for risk reduction, therefore, tend to focus on individuals and communities, clustering around education, behavioral change, and population prevention measures.

The other major approach to health disparities can be crudely couched in terms of a neo-Marxist political economy of health. These works critique economic and technological deterministic explanations of excess rates of poor health and death of certain populations, and instead argue that the growth of inequalities is embedded in differential power gradients. They posit that the economic, social, and political power of transnational governmental, non-governmental, and industrial establishments increasingly implement policies that have shifted labor to capital, deregulated labor markets, and decelerated redistribution through the welfare state, causing widening social inequalities in health. This kind of framing begins with the understanding that lived experiences of individuals and collectivities are embedded in a complex web of history, social status, power, structural context, and culture. Therefore, there is consent that broader social and structural forces need to be evaluated critically in epidemiological and public health analyses, replacing existing reductionistic and cursory models of factors contributing to risk. One of the most influential proponents of this model, Paul Farmer, addresses these issues in a compelling piece about the Haitian poor. He and Didi Betrand (2000) write that poor health in Haiti is attributable not to causes from within the country—poverty, ecology, qualitative difference—as touted by policy makers and public health officials, but to transnational forces outside of the country—slavery, colonialism, forced isolation, despotic rule, military occupation, political instability, and structural development programs. These adverse and deeply-rooted processes give rise to conditions which manifest in poor health and well being of a majority of Haitians. They argue:

...social forces—that is, historically given economic and cultural forces—determine, to a large extent, the health of the Haitian people....But long convinced that such matters are beyond the purview of health education, very few of us are schooled in a way that might allow us to contest the ‘immodest claims of causality’ staked by the policy-makers...Haiti offers a series of lessons for the sort of social medicine that could offer both analysis of and remedy for at least some of the ills documented here.

One of Haiti's lessons for social medicine is that social conditions will to a large extent determine patterns of morbidity and mortality, and that the strength of this association is amplified as conditions worsen. That is, the health *sequelae* of structural violence are most severe among the poor. Unfortunately, epidemiology and public health are increasingly uninterested in such broad analyses... (Farmer and Bertrand 2000: 87-88)

Most anthropological analyses similarly advocate for approaches which link local contexts to larger geopolitical processes. Rather than reject biological, psychological, and epidemiological approaches to the study of social phenomena, anthropologists promote more serious considerations of the plasticity of science and its constitution in broader social events, as well as advance critical studies that complicate highly complex biosocial interactions between environment, history, and culture (Nguyen and Peschard 2003). There is an implicit critique of the differing types of knowledge which inform perceptions of risk (cf. Fox 1999), as current biomedical and epidemiological discourses of risk are seen to contribute to the “desocialization” of poor health (Farmer et al. 1996: 198).

The ontological relations between risk and health inequalities, therefore, come to be opposed in these approaches (cf. Fox 1999). Health disparities are deemed concrete and natural, while risk is conceptualized as the subjective and value-laden rationality of individuals and establishments of real world circumstances (cf. Fox 1999). For instance, in a scathing critique of dominant public health literature focusing on poor women and HIV/AIDS, Rhatigan and colleagues (1996) posit that a majority of epidemiological research of risk not only fails to thoroughly examine multiple associations between gender inequality, poverty, and HIV/AIDS, but also locates risk at the level of the individual, divorcing it from larger social and structural constructs. Risk, thus, is seen as embedded in epistemological trends of epidemiology and public health, and operates through broader formations of structural violence. The production of the rationalities of risk itself—discourses,

assessments, categories—is viewed as emanating from combinations of institutional, technical, socio-cultural, economic, and institutional factors, arrangements through which risk becomes real and accessible to intervention (cf. Nguyen and Peschard 2003). From such perspectives, solutions are located away from individual actors and communities, in more sociologically and culturally informed analyses of the complex relations between health inequalities and the conditions which create, stabilize, and propagate them.

Even though these approaches to health inequalities seem to represent two different strands of scholarship, I argue that they both normalize and re-inscribe difference along racial and ethnic lines, and inform the mainstay of the racial and ethnically oriented HIV/AIDS intervention and prevention programs in Miami. In addition, the translation of these frameworks, based in epidemiological and positivist considerations and in the political economy of health, into local initiatives also serves to increasingly reify racial and ethnic disparities in health. For instance, a prevention specialist at the DOH, Legeme Jacques, spoke of her growing dissatisfaction with health initiatives targeted toward Haitians:

Now, imagine that when you go into a population like the Haitian community for example, you can't just say "OK. This is HIV. This is what it is, this is what it's not" because there are so many other things that need to be taught before you can even you can get to that level. It's very difficult to let the funding sources understand that you can't start with HIV education until you tackle other aspects. And you know that they're not going to fund you because they don't understand that in order for the people to actually grasp the whole concept of very basic HIV information, there needs to a whole type of work that needs to be done at another level before they're even ready to tackle that information because remember a lot of Haitians that come here... they don't read, they don't write, there's a lot of superstition, so how are you going to then come down and say "oh, this is just a virus that comes in from secretions"...you know, whoa! What is a virus? What is the difference between a virus and a bacteria? What do you mean by secretions? You mean somebody just put roots on their hands...you understand? And even for the person who is literate, there are still some barriers I would HOPE that if people were to understand that just like there are different cultures within the Hispanic populations, that is the same thing with the Haitian community. You cannot blanket the prevention message. You cannot blanket the resources, the literature, the posters, even the [public service

announcements] to one population because it DOES NOT HIT one population. Like for example, when we were working on our prevention video, we had to choose. We had to choose what kind of Haitian women we are talking about. Because the issues of the participants in that segment are not necessarily the same issues as the other Haitian woman who comes in, who has a household, who has a husband, who has an education, who speaks English very well, who is not even going to be recognized as a Haitian woman unless she decides to identify herself and that other person comes in here with a very heavy accent, does not write, doesn't have a husband, doesn't even have a high school diploma. She is still fighting with immigration. You can't tell me that we're talking to the same people here—we're not talking to the same women, you see. It's should not be on a scale of more at risk and less at risk, because risk has to be reconceptualized. We know that a lot of it has to do with education, with the socioeconomic resources, with immigration status. And people are like "What does that have to do with HIV? What does it have to do with prevention?" It has everything to do with it. Because people are not going to be as receptive to certain things when there are other underlying issues that are a lot more important to them.

