

**Contemporary Materializations of HIV/AIDS in Washington, D.C.: Poz Youth  
Potentialities?**

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## Acronyms

<b>ABC</b>	ABC is the classic formula used in HIV prevention: Abstinence, Be faithful, and use Condoms. Especially when it comes to youth, the ABC approach is supposed to be applied (and said to be most effective) in alphabetical order.
<b>AIDS</b>	Acquired Immunodeficiency Syndrome. In strict biomedical usage AIDS refers to the last symptomatic stage of HIV before death and is determined when the T cell count has dropped below a certain level.
<b>ARV</b>	A common acronym for anti-retroviral drugs, which suppresses or stops a retrovirus. Anti-retroviral treatment is commonly referred to ART and sometimes used interchangeably with ARV.
<b>CDC</b>	Centers for Disease Control and Protection. The US public health agency responsible for national disease surveillance, prevention, and treatment measures.
<b>D.C. DOH</b>	The abbreviation for the Government of District of Columbia Department of Health. The US public health agency responsible for District based disease surveillance, prevention, and treatment measures.
<b>DMV</b>	The local term for the combined metropolitan area of Washington, D.C., Maryland, and Virginia.
<b>ELISA</b>	The Enzyme-Linked-Immunesorbent-Assaya test, most commonly referred to as ELISA, was the first HIV screening test developed because of its high sensitivity for detecting antibody and antigen presence. It is the first of two tests that an individual must test positive for before they are considered HIV+.
<b>GRID</b>	Gay Related Immune Deficiency. The archaic and highly contested term used in the early 1980s for what was later re-named AIDS.
<b>HAART</b>	HAART is the acronym for Highly Active Antiretroviral Therapy, a widely used medication approach wherein several ARV drugs are taken in combination to thwart the spread of HIV amongst cells and to slow the overall life cycle of HIV in the immune system.
<b>HIV</b>	Human Immunodeficiency Virus. The aetioloical agent commonly understood to cause AIDS.
<b>HIV/AIDS</b>	Employed together herein by the author to refer loosely to both

phenomena while insisting on the inseparability of the materiality of the HIV virus from AIDS as the more general social field of disease.

- IAC** International AIDS Conference. The IAC, through the efforts of the International AIDS society, started in 1985 and is held every two years in a different host city
- IAVI** International AIDS Vaccine Initiative.
- IDU** Injection Drug User. A term used by epidemiologists to study the spread of disease among people who use or share needles when injecting drugs into his or her body.
- MMWR** *Morbidity and Mortality Weekly Report* is the weekly epidemiological digest published by the U.S. Centers for Disease Control and Prevention.
- MSM** Men who have sex with men. A term first deployed by epidemiologists in the 1990s to indicate and study the spread of disease among men who have sex with men regardless of whether these men consider themselves to be gay or bisexual. MSM, like other risk group classifications, is used frequently in medical literature, clinical study, and social research to describe such men without considering issues of self-identification.
- NGO** Non governmental organization.
- PEPFAR** Launched in 2003 by President George W. Bush as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) provides money for country based emergency responses to HIV/AIDS.
- PLWHA** People Living With AIDS or Persons Living With AIDS. Often seen as PLWHA to indicate Persons Living With HIV or AIDS.
- STI** Sexually Transmitted Infection, also commonly referred to as Sexually Transmitted Disease (STD). The term STI applies to more than two dozen disease like HIV, gonorrhea, Human Papilloma Virus (HPV) that are transmitted primarily through anal, oral, or vaginal sex.
- USD** U.S. Dollars.
- WHO** World Health Organization. WHO is the directing and coordinating authority for health within the United Nation's system.

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## **Chapter I: Introductory Remarks**

### **Introducing the Format**

This introductory chapter aims to familiarize readers with the premises and methods that foreground this interdisciplinary research on contemporary understandings of illness, health, HIV/AIDS, and young sexualities in Washington, D.C. In order to guide the reader through a number of research choices, I have organized the chapter around short questions aiming to situate my research. Having undertaken research engaged in asking other young people questions, I seek to turn the table and interview myself as an exercise to further contextualize my research choices. The fact of the matter is that when producing an academic text, the author cannot be accountable to everything and everyone. Critical and conscientious choice must be made about method and representation, which I am to make explicit here.

### **Why HIV/AIDS research?**

People frequently ask me, why study HIV/AIDS and young people? Why such a grim topic? What more can be said about HIV/AIDS? While the specter of death associated with HIV/AIDS may seem a morbid subject to pursue as one's life work, some of us see it differently and are compelled out of sheer necessity to speak because, after all, the spread of HIV is preventable. My passion derives from work experience in the field of sexual and reproductive health, from conducting peer educator trainings to going for my own first HIV/AIDS test. What follows is an excerpt from a reflection piece written following my first HIV/AIDS test, which reveals the moment when the personal became political for me, with the hope that this helps elucidate my politics of location and situate my academic interests in the wider context of my life.

*On June 27, 2006 I went for my first HIV test with all of the summer interns at Advocates for Youth when we participated in D.C.'s campaign to "Come Together D.C., Get Screened for HIV." This campaign urged all residents 14-84 to get free testing at various locations throughout the city. After braving a thirty-minute line formed outside a mobile HIV testing unit, I entered the testing RV alone to ensure confidentiality. Inside, I had to fill out a detailed form about my sexual history and sexual activities, which consisted of explicit questions about how (if at all) certain sex acts were performed and with whom (in terms of number and gender of partners). Listing sexual partners and checking off descriptors for how sex acts were performed felt like creating a dirty, little sexual resume. Next the nurse, who worked a six hour shift, swooped in and grazed my gums and mouth with a cotton-swab and set the sample in a liquid testing unit on the table before me. She left, leaving me with the Orasure testing kit that would determine my future health status. I had nothing to do but let my mind reel with possibilities. I remember thinking that twenty-minutes from now I could leave this RV a different, "infected," and terminally ill person. What exactly would that mean for me as a young woman and my future desires? Life would be different from that moment on, but it would not end then and there. I began to anticipate the ways in which my life would be different if I were HIV positive.*

*After fifteen minutes, the nurse returned and calmly began to inquire further about my sexual activities as though she was impervious to the stifling anxiousness that filled the room. If the paper questionnaire had felt invasive, it was downright embarrassing to discuss my sexual history with a stranger. I knew the nurse was trained to be non-judgmental, but I could not help but feel a mix of shame and guilt for each reply I gave that didn't adhere to gender, sexual, and safer sex norms. As required, she asked: "If your test results are positive will you cause harm to yourself or others? If your tests indicate an HIV+ status, who will share this information with?" I knew not how to answer them because it meant confronting living with HIV/AIDS in a very concrete manner. How could I tell my family and my friends that I had HIV? How would this change the way they viewed me? My lips uttered something intelligible, but I know not what, paralyzed by an anxiety, fear, and loneliness that I can only imagine someone who is HIV positive must brave habitually. Having satisfied her last questions, the decisive moment had come.*

*Yet, this was not the grandiose revelation I had imagined. The nurse picked up the Orasure testing kit from between us, recorded the results, and casually informed me—as though she were merely commenting on the rainy weather—that my results were negative. Before fully realizing my relief, she quickly added that this test would not account for any un-safe sexual behavior in the past several months. As such, she filled out my*



*form, signing-me off as HIV negative, and informed me to get tested again in November. I was now out of the RV and cleared. Outside, I waited in the rain, body tense and still grasping the paper that confirmed my negative status. I was relieved, but was unable to stop mulling over alternative outcomes and the fate of my fellow interns still waiting to be tested. In six months would the test results remain the same? For the first time I had to envision a life and death with HIV—a life of stigma and silence that statistics have no power to convey. Having been spared this outcome, I still yearn to comprehend and make sense of what this kind of life is like for so many of my peers.*

Having to come to terms with my own sexual behavior and health, as a result of this encounter with biomedicine, has informed my academic interests in the subjective experience of illness framed within the current biopolitical moment of HIV/AIDS. As I later learned through my research, this testing experience was a ‘technology of the self’, a technology of subjection and subjectification. In the words of Catherine Waldby, the HIV test is a technology “which not only compels subjects in certain ways, but which also induces the internalization of new norms of identity and self-management, above all the management of one’s health and one’s sexual practices, in the interests of minimizing illness and HIV transmission” (1996: 113-114). My interest in this topic has only augmented through further internships with sexual and reproductive health NGOs and with the highly controversial policy debate over American healthcare taking place over the past twelve months. The health care reform legislation passed under the Obama administration in 2010 earmarked \$250 (USD) million for abstinence only programming over the next five years.<sup>1</sup> Denial of access to health services in addition to forbidding the teaching of bodily and sexual health information such as condom use, is in my opinion

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<sup>1</sup> Programs receiving this funding must teach abstinence as the only ways to avoid pregnancy and STIs and these programs must teach that sex before marriage is likely to cause both psychological and physical harm. Only \$75 (USD) million was also earmarked for comprehensive sex education programs (Landau 2010).

beyond illogical and simply unjust. Denial of young sexualities has a cost, and when it comes to HIV/AIDS, a potentially deadly cost.

The opportunity to write a retrospective article for the twenty-fifth anniversary of HIV/AIDS, where I trace the historiography of the AIDS pandemic from its beginnings in 1981, only clarified the lethal danger that accompanies denying new risk groups the public attention, voice, and treatment that is just. First and falsely assumed to be a Gay Related Immune Deficiency (GRID), a quarter century of coping with AIDS has demonstrated how underrepresented and underserved communities and areas such as: Sub-Saharan Africa; African Americans; Men Who Have Sex With Men (MSM); women; and now young people are devastated by a preventable, yet lethal sexually transmitted infection (STI).<sup>2</sup> Undoubtedly, ‘risk groups’ like women and young people are not born vulnerable to HIV, but made vulnerable by persistent gender-based and age-based discrimination that involves forms of corporeal, symbolic, and linguistic violence. Whatever progress is to be made in HIV/AIDS prevention, it must clearly address these often overlooked and deeply entrenched inequalities. One cannot ignore the fact that HIV/AIDS has come to matter (more) for certain bodies in certain locales. The (co)production and (re)circulation of such ‘risk’ based discourses and its links to inequalities are investigated further in this work at the individual level of risk assessment, epidemiological projections, and global health and development rights based initiatives in

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<sup>2</sup> I do acknowledge that a large number of new HIV infections, especially globally, occur through mother-child transmission, shared needle use, and on occasion blood transfusions. My rationale in privileging sexual transmission in the United States owes itself to the persistence of the linkage between sex and HIV/AIDS in the cultural imagination and global biopolitical discourse. More importantly, I privilege sexual transmission in my work with Poz youth because it is the most common mode of transmission of infectious disease among my D.C. youth interviewees. On the whole, the U.S. case rates show shifting transmission patterns wherein instances of heterosexual transmission are on the rise while infection via drug use and prenatal transmission are on the decline (The Henry J. Kaiser Family Foundation 2009)

order to destabilize naturalized associations between certain groups and populations with that of embodying HIV/AIDS. The critiques of utilizing ‘risk groups’ articulated in this thesis makes clear how epidemiological sampling strategies have permeated medical and non-medical approaches to HIV/AIDS research in academia and prevention work in NGOs, which results in constraining the materialization and conceivability of certain livable subject positions precluded by viral contamination. Since my first internship in sexual and reproductive health, my interest and activism on the topic has only grown and eventually blossoming into the research undertaken herein.

Using a biocultural model (Morris 2000), this project aims to re-assess HIV/AIDS at the beginning of the 21<sup>st</sup> Century through the embodied standpoint of one of the most allegedly vulnerable populations; youth. This approach signifies a shift away from biomedical and epidemiological approaches *and* entirely cultural approaches to HIV/AIDS by considering the entanglement of matter (nature) and meaning (culture) in the production of positive (Poz) subjectivity. The traditional Cartesian divide between illness and disease has undergone reconfiguration in the last fifty years in ways that demonstrate an awareness of how these artificial distinctions—which relegate disease to the realm of medicine, causality, and symptoms and illness as something separate and linked to the patient’s subjective experience of ailment—limit understandings of the materialization of disease (Morris 1998: 39-40). Drawing these kinds of dialectical distinctions or boundaries between illness (mind/culture) and disease (body/nature) are non-innocent, as there are serious ontological and material implications for those groups (like ‘risk groups’). I invoke Morris’ biocultural approach—although such approaches are gaining popularity and a plethora of different names amongst (feminist) science studies

scholars such as Karen Barad's (1996) agential realism or Haraway's (2003) neologism natureculture—precisely to call attention to the centrality of matter and materiality, but to do in a way that does not forsake culture or the mind along traditional Cartesian cuts. Biocultural is a methodological approach, to borrow Barad's words, that seeks to flesh out “the nature of the interplay of the material and the cultural” (1996: 164) and biology and culture in today's HIV/AIDS epidemic.

As a response to the feminist science wars, and a corrective to purely feminist empiricist's realist approaches or that of feminist postmodernism's predilection for constructivist approaches, Morris and Barad begin from the premise of the entanglement of matter and meaning and the inseparability of these two in real world phenomena. This becomes even more crucial when one's topic is the embodiment of disease, which has both onto-epistemological effects. Pairings like mind/body, object/word, illness/disease do not pre-exist independently before they are brought into interaction with one another since from the start there is no original(s), only interaction. My use of the term materialization, most commonly and loosely referring to the process of what becomes actualized, emphasizes the very material-discursive production I have discussed above. It is no coincidence that the word matter is the root of materialization, because in no phenomena, especially phenomena that involve viral co-habitation like HIV/AIDS, can view the body or matter as passive or inert. I use the term materialization repeatedly in this thesis, and in my title, to reiterate the inseparable entanglement what is thought as the material (the embodiment of disease) from what can be said about the embodiment of disease (discourse about HIV/AIDS).

### **Why (Poz) Youth?**

I approach my research on youth and HIV/AIDS in Washington, D.C. from the assumption that we are a generation of young people (ages 13-24) that have never known a world without AIDS.<sup>3</sup> Approximately half of all new HIV infections in the U.S. occur among young people under the age of twenty-five with a new U.S. HIV infection occurring every nine and half seconds.<sup>4</sup> Of these American youth, infection rates are disproportionately higher among women, gays, and African Americans and as many as one third of all HIV+ young people do not know that they carry the virus.<sup>5</sup> What kind of information or knowledge regarding the (projected) embodiment of disease do these statistics convey and what is obscured by these statistics? The AIDS pandemic is undeniably and disproportionately affecting youth, yet we represent not only the potential of the future infected, but also those generations left to inherit, embody, and inscribe the disease's legacy. By specifically attending to the lived experiences of (Poz) youth, researchers and activists will be better able to attend to the needs of minors who can barely represent themselves legally or medically in terms of prevention and education. The embodied narratives and perspectives of these alleged 'future infected' are even fainter amongst the HIV/AIDS clamor where youth are 'outsiders within' the AIDS pandemic. Their stories, as "subjugated knowledges" (Harding 1988: 188), are absent from the dominant stories in American culture and human rights discourses about the

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<sup>2</sup> While other governmental bodies, institutions, and NGOs variously define youth, I adopt the U.S. CDC's definition as between the ages of thirteen and twenty-four.

<sup>3</sup> For instance in 1985, the year I was born, the popular science magazine *Discover* sustained the denial of the idea of a major pandemic among women and the International AIDS Society held its first International AIDS Conference in Atlanta.

<sup>4</sup> Of the new HIV infections of 2006, young adults (13-29) accounted for 34%. Among young people, teen girls and minorities have been particularly affected. In 2007, teen girls (13-19) represented 40% of reported AIDS cases while black teens (13-19) represented 68% of cases (The Henry J. Kaiser Family Foundation 2009). Moreover, the CDC estimates that 21% of PLWHA, no matter their age, are unaware of their status and that those who are unaware of their status are responsible for up to 70% of new HIV infections in the USA (Marks, Crepaz, and Jansen 2006). More information about this data can be found at the CDC's "Act Against AIDS" campaign website <http://www.nineandahalfminutes.org/>.

HIV/AIDS pandemic. What ‘we’, youth and other marginalized groups, share is a collective experience of being ‘others’, outsiders to accessing self-representation and to “methods of ruling theorizing the world” (Collins 1995: 377 qtd. in McLaughlin 2003: 68) in terms of one’s bodily health. This is not to naively privilege the standpoint of youth as somehow ‘innocent’ by dint of their subjugation, but rather a realization that starting from “how to see from below” requires actively acknowledging one’s stake in location, embodiment, and partial perspective (Haraway 1988: 584).

In common usage, Positive, also abbreviated as Poz, are terms typically adopted by PLWHA to denote the positive aspects of living with HIV, to highlight that meaningful life goes on. Poz is a type of re-valuation of identity through self-naming, which seems paradoxical given the cultural context of the body as host to the viral invader of HIV. The virus, after a latency period, colonizes the genetics of antibody cells calling into question the very ontological status of the human self. PLWHA and similar communities offer information and support and attempt to redefine illness as a certain kind of embodiment, as opposed to the traditional associations with death. My specific use of Poz youth specifically attempts to push this term, this deconstruction, further because HIV/AIDS is the burden of young generations, *no matter one’s blood status*, and is challenging metaphors, and meanings of health, illness, disease, life and death.<sup>6</sup> Our bodies need not host the disease to recognize the political impact it is having on bodies, the practice of medicine, and national economies and the equitable distribution of resources. To identify as Poz in this sense is to imagine the “possibility of webs of connections” in forging a “solidarity in politics” (Haraway 1988: 584), a political alliance

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<sup>6</sup> From this point forward Poz refers to my specific definition set forth above. Anyone who is ‘seropositive’, meaning they have the HIV virus in their blood, is referred to as HIV+ so as not to be confused with the conceptual term of Poz.

that aims to work against the stigma that stems from biological determinism—which operates upon the dialectical logic of separating the healthy out from the ill—in an attempt to recognize that the whole storied, living human organism is *not* reducible to the number of viral cells present (or not) in one’s immune system. Similarly, this term aims to work against the monopoly of biopolitical determinism in HIV/AIDS research that informs AIDS prevention and awareness through the discourse of biology. The biomedical discourse is incessant in its march towards discovery, faith in ultimately discovering the true mystery of AIDS, and eventually conquering the virus by unveiling the magical vaccine that will save humanity from the pandemic. HIV/AIDS is simply more than a viral agent because there is a parallel epidemic of meaning surrounding HIV/AIDS discourses that suggests the impossibility of one narrative or embodied explanation or reality of HIV/AIDS (Treichler 1999b). There are many embodied voices implicated in these stories, no matter their ‘immunocompetency’ (immunological health), although some may remain less audible than others. My work asserts the importance of these excluded narrations in larger, global biomedical and development-based approaches to HIV/AIDS.

Although no one I met during my research disclosed being HIV+ in blood status, nor invoked the term Poz, Poz is still a useful conceptualization for what I see as an emerging sensibility among young people in health programs and NGOs that embrace youth involvement in their own sexual lives and as viewing this as the key to preventing HIV/AIDS. While young people are actively interested in sex and the sexual health, the material presented in chapters four and five points to the fact that young people are far from deconstructing traditional understanding of illness and health. Still, Poz youth

potentialities are important to think with for the future because the term functions to signify a “practice of objectivity that privileges contestation, deconstruction, passionate construction, webbed connections, and hope for transformative systems of knowledge and ways of seeing” (Haraway 1988: 585). . My use of the term Poz in association with youth seeks to make material interventions to the way HIV/AIDS is understood through a reinvestment in a certain kind of liberatory language. Rather than inherit the ‘master’s tools’ of ‘risk’, Poz embodiment aims to ‘speak back’ by re-defining what young sexualities and HIV/AIDS means for youth today. By using this term in this way, I hope to indicate that all young people must be engaged as part of the solution and not merely as the putative cause of the problem or source of transmission of HIV/AIDS. Ultimately much of this work centers on how the embodied voices and stories of Poz youth might (re)figure into our current understanding of ‘spoiled identities’ (Goffman 1963) or ‘pathogenic’ AIDS bodies (Canguilhem [1966] 1991) within contemporary regimes of biopower and technocultures of treatment and prevention. Not only does the future materialization of HIV/AIDS lie with youth, but along with it, future understandings of illness and health.

While youth now figure squarely into biomedical ‘risk group’ shorthand, there is much resistance to addressing youth sexuality unless it is deemed a target or surveillance population. Gayle Rubin’s notion of ‘sex negativity’ (1984) remains firmly entrenched in America when it comes to youth. It is as though the axis of sexuality is said to not exist (or exist in diminished capacity for young people), thus bolstering the claim that abstinence is the best strategy to prevent HIV/AIDS transmission. Although many in HIV/AIDS work are reluctant to do so, this research also aims to address Poz youth as



sexual beings and global citizens. In the instance of the United States, cultural concepts of the AIDS-ridden, sexually contaminated body collide with American notions of the pre-sexual purity of bodies associated with childhood and young people. What this highlights is a gap between American normative values of sexuality, centered on abstinence and temperance, versus the true sexual behavior in which young people are actively engaging (Hull 2008). Moreover, even though the interviewees cited herein are well educated about HIV prevention and have access to condoms, their inconsistent use of prophylaxis illustrates the inefficacy of behavior change via (re)education programs alone (see ‘KAP gap’ in chapter five). The moral and material policing of sexual bodies has implications for young people and for the career of the AIDS pandemic insofar as both are reliant upon neglecting generationality in the epistemology of sexual epidemics. The fact remains that young people are having sex and that denying their sexuality, as many historical examples attest to, seems to only worsen the realities and spread of disease and misinformation. When NGOs and international policy devote plenty of efforts to “youth issues”, youth should be at least asked for a seat at the table to partake in that dialogue. Taking a page from the contributions of feminists like Adrienne Rich, my fieldwork and interviews with youth NGOs, demonstrates how young people are already organizing and countering dominant discourses that speak on their behalf. Increasingly, young people are moving from the position of being “the youth question” in HIV/AIDS research and activism to becoming “the youth who ask the questions” (adapted from Rich 1987: 216).

I privilege youth in this analysis, not only because I include myself in this category and because I have come to know the sexual health field through this identity

marker, but also because I wish to draw particular attention to the axis of generation and the concept of temporality in HIV/AIDS research. While much energy focuses on location, regions and cities with bad epidemics, more attention needs to be paid to the temporality of AIDS as we approach the thirtieth anniversary of the disease. HIV/AIDS is peculiar in its temporality insofar as it is an evolutionarily new disease with a recent human impact. Not only is HIV/AIDS known for having a long asymptomatic latency period, but is considered a “long-wave epidemic” by epidemiologists. Long-wave epidemics are described as having an initial rapid, but silent spread that is followed six to ten years later with a projection of cumulative cases, which in turn, helps epidemiologists predict the future impact of the disease in coming year (Whiteside 2008: 4-5). In other words, the spread and effects of long-wave epidemics of HIV/AIDS are not easily calculable or contained within a short time span. These temporal characteristics give rise to terminology and descriptors such as “Second Wave.” Although this term is predominately used to describe subsequent waves of HIV/AIDS epidemics outside of Africa, for me, it helps makes explicit not only the role of location or geography but also the role of generationality as the Second Wave increasingly impacts younger bodies. Today’s epidemic is one where people get infected at younger ages and age longer with HIV thanks to medication, which represents new challenges for biomedical prevention and treatment efforts.

This is not to innocently or blindly privilege age or generation over other axes of identity that inform subjectivity and embodiment, but to offer an embodied Poz youth standpoint as a response to the increasing attention paid to young people in HIV/AIDS research. As is reiterated throughout this work, not only is age a crucial factor in the

spread and treatments of the pandemic, but also gender, race, class, and location. Disease is undeniably lived through these modalities of generation, race, class, gender, sexuality, and citizenship, ultimately exempting no bodies. Like many feminists engaging in intersectional work, I am unhappy with the notion that these systems of identity formation and systems of oppression can be divided neatly into epidemiological categories of gender or race without assuming that one is more potent than the other. This “Euclideanization pathology” (Barad 2001) of some intersectional work relies on a geometrical imagery of a crossroads, rather than dense networks or assemblages, in ways that separate and flatten out important dynamics of the materialization of HIV/AIDS. Epidemiology’s proliferation of ‘risk groups’ and reliance on biomilitary metaphors suffer from this very pitfall. In this way my approach to Poz youth—*not* grounded in similarities between traits, places, events, but understanding that these traits, places, or events are (re)made through one another and only separable artificially—offers what Karen Barad calls the “politics of possibilities,” the “ways of responsibly imagining and intervening in the re(con)figurations of power” (Barad 2001: 104). Attending to these complexities using a (Poz) youth standpoint method for understanding experience and social relations, one is capable of producing a knowledge that could produce practical and political change in HIV/AIDS research and activism.

### **Why Washington, D.C.?**

This research focuses primarily on an American (Poz) youth perspective from Washington, D.C., a location that is both the epicenter of federal government and the epicenter of the national pandemic. Living nearly two years in the city, in addition to my interviews, I realized that it is a little known fact outside of D.C., let alone outside of the

United States, how bad the HIV/AIDS epidemic truly is in this federal city. Washington D.C. has the nation's highest overall infection rates and youth infection rates (MTA "About Us"). Government officials entrusted with delegating PEPFAR<sup>7</sup> money remain ignorant of the epidemic unfolding in the shadow of the capitol building (see chapter four). I believe this lack of knowledge among politicians is in large part due to the federal nature of the capital city, as most of the Congressman who live and work in the city represent constituents from other states rather than residents of the District of Columbia. Current research on the HIV/AIDS epidemic in North America and Western and Central Europe indicates that the trend in reducing the number of new HIV infections has stalled in some high-income countries, namely in the United States and Portugal (Hall et al, 2008; van de Laar et al., 2008). Moreover, racial and ethnic minorities continue to bear the brunt of the epidemic with African-Americans, twelve percent of the population of the United States, accounting for forty-six percent of HIV prevalence (CDC 2008 qtd. in UNAIDS 2009). The HIV prevalence among African-American residents of D.C. may be as high as five percent (D.C. DOH 2009). Despite this information, the long entrenched notion connecting HIV/AIDS with "exotic" places, peoples, and sexual practices forecloses the possibility of finding AIDS at home in one's backyard (see chapter four).

Rather than focus on the Global South<sup>8</sup> I sought to investigate how my own postindustrial country is dealing with soaring rates of HIV/AIDS. If the funding, research, and pharmaceuticals are predominately based in North America and Western Europe, how can Washington, D.C. still have such an high epidemic rate, rivaling that of

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<sup>7</sup> Launched in 2003 by President George W. Bush as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) provides money for country based emergency responses to HIV/AIDS.

<sup>8</sup> The Global South is the preferred term used by NGOs to refer to developing countries instead of the term Third World, although it too is hardly without controversy.

some Sub-Saharan nations? As this is my first attempt at qualitative research on this scale, I chose to work from within my native language and culture about the taboo subject of sex and AIDS. As such, this point of view provides a situated perspective on the local materialization of the global phenomenon HIV/AIDS. HIV/AIDS is both a localized epidemic and a global pandemic in certain respects. This study is *not* merely an effort to demonstrate local variation, but aims to reveal the incompatibility of thinking about HIV/AIDS today as easily divisible between local and global phenomenon and other binaries. Ebby, a young woman in the 4TeenzOnly focus group, pointed out that in today's globalized world, monetary and medical aid goes to Africa for AIDS despite the need for it right here in the District. These are not merely anecdotal observations, but demonstrate the very complex and contradictory assemblages that any study of the manifestation of disease must delve into. In order to better understand these 'glocal' phenomena and their materialization in Washington, D.C. my qualitative research, discussed below, took place on two continents: interviews in the USA and fieldwork in Netherlands.

### **How was research undertaken?**

With a background in feminist anthropology, I rely heavily on ethnographic methods and field research to counter the experience-distant methods of biomedicine. By undertaking interviews, and participant observation, I aimed to investigate how we can begin to understand ourselves by the stories we need to tell based on our politics of location. Furthermore, how we define ourselves (by the way in which we situate ourselves) within these embodied narratives of health and disease in the HIV/AIDS pandemic. My aim was to collect focus group interviews of roughly eight to twenty (Poz)

youth (ages 13-24) of various self-described genders, sexualities, and races. As a result, in January 2010, I was able to speak with a total of seventy-seven young people (seventy-five of which lived in D.C.) through four recorded focus groups, one non-recorded focus group, and two one-on-one interviews with peer educators for Advocates for Youth located outside of the District.<sup>9</sup> These one hundred and eighty-one minutes of tape (which were later transcribed for analysis) were supplemented by observing several health related programs run by Sasha Bruce Youthwork, 4TeenzOnly, and Metro TeenAIDS and by conducting one non-recorded focus group with Youth Build where public health posters were produced and used as a tool for discussion.

These focus groups were made possible after utilizing contacts within the non-profit world, which I have been intricately involved in throughout my employment and activist history. As such, under the strict empirical standards used outside of the humanities, my sampling strategy might be considered biased because I only sought out organizations engaging with community health education aimed at young people. Given my past experience in youth sexual health education and intervention, I privileged what I considered to be a potential Poz youth population *on purpose* to demonstrate how young people, arguably amongst the most knowledgeable amongst their peers through their participation in sexual health programs, are taking action on behalf of their own (sexual)

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<sup>9</sup> At the Summer Institute on Sexuality, Culture, and Society July 2009 at Universiteit van Amsterdam, Professor Deevia Bhana, who specializes in gender, young sexualities, and HIV in the South African context, suggested I adjust my research design to include focus groups rather than one-on-one interviews. From her ample experience working with young people, and given my time and capacity constraints, she advised that focus groups were more advantageous because it was more likely for the young people to talk openly amongst each other in their lingo with less interference or guiding from me than if I were to conduct one-on-one interviews where I may be viewed as a relative stranger attempting a rather intimate discussion on taboo topics. At this time, we also discussed ethical issues surrounding human subjects, including release forms for minors (which none of the organizations later required) and the ethics of disclosing one's HIV status.

health. The aim was to speak and interact with those young people already involved in health programs and interventions to point out the successes and shortcomings of these efforts. With the institutional support of both Universiteit Utrecht and CHOICE for Youth & Sexuality (the Dutch NGO supporting my fieldwork) I engaged in a letter writing campaign with youth health organizations in D.C. three months prior to my research period in the United States.

Before turning more fully to my complementary fieldwork internship in the Netherlands, I provide some background information on the focus groups interviews at the aforementioned organizations. It is important to note that the following organizations, with the exception of Advocates for Youth, are located in the Northeast quadrant of Washington D.C. and all share a belief that if young people are educated about their health and provided safe and interesting ways to spend their out-of-school time, they are much less likely to engage in behavior deemed dangerous and unhealthy.<sup>10</sup> Each of the following descriptions contains information about the organization that assisted me in gathering my interviews as well as a brief description of the group interviewed at each locale. Notably, the community groups with which I collaborated aimed at serving underserved minority populations, and as a result, my focus groups interviewees were only with African American youth. I also sought out groups working in D.C.'s Latino and Mexican communities, but either due to time or organizational constraints was unable to conduct interview or observations with these groups. The absence of any white young people in these programs and interviews, besides myself as the researcher, signals the

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<sup>10</sup> The city of Washington, D.C. is divided into four quadrants in addition to eight wards. The Northeast quadrant includes the national capital building, most of the organizations that assisted with my interviews, and is comprised of mostly by Ward 6 with a 2.8% HIV infection rate among residents. Despite their physical location, the organizations I worked with provided services for young people in Wards 5, 6, 7, and 8. These Wards have the highest rates of infection in the city (D.C. DOH 2009).

power relations operating upon the unmarked quality of whiteness in treatment and targeting of ‘at risk’ youth populations.

**4TeenzOnly:** The Ophelia Egypt Program Center and their 4TeenzOnly program is run by Planned Parenthood of Metropolitan Washington, D.C. (PPMW) and provides a ‘safe haven’ for teens and young adults in Wards 7 and 8 (Northeast D.C.). PPMW's Teen Program Center, 4TeenzOnly, offers a wide array of after-school programs, in addition to "Tuesday Are For Teens" Teen Clinics, daily Youth Peer Leadership activities, and free STI testing and counseling. Over my several days of observation and interviews, 4TeenzOnly watched a video on race in America, did journal exercises, prepared for a condom fashion show, and went roller skating on a Sunday evening.<sup>11</sup> Besides sitting in several afternoons after school with the 4TeenzOnly group, I conducted two separate focus group interviews. The first focus group consisted of fifteen young men between the ages of fourteen and twenty-one. The second focus group was comprised of eleven young women ages sixteen to eighteen. It was not my intention to segregate the interviewees by gender, but I had to move forward in this manner because another specialist was scheduled to speak with only the young women about a new program on pregnancy prevention.<sup>12</sup>

**Advocates for Youth** Advocates for Youth (Advocates or AFY), established in 1980 as the Center for Population Options, works at helping young people make informed and responsible decisions about their reproductive and sexual health. The core 3Rs of Rights, Respect, and Responsibility animate this vision.<sup>13</sup> While headquartered in D.C., Advocates works predominately on state-by-state interventions, national and international policy, and peer education and offers no direct services in the D.C. metropolitan area. As mentioned I completed two internships with this NGO during my Bachelor’s degree and have retained close ties with many of its employees. From Advocates, I conducted two one-on-one phone interviews with two young women: Cambria, age twenty, from Nebraska and Kim, age twenty, from Ohio. Although neither of these

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<sup>11</sup> For more information on PPMW, the Ophelia Egypt Program Center, and 4TeenzOnly, please refer to: <http://www.plannedparenthood.org/ppmw/teens-22988.htm> and <http://4teenzonly.com/>.

<sup>12</sup> I noticed that as a white women interviewing a group of young African American men about sex seemed to make respondents less comfortable and reliant on jokes to diffuse the situation. On the other hand, my interview with the 4TeenzOnly young women was one of my better interviews because they would take a topic and run with it, needing little interjection from me. Further gender and race analysis on this topic of could prove fruitful.

<sup>13</sup> To paraphrase, the 3Rs motto emphasizes that “youth have a right to accurate and complete sexual health information”, “youth deserve respect” in programs and policies that effect their health, and that “society has the responsibility to provide young people with the tools they need to safeguard their sexual health.” (“The Vision: Rights. Respect. Responsibility.”). More information on AFY, the 3Rs, and their program work can be found at their website: <http://www.advocatesforyouth.org/>



women currently live in Washington, D.C. they work as peer educators for Advocates, which is based in D.C., and frequently come to the nation's capital for training and to meet with Congressmen on youth's behalf.

**Metro TeenAIDS:** The Washington Area Consortium on HIV Infection in Youth (WACHIVIY) was founded in 1988 and shortly thereafter renamed Metro TeenAIDS (MTA). Utilizing comprehensive, science-based, culturally competent, and age-appropriate counseling and education programs, Metro TeenAIDS provides resources to help young people fight HIV/AIDS. During its almost twenty years of service, Metro TeenAIDS speaks to youth in their own language and in their own space and claims to have reached out to over 200,000 young people, family members, and youth workers in schools, nightclubs, youth centers, shelters and the streets in the D.C., Maryland, and Virginia. They host free clinical services such as a free and confidential testing, peer education programs, and the Freestyle Drop-In Center. The center generally hosts fifteen to twenty-five youth a night and provides a wide range of educational activities and special events such as my focus group interview.<sup>14</sup> The MTA Freestyle focus group interview was conducted with nineteen young people (roughly fourteen female and five male) between the ages of sixteen and twenty-two and was the last interview I conducted in Washington, D.C.

**Sasha Bruce Youthwork:** In 1974, Deborah Shore founded the Washington Streetwork Project, which later became the eighteen professionally staffed programs of what is today called Sasha Bruce Youthwork (SBY). Today SBY is one of the largest providers of services to D.C. youth by assisting young people to: find safe homes; achieve and maintain good health and mental health; create and strengthen supportive and stable families; explore opportunities in education and careers; and learn leadership skills with the aim of helping young people and their families discover their own abilities to transform their lives. With the help of SBY I was able to interview two young women together, Luly (15) and Raina (17), during a Zocola Outreach Session typically used as a weekly forum for counseling, support, and education.<sup>15</sup> Raina was a peer educator and youth employee of SBY, while this was Luly's second time at an SBY event.<sup>16</sup> Through SBY's AIDS Prevention Services (APS) programs, which provides prevention and education services to 'high-risk' adolescents, including runaway and homeless youth, commercial sex workers, street youth, teenage mothers, and court-adjudicated youth, I was able to attend and observe an APS information training hosted for Groups for Hoops. Groups for Hoops is a weekly meeting that combines an

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<sup>14</sup> More information about MTA and their programs is available at <http://www.metroteenaid.org/>, specifically the page entitled "About MTA."

<sup>15</sup> I know some researchers feel strongly about the use of only first names, however, when my interviewees were asked to create their own pseudonym for this research, they only listed first names.

<sup>16</sup> Unlike the 4TeenzOnly and Metro TeenAIDS focus groups, where participants knew each other well, this was the first time these two had met.

education program and competitive basketball match on Friday evenings for young men in group homes. Additionally, I was afforded the opportunity to conduct a non-recorded focus group during an APS session for Youth Build with a group of twenty-eight young people (ten female and eighteen male) between the ages of twenty and twenty-seven. Youth Build provides academic training toward a GED, job placement, and on-site carpentry training for young men and women ages eighteen and up. All participants are self-referred.<sup>17</sup> Since the Youth Build focus group was too large to reliably audio record, I conducted several activities designed to stimulate discussion such as: a survey (adapted from my list of interview questions); a word association game (e.g. What first comes to mind when I say HIV?); and a public health poster contest (groups asked to design a message that would appeal to youth like them and then explain it).

Prior to undertaking these interviews at the groups outlined above, beginning in October 2009 and throughout the time of the writing of this thesis, I also interned at a Dutch NGO that focuses on sexual and reproductive health rights for young people on national and international levels called CHOICE for Youth & Sexuality (CHOICE).<sup>18</sup> I was drawn towards doing fieldwork based off of anthropologist Emily Martin's idea of visceral learning, or the idea that the researcher herself is embodied. Like Martin, "I felt an imperative to place myself bodily in these contexts, to feel viscerally the threats and dangers as well as the delights of working and organizing to fight this major epidemic in the late twentieth century" (Martin 1994: xv). This type of anthropological learning seeks to augment and create an interplay between unspoken felt experience and the verbal questions posed directly to young people. My duties at CHOICE consisted primarily of developing social media and website tools for information sharing among youth activists, acting as sole coordinator for CHOICE's participation in the upcoming International AIDS Conferences (IAC) and all AIDS related events, conducting trainings for members in the previously mentioned areas, and representing CHOICE at Share-Net, the Dutch

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<sup>17</sup> For more information on SBY, YouthBuild, Zocola Outreach, or the other program run by SBY, please refer to their website: <http://www.sashabruce.org/>.

<sup>18</sup> More information about CHOICE is available in both Dutch and English at: <http://choiceforyouth.org/>.

platform for sexual and reproductive rights NGOs. My internship will culminate in my attending the 18<sup>th</sup> IAC in Vienna this July on behalf of CHOICE and as a member of the Vienna Youth Force.<sup>19</sup> Albeit somewhat unusual to undertake fieldwork in a different locale than that of the interviews, this experience has exposed me to the global dimension of HIV/AIDS discourse and its articulations with international human rights discourses on health that are so popular today. For instance, this year's IAC is themed "Rights Here, Right Now." While I am skeptical that human rights discourses provide the ultimate solution to infectious diseases like HIV/AIDS, such discourses do open up the possibility for the recognition, empowerment, and justice for those already situated as 'risk groups' in international policy and development work. Human rights are often hard to guarantee for young people, as often they do not have the right to vote or much political recourse. Moreover, human rights discourses may deflect HIV/AIDS discourses away from the taboo issue of (youth) sexuality while offering a universalizing and Western solution. As none of my young respondents once mentioned human rights, and due to the fact that I want to keep the emphasis on young sexualities, this work does not delve into or further critique the human rights approaches to (sexual) health.<sup>20</sup>

### **What can the reader expect from the remainder of this text?**

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<sup>19</sup> The Vienna Youth Force was launched after the International AIDS Conference in 2008 and is global platform for international, regional, and local youth organizations that focus on HIV/AIDS and youth sexual and reproductive health prior to and during all International AIDS Conferences. Ten organizations make up the global platform: Advocates for Youth, Community Forum Austria, CHOICE for Youth & Sexuality, Global Youth Coalition on HIV/AIDS (GYCA), International Federation of Medical Students' Association (IFMSA), World AIDS campaign, You-Act, Y-Peer, Youth Coalition on Sexual and Reproductive Rights, and Youth R.I.S.E. For more information please visit the Vienna Youth Force website at: [www.youthaids2010.org](http://www.youthaids2010.org).

<sup>20</sup> Please refer to Malinowska-Sempruch and Gallagher 2004, Rubenstein 1996, Gostin and Lazzarini 1997, and Farmer 2007 for more literature on human rights based approaches to HIV/AIDS prevention, treatment, and eradication.

I conclude by outlining the rest of this text as a roadmap for the reader. The following chapter is devoted to literature in the field of health and disease, particularly from the vantage point of feminist response to HIV/AIDS that really took off in the mid to late 1990s. I rely heavily on the work of feminist science studies scholars for applying their critique of methods and frameworks of biomedicine onto HIV/AIDS research. My emphasis on the authors Donna Haraway, Emily Martin, Paula Treichler, and Catherine Waldby represent a trajectory of feminist thought spanning the 1990s and through the early years of the new millennium. In many ways, this thesis and my work on the science of HIV/AIDS is also a bit of a recovery project, making a case for the place for youth-driven initiative as well as the place of immunology in the deluge of feminist scholarship on genetics. Before turning more fully to my interview material in the latter chapters, chapter three is devoted to the dominant practices and discourses of biomedicine, namely epidemiology and the creation and circulation of ‘risk group’ categorization endemic in HIV/AIDS research. This chapter helps to foreground this study because it problematizes ‘risk’ by highlighting how ‘risk groups’ are a historical production that changes through time to include differing bodies. Chapters four and five rely heavily upon my interview materials and address more fully youth perspectives on ‘othering’ disease and PLWHA, as well as the role of biomedical interventions in their lives and on their bodies. The desire amongst young people to distance themselves from HIV/AIDS, and when unable to do so, the desire for a medical cure is overwhelming. Despite the millions of dollars already invested in AIDS vaccines and microbicides<sup>21</sup> to date, biomedicine is impotent to

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<sup>21</sup> A microbicide refers to a type of product currently under development and human trials, usually a gel, cream, sponge, film or suppository, that people could use vaginally or rectally to protect oneself from HIV and other STIs. The microbicide, if successfully developed, is said to be one of the most important sexual and reproductive health innovations, especially where condom use is unable to be negotiated, since the

cure HIV/AIDS, yet this positivistic drive remains entrenched in the clinical regime of surveillance through testing and prophylactic intervention. The majority of participants felt that the only hope for containing the future spread of HIV/AIDS relied on science's ability to conquer 'nature' by finding a cure, the desire for an instant cure or quick fix to a largely social phenomenon. While each chapter aims to be autonomous and can be read in any order, I want to suggest that chapter two provides useful background for the interview material discussed in chapter four, while chapter three also helps foreground the interviews and topics discussed in chapter five. Chapter six is the final chapter and offers some concluding remarks, based off of what was learned in my interviews, on the future of Poz youth potentialities in Washington, D.C. as well as including some recommendations for future feminist research in this area.

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hormonal birth control pill. For more information please refer to the page "About Microbicides" at the Global Campaign for Microbicides website, available at: [http://www.global-campaign.org/about\\_microbicides.htm/](http://www.global-campaign.org/about_microbicides.htm/).

## **Chapter II: Thematic Literature Review**

Current representation of the immune system can thus be regarded as historical responses to what HIV infection is understood to *be*. (Waldby 1996: 162, emphasis in original)

### **Introduction**

The aim of this literature review is to make readers aware of the general trends of HIV/AIDS scholarship since the early epidemic, theoretical frameworks for studying illness and health, and especially, the increasingly important contributions of feminist science studies to push interdisciplinary research into new directions. Feminists dare to ask new questions of taken for granted assumptions and methodologies in HIV/AIDS research. These authors seek to establish problems with the current questions asked in biomedical and some non-biomedical HIV/AIDS research and seek new questions that critique biomedicine's reliance on Cartesian logic. Of particular importance, this chapter investigates biomilitary metaphors of the immune system not only in helping create the clinical conception of HIV/AIDS, but doing so in ways that go above and beyond simply ratifying it. The goal of this thematic literature review is to prepare readers to analyze HIV/AIDS biomedical concepts in further detail and in relation to my focus group interviews in coming chapters.

### **Trends in HIV/AIDS Scholarship**

Biomedical accounts of HIV/AIDS dominated early understanding of the epidemic, and in this capacity, served to exclude other 'non-scientific' accounts from scientific knowledge and media accounts. In the early years of AIDS in America, the biosciences directed HIV/AIDS knowledge production and continually represented AIDS as an infectious epidemic caused by a natural viral agent. Although increasingly contested, biomedicine has long established its right to represent the 'real' of disease, its

materiality. “The ubiquity of biomedical logic, its privileged authority as “truth” teller, underscores the biological root of the AIDS epidemic and makes it appear uncontested” (Marshall 2005: 2516). Critics in the latter half of the 1990s, like Paula Treichler, call into question the parallel “epidemic of signification” or set of meanings, definitions, and attributions also produced by the HIV/AIDS epidemic (1999b: 1). For Treichler, understanding both the epidemic of a lethal disease was equally as important as understanding the simultaneous epidemic of meanings. Scholarship in the 1990s like Treichler’s, which favored socio-cultural and political-economic inclusion in theorizing HIV/AIDS, began to chip away at the notion of immunology, epidemiology, and virology—the three pillars of HIV/AIDS biomedical research—as sacrosanct and producing the only ‘real’ and useful knowledge on HIV/AIDS. Whereas Susan Sontag (1991) first wrote of the emergence of HIV/AIDS as “providing a large-scale occasion for the metaphorizing of illness,” one which primarily served to distort the truth about illness and alienated patients, authors like Treichler embraced the fact that illness is a metaphor which should not be resisted in the continued effort to make sense of AIDS. Scholarship from the mid 1990s on increasingly argued that HIV/AIDS is more complicated than biomedicine allows; a place where “many entrenched narratives intersect, each with its own problematic and context in which AIDS acquires meaning” (Treichler 1999a: 370) that are in excess of biomedical representation. This ‘over-medicalization’ of the field obscured the significant socio-cultural and political-economic dimensions of health and disease.

Increasingly from the mid 1990s through the first decade of the new millennium, interdisciplinary scholars began to document the social, cultural and linguistic

dimensions of HIV/AIDS.<sup>22</sup> In large part due to the work of medical anthropologists like Paul Farmer, there has been a slow shift from predominately biomedical discourse about HIV/AIDS to the central role of socio-cultural, economic and political factors (Taylor 2007: 965-966). As Paul Farmer notes, early epidemiological literature reveals the absence of any mention of sexism, racism, and structural powerlessness, but there was some mention of culture indicating that biomedical narratives were forced to concede to include ‘cultural differences’ in their repertoires of risk formulation and subsequent intervention (1999: 85). Yet, to trade in or treat as separate but equal the ‘cultural’ (social science or humanities) for the ‘natural’ (bioscience) explanation did little to critique or address the larger binaries plaguing HIV/AIDS research; it did little to attack the long-entrenched Cartesian logic of medicine and the inequality in access and representation it perpetuates.

Where researchers have claimed ‘culture’ has the potential to assist [HIV/AIDS] interventions, local perspectives are essentialized thus creating a version of local ‘culture’ that mimics epidemiological categories thus not only asserting ‘difference’ but the subtle enforcement of inequality between ‘self’ and ‘other’ through such differences. (Taylor 2007: 973)

In this way ‘culture’ can function much like the taken for granted notion of ‘nature’ in biomedical HIV/AIDS research, both working to perpetuate and legitimate inequality based on difference.

As a result, culture has been deployed, like ‘risk groups’, as a subtle tool for maintaining or reasserting difference; it relies upon and reasserts boundaries through the Cartesian logic of self/other, inside/outside, and nature/culture. Culture, like gender,

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<sup>22</sup> The works mentioned in the text represent but a minute slice of the burgeoning HIV/AIDS scholarship in the social sciences and humanities in the 1990s. For further examples please see: Kalipeni et al. 2004, Farmer 1992, Farmer 2003, Rödlach 2006, Reddy et al. 2009, and Setel 1999.



should not be abandoned, says Julie Taylor, but rather awareness must be raised about its subordinating potential when used in existing schematization of the body and disease (2007: 974). In the end the addition of 'cultural' dimensions or admixture of socio-cultural approaches to that of biomedicine did not suffice. While scholars were increasingly skeptical of biomedicine's universalizing claims to knowledge and truth about the body, few did more than proliferate a source of alternative narratives rather than critique the central logic and power of HIV/AIDS science. All camps began to argue that the social dimensions of HIV/AIDS were far more central than scholars were accustomed to thinking in the early epidemic. Clearly, the apparatus of contemporary feminist theory would have been useful in analyzing AIDS in relations to questions of language, representation, narrative, binary division, and political context of meaning, but where were these voices?

The aforementioned work of Paula Treichler is theoretically vital for gender scholarship on HIV/AIDS because she was amongst the first scholars to not only assert the failures of biomedicine, but also to reveal certain failures of American feminists. She chastised American feminists for their lack of response in the early epidemic and was one of the first to examine the gendering of American AIDS discourse. Treichler highlights how early occurrences of HIV in women reported by the CDC linked the disease to sex workers, IDUs, and women from the Third World (primarily African and Haitian). American middle-class feminists were led to believe, by biomedicine, that their bodies would be untouched by the new HIV virus and therefore paid little attention. Treichler argues that the insights gained from the women's health movement and from feminist theory were not applied and did little to illuminate AIDS for women in the early

epidemic. “Despite all that we had learned about the social construction of sexual difference and how it had been used against women in the past, the categorization process was given scant scrutiny [by feminists] in the case of AIDS” (Treichler 1999b: 96). Aside from a few lesbian writers and activists, who expressed solidarity with the gay community, few feminists countered the dominant biomedical account of AIDS and participated in the erasure of difference among women and the categorical silencing of women ‘marked’ by race and class (and subsequently more instances of disease) (Treichler 1999b: 42). Treichler rallied for feminists to turn away from the alleged protection and safety offered by non-intersectional approaches to gender and HIV/AIDS, which early American feminists wrongly embraced. As evidence mounted for women’s ‘risk groups’, Treichler tasks feminists to fundamentally challenge the value of dividing HIV/AIDS into the “the disease of them” from the “disease of us” (1999b: 96). In the early epidemics, white, middle-class American feminists sought refuge in their gender rather than standing united with other women and other ‘risk groups’ affected to challenge the binaries that undergird biomedical description. Treichler’s work is also critical in this sense; she called for feminist scholarship that assessed both social and biological dimensions of AIDS but not to forsake the former in the name of the latter (Treichler 1999a: 357-359). For Treichler, echoing Donna Haraway and Emily Martin, science does not merely speak reality, it creates or produces a reality through representation and rhetoric emphasizing the continuum rather than dichotomy between popular and medical discourses. Using Bruno Latour and Steve Woolgar to emphasize Treichler’s point, there exists “a continuum between controversies in daily life and those occurring in the laboratory” (Latour and Woolgar 1979: 281). Knowledge of the body

and the natural world can no longer solely be viewed as the result of scientists doing proper science; neatly separable and wholly rational. Rather than presenting the ‘real’, science is a type of fictive narrative in and of itself, albeit one that has serious and material consequences for the materialization of individual bodies and the body politic.