Legeme's arguments are highly sophisticated and employ multiple frames to describe the potency of the politics of difference in HIV/AIDS prevention programs. First, she asserts that there is a "disconnect" between the demands of institutional donor agencies such as the CDC and the administration of culturally and socially appropriate programs. She does this by positioning the CDC as only interested in individual and collective risk reduction through biomedical education, rendering them as "incapable" of understanding the cultural and structural impediments that prevent Haitians from participating fully in intervention efforts. Second, in the same vein, she portrays Haitians not only as passive recipients of official interventions ("receptive to certain things"), but also hindered by cultural "barriers" and mired in the social and structural violence of daily life. She asserts that there are broader social and structural forces which must be taken into consideration in HIV/AIDS prevention "because people are not going to be as receptive... when there are other underlying issues that are a lot more important." Prevention efforts, therefore, must not only address "superstitions," but also issues of illiteracy, poverty, and immigration. Even the concept of risk cannot be "blanketed" and has to be "reconceptualized" because Haitians cannot be

lumped into one uniform group. In her framing, Legeme situates herself, and others working with Haitians, as cultural and official experts who construct relevant knowledge about HIV/AIDS prevention (cf. Briggs and Hallin 2007). On the one hand, her role is to mediate communication between the official directives of health disparities and HIV/AIDS prevention to a passive and uninformed public; on the other hand, Legeme is a broker who helps Haitians overcome their cultural and structural restraints, so that they are able to access apparently available resources and proper biomedical knowledge (cf. Briggs and Hallin 2007).

Many clients also share Legeme's views that reaching Haitians will continue to be difficult if current HIV/AIDS prevention and intervention programs are not overhauled. In HIV/AIDS prevention clinical educational classes for Haitians, clients often directed lectures and discussions away from HIV/AIDS transmission and risk to those that focused on religion, discrimination, and economic and legal struggles. They expressed their desires to have more informative classes on legal, economic, health and social services. For instance, during a class, a woman whom we had never seen before came in with Julie, the Haitian educator. This woman looked nervous as if Julie forced her to come, gazing at the floor with tightly clasped hands. Mona, the Haitian patient advocate, was thrilled at having a new face in the class. She pointed to the lady and asked her to introduce herself. Although the woman looked as if she was about to run out of class, she quietly just stated her first name. When Mona asked her to fill out the sign-in sheet, she refused. After Mona coaxed her into it in front of the class, she filled it out, explaining that she did not like coming to classes because she was uncomfortable with anyone knowing her "business." She said that she was also tired of hearing about HIV/AIDS. Mona immediately looked at me sternly, and began to ask me

to write whatever she was going to say carefully because she wanted me to communicate to “the higher ups” what Haitians really wanted. She explained:

What I am going to say they probably won't want to do it but I always think put the Haitian on the phone, put them on the speaker, so they don't see the face. If they don't see the face, they will come. Or if there is a clinic which says you don't have to speak English, you can speak Kreyòl, you better believe it you not going to meet any Haitian there. Give Haitians a choice; those who don't want to meet face to face will come to that clinic just because they know someone will translate for them but they don't have to see nobody. One thing is the entrance door is not really outside door. They come in the door, they go inside, they do what they have to do and they go out of another door. Waiting room should be like little booths. You come, you go to that booth, and let me tell you, it's like there is a big hallway behind the booth. You come and you go into that booth, and then there in the hallway, there are some health care workers who manage three booth doors that do not open at the same time and they go. WE WILL GET ALL OF THOSE who don't want to come. We will get all of them to come to care. And guess what? If we have a place like that, you better believe it, other places that don't have a place like that would be in trouble because word of mouth...because “hey, you see this clinic, this is the way they do it. It's a lot of CONFIDENTIALITY.” Then you will see, they will be leaving the other place and go to our place. I know this is crazy, but this is the only way you going to get Haitians to come for anything that says HIV. It would be better if you have a clinic that gives everything to you, spiritual, immigration, lawyers, and doctors. But that is not going to happen so this is the only thing that I think will work for HIV.

Mona responds to the new client's weariness of discussions around HIV/AIDS and discomfort with others' associating her with HIV/AIDS by putting forth what she thinks needs to be done in order to have Haitians participate in such settings. Her plans for HIV/AIDS prevention and treatment sites are elaborately constructed and she takes measures to ensure that they provide physical and informational confidentiality. She admits that it would be more beneficial to have a site which incorporates health care services as well as legal, spiritual, and other social services, but since “that is not going to happen,” having draconian measures to ensure strict confidentiality seems as the only other alternative. Providers and advocates, like Legeme and Mona, are highly savvy about the limits of HIV/AIDS prevention efforts currently directed toward Haitians in Miami. They understand

that Haitians very rarely attend classes or programs which target them specifically, by either being exclusively in Kreyòl or in locations where there are large numbers of Haitian residents. Issues regarding privacy, confidentiality, and access to myriad of services outside of health play a substantive role in their critique. Much of their arguments are rooted in the premise that because individuals live within complex social, economic, political, and cultural entanglements, health preventions and interventions must be expanded to include larger efforts that address inequality, poverty, and marginalization. Like many anthropologists and social science scholars who consider a political economy of health approach to framing racial and ethnic disparities in health, they support approaches and interventions which enroll broader conceptualizations of social and structural inequalities rather than outright rejecting evidence-based scientific considerations. In so doing, they further sanction and buttress health disparities as a naturally occurring and tangible phenomenon, much like the scholars and policy makers who endorse positivist-based interventions.

Are Reconceptualizations of the Politics of Difference Possible?

Difference continues to become normalized during these times when convergences of new and older shifts in politics, economics, biology, medicine, and technology have opened up complex and multiple sites of transformation for both humans and non-humans. These shifts have led many to consider the accompanying changes in the relations between society and science and to call attention to the processes which constitute the increasing encroachment of the confluences of biomedicine, technology, and genetics into everyday life and the drastic reworking of common concepts of bodies, identities, governance, and ethics. Building on the work of Foucault's governmentality and biopower theses (1979), this

scholarship⁴⁰ proclaims that inequality and stratification are part and parcel of our post-modern times as a result of new, unstable and inconsistent assemblages of biotechnology and forms of knowledge which operate in unequal and in discriminate ways. Such scholarship not only attests that these recent shifts lead to the selective targeting and exclusion of groups along the bases of race, gender, class, and other levels of stratification, it also argues that the shifts themselves are propagated by the very same stratifying practices. In other words, race, gender, and class-based stratifications give rise to, are reproduced by, and are co-constitutive of the processes of the larger shifts in subjectification and governance.