Although largely overshadowed by feminist science studies’ work on genetics, there exists an ever-growing body of feminist science studies scholarships of HIV/AIDS. Nowadays, the tide in scholarship has shifted yet again. More attention is being paid by interdisciplinary scholars to HIV sciences—like the practices of immunology, epidemiology, and virology—rather than proposing a mere dilution of their explanatory power. Although Treichler later publicly rallied American feminists, some scholars, like Donna Haraway were already hard at work by the early 1990s. According to Haraway (1991), women have long challenged our traditional assignment to the status of natural objects by becoming anti-natural (by ascribing to a social constructionist approach), but stopped short of ever really including a critique the life sciences. Feminist and race scholars chose to distance themselves from science and technology, which led them to misunderstand the status and function of natural knowledge that relied upon a deep split between nature, culture, and the forms of knowledge relegated to these realms (Haraway 1991: 8). Biological extremism was swapped for cultural determination, which offered no sustainable solutions. According to Haraway, in order to have a ‘liberatory’ science for women and other minoritarian groups, one needed to re-think the tools of domination in ways that transform the notion of fixed boundaries between discrete entities existing in a rigid binary opposition by demonstrating how the concepts ‘nature’ and ‘culture’ are in an entangled knot and buttressing relationships. In doing so, Haraway adopts a hybrid or

interdisciplinary approach where nature and culture and not bounded, easily identifiable realities, but rather entangled (re)productions of each other. What Haraway and her feminist contemporaries share, is that they partake in critiquing the Cartesian legacy of simply equating the body with nature and matter, thus relegating it to the sole province of biology and biomedicine. In this vein, scholars like Donna Haraway and Paul Farmer reiterate that HIV/AIDS research is neither “the exclusive province of either social scientists nor of the bench scientists” (Farmer 1999: 53) and is best attempted by those scholars who actively work across traditional departmental divides. The next sections put Donna Haraway’s chapter “The Biopolitics of Postmodern Bodies: Constitutions of Self in Immune Systems Discourse” in *Simians, Cyborgs, and Women*, Emily Martin’s *Flexible Bodies*, and Catherine Waldby’s *AIDS and the Body Politic* into conversation in order to discuss crucial historical changes in the practices of biology and the subsequent prevalence of highly militarized language in immunology.<sup>23</sup> No feminist literature review of crucial thematic concepts in HIV/AIDS would be complete without taking a closer look at the role gender and sexuality play in the organization of ‘biomilitary metaphors’—Catherine Waldby’s shorthand for militarized language of immunology—which is further discussed in terms of feminist scholarship in the coming sections.

### **Setting the Scene for Immunology’s ‘War’ on HIV/AIDS**

Today’s American youth take it for granted that they have grown up in a culture dominated by the belief system that attributes illness to microbes, toxins, and internal malfunctions. Young people, when insured, are keen to rely upon doctors who perform

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<sup>23</sup> As mentioned in the introduction, I limit my focus to feminist scholarship in general, and particularly the feminist science studies of these three scholars, in order to traverse women’s inclusion in epidemiological ‘risk’ and HIV/AIDS scholarship that began to emerge in the 1990s and spanned through the first decade of the new millennium.

tests to identify the source of discomfort in a recognized pathology. Illness, for them, is an identifiable object, whether in the body or in the community, that, once identified, can properly be named and targeted for medical treatment with the ultimate goal of achieving a cure. As will be increasingly evident, “illness, however, is not strictly speaking a [natural] object. It is not something we can know inside and out, through an inventory of its material properties, like a moon rock” (Morris 1998: 5). Illnesses, bodies, and sciences are not easily knowable objects, they are fluid processes that change as we change through time, they are enigmatic and subjective. The body and the illnesses they may come to harbor are anything but static. The interdisciplinary work of David Morris and Emily Martin reiterates this point through the idea of generationality. They demonstrate how understandings of the body, scientific practice, and thus meanings of health and illness have changed since the time when our grandparents, who were a product of the hygiene movement, were young. Morris explains that we get ill in new ways, in different ways than our grandparents, while Martin aptly points out how little the existence and idea of the immune system figured into our grandparents’ notion of maintaining health. In other words, both authors impress upon their readers that, “we fall sick from unheard-of ailments, we pass through undreamed-of treatments, we die in unsettling new ways and places” (Morris 1998: 3). Scholars like David Morris, Emily Martin, Donna Haraway, and many others have noted a shift in biological laboratories in the past fifty years, namely in the visualizing technologies used, which has substantially shifted our understandings of the biological body and our notion of health. The last fifty years have witnessed the birth of new technologies enabling the visualizing of the inner body and pathogenic processes in new ways. Corpses, as the raw material of scientific of inquiry,

were replaced with living subjects, and more accurately, previously whole beings were replaced by components or molecules (invisible to the naked eye) as the object of biological science. Mechanistic analogies for the body have given way to cybernetic systems; 'life' is about the coding, recognition, and misrecognition of information. In the same time frame as the aforementioned changes, bodies have been afflicted by the emergence of new diseases, like HIV. Morris describes this transition, occurring in the last fifty years, as the emergence of post-modern illness or "our changed and still changing experiences of human affliction" in the post-WWII era that takes shape from historical convergences between biology and culture (Morris 1998: 3). Next, I utilize Haraway's work to describe what differentiates "post-modern illness" from other eras, the status of contemporary 'nature' and 'culture', and what this means for our understanding and metaphorization of the pathological.<sup>24</sup>

Although still greatly overshadowed by genetics, immunology has made considerable strides in the past thirty years in term of technologies, both visualizing and vaccinating, and in the imaginations of the American public. As scholars Emily Martin, Donna Haraway, and Catherine Waldby point out, the immune system is a crucial icon for understanding and elaborating health and pathology in the HIV/AIDS era. Following WWII, germ theory fell out of favor as attention towards defenses within the body increased (Martin 1994: 32). Only in the mid to late 1950s did people begin to embrace an idea of immunity or viral resistance as inbuilt into the body; if the skin and the orifices of the bodily castle were breached, then the body surely came equipped with inner

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<sup>24</sup> Many feminists have been apt to point out the non-coincidental similarities between military and medical technologies and their effects on biomedical discourse. As Treichler notes, since the HIV virus can conceal itself inside a T cell, HIV is described as illusive or evading natural defenses which help contribute to HIV's "postmodern identity" as a "terrorist's terrorist, an Abu Nidal of Viruses" (1999a: 369). This militaristic link is discussed further in sections pertaining to biomilitary metaphors.

safeguards. Following the development of the Salk vaccine against polio in the mid to late 1950s, people began to embrace the idea of ‘temporary immunity’ achieved through antibody mixing (Martin 1994: 30-31). Owing to the early successes of antibody mixing in producing an effective inoculation against polio, more antibody rich gamma globulin became available for research and immunology and virology received greater attention among the biological sciences. Undeniably changes in the science of immunology to identify ever-smaller components of the blood had effects for not only the detection of HIV within the body, but also challenged notions about how bodies and immunity worked. In 1970s, immunology was swept by the concept of immunological specificity or the idea that the immune system “*first* generates a diverse population of antibody molecules [via somatic mutation] and then selects *ex post facto* those that fit or match” (Edelman qtd. in Martin 1994: 36, emphasis in original). This is what immunology historian Arthur Silverstein calls a transition from “introduction theories” to “selection theories” (Martin 1994: 35-36). Immune response was not learned, as suggested by “introduction theories”, but tailored specifically to the antigen in question, relying upon an existing and extremely diverse supply of antibodies to select from. Coordinating an ‘attack’ against foreign antigens in this scenario requires that immune systems cells recognize and communicate with one another when selecting and reproducing an antibody appropriate to the foreign antigen. Despite these post-WWII and 1970s advances, in 1981, when HIV was identified in the United States, T cell subsets had only recently been identified (Waldby 1996: 61). Since ‘war’ on AIDS has been declared, however, research about the immune system has gained a new urgency and adamant attention. Martin’s work is not only crucial for situating HIV/AIDS immunology

historically, her work also highlights another trend in the study of disease emergence. In this sense, Martin's work is important because she bookends her study of immunity with the discussion of Polio and HIV/AIDS, the two autoimmune dysfunctions to reach epidemic status in the United States in the past hundred years. Her book, recalling the lasting contributions of Georges Canguilhem,<sup>25</sup> demonstrates how throughout recent history the failure of the immune system has been the impetus for immunologists to work to restore norms of health.

Today's almost manic quest for the AIDS vaccine not only captures biomedicine's desire to elude death or transcend mortality, but elaborates how the discovery of pathology or failures works as the precursor to any study of the norms of health. As Martin explicates, most people tend to only think of their immune system in connection with disease. Thus if one embodies health, then one does not think about the daily maintenance functions undertaken by the immune system. The work of Canguilhem demonstrates the impossibility of having a science of the pathological (seropositive) without a science of the normal (immunocompetent), pathology can only be figured as various kinds of departure from a concept of the healthy functioning of bodies. Without immune system dysfunctions, like polio and HIV, advances in the sciences aimed to tame the disease in question would not have occurred. According to Canguilhem, the description of the pathological failure precedes the description of their normal operation. In other words, norms of health are only recognizable when they are broken so that the abnormal arouses interest in the normal. "Functions are revealed only when they fail" (Canguilhem 1991: 208-209). As this demonstrates, Canguilhem's concepts of the normal

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<sup>25</sup> Canguilhem gained lasting notoriety in the field of the history of science when he published his medical thesis in 1943 entitled "Essais sur quelques problèmes concernant le normal et le pathologique" and is also frequently cited today in scholarship about genetics like that of Sarah Franklin and Paul Rabinow.



and the pathological are being applied anew in the immunological era of health. In his doctoral work he explains how medical training understands disease as a deviation from a fixed norm. Medical practice, by extension, is then directed toward “re-establishing the norm from which the patient had strayed” (Rabinow 1994: 16) Canguilhem maintains that illness is ultimately “a reduction to constants, the very norms by which we measure ourselves normal” thus health is “not being normal; health is being normative” (Rabinow 1994: 16 and 18). Hence health can only be inferred as a negative imprint of what HIV/AIDS is understood to be, and norms of health exercise transformative effects on imperfect bodies. To embody health is to be normative and go unmarked by illnesses’ stigma. As if almost predicting the future, Canguilhem believed that it should not come as a surprise that one day the "general theory of servomechanisms, that is of machines constructed so as to maintain certain outputs (products or effects) within fixed or variable limits" finds analogies with self-regulating organic systems like the nervous system or immune system (Canguilhem 1994: 86). Haraway and Martin, Canguilhem’s feminist contemporaries, take up these questions anew by asking precisely how narratives of the normal and the pathological function when the biological body is symbolized and operated upon as “coded text organized as an engineered communications systems, ordered by a fluid and dispersed command-control-intelligence network” of the immune system (Haraway 1991: 211).

### **Feminist Contributions to the Immunological: The Biomilitary Metaphor**

Feminist scholars such as Haraway, Waldby, Martin, Sontag and Treichler are adamantly united in the belief that whether one is reading medical literature, health education material, activist literature, or popular media outlets, the language describing

HIV/AIDS, occurring both in the immune system and on the societal level, is highly militarized. The literature is equivocal in stating that the spread of HIV/AIDS must be combated against no matter the cost. As Sontag makes clear, the metaphor of invasion is not unique to HIV/AIDS and is also deployed when conceptualizing cancer, leprosy, syphilis, and other diseases (1991: 103). Precisely what is new is an emerging understanding of the healthy body as linked to the idea of a flexible immune system, one that is predicated on the capability to communicate and coordinate a specific immunological response. Although first stated by Haraway, Waldby's and Martin's work reiterates how the "immune system" remains a "flexible iconic device which can stand for various kinds of bodily coherence and incoherence" in the HIV/AIDS era of late capitalism (Haraway 1991: 201). The immune system is the biological mechanism by which 'difference' is delineated between 'self' and 'other'. That is, the immune system is a plan for meaningful action to construct and maintain the boundaries for what may count as self and other in the cruel realms of the normal and the pathological (Haraway 1991: 204). Hence, for Haraway, the postmodern body is conveyed in terms of strategic systems and is highly militarized in key arenas of imagery and practice (1991: 211). The job of biomedical discourse on immunology is to construct an organism's boundaries in the dialectics of attack and defense. In this way a militarized and hierarchical immune system organizes a highly individuated body, a way of organizing bodily coherence and conferring subjectivity through the assertion of rigid body boundaries between inside and outside and between self and other. Treichler (1999b), reflects upon the importance of Haraway's early work on the immune system and emphasizes that Haraway was a pioneer in articulating instrumentality of the biomilitary metaphor in biosciences and how

it has merged with postindustrial information age metaphors of coding and communication, which ultimately helped the immune system claim its current high theoretical status amongst other feminist scholars (Treichler 1999b: 170). Martin elaborates precisely how the drama of biomilitary metaphor is enacted on the cellular level. Following Martin, Waldby's more post-humanist framework reframes the biomilitary metaphor along evolutionary terms.

Building upon her acclaimed ethnography *The Woman in The Body: A Cultural Analysis of Reproduction* (1987), in *Flexible Bodies* Martin focuses predominately on media coverage and textbook representations of the immune system and finds the language used evokes images of the body at war. In all arenas, she proclaims, "the story of the human immune system reads like a war novel" (1994: 54). In this embattled scenario, the cells of the healthy immune system serve as an effective natural army that seeks out and destroys alien invaders. Both medical textbooks and popular magazines like *Time* and *Reader's Digest* describe HIV as invading 'foreign' agents while killer T cells mount the first-line of the body's coordinated and specific defense, which are supplemented by medical treatments like ART as the second line of defense. Once an antigen is identified or recognized as 'foreign' by the macrophages, the T4 cell line is important because of its power to communicate instructions in case of attack by antigens to the rest of the immune cells (Waldby 1996: 62).<sup>26</sup> I will return to the point of the personification of immune cells later, but it will suffice to say for now, that there exists an army within each of us, an army of specialized cells of the immune system which are

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<sup>26</sup> The main cellular components of the immune system are T cells, B cells, macrophages, and other white blood cells. Macrophages come from the phagocyte cell line, while T and B cells stem from the lymphocyte cell lines. T cells are further sub-divided into helper T cells (T4 or CD4 cells), suppressor T cells (T8 or CD8 cells), and 'killer' T cells. (Martin 1994: 54-59; Waldby 1996: 60-70; Whiteside 2008: 24). The role and function of these cells will be discussed further in the section entitled *Gendered Cells, Gendered Inequalities*.

tasked with defending the 'self' from the 'nonself' of the disease causing microbe. When conceptualized in such a tight biomilitary hierarchy, rather than a more decentralized and uncertain system, a change in conditions at the top of the hierarchy precipitates profound effects throughout the system that can lead to its complete collapse or implosion like HIV/AIDS (Martin 1994: 130-131; Waldby 1996: 62). What is so devastating about AIDS is that it kills T4 cells and thus wipes out the body's ability to communicate to the rest of the immune system and coordinate a response. Martin concludes, then, that the specific horror aroused by AIDS is the horror of systems breakdown; the inability to keep the outside from the inside, the self differentiated from the other, and nature separate from culture.

For Catherine Waldby, "declaration of epidemics are [also] declarations of war" because epidemics represent "crisis points in the Darwinian evolutionary struggle" between the bacteria and viruses and human populations (1996: 1). The HIV/AIDS epidemic, in her view, is a battle to control the nature/culture distinction because epidemics occur when "the virulent natural world flows across the distinction into the proper domain of the culture and the human" (1996: 19). Waldby points out how all forms of infections are in fact forms of hybridization between the non-human and the human since viruses use humans as the very locus or site of self-multiplication. Contemporary understanding of the HIV pathogenesis occurs through colonization, when viruses take over the reproductive apparatus of the cell and force human host cells to manufacture alien viral cells. "In this form of genetic colonization human identity forcefully participates in its own infectious defeat" (Waldby 1996: 1). The contagion or infection colonizes the human body and human subjectivity, "making them amalgams of

the microbial and the human” (Waldby 1996: 19). AIDS, and other autoimmune diseases, are in fact incidences of self-attacking the self, where any disparity between ‘self’ and ‘other’ has ceased to exist. In the case of HIV/AIDS, there can be no exterior antigenic structure given the exceptional diversity of antibodies already available in our bloodstream, no ‘invader’ that the immune system had not already ‘seen’ and mirrored internally causing ‘self’ and ‘other’ to lose their oppositional quality (Haraway 1991: 218). Despite the persistence of these rigid, hierarchical, metaphors, we are living in excess of these metaphors insofar as Poz ontologies can no longer be adequately captured by existing epistemologies. Evidence seems to mount every day that breaks down the notion of singularity of the human as shut off to other organisms or species. For example, new findings reported in *Nature* state that each individual human “gut” or stomach hosts a minimum of one hundred and sixty species of microbial bacteria with a total of 3.3 million genes, that far outnumbers the cellular composition of human body with 23,000 genes. (Qin 2010: 59). What Waldby reiterates in increasingly post-humanistic terms is that today’s world, and AIDS as a communicable disease, lacks firm border differentiation between body and environment, self and other, health and illness, human and non-human. Part of the ‘war’ on AIDS is the war to reinvest in or reinforce an intellectual edifice that takes at its structure the opposition between these categorizations.

Yet what is central to Waldby’s, Martin’s, and Haraway’s argumentation is that non-militaristic, liberatory possibilities for an immune system discourse that is “replete with the non-self” or full of difference exist (Haraway 1991: 214). Rather than be horrified by what is misdiagnosed as the unnatural blurring between boundaries and borders, today’s world of cybernetics leads us to believe that this is actually the norm

rather than the pathology. Even though immunology was first colonized by biomedicine's military metaphors, over the last thirty years one begins to see an emerging view of the body, and its subsystems like immunity, "that actively relates to the world" in increasingly flexible ways (Martin 1994: 37). Martin does an exceptional job in demonstrating how resistance to the breakdown of borders, among knowledge producers within a given society and among the distinction between the antibody 'self' and the 'virus other', is beginning to give way to new ontologies, new ways of embodying health. For instance, Martin uses alternative medicine in *Flexible Bodies* as a counter-narrative to those of biomedicine, providing a glimpse into treatment options that does not presuppose a split between the body and the mind and opens up a space for "treatment to focus on something other than a cure" (1994: 83-84). Martin cites the increase in the number of Americans attending alternative practitioners annually as evidence for a growing "incompatibility between biomedicine's view of the body and the immune system and the views of many non-medical people" (1994: 89). Alternative medicine practitioners and their patients utilize a predominately non-militaristic approach, which emphasizes health as 'establishing a balance' with pathogens rather than 'obliterating' them. Achieving health requires cooperation in which great numbers of elements in a complex system are being sufficiently managed in relation to each other and other systems. Balance is sought through co-existence rather than tactics of mutually assured destruction (Martin 1994: 88-89). Health under the new idiom of our time is not a static equilibrium, but is anticipatory, flexible, specific, nonlinear, embedded, and responsive. It is flexible in the sense that immunity can manipulate the meaning of boundary in relation to different circumstances. Today, flexible specificity is the new 'currency' in

which those with these desirable qualities (either inherited through one's genes or by training one's immune system through the limited exposure of vaccination) is figured as health (Martin 1994: 237) In light of this emerging view of health, Treichler insists that scholars must resist analyses based on the existing inventory of narratives. At all costs scholars should avoid indulging in the “luxury of listening to the thousands of language tapes playing in our heads, laden with prior discourse, that tell us with compelling certainty and dizzying contradiction what AIDS ‘really’ means” (1999a: 373) because no issue in the AIDS epidemic is fully settled or fully free of history. As we approach HIV/AIDS research today, more flexible notions of bodily relations bolster support for the type of Poz youth community envisioned herein, but also make it more difficult to visualize and stigmatize PLWHA or the ‘future infected.’

### **Several Notes on HIV/AIDS, Gender, Sex, and Sexuality**

In the end, what are the effects of such biomilitary rhetoric? What are the effects of such representations of immune system cells? For Catherine Waldby, “the militarization of the immune system in the face of AIDS” is the precise mechanism by which biomedicine translates broader cultural concerns and anxieties in the face of infectious threat into its own technical narrative (1996: 57). The next section highlights the gendered and sexual aspects of this technical narrative on HIV/AIDS.

### ***Gendered Cells, Gendered Inequalities***

The immune system, the dominant metaphor for envisaging contemporary health, provides what Catherine Waldby describes as a kind of “corporeal nanospectacle” where gender and sexual identities, understood to participate at the social level in HIV infections, can be rendered into scenarios played out at the microscopic level (Waldby

1996: 70). Martin's work in *Flexible Bodies* (1994) demonstrates how the gendered language of immunology works. She states that identities involving gender, race, and class are ever-present in the 'immunological war scene'. The hierarchical division of labor between categories of immune system cells, macrophages, B cells, and T cells are overlaid with familiar Euro-American gender and racial biases. Medical textbooks, used to train the next generation of clinical practitioners, describe the lowly macrophages as the "housekeepers" or lower form of cell that engulfs and digests foreign organisms. On the other hand, T cells are posited to be masculine, more evolutionarily advanced, and use memory to identify and penetrate the 'foreign' antigen, via injection, with a lethal toxin (Martin 1994: 55). Meanwhile a B cell, located in the bone marrow, "orchestrates" the immune response by producing the proper antibodies for attack. These cells are sometimes feminized but rank much higher in the hierarchy than the lowly macrophage, which due to their specialization, form a kind of upper-class female or a suitable partner for the top-ranked T cell. Together, medical textbooks portray the B cells and the T cells as "the mind of the immune system" and the macrophage as the racially or ethnically marked woman (Martin 1994: 56). As a result the immune system is understood as a hierarchy of cells operating to defend the body against foreign invaders. Atop this hierarchy is the T cell, the "virile heroes of the immune system", which when toppled by HIV/AIDS, inevitably equates to complete immunological failure (Martin 1994: 57).<sup>27</sup> By extending her original study of the personification of sperm and ova, her research on the immune system cells demonstrates the implications of gendering internal body parts. These biomedical narratives are deployed to evoke gender roles as natural and further

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<sup>27</sup> Reiterating Martin, Waldby also understands the military hierarchy of the immune system as an already gendered narrative at the level of immune system cells, "where masculine cellular heroics can be pitted against the feminizing and perverting influence of disease" (1996: 59).



naturalize them on the cellular level. A consequence of such cell personification or performativity, Martin warns, is that concepts of gender and sexual identity can be readily grafted into biomedical explanation for HIV at the microscopic level and magnified outwards. As Haraway points out, such imagery in the biosciences is not merely a mirror of our own social world, but a powerful tool in helping to reproduce that world by supplying legitimating ideologies and enhancing material power (1991: 10). The gendered personification of immune system cells helps naturalize and reproduce a world understood through gender hierarchies and unequal power relations.

### *Sex(uality) and the Threat of (Immune) Systems Breakdown*

As many authors note, HIV is different than other infections or diseases because of its connotation with sexual difference and sexual transmission. In what ways does AIDS differ from other non-sexually transmitted diseases? Susan Sontag states that AIDS has a “dual metaphoric genealogy” (Sontag 1991: 103).<sup>28</sup> The first metaphor is common to all disease from HIV/AIDS to cancer, focuses on micro-processes inside the body and relies on the notion of invasion. The second metaphor, which aligns it with syphilis and other sexually transmitted infection, invokes pollution via the permeability or porousness of boundaries. Although by definition AIDS requires the co-presence of other illnesses, AIDS, unlike cancer, is regarded as one illness primarily because it is thought to have a

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<sup>28</sup> Sontag notes that in the United States the disease’s putative carriers connotes those who are poor and/or have darker skins and are defined as such by health professionals and other bureaucrats. While not much has changed on this front since the time of Sontag’s writing, one important change has taken place. Since the early epidemic, the equation of sex with death no longer resonates at the same pitch. With the introduction and increased availability of anti-retroviral medications during the 1990s, HIV/AIDS began to be perceived as a chronic or manageable disease. As a result, the initial fear and panic surrounding sex in the era of HIV/AIDS has diminished somewhat. Pleasure and desire can be fulfilled, states the new rhetoric, pending proper usage of prophylaxis. As chapters four and five will demonstrate, HIV does not dissuade young people from engaging in sex (sometimes protected, sometimes not). Thus, lingering notions of a Victorian, pre-sexual youth, that view young sexualities as unnatural and deviant, seem inapplicable in preventing the spread of HIV/AIDS.

single cause via the exchange of bodily fluids such as blood, semen, and vaginal fluids. (Sontag 1991: 102-103). Sontag notes that plague metaphors are most frequently associated with sexual license, thus deploying the two metaphors mentioned above, and are understood as illnesses inflicted as punishment rather than something simply endured. Sontag notes that in particular AIDS is understood as “disease not only of sexual excess but of perversity” (Sontag 1991: 111). Those with AIDS are those people who have indulged in ‘unsafe’ behavior such as addiction to illegal substances or sex regarded as deviant. Despite data that seems to indicate that urban, American young people are engaging in sex *and* that heterosexual sex is the primary mode of transmission for young people, young sexualities are still deemed deviant under the lingering moral weight of Victorian ideals of childhood, innocence, and purity. Even as IDU is on the rise, the conceptual links with HIV to gay men and sodomy, prostitutes, and the hyper-sexuality of the African ‘other’ has been difficult to shake.<sup>29</sup> Epidemic diseases associated with sex, in particular, generate a preoccupation with distinguishing between putative carriers and the so-called ‘general population’ (Sontag 1991: 113). Waldby describes this logic of contagion as mapping itself onto different risks associated with various genital practices and the sexual identities they are said to denote; “it simultaneously assumes a relationship between genital capacity and subjectivity, and orders this capacity into a hierarchy of pathology” (1996: 41). In other words, biomilitary metaphors facilitate hierarchies of pathology along lines of sexual or gender identity, that ultimately results in the all too common practice of stigma and discrimination for PLWHA or imagined as putative

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<sup>29</sup> For instance, the 18th International AIDS Conference in July 2010 is increasingly focused on addressing the world’s fastest growing epidemics in Eastern Europe and Central Asia. The epidemics in these regions are fueled primarily by IDU coupled with inadequate responses to criminalization of IDU. In addition to its emphasis on ensuring rights for women and girls, this year’s conference also emphasizes discussions of how harm reduction strategies—like needle exchange programs—can be expanded (“Conference Objectives”)

carriers. After all, as Catherine Waldby reiterates, “declarations of epidemic are declarations of war” (1996: 1). Thus epidemic status is granted when public health officials deem that too many individuals have been afflicted, thus threatening the, both moral and physical health, of the public. Upon these grounds, interventions are launched to prevent the epidemic to grow into a plague constituting a complete public health crisis where disease is no longer localized in specific areas or among specific groups of people. If plague status is the point of no return, then epidemics signify the need for biomedicine to launch its immediate attacks against viral invaders on the cellular level, the individual bodily level of the putative carriers, and on the level of society or populations in the name of public health.

Waldby’s work on AIDS and the body politic demonstrates how the militarized lexicon of immunology, epidemiology, and virology exploits the nature/culture binary in ways that specifically create hierarchies of pathology along lines of sexual identity. Working from Foucault, Waldby emphasizes how biomedicine’s representation of AIDS can be read as a narrative of social order, about the ideal organization of the body and by extension the body politic. Foucault, in his work on the *History of Sexuality* and *Discipline and Punish*, is also adamant that sexual pandemics differ from other public health crises in that they present a double threat to order, both to general health and processes of sexuality. Foucault singles out sexual health because he argues that sex can be seen as the densest point of connection between individual bodies and population, one which remains the primary concern and source of legitimacy for modern forms of government concerned with maximizing a healthy, productive, and reproductive citizenry (Waldby 1996: 89-92). As Catherine Waldby argues, the history of AIDS with ‘risk

groups' like gay men is an implicitly sexualized image of immunological health, one that imagines the direction of the infection of the body politic so that the white heterosexual male appears threatened by these 'risk groups' rather than threatening these bodies (Waldby 1996: 87).

As later chapters will further explicate, white, heterosexual masculine bodies are exempted from 'risk group' classification, and as the unmarked norm of health, their bodies forego medicalized treatment and prevention efforts. The white, heterosexual masculine body is 'immunocompetent' or healthy as it is closed off or impenetrable to the risk of HIV infection. Waldby argues that the body politic, like all bodies, is sexed and does so in a way that the capacity to infect is conceptualized according to its departure from white phallic integrity or the immunocompetent body (Waldby 1996: 94). Like Waldby and Elizabeth Wende Marshall, I also believe that epidemiological discourse of HIV/AIDS fails to address specific gendered, racialized, and classed relations of power and elides significant political-economic and socio-cultural realities that put people "at risk of risk" in a way that valorizes Western biomedical logic at the expense of other ways of interpreting the world (2005: 2515-2516). Notably, modern epidemiology assigns a primary importance to studying individual risk. As a result, "by concentrating on these specific and presumed free-range individual behaviors, we then pay less attention to the underlying social historical influences on behavioral choices, patterns, and population health" (McMichael 1995: 633-634 qtd. in Farmer 1999: 43). The next chapter illuminates this very individualized 'biomedical logic', implicit in epidemiological HIV/AIDS work. These links with the body politic and bodily

permeability through gender and sexuality will be addressed further in relation to my interview material.

### **Conclusion**

Albeit highly selective given the amount of published scholarship on HIV/AIDS that exists to date, this thematic review emphasizes feminists' (tardy) arrival and their contributions towards (re)framing approaches and critiques of biomedical HIV/AIDS research. Topics introduced here such as biomilitary metaphors, bodily boundaries, and 'risk groups' will be explored in greater length throughout the coming chapters. Having introduced an array of themes and concepts central to HIV/AIDS research in this chapter, I extend the feminist endeavor to my own research on HIV/AIDS in hopes to explore features of embodied disease emergence obscured by dominant analytic frameworks like 'risk groups', and as such, advocate conceptual shifts that lessen the unequal distribution of disease. Biomilitary metaphors, inevitably locating blame amongst 'risk groups', suffer from a fundamental intellectual error in causality that implicate individuals and deflects attention away from the real engines of the AIDS pandemic like structural inequality (Farmer 1999: 42). Like Paul Farmer and the theorists cited above, this work seeks to build upon a nascent critical epistemology of emerging infectious diseases by asking precisely what is obscured and what is brought into relief by a youth perspective on existing conceptual frameworks of health and disease in the HIV/AIDS era. Rather than utilize inherited categories like 'natural', 'risk group', and 'pathological', feminists must re-make them anew, along more democratizing and ethical lines. Farmer's work is critical in this sense because he examines the contributions of specific social inequalities to illustrate features of the disease's embodied emergence obscured by dominant analytic

frameworks of HIV like 'risk groups'. Who is excluded and to what ethical ends?

Without asking these questions, immodest (and deadly) claims of causality will persist and the stigmatization and discrimination (not to mention increased HIV/AIDS occurrences for some) will continue.

### **Chapter III: The Politics of Epidemiological ‘Risk’**

#### **Introduction**

Undoubtedly HIV is one of the most-spectacularly studied infections in human history, however some questions have been much better studied than others. In the effort to maximize ‘public health’, epidemiology provides forms of expert knowledge about illness and health that relies on the classification and sorting of bodies and behavior types that are not necessarily reflective of embodied realities. It is precisely what biomedical “epistemic sense of relevance filters out” via such categorization that should serve as an occasion to critique these filters (Farmer 2004: 309). In the words of Paul Farmer, “careful investigation of the mechanisms used to propagate immodest claims of causality is an important part of a critical epistemology of emerging infectious diseases” (1999: 50) like HIV. The production of ‘risk’ as outlined throughout this chapter is the precise mechanism used to establish causality and permit bodily intervention or biomedical management, which will be discussed further in the final chapters. This thesis argues that HIV/AIDS is more complicated than epidemiology allows, and that ‘over-medicalization’ of prevention efforts obscures the significant socio-cultural and political-economic realities that shape the global pandemic because “it is precisely this taken-for-granted nature of AIDS, and the generally unquestioned hegemony of scientific knowledge production, that occludes the possibility of other interpretations of life and death, health and disease” (Marshall 2005: 2515).

As such, this chapter focuses on one particular sub-discipline of HIV/AIDS science, epidemiology, in order to investigate the concept of ‘risk’ and HIV/AIDS

infection so endemic to the majority of scholarly and NGO work in this field.<sup>30</sup>

Epidemiology is specifically concerned with the monitoring and maintenance of the greater ‘public health’, usually that of a nation or other geopolitical entity like a region or city. Rather than focus on bounded individual bodies or the microbes they contain, AIDS epidemiology is committed to controlling the capacity for flow and circulation *between* bodies and can be defined as the study of incidence and distribution of disease in the composite body of a given population (Waldby 1996: 94). In practice, epidemiology extends biomedicine’s power, an extension of the clinical gaze, to make authoritative pronouncements about particular bodies, but also the proper biopolitical ordering of large numbers of bodies. Unlike virology or immunology, the other biomedical sub-disciplines of AIDS science discussed in this thesis (see chapters two, four, and five), which focus on the micro level of cells, epidemiology works on the macro level of bodies. According to Catherine Waldby (1996), “if immunology specifies the relationship between the body’s interior and its boundary, epidemiology is concerned to regulate relationships between its boundary and social space” (83-84). The United States national Centers for Disease Control and Prevention (CDC), from the beginning of the epidemic until now, has been the major generator and gatekeeper of official AIDS discourse by defining its parameters. I begin by further discussing epidemiology, and its main authoritative body the CDC, and then move on to discuss the practice or methods of epidemiology in more detail. The second section of this chapter turns more fully to describe the historical inclusions and exclusions of HIV/AIDS ‘risk’ for certain bodies as a result of these epidemiological practices.

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<sup>30</sup> The ‘risk group’ and ‘general population’ division has been the central binary that historically organized AIDS rhetoric (Waldby 1996: 84).



The term ‘risk group’ was first used in relation to AIDS in 1983 by the CDC to “designate those groups thought to be the subpopulations vulnerable to both contracting and transmitting AIDS” (Waldby 1996: 85). Since then ‘risk groups’ have functioned as the biomedical shorthand for differentiating the likelihood of pathological presence in subpopulations of the healthy general population. The history of the early epidemic of HIV/AIDS, primarily recounted by the surveillance carried out by the CDC, not only casts bodies at ‘risk’ as an implicitly sexed and racialized image of immunological health, but legitimizes these claims under the guise of natural science methodologies. Epidemiology does more than merely record the incidence of disease; it has the power to organize disease transmission into a coherent narrative by establishing reasons for the concentrations of particular diseases within particular subpopulations in what Waldby describes as a kind of “hierarchy of pathologization” (1996: 100) that will be explored further below. As defined by the CDC the entity called ‘public health’ dichotomously divides a ‘general population’ from ‘risk groups’ and is not a neutrally descriptive concept. Instead epidemiology’s methods rely upon particular bodily morphologies to imagine and organize itself. In discussing the historical production and maintenance of ‘risk group’ thinking, notions of populations as working objects rather than natural objects, the politics of exclusion and inclusion resulting from organizing a ‘general population’ as distinct from ‘risk groups’, and the ‘immunocompetent’ body’s (see chapter two) alignment with heterosexual masculinity will be explored. At the end of this chapter, I will turn to youth, the most recent wave of epidemiological inclusion into ‘at risk’ categorization. Lastly, armed with evidence on how exclusionary politics of epidemiological categorization of ‘risk groups’ can foreground ignorance and tardy

responses, the final section of this chapter investigates the implications of the recent inclusion of youth as a category increasingly vulnerable to HIV/AIDS infection.

### **Examining Epidemiological Methods**

In this section, I examine ‘risk groups’ as working objects or constructed populations rather than natural objects of science. Working objects include, but are not limited to, atlases, specimens, and laboratory techniques that can be understood as “any communal representatives of the sector of nature under investigation” that facilitate generalization and comparison (Datson and Galison 1992: 85). Thus, rather than a ‘natural object’, a population, as compiled from HIV testing data, is a technology-enabled working object (M’charek 2000: 183). Just as the feminist anthropologist Amâde M’charek’s work on laboratory genetics demonstrates,

Population is neither a matter of nature, one that can be discovered nor a matter of definition, which more or less represent a detached object. What population is depends very much on the practices in which it is studied and the technologies applied to it. (2000: 182)

To understand ‘risk groups’ as the negative imprint of (unmarked) health we must first understand their epidemiological material and discursive production. Central to this review of epidemiological practices is that biological knowledge production is a discursive practice involved in *producing* rather than simply *revealing* or discerning meaning and matter unmediated by method. Biomedicine’s determination of the natural is always and necessarily made within culture, the domain of meaning-making practices (Waldby 1996: 24). In this respect the interdisciplinary feminist scholars cited herein, engaging with the laboratory practices of the HIV/AIDS biosciences, have been particularly fruitful in emphasizing how no method of knowledge production is merely transparent, accessibly free from human bias or influence, and easy transposable onto

other situated phenomena. Before turning more fully to the specific, historical production and definition of ‘risk’ throughout the United States HIV/AIDS epidemic, I wish to briefly explicate how the biomedical sub-discipline of epidemiology maps disease and produces its knowledge about normal and pathogenic bodies.

As already mentioned, the differentiation between ‘general population’ and ‘risk group’ binary is the principle mode of surveillance of the epidemic in industrialized democracies like the United States of America, Western Europe, and Australia.

This mapping procedure is performed through the assimilation of certain groups of persons to categories generated by this explanatory schema, that is with reference to ‘risk groups’ or the more contemporary ‘transmission categories’. (Waldby 1996: 99)

HIV/AIDS epidemiology can graphically depict or map the virus’s current location within the ‘general population’, and provides authoritative speculation as to its future direction by classifying populations designated as a ‘risk group’. In other words, ‘risk groups’ are “artificial categories constructed for disease surveillance” (Treichler 1999b: 244), they are mathematized categories that inadequately capture the complexities of the postmodern embodiment of illness. As discussed, epidemiology is knowledge dedicated to ‘imagining’ the direction of future illness, which relies on ‘imagining’ the entity of ‘population health’ from extensive data collection infrastructures. Only after extensive data collection, statistical analysis, and the organization and simplification of data into tables and columns can an entity called ‘the health of the population’ or public health can be envisaged (Waldby 1996: 96). Importantly, epidemiological surveillance can ‘see’ infection in the population through the data collection device of the HIV test, it cannot however ‘see’ a thing called the health of a population. Rather the ‘public health’ of the ‘general population’ is an inference of normalcy à la Canguilhem, based on that which is

excluded by ‘risk group’ classification, (for a concrete example please refer to current CDC classification in section three). Public health surveillance of illness and disease uses “statistics to provide a critical scientific database for studying the outbreak of illness, define the scope and nature of the problem, and track change”, in other words, to know who gets sick (“who you are”) and how they get sick (“what they do”) (Treichler 1999b: 242-243). Despite allowing no double classification when recording causes of transmission, close examination of CDC ‘risk groups’ reveals that ‘risk group’ classification does in fact mix “modes of exposure” thereby confusing and collapsing “who you are” with “what you do” (Treichler 1999b: 243).<sup>31</sup> Thus, the CDC examines and often conflates identity characteristics—age, gender, and race—along with certain behaviors—unprotected sex and shared or unclean needle use—in the categorizing of ‘risk’.

Generally speaking, the biomedical sciences rely on processes of quantifying pathological processes in both bodies (T cell counts) and populations (HIV testing data), which are mathematized and rendered into disembodied units which can be graphed, counted, and compared allowing a relationship to be expressed between each of the phenomena. The contemporary study of ‘life’, the iconic object of biomedical practice, relies on an economy of information and the translation of flesh into data, which conditions the meaning of living matter (Waldby 2000: 28-29). The mathematicization of both fields, immunology and epidemiology, sets up a reciprocity or homology insofar that discovery in one arena can be translated easily into the knowledge of the other with little mediation or distortion; similar propositions about models and processes are moved through different levels of scale with ease (Waldby 1996: 98). Waldby describes this

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<sup>31</sup> An example of this is provided in the last paragraph of this section.

slippage between scales as biomedicine's power to 'anatomize' cultural events in ways that legitimate certain understandings of social order—particularly ageism, sexism, and racism—as already inscribed at the molecular level, cellular level, and level of the organism. Waldby continues by stating,

In other words, epidemiology seeks to do in the social body what the immune system does in the healthy body and clinical medicine does in the diseased body... Just as the immune system is endowed with the capacity to distinguish between clean and infected cells and to prevent the spread of infection through the healthy cells of the body, so epidemiology has the capacity to distinguish between the infected and the uninfected and to protect the latter from the former. (1996: 95)

As such, the production of epidemiological knowledge relies on a sophisticated repertoire of statistical methods to compress, centralize, and summarize disease and the number of HIV/AIDS implicated bodies. Through homology, military metaphors of an individual's immune system response are translated onto the social level through epidemiology.

How precisely is this data about life, disease, and by inference health produced in epidemiology? According to Susan Sontag, the calculation of an epidemic totals the number of tabulated cases in addition to “calculating about a much larger number of people apparently in good health or seemingly healthy, but doomed as the future infected” (Sontag 1991: 119). The technology for surveillance of disease cases is the HIV test, which will be addressed again and more fully in chapter five. Yet importantly, through visualizing biomedical technologies like the HIV test, it is now possible to create what Sontag deems a “new class of lifetime pariahs, the future ill” (1991: 119). To get AIDS is to be revealed “as a member of certain ‘risk group,’ a community of pariahs” (Sontag 1991: 110). To be a PHLWHA is to confirm an identity as someone deviant or someone fallen from grace, someone who could not abstain from behaviors that resulted

in 'risky' bodily fluid exchange. Put differently, in the biomedical imagination, the battle with the virus has extended beyond just those who are HIV+ to include the future infected, those individuals that are simply associated with the virus by the statistical likelihood of engaging in certain behaviors. To borrow Waldby's words, "the distribution of infection is taken to be indicative of a certain complicit and eroticized susceptibility, a biological compatibility or desire between the virus on the one hand and the cell and/or body on the other" (1996: 98). By virtue of this infection or association with it, these future ill are colonized by the 'other' and have passed irrevocably over onto the side of the inhuman, the side of the virus, the side of death, and have become the enemies of the medical campaigns which aim to contain virus's spread. Thus, 'risk groups' or those 'at risk' are habitually cast as allies of the virus, they operate as a medium of infection, "conduits which carry the virus throughout the corporeal matrix of the 'public health'" (Waldby 1996: 106). Identified as such, 'risk groups' have been located as bodies through which HIV infection moves, "they are considered important not because they are themselves *infected*, but because they are *infecting*" (Waldby 1996: 110-111, emphasis in original). This point will be taken up further in the following chapter on practices of 'othering' HIV/AIDS and the spoiled identities associated with HIV 'risk groups'.

Lastly, it is important to reiterate that CDC methodology requires that sources of transmission be classified according to a hierarchy of factors, with no dual assignments or ambiguity permitted when recording a vector of transmission. This lack of tolerance or acknowledgement of ambiguity caused by the presence of co-factors distorts the actual materialization of disease and illness in society. For example, take early studies on HIV infection and female sex workers, where no distinction was made between drug use and

sexual contact as a mode of exposure in women. This example demonstrates how “who you are” gets conflated with “what you do” in epidemiological risk classification. Early on the CDC attributed female sexual worker transmission to be caused by sexual contact with multiple sex partners, despite a multitude of other studies and the claims of sex workers themselves that demonstrated the likely cause of infection to be intravenous drug use. From the mid-1980s on, as consensus shifted, the CDC’s hierarchical reporting system was reversed, privileging drug user over sex as the primary mode of exposure in HIV+ female sex workers (Treichler 1999b: 63-64). As this and the historical examples of the ‘4-H Club’ shorthand below demonstrate, definitions have great power: they include and exclude, and sometimes they reflect compromise, politics, convenience, guesswork, lobbying efforts, economics, and cultural stereotypes as much a scientific ‘evidence’ (Treichler 1999b: 60).

As the following section aims to demonstrate, once scientific discourse admits such a form of shorthand like ‘risk groups’ as a well-defined nomenclature, the complex and sometimes incongruous facts are compressed and no longer need to retain “the history of their fabrication”(Treichler 1999b: 170). Early CDC classifications and definitions of what later became known as HIV/AIDS seem to erase the complex and politicized pathogenesis of the epidemic in the United States; it allowed for some bodies to be targeted while others were exempted from illness. Despite the differences these categories allegedly embody as different than the ‘general population’, all ‘risk groups’ do share a central commonality, what feminists aptly critique as “sensitivity to the exploitative economies operating in dichotomous logic” (Waldby 1996: 24). In this exploitative economies where ‘risk groups’ are a deviation from the norm of health, the

dominant term of ‘immunocompetency’ is defined through its negation or more specifically through the ever-growing delineation of ‘risk groups’. Although most efforts are deployed in differentiating ‘risk’ at the subpopulation level, difference within ‘risk group’ categories is portrayed as rather homogenous in epidemiology or other subdivisions are made without clearly defined parameters and indications of overlap.

### **Figurations of ‘Risk’ in the U.S. HIV/AIDS Epidemic**

AIDS became a public phenomenon on June 5, 1981 when five Los Angeles deaths were initially described as Gay Related Immunodeficiency Disease (GRID) in the CDC’s *Morbidity and Mortality Weekly Report (MMWR)*.<sup>32</sup> What had variously and unofficially been called “gay pneumonia”, “gay cancer”, an “epidemic of immunosuppression”, and “WOGS” (Wrath of God Syndrome) came provisionally to be known as GRIDS, which worked to convey both the syndrome’s target organism (the homosexual body) and its disease process (anal sex) (Treichler 1999b: 46). Early CDC reporting considered ‘homosexual’ practices or the ‘gay lifestyle’ as direct ‘causes’ of the syndrome, which in fact contributed to the perception of HIV/AIDS as caused by the emergence of a single disease (Waldby 1996: 60). One year later at a conference held in Washington, D.C., GRIDS was re-named AIDS to reflect the growing number of confirmed cases of illness amongst people other than gay men. Evidence was mounting that rendered GRIDS an unsuitable diagnosis, while AIDS sounded more descriptive without being pejorative (Treichler 1999a: 365-366). Just as eventually agreeing upon the name AIDS was an embattled and political process, so too was the naming of HIV.

Although other viral nomenclatures were proposed, after a series of heated international

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<sup>32</sup> Although isolated cases of HIV/AIDS may have occurred earlier, scientists believe that the first cases linked to the current epidemic were forms of zoonoses (diseases spread from animals to humans) and occurred sporadically as early as the 1930s and later spread rapidly in the 1970s (Whiteside 2008: 1-2).



disputes between American and French laboratories, scientists settled on the name HIV because it conforms to the nomenclatures of other viruses where the first letter indicates the host species (human), second is the major pathogenic property (immunodeficiency), and the last is V for virus (Treichler 1999a: 368). These examples, albeit highly condensed, demonstrate the politics of naming and identifying of HIV/AIDS and how early CDC definitions link the virus to the homosexual body, thus carving out the first subpopulation of risk.

Following shortly after the re-naming from GRIDS to AIDS, the CDC unveiled its '4-H' model of risk. The fall 1982 *MMWR* report emphasized that members of the "4-H Club", (male) Homosexuals, Haitians, Heroin users, and Hemophiliac, were the populations "at risk" and to watch (CDC qtd. in Treichler 1999b: 51). The original '4-H' list associated 'risk' for acquiring AIDS to being a particular kind of deviant person who was alien or exotic to the mainstream, those who engaged in homosexuality, those who used needle drugs, or those who had black skin (Treichler 1999a: 361).<sup>33</sup> In referring to the early HIV epidemic in the United States, when heterosexual transmission and female infection was thought of as extremely rare, Susan Sontag makes the point that AIDS was and still largely is understood as a "disease not only of sexual excess but of perversity" (Sontag 1991: 111). While 'backward' sexualities—either those that were foreign, exotic, or hyper-sexualized—dominated the early delineation of 'risk', gender and race was

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<sup>33</sup> It is important to think how AIDS simply might not have been recognizable as a coherent nosology at an earlier historical moment prior to 1981. Without particular developments in immunological sciences and technologies in the 1960s and 1970s, which resulted in the identification of T cell subsets, along with gay activism in the same time period, it is likely that the 1981 cases would have remained un-locatable and undiagnosable in bodies and populations (Waldby 1996: 60).

largely obscured or ambivalent and the chronicle of the disease for women is less well known.

Paul Farmer points out that merely months after the first 1981 *MMWR* report, instances of infection were discovered among not only among gay men, but also among women, injection drug users, hemophiliacs, and their sexual partners were also implicated in the burden of risk.

The initial misunderstanding—that AIDS was a disease of men—can perhaps be attributed to historical accident: the new disease was first characterized in the technologically advanced United States, where it did, initially at least, primarily afflict men. But from the outset of the world pandemic, it was apparent that women were also vulnerable to AIDS; and within in a year or two, data suggested that women were at least as likely to become as infected as men. (Farmer 1999: 61)

Since some women as early as 1982 had HIV/AIDS, along with reports as early as 1984 that indicated AIDS in other countries was spread primarily through male-female sexual intercourse, the listing of risk groups should have been modified to reflect gender explicitly: “male and female homosexuals, male and female heterosexuals, men and women who use intravenous drugs, men and women of Haitian origin, etc.” (Treichler 1999b: 47 and 59). Failure to do so not only cost lives, but also perpetuated deadly stereotypes around ‘risk group’ thinking that are still prevalent today.

Yet the 1985 publication of the popular science magazine *Discover* sustained the denial of the idea of a major pandemic amongst women. Despite the historical propensity to align women’s bodies as more natural, thus containing an innate susceptibility to pathology or contamination, at this time the CDC claimed that the naturally “rugged vagina”—in contrast to the “vulnerable anus”—was designed for withstanding the rigors of intercourse and birthing and made it seem unlikely that women could get infected

through heterosexual intercourse.<sup>34</sup> This had the dual effect of imagining women as less susceptible to HIV and welcoming moralizing commentary on anal sex (Farmer 1999: 61; Treichler 1999b: 240).<sup>35</sup> In the fall of 1984, just prior to this proclamation, *MMWR* briefly tried to re-cast ‘risk’ to include the category of female ‘prostitutes’.<sup>36</sup> Thus, some early variations on the ‘4-H Club’ model of risk did include women under the highly offensive ‘H’ terminology of ‘hookers’. As CDC research provided mounting evidence refuting the notion that sex workers were transmitting the virus to their clients, ‘hookers’ was replaced by hemophiliacs in the ‘risk group’ hierarchization. In this way, women lost their only presence on the AIDS research agenda early in the epidemic. Later, in a 1986 debate over heterosexual transmission, a new category had been proposed to catch women’s attention: “women at risk”, however, it was later collapsed into another new category called “multiple partners of sexually active adults” (Treichler 1999b: 57). The classification of “multiple partners of sexually active adults” collapsed gender, risk behaviors, and sex, rendering it a poor fit with the world most women inhabit. Since the beginning of the epidemic in the United States, new groups have been implicated in the HIV/AIDS ‘risk’ classification, however, only epidemiologists have considerable authority in ascertaining and rendering visible the contours of this embodied ‘risk’.