I argue here that such scholarship is a critical contribution to current approaches of understanding difference and health disparities. These studies which call attention to the transformative practices in health, from the diagnosis and treatment of disease through clinical mediation to the emphasis on risk factor analyses and prevention, are crucial to the understanding of the increasing importance of patient-consumer centered models of HIV/AIDS prevention such as the “positive living” movement. They enable health disparities to be reconceptualized as a site of authoritative knowledge production about the differential distribution of disease. That is, in addition to focusing on the ways in which health disparities continue to reproduce schemes of hegemony and structural violence, it is also necessary to emphasize the productive capacity of the framework of health disparities in determining subjectivities, citizenship, and governance. As I have shown, although current approaches to health disparities continue to have relevance in HIV/AIDS prevention, they are becoming positioned by both providers and clients as inadequate and too limiting as discussions become increasingly centered on issues of racial and ethnic differences in health and culturally appropriate models of care. I contend that by bringing this scholarship, rooted

in governmentality studies, into dialog with studies on health disparities, it may give us broader perspectives with which to act.

This scholarship, which builds on studies of governmentality, does not directly challenge those who argue that biosocial factors and globalizing and industrial practices are harmful to a growing number of individuals. Instead, this framework focuses on the forms of knowledge, discourses, techniques, and institutions that create sites in which difference, disparities, and the circumstances on which they are predicated become rationalizable (cf. Lupton 1999). In comparison to the aforementioned approaches to health disparities, these arguments posit that it is no longer a matter of the reality or materiality of health disparities because neither differences nor inequality themselves are of importance. Rather, it is the contingent discourses and practices by which they are brought forth and which imbue them with meaning that should be the focus of study (cf. Fox 1999). In an increasingly transformative time, where there is a moderation of the burden individuals on society, distinctions between healthy and unhealthy populations are rapidly dissolving as everything becomes a potential hazard and everyone becomes subject to risk (Peterson 1997). The contingent nature of these conditions, however, marks the development of constructs of risk and its underlying causes as “a deeply political activity” that leads to the privileging of particular types of behaviors and subjectivities over others (Fox 1999: 29-30). Thus, the inequitable distribution of risk is understood as always already embedded in and constructed through the constant evolving lives of self-managing individuals living in a neo-liberal world. Inequalities and the risks associated with them, in this sense, are no longer viewed as real, imaginary, detrimental, or favorable; they are representative of broader transformations in the rationalities and practices of governance of life itself. This scholarship brings to the

forefront the productive power of differentiation and disparity, and the new forms of governance and subjectivities that spring forth from them. These shifting modes of reality as well as the backdrop of the Human Genome Initiative⁴¹ constitute the formation of new individual and collective identities (Rabinow 1996) which are taking part in interventions that may help prevent not just immediate ills, but potential risks of future hazards.

I posit that it is imperative to consider how recent transformations in commerce, biotechnology, and medicine have produced unstable and contradictory assemblages of knowledge and practice that organize themselves in unequal ways. But, like many anthropologists who focus on the political economy of health, I have shown throughout this chapter and the previous chapters that it is equally important to emphasize the ways in which various structures and ideologies constantly attempt to stabilize, naturalize, and make inevitable the politics of difference that ground such assemblages. It is too limiting to position inequality and disparity as merely representative of broader transformations in governmentality or to presuppose that they exist without much significant impact or consequence in determining and stabilizing the politics of difference. Although I argue that it is critical for existing scholarship on disparities in health (based on studies grounded in social epidemiological and political economy of health) to be in dialog with the growing scholarship on governmentality and biopolitics, I also posit strongly that studies in biopolitics and governmentality must take into consideration broader questions related to social inequality and structural violence. As I have illustrated, the politics of difference both grounds and is borne of these shifting configurations of subjectivities and governance. By opening up lines of communication between such disciplinary, epistemological, and political divides, we may be able to produce better scholarship and platforms for social justice.

Through ethnographic critiques of the notions of biosociality and biological citizenship, in this chapter, I have argued that these “new” ways of being and belonging continue to exist alongside “older” biological categories of race and gender. Therefore, my work deviates from and expands this scholarship by maintaining that both “new” and “old” forms of citizenship can cultivate similar and equally powerful outcomes. My research contends that current political and health agendas, disparities in medical access, and social inequalities have just as much power and clout to propel economy and commerce as do Icelandic and Swedish national genetic databases or identity-based illness movements in the United States (Petryna 2002; Rose and Novas 2004). As I have illustrated, health disparities has become a powerful industry, one that commands considerable monetary and administrative resources and enables the proliferation of numerous forms of research agendas and scholarship funding. In fact, the constellation of processes and discourses that make up health disparities hold vested interests far beyond themselves, in informing local, national, and international policy initiatives (i.e. Healthy People 2010,⁴² World Health Organization’s goal of “Health for All”⁴³); funding and research (i.e. the Whitehall Study); and the social contexts of embodied experience and behaviors (cf. Rapp 1998; Lock and Kaufert 1998).

Thus, I argue that contemporary forms of citizenship and self-management do not have to represent only genetic responsibilities in order for the state or its citizens to play an active role in transforming citizens into a potential resource of wealth and health (cf. Rose and Novas 2004). Disparities and stratifications in health and biomedicalization, as realized in the sociopolitical, scientific, and economic realms in which they come to be engaged, are also being rationalized and made into social instruments of action (cf. Petryna 2002). Additionally, like some citizens in post-Chernobyl Ukraine who, through the platform of

suffering and pain, have come to rely on technologies, medical knowledge, and legal actions to secure political acknowledgment and access forms of welfare benefits (Petryna 2002) and the “ethical pioneers” who forge new ways of conceptualizing and shaping themselves (Rose and Novas 2004), those implicated within health disparities and those deemed at “high risk,” must also (and need to) be understood through their productive actions, choices, and rationalities in the name of inequitable burden of affliction and illness.