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<sup>34</sup> The December 1985 issue of *Discover* magazine published findings on the “vulnerable rectum” and the “rugged vagina” thus popularizing this notion (Treichler 1999b: 240).

<sup>35</sup> This seemingly contrasts the conclusions drawn by feminist science studies that the entire discourse on medicine, even on the cellular level, has imagined the female body as more susceptible to pathologies and ailments than the male body (Åsberg 2007: 30), HIV/AIDS was said to operate differently in the early epidemic. Importantly, however, sexual receptivity (rather than penetration), usually aligned with female sexuality or the feminine, was a key component to exposure via anal sex. Whereas later on familiar gendered scripts would be reinstalled through immunological ‘biomilitary’ metaphors, and evidence that the vagina’s mucosal surface area actually increases vulnerability, women’s reproductive capacity namely their “rugged vagina” offered them immunity in the early epidemic.

<sup>36</sup> Interest in studying HIV transmission and female prostitutes was sparked in 1985 when the *Journal of the American Medical Association* reported finding of HIV infection in U.S. servicemen based in Germany who claimed heterosexual contact with only female prostitutes (Treichler 1999b: 61).

Despite increasing attempts at a corrective proliferation of ‘risk group’ categories, both the voices of HIV+ women and American feminists were occluded by the CDC’s narrative of risk in the early epidemic.

In the cases demonstrated above, women in the early epidemic came to be seen as a sort of ‘invisible pass-through’ who could transmit HIV without getting it (Treichler 1999b: 61). In other words there was no intrinsic concern for women as women; women in risk groups were given that status only by virtue of their sexual or familial attachments rather than by virtue of their own activities and autonomy.

Women not considered “women” included those infected by transfusion, mothers of infants with AIDS/HIV, and lesbians. The categories (of existing “risk groups” and “modes of exposure” to which these “women” were farmed out and thus erased as gendered beings included “transfusion victims,” “Intravenous drug users,” “sex partners of persons with/at risk for AIDS,” “minorities,” etc. Thus these “women” considered “not normal” included sex workers, drug abusers, minority and poor women, and women in the Third World. (Treichler 1999b: 62-63)

Risk by risk and reason by reason women’s exclusion from the statistics as a population also meant that their absence could only be refuted with evidence, yet, women’s absence also meant that no epidemiological evidence would be gathered. Similar to youth today, “as an issue for women, AIDS unnamed meant AIDS unclaimed” (Treichler 1999b: 66). Only following the January 1987 *U.S. News and World Report* cover story of a white couple stating that the “disease of *them* is the disease of *us*” (Farmer 1999: 61; Treichler 1999b: 55, emphasis in original), did the popular belief of heterosexual AIDS as a myth or impossibility begin to be dispelled. Many similar stories covering the “heterosexual spread of AIDS” had begun to appear between 1986 and 1987 in *Time*, *Newsweek*, *Atlantic*, and *Scientific American*, marking the media explosions of the idea of “heterosexual AIDS” in the public consciousness. Still, only after Ronald Reagan first

spoke the word AIDS publicly (1987) and when the postal service delivered the U.S. Surgeon General's booklet *Understanding AIDS* to every household in the United States (1988), did the epidemic gain the widespread attention of the 'general public' or those not previously included in categorizations of 'risk' (Treichler 1999b: 48). Even though by 1991 AIDS was statistically the largest killer of young women in most large U.S. cities (Farmer 1999: 62), it was not until 1992 that HIV/AIDS scientists first began to study how HIV pathogenesis may differ in women's bodies and men's bodies. Here the idea was introduced that the symptoms and the precursors to HIV/AIDS might look different in women and men, which later resulted in the selection of gynecological conditions to be added to the suspected clinical profile of HIV infection and AIDS (Treichler 1999b: 253). Although not addressed directly here, the overlap and conflation between heterosexuals and women needs further close examination to fully unpack the relationship between gender and sexuality in the production of HIV/AIDS 'risk'.

### **Making the Case for Youth**

I have recounted the initial exclusion and reluctant inclusion of women in the early HIV/AIDS response in contrast to the perceived prevalence among gay men to demonstrate the biopolitics involved in the boundary maintenance between 'general population' and 'risk groups' in epidemiological determinations of population health. Erasing or distorting the early AIDS history in this way, biomedicine is "part of the process of de-localization necessary for the emergence of hegemonic accounts of what happened and why" (Farmer 2004: 308). What this reiterates is that questions of identity relating to who is infected and how HIV is transmitted ultimately "shape fundamental understanding of what AIDS *is*; in turn, these understandings have shaped the ways we

identify and classify those whom HIV infects as well as its modes of transmission” (Treichler 1999b: 238). In reality, women and young people have been vulnerable to HIV transmission from the beginning, in ways that are in excess of the CDC’s statistical manipulations of HIV/AIDS distributions. However, it is not until these categories are mobilized through biomedical production and recognition of ‘risk’ that they begin to garner further research and intervention. As current epidemiological data suggests, we are witnessing another demographic shift in ‘risk’ inclusion, with the inclusion of young people into this risk schema. Here, the question of youth becomes an interrogation of a future population deemed ‘at risk’ and adversely affected. Just as gender, sexuality, and race are deeply entrenched in origins and meanings of biomedical constructions of HIV/AIDS, I argue so too is generation. The notion of pathological progression through stages, the evolution of the biomedical and cultural discourses of HIV through time, and demographic shifts in disease materialization demonstrate the need to examine temporality and generational shifts in the conceptions and materialization of postmodern illness and health. I begin this discussion of a generation ‘at risk’ by first examining the current CDC data on HIV/AIDS in the United States made available to the public on the government’s website.

Nowadays, the populations under HIV/AIDS epidemiological surveillance have multiplied greatly from the original ‘4-H Club’ and currently include fourteen subpopulations listed as follows on CDC’s HIV/AIDS “Fact Sheets” website.<sup>37</sup>

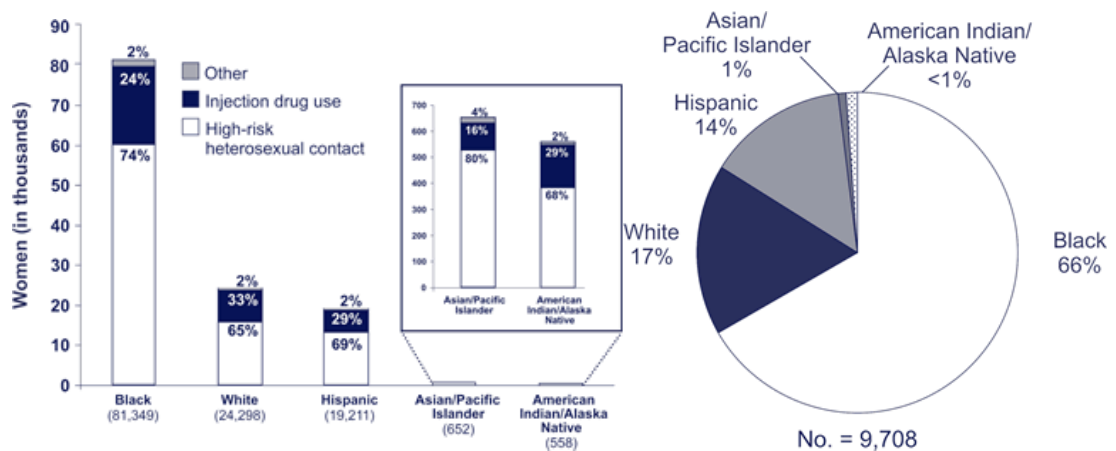
- Geographical region
- HIV/AIDS among Gay & Bisexual Men
- Drug-Associated HIV
- Mother-to-Child (Prenatal)

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<sup>37</sup> Each of the Fact Sheets that is cited specifically in this text has its own bibliographic entry. To access this the CDC’s homepage please visit: [www.cdc.gov](http://www.cdc.gov).

- HIV/AIDS among African Americans
- HIV/AIDS among Hispanics/Latinos
- HIV/AIDS among Women
- HIV/AIDS among Youth
- HIV/AIDS among Asians & Pacific Islanders
- HIV/AIDS among American Indians and Alaska Natives
- HIV/AIDS among Persons Aged 50 and Older
- HIV/AIDS among Women Who Have Sex with Women
- Occupationally Acquired HIV/AIDS in Healthcare Personnel

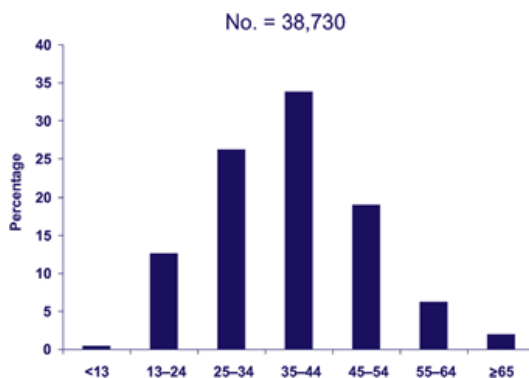
Notably, each of these fact sheets utilizes pie charts and bar graphs to further carve up the distributions of HIV/AIDS along lines of gender, race, and mode of transmission (or in the case where the mode of transmission is known, identity of the host). In true Latourian fashion, the CDC literally responds to the question of what does HIV/AIDS look like in the United States by showing the reader graphically. According to the CDC, rather than embodied stories, the way AIDS looks like today is portrayed and depicted in the pie charts and graphs, which not only informs but also performs.<sup>38</sup>



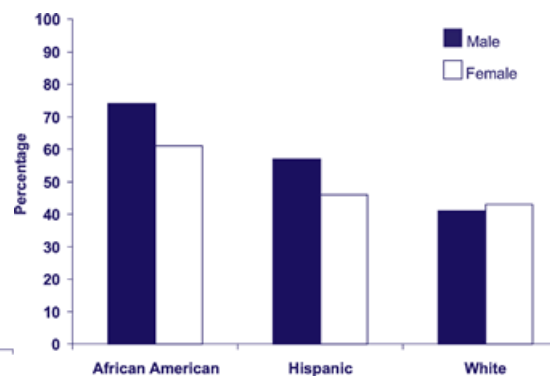
<sup>38</sup> Latour, in discussing the effects of a compressed informational format like that of epidemiology, highlights the power of such charts and graphs. He goes on to say, ““You doubt what I say? Ill show you’ And without moving more than a few inches, I unfold in front of your eyes figures, diagrams, plates, texts, silhouettes, and then and there present things that are far away and with which some sort of two way connection has been established” (1990: 36). In other words, the object of the scientific gaze is the visual text produced about the object rather than some natural object (Waldby 2000: 29). Bringing together far flung processes of health, illness, behavior, and identity epidemiologists translate the technical discourse of medical research of immunology and virology into terms that legible and useful to governments and bureaucracies.

**Fig. 1: Transmission Categories and Race/Ethnicity of Women Living With HIV/AIDS Diagnosed During 2005 (CDC August 2008b).**

**Fig. 2: Race/Ethnicity of Women With HIV/AIDS at The End of 2005 (CDC August 2008a).**



**Fig. 3. Age of Persons With HIV Infection or AIDS Diagnosed During 2004 (CDC August 2008b).**



**Fig. 4. High School Students Reporting Ever Having Had Sexual Intercourse 2003 (CDC August 2008b)**

Through graphic depiction and cumulative list making, the CDC pays lip-service to the idea of intersectionality, while in reality separating apart traits and allotting people to fill the slots of identity based ‘risk groups’ that may have little to no resemblance to the complexity of embodied subjecthood.

In the long list of subpopulations, generation was reflected in three of these subpopulations: prenatal, youth, and persons aged fifty and older. For the CDC, while the new trends with youth are alarming, they maintain a positivist stance where further epidemiological intervention can play a palliative role.

Young people in the United States are at persistent risk for HIV infection. This risk is especially notable for youth of minority races and ethnicities. Continual HIV prevention outreach and education efforts, including programs on abstinence and on delaying the initiation of sex, are required as new generations replace the generations that benefited from earlier prevention technologies. (CDC August 2008b)

These ‘youth’, which the CDC defines as between the ages of thirteen and twenty-four, are further subdivided by another set of behavioral ‘risk factors’ that pose as ‘barriers to



prevention' when no cure exists. These 'risk factors', which seem most apt to describe racialized young bodies, include:

- Sexual Risk Factors including early age of sexual initiation, heterosexual transmission, MSM, and presence of other STIs
- Substance abuse
- Lack of awareness
- Poverty & Out-of-School Youth
- The Coming of Age of HIV-Positive Children

Notable emphasis is on sexual risk factors, as most of website's section is devoted to explicating further divisions of sexual risk. In this sense biomedicine seems to "anatomize its narratives" in the sense that it both orders its images of bodies according to their performative (sexual) logic, but it also "anatomizes them in the sense that it reads them [narratives] into lived bodies in ways that are constitutive of important aspects of corporeality itself" (Waldby 1996: 32). Prescribing youth 'risk' along these lines of corporeality only demonstrates the inevitable and problematic entanglement between "who you are" and "what you do" that in the end does little to capture the lived realities of youth and the structural inequalities that may foreground this 'risk'.

Despite the connotation of maximum inclusion implied by the term 'general population', the breadth covered by these fourteen subpopulations and youth differentiated 'risk groups' is so comprehensive that it seems to make the category of 'general population' residual. Who is left after this long series of exclusions and subdivisions? Similar to the finding in Catherine Waldby's Australian research, what these listings of CDC subpopulations of 'at risk' and the 'risk factors' among youth share is an explicit absence. White, heterosexual men go unnamed and remain absent from 'risk group' delineation (1996: 84-85). In this way the white heterosexual male body is configured outside the circuits of AIDS contagion, allocating 'risk' to all other forms of

sexuality and corporeality in ways that place demands back upon these ‘risk groups’ to actively control the spread of infection through modification of their (sexual) behaviors. In other words, the ultimate reservation of the category of ‘general population’ is for white, heterosexual men and thus, Waldby argues, public health measures can be seen from the vantage point of the masculine body and its protection (Waldby 1996: 84).

The question ultimately prompted by this concern for isolating populations ‘at risk’ from within a ‘general population’, is of course, how do young people want to be made into an epidemiological population? (M’charek 2000: 57). This issue, first brought up in work by Amâde M’charek, questions how biological practice imagines and constructs populations versus how those populations, when narrative power is granted to the young people described and targeted in epidemiological work, view themselves. Importantly, adding to this critique of epidemiological methods, it is also critical to challenge mathematical models for being able to properly contain and capture the contemporary embodied experience of HIV/AIDS. Can these old models be adequately reworked for new realities and new ontologies? Or, as Paul Farmer asks, “can integrated mathematical modeling be linked to new ways of configuring systems, avoiding outmoded units of analyses such as the nation-state in favor of more fluid biosocial networks through which most pathogens clearly move?” (1999: 56). What these questions ultimately upend is the facile issue of statistical causality or a certain viral association that facilitates bodily intervention in certain populations and subpopulations in the name of ‘public health’.

Like Paul Farmer, I envisioned my ethnographic fieldwork and interviews as a corrective to the ‘risk group’ thinking and line of causality presupposed by “slipshod

epidemiological research” (Farmer 1999: 52). Paul Rabinow, cited in Martin’s *Flexible Bodies*, notes that the dominance of computerized calculations of risk factors for the hazards or occurrences of disease among populations allows for the problematic grouping together of individuals sharing certain traits. He goes on to say that,

Individuals sharing certain traits or sets of traits can be grouped together in a way that not only decontextualizes them from their social environment, but also is non-subjective in a double sense: it is objectively arrived at, and does not apply to, a subject in anything like the older sense of the word (that, is the suffering, meaningfully situated integrator of social, historical, and bodily experiences. (Rabinow 1992: 243 qtd. in Martin 1991: xvii)

Ethnography of this sort poses, for Farmer, Martin, and myself, the opportunity to engage intimately with the emerging epidemic in a certain locale that, most importantly, opens up the chances for dialogue and self-narration by giving young people the opportunity to define and theorize their own bodily experiences. By turning definitional power over to young people, we make sense of AIDS anew, we add new stories to the already dense and multi-layered AIDS discourse. Similar to the work of Paula Treichler, this chapter demonstrates that “no issue in the AIDS epidemic is fully settled, and no discursive term is ever free of its history” (Treichler 1999b: 5). With that in mind, and a critique of the dominant biomedical discourses of immunology and epidemiology firmly in place, the rest of this paper is devoted to returning narrative power back to youth.

### **Conclusion**

By adding a Poz youth perspective as a counterpoint to the “experience-distant” statistical models of biomedicine we arrive at something that “has much to tell about the difficult changes we are living through—changes that help to shape and, inescapably, define us... it can help us recognize the outlines of our emerging future” (Morris 1998: 19). Precisely part of what makes the postmodern experience of illness differ from that of

the modern or pre-WWII illness is that nowadays ill people recognize that there is more involved in their bodily experiences than the medical story can tell, especially since purely technical explanations “flatten the story of illness” (Morris 1998: 45). This is not to proclaim the narratives of Poz youth as ‘real’ or ‘more real’ than that offered by biomedical categorizations, but to emphasize that they offer a mode in which patients reclaim power as creators and narrators of their own distinctive stories, ones that are frequently excluded by biomedicine (Morris 1998: 24-25). These stories do not promise to help us live forever, for nothing will, “but it just might reorient our thinking about health, prevent a disastrous medical error, and keep us from wasting our lifeblood in the pursuit of shopworn mechanistic illusions” of perpetual repair and maintenance (Morris 1998: 19). This chapter attempted to highlight “how there is no single story of AIDS, but rather competing narratives of it” (Taylor 2007: 972). Hopefully this chapter has illuminated how some of these narratives, through the early stages of the epidemic, gained control while others were overlooked with serious consequences, the categorical silencing and bodily prospect of illness and/or death for some. The next two chapters are devoted precisely to the embodied self-narration, from a (Poz) youth standpoint of HIV/AIDS in Washington, D.C., and present several major themes that emerged in my focus group interviews. From the interview material that follows, one can judge whether or not the youth vantage point of my interviewees was or was not in fact Poz, a topic more fully attended to in the Conclusion.

## Chapter IV: The ‘Othering’ of HIV/AIDS

### Introduction

While the review of HIV/AIDS literature in chapter two introduced the concept of the military metaphor, this chapter seeks to expand upon this by investigating the relationship between these biomilitary immunological narratives and the kind of subjectivity and body boundaries they project and naturalize. This chapter relies heavily on my focus group interviews with young people and the ways in which they envisaged disease and their human carriers as ‘other’ or alien enemies (denoting that they are ‘worth less than’) in the attempt to ‘purify’ themselves from infectious diseases. The bulk of this chapter concentrates on responses to a question asked of nearly every focus group and interviewee, recorded and written, asking participants to respond to how the District and youth statistics, both rising, made them feel. I wanted their reaction to the epidemiological statistics and the way it figures (or not) into their lives. I wanted them to hold the mirror up to themselves, so to speak, to incite reactions to the very statistics that implicated their bodies and subjectivities in this epidemic. Although interviewees were astutely aware of the prevalence rates in Washington D.C., there was considerable resistance among young people to the idea that HIV infection could really happen to them. The strategy utilized by young people, very much reminiscent of the self/other boundary maintaining biomilitary immunological narrative, casts or deflects risks as something outside of themselves, or attributable to certain ‘other’ or distinct bodies and/or subjects. Despite the possibility for immune systems thinking and metaphorization to open up non-binary relationships of difference between healthy and ill bodies (see chapter two, alternative medicine practitioners), the young people readily clung to strategies of ‘othering’ to distance themselves from disease and its putative carriers. In this sense, these young people are not really living in

excess of these old-fashioned, military metaphors, but as will be shown, they reinstate them anew on the level of the body politic. What this highlights is the need for prevention efforts to redouble their efforts on stigma and discrimination against PLWHA, perhaps taking a page from feminist scholarship in endeavoring to re-frame disease and difference altogether.

Susan Sontag's work on metaphorization and illness was pioneering in the sense that she exposes the power of military metaphors of HIV/AIDS to contribute to the stigmatization of certain illnesses and, by extension, those who are deemed ill like PLWHA. Sontag writes, the military metaphor, "implements the way particularly dreaded diseases are envisaged as an alien 'other,' as enemies are in modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if the patients are thought of as victims" (1991: 97). The individual is blamed as the source of 'contagion', connoting all forms of anxiety relating to the blurring of the self/other distinction, which enables them to be viewed as dangerous, infecting, and polluting elements within society. Biomilitary metaphors of understanding the relationship between the immune system cells also entails certain propositions about body boundaries between the self/other and the body's inside/outside which are maintained through the dynamics of attack and defense (Waldby 1996: 55-57). According to Sontag, the very potency of this military metaphor of the immune system—one which is lived out in the flesh—is that it penetrates both explanations of the inner functioning of immune cells along with public health discourses where disease is predominately figured as invading society (Sontag 1991: 95). Both the body and the body politic are potentially infected. Ultimately what HIV/AIDS in bodies and between bodies attests to is the impossibility of attaining the 'clean and proper body'. Thus it "haunts the

subject who constantly reanimates his/her drive to bodily mastery” (Waldby 1996: 74) by reinvestment in its boundaries through practices of ‘othering’, abstinence, and perhaps even advocating quarantines or the physical separating out of the infection from the healthy general population. If the borders of bodily integration are ‘at risk’ from becoming undifferentiated, the young people in my interviews clung to ways to avoid such prospective dissolution of the autonomous, individuated ‘self’ as they knew it.

What this helps to illustrate is that notions of infection and contagion are in excess of strictly biomedical understanding, which limits contagious elements only to body fluids that contain microbial agents, highlighting how the fear surrounding infection and illness can readily stand for “more general fears of subjective engulfment” (Waldby 1996: 74). As this chapter demonstrates, “fears of otherness are easily translated into fears of infections of various kinds” (Waldby 1996: 74) by deflecting their own vulnerability onto stereotyped images of ‘others’ at risk such as older IDUs, women, and immigrants. In doing so, the young people interviewed were able to align themselves with health and distance themselves from any alliance or allegiance with the ‘foreign’ contagion. This should come as little surprise, given that the customary impulse is to distance oneself from the abject prospect of disease. According to Catherine Waldby’s work on AIDS, sexual difference, and the body politic in Australia, “the intensification and reinforcement of body boundaries is carried out in the age of AIDS as a means of projecting infectious capacities safely ‘outside’ the body, as effects of other bodies, and simultaneously guarding against this infection” (Waldby 1996: 75). Just as feminists in the early epidemic took refuge in their own identity (or aspects of their identity) so too do youth and their political representatives. In reality, being ill comes down to being unable to distance oneself from pathogenic viral agents. To embody health one needs to be able to create distance between

oneself and pathological agents and the abject prospect of the dissolution of the self. Yet what the ensuing chapter demonstrates is that even those, like young people, cast as epidemiologically vulnerable, tend to insist that the cause for this epidemic lies elsewhere and how this takes place through the ‘othering’ of the people either living or thought to be living with HIV/AIDS. Before delving further into youth reactions to the increasing number of HIV cases reported among certain age brackets, I first wish to highlight and discuss some of the confusion concerning Washington D.C.’s epidemic. After recounting youth reactions to HIV/AIDS statistics, this chapter concludes by addressing the growing issue of stigma and discrimination, how military metaphors seem to effect discriminatory thinking, and how prevention and education might consider tackling this issue.

### **Confusing (the) Statistics**

In what follows, confusion and disbelief surrounding the extent of Washington, D.C.’s epidemic helps deny the disease’s proximity to an individual or group and thus mitigates any shared political responsibility. I begin by recounting a story told by Cambria about her lobbying experiences in Washington, D.C. and juxtapose that to the skeptical or confused reaction of the 4TeenZOnly focus group with young women. Cambria’s story, included in its entirety, narrates the first time this twenty year old peer educator went to lobby her Congressman on behalf of Advocates For Youth. Here, Cambria’s message about HIV/AIDS in the city was met with utter disbelief. In stark contrast to the reactions of fear and sadness felt amongst the young people, recounted throughout this chapter, the politician seemed to be amazed and disbelieving. In a capitol city devoted to national policy making, the city locals are often outside of the radar for the political elite. As Cambria explains, politicians were not alone in their shock.



Cambria: When I first heard that statistic [D.C. rates are comparable to some Sub-Saharan nations] it stuck in my mind. I couldn't believe that was true because like when you were talking about 1 in 40 people have HIV, or AIDS in D.C. and that's just crazy. I learned that the day before we went and talked to our Senators and Representatives. Whenever I brought that up they were like, "I'm not sure if that's true. I have never heard that statistic", like they didn't know it and I didn't know it before either... I guess I was really shocked because I wasn't aware of how bad it was. I see D.C. as kind of a really – I guess they have education problems too that I didn't know about, but an educated center of the United States, politics, all kinds of stuff, and they seem really forward but they never ever mentioned that. To think that the place that has the biggest epidemic in the United States is the actual capital, still nothing is getting done about it was really surprising, and how people in the capital when we talked to them didn't even seem to be aware of that.

***You're saying that you, on behalf of Advocates, went to talk to Senators and Representatives and they said they were unaware of the D.C. statistics?***

Cambria: One of those people had heard the statistic and they were like, "Yeah I know, it's a really big problem." It was like a girl that was an intern. She was probably like 25 or something so she is really young and probably learned it through something recent. But the actual politicians that we met and some of the older people that worked with them looked really shocked. Only one person was like, "I'm not sure that's correct. I might have to look into it." The other ones believed us but they were really shocked, because they were like, "Really? Is that a recent fact?" I was like "Yes, it is." One of the people was like, "I'm going to have to look that up because there is no way that could be true."

What Cambria elaborates is that those entrusted with enacting political change and maintaining citizen's rights have yet to be convinced there is a problem, especially one at the epicenter of national government. The current public health model of 'health transitions' suggests that as nation-states develop, they go through a predictable epidemiological transformation—where causes of death from infection are gradually replaced by death due to malignancies and coronary artery disease—which reinforces this idea that HIV/AIDS is elsewhere, outside of the District and outside of America. As Paul

Farmer aptly points out, such a developmental model makes it increasingly difficult for politicians to view the health needs of Americans as the same as Africans, further masking HIV/AIDS morbidity and mortality differentials within nations like the United States (1999: 42). Those in seats of political power seem skeptical of the claims made by their youth constituents that HIV/AIDS is a real problem in America and especially within the District. Despite the hard work organizations like CHOICE and Advocates for Youth do on behalf of training for and facilitating youth advocacy, meaningful youth participation still faces barriers when it comes to policymakers. Firstly, people need to be convinced that HIV/AIDS is not only in Africa, but also that U.S. youth are meaningful, well-informed, and active constituents in effecting political change. Compared to the politicians, ignorance or sheer disbelief among young people is noticeably less prevalent, however, the tendency to imagine the disease as foreign—this time to themselves versus that of their geographical locality—seems firmly entrenched.

The next example, surrounding the confusion and reliability of statistics, comes from my focus group with the 4TeenzOnly with young women. When asked about what they knew about HIV/AIDS, one young woman responded by saying that “it’s leading more among African American females than any other group in this city” (Krista). Intrigued by this association, I asked the rest of 4TeenzOnly female group for their reaction to this information and the conversation that ensued is quoted in its entirety below.

Nora: Never will I go out there and have sex.

Lena: It makes me feel like someone’s going to statisticize me because I’m -African American, like look at me as I got it or every other three females got it or something like that. I don’t think that’s right.

Merci: I agree with what she was saying.

Krista: Don't become a statistic. Watch yourself.

Ebby: My question is, is it the young people that have it or is it the people that are homeless and do drugs and stuff? Is it that side or is it just young? Which is the highest percentage because you just said D.C. as a whole? Are you sure it's the DMV area,<sup>39</sup> you just saying it's like the whole D.C. area? It's not DMV, just D.C.?

Beyond the gut reaction of fear, Ebby's questions indicate there also existed confusion about precisely what these statistics describe and whom they implicated. Ebby demonstrates that statistics represent HIV prevalence and transmission rates in a way that reveals certain static elements of 'risk group' categories and obscures other relational factors important to people's lived realities. Notably this group of young women did not want to be viewed as a HIV/AIDS statistic both as a group or individually. While they felt it was unfair to be implicated solely because they were African American and female, their reaction to potential vulnerability was one of deflection onto other possible sub-populations of the D.C. community 'at risk'. In order to distance themselves from HIV/AIDS risk they implicated other groups as more adversely affected than they perceived themselves to be. Despite thinking HIV/AIDS is a livable or somewhat manageable disease and having a positive approach to young sexualities, none of the young people wished to be lumped in together with the possibly infected; it was a future they wished not to imagine nor realize themselves. What follows are other examples from my focus group interviews with young people that pertain to the 'othering' of HIV/AIDS.

### **'Othering' of HIV/AIDS**

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<sup>39</sup> Although commonly abbreviated to mean the U.S. Department of Motor Vehicles, here DMV refers to the local term for the combined metropolitan area of Washington, D.C., Maryland, and Virginia.

The strategy for coping with individual and identity based vulnerability, dissociation from the group of abject putative carriers, will be explored in more depth in this section. Most frequently young people referred to feeling saddened by the prevalence rates, scared of HIV/AIDS, and harboring feelings of mistrust for potential sexual partners. “I don’t feel scared but at the same time I feel scared because you don’t know who by you and you don’t know – people lie all the time so you could ask somebody, “No, I don’t got it”” (Tina-Metro TeenAIDS). The very fact that you cannot tell by the way someone looks that he or she is HIV+ perpetuated those feelings of fear and generalized anxiety about potential sexual partners. “It makes me feel cornered. You can’t just go out there and point, “You got it.” I think you have to look out for yourself” (Luli-Sasha Bruce Youthwork). Despite this seemingly ‘faceless’ quality of AIDS and the general anxiety it perpetuates in their neighborhoods, young people interviewed were quick to visualize the ‘true’ identities of the bearers of HIV/AIDS. Uncertainty surrounding putative carriers of HIV/AIDS is diffused through the process of ‘othering’. Although some people saw AIDS as a not-so-deadly chronic illness, the profound consensus was that acquiring HIV/AIDS was something they all took steps to combat and that they themselves would rather not be associated with high risk of HIV infection, let alone infection itself. In the following quote, Kim, who is a twenty year old peer educator, nicely articulates the widespread desire to distance oneself from any association with disease and ill health.

But, I still feel like people choose not to think it could happen to them. Even if they have information, they just still don’t think it’s a risk for them, even though they know, based on the information, that it is. I know a lot of people who are really well educated about sexual health, etc., but they still make decisions to have sex without condoms and not know peoples’ sexual history because they don’t think it is a concern to them.

They don't want to think about it as something that could happen to them.  
(Kim)

Notably, interviewees besides Kim also tried to distance themselves from the disease by blaming another gender, generation, ethnicity or epidemiological risk group like IDUs to create doubt about their capacity as spreaders or contagious hosts of HIV. The compelling trend was to associate the disease with something that was alien or 'other' to their identity as young people, which epidemiologically marked them as 'at risk'. What this demonstrates is that 'risk groups' are habitually cast as the allies of the enemy, the HIV virus. In these examples, young people continually conflate certain identities, certain bodies with HIV causality. They facilitate 'othering' that leads to stereotyping and to stigma and discrimination of PLWHA and beyond, to those simply imagined to be infected with HIV/AIDS. What follows, traces such patterns of 'othering' along lines of nationality, gender, and age.

### *Nationality*

In the United States today, AIDS pathogenesis follows the classic script of having originated in Africa, spreading to Haiti, next to America, and finally Europe (Sontag 1991: 137). Importantly, Sontag notes that this classic script for AIDS in America completely leaves out any mention of Latin America and Asia. Clearly, this omission speaks loudly, the association between AIDS and black skin predominates. '4-H' rhetoric in the United States—which blamed the early epidemic on homosexuals, Haitians, hemophiliacs, and heroin addicts—all but solidified the idea of black bodies, primarily Haitians, as the route of pathogenesis into America. These notions of HIV/AIDS coming from afar and spreading rapidly by travel and migration were so well entrenched in American thinking about HIV/AIDS that it was not until October 2009 that the Obama

administration announced the official termination of the travel ban of PLWHA to the United States.<sup>40</sup> Travel bans like this utilize the familiar trope for plague, as something come from elsewhere “a link between imagining disease and imagining foreignness” (Sontag 1991: 133-134). As was demonstrated in my interviews, origin, causality, and blame are given an identifiable outlet.

Returning now to the 4TeenzOnly all-female group discussion demonstrates how this trope works, the foreigner is viewed as bringing the immunologically foreign antigen into their communities and spreading it.

Merci: Do you think the reason it’s so high in D.C. is because people that don’t live here, that come from other countries come over here and give it to us?

Ebby: True, true.

Merci: I’m asking. It wasn’t all that serious like some years ago. It just started getting that serious when they started coming over here. I’m just asking because when they started coming over here, taking over all the McDonalds, that’s when we started having the...

Shali [interrupts]: I don’t think it’s other countries so much. It deals with society. A lot of people is having sex.

Merci: Can you elaborate on that for me because when I had to write this little thing on AIDS, HIV, and I researched that it’s been around since the 1970’s. People was traveling a lot more during that period. People was going to other countries and then those other countries like Africa, they was bringing the disease back over here. Just recently that’s why it became so prevalent in America. People was traveling a lot and was bringing the disease here. I disagree [that HIV/AIDS was already a problem here in America]. I do think that it’s partially because of migration and people coming to America with that disease.

Donna: That’s what I was thinking because it wasn’t even all that bad until like a lot of people started migrating over here.

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<sup>40</sup> The lifting of the travel ban coincided with the announcement that Washington, D.C. would host the next International AIDS Conference (IAC) in 2012 on World AID Day December 1, 2009 (Preston 2009). The United States has not hosted the IAC, the world’s largest HIV/AIDS conference since 1990. Since PLWHA are an integral part of IAC, Conferences cannot be held in countries where travel bans exist.

For these young women, the permeability of national borders—through the increased tourism and migration permitted via globalization in late capitalism—has permitted HIV to leak into Washington, D.C. through African and other immigrant bodies. By ‘othering’ immigrants, who were imagined to be PLWHA, they locate themselves far away from the disease. As is implied in their discussion, the borders to the nation and the individual body should be closed; *neither* foreigner—the virus or its human host—is welcome. If the disease is abject so too are its putative carriers. They reject the abject as a way to reinstate a boundary narrative that differentiates one from another according to the inside/outside dialectic that underwrites their purity claim. As HIV signifies an immunological ‘systems breakdown’, then youth attempt to re-establish the neat division of inside and outside, by casting infectious agents as somehow nationally and ethnically different from themselves. This narrative of fear surrounding the transgression of national borders seems to reiterate Paul Farmer’s point that HIV/AIDS emergence can no longer be adequately captured or addressed in nation-by-nation analyses since the virus is not contained by national borders (1999: 42). For these young people, the diseased ‘other’ seems easily identifiable, a type of identification that seemed to thrive off endless specificities of ‘risk’ types and ‘risk’ behavior that was elaborated in the previous chapter.

### *Gender*

After the above conversation with the 4TeenzOnly female focus group, I continued to ask several other focus groups to react to the epidemiological statistic that African American young women are more adversely affected than African American young men. In this section, I will focus on the racialized gender differences involved in

the responses outlined below. When the 4TeenzOnly male focus group was told about these statistics, they were relieved to excuse the problem as that of the females and not the males, and thus of little concern to them. They portrayed their female peers as overtly or intensely sexual objects, going after sex in a reckless and voracious manner. “That’s because they want it [sex] more. I’m not saying like that way—like they actually want the disease. They get around the cul-de-sac. Passed around like they cookies” (Elliot). In the Metro TeenAIDS focus group, where both young men and women were interviewed together, one young man responded that statistic was “sexist.” It wrongly portrays the problem as only that of young women by not including their sexual partners; it provides a partial picture of reality. He says, “It scares me more than it scare them... I’m a boy and I like girls, so that make it worse. D.C. got higher rates, plus girls got more than boys” (Keon) He continued by saying that what makes it worse is the population demographics, where women greatly outnumber men in the District. Still, despite the partiality of focusing on women and not their heterosexual partners, Keon illuminates that explanatory power is still granted to women’s bodily affinity with the natural.

Keon was the only one in all my interviews to bring up differences between the biological bodies of men and women as the potential explanation for the statistical difference for HIV/AIDS prevalence rates. Gesturing with his hands, he tried to elaborate how women had increased biological susceptibility given the shape and surface area of their sex organs.

Because girls – it’s like, they got this [hands in a V]. Boys we got this [hands in a line]. I’m talking about sexually wise. You got to get through this [pinches fingers together indicating the penis’ urethra]. Come on, I can’t stick my fingers through. (Keon)



Despite the widely adopted “fragile anus” and the “rugged vagina” hypothesis in biomedicine in the early epidemic (see chapter three), Keon reiterates the contemporary scientific view that women are more biologically susceptible to disease transmission through sexual body fluid exchange versus that of men given the greater availability of surface area across which transmission can take place. As many feminist scholars have articulated, bodily fluids attest to the permeability of the body and thus women’s increased potential for bodily fluid transmission renders women as more permeable, more amenable to the confusion of inside and outside.

Bodily fluids and their associated processes involve the ingress of that which belongs ‘outside’ the body (food, sexual partner, etc.) and egress of that which is internal (urine, sperm, faeces, saliva, vaginal secretions, etc.). (Waldby 1996: 74)

Biological difference in genital capacity for bodily fluid transmission seems to naturalize higher rates of infection among women in the city as inevitable. This line of reasoning, also found amongst my interviewees, views women as ‘reservoirs of infection’ within the community and does little to address the larger role of structural inequalities at work here. Again, bodies coded as feminine (or sexually receptive or passive) become the ally of the virus. As demonstrated by the historical association of HIV/AIDS with homosexuals and prostitutes in the early epidemic (see chapter three), these bodies lend themselves to viral hybridization because they are already imagined on the side of the natural (Waldby 1996: 20-21).

For young women from the Metro TeenAIDS focus group, these statistics also seemed to distort the realities of young women’s and young men’s sexual behaviors. One girl reacted in disbelief because she typically hears boys saying “‘I hit [had sex with] this

girl, this girl...” and it puts you in a dang, “He really doing all that?” I know he probably got something” (Shana). Upon further reflection she adds,

As far as females, it’s probably like because so many females are scared to talk to they partners about they sexual partners. If I ask him about if he had sex with that girl, he going to think I’m so like a little girl, or I’m so this, that, and the third. Who care though? You protecting yourself.” (Shana)

Her female friend reacts by informing Shana that,

The only reason you think the guy is going to have more is because they talk about it more. You know females are probably hitting [having sex with] five or six more than the guy but the thing is she don’t talk about it. She might say, “I hit two,” but she won’t tell you about the other six she just hit. That’s why girls would be more. (Ebony)

Importantly the young women, unlike the young men, indicate that racialized, gendered power relations make it more difficult for young women to navigate and express their sexual agency. Their inability to talk freely about the number of sexual partners with a prospective partner constrains their access to information and ability to negotiate condom use. As this and other studies show, women are often fearful of demanding condom use or testing for fear of their partners reacting in suspicion to her own faithfulness or in anger as a challenge to his faithfulness.<sup>41</sup> If what young people say is true, then young women may be having more sex than their male peers, however, their ability to assert their sexual subjectivity or utilize safer sex practices remains constrained. Moreover, this conversation indicates that these young women may be participating in the materialization of dominant discourses about of self-blaming or the victimization of their own sexual agency.

### *Age/Generation*

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<sup>41</sup> For more on this, please refer to the work of Vera Paiva such as “Gendered Scripts and the Sexual Scene: Promoting Sexual Subjects Among Brazilian Teenagers” (2007).

The last mechanism young people deployed to further distance themselves from HIV/AIDS was that of age or generation. Young people admit to having sex and using drugs, but are able to assert certain differences in these behaviors. Young people are having sex, but unlike the adults they claim to fall ill from STIs besides HIV/AIDS. “The young people got like Chlamydia and Syphilis. That’s what they said was the most teens in D.C. Older people, that’s like 18 years or older, they be the ones with it [HIV/AIDS]” (Ebby). Noting that a large number of D.C. teens have an STI, HIV/AIDS is thought to be reserved for and contained amongst the older African American populations of these wards. In doing so they negate the fact that sex without a condom is the primary way to contract STIs like Syphilis and Chlamydia *and* HIV/AIDS! The prevalence of these other STIs indicate that in spite of engaging with sex without condoms they feel immune to HIV. Young people also use drugs, but “not them kind of drugs [injection drugs]” (Luli). Luli, from Sasha Bruce Youthwork, went on to elaborate that young people use “weed, and probably pills” but not crack, heroin, and PCP. When I asked the Metro TeenAIDS focus group who used needle drugs in the District of Columbia, the consensus was that, “the older people do” (Anthony). Furthermore, young people showed considerable resistance to thinking about HIV/AIDS transmission as associated with anything other than sex.

Tattoos and the issues of clean needles came up in only one interview by a young woman explaining what the tattoo needle should look like. “It’s like a white package that they take the needle out. It look like a little hook, so just make sure they take it out of the package” (Krista). The relative silence or lack of elaboration on clean needles is indicative of how HIV/AIDS is predominately linked to sex for young people. Cambria,

the AFY peer educator, explains how needle use is not emphasized in the knowledge she gives to her peers.

When we teach about it, we usually ask questions about the sex part but when we ask ways that you can transfer HIV from someone to someone else, no one ever brings up the needle part. I think the Red Cross does a good job teaching about it but I don't think a lot of people really associate HIV with anything other than sex. (Cambria)

Despite engaging in the same behaviors that can lead to HIV transmission through bodily fluids—other illicit substance use or tattoo needle use (which may impair judgment or allow access directly to the bloodstream) and sex (sometimes protected, sometimes not)—youth were able to indict adults as the bearers of HIV/AIDS. This was especially the case when it came to needle use, which assisted D.C. youth in freeing themselves from any shared responsibility.

### **Re-thinking Stigma and Discrimination**

Since Sontag's writing on military metaphors and HIV/AIDS, the prevalence of HIV/AIDS-related stigma and discrimination has only increased given the advent of new treatment technologies that allow people to live longer with HIV/AIDS. Not only are there increasing numbers of people with HIV/AIDS but they continue to live longer with the illness. Renewed attention is being given to stigma and discrimination in HIV/AIDS scholarship and NGO campaigns to secure the rights of PLWHA. Discussions of HIV/AIDS related stigma and discrimination, like Sontag's, rely heavily on Ervin Goffman's classic work *Stigma: Notes on the Management of a Spoiled Identity* (1963), which argued that stigmatized individuals are viewed as people possessing an undesirable difference or deviance, creating a kind of 'spoiled identity' for the person concerned. Working from Goffman, Richard Parker and Peter Aggleton state, "thus stigma,

understood as a negative attribute, is mapped onto people, who in turn, by virtue of their difference, are understood to be negatively valued in society” (2007: 444). Stigma can be seen as a ‘mark’ that links a person to undesirable characteristics in ways that imagines them as stereotypically infected.

In the case of HIV/AIDS, which only produces visual symptoms in latter stages, stigma and the discrimination helps to imagine, visualize, and name certain persons or groups of persons as putative carriers. Pointing the finger at another group situates the disease at a safe distance from oneself, it creates a stereotypical image of what groups of HIV/AIDS carriers ‘look’ like. Once visible, the infectors, and by extension the spread of infection, can be contained through public health measures carried out by the joint efforts of governments and scientists. According to biomedical discourse, if the body’s response to the presence of a foreign antigen is to launch a ‘coordinated attack’, in the case of HIV/AIDS, where immunological response is suppressed, then a similar ‘assault’ should be carried out on the level of the body politic. This substitute army for the body consists of politicians and scientists who seek to defend against disease on the social level, to mirror the ‘natural’ biological responses of the immune system in the “war on AIDS” (Waldby 1996: 3). Clearly, the militaristic rhetoric of command and control systems seems to have been transposed from the micro-level of the immune system to the macro-level of the body politic, a topic explored further in the following chapter.

If epidemiological statistics, like the ones discussed in former chapter, are forms of coded information about HIV/AIDS transmission and its carriers, then what is recounted is young people’s attempt to decode and make sense about such information and health and disease. Inevitably, in efforts to align themselves with health, young

people cast the shadow of prospective illness outward onto others who were viewed as irrevocably different from them in age, gender, race, or nationality. Strategies of ‘othering’ the risk for HIV/AIDS attempted to reinstate boundaries—a clear divide between the healthy ‘self’ (inside) and the infected ‘other’ (outside)—that are highly confused by HIV/AIDS viral pathogenesis within the body and the social realms. The result of boundary maintaining through ‘othering’ in epidemic conditions—which in science studies is called ‘boundary work’ (Gieryn 1995)—invariably results in stigma and discrimination against those PLWHA. While most respondents advocated more education and free medicine as possible responses to the District’s high rate of HIV, some opted for more draconian disciplining measures; for example, quarantining PLWHA entirely. When asked, what do you think should be done about such high rates of HIV in D.C., one female focus group participant from Youth Build responded, “Lock everybody up that has it and that’s spreading it” (Maneka). Another young woman from the same group added that although she feels sad for these people went on to say that “I think there should be separations and people should live on different sides like positive people should live in Southeast or Northeast and negatives should live in Southwest or Northwest [D.C.]” (Chelse). Clearly it is an infringement on one’s rights to limit mobility in this way, to separate the clean and healthy from the allegedly tainted. This discrimination and denial of rights is based in part upon the belief that since PLWHA bodies host the HIV virus they do not maintain the status of a purely human organism and consequently not fully deserving of human rights.

With that said, I suspect that the issue of stigma and discrimination is more complex than sheer callousness on behalf of young people. It is important to note, that

perhaps some of the perceptions of the threat associated with PLWHA can be attributed to the fact that nearly all of the individuals who partook in the focus groups reported not knowing someone really close, like a family member or a friend, with HIV/AIDS.<sup>42</sup> There were two exceptions to this. Monet, from Youth Build, said she had a close friend with HIV who was “in denial” and had sadly passed away. Shannon from the Metro TeenAIDS focus group said she later learned her aunt had died from AIDS. She knew her aunt was ill and dying, but either no one knew the cause or Shannon was shielded from this information because of her young age. For the most part, the only knowledgeable contact these young people had with PLWHA was in educational settings where HIV+ people sometimes spoke about what it was like to live the disease and how to prevent it. The most commonly referred to PLWHA was Magic Johnson, who is addressed more fully in the following chapter. What ensues appears to be a vicious cycle where stigma and discrimination prevent many people from disclosing their status, which in turn, fosters the belief that AIDS is something that does not touch most people personally.

Even a descriptive study on HIV/AIDS-related stigma among young people in D.C., such as mine, should include final analyses that should nurture advocacy and intervention aimed at reducing levels of stigmatization and the effects of discrimination on both individuals and groups. In my opinion, socially responsible research should ultimately critique existing structures and categorizations with the aim of disabling forms of thinking and knowledge production like that of the military metaphor that perpetuate stigma and discrimination and limit the realization of rights for PLWHA. The point is that stigma and discrimination are social processes with long histories rather than

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<sup>42</sup> Admittedly, this claim may be distorted as many people neither wish to disclose their status nor ‘out’ someone they may know with HIV/AIDS.

individual, static processes. For Parker & Aggleton, the individualization of AIDS risk further masks how ‘risk’ for the material embodiment of disease is linked to social inequality (2007: 447). While some interviewees suggested politicians had the wrong priorities, sending money for AIDS away to Africa and for fixing potholes and renovating Union Station rather than addressing the city’s HIV/AIDS epidemic, none of them pointed out how the groups identified by them as ‘at risk’, such as older African Americans and IDU, followed the historical fault-lines of gender and racial inequality. More attention should be paid to stigma and discrimination as a social process rather than attributes of an individual that one can easily dissociate from. Perhaps future health education and prevention efforts should consider the above responses from young people, where “stigma comes to be seen *in* the person stigmatized, rather than as a designation that the other attaches *to* the individual” (Parker & Aggleton 2007: 445, emphasis in original), in addressing the larger structural inequalities such a racism and sexism that lead to patterned health outcomes. Rather than focusing on the type of stereotyping perpetuated by the proliferation of ‘risk group’ classifications that was demonstrated above, increased attention should be paid to the structural conditions that foreground exclusions such as these.

### **Conclusion**

The ‘othering’ of illness, and the stigma and discrimination that often ensues, is hardly unique to HIV/AIDS. What this chapter demonstrates is that the strategy of ‘othering’ deployed by the D.C. youth I interviewed readily makes use of other negatively stereotyped images of immigrants, foreigners, African Americans, and women in ways that actively recycle narratives about these groups alleged sexual proclivity and



thus debased alignment with the 'natural'. As a result of the increased rates of the materialization of HIV/AIDS, especially as people acquire HIV at younger ages (sometimes in vitro) and live longer with HIV/AIDS (well into old age), it seems ethically imperative to re-examine the mechanisms that facilitate the distancing of disease and its putative carriers. In turn, this act of dislocation disassociation from the abject seemingly negates any claim of shared responsibility or call to action in ways that question present categories, definitions, and tools. Poz approaches not only signify the embodiment of positive approaches to young sexualities, but also a new approach to health and illness that aims to bridge the hostile demarcation between the country of the ill from the land of the healthy.<sup>43</sup> As indicated by this chapter, there seems to be little evidence as of yet for the latter. Youth are exploring and vocalizing their sexuality in an alignment that seems Poz, however, despite being framed as a pathogenic element 'at risk' of infecting the rest of society, young people seem to shun the mere association with HIV/AIDS let alone proclaim any alliance with those young people whose health status may be in question. Although there appears to be an emerging partial connection with being Poz insofar as agency relating to sexual health, young people have not yet forged a solidarity politics in a way that contests stigma and discrimination or further deconstructs the bifurcation between illness and health. Critical to such a solidarity politics is the promotion of the idea amongst youth that health is not something contained by one's skin, or defined merely through the lack of illness, but rather that health is a material-

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<sup>43</sup> In this sentence I am referring to Sontag's (1991) often quoted epigraph linking citizenship and illness. "Illness is the night-side-of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged at least for a spell, to identify ourselves as citizens of that other place" (3).

discursive assemblage of various systems (not limited to human organisms) that are in part maintained or abetted by society.

## Chapter V: HIV/AIDS Interventions and D.C. Youth

### Introduction

Currently three percent of all Washington, D.C. residents are known to be living with HIV/AIDS. By CDC and WHO standards, where an epidemic is defined by overall percentage of disease among residents of a specific geographic area exceeding one percent, the HIV/AIDS in the District qualifies as “generalized and severe” (D.C. DOH 2009).<sup>44</sup> Epidemic conditions, especially when so severe, call for the immediate mobilization of resources and bodies to thwart the continued and unchecked spread of the virus. Epidemic conditions provide the urgent occasion and rationale for intervening into the lives and bodies of ‘risk group’ populations. The CDC has the power to define an epidemic by locating and targeting ‘risk group’ populations, as such, “an epidemic emerges as a product of a socially authoritative discourse in light of which bodies will be mobilized, resources will be dispensed, and tactic of surveillance and regulation will appear to be justified” (Singer 1993: 117). Nothing demonstrates how biopower foregrounds governmental intervention into certain bodies more than current D.C. Mayor Fenty’s endorsement of epidemiological surveillance for targeted interventions. Mayor Fenty, in the most current an authoritative statistical report to date called *District of Columbia HIV/AIDS Epidemiology Update 2008*, states that, “these [epidemiological] facts serve as a blueprint that allows us to improve how we prevent HIV and better serve people living with the virus” (D.C. DOH 2008). As discussed at length in chapter three, epidemiology relies upon statistical significance to correlate causality of HIV/AIDS infection and spread to ‘risk groups’ such as youth from the unmarked ‘general

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<sup>44</sup> Whereas three percent of *all* D.C. residents are living with HIV/AIDS, five percent of the African American residents of D.C. are living with HIV/AIDS (D.C. DOH 2009).

population'. A crucial reason for the CDC's epidemiological surveillance of an epidemic is to target interventions at groups 'at risk' like young people. This chapter is devoted to explaining Washington, D.C.'s regimes of epidemiological surveillance and intervention as well as contextualizing these experiences from an embodied and situated youth point of view. Sections are specifically devoted to not only how technologies of testing and medication, condom distribution, and education programs work within the city, but specifically how young people feel about these bodily interventions.