FIVE

West is the Rest: Afterthoughts on Future Directions

In 2005, a series of events were organized around the World AIDS Day celebrations to highlight the unequal impact of the epidemic on African-Americans in Miami. These included a special luncheon at Miami General Hospital, a day long celebration at the local convention center, and a series of marches in Liberty City, an area with a large African American and Haitian population. Almost all of these events were being organized by a committee made up of members from local community based organizations serving African-Americans in Miami. Health officials and event organizers framed the unequal burden of HIV/AIDS on Black and African-American communities nationwide and in Miami through the rhetoric of personal and social accountabilities. Activists commended the resiliency of those who were living with HIV/AIDS, and clients recounted stories of personal triumph through representations of cellular statistics. For instance, Terry Smith, a top DOH official, expanded on the World AIDS Day theme “Stop AIDS: Keep the Promise” by arguing that the notion of “promise” symbolized “accountability” and “personal responsibility.” He explained that “keeping the promise” was “not only aimed at political leaders but also every individual person.” He implored each individual audience member to take the “opportunity to educate those around you” by quoting Kofi Annan: “All of us should make AIDS our problem.” Mr. Smith continued by saying:

We have much to be thankful for in terms of accomplishments. The perinatal decline in AIDS was a huge marker of success and a great hope for women and children. Last year, only two cases of perinatal infection were reported in Miami. Florida has one of the most aggressive testing and counseling programs in the country. We test more people than other states. I encourage all of you to pray for a day when there will be a vaccine. I don't want this job forever, because I want to see a cure soon.

Through such statistical portraits and new programmatic interventions like the Black AIDS task force, the Latino AIDS task force, and the Florida Black AIDS Network, he depicted notions of change, control, and success. He ended his speech by indicating that local governing bodies were intensely concerned with “implementing the national health disparities goals locally,” and that they had ensured that in the past six years, the number of HIV/AIDS cases among Black/African-Americans had decreased by 28% county-wide and by 30% in Florida overall.

Similarly, at a largely pharmaceutical-sponsored World AIDS day luncheon at Miami General Hospital, providers joined patient activists and clients in calling for progress in HIV/AIDS treatment and prevention and celebrating those living with HIV/AIDS. Clients recited poems and stories of their miraculous transformations from sickness to vitality. They utilized statistical enumerations to describe these personal achievements, not unlike Terry Smith’s illustrations of the successes of the health department initiatives. Community activists applauded these clients as “leaders” who truly embodied the notion of “positivity,” as having hope and self-perseverance in the midst of hardship. A young Haitian activist emphatically pronounced that “Being HIV positive means life not death!” to an audience who gave him a standing ovation for such remarks. Providers also joined in, praising and reminding clients to be informed, aware, and knowledgeable about their medical care and risks. A social worker, for instance, encouraged clients to always keep “questioning why we can’t do better in the field of HIV/AIDS,” while giving a series of statistics about current rates of HIV/AIDS in Miami.

Although both of these events were organized against a backdrop of bringing attention to what many, including the CDC, label as a “HIV/AIDS crisis” among African-

American communities, both of these events were not well attended. Even those confirmed on the agenda, local politicians, community leaders, providers, and clients failed to be present. Local DOH officials attending the World AIDS Day event departed after Terry Smith's presentation of the department's accomplishments in reducing local rates of racial and ethnic health disparities in HIV/AIDS, which left about 20 people at the event even though over 400 people had confirmed attendance. The mayor and various council members also failed to show, although they were mentioned as primary speakers in the programs, and none of the organizers explained their absences to audience members. A fellow volunteer at the event surmised that this lack of official attention was due to what she called "racial tension," indicating that the organizers had been African-American and worked for community organizations that served minority populations while top officials in Miami were either Hispanic or White.

This sentiment was echoed by the handful of residents who attended a march in Liberty City, an area that is home to predominately disadvantaged African-American and Haitian residents, and according to the DOH, has the "highest number of cumulative AIDS and HIV cases in the county" (Miami-Dade DOH 2007). There were four people who participated in the grassroots march. One participant was the organizer, a local resident, who when asked about her motivation to hold the march declared "Do you see any candlelight services in Liberty City? We have the highest percentages of AIDS cases in the community but who is having a rally here? No one!" (Berggren 2005). This resident, utilizing HIV/AIDS surveillance statistics, points to the disconnectedness between the high rates of HIV/AIDS among African-Americans and the dearth of attention focusing on their plight. She directs the blame on officials, for not acknowledging through public demonstrations and

campaigns the vast numbers of African-Americans who have died and who continue to be affected by HIV/AIDS.

Similarly, although the HIV/AIDS luncheon at Miami General Hospital attracted many social workers, health educators, patient activists, and clients, prominent physicians and other HIV/AIDS specialists, including the main speaker, failed to not only attend but also give notice of their absence to organizers. In addition, local media outlets neglected to report on or about local or national events related to World AIDS Day. When I tuned into the local news broadcasts at 5:00PM, 5:30PM and 6:00PM, there was absolutely nothing on the news about World AIDS Day, either in terms of local, national or global celebrations. There was news, however, about a bird which got stuck in a shipment of Christmas trees and even one about an impending poinsettia shortage in Miami-Dade. At the late night newscast, at 11:00PM, there was a story about a local World AIDS Day celebration in Ft. Lauderdale that lasted about 15 seconds.

The lack of attention and participation at these events is not surprising even with the official rhetoric that consistently frames HIV/AIDS as a major health concern for ethnically minority populations in South Florida through recent statistics that indicate that Broward and Miami-Dade counties have the highest rates of new infections in the state. These World AIDS Day events seem to represent just one of many broader disconnects between official discourses of community “needs” and the practices they engender. The CDC and the Miami DOH, for example, recently promised to allocate funding proportionately to African American communities in order to increase resource efforts in racially and ethnically tailored HIV/AIDS prevention programs even though federal support of HIV/AIDS has continued to decline. The CDC (2007) states that in 2007, half of their HIV/AIDS prevention budget of

\$652 million and 63% of new funds have been allotted to programs “designed for African Americans.” In Florida and especially in Miami, however, these initiatives of the CDC fail to be realized, as decreasing resources for HIV/AIDS become the norm, especially for racial and ethnic communities. In a county planning board meeting, for instance, DOH officials indicated that the county DOH was going to “absorb” millions of dollars in funding cuts by the CDC and the federal government. Also, at the level of local health and social service organizations, administrators and directors spoke of dwindling funds and HIV/AIDS prevention programs for racial and ethnic minorities, especially those who cater to Haitians. At Santè Ayisyen, for example, the staff was exasperated with finding funding for their fledgling clinical programs, pointing to donors who are seen as “out of touch” with the Haitian community by expecting more collaborations between competing organizations and being inflexible about local translations of certain programmatic interventions. These were pressing issues for this organization, which even with its ties to local research universities and to the DOH, was struggling to meet demands in Little Haiti and in early 2007, they had closed their clinical operations (medical clinic and HIV counseling and testing) altogether, and a staff of six, including physicians, nurses, and case managers, had been let go (L. Marcelin, personal communication, 2007). Dr. Paul, the head of one of the only clinics catering to HIV-positive Haitians in Miami, was also being forced to relocate his practice administratively to Miami General Hospital, which meant he could no longer see patients.

These observations of World AIDS Day events and the disconnectedness between official rhetoric of “need” and lack of funding on the ground illustrate the ways in which the concept of difference in health among populations and groups, particularly through notions of race and ethnicity, has become a normal and a natural part of the political, social, and

medical landscapes, so much so that public forums dedicated to addressing the continuing health disparities like the World AIDS Day celebration in Miami or the closing of clinics catering to Haitian clients attract very little attention. Official discourses of HIV/AIDS no longer contend the existence of health disparities based along racial and ethnic differences. Instead the CDC, local DOHs, providers, scholars, activists, and clients focus on how to alleviate the inequitable burden of illness that falls on many racial and ethnic minority communities. Public health institutions and governing bodies insist that they spend a significant portion of a continually decreasing budget of HIV/AIDS on the African-American community, in keeping with the initiatives of the national health disparities referendums, implicitly maintaining that they are doing their part in alleviating health disparities and absolving themselves from any “failures” that result from these initiatives. State and county departments of health also vow to “absorb” federal cuts in order to keep initiatives to reduce health disparities in HIV/AIDS functioning. Thus, if disparities in health continue to rise, then the culpability becomes aligned with either local programmatic translations or racial and ethnic populations themselves.

Clients and activists also utilize such narratives of racial and ethnic disparities to make transparent local struggles to increase public support and awareness for racial and ethnically-specific programs. They employ complex strategies to formulate notions of responsible, ethical, and enlightened governance and citizenship, and strive to fuse individual accountability with social responsibility. They extol the changes brought upon by a HIV-positive status that enable them to live as responsible citizens, with control over their health and well being. They symbolize their marks of progress through cellular statistics, meticulously documenting CD4 levels and T-cell counts. They also utilize official statistics

to call for greater allocations of resources to communities in “need” and question why more has not been done to ease the inequitable burden of disease.

However, as illustrated throughout the preceding chapters, such configurations of subjectivity and governance are not easily translatable or sustainable for Haitians in Miami, for whom such projects of biological citizenship always already embody racial and ethnic inequalities and discrimination. These processes, although steeped in multiple gradients of power and authority, do not completely render Haitians powerless or immobile. Haitians struggle to produce alternative discourses and actions which challenge the very foundations of the circulation of knowledge in HIV/AIDS prevention. They refuse to interpellate themselves to official constructions of the management and mediation of risk, and as a result, become positioned as impossible biological citizens. By conceptualizing notions of HIV/AIDS, risk, and subjectivity through multiple configurations of community and identity, Haitians in Miami problematize structural and social inequalities as broader questions of authority and social order. In this way, Haitian clients remake HIV/AIDS prevention as a site not only of constant struggle over meanings and discourse, but also a space where rationalities of governmentality, race, and health become contested through everyday practices.

Looking Back: Chronicling HIV/AIDS at the Margins

These analyses of World AIDS Day 2005 serve to bring this research full circle. Throughout the preceding chapters, I have sought to trace how the politics of difference circulate alongside notions of individual, group, and universal risk in the field of HIV/AIDS prevention and intervention efforts in Miami, Florida. Each chapter represents particular

convergences of these various types of circulations. I first begin by utilizing HIV/AIDS surveillance statistics and categorizations to demonstrate the linkages between multiple rationalities of risk and notions of community, identity, and culture. By focusing on the various transformations that have occurred and that continue to arise in HIV/AIDS surveillance systems such as PEMS and STARHS, I illustrate that such processes of data collection and transmission are not only highly dynamic, but are also in the continual process of being standardized. Using Susan Leigh Star's (1989) concept of "triangulation," I posit that the practices of standardization enable seemingly fluid and self-evident translations of various structural and social inequalities into comparable and discrete categories while simultaneously claiming that these products represent "real" and "factual" maps of the epidemic.

Such changing practices are by no means only controlled by powerful institutions like the CDC or DOH; processes of standardization and data-making also involve the active and non-active participation of clients who are the objects of standardization. Notions and categories of risk in HIV/AIDS prevention present productive spaces in and through which clients interpellate themselves to what I call "numerical subjectivities" and prevention goals, while HIV/AIDS institutions and experts construct them as "risky" subjects and citizens. By using ethnographic accounts of HIV/AIDS clinical education programs and counseling sessions, I illustrate how perceptions of external risk are transformed into internal risk, and how such changes serve to naturalize the associations between risk, race, and ethnicity in both official discourses of HIV/AIDS and public imaginaries. Finally, I show that although the transformation of risk in HIV/AIDS research and surveillance from representative modality of social insurance to that which is self-managed continues to occur, these

formulations co-exist with and are co-constitutive of various articulations of targeted surveillance informed by biomedical constructs of difference, especially in relation to Haitians in Miami. Haitian clients continually negotiate official and non-official discourses of HIV/AIDS risk and numerical subjectivities, often refusing expert mediation in the management of risk, and in the process, become constructed as incompatible subjects and objects of governance through systems of surveillance.