Many of the young people I spoke with were already implicated in this intervention schema through their participation with centers like Sasha Bruce Youthwork, Metro TeenAIDS, and 4TeenzOnly. Moreover, most of the young people who attended the focus group interviews participated by choice as employees, peer educators, or after-school members within these sexual health programs and were all well versed in testing and prophylaxis technologies. Despite young people generally not having adequate access to health information and services, the population of young people interviewed herein did not conform to this general trend precisely because of their participation in youth health intervention programs. As a result, all the people I spoke with had access to and were frequently tested for HIV/AIDS as well as being knowledgeable about transmission and prophylaxis methods, which will be discussed in more detail in this chapter. In the sections below, some young people recount their own experiences with various technological and educational HIV/AIDS interventions that occur on the cellular and individual organismic level. Through what I am calling the 'epidemiological regime of behavior change' through education and condom use, testing, medications, and the

prospect of a cure, young people in Washington, D.C. are clearly being mobilized in an effort to counter the spread of HIV/AIDS and other STIs in the name of ‘public health’.

### **Testing as a Surveillance Technology**

*Getting an HIV test is just the beginning. A positive test result gives you the chance to keep ahead of the virus. A negative test result gives you the opportunity to stay that way.*<sup>45</sup>

Current statistics from the District of Columbia’s Department of Health (D.C. DOH) states that between 2007 and 2008, the number of young people tested for HIV doubled from ten to twenty thousand (D.C. DOH 2009). Still, only about half of young people under the age of twenty-five have gotten tested and are aware of their HIV status (Sasha Bruce Youthwork). For the young people I spoke with, free testing was available at most of the adolescent health facilities they attended and HIV testing was a frequent and conscious part of their lives. The HIV test is discussed in this section as the central technology in the biomedical mapping of the virus’s presence in the body and the body politic. According to Catherine Waldby,

The procedures of the laboratory tests render the concealed infection visible to the particular body, while the designation of each subject’s infection according to the classificatory logic of sexual identity render them visible and *meaningful* to the scopic technologies of epidemiology and various other bureaucratic surveillance practices. (1996: 113)

Most young people I spoke to regularly got tested every two, three, six, or twelve months a year and most respondents began getting tests around the age of fifteen or sixteen.<sup>46</sup>

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<sup>45</sup> Quoted from the “Am I Infected?” page on POZ.com, the online outlet for POZ Magazine available at: [http://www.aidsmeds.com/articles/HIVtests\\_5029.shtml](http://www.aidsmeds.com/articles/HIVtests_5029.shtml).

<sup>46</sup> HIV tests only work after ‘seroconversion’ that is after the immune system produces antibodies to HIV infection (Waldby 1996: 119). In most instances antibodies to HIV will develop within four to six weeks after exposure, with ninety-nine percent of those who are going to seroconvert will do so within three months. To ensure a reliable test result one should wait at least three months after one’s last possible exposure to the virus before testing. Some testing centers may recommend testing again after six months since it is extremely rare for seroconversion to take longer than six months (“Am I Infected?”).

Some opted for ELISA and Western blot<sup>47</sup> blood tests while others preferred the new rapid, oral testing that uses saliva (requiring no needles) and produced results outside of clinical settings in about twenty-minutes. Most people said they have gotten tested at free clinics or for free at hospitals, although one young woman at the Metro TeenAIDS focus group did express that these free services made her scared of HIV testing, preferring to incorporate testing into her normal doctor's visit as part of her health regimen.

I want to say something about people don't know they status. It's a lot of people that's scared to know. It's like even if they ain't do nothing, they still just scared for no reason. I know I would be scared. That's why if I get tested, I'd make a doctor's appointment. It feel normal. There they just tested anyway. A lot of people like, "Come on, let's go take a HIV test," like it happen normal. I don't like... why I'm going to go just take a HIV test, just something like I take a physical and it's the whole process. You won't even realize that "Oh, they tested for this, they tested for that." It's better than just saying I'm going to take a HIV test and then they give you this big answer, yes or no. That's how I do it. (Shana)

For Shana, going separately and *only* for an HIV test is undesirable because it demarcates HIV/AIDS as something (negatively) different from the plethora of tests for other ailments she typically receives at an annual doctor's visit. She wishes to not to differentiate between a HIV test and her other tests so as not to raise increased fear regarding her status and the testing process itself.

HIV testing is important because it works as a crucial diagnostic technology for clinical medicine, the main surveillance technology of epidemiology, and also a disciplinary technology for the socio-medico management of PLWHA. These regimens, like testing, act as hinge technologies for a two-way visibility; "they

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<sup>47</sup> The Enzyme-Linked-Immunesorbent-Assaya test, not commonly referred to as ELISA, was the first HIV screening test developed because of its high sensitivity for detecting antibody and antigen presence. The Western blot is only performed as a confirming technology to the ELISA test by detecting anti-HIV antibodies. Only once someone has tested positive for the presence of anti-HIV bodies in *both* tests are they considered HIV+ (Waldby 1996: 112-113).

place the microscopic development of HIV infection within the person under a regular form of inspection, and they place the person's practices under a regular form of surveillance" (Waldby 1996: 123). Before a test, a HIV seropositive person may 'pass' irrespective of his or her own knowledge of infection since the virus is able to 'pass' within the immune system, undetected for a number of years (Waldby 1996: 120). This problem of invisibility, or remaining asymptomatic on the skin's surface until the last stage of full blown AIDS, is solved by HIV testing. As, Tina from the Metro TeenAIDS focus group aptly stated, "you can't just automatically judge someone. It [HIV] doesn't have a face".<sup>48</sup> Thus, the HIV test is the quintessential example of how technology is often used to visualize the 'inner body' or parts of the body too small for the human eye to register (M'charek 2000: 183). The test in actuality does not test for the presence or existence of HIV virus *per se*, but tests for the production of antibodies to certain HIV virus proteins. In other words, the HIV test tests for the products of the immune system generated in a protective response to an infection. Hence, testing is organized around the virus's failure to 'pass' as a 'master of disguise' within the immune system and works to sort the infected from the uninfected in a straightforward fashion (Waldby 1996: 119). Testing not only exposes the virus hiding within the cells of the immune system, but also exposes those who are infected, who in the absence of visible symptoms, can pass in the 'general population' as uninfected. After the HIV tests mark someone with the sign of the virus, it allocates the infected person a position within epidemiological

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<sup>48</sup> There are generally no signs that mark the person off as infected, some people may go as long as fifteen years without having any recognizable symptoms for the patient or for others, until the development of 'full blown' AIDS with visible symptoms.

hierarchies of pathology (Waldby 1996: 18).

Importantly, these HIV testing technologies are integral to what AIDS is understood to be. With the early advent of HIV tests, the disease became understood by those conditions that could be detected by the test and eventually lent credibility to the idea or confirmation of AIDS as a single disease. Through this kind of “reciprocal redefinition” the supposed coherence of AIDS symptoms confirmed the efficacy of early HIV tests (Waldby 1996: 127). Notably, most HIV tests also contain a confessional element as they are accompanied by series of questions relating to one’s sexual or risk behavior history in order to determine mode of transmission (refer to my personal HIV testing experience in chapter one for more ). Hence, the test collects both a combination of someone’s antibodies and the confession of their sexual history (Waldby 1996: 121). According to Waldby, HIV tests work as “the most important technology through which the virus is personified, that is made coterminous with the person infected, who is in turn rendered into an identity category” (Waldby 1996: 125). Not only does this test have the potential to reveal someone as HIV-positive, it subsequently facilitates the medical management of seropositivity or those deemed ‘at risk’ for seropositivity. For the young people I interviewed, frequent testing or ‘knowing your status’ was part not only part of their (sexual) health repertoire but often a stated precondition for sex. Keon from Metro TeenAIDS stated,

Every time I take a girl seriously, I bring her down to Freestyle to get tested. I ain’t even going to... no bull. I be nervous because you don’t want to get it. One time, and you know. I probably just ask for it.

Rashika, in the same interview as Keon, stated,

For me, if I find myself getting serious with somebody, I’m not interested in having sex or I’m not having sex so to me if I get close to a person, I



don't mind bringing him to get tested. I want to know their status and I want them to know their status.

A lot of young people, both male and female, expressed that when you are serious with someone you go down and get tested together prior to engaging in sex. For my interviewees 'knowing your status' was a source of power for action, either medication if results were positive or sexual activity if results were negative. Although sex was often postponed until after testing, youth indicated that testing was part of their sexual repertoire rather than a mechanism for postponing it altogether until marriage. Still most young people found it hard to envision themselves staying with a partner if they tested HIV+, particularly if they had lied about their status or had shown reluctance to get tested.

### **The Quest for a Cure and Other Pharmaceutical Pursuits**

This section further discusses the pharmaceutical pursuit to develop microbicides, antiretroviral drugs, and the AIDS vaccine, from a youth standpoint, which reflects the desire of science to find the means of eradicating AIDS. What I mean by pharmaceutical pursuit is that science is placed in the "implausible position of supporting one magic cure after another, which have never (at least not yet) materialized" (Marshall 2005: 2520). Undeniably, these cyborg technologies are life prolonging with an aim to make the body forever young and able to live forever. This is not to dismiss how biomedical technologies can and do alleviate material suffering in this world, but rather to interrogate the ways of thinking that underscore the unequal distribution of these resources in ways that aid and abet the patterned distribution of HIV/AIDS in certain locales and certain bodies. For example, if the death of Rock Hudson by AIDS marked the early epidemic, then the diagnosis of Magic Johnson as HIV+ is the most notable celebrity representative of PLHWA of my generation. Unprompted, in all of my focus group interviews, young

people were not only quick to think of Magic Johnson when asked about people they knew living with HIV, but also readily associated him with life-extending possibilities of AIDS medications. Whereas Rock Hudson came to symbolize the idea of the early epidemics as the inevitably terminal ‘gay disease’ of white men, Magic Johnson symbolizes the heterosexual pandemic predominately afflicting the African American communities, as well as how AIDS has been transformed into a ‘livable’ chronic illness. Since epidemiology, through testing, sorts bodies into those in need of treatment and intervention, then this section explores understandings of the medical management of the seropositive. The following conversation among a group of young women at the Planned Parenthood 4TeenzOnly center in North Eastern D.C. recounts the complex ways in which AIDS is understood in light of biomedical life extending technologies that developed through the 1990s and continues now, and the politics that undergird affordable access to these technologies.

***What do you know about HIV/AIDS medications?***

Merci: I think they really have a cure for it. I think they’re only not bringing up the cure because it’s money for the medication.

Lena: Magic Johnson got it. You can’t even detect it in his system now. He’s got so much money that he paid for, that you can’t even tell that it’s in his system. They have a cure. He has money to take care of it. It’s not fair to other people that don’t have money.

Ebby: She stole my answer, but I was about to say about Magic Johnson. How come he cured or whatever?

Krista: He not cured.

Lena: I know, listen. I ain’t finished. He’s not cured, but you don’t know. You can’t tell it’s in his system, basically, because he has the money to get all the medications that he needs.

Emma: The thing about it is, the people who do have at least a little bit of money to at least get their medication, they said the medication after a while starts to get immune to you, you get immune to it, so you have to buy more medication and more expensive to treat your HIV.

Merci: I'm just upset because I don't believe that the government should do that. It shouldn't be all about money. If people need help they should just help them.

Shana: People are dying.

Merci: The only way I think the government is actually going to give up this cure that they I know they got, is when they just see people dying off.

Jonyce: They don't care about nobody but themselves, unless they family get it, or unless they get it.

In debating whether Magic Johnson was cured (he is not), it became apparent that these young women understood that only certain celebrities and other rich and powerful people could afford to access the medications that rendered HIV/AIDS nearly undetectable in their bodies. The privilege of accessing these powerful medicines seemed linked more to do with class, than race or sexuality.

During the 1990s, the perception of HIV/AIDS as a sexually transmitted fatal disease—a so called 'death sentence'—was shifting, at least in the West, into a manageable chronic illness with the advent and increased availability of HIV/AIDS drug treatments like HAART (Morris 1998: 191).<sup>49</sup> Already by 1989, at the International AIDS Conference in Montreal, there was a noticeable shift from the perception of AIDS as inevitably fatal to a chronic or manageable disease. (Treichler 1999b: 171). By the International AIDS Conference in 1996 in Vancouver, the tone was even more optimistic about combination therapy and new viral-load testing because the medical community

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<sup>49</sup> HAART is the acronym for Highly Active Antiretroviral Therapy, a widely used medication approach wherein several ARV drugs are taken in combination to thwart the spread of HIV amongst cells and to slow the overall life cycle of HIV in the immune system.

had at last begun to think it was gaining the upper hand against HIV (Farmer 1999: 263). In 2000, four years after the introduction of HAART, death rates for people with HIV/AIDS in developed countries had dropped by 84% (Porter 2003).<sup>50</sup> One *Newsweek* article wrote: “More drugs keep coming, more options, more time, more hope. It is the circle of life: all you have to do is stay alive until the next drug comes out, and the next, and the next” (Leland 1996 qtd. in Farmer 1999: 264). The introduction of viral-load testing also helped monitor the cell counts and the effectiveness of medications, which seemingly provided quantifiable evidence that instituting combination therapy usually led to a marked decline in detectable HIV in patients with very high viral loads. At the time of its introduction, the annual cost of combination therapy was \$20,000 (USD), which at those prices rendered them an inappropriate technology for residents of poor countries and poor people in industrialized countries (Farmer 1999: 264-267). What pharmaceutical developments have occurred since the early epidemic era of Rock Hudson? Thanks to the sustained pressure from AIDS activists, generic competition in the production of HIV/AIDS medication was first allowed in 2000, and since then the annual cost of the antiretroviral drugs used in HAART treatment has fallen from \$10,000-\$15,000 USD to only several hundred USD in resource poor settings.<sup>51</sup> As the above conversation makes clear, these ‘miracle medications’ are simply not available to everyone, even within countries that are large producers of antiretroviral drugs and where

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<sup>50</sup> Most doctors begin medical treatment once an individual with HIV has fewer than 200 CD4 cells, a type of helper T cell, with some doctor’s advocating to start treatment with cell counts as high as 350 CD4 cells. (“POZ Focus: Immune System”). A ‘healthy’ CD4 cell count is normally over 1,000 cells per mm of blood (Whiteside 2008: 27).

<sup>51</sup> In 2000 pharmaceutical companies conceded to allow the production of generic HIV/AIDS drugs, which are an identical copy or bioequivalents of a brand name or proprietary drugs, which has drastically reduced the cost for those in resource poor settings to several hundred dollars annually (“AIDS, Drug Prices, and Generic Drugs”).

ample vaccine research is underway. Undoubtedly, advancement in treatments such as HAART and prophylactic medications are allowing people with HIV/AIDS to live longer. Still, as no cure yet exists, AIDS is still associated with death or thought of as a death sentence, although one that can theoretically be postponed for years through biomedical management.

Undoubtedly the 'Holy Grail' of HIV/AIDS research is the development of the AIDS vaccine or the quest to find the 'magic bullet' to viral eradication similar to that of the Salk vaccine for polio. After all, as Susan Sontag notes, one of medicine's central premises is that diseases can be cured (1991: 5). This is a positivist approach, in which science "harbors a peculiar belief that a single cure will eradicate HIV/AIDS" and denies the "reality of the inefficacy of vaccines in most of the world" (Marshall 2005: 2520). Thus in a virologists approach to HIV/AIDS, where the immune system is unable to detect the virus and post a proper response, biomedicine acts in lieu of inner defenses through the artificial introduction of the natural 'pathogenic' virus in order to teach the immune system how to react to the HIV virus. "Vaccinations play their role in this world as special courses, a designer education for the (usually) young immune system. The vaccine gives the immune system a kind of post-thymus and post-marrow course in recognizing a disease (small pox, diphtheria, polio, or whatever)" (Martin 1994: 196-197). The science of virology, largely based in North America and Western Europe, literally aims to re-educate the body's T cells, to enable the cells of the immune system to detect and defend against HIV. According to the International AIDS Vaccine Initiative (IAVI), which was founded in 1996 and is one of the leading global not-for-profit partnerships working to accelerate HIV vaccine development, "North America has an

abundance of the financial and scientific resources required for AIDS vaccine development, and the governments of both Canada and the United States have long championed the effort” (“In Country Programs: North America”). Currently the United States and Canada account for sixty-two percent of the global funding for AIDS vaccine research and development.<sup>52</sup> To date there are forty-three ongoing biomedical HIV prevention research trials in United States of America testing of microbicides, vaccines, PrEP,<sup>53</sup> and partner treatments tests (“In Country Programs: North America”). What this demonstrates is that biomedicine’s impotence to cure HIV/AIDS only seems to further fuel the drive to unveil the mysteries of HIV/AIDS and thus masterfully contain its spread.<sup>54</sup> When the ‘natural’ defenses of the immune system fail to combat HIV/AIDS, biomedicine steps in to intervene and artificially stimulate immunological defense.

In light of these advancements, many of my interviewees thought the only real solutions to HIV/AIDS in their communities would be a cure. This general sentiment was well articulated by one girl, Luli who attended Sasha Bruce Youthwork for the second time.

The only thing I can think about of a solution that will help these kids is a cure for AIDS and HIV. If it’s nothing else out there, then ain’t nothing going to help the situation. Once you got it, you got it, unless there’s a

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<sup>52</sup> IAVI utilizes a ‘comprehensive approach’ that includes expanding HIV education programs and promoting behavior change (including the use of male and female condoms), addressing underlying social and cultural issues such as gender inequality and poverty, reduce mother to child transmission through preventing pregnancies among HIV-infected women and providing antiretroviral drugs, supporting HIV-related health services, and providing care ad support for PLHIV through providing antiretroviral drugs and other medications support (“Why A Vaccine: Comprehensive Response”). However as their name belies and mission states, “While there will never be a single solution to HIV and AIDS, we know from history that no major viral epidemic has ever been defeated without a vaccine” (“Why A Vaccine: The Pandemic”).

<sup>53</sup> PrEP stands for Pre-Exposure Prophylaxis and is an experimental HIV prevention approach, which involves using HIV antiretroviral medication before possible exposure to the virus as is the case for those who take anti-malarials before they travel to a malaria dense area. The CDC does not yet have recommendations or guidelines for PrEP because trials are still underway (“Am I Infected?”).

<sup>54</sup> The rise of molecular biology, especially molecular genetics, helped biology achieve a truly scientific status, like that of physics, one that tolerated no secrets (Fox Keller 1990: 179).

cure. Like these kids, they probably don't got no money to pay for no medicine, so they just dying slowly. (Luli)

Aside from issues of cost, there was also significant confusion surrounding the efficacy and side effects of such pills. Raina later explains to Luli in the same interview that ARV pills really are not as straightforward and easy as people may think.

But it's not like only one pill. You have to take a pill for the disease, then with that pill you have to go to the bathroom so you have to take another pill, and another pill. That pill make you sleepy so you take another pill to keep you awake. It's a lot. (Raina)

Reflecting upon Raina's comment about this difficult medication regime, Luli responds that, "I'll give an example, if [Magic Johnson] might have HIV, if he take his medicine, I guarantee you most young boys and girls take their medicine, just because he doing it."

Doubts about commitments to regimes and the possibility of resistance were also raised in my one-on-one interview with Cambria.

For people that already have HIV, I think something—and as we're talking about healthcare and things like that, I think that their medicine is very expensive and I think they need to have people who are trained in that to tell people how to properly treat their medicine. I know if you don't take it continuously or you miss it then you have to change to a different medicine. (Cambria)

While medication seems to offer results that work (see cited conversation about Magic Johnson) young people seemed to be aware of many of the less glamorous realities associated with gaining access to AIDS medicines as well as the side effects from treating HIV by "taking whole bags full of medication" (Jamie-4TeenzOnly).<sup>55</sup>

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<sup>55</sup> There are a great number of side effects and short- and long-term complications of HIV and its treatment such as: lipodystrophy and wasting; facial lipoatrophy; hyperlipidemia of the heart; fatigue and anemia; peripheral neuropathy; stomach sickness, hepatotoxicity of the liver; renal health issues; osteopenia and osteoporosis; and co-infection by HPV and/or Hepatitis A, B, or C. With advances in treatment that allow people to live longer with HIV, a new set of non-AIDS-related health issues such as those diseases and infections typically associated with aging are also beginning to emerge for those receiving AIDS medicines ("Side Effects and Other Health Problems").

Despite the immense desire to find a cure through vaccination or other biomedical means, no HIV vaccine or microbicide trial has yet reached the policy benchmark of thirty percent efficacy. In the case of HIV, a great many strains of the genetic virus pose difficulties for the development of vaccines since a vaccine would require alerting the T cells to the spectrum of genetic variations (Waldby 1996: 118). This does not even begin to include the obstacles relating to normalizing inoculation in cultures not already inundated by Western biomedicine. As this reality attests, despite the advances made by the pharmaceutical pursuit, a cure though ‘eminently desirable’, will unfortunately *not* change the prognosis for the vast majority of PLWHA.

Cost and access to these high-tech interventions remains a concern for the large majority of those communities worst affected. In many places, the formulation of health policy has already declared antiviral therapy to be “cost-ineffective” in the very places in which HIV is most endemic. (Farmer 1999: 52)

The conversation below, from my focus group at the Metro TeenAIDS, further demonstrates the confusion surrounding the realities of accessing HIV/AIDS medication in the District.

***For those of you who know people who have HIV or you think it’s a livable disease, how accessible do you think medications are to the community?***

Shana: It’s hard. I think it’s hard.

Rashika: It take a lot of money.

Tina: We’re the minority. It’s like a lot of people that live in the United States is a high rate of HIV. It wouldn’t be – I don’t know. I just heard the medicine is real high and that’s why a lot of people die from AIDS. Nobody not giving it for free. It’s going to be hard...that’s why a lot of people don’t go to the doctor.



Janice: I know from personal experience that some medicines are free. Most of the medicines are. For D.C. residents, they are free through Medicaid.

Rashika: It depends on your parents' salary what kind of medicine you get.

Janice: No, it's all free.

Keon: Some people say it's expensive.

Janice: But whatever they doing, they not doing what they supposed to be doing because that medicine should be free for them.

*So it's free but maybe a lot of people don't know how to access that free medicine?*

Rashika: Yes

Janice: And if they get a case manager...

Shana: Since they never told nobody, they not going to go to a doctor, so they feel like "I'm going to try see what's going to happen," and they end up dead.

Founder of The Women's Collective in Washington D.C., Patricia Nalls's World AIDS Day<sup>56</sup> statement seems to further this ambivalence surrounding the availability of AIDS medicine. She states, "when we talk about World AIDS Day, and also when we talk about AIDS in America, people think, '*Oh, look, there are pills, there are medications, there's a solution.*' But HIV is more than just a pill. HIV is a symptom of bigger problems" (qtd. in Vargas 2009, emphasis in original). Certainly lack of access to health information, services, and interventions—especially high-tech aspects of the latter—outline the fault lines of social inequalities, such as racism and sexism, that the epidemic follows. Case in point is IAVI's claim that many of the new intervention technologies appeal to gender insofar as they claim that new prevention technologies benefit groups like women the most because PrEP, microbicides, and vaccines will be a

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<sup>56</sup> World AIDS Day is celebrated yearly on December 1.

powerful tool that women can use without having to negotiate their use with a partner (“Why A Vaccine: Comprehensive Response”). In this scenario, women’s unequal power relations (in society and in relationships) are solved through the biotechnical ‘fix’, which precludes any need to seriously address regimes of biopower and social inequality. The focus on (re)education of individuals or their T cells does little to address the structural inequalities that render young African American women in Washington, D.C. so vulnerable to not only HIV but also other forms of structural and symbolic violence. From this logic, women’s emancipation and equality allegedly stems from individual maintenance of reproductive and sexual health in a way that elides the other structural impediments to health and equality. Fixating on the biomedical cures or life extending technologies for those with HIV/AIDS invariably leaves social determinants of health under-investigated as well as undermining other configurations of health in spite of disease. What exempts Magic Johnson from this outcome is his sport’s celebrity status and a salary, which allow him to receive cutting edge treatments. In a world where HIV/AIDS respects no social, geographic, or generational borders, medical resources including cumulative scientific knowledge still seems to be “blocked at customs” (Farmer 1999: 54). Again, this is not to denigrate the advances in immunology, epidemiology, and virology that have life preserving or pain alleviation effects, but rather to criticize the narrow or uncritical use of these tools that seem to assist rather than re-cast historical fault lines of inequality and disempowerment.