In the next chapter, I continue to document the ways in which Haitians navigate several realms of existence, as both productive and responsible citizens and as unmanageable subjects, even as official discourses of HIV/AIDS diametrically position notions of “sanitary citizens” and “unsanitary subjects” (Briggs and Mantini-Briggs 2003). I do this by concentrating on how expertise and governance come to be institutionally constructed and subsequently translated to the daily practices of HIV/AIDS prevention in Miami. By documenting the multiple ways HIV/AIDS is framed in counseling and educational sessions, I posit that culture has come to equal risk for HIV/AIDS and that such cultural rationales of risk are rooted in ideological correlations of race and disease. Furthermore, I argue that HIV/AIDS experts and programs, in targeting prevention at the level of community intervention, naturalize social and structural inequalities and the connections between race and disease through the rubric of culture. That is, through practices which promote self-controlled medical destinies to Haitian clients irrevocably positioned as hopeless and trapped by culture, notions of individual responsibility in HIV/AIDS prevention and self-management of risk become indistinguishable from notions of collective and individual identities.

Haitian clients and advocacy groups also participate in the circulation and rejection of these discourses of HIV/AIDS, risk, and subjectivity. By conceptualizing HIV/AIDS through multiple frames of meaning, as something experienced, as a consequence of particular actions, and as a means to garner necessary resources, many clients challenge the epistemological foundations of HIV/AIDS risk reduction. Their stories of health and illness become configured through illustrations of poverty, discrimination, and marginalization, and disclose myriad of practices employed to traverse health and social service systems and government bureaucracies. Conceptualizations of health are also entrenched in fractured notions of community and collective identity, as a result of complex and difficult historical contexts of Haiti's sustained (and sustaining) geographical, political, economic, and social isolation. Such interpellations to various diseases and institutions serve to combat official narratives that position them not only as incapable of political self-governance and economic self-realization, but also as naturally diseased, poor, and suffering.

These illustrations direct us to an increasingly standardized notion of "positive living" in the field of HIV/AIDS prevention. The "positive living" movement gains traction through the production and management of responsible, ethical, and enlightened biological citizens vis à vis HIV/AIDS. By examining discourses of disclosure, adherence, and safe sex, three of the foundational tenets of the concept of "positive living," I demonstrate that such configurations of biological personhood and citizenship do not hold together well for many Haitians in Miami because these projects of citizenship are always already rooted in ideologies of racial and ethnic differences. Through various forms of participation and non-participation, Haitians continually interpellate themselves away from biological conceptions despite such official and popular renderings by simultaneously claiming and rejecting

citizenship projects of a biological kind. Finally, I contend that we must rethink current notions of biosociality and biological citizenship in light of these individuals and collectivities who continually strive to decouple citizenship from biology and biology from citizenship.

The practices and discourses employed by Haitians to decouple associations between biology and citizenship, in turn, render visible the politics of difference embedded within contemporary projects of biological citizenship. As “tailored” HIV/AIDS prevention programs for racial and ethnic minorities become viewed not only as desirable but also as necessary to the mediation of the inequitable burden of disease, concepts of race and ethnicity become more fundamentally entrenched in the discourses and practices of HIV/AIDS prevention. By documenting the propagation of racially and ethnically specific HIV/AIDS prevention programs in Miami, I show how the concept of health disparities has become a natural and commonsensical part of our national landscape. I argue that these politics of difference in health are being continually buttressed and stabilized through various scholarships that attend to social and structural inequalities and biological citizenship as well as through institutional practices and policies.

Moving Forward: Present and Future Reconsiderations

In order to critically examine contemporary biological modes of identity and belonging in more transnational frames, we, as anthropologists, must ground our work in disciplinary convergences. Here, I emphasize my own intellectual and ethical struggles to adequately portray problems of social inequality and the immense vulnerability of Haitians while simultaneously bringing in scholarship in STS, governmentality, and biopolitics to

critique current social epidemiological, clinical, and (even) anthropological approaches to the production of knowledge and facts about HIV/AIDS and health disparities. As circulations of collective and subjective modes of being, public health practices, and scientific rationales become increasingly configured in complex ways, it becomes necessary to employ multiple frames of analyses that attend to the linkages between political economies of health, biomedical discourses, and historical trajectories in addition to narratives of social suffering and structural violence. Modes of being and belonging that occur in diverse geographical and sociopolitical contexts vary, and thus, contemporary studies of biosociality and biocitizenship also have to reconfigure their considerations of biosocial formations accordingly. Finally, at a time when many anthropological programs of study and funding streams are partial to scholarship situated in “global” locales, it becomes exceedingly important to question the ways in which such spaces are configured and how they are constituted relationally to other sites.

HIV/AIDS prevention in the United States presents a rich and highly relevant frame through which to explore such contemporary issues. The complex movements of knowledge, discourses, and practices of the multiple institutional and individual constituents who work in the field of HIV/AIDS open up abundant sites from which to consider the ways that biomedical technologies and expert rationalities travel and situate themselves in many contexts. These investigations allow for better understandings of the social and structural inequalities which become instilled and refashioned through transnational circulations. They also allow for a re-envisioning of the relations between science, medicine, and the politics of inequality and difference as highly productive. Therefore, I continue to argue that it is crucial not to black box notions of “Western” or “American” HIV/AIDS prevention, policies,

experts, and lay publics. We must still attend closely to these processes in the United States both within and outside biotechnical settings and in out-of-the-way places.

I demonstrate that constructions of HIV/AIDS risk and prevention in the United States are continually evolving in places such as Miami. The CDC and local DOHs are persistently developing and implementing various procedures of standardization in HIV/AIDS surveillance, testing, and risk assessments, while the operationalization of new technologies like PEMS and STARHS serve to highlight that interpretations and transmission of official representations of HIV/AIDS risk are highly unstable. Discourses and practices of HIV/AIDS experts and officials, thus, are not wholly solidified—health officials problematize the feasibility of translating interventions and HIV/AIDS counselors convey uncertainty about the mediation of risk. These fissures in expert rationalities continually interface with Haitian clients' refusals to conceptually disconnect internal and external risk. Such collisions result in multiple uneven spaces from which official notions of risk become fused with social and structural inequalities. Therefore, a reimagining of HIV/AIDS studies in the United States must occur, one which does not constitute various circuits of knowledge and practice as established or closed.

In tracing the paradoxes between the advocacy for progressively more specific groupings of difference, the development of population and cultural-specific programs, and the discourses which shift away from constituting race and ethnicity as markers of risk, I contend that the concept of health disparities has become a taken-for-granted reality, no longer needing clarifications or deliberations. I argue scholarship on risk discourses is fundamental to the unsettling of health disparities and a focus on notions of biosociality and biological citizenship among Haitians in Miami is also a necessary contribution because they

bring to the forefront the productive and dynamic shifts in subjectivities and governance of life itself. However, I assert that there needs to be a broadening of this scholarship.

Although it is imperative to attend to the uneven transformations brought about by assemblages of biotechnology, economies, and subjectivities, it is equally vital to consider the ways in which various structures and ideologies routinely stabilize and make inescapable the politics of difference that ground such assemblages. Inequality and difference cannot be perceived as mere representations of shifts in governmentality; the politics of difference opens up multiple and powerful conditions of possibility for the study of both experts and those they seek to manage.

The ways in which official and non-official discourses about risk, health disparities, and biomedicalization operate at the level of situated experience among Haitians and Haitian-Americans demonstrate that new and existing forms of subjectivities and citizenship can indeed generate productive effects. Disparities in health outcomes, political and public health agendas, and social inequalities can and do drive economies because they nourish and help to proliferate many policy initiatives, research agendas, and social activism. Individual and collective identities represent resources for the creation of biovalue (cf. Waldby 2000; Rose and Novas 2004) not only through their genetic potential, but also through what they come to symbolize in terms of disparities in health. It is in this way that the politics of difference through the rubric of health disparities participates in the production of contemporary forms of citizenship and social action. Haitians in Miami, much like others grounded in the discourses of health disparities are “ethical pioneers” (Rose and Novas 2004: 450), actively shaping these transformative processes and redefining what it means to suffer from the inequitable burden of disease at the margins.

NOTES

¹ Image reprinted with permission from the American Foundation for AIDS Research (amfAR).

² Following Paula Treichler (1999), I utilize “HIV/AIDS” to refer to several things interchangeably: 1) an epidemic representing a wider social and cultural crisis, and 2) the broad clinical range of HIV-related conditions from asymptomatic infection to diseases used to define AIDS.

³ For a more complete and thorough discussion of scholarship that has discussed changes in the relations between science and society, please see Thompson 2005.

⁴ David Harvey (1990) states that in the postmodern time, there is both a celebration of fragmentation as well as an embrace of unification (globalization) in a world that is becoming increasingly defined through transnational communications and commodified culture.

⁵ “Biomedicalization” (Clarke et al 2003: 162) is defined as processes which constitute the increasing encroachment of the confluences of biomedicine, technology, and genetics into everyday life and the drastic reworking of common concepts of bodies, identities, governance, and ethics. Thompson (2005: 249) calls it “biomedicalism.”

⁶ Although commonly referred to as Haitian Creole in English, “Kreyòl” or Kreyòl Ayisyen is how it is pronounced and spelled in Haiti; this version is increasingly being used among speakers and teachers of the language in the US. I use “Kreyòl” instead of Creole because it indicates the official language of Haiti and a language in its own right rather than pidginized French.

⁷ I do not speak or understand Spanish, so I do not know what was said in this situation. I also could not hear the tone of the voices and was unable to see facial expressions as I was viewing their back sides.

⁸ The Liberty City riots occurred in the neighborhood of Liberty City which comprises half of Miami-Dade county’s African-American population (US Census 2004). The riots began after an all white jury acquitted four white police officers of violently beating and killing Arthur McDuffie, an African American insurance agent. The riots lasted about three days, killing 18 people and causing millions of dollars in damage.

⁹ In both 1982 and in 1989, days of rioting occurred when a Hispanic police officers killed unarmed African American men.

¹⁰ In November 1980, an anti-bilingual initiative passed in Miami-Dade, prohibiting expenditures involving non-English languages and non-US cultures. This legislation paralleled the Mariel boatlift, which brought into Miami younger and poorer Cubans, and mobilized Miami Cubans on local political issues. It was repealed in 1993.

¹¹ This boycott was organized by African American leaders in Miami after local Cuban business and government leaders refused to give Nelson Mandela a key to the city during his visit in 1990 because of his affiliation with Fidel Castro. The boycott deepened race relations between African Americans and Cuban Americans and affected the flow of tourist dollars into Miami.

¹² Francois Duvalier, was president and dictator of Haiti from 1957 until his death in 1971. His government grew to be one of the most repressive in the world, marked by corruption, violence, and autocracy.

¹³ Disciplines such as sociology, health psychology, and political science (Parker 2001).

¹⁴ Due to space constraints, these are broad definitions: (1) Symbolic interactionism is a perspective which follows Blumer’s (1969) stance that people act based symbolic meanings derived from social interaction and interpretation. (2) The postmodern turn in anthropology, mostly associated with Clifford and Marcus (1986) and Geertz (1988), reflects an emphasis on the social role of knowledge. It was a response to a perceived “crisis of representation” and resulted in critical self-consciousness and self-reflection of the field and of the discipline. Scholars incorporated the ideas of postmodern theorists, and questioned the authority of their own knowledge which led to experimental and reflexive ethnographies, and ethnographic writing itself became an end in itself, a genre of literature. (3) Women’s studies is an interdisciplinary field of study devoted to issues on women, sexuality, gender, and feminism. (4) Queer Studies is an interdisciplinary field of study with emphasis on gender, sexuality and identity.

¹⁵ I am directly in conversation with Pigg’s (2001) claim that public knowledge about HIV/AIDS in Nepal in the 1990s was being produced from pre-packaged established views of HIV/AIDS and prevention efforts. She states “Seen from the receiving end of this knowledge, however, and from the margins of its production, knowledge about AIDS and AIDS prevention does, however, come rather tightly packaged” (Pigg 2001: 527). I’m not debating her stance about what is happening in Nepal; rather, I argue that the presumption here is that in the United States or in other countries where HIV/AIDS has had a longer history, knowledge about HIV/AIDS

and its prevention is established, and that there are no controversies or struggles against various approaches to HIV/AIDS programs.

¹⁶ See Kearney (1995) for a more comprehensive review of the anthropology of globalization and transnationalism.