### **Behavior Change & Condom Use**

If epidemiological testing helps render the materialization of HIV/AIDS visible and if no biotechnical solution has yet been arrived at, then the focus of intervention must

necessarily remain on HIV/AIDS education and behavior change. Thus, biomedical strategies to control the AIDS epidemic do not ‘target’ the virus alone, but also ‘target’ the person as viral agent by inscribing themselves upon the bodies and desires of the infected and the potentially infected (Waldby 1996: 20). Since the spread of the virus cannot yet be controlled by medical prophylaxis, “the scale of control moves up to the level of the person infected” (Waldby 1996: 125) and “raises the social stakes attached to individual behavior choices” (Singer 1993: 62-63). It is assumed that if the immune system cannot yet be re-educated via biomedicine, then the individual can. Insisting on the capacity of culturally sensitive education programs relies on the belief that the way to diminish ‘risk’ is to increase knowledge. According to Paul Farmer, “through this cognitivist legerdemain, we have expediently moved the locus of the problem—and thus the focus of the interventions—away from certain features of inegalitarian society and toward the [subpopulation] deemed ‘at risk’” (1999: 86) By this logic, if the problem of the future of the epidemic is with young people, particularly their individual behavior choices, then the intervention should generate new forms of sexual discipline and management for young people’s behavior. To date, most of the behavior change efforts rely on a ‘rubric of safe sex’, which offers the possibility of each person re-choreographing their sexual practice according to the new dangers posed by HIV (Waldby 1996: 125). Even in the Post-Bush era the ABC<sup>57</sup> approach to safer sex remains firmly entrenched in education and behavior change interventions, although recently

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<sup>57</sup>ABC is the classic formula used in HIV prevention: Abstinence, Be faithful, and use Condoms. Especially when it comes to youth, the ABC approach is supposed to be applied (and said to be most effective) in alphabetical order. This reiterates my claim that acknowledging the sexual activity of young people, let alone young people’s sexual pleasure, is far from the core of HIV/AIDS prevention strategies.

there has been an increase in condom information and distribution particularly within Washington, D.C.

D.C. is one of only two cities in the United States with a large-scale condom distribution program. The city's HIV/AIDS Administration has set the goal of distributing three million condoms per year (in a city with nearly 600,000 residents) and in 2008 distributed one and a half million condoms (D.C. DOH 2009). Starting April 2010, Washington, D.C. will distribute 500,000 female condoms in beauty salons, convenience stores, and high schools in the city wards with high rates of HIV infection, becoming the first U.S. city to distribute free female condoms ("D.C. is First U.S. City"). While reported cases of HIV remain relatively low among young people in the District, there lingers the threat of exponential growth given the high rates of STIs among young people, which "reveals risky behavior" that could lead to HIV acquisition (D.C. DOH 2009).<sup>58</sup> A survey conducted in the D.C. public schools on youth risk behavior survey in 2007 found that twenty-two percent of all high school students in D.C. reported having had sex with four or more people—up from sixteen percent in 2005 (Sasha Bruce Youthwork). A majority of the young people I interviewed portrayed themselves and their schoolmates as sexually active, with considerable pressure to have sex by the time they are in high school. "Most people are ... when you were in elementary school or middle school; they make fun of you because you're a virgin" (Shawn). The same 2007 survey found that seventy-one percent of sexually active high school students in D.C. report

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<sup>58</sup> According to the Sasha Bruce Youthwork pamphlet entitled "STDs and HIV in D.C. and the United States," one in every four sexually active young people between the ages of fifteen and twenty-four contracts an STI every year. Moreover, compared to older adults, people under the age of twenty-five are at higher risk for contracting an STI (Sasha Bruce Youthwork).

using a condom the last time they had sex, which is down from seventy-six percent in 2005 (Sasha Bruce Youthwork).

From my focus group discussions and surveys (used in the large non-recorded focus group with Youth Build), I also gathered that the majority of young people were sexually active and that they or their friends did not consistently and properly use either a male and/or female condom. Still ignorance, especially in the young people I spoke with, was not really the issue. Despite the emphasis on education leading to behavior change, they all knew about modes of transmission and what behaviors might place them ‘at risk’. Everyone who spoke up could identify that HIV was spread through bodily fluid exchange—namely blood, semen, vaginal fluids, and breast milk—and not through casual contact. Yet, condom use was not consistent. As one young woman from the 4TeenzOnly focus group aptly stated, “education alone won’t stop you from having it [unprotected sex]” (Merci). Merci’s statement and my findings are in keeping with what is called the ‘KAP gap’, a term used to highlight the *lack* of a simple correlation between knowledge about HIV with the undertaking of ‘safer sex’ practices such as consistent condom use. Particularly well documented in the Caribbean, studies there illustrate that even where knowledge about HIV/AIDS is seemingly universal only between sixteen to forty-four percent of young people use condoms consistently (Plummer 2009: 240-241). Even amongst some of the most well informed young people in D.C., the ‘KAP gap’ remains one of the largest obstacles for prevention efforts reliant on prophylaxis and behavior change. Rather than blame the ‘KAP gap’ on the failure of youth to conform to ‘safe’ behavior, researchers like David Plummer are placing emphasis on investigating the role of gendered power relations in negotiating sex and condom use.

Despite the difficulties posed by the ‘KAP gap’, the most promoted prophylaxis method against sexual contamination by the HIV virus, when used properly, is the condom. As one young woman at 4TeenZOnly stated, “HIV is not a get *on* you disease. It’s a get *in* you disease” (Krista, emphasis in original). Young people predominately embraced the idea, as evidenced by their sexual behaviors and public health posters (designed in non recorded focus groups and reproduced below), that practices and protections—like the male and female condom—prevent the virus from entering one’s bloodstream rather than abstinence and monogamy (Treichler 1999a: 363). A fear of HIV, and its revealing technology, the HIV test, seems to prompt the inclusion of ‘safer sex’ practices into their repertoire. The examples given below, which include quotes from the recorded focus groups and the public health posters produced in the non-recorded Youth Build focus group, indicate how centrally condoms figured into these young people’s sexual desire and behaviors.

Me, I know for sure if I have sex I’m using a condom. I don’t care if I been with you for 5 years, I’m still using a condom because people cheat. People do a lot of stuff. On top of that, there’s a lot of peer pressure out here [to have sex]. If I do have unprotected sex, and I get an HIV test, I’d be scared. (Raina-Sasha Bruce Youthwork)

I think that a whole lot of people in the community has it because you can give out 300 million condoms, but it’s all about the fact if they going to use it. People can have whole drawers full of condoms, but are they really going to use it? Some people scared to go get tested. The people who are scared to go get tested, you better defeat your fear or something because it’s not going to work. (Krista-4TeenZOnly)



Fig. 5. “No Glove No Love, No Rubber Burnt Brother” and “Rap It or Catch It, HIV That’s Dead” are the slogans featured on this poster. This poster contains a montage of slogans, images, and facts about both HIV and condoms. The poster produced by Jason, Britney, Sean, and Luanna, was the only one to feature any explicit mention of HIV/AIDS and the female condom. The cigarettes, the group explained, are in the scene because they are for after sex (Youth Build).

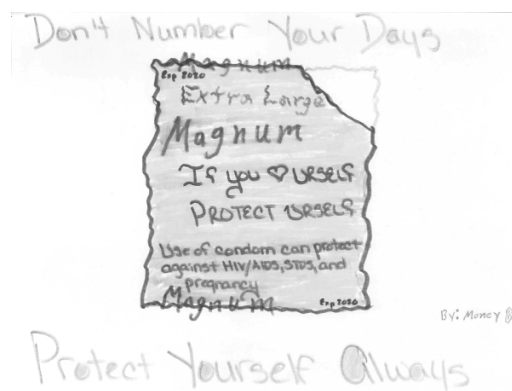


Fig. 6. “Don’t Number Your Days, Protect Yourself Always.” Kelly’s, Annika’s, Quanna’s, and Emily’s poster features a magnum “extra large” condom with an additional message stating that “if you heart [love] urself, protect urself.” Their condom drawing emulates a real condom package, featuring both two expiration dates and the a statement that condoms protect against pregnancy and STIs including HIV/AIDS (Youth Build).



Fig. 7. “Sex Is Great But Life Last Longer.” Anita, Angela, and Donald explained that the man in the drawing is opening a condom while the women is reminding her partner to use protection in preparation for sex (Youth Build).

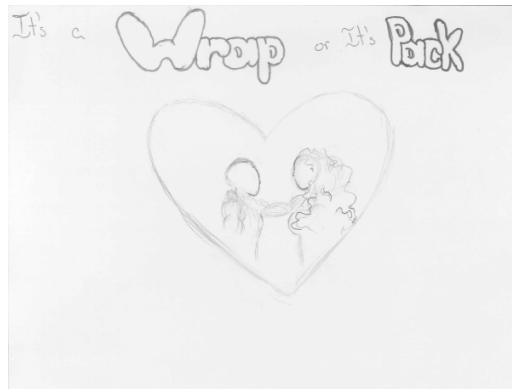


Fig. 8. “It’s Wrap or It’s Pack.” Mike, John, Kenny, Joel, and Darion explained to me that this phrase means to use a condom or I’m packing my backs to leave. Like the previous poster, this groups emphasizes heterosexual sex, by featuring a man and a woman within a heart (Youth Build).

Although there was a general sentiment that using a condom hampers young men’s sexual sensation, “unprotected sex, feels better without one” (Dave), everyone who admitted being sexually active used condoms to prevent both pregnancy and HIV.<sup>59</sup> On the topic of why it was difficult to discuss sexual history or negotiate condom use with partners, Luli responded “I think people just want to get straight to the point.” Only a few young women and men in all the focus groups chose abstinence and these individuals were quite vocal on their choice as the only absolute way to ensure safety from HIV/AIDS infection. As Sherrod from the Metro TeenAIDS focus group asserts, the only truly way to be safe from sexual transmission from others is not to have sex or ensure that one’s sexual partner(s) status is ‘legit’. “No, you got to practice abstinence. You could have sex or better yet practice abstinence. I’m not going to say my sexual life is out there, but you got to make sure that person’s legit before you get in” (Sherrod). For the majority of interviewees having sex, using condoms as a barrier method, and testing seem to be integral components of young sexual repertoires.

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<sup>59</sup> Admittedly this statement may have been skewed towards giving me a socially desirable or politically correct answer rather than reflecting actual rates of condom usage among my interviewees.



Prevention campaigns rise to the fore in instances when there is no cure or immediate prospect of a vaccine. Historically there have always been additional difficulties in preventing people from spreading and falling ill from venerally transmitted diseases (Sontag 1991: 160), which I believe are only further compounded by the reluctance of adults and politicians to acknowledge young sexualities. There is a pervasive fear in America that simply talking to young people about condoms and needle exchange is tantamount to condoning these behaviors. Despite the evidence that teens in middle school and high-school are sexually active, many education and behavior change interventions are wary of discussing young sexuality in a open and honest manner for fear of promoting sexual behavior among young people. When asked, three respondents from three different interviews suggested reasons for the popular conception of young people as pre-sexual and the public silence around discussing young sexualities.

***Why would you think that a lot of adults are reluctant to speak to young people about sex?***

Kim: I think it's the idea that children are born these innocent, non-sexual beings and it fails to take into account the fact that human beings are sexual people and looks at sexuality as simply something for procreation and adults. The idea that young people are unable to make their own decisions, unable to make safe decisions, and unable to be engaging in something that is actually pretty natural for their age and for being human.

Cambria: Yeah, I would think the same thing for kids also just because we don't really grow up talking about it; at least most people I know don't really grow up talking about it. I was hesitant to talk to my parents about it. I wouldn't have wanted to be the one to bring it up or anything, so I think kids are kind of the same thing. They don't want their parents to accuse them of doing something or think they're guilty of doing something. They won't bring it up. I also think it's awkward to bring it up with your parents, just because it's kind of really taboo and stuff.

Luli: Some just don't care; feel like it's too late. They ain't going to listen to you. They feel like it's just all teenagers so why waste my time talking to you.

In this equation, sexual information is perceived to translate into direct action.

Withholding taboo information from young people preserves what adults perceive to be the purity and innocence of youth, which they themselves have lost. If information about one's body translates into power over one's body, then withholding information from young people dis-empowers them to make informed decisions regarding their bodies and their health. In the end, American society must ask of itself whether it has misdiagnosed the problem, fear and panic surrounding young sexualities as a result of 'sex negativity', rather than realistically approach HIV/AIDS prevention through an open and honest dialogue about sex and sexual pleasure.

### **Young People & Sexual Pleasure**

Before concluding, I want to return briefly to the topic of condom use and pleasure. Although sex with a condom was deemed less pleasurable (at least for young men) in some instances, it was considered a necessary barrier against disease in today's world. As Figure 8 demonstrates, "It's a Wrap or it's Pack" means that if there is no condom, then there is no sex and he or she is packing their bags to leave. Interestingly, however, for the young people I talked to not any condom would do. The pleasure of 'safer sex' with a condom was specifically branded Trojan. Although Durex was the most readily available condom, provided by the D.C. DOH and the teen centers free of cost, pleasure factored into condom use depending upon which condom was available. One crucial factor in determining to wear (or not wear) a condom and precisely which condom depends on the maximization of sexual sensation or pleasure for both young men and young women.

***Do you think people might use condoms if they were popular brands like Trojan, and other stuff?***

Raina: Yeah, that's why I wish there was a request for all teenagers, to go to a station or something and give teenagers a form like would you rather have Trojan at Outreach, or Durex? I guarantee that all ethnic teenagers say Trojan because they last longer, and they give you pleasure. It make you want to wear a condom. Most boys don't like wearing condoms because they like to feel more. It's like Durex don't really have that much pleasure. It's like a piece of rubber or some plastic.

Luli: Trojans are a company, they're not going to give out condoms unless they donated or something. The money comes from somewhere

These young women spoke extensively on the topic of condom use and sexual pleasure, also preferring Trojans. Yet it seemed to me that the pleasure they spoke about referred to the pleasure of (young) men. If men liked how the condom felt or if it fit well, that meant young men were more likely to use one, which I suspect was a vital concern for young women who felt less able to negotiate condom use. Again this reiterates the subordinate position women's sexual pleasure has when factored into HIV/AIDS and other sexual and reproductive health programs. When this topic is addressed, it is in most often in the context of the containment of female sexuality rather than the maximization of her sexual pleasure. Still the overwhelming sentiment of my interviewees was that young people desired to not only use condoms when having sex, but also a clear desire to maximize their pleasure through 'safer sex' methods. This reveals that the most effective way to encourage condom use is to not only address the gendered power relations involved in negotiating condom use, but importantly to appeal to both young men's and young women's sexual sensation and aim for the maximization of pleasure.

**Conclusion**

What this chapter demonstrates is that biomedicine is a practice enabled through technologies— from low-tech barrier methods like male and female condoms to high-tech developments in microbicides, antiretroviral drugs, and trial vaccines—which provide biomedicine with the very tools to work directly upon bodies and intervene in and transform them (Waldby 1996: 5). This chapter also demonstrates how those practices are understood, not from the top-down point of view of epidemiological implementation to combat ‘risk’, but from the experiences of youth already interpellated into intervention schema. Clearly since young people are engaging in sex and embracing sexual pleasure, a youth standpoint on various sexual health and HIV/AIDS issues could ensure epidemiological deliverables that are well-tailored, but applicable to the population in question. Pleasure is a crucial factor in that equation. Knowing that young men prefer Trojans over Durex (e.g. no two condoms are quite alike) might help explain patterned usage and the ‘KAP gap’ despite the widespread availability of free condoms in Washington, D.C. Rather than deem young people as too immature to consistently use condoms, pleasure needs to be factored into designing existing behavioral change and education programs targeted at youth.

Notably, most of my interviewees seemed to reiterate Luli’s embrace of biomedical solutions not only as necessary, but quite possibly the only feasible solution at this point. Rather than mention the need for structural changes to reduce inequality, most of my focus groups agreed that a cure or a vaccine was needed to adequately combat the spread of HIV/AIDS. This embrace of biomedicine’s drive to cure only facilitates in papering over and further obscuring the long-entrenched inequalities that exist between men and women and people of various class standings in America. My interviewees may

not agree with the current distribution of access to health services in Washington, D.C., however, all of them embraced a more equitable distribution of biomedical knowledge and treatments rather than an outright dismissal of them. To borrow the words of Paul Farmer, “no one who has access to the vast array of drugs and diagnostic tools of a modern hospital could fail to appreciate the century’s remarkable return on investments in bench science” (1999: 10). Yet, with epidemics for which there is neither a vaccine or cure, the spread of illness can only be contested through addressing core structural inequalities and not merely controlled via social reordering of ‘risk groups’ and hierarchies of pathology. Biomedical interventions such as the ones outlined in this chapter wrongly focus on the disciplining of young sexualities as the one way to stymie the future spread of HIV. Rather than aiming to form a Poz coalition, my interviewees’ faith in biomedicine highlights a collusive preference to eradicate illness rather than to re-define it.

## Chapter VI: Concluding Remarks

Although considerable analysis was given in each chapter, I will briefly offer some concluding remarks to this work in its entirety as well as adding some future recommendations for similar research. Ultimately this work on the materialization of (Poz) youth argues that despite the deluge of scholarship on HIV/AIDS, the story of this pandemic is far from closed or complete. As such, feminist science studies scholarship should more rigorously apply the theoretical advances made in their studies on genetics onto the topic of HIV/AIDS. Epidemiological models of HIV/AIDS—whose technologies are naturalized in the everyday implementation of HIV/AIDS research in public health, NGOs, and governmental sectors—rely on constructing and targeting ‘at risk’ populations, and in doing so, frequently operationalize the biomilitary language of the immune system at the level of the body politic. This has an immense material impact on those people who find themselves caught in the ‘crossfire’ of ‘risk group’ classification, which operates by constructing a hierarchization of pathological identities. It is crucial to note that as ‘risk factors’ such as gender, age, sexuality, and/or nationality are figured as organizing principles in determining epidemiological ‘risk’, “we move from the recognition of differences and division [among healthy and sick populations] to the production of difference and the ordering of that division and inequality” (Dowsett 2003: 21-22). Utilizing ‘risk group’ categorization uncritically, even with the best of palliative intents, deflects attention away from the real engines of the pandemic and further obscures the reasons why biotechnical prevention methods have failed to reach desired eradication results.

From my interviews I found that although youth were Poz, in the sense that they took action on behalf of their own (sexual) health and had a positive attitude towards young sexualities, future work in both academic and NGO realms needs to continue to build upon this to forge a stronger alliance with the idea of embodying Poz subjectivity no matter one's 'sero' or blood status. Considerable resistance to locating the disease as 'our' problem or anywhere near young people's bodies remains a critical step in not only preventing future HIV transmissions, but also meaningfully addressing the extensive stigma and discrimination felt by those perceived as PLWHA in American society. Moreover, in speaking with young people and working for an NGO, I found considerable faith in medical science among young people. Specifically they believed in biomedicine's ability to continue to effectively prolong the life of PLWHA and to one day eventually find a cure for HIV/AIDS. The ultimate solution for my interviewees, after all, was to be sought in the laboratory and *not* the individual or community. While not aiming to discount the life prolonging and palliative effects of these technologies, it is critical to work with young people to question the prevalent rhetoric of Western biomedicine in order to understand that medical intervention is not necessarily a panacea. Diseases like HIV/AIDS have considerable social origins and social co-factors and are said to be preventable in the first place. Yet, biomedicine gives us a certain kind of order with which to make sense of the realm of infectious disease that lacks clear border differentiation. Biomedicine does the 'boundary work' that provides outmoded reassurances while holding us back from realizing more liberatory and equitable forms of (technology-enabled) embodiment. This thesis has hopefully elucidated that biomedicine deflects the cause of complex phenomena onto an identifiable and nameable microscopic

agent in ways that preclude the examination and tackling of structural inequalities and other forms of violence. In this scenario, equality in health outcomes does not stem from addressing ageism, racism, sexism, and class inequalities, but aims to cure these societal ills through bio-technical advances that can mask or erase any alleged biological proclivities (e.g. hormonal birth control pills, Attention Deficit Disorder medications, or the AIDS vaccine).

Throughout these chapters, I utilize examples of how biomedicine used and abused women's bodies under the guise of public health in order to not only make the case for youth, but in the hopes that young people and HIV/AIDS scholars alike can learn from the contributions of the women's health movement and feminist debates since the 1970s. Importantly, feminists since the 1970s have countered the assumptions, methods, and practices of biology—critiquing biological determinism (anatomy as destiny), scientism (the masculine gendering of expertise), objectivity (such that bodies have exteriors), and the disembodiment of science ('floating brain' syndrome)—in order to demonstrate the ideological function of biology, the manners in which biology has been deployed to justify unequal power relations in society, and by insisting that research (and the mind) is always bodily embedded. This project aims to extend the feminist science studies project of preventing new biological discoveries, from the discovery of T cells to the development of anti-retroviral drugs and microbicides, not from existing, but from being (re)cast along existing fault lines of ageism, racism, sexism and class inequalities. In doing so, I hope to situate my research in the larger feminist approach to science studies that not only speaks to the fiction of the universal (hu)man, but creatively critiques dichotomous logics of epidemiology by "recalibrating its thinking tools, models,



and figures to less oppressive ends” (Åsberg 2009: 37). I not only critique the biomedical sub-disciplines involved in HIV/AIDS science, but open up immunological, epidemiological, and virology practices so that NGOs and governments who rely upon their findings can benefit from including the embodied narratives of youth.

Not only have my interviewees stated that sex is something most of them engage in prior to marriage, often even before high school, but they also illuminate some of the barriers that still stand in the way of HIV/AIDS prevention work and Poz potentialities. Returning now to the Poz embodiment proposed in chapter one, young people’s prolific use of ‘othering’ and faith in biomedicine outlined in chapters four and five points to the failure of the full realization of my term Poz. In light of the interview material presented in the last two chapters, it appears that the Poz figuration—as a possible alliance among youth engaging in sexual health education on their own behalf that, regardless of the antigens present in their blood, refigures the relation between health and illness—is floundering on the latter count. Despite the high level of knowledge regarding sexual health in comparison to their peers, my focus groups illustrated that young people seemed to not only recycle the biomilitary metaphors of immunology by ‘othering’, but also embrace biomedicine’s quest for a cure. The young people I spoke with recognized how their own racial, class, and gender backgrounds were unjustly entangled with access to medications, information, and power to negotiate sexual practices, yet, they still strongly desired a biotechnical ‘fix’ for both the spread and the deadliness of HIV/AIDS. In spite of these findings, if Poz is taken to be a diffractive lens or form of optics rather than “the identity based fetishized perfect subject of oppositional history” (Haraway 1988: 586), it still may have some value. The critical positioning of Poz, albeit utopic, attempts to

further the larger feminist project insofar as it investigates “perspective from those points of view, which can never be known in advance, that promise something quite extraordinary, that is, knowledge potent for constructing worlds less organized by axes of domination” (Haraway 1988: 585). In this way the figuration of Poz is useful, no matter if it was successful in fulfilling my ambitious criteria, because it helps expose ways and promote strategies that alleviate suffering and inequalities in academic debates and NGO efforts.

Because the pervasive biomedical narrative described herein precludes other narrative voices and embodied explanatory schema, I emphasize how other issues often overshadow young sexualities. Importantly withholding information from young people about their (sexual) health and about HIV/AIDS is not only unjust, but seemingly foolish when evidence demonstrates that young people are engaging in sexual behaviors. A preference for the Trojan brand of condoms, preferred for ‘maximizing pleasure’, implies that young people are having sex and negotiating ‘safer sex’ options like condoms. Victorian ideals about sexuality and the purity of childhood are equally as dubious as the Cartesian logic that plagues biomedicine’s approach to health and illness. In the end it is not the sanctity of these ideologies I am concerned with, but rather the material implications for D.C. youth. I suggest, like the organization The Pleasure Project, that the best way to hurdle the ‘KAP gap’ is to call on strategies that appeal to (sexual) pleasure in conjunction with safety.<sup>60</sup> Young people should be given the tools to develop their own programs and prevention strategies rather than inherit epidemiological ‘risk group’ based strategies, especially those entrenched in Cartesian models and Victorian notions of

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<sup>60</sup> The Pleasure Project mission states, “Because sex education is rarely sexy, and erotica is rarely safe. Putting the sexy back into safe sex.” More information about the pleasure project is available at: [www.thepleasureproject.org](http://www.thepleasureproject.org).

sexuality. Rather than ascribe to these categories of 'risk', it is imperative that young people resist such epidemiological reductionism. Part of this project entails stopping the endless proliferation of 'risk groups' and aims to embody and politicize them anew.

In this thesis I work from the within the context I am most familiar with, with the hope of one day carrying out similar studies in other Second Wave cities in Eastern Europe. Future studies in this vein would allow for comparisons of 'glocal' HIV/AIDS materialization, but also delve into other modes of transmission such as IDU more fully. Just as sex is taboo for most youth, so too are drugs, both of which are on rise amongst many urban youth populations. If able to carry out said research, I would allot a longer research period for fieldwork because I would have liked to spent more time at the teen health centers getting to know my respondents so as to more fully understand the narrations of my young interviewees. Although in my configuration of Poz I emphasize an alliance no matter 'sero' or blood status, seeking out and incorporating the points of view of young people who are openly living with HIV/AIDS would also contribute to future analysis on this topic. Importantly, how do they feel about such a configuration? What does it mean for them to be Poz versus HIV+? Is Poz a useful lens to retain? In addition to the inclusion of the narratives of PLWHA and young IDUs, it would be interesting to undertake interviews with actual bioscientists and to conduct fieldwork in epidemiology, immunology, and/or virology labs. While the fieldwork undertaken for this research was centered on the world of NGOs, a comprehensive ethnography of the lab in the tradition of Georges Canguilhem, and his feminist counterparts like Amâde M'charek and Emily Martin, would offer a more comprehensive analysis and likely result in a more nuanced critique of the biosciences. Admittedly, just as it is inaccurate to view

scientific understanding as only flowing linearly outward from the lab, or vice versa, I feel it is also unfair to critique the biological sub-disciplines of HIV/AIDS science without putting myself (bodily) there in the first place.

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