¹⁷ For some notable exceptions, please see Mishra et al. 1996, Weatherby et al. 1997

¹⁸ For a critique of Boasian anthropology and its neglect of examining the effects of economic, political, and social racism of minorities within the United States, as well as other, less known, anthropological works operating under other theoretical influences, opening up promising windows for fieldwork focusing on the political economy of Jim Crow laws, see Shanklin (1998).

¹⁹ There have been, however, a few notable exceptions of anthropological works that have critically examined the concepts of race and ethnicity and its usefulness in studying the American situation. These efforts mainly analyzed social stratification of various groups, problematized the applicability of ethnic models that imposed normative categories residual of European immigrants onto U.S. race relations, examined ethnic identities as dimensions of nation-building projects, and highlighted the ways in which ethnicity operates as a form of resistance to prevalent racism (Harrison 1995, 1998).

²⁰ HIV/AIDS educational classes are offered by many constituents within Miami General Hospital. Two separate English classes are offered weekly on different days by different departments, and often, the same clients come to both. There is only one class in Kreyòl which is offered bi-weekly, and there is currently a weekly Spanish class.

²¹ These materials included informational pamphlets, publicity flyers, reports, articles, media packets, and periodicals as well as surveillance data, statistical reports, and program evaluations.

²² A very recent example of the complex and contested nature of HIV/AIDS surveillance occurred in 2007, when UNAIDS conceded that they had long overestimated HIV/AIDS rates globally, and dropped the number of those with HIV/AIDS from 39.5 million to 33.2 million (McNeil Jr. 2007). This revelation pointed to long disputes among epidemiologists and other public health scholars on the validity of research methodologies used to arrive at estimates (McNeil 2007).

²³ See pages 64-65.

²⁴ SIDA stands for the French acronym “Syndrome d’Immuno-dèficience Acquisè” in Haitian Kreyòl as well. For a discussion of the evolution of the word SIDA in rural Haitian lexicon, see Farmer 1990.

²⁵ Except for the MSM/IDU category.

²⁶ Additional surveillance was conducted through laboratory CD4+ reporting and through HIV/AIDS treatment centers outside of clinical inpatient settings such as tuberculosis and other disease registries (CDC 1993; Hammett et al. 1996)

²⁷ The most notable changes included CD4+ T-lymphocyte counts of <200 cells/µl or <14% of total lymphocytes, or who had pulmonary tuberculosis (PTB), recurrent pneumonia, or invasive cervical cancer (CDC 1993; Hammett et al. 1996)

²⁸ For further information, see Green 1998.

²⁹ At the time of writing, I could not get any of my contacts to reveal the specifics of what they termed a “political” situation that followed decreasing pools of money used to support these programs.

³⁰ For instance, in this case, 20.4% of non-Hispanic blacks are said to be at behavioral risk; that is, 20.4 out of 100 non-Hispanic blacks. CDC (2007) estimates that non-Hispanic blacks accounted for 49% of new cases of HIV/AIDS diagnosis in 2005; that is, 18,121 out of 37,331 new HIV/AIDS diagnoses in 2005 (includes all racial/ethnic groups).

³¹ For further reading on STS and the construction of credibility, please see Epstein 1996.

³² For further readings on Haitian politics, please see Fauriol 1995; Trouillot 1995; Nicholls 1996; Preeg 1996; Depuy 1997; Kumar 1998; Rotberg 1997.

³³ For further examples and discussions, please see Chapter 3.

³⁴ The most recent being a 2007 article in the Proceedings from the National Academy of Science (PNAS) stating that subtype B HIV virus in Haiti originated in Africa, and that Haiti, and by implication, Haitians, were the conduit for the spread of HIV/AIDS to the United States and the Americas. The authors’ use of various phylogenetic techniques, including bioinformatics and new cutting edge sampling techniques have won them support as well as critique. There have been numerous reactions to the implications of this article, both positive and negative, from the scientific community and the public at large. To read the article, please see: Gilbert et al. 2007. The emergence of HIV/AIDS in the Americas and beyond. PNAS. 104: 18566-18570.

³⁵ For additional discussion, please see Chapter 3.

³⁶ Haitians who do attend often participate in classes offered in English and sometimes in Spanish.

³⁷ In February 1990, Haitians Federal Drug Administration barred blood banks from taking blood donations from all Haitians because of potential contamination from HIV/AIDS. Although this ruling was later repealed in December 1990 after massive protests by Haitians in the U.S., it cause massive negative reverberations for Haitians living in and outside the U.S. (Pape 2000)

³⁸ In DOH forms, “Haitians” only if they were born in Haiti; Haitians born in the U.S. or in other countries would not get labeled as “Haitian” in official reports. When this data is aggregated to indicate only the official census categories of race and ethnicity, “Haitians” are grouped under the “Black/African-American” race category.

³⁹ Please see Chapter 2.

⁴⁰ Please see: Rabinow 1999; Rose 1999, 2007; Lock et al. 2000; Dumit 2003; Franklin and Lock 2003; Clarke et al. 2003; Thompson 2005.

⁴¹ The Human Genome Initiative is the collective name for several projects begun in 1986, led by Department of Energy and the National Institutes of Health, to create DNA segments from known chromosomal locations, develop new computational methods for analyzing genetic map and DNA sequence data, and develop new techniques and instruments for detecting and analyzing DNA. Rabinow (1996) argues that the Initiative, its related enterprises and institutions, and its mission to generate knowledge about the human genome for the specific purpose of altering it will profoundly shape society, life, and labor.

⁴² Healthy People 2010 is a governmental initiative that indicates particular health measures to be met for the U.S. as a whole in the first 10 years of the 21st century. It builds on past initiatives that arose out of the 1979 Surgeon General’s report: *Healthy People*, and *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. Its goals are to 1) increase the quality and years of healthy life and 2) to eliminate health disparities.

⁴³ In 1981 the World Health Assembly adopted the ‘Global Strategy for Health for All by the Year 2000.’ Its aims are not the eradication of all disease and disabilities, but to ensure that resources for health are evenly distributed and that essential health care is available to all. This strategy was renewed in May 1998, with the adoption of the World Health Declaration by the 51st World Health Assembly.

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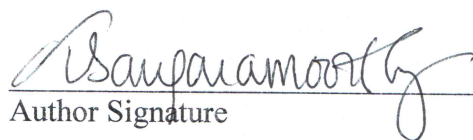
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